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## Preparing for end of life in a new country: A grounded theory study on African migrants living in Australia

Gertrude Gondwe Phiri  
*Edith Cowan University*

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**Edith Cowan University**  
**School of Nursing and Midwifery**

**Preparing for end of life in a new country: A grounded  
theory study on African migrants living in Australia.**

**This thesis is presented for the degree of  
Doctor of Philosophy (Integrated)**

**Gertrude Gondwe Phiri**

**2024**

Principal Supervisor: Professor Davina Porock

Associate Supervisor: Dr Joyce Muge-Sugutt

## Declaration

I certify that this thesis does not:

- i. incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education;
- ii. contain any material previously published or written by another person except where due reference is made in the text of this thesis; or
- iii. contain any offensive material.

Signed:

A black rectangular box redacting the signature.

Name: Gertrude Gondwe Phiri

Date: 13/10/2024

## Acknowledgements

Completing this doctorate has been an eventful four-year journey but I have not travelled alone. Many people have made significant contributions to this undertaking and supported me as I have been undergoing my own ‘dynamic process of toing and froing’.

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In addition, I have been supported by the Degree by Higher Research community at Edith Cowan University (ECU), and thanks to Dr Tanya Lyons for editing the final thesis.



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## Abstract

African migration to Australia has grown in the past 20 to 25 years with many migrants staying permanently. This has led to migrants dying away from their birthplaces where family is responsible for end-of-life care planning for the individual. Although migrating to Australia is considered a great achievement, many migrants also experienced challenges. Previous studies have explored the barriers faced by migrants in relation to end-of-life care but have not addressed the cause of those challenges. This constructivist grounded theory study examines how migrants from three African countries, Malawi, Zambia, and Zimbabwe (MZZ) prepare for end-of-life in Australia. The study objectives are to: 1) Describe the experience of migration and settling in Australia for migrants from MZZ, and how they plan for end-of-life; 2) Examine family relationship structures and their impact on preparations for end-of-life for migrants from MZZ; and 3) Describe the social processes of African immigrants from MZZ as they prepare for end-of-life in Australia.

Face-to-face in-depth, semi-structured interviews, using semi-structured, open-ended questions were conducted with 14 participants on two occasions, two to four weeks apart. Participants were migrants with indigenous heritage from either Malawi, Zambia, or Zimbabwe, and living in Australia. Data analysis occurred concurrently with data collection, using constant comparative analysis to guide both ongoing data collection and analysis. Categories exploring relationships and dimensions are developed here into a substantive grounded theory, named '*The dynamic process of toing and froing*' (DPTF).

Migrants' ability to prepare for end-of-life in Australia is impacted by the challenges they face in relation to culture, at every level of their lives, from migration to resetting the life button, shuffling back and forth, disintegrating family dynamics, finding equilibrium, and

pursuing the horizon. Migrants' lives appear to be on a non-linear continuum, that is, participants' lives were notably going back and forth in various circumstances, in their attempts to find equilibrium, and pursue the horizon. However, even when a state of equilibrium was thought to have been realised, the DPTF continued, triggered by prevailing circumstances related to their immediate and extended family members both in Australia and in their respective countries of origin.

The significance of this study is that it reveals the processes that African migrants from MZZ go through as they attempt to adapt to the culturally foreign concept and find new ways of planning for their end-of-life in Australia. This gives rise to the DPTF which frames the continuum on which African migrants from MZZ must find culturally appropriate palliative care services. This study recommends the co-designing of education resources for healthcare professionals, including for intervention strategies, and adopting a public health approach to palliative care, would result in increased utilisation of services, including planning for end-of-life by African migrants from MZZ. This study identifies implications for policy, professional practice, and future research in relation to African migrants from MZZ in Australia and their preparations for end-of-life.

# Contents

Declaration .....	i
Acknowledgements .....	ii
Abstract.....	iv
<b>Contents .....</b>	<b>vi</b>
List of Tables and Figures .....	xi
List of Acronyms .....	xii
Glossary of Terms .....	xiii
List of publications, conference presentations and future research dissemination .....	xv
Published articles .....	xv
Forthcoming article submissions .....	xv
Conference papers.....	xv
Forthcoming conference presentations .....	xvi
<b>Chapter 1: Introduction .....</b>	<b>1</b>
Introduction .....	1
African Migration .....	6
Transcontinental slave trade .....	14
Colonisation.....	17
Migration of indigenous Africans to Australia.....	19
First Known Indigenous African Migrants to Australia .....	20
From migrants to African-Australians .....	22
A personal account of migrating to Australia.....	24
Arriving in Australia.....	24
Cultural differences.....	24
Racism .....	28
Raising Children .....	29
Initial Plans Change .....	31
Personal and Professional Background .....	32
Theoretical perspectives .....	33
Purpose of the study .....	33
Research question .....	33
Research objectives.....	33
Significance of the study .....	34
Thesis structure.....	35
Summary.....	36

<b>Chapter 2: Literature Review .....</b>	<b>37</b>
Introduction .....	37
Updated literature search .....	52
Summary .....	53
<b>Chapter 3: Methodology and Methods .....</b>	<b>54</b>
Introduction .....	54
Philosophical assumptions .....	54
Methodology .....	56
Paradigms of knowledge development .....	57
Qualitative research .....	57
Theoretical approach .....	60
Grounded theory .....	61
Axiology .....	66
Ontology .....	67
Epistemology .....	68
Maintaining rigour and quality of study .....	70
Methods .....	74
Design .....	75
Participant Recruitment .....	76
Data Collection .....	78
Data Analysis .....	81
Theoretical sensitivity .....	81
Memoing .....	82
Diagramming .....	86
Simultaneous Data analysis .....	86
Coding .....	87
Ethical considerations .....	93
Ethics Approval .....	94
Informed consent .....	95
Confidentiality .....	96
Managing vulnerable participants .....	96
COVID management .....	97
Data management .....	97
Summary .....	98
<b>Chapter 4: Findings .....</b>	<b>99</b>
Introduction .....	99
Study participants .....	100

Category A: Remodelling self .....	107
Education .....	107
Work .....	116
Socio-Economic and Political.....	121
Testing the waters .....	123
Category B: Disintegrating of family dynamics.....	126
Physically disengaged.....	126
Losing cultural identity .....	128
Category C: Resetting the life button .....	132
Adapting to new environment.....	132
Settling in.....	134
Acculturating .....	142
Realising opportunities .....	145
Finding employment.....	146
Permanent visas .....	148
Leaving a legacy .....	151
Belonging.....	153
Growing families .....	157
Category D: Shuttling back and forth.....	159
Longing for home .....	159
Ever-changing thoughts .....	164
Category E: Finding equilibrium.....	165
Living with regret .....	167
Category F: Pursuing the horizon.....	170
Cultural practices .....	172
Spirituality .....	175
Place of care.....	180
Place of death.....	183
Voluntary Assisted Dying.....	185
Advance Health Directive/Advance Care Planning.....	187
Overview of findings.....	190
Summary.....	192
<b>Chapter 5: Theory Development .....</b>	<b>193</b>
Introduction .....	193
The Dynamic Process of Toing and Froing.....	193
Summary.....	200
<b>Chapter 6: Discussion .....</b>	<b>202</b>

Introduction .....	202
Study Overview .....	203
Migration .....	205
Push Factors .....	207
Pull Factors .....	209
Other factors .....	212
Transition theories .....	214
The Dynamic Process of Toing and Froing .....	216
The Elements .....	216
<b><i>Pursuing the Horizon</i> .....</b>	<b>226</b>
An Emergent Theoretical Model .....	227
End-of-Life Planning .....	233
Codesigning Educational Resources .....	235
Codesigning Service Interventions .....	238
Public Health Approach .....	239
Summary .....	241
<b>Chapter 7: Recommendations and Conclusion .....</b>	<b>243</b>
Introduction .....	243
Recommendations .....	243
Future areas of research .....	244
Implications for Policy .....	245
Implications for practice .....	247
Limitations .....	247
Strengths .....	249
Conclusion .....	251
<b>References .....</b>	<b>255</b>
<b>Appendices .....</b>	<b>271</b>
Appendix 1 .....	272
Literature search details .....	272
Appendix 2 .....	275
Studies included .....	275
Appendix 3 .....	279
Supporting letter from OACWA .....	279
Appendix 4 .....	280
Invitation Letter to potential study participants .....	280
Appendix 5 .....	281
Participant information letter .....	281

Appendix 6 .....	284
Participant Consent Form .....	284
Appendix 7 .....	285
COVID-19 Symptom Checklist.....	285
Appendix 8 .....	286
Pilot Study Interview Questions .....	286
Appendix 9 .....	287
First Interview Questions.....	287
Appendix 10 .....	288
Second Interview Questions .....	288
Appendix 11 .....	289
Ethics Approval Letter.....	289
Appendix 12 .....	292
Advance Health Directive.....	292
Appendix 13 .....	296
Advance Care Fact Sheet for Individuals .....	296



## List of Tables and Figures

Figure 1.1 Map of Southern Africa showing position of MZZ.....	2
Figure 1.2 Map of countries of Africa .....	8
Figure 1.3 Map of regions of Africa .....	9
Figure 1.4 Map of initial Bantu Migration, 14th century Africa .....	11
Figure 1.5 Map of Southern Africa showing population dispersion south to north .....	12
Figure 1.6 Slave Trade route.....	15
Figure 1. 7 Shackle for slave while in transit.....	15
Figure 1.8 : Slaves being forcibly loaded in the Ship's Hold .....	16
Figure 1.9 Slaves packed like sardines in the ship's hold.....	17
Figure 1 10 Africa divided by colonising country .....	18
Table 3.1 Qualitative Research Approaches .....	59
Table 3.2 Versions of grounded theory.....	66
Figure 3.1 Paradigms informing methodology. ....	69
Figure 3.2 Theoretical sensitivity chart modified from Strauss & Corbin, 1990 .....	82
Table 3.3 Examples of memo excerpts .....	85
Figure 3.3 Data Collection and Analysis .....	89
Figure 3.4 Initial Coding Process.....	89
Table 3.4 Example of NVivo .....	90
Table 4.1 Participants' pseudonyms and demographic data. ....	101
Figure 5.1 Emergent Theoretical Model: The Dynamic Process of Toing and Froing .....	197

## **List of Acronyms**

ABS	Australian Bureau of Statistics
ACP	Advance Care Plan
AHD	Advance Health Directive
CaLD	Culturally and Linguistically Diverse
CRAC	Centre for Research in Aged Care
DPTF	Dynamic Process of Toing and Froing
ECU	Edith Cowan University
EOL	End-of-life
GT	Grounded Theory
MZZ	Malawi, Zambia, and Zimbabwe
OACWA	Organisation of African Communities Western Australia
OECD	Organisation for Economic Co-operation and Development
VAD	Voluntary Assisted Dying
VIPP	Visualisation in Participatory Programm
WA	Western Australia
WHO	World Health Organisation

## **Glossary of Terms**

**Apartheid:** A policy of 1948 to 1990 founded on the idea of separating people based on racial or ethnic criteria: A system of racial segregation practiced in South Africa under the all-white government which discriminated against non-white South Africans who were required by law to live in separate areas from whites, use separate public facilities including public transport, schools, and health care facilities (Jakubowicz, 2009; Phillips & Spicks, 2012).

**Bantu peoples:** An ethnolinguistic grouping of approximately 400 distinct native African ethnic groups who speak Bantu languages (Ngcobo, 1953).

**Culture:** The ideas, customs, and behaviours of a particular people or society (Spencer-Oatey & Franklin, 2012).

**Collectivism:** The practice or principle of giving a group priority over each individual (Triandis & Gelfand, 1998).

**Mfecane:** A period of political disruption and population migration in Southern Africa during the 1800s (Cobbing, 1984).

**Migrant:** A person who moves away from his or her country of usual residence temporarily or permanently to another country (ILO, 2021).

**Migration:** The process of moving from one geographical location to another (ILO, 2021).

**End-of-life:** EOL care is an essential part of palliative care, although restricted to the EOL phase, when death is imminent, within months, weeks, or days. The focus is on symptom management to promote quality of life, and family support (Koekkoek et al., 2016).

**Palliative Care:** An approach that improves the quality of life of patients and their families who are facing problems associated with life-limiting illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain

and other problems, whether physical, psychosocial, or spiritual (World Health Organisation [WHO], 2018).

**Slave:** A person who is forced to work for and obey another and is considered be their property (Thomas, 1997).

**Slavery:** The ownership of a person as property, especially in relation to labour (Thomas, 1997).

**Race:** A group of people sharing the same culture, history, and language (Drescher, 2010).

**Racism:** Prejudice, discrimination, or antagonism by an individual, community, or institution against a person or people on the basis of their membership of a particular racial or ethnic group, typically one that of a minority or marginalised (Hirschman, 2004).

## **List of publications, conference presentations and future research dissemination**

### **Published articles**

Phiri, G. G., Muge-Sugutt, J., & Porock, D. (2023). Palliative and End-of-Life Care Access for Immigrants Living in High-income Countries: A Scoping Review. *Gerontology and Geriatric Medicine*, 9, 1-13, <http://doi:10.1177/23337214231213172>

### **Forthcoming article submissions**

Phiri, G. G., My family near and far: Who will help me plan my EOL? - *June, 2024*

Phiri, G. G., The Dynamic Process of Toing and Froing: Experiences of migrants from MZZ in Australia - *September, 2024*

Phiri, G. G., Does undertaking 2 interviews constitute an intervention? - *December, 2024*

### **Conference papers**

Phiri, G. G. (December 2022). Preliminary study findings: Centre for Research in Aged Care Seminar. Edith Cowan University

Phiri, G. G. (2023, May 17). Study findings: Centre for Research in Aged Care Seminar. Edith Cowan University

Phiri, G. G. (2021, May 29). Cultural Shock: challenges for migrants in their end of life, Aged Care Insite

Phiri, G.G., Vafeas, C. & Porock, D. (2021, September 14). *Preparing for end-of-life in a new country: Cultural perspectives of African migrants living in Australia (pilot)*, Bethanie Spiritual Care Conference. Bethanie on the Park, Menora, Perth.

Phiri, G.G., Vafeas, C. & Porock, D. (2022, May 2 - 4). *Preparing for end-of-life in a new country: Cultural perspectives of African migrants living in Australia (pilot)*, Palliative Care Nurses Australia Virtual Conference.

Phiri, G.G., Muge-Sugutt, J. & Porock, D. (2022, October 23-28). *Preparing for end-of-life in a new country: A grounded theory study on African migrants living in Australia (preliminary findings)*, Australasian Conference on Care of Older people, online conference.

Phiri, G. G., Muge-Sugutt, J. & Porock, D. (2022, December 19-20) *Preparing for end-of-life in a new country: A grounded theory study on African migrants living in Australia (preliminary findings)*, 1<sup>st</sup> IIMAD International Conference on Ageing and Social Care, Kerala, India.

### **Forthcoming conference presentations**

27<sup>th</sup> Nordic Congress of Gerontology – Stockholm, Sweden. 12 - 14 June 2024. Abstracts accepted:

- 1- Phiri, G.G., Muge-Sugutt, J & Porock, D. (2024, June 12 - 14). *Preparing for end-of-life in a new country: A grounded theory study on African migrants living in Australia*. 27<sup>th</sup> Nordic Congress of Gerontology, Stockholm, Sweden.
- 2- Phiri, G.G., Muge-Sugutt, J & Porock, D. (2024, June 12 - 14). *My family far and near: Who will help me plan for EOL*. 27<sup>th</sup> Nordic Congress of Gerontology, Stockholm, Sweden.

2024 Palliative Care Nurses Australia Biennial Conference – Melbourne, Australia. 31 July – 2<sup>nd</sup> August 2024.

The 57<sup>th</sup> Australia Association of Gerontology Conference – Hobart, Tasmania. 12 - 15 November 2024.

# Chapter 1: Introduction

*“You cannot swim for new horizons until you have courage to lose sight of the shore.”*

— William Faulkner

## Introduction

This thesis presents a constructivist grounded theory developed from primary qualitative research on how migrants of indigenous heritage from the African states of Malawi, Zambia, and Zimbabwe (MZZ) living in Australia are preparing for their end-of-life (EOL). The study explores issues concerning the process of planning for EOL among this particular group of migrants whom all originate from either Malawi, Zambia or Zimbabwe which for the purposes of this research are identified as belonging to a unique region of countries in Southern Africa that have similar stories in terms of the exodus of migrants to Australia (see Figure 1.1). Hence the acronym MZZ will be used throughout the thesis to acknowledge this heritage. Traditionally, individuals from communities such as MZZ practice ‘collectivism’ and as such do not see the need to plan for EOL. However, relying on extended family members in Africa to make decisions on their behalf while in Australia is challenging, particularly in relation to the difficulties surrounding logistics.



Source: Mayaux et al., 1986

Figure 1.1 Map of Southern Africa showing position of MZZ

Some cultures engage in planning for EOL however, most communities from culturally and linguistically diverse (CaLD) backgrounds do not consider it necessary, as seen in the African communities that practice collectivist cultures. These cultures tend to rely on immediate and extended family members to plan for such care on their behalf (Shavitt & Cho, 2016), at the time when that care is needed. Having migrated to Australia, the MZZ migrants no longer live in close proximity to their extended family members, who would collectively take the responsibility for making decisions about, and planning for care on their behalf, resulting in an arduous decision-making task during major events.

Thus, the process of migration to Australia has created challenges with particular reference to death and dying, and EOL for migrants, especially those from Culturally and Linguistically Diverse (CaLD) backgrounds (Chuang et al., 2017), such as the participants in this study who have all migrated from MZZ. These challenges are also experienced by the healthcare workers who work with these individuals experiencing EOL care.



Every person will one day reach an end: They will die. People may die at a young age but mostly they die in older age (Fulton & Fulton, 2019) which provides an opportunity to plan for EOL and all the advantages that it may bring. With the knowledge of dying one day in the future, migrants have an opportunity to plan for their EOL to ensure their care preferences are made known to their families.

EOL here refers to the time when the palliative care patient is nearing death, where the focus of care shifts from treatment of the life-limiting illnesses to symptom management to ensure comfort for both the patient and family or significant others (Koekkoek et al., 2016). In this context palliative care refers to the approach that improves the quality of life of patients and their families who are facing problems associated with life-limiting illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (WHO, 2018). Palliative care neither emphasises the hastening nor postponing of death but, allows the progression of the natural process of dying to occur (Janssens, 2001).

In Australia up to 70 percent of Australians prefer to die at home, in a familiar and private environment, surrounded by family (Australian Institute of Health Welfare, 2022). However, only 14.8 percent fulfil their preference with as many as 51 percent dying in hospital, a place considered public. Dying in a public place can be distressing not just for the dying person but, for significant others as well (Australian Institute of Health Welfare, 2022).

A Western Australian study exploring the impact of using a dedicated space for EOL care in an acute hospital for dying patients, found that providing a separate room for EOL care, has positive outcomes for the dying person, the family, as well as staff looking after the patient (Slatyer et al, 2015). This confirms the findings of Porock et al. (2009) whose observations of practice relating to dying in public in the United Kingdom recognises the importance of privacy and asserts that providing palliative care is rightly focused on the

patient and the family but neglects to consider the space in which care is provided. Dying in a preferred environment can be achieved if EOL planning is undertaken and preferences are documented. The care provisions for migrants from CaLD backgrounds in Australia should be no different from other Australians, with the assumption that they can achieve their EOL preferences if prior planning is undertaken.

The most recent Australian census found that Sub-Saharan African migrants in Australia make up 1.3 percent of the Australian total population, or a total of 330,496 people (Australian Bureau of Statistics [ABS], 2021). While the total number of these migrants may be considered insignificant at present, in comparison with other migrant groups that are much larger, the migration trend is projected to continue for the foreseeable future (Australian Government the Treasury and Department of Home Affairs, 2018). For many migrants from MZZ, the decision to stay for the long term in Australia, following completion of education or a temporary work period, is an easy one to make. This is because their primary objective from the start is often to bring their families to Australia, to enable their children to get a university education which they are not able to do in their countries of origin because of limited tertiary education places (Kamwendo, 2013; Masaiti & Chita, 2014).

Additionally, in MZZ, an overseas education is perceived to be superior, and seen as one that will provide their children knowledge and skills to enable them to compete favourably on the international labour market (Kudakwashe & Richard, 2011; Mwalimu, 2014). However, with this quest for a good education for their children, migrants soon realise that it is at the expense of their cultural values, importantly including their more collectivist culture which views extended family as very close, and needed to help make with life decisions, such as EOL care provisions. In most cases, the extended family becomes the hinge on which decision-making rests. However, in the absence of extended family, due to migration, the

need for EOL planning for migrants of indigenous heritage from MZZ in Australia is growing.

Individuals have long migrated from their homelands to settle in other places (Benson & Osbaldiston, 2014). Such moves come with difficulties for the migrant who not only moves into a new environment, but into a new culture as well as new systems, such as healthcare (Heger Boyle & Ali, 2010). This is no different for migrants to Australia, especially those from African countries and other CaLD backgrounds, and of relevance to this research and more specifically, those from MZZ. As these migrants stay longer and grow older, they may require in addition to general medical care, palliative care, and perhaps EOL care.

This study thus aimed to explore how migrants from MZZ navigate their preparations for EOL care in Australia, in the absence of their significant extended family members. Additionally, the study aims to generate a distinctive grounded theory which can potentially be applied to other migrant groups in Australia to verify these findings. Described here as the ‘Dynamic Process of Toing and Froing’ (DPTF), this term coined by the author through this present research provides insights into the uncertainty experienced by migrants from MZZ to Australia that has hindered their preparations for EOL.

This Chapter provided the necessary background context and definitions required to establish the significance and rationale for this research.

Secondly, this research provided a historical perspective of the African continent, with reference to significant patterns of global migration experienced by Africans, which examined the origins and development of traditions and cultures which ultimately leads to the motivation for this study, focussing on African migration to Australia, its people, their movements, their culture, and religions as they impact on their settlement in a host country, such as Australia, in terms of EOL.

Thirdly, my own personal migration story is examined followed by an overview of my personal and professional background which underpins the assumptions and theoretical background to this present research.

Fourthly, an overview of the purpose of the study, its significance, and the research questions and objectives will be provided. Finally, this chapter provide an overview of the structure of this integrated PhD research thesis.

## **African Migration**

Modern human migration is said to have started 100,000 to 200,000 years ago with migration out of Africa. According to the Deoxy-riboNucleic Acid (DNA) testing of fossils, modern humans can be traced to one source, the Mitochondrial Eve (Frayer et al., 1993). Multiregional evolution theory on the other hand, also asserts that modern humans originated from Africa, before populating every corner of the globe over thousands of years (Benson & Osbaldiston, 2014; Frayer et al., 1993; Thorne & Wolpoff, 1992). Although there is fierce debate about the details of this historical migration, there is paleontological evidence that brings scholars to a point of consensus, which is that the human race, originated from the African continent (Frayer et al., 1993). This evidence leans heavily on the suggestion that all modern homo sapiens were of black skin because of melanin pigmentation that provides protection from the sun. There was loss of the melanin pigmentation over a significant period of time for those who migrated to climates with colder weather, from high to low ultraviolet light as the skin was not exposed to much sun in the colder weather, therefore, did not require melanin, the natural sunscreen for skin protection and the northern climate needed more exposure to the sun in order to gain the vitamin D activation. However, the Bible paints the creation perspective, which also records the movement of people across regions as a phenomenon that has been happening for many thousands of years, such as Abraham going to

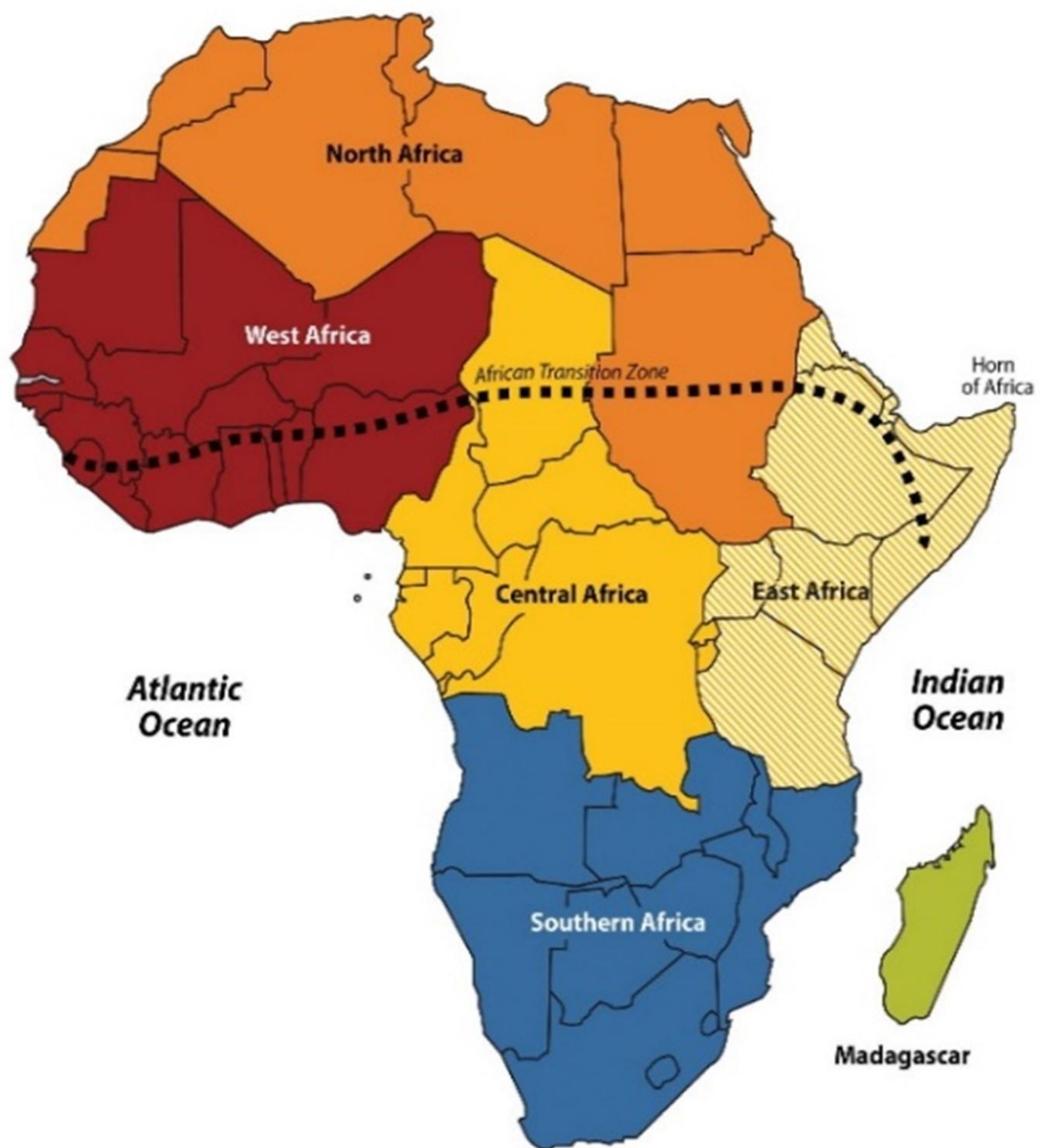
Cannan, Jacob and his family going to Egypt (*ESV Bible*, 2008, Genesis) and Jesus fleeing to Egypt and later going back to Israel (*ESV Bible*, 2008, Matthew). The multiregional evolution theory, and the Mitochondrial Eve theory, both agree that modern humans migrated from Africa to populate the entire world (Benson & Osbaldiston, 2014). Therefore, African migration is as old as humans have been in existence.

Nonetheless, as the second largest continent in the world, modern Africa is made up of 54 countries (see Figure 1.2), with five distinctive regions namely, North Africa, West Africa, East Africa, Central Africa and Southern Africa (see Figure 1.3). It is also the second most populated continent after Asia, with a population of 1.4 billion as of 2021 (International Monetary Fund, 2022; Worldometer, 2024) and is home to between 1250 – 3000 native languages, and thus very rich in culture (de Filippo et al., 2012).



Source: Mayaux et al., 2004.

Figure 1.2 Map of countries of Africa



Source: Mayaux et al., 2004.

Figure 1.3 Map of regions of Africa

Mazrui (1986) asserts that the African continent's identity stems from three major influences; traditional or indigenous practices, Christianity and Eurocentric capitalism inherited from the colonial masters, and Islam. Many archaeological studies have been conducted to ascertain the origins of the continent's population. One such study looked at bringing together linguistic and genetic evidence to test the Bantu people from Africa (de Filippo et al., 2012). The Bantu population is a group of indigenous African people comprising of hundreds of ethnic groups, who migrated from the Cameroon grass fields, near present day Nigeria, over 3000 years ago, where they speak Bantu languages, and are spread across Eastern, Central and Southern Africa (Vansina, 1984). There is no consensus on the reasons for this great migration however, there are theories to suggest why population movement occurred. Bantu people were agriculturists who depended on the land to grow their crops. It has been hypothesised that there may have been high competition for land and other resources as the population grew, therefore, movement was inevitable to find land for grazing and cultivation (Currie et al., 2013). The limited resources due to overpopulation may also have caused conflict amongst families, leading to infighting, and then to break-away groups by the weaker, less dominant ones, or those not interested in conflict (de Filippo et al., 2012). It could also have been due to exhaustion of agricultural land due to overuse that led to low crop yields leading to population movement in search of more fertile lands (de Filippo et al., 2012). As they trekked east and southward, they conquered any local populations, and also shared their agricultural knowledge and iron working technology (de Filippo et al., 2012). Figure 1.4 illustrates the Bantu peoples' original homeland and their initial migration.





Source: Grollemund et al., 2015

Figure 1.4 Map of initial Bantu Migration, 14th century Africa

This dispersion in the 14<sup>th</sup> century was not the end of big population movement in Africa because, five centuries later in the 1800s, there was another great movement of people, this time starting from the south and heading north, as people were forced to migrate seeking quieter environments, free from the constant wars over land and resources known as the Mfecane (Vansina, 1984). In the process, groups of people settled in clusters as others continued their northward journeys, ending up in the area where present day Malawi, Zambia and Zimbabwe are located, including other neighbouring countries (Currie et al., 2013). It

has also been suggested that these migrations were to escape the slave trade, responsible for capturing and transporting many Africans to work as slaves on Brazilian sugar plantations (Cobbing, 1988), and which is discussed in further detail below. The population movements continued to facilitate the formation of new cultures including religions as new arrivals settled amongst different existing communities. Figure 1.5 illustrates the major routes taken during the Mfecane in South Africa.



Source: Grollemund et al., 2015.

Figure 1.5 Map of Southern Africa showing population dispersion south to north

Africa has long deep-rooted beliefs that have influenced its culture. Traditional religion has always been a part of the African culture where spirits are recognised as spiritual entities that influence a family or an entire community (Turaki, 2000). These spirits can either be bad, bringing misfortune to individuals, or, good, bringing good health and prosperity to a community. It is imperative, therefore, for communities to do everything in their power to appease these spirits, especially for dead older relatives (Turaki, 2000).

However, Christianity came to Africa in the first or second century which began to challenge most of the traditional African religious beliefs (Mazrui, 1986; Turaki, 2000). Islam was also introduced to the continent, resulting in further challenges to the African traditions. Islam is reported to have either been brought to Africa by traders from the Persian Gulf and Oman, in about the seventh or eighth century, starting along the coast or, when Muslims were escaping persecution in Mecca and sought refuge in Abyssinia, now known as Ethiopia, a country situated within the Horn of Africa (Mazrui, 1986). This coming together of three major religions, has greatly influenced the African population's traditions and culture as communities migrated and settled in new locations.

Turaki (2000) asserts that tradition in Africa has a host of specialists who are professionals in their various disciplines such as priests, medicine men/women, diviners, mediums, sorcerers, witches, and midwives. These traditions play a greater role in shaping one's beliefs, leading to certain behaviours and cultures (Turaki, 2000). It is important, therefore, to bear in mind the triple heritage position of the people from MZZ and how that influences their views, culture, and traditions, in particular post-migration to a host country such as Australia and through long-term settlement, thus necessarily including preparation for EOL.

Although there is diversity in language on the African continent, there are similarities in traditions and culture. Similar to the archaeological study by de Filippo (2012), MacCulloch (1951) also discusses the cultural inter-relatedness of Africa's population. This study found

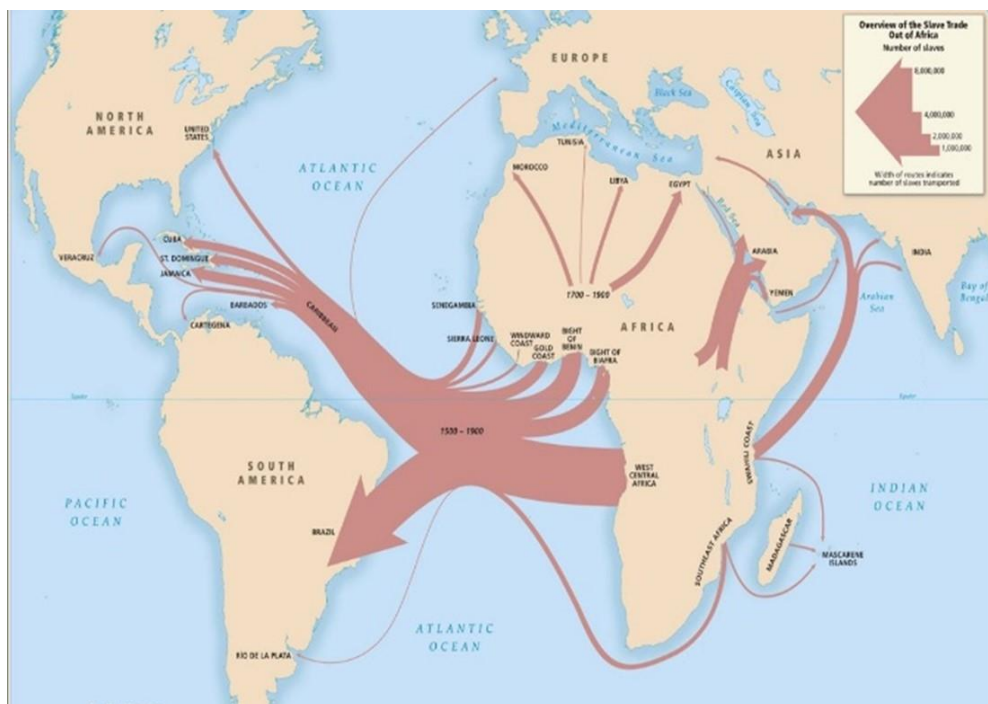
that the Lunda, Luena and related peoples resided in Angola, North-western Zambia, and Katanga in Belgian Congo (MacCulloch, 1951). These parallels are also confirmed by other authors such as Wright (2006) who asserted that during the reign of Shaka, a Zulu chief in South Africa, many people fled northward ending up in Mozambique, Tanzania, and MZZ. While the reasons leading to the population dispersion in the 1800s are debatable, as highlighted by Cobbing (1988), who argued that Shaka was not responsible for the migration during his tyrannical reign, writers agree that population movement did occur (Currie et al., 2013; Omer-Cooper, 1993). This movement also facilitated similarities in culture as populations moved to new environments, intermarried, and blended cultures with the host and the migrant communities.

### **Transcontinental slave trade**

In addition to intracontinental population movement as discussed above, there has also been long-standing transcontinental migration of Africans, especially through the inhumane and brutal practice of slavery (Elliott, 2019; Thomas, 1997). This Transcontinental slave trade involved a number of European countries over 400 years until it was officially abolished in Britain in 1807 and later by 1838 across other European colonial nations (Drescher, 2010). Figure 1.6 below illustrates the slave trade route from where the slaves were captured and then sent to their final destinations. When slaves were in transit from their place of capture to the markets in America or England, they were held securely and unable to escape (Buzasi, 2016). Figure 1.7 illustrates the yoke clipped around the neck, and the chain to link the slaves one to another, forming a single line. The yokes were of different sizes, indicating that among the slaves captured were children as well who were also linked to the single line by the use of chains. While most of the slaves ended up in plantations in America, there were a sizable number that ended up in England (Buzasi, 2016; Thomas, 1997), and it is



this situation that explain how Black African convicts where part of the First Fleet from England to Australia.



Source: Thomas, 1997

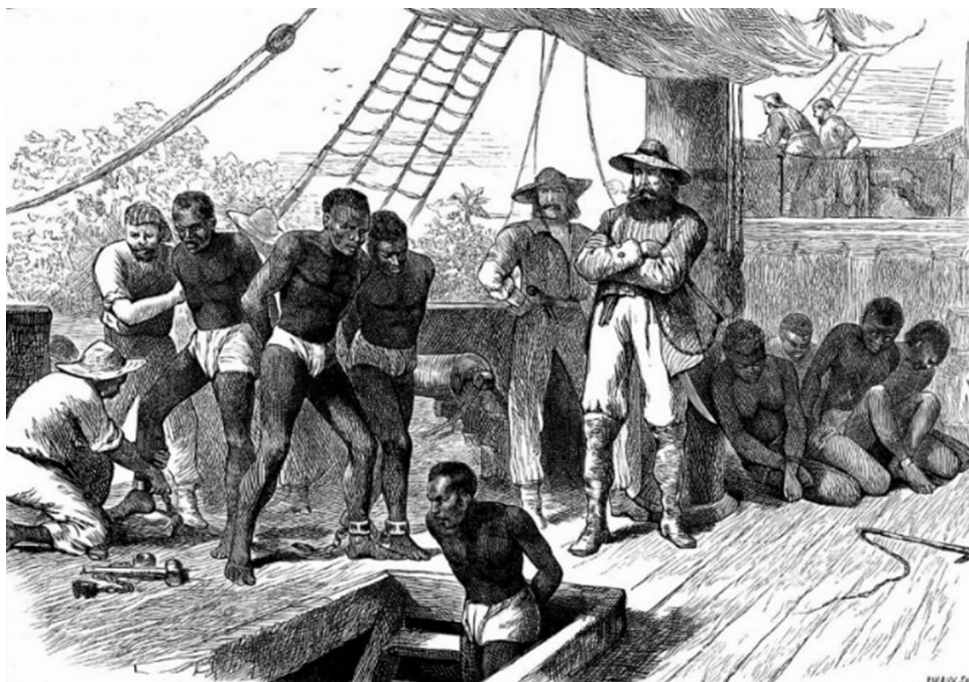
Figure 1.6 Slave Trade route



Source: Thomas, 1997

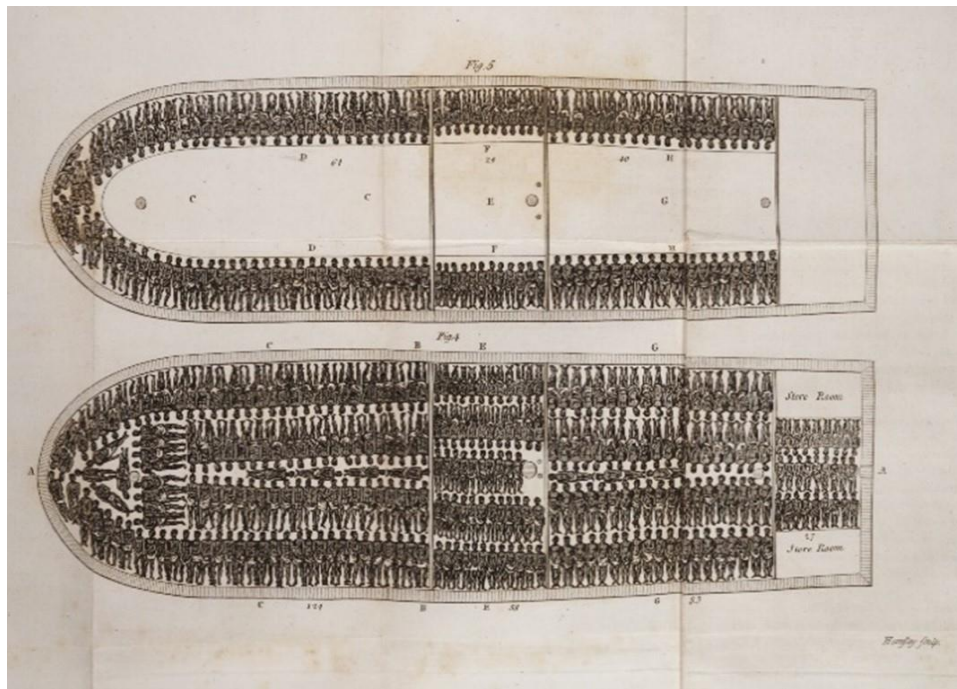
Figure 1. 7 Shackle for slave while in transit

The Portuguese had already been transporting Africans to their plantations in Cape Verde and Madeira to be used as slave labour since 1444 (Elliott, 2019). To maintain a clear conscience, the slave traders sought the blessing of the church. The Roman Catholic Church through Pope Nicholas V, issued a *Romanus Pontifex* in 1455, allowing Portuguese exclusive rights to territories it had claimed in Africa (Elliott, 2019; Thomas, 1997). The *Roman Pontifex* gave the Portuguese authority to invade, plunder, and reduce the number of people in those areas. Although the Dutch were the biggest traders of enslaved people from Africa in the 1600s, there were other nations at play as noted earlier, including Denmark (Elliott, 2019). By 1867, about 12.5 million men, women, and children had been forced into slavery and transported across the Atlantic, to places unknown to them (Thomas, 1997). The journey to the ‘unknown’ was a difficult one for the slaves, they were crammed in small spaces with no proper ventilation. Figure 1.8 illustrates how slaves were forcibly loaded into the base of a ship’s hold; and Figure 1.9 provides a visual illustration of how the slaves were packed tightly and securely into the ship’s hold.



Source: Mintz, 2022

Figure 1.8 : Slaves being forcibly loaded in the Ship’s Hold

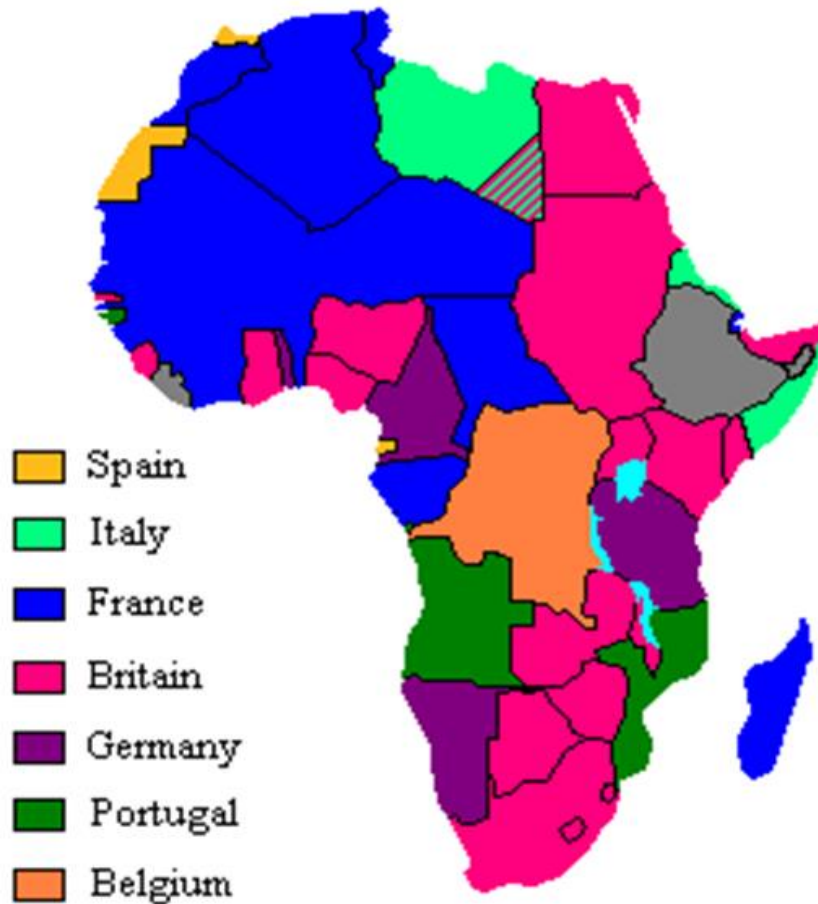


Source: Mintz, 2022

Figure 1.9 Slaves packed like sardines in the ship's hold

## Colonisation

Colonisation also facilitated population dispersion. Africa was colonised by several European countries in the 19<sup>th</sup> century in what has been labelled the ‘Scramble for Africa’ — the invasion, annexation, division, and colonisation of Africa by Western European powers (Pakenham, 1992). The activity of colonisation was termed the ‘Project’. Countries in sub-Saharan Africa were colonised by seven European governments namely, Britain, France, Italy, Belgium, Germany, Portugal, and Spain (Buzasi, 2016). Noteworthy here, Malawi, Zambia and Zimbabwe shared a colonial master, Britain (Gibbons, 1916; Pakenham, 1992). Malawi and Zambia were held by the British as protectorates while Zimbabwe became a British colony (Pakenham, 1992). Figure 1.10 shows a map of Africa divided up according to countries that colonised them.



Source: Griffiths, 1986.

Figure 1 10 Africa divided by colonising country

While colonisation allowed a small number of colonial subjects to travel to colonising countries, they were not able to migrate there. The objectives of colonisation from the outset were economic, financial, political, scientific, and sociological (Gibbons, 1916).

A federation amalgamating Southern and Northern Rhodesia (Zimbabwe and Zambia) and Nyasaland (Malawi) came into existence in 1953 (Żółkoś & Kavaliski, 2008). The federation fostered population movement between the three countries as people moved to look for work or were relocated for the same reason. This led to intermarriages (Robert, 1967; Wright, 2006) enabling cultural sharing and leading to new cultural formations, as communities blended two or more cultures, thus facilitating cultural evolution (Whiten et al., 2011). The



federation had two main aims for the amalgamation namely, economics and governance (Rosberg, 1956). The formation of the federation concretised the three countries' populations even further, as their residents moved freely between countries for work, strengthening the inter-relatedness in culture and traditions. While the federation was disbanded ten years later in 1963 (Żółkoś & Kavaliski, 2008), the legacy of cultural connections continued, despite the eve of political independence looming over the continent.

### **Migration of indigenous Africans to Australia**

The Immigration Restriction Act of 1901, also commonly known as the 'White Australia policy', discriminated against Africans of indigenous heritage from migrating to Australia. In the 1960s when most African countries were going through their independence struggles against colonisation, there was an increase in migration from African states, but this was mainly white South Africans (Willard, 1967). Although there was this tightening of the migration law, small numbers of indigenous African students began to come to Australia. After 75 years of this racist policy in Australia a review resulted in the easing of restrictions. This allowed Africans of indigenous heritage to migrate to Australia, especially following the abolition of **apartheid** in South Africa (Jakubowicz, 2009; Phillips & Spicks, 2012; Australian Government the Treasury and Department of Home Affairs, 2018).

Following the 1980 migration review, migration of indigenous heritage Africans to Australia did not pick up in numbers until the 1990s when increasing numbers started to migrate to Australia for both higher education and work (Khoo et al., 2005; Phillips & Spicks, 2012). Australia, and other Organisation for Economic Co-operation and Development (OECD) countries, saw the potential of Africans as skilled migrants, and began to recruit workers from the continent to fill up their skills shortage (d'Aiglepieire et al., 2020; Woodward, 2009). As Australian migration laws became more favourable to Sub-Sahara

Africans of indigenous heritage, they began applying to Australian tertiary institutions for their higher education (Immigration and citizenship, 2021; Vergalli & Moretto, 2005).

### **First Known Indigenous African Migrants to Australia**

The migration of indigenous Africans to Australia actually dates back to the First Fleet in 1788 which is reported to have carried about 11 or 12 men of African indigenous heritage. These were convicts from Britain who later settled as farmers on land they bought in the Pennant Hills area of Western Sydney (Pybus, 2002). One theory advanced is that these men of had been slaves in Britain (Gergis et al., 2010).

One of the men John ‘Black’ Caesar, was said to have been a runaway slave in America, who fought alongside the British forces in the American Revolution in exchange for freedom from slavery. From the war, Ceasar went to Britain with the returning soldiers where he later encountered difficult situations causing him to steal. He was caught, imprisoned, and sent to Australia on the first fleet (Pybus, 2002). Willian Blue was another African convict who arrived in Australia on the third fleet, and is remembered in the naming of Blue’s Point in Sydney (SBS, 2020) (see Figure 1.11). Figure 1.12 is a picture taken in 1895 also illustrating the presence of African indigenous people in Australia at that time. Thus, African-Australians have been a part of the Australian community for over two centuries. There were 400,000 sub-Sahara migrants in Australia in 2020, of which 58 percent were of Caucasian descent while 42 percent (168,000) were of African indigenous heritage (ABS, 2021). Yet, despite this historical backdrop about the African-Australians, there has been little recognition of this group of individuals being a part of the Australian fabric.



Source: The NSW Library

Figure 1.11 Portrait of William Blue (Billy Blue)



Source: Ancestry.com

Figure 1.12 Afro-Australians: Group picture at Wattle Flat (near Bathurst) circa 1895

## **From migrants to African-Australians**

From the 11 to 12 convicts of African indigenous heritage in 1788 first fleet to Australia from England, it would have been unthinkable at the time to imagine that there would be so many indigenous Africans from sub-Sahara Africa who would call Australia home. Not all Africans have migrated to Australia in pursuit of higher education or work, others have arrived on Australia's shores due to conflict in their countries of origin, such as the Democratic Republic of Congo and Sudan. Their countries have continued to experience war, resulting in displacement of their populations with many ending up in OECD countries (Fang et al., 2020).

However, while the post-independent countries of MZZ have had relative peace for most of the time, other issues such as internal conflicts, poverty and opportunities for education and work have driven the migration, notably driven by the free will of the individuals. This freedom availed to indigenous Africans to migrate to Australia, has enabled them to stay in Australia long term (Healey, 2007).

Many migrants come with their cultures and traditions which may not be aligned to Western culture, such as those held and practiced by mainstream Australians which are aligned to European cultural values. Of significance to this research is how these differences in culture are seen in relation to the health care sector, in particular in accessing health care and the expectations of both migrants and health care providers: the differences often result in misunderstandings between the two groups (Jovanovic, 2012; Mason, 2013).

As has been identified above, the migrants who came to Australia for the purposes of higher education or work, and have stayed for the long term, are now getting older and many are requiring aged care services (Han et al., 2019) and this also indicates there is need to prepare for this population's anticipated increased palliative and EOL care needs. However,

preparation is only possible when the needs of this cohort are identified through dialogue.

This is the intention of this doctoral research thesis.

Fitting into a dominant culture can be a challenge for new arrivals. There have been calls and expectations for migrants to make an effort to become a part of the Australian fabric through acculturation (Rumbaut, 2015). Acculturation is the cultural, physical, and psychological change that occurs when two groups of people from different cultures come into contact. Assimilation is described as a cultural shift by the migrants whereby they totally reject their traditional values and fully embrace the host's values. Assimilation, however, brings with it various challenges to both the migrant and the host community (Rumbaut, 2015). Another scenario is when the migrant completely ignores the culture and values of the host population. The latter two scenarios are considered detrimental to the individual and the community in which they live. On the other hand, there is integration acculturation where the migrant considers both cultures and makes changes or adjustments to become bi-cultural (Rumbaut, 2015). Many indigenous Africans who call Australia home have integrated and adopted this bi-cultural position. They have kept some of their culture from Africa while incorporating some of the Australian mainstream values. It is the bi-cultural position that brings about other challenges when considering the preparations needed for EOL in Australia, in particular because these individuals are often far away from their extended families, but are still connected to them, yet unable to seek the support needed at this vulnerable time.

## **A personal account of migrating to Australia**

### **Arriving in Australia**

I arrived in Australia over two decades ago with my children and husband, who had had the opportunity to undertake postgraduate studies. The preparatory phase of migration from Zambia to Australia brought mixed emotions as I thought about how far away I was going from my extended family - almost ten thousand kilometres - to an environment I knew only from reading. I felt anxious as I thought about what kind of place I was going to: Would I easily find my way around? Would I find friendly people? Would I find familiar food? What kind of cultural shock was awaiting me upon arrival in Australia? While these questions occupied my mind and gave me some anxiety, there was also excitement, looking forward to the adventure ahead. My extended family also went through anxious moments as they were asking many questions including whether we were coming back home after the studies. We were part of a family and community that relied on one another for financial and social support, during difficult times as well as in good times. At this point, we were positive that as soon as my husband completed his studies in Australia, we would return to Zambia. The extended family was reassured that it was a temporary move to Australia. Finally, we arrived in Australia, greeted by many cultural differences.

### **Cultural differences**

We arrived in Western Australia in the middle of a summer with temperatures reaching 40+ degrees Celsius; this weather was different. We were accustomed to more tropical weather, with wet summers and dry winters with average temperatures of only 30+ degrees in summer. I felt as though there was no air to breathe. Air conditioning and the colloquially known 'Fremantle Doctor' - a cool breeze coming in from the ocean - helped us to survive this physical challenge.

During the first few months, I met very few Africans of Malawian, Zambian and/or Zimbabwean indigenous heritage. It was a time of quick adjustment to our identities: Coming from a society predominantly made up of people with a complexion like mine and arriving in a society where our complexions made us the minority. In addition to differences in appearance, the culture was also different, which was a shock to me. For instance, I found it strange that someone would invite a friend for a meal at a restaurant or to watch a movie at the cinema and expect that they pay for themselves. In my culture, when you invite someone for an outing, you are basically saying, they are your guest, and you will cover the expenses. It was also strange for me when I was first invited for a 'barbeque' with the instructions on the invitation that each invited guest 'bring a plate'. Why did they not just say 'bring something to share'? I asked myself. My initial understanding was that maybe the hosts had limited crockery in their home and that was why we were asked to bring plates!

Furthermore, arriving in the middle of summer and living in Fremantle, we also found it strange that people were walking along the streets in their bathers with towels wrapped around their waists, as though they were in a swimming pool area or at the beach. By comparison, the dress code in Zambia is considered modest, with a culture that expects people to be 'adequately dressed'. For example, bathers are only allowed to be worn in and around swimming pool areas (the country is landlocked so there are no beaches), and you are expected to change into appropriate clothing before entering public places.

Language was another area that required us to learn quickly. Although coming from Zambia I was competent in written and spoken English, I found it a challenge to understand some words. I learnt very quickly that there were words that were not typical English in the vocabulary. For instance, not long after we arrived in Australia, I visited an internet café. It was another very hot day outside. After I settled at the allocated computer, an attendant came over to me and asked, "Are you cool?" I answered by telling her that yes, the room was cool,

the air-conditioning was working just fine. The young attendant smiled and explained to me that she was asking if everything was alright. At another time while at work, I was confused when my colleague asked me if I wanted to go for tea. I asked her what she meant because the time was 5.30pm. She explained that 'tea' was the evening meal, which is later followed by a light meal, often a hot drink just before bed, which is called supper. At another time while waiting for public transport, a man walking past raised his hand and said, "How are you going?" I wondered why he asked me that question when I was standing at the bus stop. I thought to myself, surely, he is not telling me that the bus is not coming. But because he also raised his hand and nodded his head, I thought to respond to him by just saying 'Hi'. Later, I asked my colleagues at work why someone would ask me how I was going while I was standing at the bus stop waiting for a bus. My work colleagues explained to me that the man was asking how I was, and that I guessed right by responding to him with a 'Hi'. These are just a few examples of times when I found language confusing and wondered how to respond when I did not understand what the other person was saying.

My family and I found the people around us, whether it was fellow parents at our children's school, my husband's university colleagues or people at my workplace, they were all very helpful in answering our many questions and provided us with some tips about life in Australia. We looked for and identified a church that we were able to affiliate ourselves to. It was initially difficult to make connections and new friends, and we relied on the networks made in the church and through my husband's university colleagues for support and guidance as we settled in. After about three years of living in Western Australia, the population of indigenous heritage Africans living in Fremantle began to grow. I saw more people of my complexion in the streets, and I began to make connections and spend more time with them as a community. We gathered for birthdays, kitchen parties (bridal showers), and even weddings; we became family to each other. Gatherings were not just limited to happy



moments but also in times of distress and sorrow. Occasions that come to mind are two very tragic situations, one where a single mother died in a road accident, and another when a woman, studying as an international student in Australia, was found deceased by her husband and children when they returned home. Both instances called for community support and the community came together to provide that, especially in the absence of extended families of the deceased. These were difficult moments because arrangements had to be made to have family from Africa represented at the funeral here in Australia, a process that was not easy. This meant community members had to give their time and sometimes other resources to assist in achieving the goal of having family representatives travel from Africa to attend the funeral.

These events caused me to begin thinking about my own mortality and how events would turn out if I had of been the one who passed away or required some sort of assistance from my extended family back in Zambia. Thoughts about where I would turn to in such difficult circumstances flooded my mind. I thought about my culture that considered extended family members as close relatives, but they were not here in Australia with me. My mother's sister's children are considered my brothers and sisters and so are my father's brother's children, while my mother's brother's children and my father's sister's children are considered cousins. I had three 'mothers' because my mother had two sisters and one aunty because my father had one sister. These relationships are not superficial, they are glued together. This means that family responsibilities go beyond immediate biological parents and siblings. It was this phenomenon, that ignited my thinking about what would become of me when I am at the end of my life in a place so far away from those I know to be family. In addition to thinking about myself and my immediate family here in Australia, I also considered my responsibilities for my family members back in Zambia, my nieces, nephews, cousins, and parents.

## **Racism**

Racism is something that I experienced and continue to experience in Australia. It is something that I find challenging to understand and difficult to deal with, especially when I first arrived. For the purpose of this discussion, racism refers to the prejudice, discrimination, or antagonism by an individual, community, or institution against a person or people on the basis of their membership to a particular racial or ethnic group (Hirschman, 2004). When we first arrived in Australia, my children were the only two students from an African indigenous heritage at their local primary school. While there were some students who were open to accept them as friends, many did not see them fit to be in their midst. The first few weeks of school in Australia was tough for my son as he faced bullying. The bullying continued into secondary school, and it was so bad that he began to skip one particular class. I was called to the school to discuss his non-attendance in the class which came as a surprise to me. I later found out there was a group of boys in that class that called him derogatory names and threatened him with severe beatings if he reported it to anyone. It was a difficult time.

One other instance of racism: I went into a supermarket and was followed by a staff member, from a distance, through the aisles. I could hear them saying, “watch her, these people like to take things without paying”. The assumption was that I would steal something. But when it came to paying for my shopping at the checkout the cashier went off to talk to other staff, ignoring me, making me wait to pay for the goods.

Applying for rental housing was also an issue, some real estate agents told us that they were not keen to rent a house to a person from my cultural background, a person with my skin colour, because they assumed I would keep the place filthy. My mind cast back to my own country, where people from the West were viewed as individuals who had no culture and were selfish. Although I am too young to recall what colonialism was like in Zambia, there is

still a perception of superiority among migrants from developed countries towards local Zambians.

In light of these views, it would be true to say that everyone is racist, it just depends on how the individual deals with that reality either reinforcing it by acting it out or, consciously refusing to be guided by such thoughts when they come into contact with people of different cultures. In this respect, people choose to be caught up in racial discourse and allow their beliefs to be shaped by inaccurate interpretations or incorrect assumptions about a minority group, in this case, a migrant from MZZ. Serrant-Green (2011) argues that disquisitions on marginalised populations start from mainstream cultures and the missing voices of those affected. This has been my experience and is the driving force to undertake this study; to be seen and to be heard by the mainstream.

These experiences at times made me feel as though I was invisible, yet very much seen when it was convenient. These feelings resulted in deep contemplation of the question: Do we go back to Zambia or stay on in Australia? The thought of going back before accomplishing what we had set out to do in Australia was out of question. We had already spent a substantial amount of money to get this far, and we were not going to abandon the plan. Although friends and work colleagues were helpful, there was still a feeling of discomfort in this new culture, especially with racial profiling evident.

### **Raising Children**

Our children were quickly adapting to the Australian culture as they interacted with other children at school and at church. It was as if they had been in Australia for many years. Their friends invited them to activities such as sleepovers. I found it very strange that parents would organise an event whereby children would be allowed to stay up late at night playing video games or watching movies. I wondered how I was going to raise up my children in such an

environment while at the same time, observing my own culture. I was well aware that culture was not static, having found some differences in my culture when I went back to Zambia to visit after four years of being in Australia. Although the changes were minor, I noticed the differences. Nonetheless, there were still those values that were deeply embedded in my culture that I did not observe in the Australian culture, and I was concerned my children would lose this as they immersed themselves in the Australian way of life.

In my culture, anyone older than me, even if not related would be referred to as uncle or aunty. It was surprising when older people declined such titles: perhaps because they were not related or felt the titles made them feel too old. Additionally, no one wanted to be referred to as Mr ... or Mrs .... Younger people called older married people by their first names. This was unusual for us, and it felt very odd. When on the bus or train, I noticed that older people would sometimes decline any courtesy from younger people trying to offer them a chair to sit down while the younger person stood up. Sometimes it was younger people who did not want to offer seats to the frail or older people. Those were automatic actions that would happen in my culture and would be appreciated by the older person, but not so here. This was a shock for me. I wondered if I had done the right thing by bringing up my children in Australia.

The difference in the concept of family and responsibilities towards the family unit was also something that I could not get my head around. In my culture, the family looks after the older members, sharing the caring role among family members, female carers for an older woman, and male carers for an older man.

I gained employment in an aged care facility in Perth, and I looked after residents who had daughters, sons, and grandchildren. While it may be understood why these residents were in an aged care facility, I could not understand why some of them were not being visited by their families. This scenario made me feel sad, I started to think about what would happen to me if I were in that situation, coming from an extended family arrangement, where caring for

the sick and elderly was everyone's business. However, in my mind, the cultural concerns did not outweigh the benefits of my children being in Australia, such as educational opportunities. It is these benefits that played a significant role in deciding to stay in Australia while also being mindful of my connections and responsibilities to family in Africa.

I regularly talk to my extended family in Africa on the phone, to learn what is happening at any given time and if there are any needs I can assist with, such as school requirements for extended family relatives' children, contributions for occasions like weddings, funerals and other major milestones that happen in life. Going back to visit is also important to keep those connections and to get to know younger family members growing up so that I do not become a stranger whenever I visit.

### **Initial Plans Change**

From the time we arrived in Australia, the plan was for my husband to study, for me to experience what it was like working in Australia, for the children to go to school and eventually we would all go back to Zambia. This was the view we held for many years. Until one day when one of our children got married and started a family. My thoughts began to change from planning to go back to Zambia to thinking about where my responsibilities lay in Australia. I thought about what would happen if my daughter could not find help with her children if I went back to Zambia; I asked myself, how would I benefit from leaving my children and grandchildren in Australia? That question bothered me as I reflected on it and realised that going back to Africa would disadvantage my family in Australia. Additionally, I thought I would feel unsettled if I lived in Zambia while my children remained in Australia. And so, after considering all the pros and cons, a decision was made to stay in Australia for the long term. However, our responsibilities in Africa have not ceased. I have extended family members with whom I feel closely connected, I maintain my support of them, and I

communicate with them from time to time, and so I still feel connected to that community. As I considered all of the above, I wondered if there were other Africans who were experiencing similar tensions within their own lives and if they were also preparing for EOL in Australia.

## **Personal and Professional Background**

Constructivist grounded theory acknowledges the researcher's background as significant in data analysis and theory generation, and co-constructing with the research participants (Charmaz, 2006). I graduated as a registered nurse in Zambia where I worked for a considerable number of years before migrating to Australia. My professional experience is in palliative and hospice care in both Zambia and for the past 20 years in aged care in Australia. I have completed a Masters in Palliative Care (coursework) which has continued my interest in this field of research. Caring for residents in aged care and providing EOL care has been the key driver to arrive at this particular research topic, and also because I am a migrant who is thinking about her own mortality. Therefore, with my extensive nursing experience in palliative care, as with my experiences of being an Africa migrant in Australia, I am well-suited to undertake this important study.

As a nurse, the primary assumption I bring to this study is that migration necessitates a change in thinking about health and wellbeing including EOL preparation. Health and wellbeing are fundamental to every individual whether in their original home or in their host country following migration (Mwanri et al., 2012; Nyen & Tveitn (2018). Additionally, there is an evidence suggesting that migrants from MZZ living in Australia are not accessing palliative and EOL, and thus these factors need to be investigated.

## **Theoretical perspectives**

I have chosen to consider the theoretical perspectives of the science of nursing and knowledge of being a migrant as they inform this study. Nursing science aims to generate knowledge about the phenomenon of nursing in relation to humans as caring beings (Fjelland & Gjengedal, 1994). The migrant perspective aids in understanding migrant issues pertinent to interaction with the healthcare system in Australia. Together, both the nursing science and African migrant are the lenses through which the literature and data for this research has been viewed and analysed, therefore, they have a significant bearing on the generation of the findings and substantive theory in this research. Additionally, symbolic interactionism which considers interaction as a way by which humans interpret and ascribe meaning to their experiences and of their world (Carter, 2019), has also assisted in providing a framework for understanding the paradigms within which migrants from MZZ are contending as they consider preparing for EOL in Australia.

## **Purpose of the study**

The purpose of this study is to explore perceptions of migrants from Malawi, Zambia, and/or Zimbabwe in Australia about their preparation for EOL.

### **Research question**

- How do migrants from Malawi, Zambia, and/or Zimbabwe prepare for end-of-life in Australia?

### **Research objectives**

1. Describe the experience of migration and settlement in Australia in relation to planning for end-of-life for migrants from Malawi, Zambia and/or Zimbabwe.

2. Examine family relationship structures and their impact on preparation for end-of-life for migrants from Malawi, Zambia and/or Zimbabwe.
3. Describe the social processes of African migrants from Malawi, Zambia and/or Zimbabwe as they prepare for end-of-life in Australia.
4. Develop a substantive theory on preparing for EOL by migrants from Malawi, Zambia and/or Zimbabwe living in Australia.

### **Significance of the study**

The Australian government recognises the relevance of beliefs, cultures, values, and traditions in relation to provision of palliative and EOL care for CaLD communities (Palliative Care Australia, 2018). African migrants of indigenous heritage are an emerging population in Australia, that require further research to understand their palliative care needs in order to enable Australian health professionals prepare for increased palliative care needs of an ageing African migrant population. This study contributes to the body of knowledge on MZZ migrants of CaLD backgrounds and their EOL care needs in Australia. It is also anticipated that the study will identify areas for further research in palliative and EOL care for MZZ migrants. In addition, the study has implications for practice as it provides more insight to enable health workers better understand MZZ migrants' palliative and EOL needs during care planning and to understand the key factors surrounding death and dying within this community. Furthermore, the results of this study will be beneficial to policy review on palliative and EOL care for MZZ migrants, by providing an explanation for barriers to accessing palliative and EOL currently being experienced by MZZ migrants of CaLD background in Australia. This understanding will inform a review of culturally appropriate palliative and EOL care service provisions.



## **Thesis structure**

This Chapter 1 has set the scene for this thesis, presenting the topic to be researched, providing a brief historical context of the migration of African people over a period of time, explicating the aim and purpose of the study, and highlighting personal reasons for engaging in this research. Personal reasons include my connections with the study and the assumptions I have brought to the project. A preliminary discussion of the significance of the study provided a context and rationale for this research.

Chapter 2 presents the pertinent background literature review informing this study, beginning with an overview of the palliative and EOL care situation for migrants of CaLD backgrounds in Australia. This is followed by the exhibition of my co-authored published article entitled “Palliative and End-of-Life Care Access for Immigrants Living in High-income Countries: A Scoping Review” (Phiri et al, 2023). Following this an updated literature review is presented.

Chapter 3 presents the methodology of grounded theory, and the methods used in this study. Firstly, the historical perspective of grounded theory is articulated, then secondly, the methods used in the research is outlined including their philosophical underpinnings and the epistemological position to provide rationale for using the grounded theory methods. Participant sampling, ethical considerations, and data collection and analysis is also explicated.

Chapter 4 presents the study findings, starting with the demographic data of the respective participants, followed by an overview of the analysed and synthesised findings before delving deeper into the study findings, presenting excerpts from participants. The chapter identifies and introduces core categories that emerge from the data analysis: Remodelling self; disintegrating of family dynamics; resetting the life button; shuttling back and forth; finding equilibrium; and pursuing the horizon.

Chapter 5 progresses into the substantive theoretical development of the Dynamic Process of Toing and Froing (DPTF), which emerges from the core concepts as discussed in Chapter 4. This chapter articulates the step-by-step process of constructing the grounded theory using the core categories identified, commencing from the collection of data to analysis.

Chapter 6 discusses the findings of this research which focuses on the interpretation of the study findings in light of the existing body of literature on the topic of preparing for EOL in Australia for migrants from Africa, specifically those from MZZ.

Chapter 7 provides recommendations for policy in palliative and EOL care in the context of migrants of CaLD background and suggests future areas of research. The implications for policy and practice within the palliative and EOL service provision to MZZ migrants of CaLD backgrounds in Australia is discussed followed by an overview of the limitations and strengths of the study. This chapter concludes the thesis.

## **Summary**

This chapter has provided the background for this research with an overview of African migration from the slave trade to colonisation which influenced the movement of peoples and their culture. It also provided an explanation as to what is understood by EOL care in the context of palliative care. The historical and cultural connections among three African nations, Malawi, Zambia and Zimbabwe were briefly discussed to highlight the significance of MZZ as a unique region of Africa whereby migrants hailing from there and living in Australia share a similar background that has some bearing on their experiences of settlement in Australia, hence the reason to focus this study on migrants from MZZ, living in Australia. Importantly, this chapter has also provided my own personal account of migration which lends to the development of grounded theory in this thesis. The following chapter explores the literature on this topic and themes.

# Chapter 2: Literature Review

## Introduction

Chapter 1 provided a brief history of African migration and briefly discussed the significance of MZZ as a unique region of Africa and outlined my personal and professional credentials and reasons for undertaking this research according to grounded theory.

This Chapter 2 presents a review of the literature in its 2023 published form, co-authored with my supervisory team and entitled: “Palliative and End-of-Life Care Access for Immigrants Living in High-income Countries: A Scoping Review”, in *Gerontology and Geriatric Medicine*, (Phiri, et al, 2023). This review considers migrants from CaLD backgrounds across OECD countries and is not specific to African migrants in Australia. After this publication is exhibited, an update to the literature review is provided by detailing the search for literature and published articles ranging from December 2021 to January 2024.

Grounded theory in its traditional sense is not supportive of conducting a literature review prior to starting research (Charmaz, 2006, 2014; Polit & Beck, 2006). Constructivist grounded theory studies, however, suggest the need to review the literature to learn about the respondents’ world before entering it because respondents do not have the opportunity to teach the researcher about their world, they just talk about it (Charmaz, 2014). Nonetheless, constructivist grounded theorists generally do not support doing an in-depth pre-research literature review. They argue that an in-depth review would result in having preconceived theoretical ideas that could influence the interpretation of research findings (Glaser, 1978). Polit and Beck (2006) agree with this notion asserting that the researcher's conceptualisation of the phenomenon under study may be unduly influenced by previous studies. Creswell and Poth (2018) further argue that not carrying out an extensive literature review at the

commencement of a research project, helps the researcher to focus on generating theory from the collected data. Nonetheless, for this study, a cursory literature review was conducted at the outset of the research to serve as a starting point for the study. Then a more comprehensive and focused review was conducted later in relation to the study findings. The literature discussed in this Chapter is on palliative and EOL care access for migrants.

The movement of people around the globe in the past 30 years has created culturally diverse communities, especially in developed countries, including Australia. Ageing and dying away from their countries of origin for these migrants is attracting some attention, because there is scant evidence-based research conducted on this cohort and thus very little is known about their palliative and EOL care needs. Dying in a foreign land can be difficult to imagine especially for individuals coming from CaLD communities who practice collectivist cultures and collective decision-making. Palliative and EOL care can be challenging for individuals when they live far away from their home countries, with no extended family members present. Below, my published scoping review on palliative and end-of-life care access for migrants living in high-income countries, is presented with the aim to highlight the significance of this present study.

# Palliative and End-of-Life Care Access for Immigrants Living in High-income Countries: A Scoping Review

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## Abstract

This scoping review aimed to explore what is known about palliative and End-of-Life (EOL) care access by immigrants with culturally and linguistically diverse (CaLD) background living in high-income Organization for Economic Co-operation and Development (OECD) countries. CaLD immigrants have low utilization of palliative care services with patients' family members taking up the role of caring, leading to immigrants not fully benefiting from the specialized services that are offered to alleviate suffering and promote quality of life. While there is some research in this area mainly in Europe, it cannot be said about all high-income OECD countries. Achieving person-centered care in high-income countries, requires identifying and addressing barriers to care access, especially by immigrants with CaLD background. Five-stage methodological framework by Arksey and O'Malley was used to undertake the review. Immigrants in OECD countries experience challenges in accessing palliative and EOL care services. The review also identified limited literature on the subject and establishes need for more research on the subject.

## Keywords

palliative care, decision-making, end-of-life, advance care planning

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## What this paper adds

1. Challenges health care professionals to establish at the onset, EOL preferences of patients from CaLD backgrounds especially in the area of decision-making.
2. Health care professionals and patients to co-designs EOL care strategies.
3. Health professionals to consider incorporating spiritual care and or other treatments that maybe unfamiliar in the healthcare setting but can bring comfort to the patient.

## Applications of study findings

1. At policy level; as policy makers consider improvements and reviews to palliative care for CaLD populations in the local geographical areas.
2. At healthcare professional level; training staff on how to approach the subject with patients who consider it taboo.
3. At CaLD community level; sensitization of the community to work with healthcare workers, to feel comfortable to express what their care needs are so that care strategies can be co-designed.

promote comfort for the patient (Department of Health, 2018). Immigrants from CaLD background in high-income OECD countries have low utilization of palliative and EOL care services. As a result, patients' family members take up the role of caring, leading to immigrants not fully benefiting from the specialized services that are offered, to alleviate suffering and promote quality of life (Shabnam et al., 2022). The situation has become more pronounced due to the increased rates of movement of people across borders from low to high-income countries, the final destination for most immigrants (McAuliffe et al., 2022). This has created culturally diverse communities, posing challenges in attaining the desired quality palliative and EOL care for all, especially CaLD immigrants (World Palliative Care Alliance, 2014).

Globalization, the interdependence of economics, cultures, populations, and other human activities across

## Introduction

Caring for individuals during palliative and EOL stage, reflects compassion as symptoms are managed, to

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borders, is a concept that dates back centuries. However, it became more prolific in the early 1960s with easier and quicker travel (d'Aiglepiere et al., 2020; Triandafyllidou, 2018). Technology has also played a big part in globalization, facilitating exchange of information and migration. Inevitably, this has led to migrants dying away from their country of origin (Bray et al., 2018; OECD, 2017). Literature reviews undertaken in this area in the recent past identified communication, culture (Gerber et al., 2020; Kwok et al., 2020; Shabnam et al., 2022), limited knowledge and awareness of health information (Gerber et al., 2020; Shabnam et al., 2022), collectivism (Gerber et al., 2020; Kwok et al., 2020) and lack of focus from migrants' perspective (Kwok et al., 2020) as barriers to utilization of palliative care services by immigrants.

Worldwide, there were 272 million international migrants in 2019. Of the total migrant population, 120 million (over 44%) were to OECD countries (d'Aiglepiere et al., 2020; OECD, 2022), because of economic benefits (OECD, 2022; Phillips & Spicks, 2012). The OECD is an organization of 38 market-based economies which work collaboratively to develop policy and standards for sustainable economic development (Woodward, 2009). Within the OECD, there are low-income countries but, migrants target the high-income countries as their destination. This migration trend is projected to continue; therefore, it is important to incorporate practices that would meet person-centered palliative and EOL care needs of all, including immigrant populations.

A scoping review of relevant articles published between 2009 and 2021, was conducted to explore palliative and EOL care access by CaLD immigrants in high income countries. Included in the review were papers from Australia, Canada, Sweden, New Zealand, and the United States of America.

## Aim of the Review

The aim of the scoping review was to gain greater understanding of access to palliative and EOL care services by CaLD immigrants in high income countries.

## Review Question

What is known about CaLD immigrants in high-income countries access to palliative and EOL care services?

## Methods

The scoping review utilized the five-stage methodological framework namely, identifying the research question, identification of relevant studies, study selection, charting of data, and collating and presenting the results (Arksey & O'Malley, 2005).

## Inclusion and Exclusion Criteria

Pre-planned inclusion and exclusion criteria were used to maintain consistency. The first author

conducted the review with the oversight of co-authors who are also supervisors, to ensure relevance, accuracy, and high quality of evidence available. Literature included were of primary research studies from 2009 to 2021, from high-income countries of the OECD, related to palliative and end-of-life care access by CaLD immigrants, with full text and in English. Excluded were literature over the same period on palliative and EOL care access by indigenous or minority ethnic groups. Articles about palliative care for immigrants of English-speaking background were not part of the review. Also excluded were articles from low to medium-income countries of the OECD, as well as systematic and scoping reviews. Reference lists were reviewed for additional resources.

## Search Strategy

A comprehensive strategy was developed for literature search by the authors which included the search terms "Palliative care," "end-of-life care," "cultur\*," "migrant\*," and "OECD countries."

The literature search was conducted in November 2022 using Google Scholar, Medline, CINAHL, and PsychINFO databases.

## Data Charting

Data analysis was facilitated by extraction of data from included articles which were recorded onto a spreadsheet under the following headings: Author/s and Year Published, Study aim/s, Sample and Methods, Where study conducted, and Key findings (Peters et al., 2020). Data extraction (Table 1) Appendix 1, provides information about articles included in the scoping review.

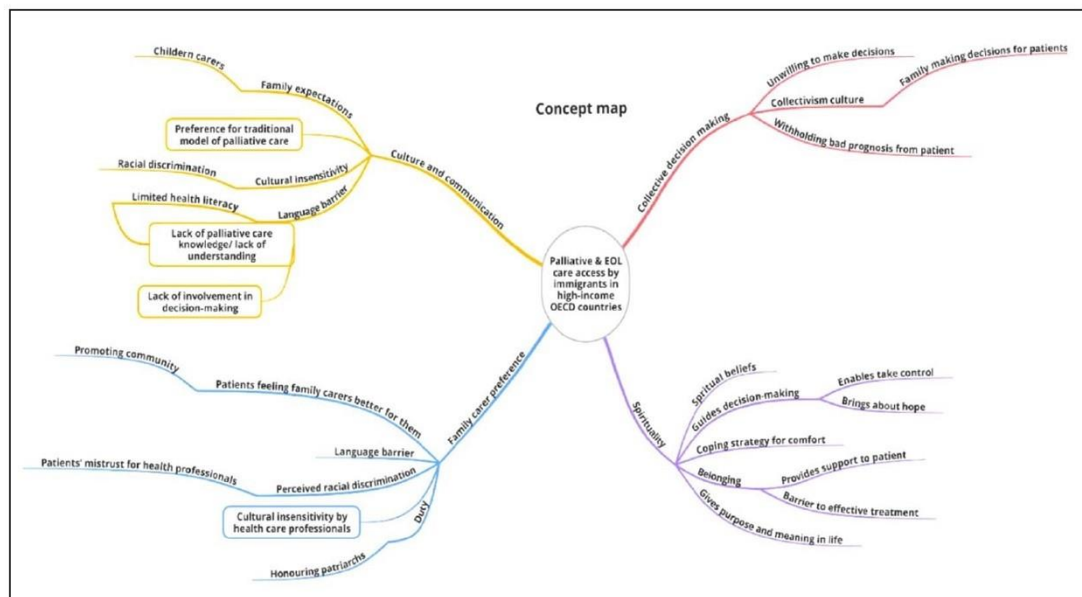
## Selection of Evidence

Articles reviewed included two New Zealand qualitative and interpretive phenomenology studies (18 and 10 participants respectively), five Australian studies using survey (239 participants), case study (1 participant), focus group (15 participants), qualitative descriptive study (a family of six), and a qualitative study (30 participants). Other articles included were a Swedish study using national quality register to investigate 81,418 deceased patients in relation to palliative care, a Canadian focus group study (6 participants) and two United States of America (USA) studies; a case study (1 participant) and a qualitative study (13 participants).

## Findings

This literature revealed barriers to accessing palliative and EOL care by immigrants in high-income OECD countries. The identified barriers are discussed under four main themes including: culture and communication; collective decision making; spirituality; and family carer preference. Figure 1 illustrates the complexities





**Figure 1.** Palliative and EOL access concept map.

related to palliative and EOL care access by immigrants of CaLD background.

Figure 1 illustrates the four co-concepts of barriers to accessing palliative and EOL care by immigrants of CaLD background in OECD countries. Each co-concept commences with elements in the peripheral, which culminate in the identified co-concepts largely responsible for negatively impacting the care service access by immigrants of CaLD background.

### Culture and Communication Barriers

All the studies discussed culture, two of them specifically included culture and communication barriers (Hiruy & Mwanri, 2014; Kirby et al., 2018). Culture plays an important role in how individuals understand, experience, and manage illness (Germov, 2014) including palliative and EOL care choices and decision-making. The literature suggests that lack of access to, and use of palliative and EOL care services by the CaLD immigrant population in high-income countries, was partly due to cultural and communication barriers (Bray et al., 2018; Hiruy & Mwanri, 2014). Knowledge about palliative and EOL care services was minimal or absent in these communities and this also was attributed to communication and cultural barriers (Sneesby et al., 2011). For example, participants reported that in Sudan, they relied on herbs and plants for medicinal purposes which were not available in Australia. The palliative care concept was described to participants by the researcher, as care aimed at promoting and improving quality-of-life for the dying person by managing symptoms.

After gaining an understanding of the concept, older community members reported a preference of the traditional model of families taking care of the dying without involvement of specialist palliative care teams, while the younger members of the community were observed to be receptive of the western palliative care concept. Older community members sought medical treatment for symptoms however, participants reported that the prescribed treatment may either be discontinued or medications may be shared with other family members, rendering treatment ineffective (Sneesby et al., 2011).

In another study, older adults and adult children's groups preferred family carer arrangements, citing language barriers and cultural insensitivity by healthcare workers (Eckemoff et al., 2018). For participants who migrated to the USA as adults, language was a significant barrier as most participants did not speak English and there was no palliative care information written in Russian accessible to them. Hospice staff also alluded to the fact that it was a challenge to care for clients from a different linguistic and cultural background due to lack of knowledge about patients' cultures and language. Similar cultural issues were also identified with Latino patients in the USA (Smith et al., 2009).

In their study, Smith et al. (2009) explored ways of improving care delivery to immigrants in the USA. The participant expressed culture and racial discrimination as some of the barriers to accessing palliative care. In addition to the perception of cultural and racial discrimination, this participant had health literacy challenges which resulted in communication barriers. As a result, relied on family for explanation of the health information provided by health care staff. This usually led to

patient's lack of understanding of information provided as well as lack of involvement in decision making.

The two USA studies (Eckemoff et al., 2018; Smith et al., 2009) found that cultural barriers and racial discrimination led to mistrust for the clinical care system. The hospice staff confirmed that the care provided to CaLD was not up to standard, stating that communication with patients was the main reason for providing "substandard" care (Smith et al., 2009). Culture as a barrier to accessing palliative care was not unique to studies in the USA, New Zealand reported similar findings.

Bray and Goodyear-Smith (2013) study also reported that culture was one of the major barriers to accessing palliative care. The findings were again observed in Bray et al.'s (2018) phenomenological study. Participants preferred to receive care at home to promote continuity of social connection to their community. Family caregivers, predominantly adult children of patients, wanted to provide EOL care in their own homes as a way of honoring the patriarchs which was very important in their culture (Bray et al., 2018). The similarity in the findings suggests that not much, if at all, had changed in 5 year between the two studies.

The theme of culture influencing palliative and end-of-life care resonates through many studies of immigrant populations. For instance, the study of the terminally ill among Indian immigrants in Australia (Shanmugasundaram & O'Connor, 2009) also identified cultural insensitivity as a barrier to accessing formal palliative and EOL care. Families reported that they preferred to care for their dying relatives within the family. Additionally, the study also found that caring for the dying by family members in this immigrant community, was perceived as an honor by the family carer, similar to Bray et al.'s (2018) study findings. Australian studies have also reported communication as barrier to accessing palliative and EOL care by immigrants adding that linguistic difficulties contributed a great deal to care access. It is important to understand patients' cultures in order to communicate in a manner which will not be construed as insensitive, bearing in mind that in some cultures, discussing palliative and EOL, including death, can be seen as taboo (Gerber et al., 2020).

The Canadian study on awareness of palliative care and EOL opioids use (Maddalena et al., 2013), had similar findings as the Australian study among the Sudanese, and included the issue of not being aware of available palliative and EOL care services (Hiruy & Mwanri, 2014). These studies demonstrate that communication can be a barrier to health literacy in relation to palliative and EOL care which can lead to limited access to services. While the studies identified above found communication and culture as barriers to accessing palliative and EOL care, one study (Carlsson & Hjelm, 2021) only reported on the difference in access to palliative care between Swedish-born patients and foreign-born, reporting that the Swedish-born patients accessed the services more than the foreign-born. The reason for not providing more information on the access ratios between

the two population was because the study was conducted using deceased patients' registers.

## Collective Decision Making

Collectivism is a cultural phenomenon where people within the group are interdependent and prioritize the objectives of the group over individual goals (Krassner et al., 2017). Collectivist decision-making is predominantly practiced in simple, tight indigenous communities (Triandis & Suh, 2002) whose values are focused on the wellbeing of the extended networks not just immediate family members (Krassner et al., 2017). There are two types of collectivism identified in literature; vertical which emphasizes on solidarity and respect for authority within the group and, horizontal which values empathy, sociability and cooperation in the community (Triandis & Gelfand, 1998). Communities that adhere to collectivism values usually practice the latter as demonstrated in three studies included in this review (Hiruy & Mwanri, 2014; Jeong et al., 2015; Sneesby et al., 2011). In these communities, important decisions such as accepting that the individual is dying therefore, not requiring life-saving treatment, are generally made at family or community level (Hiruy & Mwanri, 2014).

To illustrate the horizontal collectivist approach, Hiruy and Mwanri (2014) reported that the individual at the center of the event may participate in the discussion in relation to their goals of care but, final decisions were made by elders in the family or community group. Family could withhold information provided by the health care professionals if they felt that the information would be too big a burden to bear by the person (Hiruy & Mwanri, 2014; Yoong, 2015). Sneesby et al. (2011) in their study with African immigrants in Australia, found that bad news about disease prognosis was provided to the patient only when it was felt that the patient had adequate support to handle and process the news, thereby preventing any potential self-harm. Smith et al.'s (2009) also identified collectivist decision-making practices as decisions were made by the patient's partner without involvement of the patient. The authors reported that the patient had a different opinion about her care from her partner who was unwilling to talk about comfort measures. His focus was on treatment and cure, even after being advised that the leukemia was very aggressive and nothing else could be done (Smith et al., 2009).

Collectivist cultures as opposed to individualism (Hiruy & Mwanri, 2014; Jansky et al., 2019) could be the reason why decision-making is considered a communal responsibility in some communities. The Australian study about awareness of advance care planning in older patients of CaLD background demonstrated the collective decision-making practice and found that advance care planning uptake was low (Jeong et al., 2015). This could suggest unwillingness by patients to make EOL decisions, leaving that to their children to decide on their behalf, reinforcing the collectivist values. Considering Smith et al. (2009)



example, staff, as patients' advocates have an obligation to check with patients if they want to make their own decisions or would like to rely on the family. In addition to communication, spirituality also plays a significant role in seeking quality palliative and EOL care.

### Spirituality

The theme of spirituality was identified in four studies included in this review (Hiruy & Mwanri, 2014; Kirby et al., 2018; Smith et al., 2009; Sneesby et al., 2011). Spirituality is considered an important part of an individual, whether they are religious or not (Shaw et al., 2016). Coping during times of ill-health can be difficult and spirituality has been reported to be a source of comfort for some immigrant CaLD communities (Hiruy & Mwanri, 2014; Kirby et al., 2018; Sneesby et al., 2011). Hiruy and Mwanri (2014) observed in their study that, spirituality was an important aspect during EOL care for the patient. Decisions made during this time, were based on spiritual beliefs and cultural norms. In addition, religious leaders took a leading role in visiting and encouraging the patient as he went through a difficult time. The community to which the patient belonged was religious too and, was also a source of comfort for the patient. Another Australian study, demonstrated religious faith can be a coping mechanism when one is faced with life threatening situations (Kirby et al., 2018).

In addition, spirituality is said to give a person purpose in life and guidance in decision making when faced with dilemmas in life (Cassidy & Davies, 2006; Matandiko, 1996; Shaw et al., 2016). This aligns with what psychologists have identified in people faced with difficult situations in health matters (Shaw et al., 2016). Cassidy and Davies (2006) also assert that, apart from giving meaning and purpose, spirituality may help individuals identify their role in their EOL care and in turn, enable them take control of situations, bringing about hope. Having hope through spirituality when in a dire situation can be seen in Smith et al. (2009) study.

Smith et al.'s (2009) demonstrated that spirituality could give hope when the situation is irretrievable. However, what is perceived as a coping strategy could also be a barrier to effective symptom management in palliative and EOL care as this study demonstrated. The patient's need for comfort measures was ignored because the partner who was the decision maker, was focused on praying for her to get better, insisting on medical staff to persist with treatment. Ineffective symptom management may lead patients to assume that being cared for by family, would be a better option.

### Preference for Family Carer Over Healthcare Professional

Cultural and communication barriers as well as collective decision making, are precursors to individuals preferring to be cared for at home and families wanting to

care for their loved ones (Eckemoff et al., 2018; Shanmugasundaram & O'Connor, 2009). While some acknowledge that assistance from EOL care service provider organizations would be the best way to care for their loved ones at home, most immigrants feel it is their obligation and honor to provide EOL care to their family member (Eckemoff et al., 2018; Shanmugasundaram & O'Connor, 2009). This is perceived as a duty they must do, and the patient feels that they must be cared for by family. Others choose to be cared for by family because of distrust of health care workers due to poor adaptation to the host country (Jansky et al., 2019).

Older Russians preferred family to look after them and their children preferred to be carers, stating that they would not wish to have their parents "locked up." However, in the same study, there were other participants who expressed different opinion, stating that the society needed to take some responsibility in caring for seniors (Eckemoff et al., 2018). This was a single voice amongst many, as most older immigrants felt caring for parents on EOL was the responsibility of their children.

### Discussion

There has been a call within these countries to address immigrants' access to palliative and EOL care services yet, there is still a long way to go to realizing the dream of accessible palliative care for all. While accurate estimates of how many immigrants utilize the services are not available, it is evident from the literature reviewed that there are significant barriers that need to be urgently addressed to turn the tide.

Experiencing EOL free from pain and with dignity, is something that is widely accepted however, the manner in which these are achieved vary from one community to another, largely dependent on the culture (Clark, 2012; Green et al., 2019; Speck, 2016). Culture is critical in an individual's life; significant decisions are shaped by one's cultural beliefs. When individuals emigrate, they carry with them their cultures which mostly are different from that of the host country. To access care by immigrants with CaLD background, there needs to be an understanding of, and respect for their cultural needs by the palliative and EOL care service providers (Green et al., 2019). Historically, discrimination, racial profiling, and marginalization are realities that impact on seeking health care services (Schuster-Wallace et al., 2022). The solution lies in addressing the identified vices so that immigrant communities can develop trust in the health care system, something that has been eroded. Establishing groups to engage with CaLD immigrant communities in OECD countries on issues of health, would be of benefit to both care providers and service users (Quinn & Hickey, 2008). Such an engagement would assist in establishing beliefs, values, and practices of CaLD communities which do not always correspond with palliative care policies. Once patterns are established, they would serve as a guide for policy

reviews in seeking to match them according to patients' needs (Clark, 2012) with involvement of service users (Sbaiti et al., 2021).

Cultural sensitivity by health care providers toward CaLD patients, is of paramount importance in encouraging them to utilize the services especially EOL care. Sensitivity requires recognition that not all cultures are the same, or even similar and that an effort should be made in identifying the different cultures of patients to gain confidence and trust (Schuster-Wallace et al., 2022). Culture specific engagement in palliative care is the key to accessibility by immigrant communities (Quinn & Hickey, 2008).

Cultural context and effective communication can promote comfort for the patient, essential for making informed decisions by patients in the palliative care situation. Therefore, it is important for service providers to be competent in culturally effective communication (Green et al., 2019; Long, 2011). Communication is an important part of interaction required between service users and service providers. Literacy deficits, compounded by being in a new environment, with an unfamiliar health care system can be quite daunting for immigrants. Older immigrants usually tend to depend on their children for interpretation when they visit the health care system (Sungur et al., 2022). However, attending primary health care with a family member may not always be possible. Setting up communication tools such as language cards at general practitioners, the first point of contact for immigrants in the health care system, would assist in providing information, and promoting appetite to access health care services by CaLD communities (Saito et al., 2021). General practice needs to be equipped with knowledge, skills, and time to enable them to orient the new immigrants to the new health care system. This would enable immigrants to be confident in the system which would translate into usage of the health care services. Good and honest communication is foundation to accurately assessing patients' needs and communicating empathy thereby promoting comfort (Amoah, 2011). Communication is all encompassing, however, non-verbal which is related to body expression, can be powerful where language barriers exist (Richmond & McCroskey, 2019; Steinfatt & Millette, 2019). Body language can transmit either positive or negative messages to the patients which can promote trust or reinforce the already existing barriers. Service providers must therefore be aware of their own communication skills and be able to read the non-verbal communication from their patients (Byrne, 2008). Communication also plays vital role in helping patients understand information provided relevant for making decisions.

### Collective Decision-Making

Differences in decision-making process between CaLD immigrants and health care providers translate into differences in the understanding of the issue with the two

groups having different expectations (Cain et al., 2018). Palliative care is based on individualistic approach and there is an expectation that the patient themselves get a say in their care. In CaLD communities, families are usually intermediaries between patients and service providers, shifting the autonomy that western medical systems emphasize on, leading to discomfort on the side of care providers (Bullock, 2011; Ho et al., 2010). This is a clash that creates a problem and results in tension and the palliative care team maybe getting frustrated with that form of decision-making process. To address that tension, palliative care professionals, need to be bolder in asking about how the patient wants to make decisions, who they want involved in decision-making, how to disseminate any information to the patient, if they would like to receive the information themselves or through significant others. Allowing the patient to nominate how they would like important issues in care partnership addressed, would amount to a true person-centered care approach, unlike expecting the patient to conform to the palliative care team's expectations. To reach that level of conversation with the patients, care providers must approach the role with an open mind, with respect to their patients, and acceptance of the decision-making process that the patients choose. Immigrants must, therefore, be given the opportunity on how much they want to be involved but also, respected if they decide to have less involvement in the decision-making process. Additionally, the preference of who cares for them must also be respected, a decision that is usually made along the lines of spirituality.

Like culture, spirituality plays a significant role when individuals are faced with something that requires a major decision to be made (Amoah, 2011; Byrne, 2008). It is at the core of an individual and this aspect of the person must be understood by those providing care (Speck, 2016). Spirituality is as important as psychological, social, and physical health in its contribution to improving quality of life to those experiencing life threatening illness. However, health professionals usually relegate it to the background (Amoah, 2011). Relegating spirituality to the background is in contrast with the literature which suggests that spirituality provides meaning to life, helps one find identity and, acts as a coping mechanism (Byrne, 2008; Cassidy & Davies, 2006). Since spirituality is so vital in how an individual copes with difficult situations, it would be of benefit to concurrently incorporate spiritual activities and use of conventional treatment for symptom management to promote comfort for patients. Coming to an agreement on how both spiritual activities, like praying, and administering conventional treatment for symptom management would be applied side-by-side without causing conflict would be of benefit for both the patient and caring team.

Individuals have varied beliefs which may not align with those of the caring team members. It is important to first acknowledge own spirituality position, be

comfortable with that position then come to the caring role with the understanding that those in their care, could have different spiritual beliefs (Amoah, 2011).

Holistic care can be provided when all the elements of a whole person are considered because even though one maybe facing death, spirituality provides belonging, self-worth, and faith which are transcendent, and provides hope (Byrne, 2008). The hope that comes with spirituality guides individuals in decision-making including choosing to be cared for by family members.

### Family Carer Preference

Treatment practices and traditional models of caring for dying family members is considered a family responsibility and an honorable act by the carer in CaLD communities (Eckemoff et al., 2018; Shanmugasundaram & O'Connor, 2009). Palliative and EOL care services aim to honor that, by partnering with families, to care for their loved ones (Fahlberg et al., 2016). This model is not well understood by a large proportion of the immigrant community who believe that seeking palliative care services is equivalent to abandoning their family member in need (Shanmugasundaram & O'Connor, 2009). This view demonstrates that people have different ideas of what palliative care approach is all about, and not understanding what is meant by the patient and family being the unit of care (Alam et al., 2020). These extreme views can also be noted where children of palliative care patients felt that having their parents managed by palliative care professionals, was like locking them up (Eckemoff et al., 2018). The rationale for such perceptions could be because, when faced with difficult situations, people retreat to their comfort zone (Germov, 2014; Kolcaba, 2003) which in this case, may be compounded by being in a new country. If palliative care services are to be utilized by immigrant communities in

high-income OECD countries, the issues identified above need to be addressed.

Although barriers to palliative care are well documented (Nyatanga, 2002; Schuster-Wallace et al., 2022), much still needs to be done. Literature continues to emphasize on the need to raise awareness and have education for both palliative care professionals and the different immigrant groups. Awareness and education are essential for ensuring that accurate and beneficial information is disseminated to the targeted populations. This review provides pointers to what needs to be addressed for palliative and EOL care access by immigrants in OECD countries to gain momentum. There must be a different approach in the way the barriers are addressed, if a change is to be realized.

### Conclusion

This study has provided valuable insight into issues of limited access to palliative and EOL care services by immigrants in OECD high-income countries. In this review, 11 articles were included in the analysis, from the palliative and EOL care access by immigrants in high-income OECD countries perspective. The literature reviewed demonstrated that culture and communication were barriers to access to care by the immigrant communities. Additionally, spirituality, and collective decision-making, were also identified as points of tension between palliative care patients and professionals. This paper advances that palliative care professionals be bolder to ask patients about preferred channels of communication, how or, who would be making decisions for the patient and how much of the care process the patient would like to be involved in. If the patient preferred not to be involved, their preference must be respected even when it is strongly preferred by professionals that the patient participate in their care delivery.

## Appendix I

Table 1. Data Extraction Table.

List of reviewed studies (11 in total)					
	Author/s & year	Study	Study aim/s	Sample and methods	Where conducted
1	Bray and Goodyear-Smith (2013)	Patient and family perceptions of hospice services: "I knew they weren't like hospitals"	To gain a patient-and-their-family perspective on the hospice, including exploration of components of service care that could be improved for various cultural groups.	18 palliative care patients or carer family members, ranging in age from 39 to 81 years, who reflected the ethnic diversity of the population of the region using qualitative study technique.	New Zealand
2	Bray et al. (2018)	Exploring the lived experience of migrants dying away from their country of origin.	To explore the lived experiences of migrants dying away from their country of birth or origin	10 participants, migrants to New Zealand, recruited through four hospices. Semi-structured interviews were used in Interpretive Phenomenology.	New Zealand
3	Jeong et al. (2015)	"Planning ahead" among community-dwelling older people from culturally and linguistically diverse background: a cross-sectional survey.	To explore preparedness of end-of-life care planning among community-dwelling older persons of culturally and linguistically diverse background.	229 community older adults (65+) who attended 17 day care centres using survey study.	Australia

(Continued)

Key themes emerged — 1. hospice personnel's approach to patients, 2. quality of service, 3. cultural barriers, and 4. strategies for future improvement.

1. Living with 2 identities bringing about a feeling of aloneness, while for some that brought about a sense of belonging. Social connection was important. 2. Migration brought about thoughts of having attained a better life, but lost dreams because of the illness and also reminiscing about their country of origin. 3. Making immediate plans of what needs to be accomplished before dying.

Awareness of advance care planning was low, and completion of advance care directive was very low. 37.5% of Anglo Celtic group had an enduring guardian, compared with 15.5%, 24.1%, and 13.3% from Mediterranean, Eastern European and Asia/Pacific group, respectively. Children were the most preferred substitute decision-makers more for Asia/Pacific group than Anglo Celtic, Mediterranean and Eastern Europeans. The various difficulties experienced included being time-consuming, difficult to understand terms and forms, and do not know how to do it.

Table 1. (Continued)

List of reviewed studies (11 in total)					
Author/s & year	Study	Study aim/s	Sample and methods	Where conducted	Results
4 Hiruy and Mwanri 2014	End-of-life experiences and expectations of Africans in Australia: cultural implications for palliative and hospice care.	To explore sociocultural end-of-life experiences of Africans and their interaction with the health services.	One Sudanese male participant of refugee background, using case study.	Australia	1. Culture plays a significant role in end of life for an African migrant. 2. Decision making in important matters such as end of life, is a community responsibility. 3. Religion and religious leaders play a vital role in end of life matters in the Sudanese community. 4. It is very important for immediate and extended family to visit the sick before they die.
5 Sneesby et al. (2011)	Death and dying in Australia: perceptions of a Sudanese community.	To obtain information to support Palliative Care health workers to meet the needs of Sudanese population in death, dying and bereavement.	15 participants were recruited. Four focus group interviews were conducted. Each focus group comprised of three to four participants.	Australia	1. Participants were not aware of the palliative care concept initially. 2. Older members of the Sudanese community like the traditional concept of family caring for the sick/dying while the young ones prefer the western approach. 3. Consensus that bad news was withheld from patients and family until support was available. 4. Faith is an important factor for Sudanese—Christianity or Islam.
6 Shanmugasundaram and O'Connor (2009)	Palliative care services for Indian migrants in Australia: experiences of the family of terminally ill patients.	To explore the issues related to accessing palliative care services for Indian migrants, identify the effectiveness of palliative care in supporting the patient and family and to recommend strategies for improving this care.	Participants were six, members of one family. In-depth interviews were used in a qualitative descriptive design.	Australia	1. Challenges in accessing care. Lack of sensitivity by health staff was identified as the reason. 2. Cultural issues; food was a factor; described as medicine. 3. Caring for a dying family member is seen as an honour. 4. Presence of large numbers of family member as death draws near.
7 Maddalena et al. (2013)	Awareness of Palliative Care and End-of-Life Options Among African Canadians in Nova Scotia.	To assess the knowledge African Canadians living in Nova Scotia have regarding their options for palliative and end-of-life (EOL) care.	Six caregivers from the black communities who had looked after someone who died. Focus group interviews were utilised.	Canada	1. There was a cultural expectation that family/community members would provide the bulk of the care required at home. 2. Caregivers had very little information about accessing palliative care services. 3. Health system lacked effective processes to engage with African black community to assess, understand and attend their health care needs.

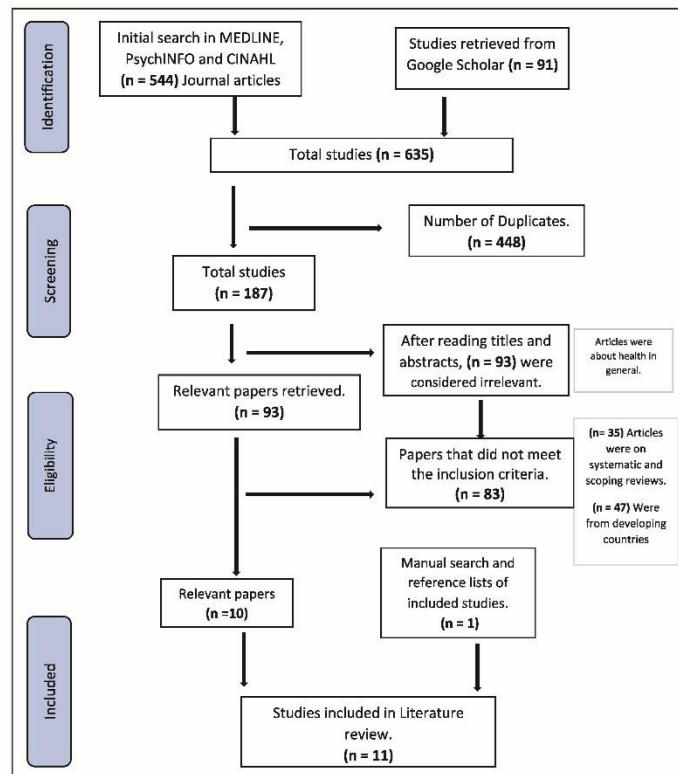
(Continued)

Table 1. (Continued)

List of reviewed studies (11 in total)					
Author/s & year	Study	Study aim/s	Sample and methods	Where conducted	Results
8 Kirby et al. (2018).	"It doesn't exist. . .": negotiating palliative care from a culturally and linguistically diverse patient and caregiver perspective.	To develop a critical, evidence-based understanding of the experiences of people from Culturally and Linguistically Diverse (CALD) backgrounds, and their caregivers, in a palliative care setting.	16 patients and 14 caregivers from a range of CALD backgrounds participated in semi-structured interviews.	Australia	Four themes were identified among participants: (1) Terminology in the transition to palliative care; (2) Communication, culture and pain management; (3) (Not) Talking about death and dying; and, (4) Religious faith as a coping strategy: challenging the terminal diagnosis.
9 Smith et al. (2009)	Palliative care for Latino patients and their families.	To understand Latinos palliative care needs and provide concrete suggestions.	Case study of 1 Latino woman diagnosed with leukemia.	USA	Provided recommendations for issues identified related to culture, religious/spiritual, trustworthiness, health literacy and racial discrimination.
10 Eckemoff et al. (2018)	End of Life Care for Older Russian Immigrants - Perspectives of Russian Immigrants and Hospice Staff.	Examined immigrant Russian seniors and adult children's views on end of life care and hospice staff members experiences providing care to diverse immigrant clients.	Qualitative research, 3 groups of participants. (1) 4 female Russian immigrant seniors aged 60 years and over, (2) 5 (2 male, 3 female) children of Russian seniors, (3) 4 female hospice staff.	North Carolina, USA	1. Preferred family carer. 2. Participants had different perception of end of life care. 3. Participants had different views about end of life care due to acculturation. 4. Lack of Advance Care Planning. 5. Participants felt that society should take some responsibility in caring for seniors.
11 Carlsson and Hjelm (2021).	Equal palliative care for foreign-born patients: a national quality register study.	To use data from a national quality register to investigate if there are differences relating to migrant background in the quality of end-of-life care of patients dying in Sweden.	81,418 deceased patients, over 18 year of age, registered in the Swedish Register of Palliative Care during 2017 and 2018, of expected death were included in the study.	Sweden	There were several significant differences in various quality indicators but not in a specific direction. Sometimes, the quality indicators showed an advantage for Swedish-born patients but just as often, they were also favorable for foreign-born patients. Swedish-born patients had greater access to specialized palliative care than foreign-born patients. Foreign-born patients were more often cared for in general home care setting, despite a higher frequency of cancer diagnosis.



## Appendix 2



**Figure 2.** Prisma flow chart (Briggs, 2020 ).

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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## Institution Review Board

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## IRB Approval Number

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This scoping review did not use protected health information.

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## References

- Alam, S., Hannon, B., & Zimmermann, C. (2020). Palliative care for family caregivers. *World Journal of Clinical Oncology*, 38(9), 926–936.
- Amoah, C. F. (2011). The central importance of spirituality in palliative care. *International Journal of Palliative Nursing*, 17(7), 353–358. <https://doi.org/10.12968/ijpn.2011.17.7.353>
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32. <https://doi.org/10.1080/1364557032000119616>
- Bray, Y. M., & Goodyear-Smith, F. (2013). Patient and family perceptions of hospice services: 'I knew they weren't like hospitals'. *Journal of primary health care*, 5(3), 206–213.
- Bray, Y., Wright-St Clair, V., & Goodyear-Smith, F. (2018). Exploring the lived experience of migrants dying away from their country of origin. *Quality of Life Research*, 27(10), 2647–2652. <https://doi.org/10.1007/s11366-018-1909-1>
- Briggs, J. (2020). Prisma Flow Diagram. In: Australia: JBI.
- Bullock, K. (2011). The influence of culture on end-of-life decision making. *Journal of Social Work in End-of-Life & Palliative Care*, 7(1), 83–98. <https://doi.org/10.1080/15524256.2011.548048>

- Byrne, M. (2008). Spirituality in palliative care: What language do we need? *International Journal of Palliative Nursing*, 14(6), 274–280.
- Cain, C. L., Surbone, A., Elk, R., & Kagawa-Singer, M. (2018). Culture and palliative care: Preferences, communication, meaning, and mutual decision making. *Journal of Pain and Symptom Management*, 55(5), 1408–1419.
- Carlsson, M. E., & Hjelm, K. (2021). Equal palliative care for foreign-born patients: A national quality register study. *Palliative & Supportive Care*, 19(6), 656–663. <https://doi.org/10.1017/S1478951521000110>
- Cassidy, J. P., & Davies, J. D. (2006). Cultural and spiritual aspects of palliative medicine. In G. H. D. Doyle, N. Cherny, & K. Calman (Eds.), *Oxford Textbook of Palliative Medicine* (3rd ed., pp. 951–957). Oxford University Press.
- Clark, D. (2012). Cultural considerations in planning palliative and end of life care. *Palliative Medicine*, 26(3), 195–196. <https://doi.org/10.1177/0269216312440659>
- d'Aiglepierre, R., David, A., Levionnois, C., Pielvogel, G., Tuccio, M., & Vickstrom, E. (2020). *OECD social, employment and migration working papers*. OECD.
- Department of Health. (2018). National Palliative Care Strategy. Australian Government. <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>.
- Eckemoff, E. H., Sudha, S., & Wang, D. (2018). End of life care for older Russian immigrants - Perspectives of Russian immigrants and hospice staff. *Journal of Cross-Cultural Gerontology*, 33(3), 229–245. <https://doi.org/10.1007/s10823-018-9353-9>
- Fahlberg, B., Foronda, C., & Baptiste, D. (2016). Cultural humility: The key to patient/family partnerships for making difficult decisions. *Nursing*, 46(9), 14–16. <https://doi.org/10.1097/01.NURSE.0000490221.61685.e1>
- Gerber, K., Maharaj, E., Brijnath, B., & Antoniadis, J. (2020). End-of-life care for older first-generation migrants: A scoping review. *BMJ Supportive & Palliative Care*. Advance online publication. <https://doi.org/10.1136/bmjspcare-2020-002617>
- Germov, J. (Ed.). (2014). *Second opinion : An introduction to health sociology* (5th ed.). Oxford University Press.
- Green, A., Jerzmanowska, N., Thristiawati, S., Green, M., & Lobb, E. A. (2019). Culturally and linguistically diverse palliative care patients' journeys at the end-of-life. *Palliative & Supportive Care*, 17(2), 227–233. <https://doi.org/10.1017/S1478951518000147>
- Hiruy, K., & Mwaani, L. (2014). End-of-life experiences and expectations of Africans in Australia: Cultural implications for palliative and hospice care. *Nursing Ethics*, 21(2), 187–197. <https://doi.org/10.1177/0969733012475252>
- Ho, Z. J., Radha Krishna, L. K., & Yee, C. P. (2010). Chinese familial tradition and Western influence: A case study in Singapore on decision making at the end of life. *Journal of Pain and Symptom Management*, 40(6), 932–937. <https://doi.org/10.1016/j.jpainsymman.2010.06.010>
- Jansky, M., Owusu-Boakye, S., & Nauck, F. (2019). "An odyssey without receiving proper care" - experts' views on palliative care provision for patients with migration background in Germany. *BMC Palliative Care*, 18(1), 8.
- Jeong, S., Ohr, S., Pich, J., Saul, P., & Ho, A. (2015). 'Planning ahead' among community-dwelling older people from culturally and linguistically diverse background: A cross-sectional survey. *Journal of Clinical Nursing*, 24(1–2), 244–255. <https://doi.org/10.1111/jocn.12649>
- Kirby, E., Lwin, Z., Kenny, K., Broom, A., Birman, H., & Good, P. (2018). "It doesn't exist. . .": Negotiating palliative care from a culturally and linguistically diverse patient and caregiver perspective. *BMC Palliative Care*, 17(1), 90. <https://doi.org/10.1186/s12904-018-0343-z>
- Kolcaba, K. (2003). *Comfort theory and practice: A vision for holistic health care and research*. Springer Publishing Co.
- Krassner, A. M., Gartstein, M. A., Park, C., Dragan, W. L., Lccannclier, F., & Putnam, S. P. (2017). East-west, collectivist-individualist: A cross-cultural examination of temperament in toddlers from Chile, Poland, South Korea, and the U.S. *European Journal of Developmental Psychology*, 14(4), 449–464. <https://doi.org/10.1080/17405629.2016.1236722>
- Kwok, H. H. Y., Low, J., Devakumar, D., & Candy, B. (2020). Experience and perspectives on palliative or end-of-life care of Chinese people and their families as immigrants to high-income countries: A systematic review and thematic synthesis. *BMJ Global Health*, 5(12), 1–13.
- Long, C. O. (2011). Ten best practices to enhance culturally competent communication in palliative care. *Pediatric Hematology Oncology Journal*, 33 Suppl 2, S136–S139. <https://doi.org/10.1097/MPH.0b013e318230dfb4>
- Maddalena, V., Bernard, W. T., Davis-Murdoch, S., & Smith, D. (2013). Awareness of palliative care and end-of-life options among African Canadians in Nova Scotia. *Journal of Transcultural Nursing*, 24(2), 144–152. <https://doi.org/10.1177/1043659612472190>
- Matandiko, C. M. (1996). *A Christian response to Zambian death rituals*. WorldCat.org
- McAuliffe, M., Abel, G., Oucho, L., & Sawyer, A. (2022). 7 International migration as a stepladder of opportunity: What do the global data actually show? In: M. McAuliffe & A. Triandafyllidou (Eds.), *World Migration Report*. International Organization for Migration (IOM). <https://doi.org/10.1002/wom3.28>
- Nyatanga, B. (2002). Culture, palliative care and multiculturalism. *International Journal of Palliative Nursing*, 8(5), 240–246.
- OECD. (2022). *International migration outlook 2022*. <https://www.oecd-ilibrary.org/content/publication/30fe16d2-en>
- Peters, M. D. J., Godfrey, C., McInerney, P., Munn, Z., Tricco, A. C., & Khalil, H. (2020). Chapter 11: Scoping Reviews. In Z. Munn & E. Aromataris (Eds.), *JBI Manual for Evidence Synthesis*, (2020): 406–451.
- Phillips, J., & Spicks, H. (2012). *Skilled migration: Temporary and permanent flows to Australia*. Parliament of Australia.
- Quinn, S., & Hickey, D. (2008). Valuing local diversity in palliative care: Translating the concept. *The British Journal of Nursing*, 17(17), 1084–1087.
- Richmond, V. P., & McCroskey, J. C. (2019). Human communication theory and research. In D. W. Stacks, M. B. Salwen, & K. C. Eichhorn (Eds.), *An integrated approach to communication theory and research* (3rd ed., pp. 237–246). Routledge.
- Saito, S., Harris, M. F., Long, K. M., Lewis, V., Casey, S., Hogg, W., Cheng, I. H., Advocat, J., Marsh, G., Gunatillaka, N., & Russell, G. (2021). Response to language barriers with patients from refugee background in general practice in Australia: Findings from the OPTIMISE study. *BMC Health Services Research*, 21(1), 921–1012.
- Sbaiti, M., Streule, M. J., Alhaffar, M., Pilkington, V., Leis, M., Budhathoki, S. S., Mkhallati, H., Omar, M., Liu, L.,



- Golestaneh, A. K., & Abbara, A. (2021). Whose voices should shape global health education? Curriculum code-sign and codelivery by people with direct expertise and lived experience. *BMJ Global Health*, 6(9), e006262. <https://doi.org/10.1136/bmjgh-2021-006262>
- Schuster-Wallace, C. J., Nouvet, E., Rigby, I., Krishnaraj, G., de Laat, S., Schwartz, L., & Hunt, M. (2022). Culturally sensitive palliative care in humanitarian action: Lessons from a critical interpretive synthesis of culture in palliative care literature. *Palliative & Supportive Care*, 20(4), 582–592. <https://doi.org/10.1017/S1478951521000894>
- Shabnam, J., Timm, H. U., Nielsen, D. S., & Raunkiaer, M. (2022). Palliative care utilization among non-western migrants in Europe: A systematic review. *Journal of Immigrant and Minority Health/Center for Minority Public Health*, 24(1), 237–255.
- Shanmugasundaram, S., & O'Connor, M. (2009). Palliative care services for Indian migrants in Australia: Experiences of the family of terminally ill patients. *Indian Journal of Palliative Care*, 15(1), 76–83. <https://doi.org/10.4103/0973-1075.53589>
- Shaw, R., Gullifer, J., & Wood, K. (2016). Religion and spirituality: A qualitative study of older adults. *Ageing International*, 41(3), 311–330. <https://doi.org/10.1007/s12126-016-9245-7>
- Smith, A. K., Sudore, R. L., & Pérez-Stable, E. J. (2009). Palliative care for Latino patients and their families: whenever we prayed, she wept. *The Journal of the American Medical Association*, 301(10), 1047.
- Sneesby, L., Satchell, R., Good, P., & van der Riet, P. (2011). Death and dying in Australia: Perceptions of a Sudanese community. *Journal of Advanced Nursing*, 67(12), 2696–2702. <https://doi.org/10.1111/j.1365-2648.2011.05775.x>
- Speck, P. (2016). Culture and spirituality: Essential components of palliative care. *Postgraduate Medical Journal*, 92(1088), 341–345.
- Steinfatt, T. M., & Millette, D. M. (2019). Intercultural communication. In D. W. Stacks, M. B. Salwen, & K. C. Eichhorn (Eds.), *An integrated approach to communication theory and research* (3rd ed., pp. 307–319). Routledge.
- Sungur, H., van Den Muijsenbergh, M. E. T. C., van Weert, J. C. M., & Schouten, B. C. (2022). Caring for older culturally and linguistically diverse patients with cancer: Healthcare providers' perceived barriers to communication. *Journal of Geriatric Oncology*, 13(6), 862–870.
- Triandafyllidou, A. (2018). *Handbook of migration and globalisation*. Edward Elgar Publishing.
- Triandis, H. C., & Gelfand, M. J. (1998). Converging measurement of horizontal and vertical individualism and collectivism. *Journal of Personality and Social Psychology*, 74(1), 118–128.
- Triandis, H. C., & Suh, E. M. (2002). Cultural influences on personality. *Annual Review of Psychology*, 53, 133–160. <https://doi.org/10.1146/annurev.psych.53.100901.135200>
- OECD. (2017). How technology and globalisation are transforming the labour market. In (pp. 81–124): OECD Publishing Paris, France.
- Woodward, R. (2009). *The organisation for economic co-operation and development (OECD)*. Routledge.
- World Palliative Care Alliance. (2014). *Global atlas of palliative care at the end of life*. World Health Organization. <http://www.thewhpc.org/resources/global-atlas-on-end-of-life-care>
- Yoong, J. (2015). What can we do to help Australians die the way they want to? *The Medical Journal of Australia*, 203(5), 211.

## Updated literature search

An update to the literature search was conducted after the publication of the above article and with the intention to capture any more recently published articles on the subject between December 2021 and January 2024. The literature search was conducted using Google Scholar, Medline, CINAHL and PsychINFO databases, and the same search terms were utilised in the above scoping review. However, because of the publishing journal's requirements to include only five search terms in the publication, the full range of search terms used were not included in the above publication.

Hence for the purposes of this research the following search terms were used when conducting the literature review, both the published version above and this update to the literature here: Palliative care, end-of-life care, cultur\*, belief\*, African migrant\*, immigrant, emigrant, Malawi\*, Zambia\*, Zimbabwe\*, Australia.

A search of CINAHL, Medline and PsychINFO databases retrieved 414 journal articles and Google Scholar 81, yielding a total to 495. Duplicates were removed leaving a total of 398 articles. After reading titles and abstracts, 318 articles were discarded as they were not relevant. The remaining 60 articles did not meet the criteria of full text, references available, peer reviewed, age group 45 years and older. Therefore, no additional sources or reviews of the literature were required to be included this study, simply because there were no further published articles found to be relevant to the subject.

Appendix 1 provides an overview of the literature search used to inform this study and provides the PRISMA diagram which illustrates the updated literature search process.

Appendix 2 contains a table listing the studies included in this present research.

## **Summary**

This Chapter 2 has presented the context of the current study through a broad overview of the literature which considered in general, migrants in OECD high-income countries through the exhibition of the article; “Palliative and End-of-Life Care Access for migrants Living in High-income Countries: A Scoping Review” in its published form. Constructivist grounded theory favours conducting a broad pre-study literature review for the purpose of providing a guide to the research, and then undertaking an in-depth review later in the study (Charmaz, 2014). This chapter and the exhibited published article highlight that researchers have been focusing on the area of palliative and EOL care for migrants of CaLD backgrounds in OECD countries of which Australia is one. The literature review revealed that barriers to palliative and EOL care by CaLD background migrants have been well researched for a considerable period. However, time and resources have not been dedicated to investigating why access barriers continue. This chapter also presented a narrative of the updated literature search conducted in January 2024 which confirmed if any new research had been published since the initial literature search and review was conducted back in 2021. This latter search did not reveal any new publications related to the topic. The following Chapter 3 presents the methodology and methods used in this study.

# **Chapter 3: Methodology and Methods**

## **Introduction**

Chapter 2 above discussed the literature and background that situates this research within the field of palliative and EOL care access, including the impact of collective decision-making for migrants from CaLD backgrounds in Australia. This Chapter 3 outlines the grounded theory methodology for this study and the methods used to collect and analyse the data. Firstly, this chapter will provide an overview of methodology and establishes the philosophical assumptions and stance for knowledge development in this research and provide a justification for using grounded theory as a qualitative research approach. Secondly, the chapter will discuss the historical background of grounded theory and explain why a constructivist grounded theory approach was chosen for this research. Thirdly, the chapter will outline the detailed protocol for data collection, the process of analysis and coding which includes the constant comparative technique and memoing. Fourthly, the chapter will discuss the ethical considerations for this study.

## **Philosophical assumptions**

Every single piece of formal knowledge development using scientific methods has an ontological perspective about understanding the nature of reality and nature of existence, and this formalises and presents it as part of scientific knowledge (Creswell & Creswell, 2018). As a researcher, I value the voice of the people taking part in the study so that, if there were interventions to be devised, they would be done with the concerned group of people. My experience as an African migrant in Australia is also valuable and is used to understand and explicate the data for the greater good. These values are not explicit in quantitative research,

but they are in qualitative studies. Therefore, a qualitative approach is appropriate for this study. The ontological stance in this study assumes the constructivist paradigm, to investigate the process of planning for EOL by African migrants in Australia, recognising that there are different ways of looking at the process. It is therefore important to incorporate different views and multiple people in order to identify a core process of how individuals plan for a good process or experience of dying and thus a good death in Australia.

The nature of knowledge is usually individual reconstructions of ideas around consensus by community regarding what is real, useful and has meaning for action (Denzin & Lincoln, 2000). The aim of talking to African migrants in Australia in relation to EOL planning is to encourage them to talk about what process they envisaged they might go through; help them to illustrate the process they imagine they will plan for their EOL. The overall aim is to arrive at a community consensus regarding the phenomenon.

An initial pilot study phase was completed for this research which included an initial interview with three participants in February and March 2021. It was evident during this pilot study that the participants had not previously thought about the process of preparing for EOL in Australia. It was important to bear in mind the value of the participants' views expressed as knowledge created was as a result of this interactive relationship with the participants (Charmaz, 2014). To make the interactive relationship with the participants worthwhile to create or co-construct knowledge a second interview was necessary to allow participants time to think about how they saw themselves preparing for end-of-life in Australia.

The philosophical stance in positivism suggests that there is a realism which the positivist way of conducting research can reveal one truth on which everyone can agree. This view emphasises that there is a world out there to be analysed, and therefore seeks to study facts by gathering physical evidence represented by numbers. However, this reality changes with time

therefore, it is reality as it is known at that moment. In addition, while there could be one reality, it depends on an individual's perspective and how they view and talk about it (Charmaz, 2006, 2014). In a constructivist perspective, there is a recognition that there could be multiple realities expressed by different individuals. This thought is in line with Charmaz (2000) who asserts that there are multiple realities dependant on the person's standpoint. Coming from that perspective, it is important to present those multiple realities as participants express them during interviews. Thus, for the purposes of this research there is a recognition that professional nursing needs to come to an agreement of some sort of reality and understand different people's viewpoints.

## **Methodology**

Methodology is the conceptual framework which reflects the major assumptions of a particular human science (Van Manen, 1997). The researcher positions themselves within this formalised framework dependent on the beliefs and/or assumptions they hold (Birks & Mills, 2011) forming the philosophical worldview that guides action (Guba, 1990) about how knowledge is developed. Research methodology is considered within the broader research traditions namely, quantitative, qualitative, and the more recent mixed methods (Creswell & Creswell, 2018). Within these research traditions, the researcher's stance in regard to epistemology — the study of knowledge (Schutz, 1962); ontology — what is real (Creswell & Creswell, 2018); axiology — the value that the researcher brings to the study (Charmaz, 2014; Creswell & Creswell, 2018; Creswell & Poth, 2018) and how these elements inform the research process; and finally methodology which guides and directs the research methods or protocol (Jeon, 2004).

## **Paradigms of knowledge development**

A quantitative research approach is a scientific inquiry that aims to explain a phenomenon of interest through quantifying variables numerically (Creswell & Creswell, 2018; Polit & Beck, 2006). The approach is deductive in nature and emphasises commencing with a hypothesis with the aims of testing a *priori* theory (Creswell, 2009; Polit & Beck, 2006). Quantitative research is the process of gathering empirical evidence. This evidence is deeply rooted in objective realism, and it is gathered through the senses and not people's personal thoughts and beliefs (Polit & Beck, 2006).

## **Qualitative research**

A qualitative research design takes a different approach. Historically, a qualitative research approach was not considered a pure science by quantitative researchers because of the absence of measuring instruments to justify research findings (Hallberg, 2006). Unlike a quantitative research design, the qualitative approach focuses on processes and individuals' interpretations of the phenomenon being examined. These processes and people's interpretations cannot be measured using numbers (Creswell & Poth, 2018; Denzin & Lincoln, 2000). This study utilises a qualitative approach because data on how participants are preparing for EOL in Australia, can only be obtained through qualitative methods such as, face-to-face interviews with participants or even an open-ended survey or questionnaires that invites participants share their thoughts on a particular issue, and thus explain the how of something that cannot be achieved through objective measurement and instruments.

There are occasions when a mixed methods approach may be beneficial to answering the research question. In this instance, the researcher may choose to use selected components of qualitative and quantitative elements in combination in one study (Creswell & Creswell, 2018; Creswell & Poth, 2018). A mixed methods approach was not deemed necessary for this

research project because the focus was on listening to individuals and understanding how they were preparing for their own EOL care in Australia. As such, it was considered that a quantitative method would not deliver the data needed, but that a qualitative method would enable me, as a researcher, to explore participants' thoughts through the process of interviews which allows participants to explain and express themselves in their own words. Therefore, a qualitative methodology was considered the most appropriate methodology for the study.

Within the qualitative research methodology there are five main traditional research approaches: phenomenology, ethnography, narrative inquiry, case studies and grounded theory (Creswell, 1998; 2013; Creswell & Poth, 2018). Each approach carries its own philosophical assumptions. Table 3.1 below illustrates the five main traditional qualitative research approaches, when they are appropriate for use as the research method of choice and the reasons why grounded theory is considered the most appropriate approach for this study. As Denzin and Lincoln (2011) point out, qualitative approaches in research operate within philosophical assumptions that lay within interpretive frameworks. The various frameworks take a position on ontology, epistemology, methodology and axiology, and these will be discussed below. The researcher using interpretive frameworks must be clear on the ontological, epistemological, methodological, and axiological assumptions underlying their philosophical stance which guide the study methods.



Table 3.1 Qualitative Research Approaches

<b>Research approach</b>	<b>Research focus</b>	<b>Research problem</b>	<b>Unit of analysis</b>	<b>Rationale for selection</b>
Narrative inquiry	Explore the life of an individual	Tell stories of individual experiences	Studying one or more individuals	Ruled out – this methodology was inappropriate. The research was not about exploring the life of an individual.
Phenomenological Research	Understand the essence of the experience	Describe the essence of a lived phenomenon	Studying several individuals who have shared the experience	Ruled out – this methodology was inappropriate. Participants have not experienced end-of-life yet. The study was about how participants are preparing for the future.
Ethnographic Research	Describe and interpret a culture-sharing group	Describe and interpret the shared patterns of culture of a group	Studying a group that shares the same culture	Ruled out – this methodology was inappropriate. The research was about how participants were preparing for end-of-life and not about shared culture.
Case Study Research	Develop an in-depth description and analysis of a case or multiple case.	Provide an in-depth understanding of case or cases	Studying an event, a program, an activity, or individual/s	Ruled out – this methodology was inappropriate because the research was not to study a case or cases
Grounded Theory Research	Develop a theory grounded in data from the field.	Ground the theory in the views of participants	Studying a social process, an action, or an interaction involving many individuals	Selected – this methodology was used to theorise around a social process. The study was on social processes on end-of-life preparation for African migrants in Australia.

Source: Modified from Creswell and Poth (2018).

## **Theoretical approach**

This research is essentially about the activities of individuals sometime in the future; about something they have yet to experience. Therefore, the choice of grounded theory as the approach here was arrived at after much consideration of the research question. The other potential approaches included the following: Firstly, narrative inquiry – this study approach is appropriate when the study's aim is to interpret individuals' or a defined group's stories to help understand how participants make sense of perceptions and experiences (Clandinin, 2007; Denzin & Lincoln, 2000). In this approach, it is important that these experiences and perceptions are written in chronological order (Clandinin, 2007; Clandinin & Connelly, 2000). Secondly, phenomenology – on the other hand seeks to understand the essence of the phenomenon of interest by investigating the lived experiences of participants (Creswell, 2013; McGovern, 2017). Neither the narrative nor phenomenology approaches could be utilised here to answer the research question because this study focuses on an anticipated action in the future. The study is about the unknown, an experience not yet experienced; phenomenon yet to be navigated.

Thirdly, ethnography was considered but not chosen here because this methodology is used when the research seeks to understand a cultural group (Creswell, 2013; Pink et al., 2022) which was not the objective of this study. Fourthly, the case study approach was also considered as this aims to provide an in-depth understanding of a particular case (Yin, 2009). However, for the purposes of this research it was ruled out because the objective of the research, was not about generating an in-depth understanding of a particular case study.

Finally, grounded theory was selected as the best approach to answer the present research question. The following section explains the rationale for this decision.

## **Grounded theory**

Research methods in the 1960s were dominated by quantitative research approaches whose criteria were also imposed on qualitative researchers (Birks & Mills, 2011; Charmaz, 2006). Qualitative approaches to research had at this point attained only a very low status within the sociology field, citing incapability in providing theory verification (Birks & Mills, 2011; Strauss & Corbin, 1994). It is from this backdrop that grounded theory (GT) was developed through the work of Glaser and Strauss (1967).

The development of GT disputed several dominant assumptions held in quantitative research. Firstly, it challenged views of qualitative research as “impressionistic, unsystematic, anecdotal and biased” (Charmaz, 2006, p. 5). Secondly, it challenged notions of qualitative research as only a precursor of forming quantitative tools. Thirdly, they challenged the arbitrary division between theory and research. And lastly, the elite control of construction, applying the canons of quantitative research to evaluate qualitative studies and also argued against the descriptive level of quantitative studies (Charmaz, 2014; Glaser & Strauss, 1967).

GT consists of a systematic approach to the study with several key strategies for conducting inquiry (Charmaz, 2006, 2014). The main aim in this approach, is to generate a new theory from the collected data (Corbin & Strauss, 2007) that may provide an explanation for the prevailing practice (Creswell, 2013). GT, therefore, favours theory construction over description, creation of fresh concepts over applying existing theory and, theorising processes over assuming stable structures (Charmaz, 2014; Clarke, 2019). The features of GT are that it is inductive: “...patterns, themes, and categories of analysis come from the data” (Patton, 2002, p. 306), and comparative, where the researcher interacts with the data, with the participants and with the analysis (Charmaz, 2014; Creswell & Poth, 2018). In addition, it is iterative because the researcher goes back and forth, constantly comparing between data and analysis, data and concepts and concepts with new data. GT uses abductive reasoning in that

it takes a logical approach, progressing from general concepts to a specific conclusion, requiring open-mindedness during the research to think about all possible theoretical explanations for the findings (Charmaz, 2014; Denzin & Lincoln, 2005). GT offers a conceptual understanding of the study data providing tools for summarising, synthesising, and analysing. It also provides focus and flexibility (Charmaz, 2014).

As the innovation of Glaser and Strauss (1967) while undertaking a study on awareness of dying in 1965, GT was considered revolutionary. It was during this study, that the founders questioned the use of 'scientific' methods as verification or their study, noting that those methods emphasised on verifying theories, not generating new theory (Glaser & Strauss, 1967). They argued that theory generation and verification should be treated in the same manner yet in essence, theory verification was viewed with primary importance in the sociological research arena. During the same era of the 1960s, science research discussions in American sociology were focused on grand theories and theoretical imaginations versus rigorous methodologies. Glaser and Strauss (1967) asserted that GT was about linking data analysis with theory. There was another component of the methodology that was unique, analysing data while collecting it. It was important for the pair to devise procedures to guide researchers intending to use this new methodology. Therefore, key concepts were developed. At the top of the key concepts list was constant comparison (Charmaz, 2006, 2014; Clarke, 2005).

Constant comparison must be applied at every level of data analysis. That is, constantly comparing the data from one interview to the next, or whatever form of data are being analysed, as concepts are being built up. While this constant comparison is being undertaken, the researcher focuses on the process they are engaged in and also looks out for similarities but more so, for deviations (Charmaz, 2014) or to identify a problem that would lead the researcher to seek theoretical refinement of identified categories (Polit & Beck, 2006).

In addition to constant comparison, is the writing of memos. Glaser and Strauss (1967) asserted that memoing was an important part of the GT research process. This exercise is an analytical activity undertaken to facilitate arriving at clear concepts from the data. Memoing is also beneficial in keeping track of data analysis that is, keeping a paper trail of the process being undertaken and creating transparency in the study (Birks & Mills, 2011; Charmaz, 2006, 2014; Clarke, 2005). Charmaz (2014) described memoing as an essential tool for reflection on ideas and thoughts about the data and analysis. Thus, all schools of thought in GT agree on memo writing and constant comparison as critical components of data analysis (Birks & Mills, 2011; Charmaz, 2014; Clarke, 2005; Creswell & Poth, 2018). GT is thus a method in process as well as a method that can analyse process (Charmaz, 2014). Furthermore, grounded theorists such as Corbin and Strauss support diagramming during theory development as it helps move to the conceptual process and acts as a tool to clarify the otherwise complex steps to theory development (Corbin & Strauss, 2008), and this is discussed further below in relation to data collection.

The new methodology also advocates for theoretical saturation instead of representation. This GT methodology is thus more focused on theoretical saturation, which is, the point at which collecting and analysing new data does not lead to any further new concepts. This saturation becomes evident when new data is no longer creating more clarification to the earlier arrived at concepts (Charmaz, 2014) or, when the raw data is not leading to the refinement of the inchoate theory (Glaser & Strauss, 1967). The three common paradigms of GT are the works of Glaser and Strauss (1967), Strauss and Corbin (1998) and the constructivist approach of Charmaz (2006). Although there are similarities in how to conduct a GT study, there are also marked differences.

Glaserian or Classical GT (Glaser, 1992) asserts that the primary objective of GT method is that of discovering basic social processes, which is in line with symbolic interactionism

which seeks to provide a theory on an explored human behaviour. Glaser contends that all that is around and available to the researcher is data, and the emphasis is also on being less formal while conducting data analysis (Charmaz, 2014; Glaser, 1992). This approach emphasises a more relaxed technique as opposed to the procedural focus by Strauss and Corbin (1990, 1998) contending that, this adherence to procedure provides the analyst the “desired conceptual power” and that the approach is more or less forcing theory onto data (Glaser & Strauss, 1967). Classical GT is thus more concerned with theoretical sensitivity (Glaser, 1978) than adhering to procedures.

The second version of GT is known as the Straussian paradigm as suggested by Strauss and Corbin (1998). This version attempts to refine the original GT version with a strong focus on procedures as guides for conducting research. The Straussian position places emphasis on maintaining a more systematic approach to the coding of data. The Straussian viewpoint proposes three stages of coding data: The first stage is to create open codes (inductive); the secondly stage is to group codes using axial coding; and the third stage is to perform selective coding. To aid in data analysis, this Straussian version of GT requires the researcher to be precise when coding, being deductive while coding as part of the process, asking questions to the data and applying properties to organise the categories. The properties are conditions and context in which the behaviour occurs; consequences of that behaviour; and actions and interactions that lie behind the behaviour. The final stage of coding is selective coding by integrating all categories leading to a core category which will result in the theory (Strauss & Corbin, 1994).

The third version of GT is Constructivist as advanced by Charmaz (2006, 2014), and is the approach adopted in this research study because of the favourable stance that it offers. Charmaz (2006, 2014) argues that the researcher comes into the field with their own knowledge and interpretation of the data. Creswell and Poth (2018) also suggest that the

interaction between researcher and participants is an important component in the research. Like Classical GT and Straussian GT approaches, the constructivist approach is primarily inductive in coding data, using open, focused, and theoretical coding. However, unlike the Straussian approach, constructivist is more moderate in process application, with more relaxed processes that allow the researcher to use their prior knowledge and experience while analysing data. The ontological position of constructivist GT is that there are multiple realities dependant on the viewer's standpoint (Charmaz, 2014; Creswell & Poth, 2018).

Constructivism also states that reality is constructed by individuals (Charmaz, 2006, 2014; Creswell & Poth, 2018) and enables us to gain knowledge about a phenomenon using the methodical steps suggested during the study. The researcher shares this stance that participants form their own interpretation of society and reality as they interact with the environment and, that researcher engagement with participants is a crucial component in theory construction (Charmaz, 2014). Table 3.2 below illustrates the GT paradigms and their philosophical underpinnings.

Table 3.2

Versions of grounded theory

Areas of differences	Differences in philosophical consideration and their usefulness among three GT perspectives		
	Glaser (Classical GT)	Strauss and Corbin (Straussian GT)	Charmaz (Constructivist GT)
Philosophical considerations	Positivist perspective implied. Believes in one reality.	Postpositivist perspective implied. Acknowledges implausibility of seeing reality as it 'really' is.	Constructivist perspective. Believes in multiple perspectives of reality.
Useful perspective when -	<p>Researcher remains neutral (objective) and let data speak for itself (passive approach).</p> <p>Researcher believes in one reality of phenomenon of interest.</p> <p>Personal biases can contaminate data, remaining uninformed about the phenomenon is helpful for the inquiry.</p>	<p>Researcher controls personal influence by using procedures to maximise objectivity.</p> <p>Researcher is hesitant to apprehend reality as 'reality' is.</p> <p>Personal biases can contaminate data but are unavoidable, however, could be minimised.</p>	<p>Researcher intensely engages in interpretation while also acknowledging that it is not in isolation with the process.</p> <p>Researcher is aware of changing context or competing perspectives of reality.</p> <p>Personal knowledge and experience can aid knowing</p>
<b>Rationale for selection</b>	<b>Classical GT not selected</b> because of the philosophical stance that there is one reality.	<b>Straussian GT not selected</b> as is considered inflexible procedures	<b>Constructivist GT was selected</b> due to multiple reality perspective and researcher being a co-construct of that meaning.

Source: Modified from Singh and Estefan, 2018

### Axiology

According to Redman-Maclaren and Mills (2015) "Axiology describes values central to the research process, the way of being in and doing research." (p. 3) and also encapsulates the rights and justice for the individual. As an African migrant to Australia, I share a similar culture with the study participants in this research and thus value the expertise of experience in voices of the participants. My own migration story and experiences prompted the initial



question on how migrants prepare for EOL in a country far away from their birthplace. Measuring and/or quantifying participants' experiences and thoughts requires the focus to be on that person's voice and placing great value in their voices in understanding the phenomenon. As inductive research, this requires starting from the ground up in the process of theorising. It is thus also important to ask oneself throughout the research process if personal values are influencing how the research is being conducted (Charmaz, 2014; Denzin & Lincoln, 2005). The question about personal values is critical because if not addressed, they can affect neutrality in the research findings (Charmaz, 2014; Denzin & Lincoln, 2000). Personal values require reflection and need to be kept in check (Ghosh, 2002). The objective here is to eventually see African migrants actively preparing for EOL in Australia and to be better prepared for death, which in turn should also prepare family and extended family for a better grieving process. My personal values sit better within the constructivist paradigm because I recognise that there are multiple versions and many perspectives of reality. These versions are dependent of how the situation is being viewed at each given time.

## **Ontology**

Ontology refers to the study of what is real and the nature of reality or what is there to be known (Creswell & Poth, 2018; Denzin & Lincoln, 2000). This concerns itself with issues of existence or being (Creswell & Poth, 2018; Guba & Lincoln, 1989). When one migrates to a new country, they may start to reflect on the nature of existence and what it means to be who they are and where they are. The participants in this study came from different geographical places and have experienced different situations that led them to migrate to Australia. However, it was about making connections while maintaining distinctions. Qualitative researchers conduct studies with a view of reporting the varied realities that exist from one individual to the other (Creswell, 2013). Crotty asserts that ontology "... is concerned with

‘what is’, with the nature of existence, with the structure of reality...” (Crotty, 1998, p. 10).

In this study, the quest is about the nature of African migrants in Australia, planning for EOL. This reality is known by the people who are going to be planning for the EOL. As a constructivist, I positioned myself in a way that was potentially helping participants reveal the nature of reality for them, through the interview process because of holding the philosophical assumption that reality is as an individual views it, and this may change over time. To gain that understanding, it was important to allow participants express their thoughts without judgement bearing in mind that each participant was unique in their experience.

### **Epistemology**

Epistemology is concerned with how we know about the world, encompassing the origin, nature and limits of human knowledge (Guba & Lincoln, 1989) and how this knowledge is justified (Creswell & Creswell, 2018). This epistemology can either be realism versus idealism or positivism versus social constructivism. In realism, the philosophical position is that objects exist independently of one’s mind while the position of an idealist is that the object exists only in one’s mind (Schutz, 1962). Positivism on the other hand is a stance which views knowledge as trustworthy if it is factual and gained by observing and through the use of measurement instruments (Denzin & Lincoln, 2000; Rutzou & Steinmetz, 2018). Therefore, empirical verification is what is required to identify truth (Schutz, 1972). One such assumption is that knowledge is already out there, just waiting to be uncovered. On the other hand, others believe that people develop knowledge based on perceptions and experiences, meaning that knowledge is a social construction and that there is no universal or absolute truth (Charmaz, 2014; Creswell & Creswell, 2018). The researcher’s epistemological position thus influences the research methodology and choice of research methods used in any given study. In this constructivist GT study, the epistemological position assumed is that there are

multiple realities. It is important to bear in mind that as a researcher, I am interlocked with participants in creating meaning in relation to how they are preparing for EOL in Australia as African immigrants (Guba & Lincoln, 1989). The knowledge being created is the revelation of these ideas that the research process will facilitate for the participants (Figure 3.1).

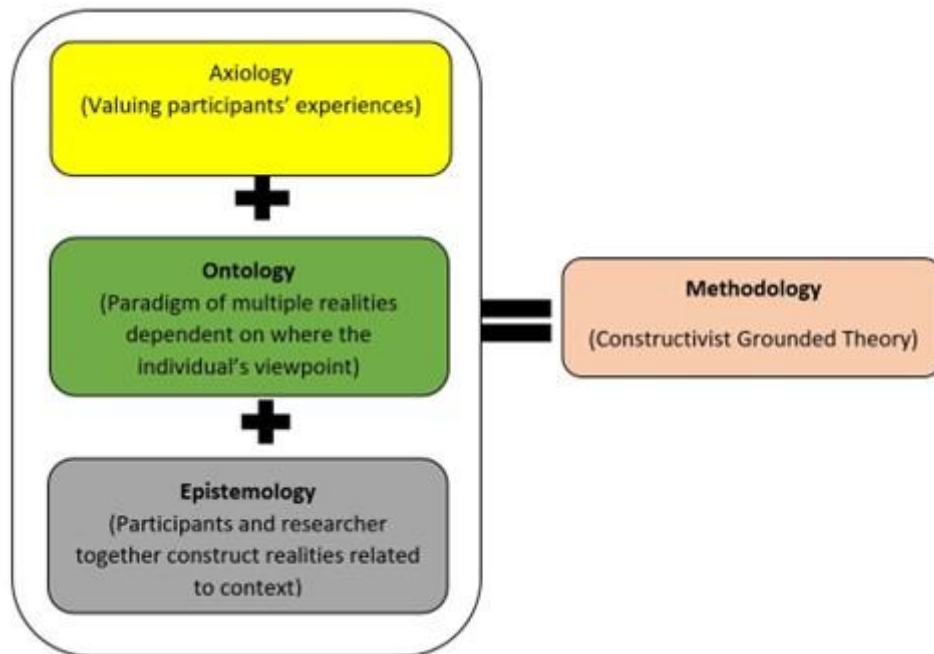


Figure 3.1 Paradigms informing methodology.

## **Maintaining rigour and quality of study**

For a study to be trustworthy, transparency about the process of the research is cardinal. To achieve trustworthiness in this qualitative research the following processes have been followed to achieve this rigour and quality of the study: Dependability, transferability, confirmability, credibility, reflexivity, originality, resonance and usefulness.

### ***Dependability***

Dependability refers to consistency and reliability of research findings (Charmaz, 2014; Flick, 2018), and the degree to which research procedures are documented (Guba & Lincoln, 1989). In this research, it was important that constructivist principles were followed and documented, commencing with participant recruitment, data collection, analysis, and interpretation of findings, and providing adequate information about each section so that the study can theoretically be replicated by another researcher and generate consistent results.

Dependability in qualitative research refers to the stability of data over a period of time. If the research is to be conducted by another inquirer using the same methodology, step-by-step, they should come to similar findings (Polit & Beck, 2013). Dependability, therefore, establishes the trustworthiness and credibility of the study findings (Guba & Lincoln, 1989). This research was being conducted through the application of a constructivist GT methodology. The researcher devised in-depth interview questions which are both semi-structured and open-ended. Data analysis was conducted simultaneously with data collection, applying the constant comparative technique. Memoing was also employed to capture my own thoughts as a researcher, and the relationships between codes and concepts. Writing memos also enabled me to look at the data from different perspectives during analysis (Guba & Lincoln, 1989). Tracking methods by following GT principles and protocols provided the level of dependability required in a GT study.

### ***Transferability***

Transferability is concerned with generalisation of study findings which in the traditional positivist sense, is related to random participants sampling from the same population. The constructivism GT, however, replaces external validity with the verifiable process for checking the extent of similarities between the receiving and sending contexts however, “the burden of proof for claimed generalisability is on the inquirer, while the burden of proof for claimed transferability is on the receiver” (Guba & Lincoln, 1989, p. 241). Therefore, following the constructivist GT, a thorough description of the study process is provided, with succinct and salient details of the time of the study, the place where the study was conducted, the context of the study, and the culture within which the study was undertaken.

### ***Confirmability***

Confirmability refers to the confidence that the research findings are based on views of participants (Creswell & Poth, 2018; Guba & Lincoln, 1989). To demonstrate confirmability in this study, it was important to keep an audit trail, detailing each step of the study process in a transparent manner. Included in the audit trail are interview questions, memos, and transcripts from interviews. NVivo also enabled this research to achieve a clear coding outline identifying codes and patterns throughout data analysis. Checking of theoretical statements and listing of the core categories generated and describing the interaction and relationship towards each other, demonstrates confirmability. Confirmability was further enhanced by the involvement of research supervisors as independent reviewers of transcripts against the research findings.

### ***Credibility***

Credibility involves triangulation and accuracy of data obtained during research (Guba & Lincoln, 1989) evidenced by neutrality of data analysis and interpretation of the findings (Polit & Beck, 2006). To achieve this important quality in this study, participants were interviewed twice. The second interview provided an opportunity to check with the participants, and the accuracy of data from the first interview. Data was gathered until saturation was reached, and this enabled performance of credible analysis, as per the constructivist protocol. The constant comparative technique was used throughout the study, to guide subsequent interviews and to analyse the data. Additionally, input by my supervisors was a valuable resource in developing the findings and generating theory. Techniques of the study process from data collection, data coding, core categories generation, and theory generation, are presented below in Chapters 4 and 5.

### ***Reflexivity***

Reflexivity refers to the researcher being reflective of their position in the study as well as cultural and other experiences that have the potential to influence the interpretation of the data because of beliefs and meanings that they may attribute to the data (Creswell & Creswell, 2018; Patton, 2002; Polit & Beck, 2006). In this study, as an African migrant in Australia, there was need to reflect on and acknowledge personal values in preparation for meeting and interviewing participants who were also of African indigenous heritage and migrants living in Australia. Acknowledging personal values as a researcher enabled to look at the data objectively and recognise the importance of ensuring personal beliefs and cultural affiliation did not influence the research process. The questions asked to arrive at this level of reflexivity were: What background knowledge did I have, in relation to the study topic and

the study participants' cultural background?; and how was that knowledge acquired and how would it influence and shape my perspective? (Bryant & Charmaz, 2019; Patton, 2002).

Some participants were known to me at an acquaintance level due to being a part of the same community. It was for this reason, that reflexivity became a critical tool including the input and guidance from my supervisors to ensure the analysis was about the data and not personal feelings/experiences. During the data collection, it was important to continually remind oneself that there was need to be mindful of not assuming to know what participants meant by certain statements. It was important to clarify with them. It was important to constantly listen to the voice of participants, and not assume knowledge of their position in relation to how they were preparing for EOL in Australia. It was equally important to check with participants the identifiable realities which informed the co-construction of their realities.

### ***Originality, Resonance, and Usefulness***

To further enhance the quality of this study, its originality, resonance, and usefulness were all considered. Originality, which refers to providing new insights or developing current ideas further (Charmaz, 2000), is demonstrated by generating categories rooted in data leading to the development of theory. Resonance refers to the researcher's ability to be open to multiple meanings of the data. The constructivist GT approach to inquiry favours the stance of multiple realities (Charmaz, 2014). This stance facilitated the co-construction of meaning between research participants and the researcher. In relation to usefulness, the theory developed in this study, was derived directly from the real world of participants as they shared their thoughts and experiences on the topic. To arrive at the substantive theory, data synthesis commenced at initial coding where data were examined line-by-line to identify gerunds. Following initial coding there was a focus on finding concepts which then developed into categories leading to the substantive theory (Charmaz, 2014). The

development of the core categories and development of theory were also shared periodically within the School of Nursing at Edith Cowan University and among members of the Centre for Research in Aged Care at the same university, where there was a resonance in the identified core categories and the generated substantive theory. One finding revealed during the course of this study was that during the process of second interviews, study participants expressed a desire to learn more about the topic whilst others stated that they were going to document their EOL plan as a result of participating in the study. This demonstrated usefulness of the study to participants as it clearly had an impact on them and resulted in a positive outcome as they challenged their own thoughts about planning for EOL in Australia. Charmaz (2014) considers usefulness as the ability for research outcomes to positively impact participants lives as well as facilitate opening up new avenues for further research.

## **Methods**

The following section is devoted to explaining the process of GT in action through a consideration of the step-by-step procedures – the methods - necessary to execute this research methodology (Creswell & Creswell, 2018; Crotty, 1998). Research methods are the procedural techniques applied during the course of answering the research question. The methods explain how the researcher identifies, collects, processes, and analyses the data (Creswell, 1998). The process undertaken in this study was that of co-constructing theory with participants as they talked about their journey in preparing for EOL in Australia. Firstly, the research design is outlined, participant sampling and recruitment is discussed with reference to the inclusion and exclusion criteria, the data collection process through the two interview stages are highlighted, and the process of data analysis is outlined. It is important to follow the process of simultaneously collecting data and analysing it while using the constant



comparative technique and memoing. Secondly, these research methods must necessarily be framed by a discussion of the ethical considerations to which this study adhered.

## **Design**

This research was designed as a qualitative study using constructive GT which in turn utilised interviews with MZZ migrants in Australia to generate data to examine EOL care planning among this cohort in WA. It was important for participants to narrate their stories in order to explore their thoughts about how they were preparing for EOL in Australia, identify key concepts in the phenomenon. Creswell and Poth (2018) and Birks and Mills (2015) provide a valuable guide as to how such a narration can generate a substantive theory in a study.

### ***Pilot Study***

An initial pilot study was conducted with three participants to ascertain the efficacy of this research design. The outcome of that pilot study conducted in February and March 2021, was the realisation that one interview was insufficient and that two interviews per participant were needed using in-depth, semi-structured, open-ended questions, and to be conducted on two separate occasions, timed approximately two to four weeks apart. The decision to proceed with two interviews instead of one was part of theoretical sampling because of the guide provided to ensure that participants had EOL care information and considered, prior to the second interview (Charmaz, 2014). The data from the first interviews (Appendix 8) with the three pilot study participants was ultimately included in the overall data after they agreed to participate in the main study. Hence they were not interviewed in the first round of interviews because the data collected during the pilot study were treated as their ‘interview 1’.

## **Participant Recruitment**

Purposive sampling of migrants from MZZ, was used to recruit participants to ensure those recruited were able to provide information on the phenomenon of interest (Creswell & Poth, 2018). An initial invitation was sent through the Organisation of African Communities Western Australia (OACWA), followed by a phone call to invite the organisation to kindly disseminate the information about the study seeking participants. The OACWA responded favourably to the request (Appendix 3). An invitation was then emailed to the Organisation (Appendix 4) which included the participant information letter (Appendix 5) with the request to disseminate the letter among the organisations' members. Sending the information letter with the initial invitation email was a strategy deployed to ensure potential participants were able to make an informed choice without any coercion to participate in the study.

Each potential participant who showed interest in participating in the study contacted the researcher. Two modes of contact were provided in the information letter: by mobile phone or email. Potential participants made initial contact with the researcher by means convenient to them, some used mobile phone while others emailed. Arrangements were made and each potential participant was met individually in their home; to explain the study further and answer any questions they may have had about the study. At this meeting potential participants were asked about their country of origin, their age and how long they had lived in Australia. In addition, potential participants were asked if they were still comfortable to discuss death and dying in the interviews. All those who expressed interest in the study through contacting the researcher were eligible to participate, and thus all were invited to read and sign the written consent form to participate in the study (Appendix 6), including permission to record interview sessions.

In addition to explaining all the research protocols, participants were also advised of the COVID-19 check protocol that was put in place as data collection was conducted during the

COVID-19 pandemic. Participants were advised that they would get a phone call a day before the scheduled interview and were provided with information about the questions on the COVID-19 checklist as per Western Australia Department of Health regulations at the time (Appendix 7).

Noting that one of the Australian visa requirements for migrating to Australia for work or study is a proficiency in English (Healey, 2007) no participants required an interpreter. Those seeking or receiving palliative care were not excluded from the study, however, there were none recruited from this category.

Snowball sampling also known as network or chain sampling is a sampling type where the researcher requests earlier participants in the study to refer others who meet the criteria (Polit & Beck, 2006). During interviews, three participants advised that their spouses would like to participate in the study as well. These participants thus initiated the referrals for additional recruitment. Therefore, those spouses were also recruited for the study. The participants recruited through snowballing were spoken to immediately after the interviews with their respective spouses and the study was explained to them and they were provided with the participant information letter as well as the consent form. Each of the three ‘snowballed’ participants was then asked to take time to consider their participation and advised to call the researcher if they wanted to proceed. When they called back to advise that they wanted to participate in the study, they were asked to provide written consent, an appointment was then made to conduct an interview.

### ***Inclusion Criteria***

To be included in the study, participants had to be migrants of African indigenous heritage from Malawi, Zambia, or Zimbabwe, who had lived in Australia for four years or more and were comfortable talking about death and dying. They were to be male or female, with self-

identified sound mind, and living in Western Australia. Importantly, participants had to be 45 years or older. The age range choice was because human development studies have demonstrated that humans begin to think and question their own mortality around the age of 45 years as they raise their children as well as take care of ageing parents (Erikson & Erikson, 1997; Feldman, 2019; Jensen, 2015; Lally & Valentine-French, 2019).

### ***Exclusion Criteria***

African migrants from Malawi, Zambia, and Zimbabwe who were less than 45 years of age, had lived in Australia for less than four years, and those of non-African indigenous heritage were excluded from participation. African migrants in Australia from countries other than the three selected countries were also excluded from participating in the study.

### **Data Collection**

Developing a substantive theory required collection of quality and adequate data through two interviews with each participant (Charmaz, 2014), using semi-structured, open-ended questions developed following the initial literature review and pilot study (Appendices 9 and 10). The questions developed using a guide on how to structure qualitative interview questions (Creswell & Creswell, 2018) helped to focus on the gap identified and guide towards answering the research question. At the conclusion of the first interview, the date and time for the second interview was arranged. Data were collected between December 2021 and February 2023, totalling 14 months. Each participant had two interviews scheduled in that time, and there was the requirement to postpone interviews due to the government COVID-19 restrictions at the time.

To ensure that rich data were collected and, to facilitate the generation of a substantive theory, based on the data, face-to-face, in-depth semi-structured interviews using open-ended

questions were conducted. Semi-structured, open-ended questions allowed participants to express themselves without being led by the researcher (Creswell & Creswell, 2018). The interviews were conducted in participants' homes as this was the preference for all participants. The first of the two interviews (Interview 1) was 45 to 60 minutes in duration because the interview started with general questions aimed at creating a comfortable atmosphere before going into the more specific, personal questions (Appendix 9). The first interview informed the review of the second interview questions to ensure identified ideas were followed up in the following interview. The second (Interview 2) was shorter, lasting 18 to 30 minutes (Appendix 10). Both the first interview and second interview for each participant were recorded using a digital audio recording device to ensure that conversations were captured in full as participants narrated their thoughts and feelings about preparing for EOL in Australia. The interview recordings were then uploaded to a password-protected Teams folder provided by the Edith Cowan University Research Ethics Management Systems to ensure the security of the data collected (ECU, 2017).

### ***First Interview***

Each participant was provided with an opportunity to have someone sit in during the interview if they wished, due to the nature of the questions talking about EOL and dying. All participants chose to be interviewed without a friend or close family member present.

In this first interview, it was important to understand the participant's unique migration journey, experience, and the reasons for migrating to Australia. It was also important to establish at this early stage if the participant was intending to return to Africa or planned to stay for the long term. Since participants had not previously thought about preparing for EOL in Australia, a point confirmed in the pilot study, an Advance Health Directive (AHD) (Appendix 12) and Advance Care Plan (ACP) (Appendix 13) information brochures

downloaded from the West Australian Government website, were offered to participants at the conclusion of the interview, to facilitate participants' thinking about the topic.

Participants were asked to review the documents and to discuss their thoughts about them in the second interview. Providing the EOL care documents for consideration before the second interview was considered as theoretical sampling as the aim for the second interview was to focus on specific concepts (Charmaz, 2014). Charmaz (2006; 2014) consider theoretical sampling not only in light of collecting data from new participants selected carefully to provide clarity to unclear concepts, but also the modification of interview questions.

The three pilot study participants were only offered the brochures at the start of their second interviews because it had not been anticipated that these documents would be helpful to participants, hence the need for the pilot study. As a result, for the pilot study participants subsequently enrolled in the main study, their second interviews took much longer than the other participants in the study due to the time needed to discuss the AHD and ACP brochures (which they were given at the start of interview 2). As with the first interview, participants were offered the opportunity to have a friend or family member attend the interview as a source of support. However, all participants were more comfortable to be interviewed alone.

### *Second interview*

Study participants were all invited to a second interview. All participants in the study agreed and consented to be interviewed again. The objective of the second interview was to follow up on aspects of the initial interview and to ascertain if there had been any change of thoughts following on from their first interviews, which introduced them to the topic of preparing for EOL in Australia. It was also important to check if the AHD and ACP brochures that were offered to them after their first interviews were of any benefit in guiding what to consider when planning for EOL. Alongside memoing, content from the first and

earlier interviews informed and developed the information sought in subsequent encounters. Thereby, qualifying the action as theoretical sampling described by Charmaz (2006; 2014).

### ***Transcription***

NVivo software (Edhlund & McDougall, 2019) was used to transcribe interview recordings verbatim, prior to the second interviews. Editing of the transcripts was carefully undertaken to remove errors, repetitions, and words such as ‘mmh’ or ‘uuh’. Editing was done with significant caution to ensure the preservation of verbatim texts, checking carefully to make sure that the voices of participants were not lost while transcribing, achieved by listening to recordings again and comparing with the edited text for accuracy.

Participants were identified by pseudonyms to maintain anonymity, thus maintaining confidentiality and privacy. As with the grounded theory tradition, coding was undertaken after each interview to ascertain what to explore further in subsequent interviews (Charmaz, 2014).

## **Data Analysis**

Theoretical sensitivity, memoing and diagramming were the three main concepts that guided data analysis (Creswell, 2013).

### **Theoretical sensitivity**

Theoretical sensitivity (Figure 3.2) is the researcher’s ability to gain insight, give meaning, understand, and find the relevance of the data (Strauss & Corbin, 1990) by a capacity to understand, and the capability to separate the pertinent from the relevant. In this research, it was important for the researcher’s skill to question her own assumptions in the context of data being analysed because of being a migrant in Australia and having migrated from the

same region as the study participants. It was also vital to acknowledge that the researcher did not have all the knowledge related to the study therefore, needed to be reflective and reflexive, not dismissive of any data but, ensure that participants' voices were heard by making certain that participants' viewpoints on preparing for end-of-life were captured. Reflexivity is a core component of Charmaz's constructivist grounded theory (Charmaz, 2006; 2014). In addition, questioning one's own assumptions in the context of the study being conducted, especially that the researcher was part of the community being researched, was critical in data analysis. Memo writing was key in examining own thoughts and assumptions to help keep them in check. Supervisors also played a vital role in guiding and assisting achieve theoretical sensitivity.



Figure 3.2 Theoretical sensitivity chart modified from Strauss & Corbin, 1990

## **Memoing**

Writing memos to self was an integral part of the study as memos were written throughout the data collection and analysis as part of the process of analysing data, theorising, and writing the study findings (Birks & Mills, 2011; Charmaz, 2014). The contents of the memos were conversations held with self while trying to make sense of the data collected, and how



to go forward for subsequent data collection, giving clear direction as to what to target in the following interview and how to adjust the interview questions. Memoing as an ongoing process was not only integral in assisting finding direction during data collection, but also in conceptualising, and in thinking about the meaning of the data and arriving at a substantive theory (Charmaz, 2014; Mohajan & Mohajan, 2022; Ratnapalan, 2019). Research requires solid data analysis which was the constant search for answers as active observations and accurate recalling of information was employed, thus helped with making sense of the data (Corbin & Strauss, 2015; Morse & Field, 1995). Memoing therefore, enabled capturing of thoughts in relation to interviews and the data and helped apply context to the analysis (Charmaz, 2006; Creswell & Poth, 2018). In addition, the technique was also used to capture ideas and important conversations that occurred after the recording device was turned off.

There were some important conversations that participants initiated after the interviews ended. Memos were written immediately after leaving the participants' homes to capture the essence of the conversation which were invaluable information providing further explanation of some points mentioned during the recorded interviews. Memos were also used to link codes and categories, reflect on the usefulness of identified categories, and also consider practical implications (Charmaz, 2014). For instance, initially there were categories that were separate and later merged because the two categories were about similar thought trends such as preferred place of care and cultural practices. The conclusion to merge the two categories came about after grappling with the ideas, wrote a memo about them which helped clear the discussion in self and concluded that the two belonged together because they both were related to culture.

The memos formed part of the reflective process of enabling, cognitively engaging, and interacting with the data (Birks & Mills, 2011; Charmaz, 2006). Writing of memos as an intermediate step encouraged to view data from a different standpoint which helped trigger

further coding, theoretical sampling (Charmaz, 2000) and aided in linking analytic interpretation with empirical reality. In this study, memos also helped to consider the concepts identified, and how they were creating linkages with each idea. Charmaz (2000) advocates that memos can be written about anything related to the research project; “We bring raw data into our memos so that we maintain those connections and examine them directly” (Charmaz, 2000, p. 517).

In addition to viewing data from a new standpoint and maintaining connections within the data, memo writing also brought context to the data (Charmaz, 2014) as helping in data analysis which in grounded theory is conducted concurrently with data collection (Charmaz, 2006, 2014; Clarke, 2019; Denzin & Lincoln, 2000). Memoing played a significant role in how the substantive theory was generated and presented in this study on preparing for EOL in Australia for MZZ migrants. Memos were constructed in relation to interviews, analysis, and in relation to available literature as a trail for evidence of the study process. Table 3.3 shows examples of free style memo excerpts.

Table 3.3 Examples of memo excerpts

Depending on family members to make decisions is a common theme amongst participants. This is one of the reasons given why they see no need to plan for end-of-life.
<p>There is a common theme of community support for the participants when faced with difficult situations. Chungu seems to think that his children may not receive the same kind of support because of the individualistic type lifestyle. This is like what Waitwika called “half baked” in reference to his children not knowing the African culture and also not being conversant with the Australian culture.</p> <p>Musa considers those people around at the time when he needs assistance to be family and he is not bothered if the whole community comes to visit him when at EOL even if they were just come to see him for the purpose talking about him on how poorly he is in the community. He seems to be at one end of the continuum of how much he has become individualistic and strong in his individual state and yet there have been others who desperately want to go back home demonstrating that toing and froing psychologically. There is a continuum of individualism vs collectivism which is very western view of their children, filial piety expectations at all.</p>
Participants seem to slide into talking about what they think would or should happen after they die. They were quick to talk about what should happen to their bodies, the rituals performed at funerals, and how graves are cared for in Africa. They seem to find it difficult to think and talk about end-of-life, I will need to rephrase the questions to assist participants to think and respond about preparing for end-of-life and not about death.
It sounded like Thandi would go back to Zimbabwe; at the same time, she has nothing to go back. This statement is so profound in expressing the dilemma she is facing, not knowing where to settle. It is like living in two worlds.
Thandi is concerned that she is not able to go and see her dad in Africa because of COVID and that he is getting older, so flying to Australia may not be feasible. It sounded like a feeling of being responsible for her dad. On the contrary, Simbeye seems to have left and does not want to go back. It would appear the reasons for leaving their home countries have a significant impact on how they view visiting their countries of origin.
This is more or less like the hierarchy in decision making. The more senior someone is in the family, the more they are expected to be the final authority in matters of importance.
Simbeye and Cilla both come from 'royal' background. Simbeye is relieved to be so far away from the culture that surrounds dying in his village. While for Cilla, although there is a culture attached when one dies, she does not seem to share the same concerns. This could be due to the fact that Cilla is female and Simbeye is male.
NaPhiri seems undecided on the place of care when in end of life. Earlier, it appeared as though she did not want her children to be burdened with her care. But now she would like home care managed by them. No of the participants so far have been straight forward on what they would like at end of life. It almost seems like they are on an unsteady pendulum where decision for EOL is concerned. I think I need to rephrase the question in the next interview to if there will be clarity on this matter.

## **Diagramming**

Diagramming is the use of visual images which can be powerful in illustrating concepts (Charmaz, 2014; Clarke, 2005), and can help place a concept in their right position in relation to other concepts (Morse & Clark, 2019). Using diagrams is an intrinsic part of grounded theory (Clarke, 2005, 2012; Strauss & Corbin, 1998; Corbin & Strauss, 2008). In this study, diagramming was used to support written text and illustrate ideas or concepts that may otherwise be complex. Maps showing positions of locations, charts, and figures to illustrate relationships of the completed work (Clarke, 2005) and enable visualisation of the “...the relative power, scope, and direction of the categories... as well as the connections among them” (Charmaz, 2014, p. 218), were used to enhance clarity of explanations provided in relation to the study. Morse and Clark (2019) refer to diagramming as working to facilitate puzzle pieces coming together to tell a full story of what it is all about. In this study, maps, photographs, charts, tables diagrams were all used to enhance understanding of the concepts discussed. Diagramming was beneficial in illustrating the regrouping of the codes, to generate core categories which developed into the substantive theory of the DPTF. Additionally, constant comparison and memoing helped shape the concept maps that further guided in creating the diagram.

## **Simultaneous Data analysis**

Data analysis took place simultaneously with data collection and was concluded when data saturation was reached, as guided by grounded theory principles of constant comparative technique (Charmaz, 2014; Creswell, 2013). For this study, saturation was attained after interviewing 12 participants, with each participant interviewed twice, making a total of 24 interviews. To ensure that data saturation was reached, two more participants were interviewed, bringing the total to 28 interviews. At this point, no new concepts from the

existing data were coming up; there were no new themes identified from the subsequent interviews (Creswell, 2013). The process of data analysis required constant comparison and memoing. Constantly comparing interviews while analysing, helped to focus early on the research process and identified something theoretically plausible worth pursuing going forward (Charmaz, 2014). Data analysis was conducted in stages.

Constant comparison is at the core of data analysis in grounded theory research, the technique was used to compare data from different study participants as well as categories identified during data analysis (Corbin & Strauss, 2007). The constant comparative analysis which is a set-based theory that seeks to explain the relationship between causal conditions and outcomes (Strauss & Corbin, 1998), was at play throughout the study. Data were analysed concurrently with data collection and iteratively in a back-and-forth fashion, comparing previously collected and analysed data with newly collected data through coding to identify categories.

### **Coding**

In GT, coding is defined as a process of defining what story the data is telling while being analysed (Charmaz, 2014). Coding of the data was conducted after each participant's interview, that is, each interview script was analysed carefully to guide and direct collection of next data as concepts were being followed up (Charmaz, 2006; Corbin & Strauss, 2007). As data and categories were constantly compared, differences and similarities were being identified between codes and categories through the concept of sets and their relations (Glaser & Strauss, 1967).

Segments of data sets were named and labelled in a process of coding that involved identification of theoretical concepts. Keeping an open mind during the coding process was

important to make sure that ideas were examined as they emerged and investigated further (Charmaz, 2014) for instance the concept of collectivism versus individualistic culture.

Coding as an analytical process is fundamental to grounded theory research as advocated by all major proponents of the methodology (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1990). The objective of the process is not only to identify similarities and conceptual reoccurrences in the data but also contrasts (Charmaz, 2014). Coding is also a crucial linkage between gathering data and explaining the meaning of that data as the researcher interacts with it. As expected, the codes applied to data changed over time as the comparative work continued, leading to identification of core categories (Birks & Mills, 2011).

### ***Initial coding***

In grounded theory research, initial coding is the first step in data analysis (Figure 3.3). The objective of initial coding is to carefully read the transcripts line-by-line, in order to become familiar with the text, and to apply codes (Charmaz, 2014). Openness and mindfulness during initial coding allowed for thinking about new ideas emerging. Coding with gerunds helped identify processes participants were undertaking or engaged in, with the preparation for EOL in Australia. The objective for coding with gerunds was to identify the actions of participants (Charmaz, 2006; Glaser, 1992). Gerunds reflect that the experience, thought or idea is dynamic rather than static and may yet occur again in time to come (Charmaz, 2014). It was important during this coding phase to search for opportunities for refining interview questions so to allow clarification of concepts that may have been unclear in the previous interviews. Interview questions were refined a couple of times to clarify if participants understandings of the same phenomena were being communicated (Figure 3.4).

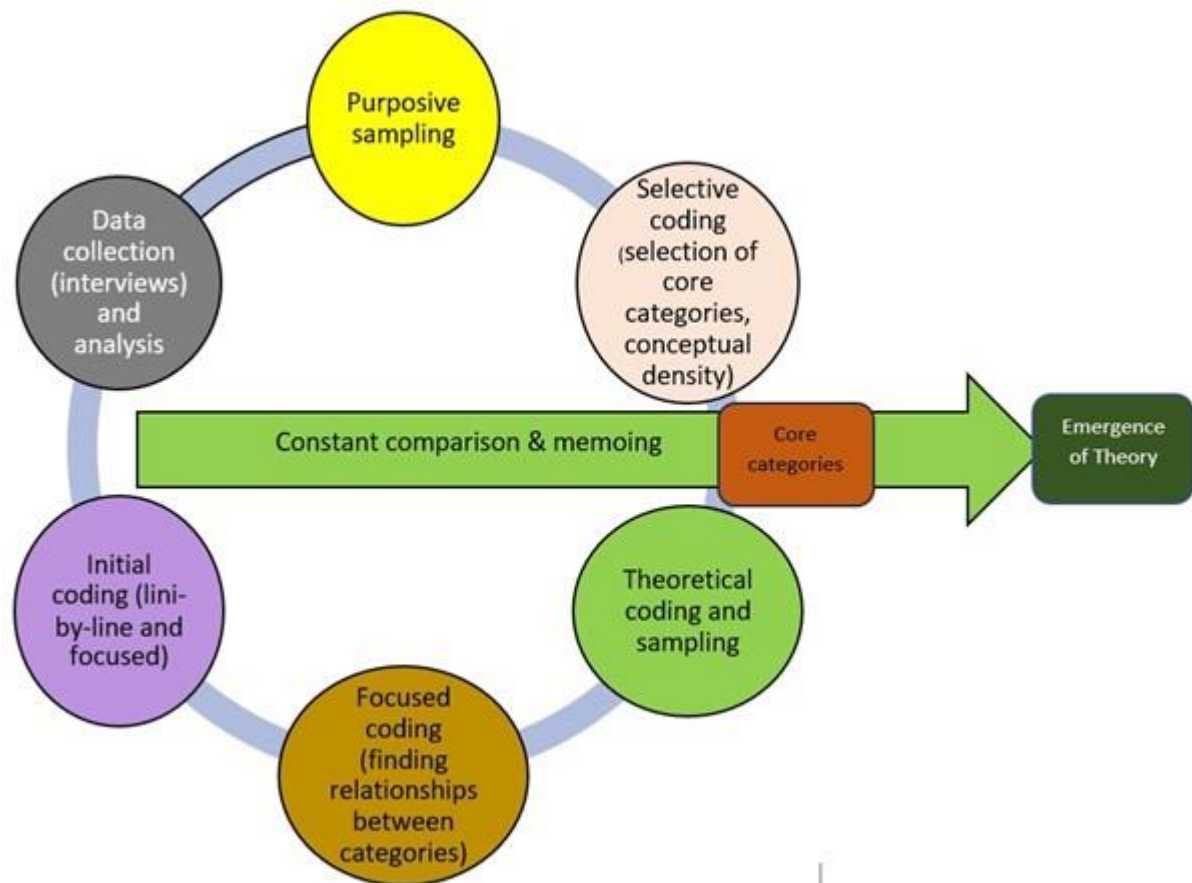


Figure 3.3 Data Collection and Analysis

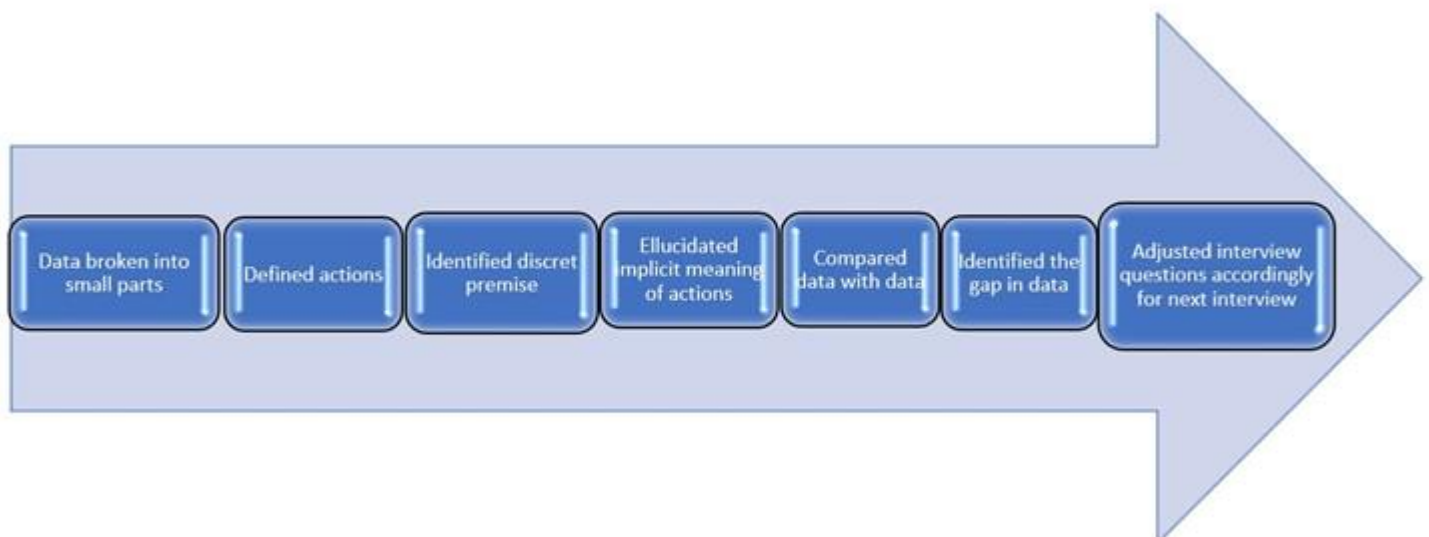


Figure 3.4 Initial Coding Process

### *NVivo codes*

To assist in organising the data, NVivo software was used to tag data for initial coding (Frieze, 2019). NVivo coding played a significant role in data analysis as it made initial coding much easier. In addition to coding, transcribing interview transcripts was of great benefit before commencing with coding. Table 3.4 is an illustration of NVivo coding employed during the initial stages of coding. Coding using NVivo enabled the creation of many nodes that were later merged as themes, and the analysis brought clarity to the data. The coding commenced with breaking down of the data into small parts by reading line-by-line and apportioning the broken-down data into appropriate groupings, paying attention to actions being expressed in the data (Charmaz, 2006; 2014). It was important during this coding phase to identify discrete premises, something not obvious or spoken with ambiguity or hidden meaning. The data were compared with incoming data to identify gaps, which were addressed prior to the subsequent interviews by adjusting the interview questions.

Table 3.4 Example of NVivo

<p><a href="#">&lt;Files\\Chungu 1&gt;</a> - § 1 reference coded [1.64% Coverage]</p> <p>Reference 1 - 1.64% Coverage</p> <p>But each time I thought I should go back, I had another thought saying yes, you can go back there. You can tell, your colleagues how hard it was and that you even did a cleaning job in order to try to make ends meet. But then, our fellow Zambians, they will sympathize with you for the first one hour, two hours and then they will laugh at you for the rest of the life that you went abroad and you didn't come back with, even with a degree. So that in itself, I used to think, I better persevere.</p>
<p><a href="#">&lt;Files\\Hyawo 2&gt;</a> - § 1 reference coded [6.53% Coverage]</p> <p>Reference 1 - 6.53% Coverage</p> <p>So the idea of having sort of guiding principles to look at as people of African origin, I think it's very important because it will help to instil what I want in my children because there would be an organization which would probably help them to cement what I have said should happen to me and to let my children take that with the support of the advance health directive, because it is a set of written documents.</p>



[<Files\\NaMbewe 2>](#) - § 2 references coded [5.99% Coverage]

Reference 1 - 5.54% Coverage

To be honest, it may be, I suppose it is also the pride the fact that I have lived in Australia for so long. So, to go to my own place, even as a dead person, it will give me some respect that she did this, she accomplished this, and she has achieved this. Yes, like I say, that little house, it is a place, even if I don't have to live in it. Even if I do not live it, but it is still there for my son and his family, if they want to visit, they will know that their stepping stone is there. They can move to the other places, but to be a stepping stone is there, the foundation is there, and they will call it, our house. So that is a good thing. Even when I am dead, they would still have those memories of cherishing that I lived there, this was our home. And that will make it even more homely for them the fact that they will be thinking, mum was here, and she built this place. She was born here, lived here and she's buried under that tree. So, for me, I think it is more of pride and a feeling of satisfaction that I have done it.

[<Files\\Simbeye 1>](#) - § 1 reference coded [1.37% Coverage]

Reference 1 - 1.37% Coverage

It is not a question but, a contribution. To die a happy man, is to see that my grandchildren are taking over whatever I have built for them and use their own ingenuity to develop and remember me that way.

[<Files\\Ted 1>](#) - § 3 references coded [8.10% Coverage]

Reference 2 - 4.03% Coverage

I believe I can write, but it can never have the same impact. It's talking to them, I am imparting our culture to them. I am telling them how things were done so that they understand. I will, I've started writing my memoirs so that they can read. The intent is that my grandchildren will ask some questions that my children cannot answer. For instance, they will say, why didn't grant father? Why did you come to see you? Why did you abandon this whole country? Was he running away from something? I don't want my children to imagine. I want my grandchildren to read and possibly listen to my voice telling them of where we came from, our stories and the reasons why we came. Have I achieved what I wanted as I was aspiring to come here? I would say on the overall, yes, and I would tell them my story, and I would tell them how I would want to be treated through story. And it will be in written form as well because I find why most of our culture is quickly eroded is because it is not written down somewhere. So I will be, yes, I hope that I will finish writing my memoirs before I pass on.

This type of coding was used as a heuristic device which provided the opportunity to look at the data from a different perspective and also to learn the participants' worlds. Charmaz (2006; 2014) argues that researchers do not get the opportunity to learn the participant's world prior to commencing a study, therefore, it is important to pay attention to gerunds which assist the researcher to have a glimpse of the participant's world. Initial coding was done mostly by focusing on actions and processes, and asking questions to find out what was happening in the data (Charmaz, 2006; Glaser, 1978) as participants narrated how they were preparing for EOL in Australia. This helped identify what participants were doing in relation to preparing for EOL in the Australian setting, and also helped identify other phenomena of interest such as their level of spirituality and the connection between spirituality and culture and the processes that participants were familiar with from the African cultural perspective and how that was being affected by them living in Australia. While undertaking this initial coding, particular attention was given to the construction of structures that migrants were familiar with, but were changing with time (Charmaz, 2014). Line-by-line coding provided something to work with, as progress was being made in analysing data. After initial coding, analysis progressed to focused coding.

### ***Focused coding.***

The aim of focused coding is to identify patterns that are repeated within the data, examine the data for different meanings, describe the disparity noted and the relationships among the themes (Charmaz, 2014). Focused coding commenced when a conscious decision was made, to progress data analysis from initial coding to a higher level (Charmaz, 2014; Creswell & Poth, 2018). Unlike Glaser (1978; 1998; 2005) who advocates for identification of a single core category through focused coding, this study followed the more sensitive and flexible constructivist approach which does not limit the analytic process to one core category.

Focused coding was achieved by taking some of the line-by-line codes generated from initial coding and elevating them to higher level, by testing them against data, getting to what story those codes were telling. This involved breaking up the data to understand underlying assumptions, what the data meant to participants' day-to-day living. For instance, looking at what participants meant when they talked about their children being culturally lost when discussing how they would prefer to be cared for during end-of-life. In addition, breaking down the data helped research process to move from a purely descriptive stage to a more abstract level as the underlying meanings in the data were uncovered. The next stage in constructivist theory data analysis is theoretical coding.

### ***Theoretical coding***

Following focused coding is theoretical coding which aims at analysing how the categories and codes derived from the data are relate to each other, a step that leads to generating theory (Thornberg & Charmaz, 2014). To achieve this amalgamation that determined the relationship between categories and codes, an examination and selection was done using theoretical coding which allowed for arranging and conceptualising the codes and categories (Glaser, 1992). Initial and focused codes were derived from the data, as a result of constant comparative work of the data, data and codes, codes, and codes. Theoretical codes on the other hand, are concerned with the rationale or the idea what the data is revealing (Thornberg & Charmaz, 2014) thus, advancing to emergent theory.

## **Ethical considerations**

Research paradigms or worldviews provide a standpoint for individuals about beliefs relating to the world and how to study it in order to gain knowledge (Creswell & Creswell, 2018). Studying the nature of the world can have huge ramifications on how those studies are

conducted in relation to morals, ethics and justice (Guba & Lincoln, 1989) however, it is nonetheless important to consider the ethical issues to ensure respect, justice, beneficence are applied during the research process, and that maleficence is avoided (Polit & Beck, 2006). Charmaz (2014) argues that the researcher's world view, status, prestige, and power can influence how they view participants and the data that are collected, and how the participants view the researcher. For the purposes of this study, as a researcher, I had no affiliation with the OACWA because this could have created a perception of power imbalance between the researcher and participants. Additionally, as a registered nurse, I was guided by the ethical code of conduct as set out by the Australian Health Practitioner Regulation Agency (Nurses and Midwifery Board (2022)). The MZZ community in Western Australia is +

### **Ethics Approval**

Ethics approval was sought from the Edith Cowan Human Research Ethics Committee. Approval was granted following the committee's satisfaction of the processes put in place to ensure participants were not at high risk (Appendix 11). Creswell and Poth (2018) identify key issues a researcher might encounter during the research process. Those key issues were carefully considered throughout this study. At the participant sampling stage, it was important for participants to participate voluntarily, therefore, there was no coercion or inducement exerted on participants to take part in the study. Participants were given time to consider participation in the study and were invited to ask questions if they needed to. Participants were encouraged to keep their copy of the participant information letter as it provided details of the research and requirements, including information on withdrawal from the study, and researcher contact details.

## **Informed consent**

Potential participants were met individually, face-to-face, following a phone call or email, expressing their interest to take part in the study. At this initial meeting, eligibility to participate in the study was checked and confirmed and if they were still comfortable talking about death and dying. Participants were also assured of anonymity by use of pseudonyms in all reports and publications. Additionally, participants were advised through the participant information letter (Appendix 5), as well as during the initial face-to-face meeting, that they could exit at any stage of the study. However, if they exited during data analysis, they were aware that their data would be included in the analysis and the study report. A written consent was then sought for participation in the study (Appendix 6).

Participants in the pilot study had expressed willingness to participate again if something of a similar nature came up in the future. The three pilot study participants were contacted to inquire if they were still available and willing to participate in this study. All three participants agreed and were happy to be interviewed again. The three participants were asked to provide a fresh written consent to cover for the second interview. This was because the consent obtained for the pilot was for one interview only.

All participants were advised that interview recordings and all data collected would be stored in a secure place at Edith Cowan University Joondalup (ECU) and would be retained for a period of seven years as per ECU data management plan for human participants, after which it will be disposed of in accordance with ECU policy (ECU, 2017).

Each participant was given the opportunity to decide and choose the place to conduct the interviews. The choice was between their home and a public place in a quiet area away from people to ensure confidentiality. All participants selected to be interviewed in their own homes.

## **Confidentiality**

To maintain confidentiality, participants were advised that information would be used for the purpose of this research project, publication, and future presentations. The information would only be disclosed with participants' permission, except as required by law. In this study, identifiers were removed and replaced by codes, but it remains possible to re-identify a specific individual by, for example, using the code or linking different data sets. Participants were also assured of confidentiality by use of pseudonyms in the thesis and in any publication. To enhance confidentiality and privacy, these pseudonyms were used in transcripts, presentations, and reports. Interview recordings and all data collected, are stored in a secure, password protected location at Edith Cowan University, Joondalup, WA.

## **Managing vulnerable participants**

As a way of risk management, participants were encouraged to attend the interview with a close friend or family member for support in the event of feeling emotional discomfort due to the questions in the interview. All participants nominated to be interviewed without a friend or family member for support. While there were no incidents of anxiety during and after the interviews, participants were aware of how and where to access help if needed. The participant information letter advised participants to seek review by their general practitioners or Beyond Blue, for free counselling services. In addition, in the plan, the researcher was to make a welfare check in 24 hours following the interview if risk was identified, and if participant was advised to seek the mentioned services. None of the participants required review.

## **COVID management**

Data collection occurred during the global COVID-19 pandemic, and thus it required vigilance of the part of the researcher, such as daily checking the Western Australia Ministry of Health website for new updates on the COVID-19 status in Western Australia and the government directives concerning the same. A COVID-19 management plan was put in place before the project commenced. Prior to attending interviews, participants were contacted by telephone to complete a COVID-19 checklist (Appendix 7). Questions included: If the participant or anyone in their household had COVID-19; if they were feeling unwell with flulike symptoms; or if they had just arrived from Australia's eastern states. The question about travel from eastern states was only applicable between January and June 2022, as this requirement was superseded by free travel within Australia. I proceeded to participant's home only if the checklist did not identify a COVID-19 risk. However, a supply of face masks was always at hand if they were required. Appropriate hand sanitiser was also available and was used prior to entering the participant's home and immediately after exiting. There were two instances when interviews were postponed because participants' responses to the checklist questions indicated that they may have had COVID-19. Each of the two interviews was completed after the government's isolation period protocol.

## **Data management**

In this project, as the lead researcher I worked with data obtained through participant interviews. Interviews were audio recorded. Code names were used during interviews to ensure participants could be identified through data. Electronic data such as, interview recordings and all data collected is stored on a secure password protected Microsoft TEAMS provided by ECU's Records as per data management plan for human participants as outlined in the ECU's Data Management policy. The data will be retained for a period of seven years,

as required by research ethics governance, after which it will be destroyed securely by the process set out by the university if appropriate under the State Records Act. Information will be used for the purpose of this research project, publication, and future presentations. The information will only be disclosed with participants' permission, except as required by law. Identifiers have been removed and replaced by a code, but it remains possible to re-identify a specific individual by using the code or linking different data sets. Participants were assured of confidentiality by use of pseudonyms in the thesis and in any publication.

## **Summary**

This third chapter has provided a detailed description of the established philosophical assumptions of knowledge development in relation to the research process and conduct of the study. An explanation of the methodology was provided, with a justification for the use of grounded theory as the methodology of choice for this qualitative research approach. The detailed protocols for data collection and data analysis were also described through the paradigms of axiology, ontology, and epistemology from the constructivist position. The application of these paradigms as elements that inform the methodology was explicated in the interconnecting steps of the methods, introducing GT as the methodology and methods of choice for the study, including constant comparative techniques, memoing and diagramming. The following Chapter 4 will present the findings of the study.



# Chapter 4: Findings

## Introduction

This Chapter Four presents the findings of the study, firstly by introducing the 14 participants enrolled in the study with an overview of the interview arrangements. Participants are referred to by their pseudonyms and an overview of their respective demographic data are provided. The findings generated from the interviews with participants were shaped using the three steps of data analysis as per constructivist grounded theory design: initial coding, focused coding, and theoretical coding. Overall, the data depicts the experiences of migrants from MZZ and their EOL planning. Data analysis using the constant comparative technique, identified six categories: A) Remodelling self; B) disintegrating of family dynamics; C) resetting the life button; D) shuttling back and forth; E) finding equilibrium; and F) pursuing the horizon. These six different conceptual categories are discussed in detail below and are further analysed and synthesised, resulting in the identification of the emergent model of the Dynamic Process of Toing and Froing (DPTF) in preparation for EOL by migrants from MZZ in Australia.

Overall, this study is about how migrants from MZZ prepare for EOL in Australia, has come about because the participants left their respective countries to come to another country; a country far away from their birthplace. Moving from a familiar environment, familiar lifestyle, and culture, takes courage and determination and each participant had a reason that prompted their migration. Although little was known about life in Australia before migration, each participant made a conscious decision to leave behind what they were familiar with in pursuit of a life they perceived to be better.

This chapter seeks to explicate the realities of MZZ migrants in relation to their preparations for EOL in Australia. Further synthesis of the data establishes that the participants are in a state of ambivalence at every level of the six identified categories. The findings show that this ambivalence stands in the way of their preparations for EOL. Identification of this ambivalent state in participants' experiences gives rise to the emergent core-category of DPTF: The 'toing and froing' illustrates the uncertainty migrants experience as they contemplate EOL in a place distant from their home countries. The theoretical development of the DPTF is detailed in Chapter 5.

### **Study participants**

The 14 participants interviewed were aged between 49 to 70 years and included eight female and six males, who at the time had been living in Western Australia for between 9 to 21 years. One participant first migrated to New Zealand before moving to Australia, while the rest migrated from Africa directly to Western Australia. Nine of the participants migrated especially for work and business opportunities, while five departed their respective nation in Africa in search of tertiary education in Australia and later decided to stay permanently. All participants had spouses during their migration, except for one female who was widowed before migrating. One female participant's spouse died after being in Australia for nine years. All participants have children of their own except for one female participant who has stepsons, her spouse's adult children from his previous relationship. Four couples that participated in the study. Participants were encouraged to attend the interviews with a family member or close friend for support as the topic had potential to be confronting. All participants chose to attend the interviews alone. Table 4.1 provides a snapshot of participants' demographic information.

Table 4.1

Participants' pseudonyms and demographic data.

Participant Number	Pseudonym	Age	Gender	Country of origin	Years in Australia
1	Thandi	60	Female	Zimbabwe	16
2	Jane	56	Female	Zimbabwe	9
3	Waitwika	59	Male	Zambia	21
4	Ted	66	Male	Zimbabwe	16
5	NaMbewe	55	Female	Malawi	20
6	Simbeye	67	Male	Zambia	21
7	Cilla	49	Female	Zambia	14
8	Tomaida	63	Female	Zambia	21
9	Towela	55	Female	Zambia	15
10	NaPhiri	60	Female	Malawi	18
11	Hyawo	70	Male	Malawi	14
12	Chungu	56	Male	Zambia	20
13	Mwada	60	Female	Zambia	15
14	Musa	65	Male	Zambia	15
Legend: <span style="display: inline-block; width: 15px; height: 15px; background-color: #4a7ebb; border: 1px solid black; margin-right: 5px;"></span> Malawi <span style="display: inline-block; width: 15px; height: 15px; background-color: #70ad47; border: 1px solid black; margin-right: 5px;"></span> Zambia <span style="display: inline-block; width: 15px; height: 15px; background-color: #fdd835; border: 1px solid black; margin-right: 5px;"></span> Zimbabwe					

The following paragraphs introduce the 14 study participants in the order of recruitment. Using their pseudonyms, a brief overview of their demographic data, migration story and individual situations are provided.

\*\*\*

**Thandi:** 60-year-old female who came to Australia in 2006 on a work visa to work as a nurse, after working as a midwife in Zimbabwe. Thandi joined her first-born daughter who was already in Australia studying. Thandi is married and has two other children

whom she left with her husband ‘Ted’ at the time of migrating. Her husband and two children joined her six months later. Thandi works as a registered nurse, has one grandchild, is a Christian, and occasionally attends church alone. Thandi was first interviewed in the pilot study phase and was also interviewed a second time as part of the main study. Her husband Ted also participated in the study.

**Jane:** 56 years old female who migrated from Zimbabwe in 2001 to New Zealand and then to Australia in 2013. Jane is an early childhood educator, and she runs a day-care business. Previously, Jane was working as a special needs teacher at one of the government schools in the southwest region of Western Australia. She is married, has no children of her own but two stepchildren from her husband’s previous relationship. The two stepchildren live in New Zealand. Jane reports that the community from her church is important to her and she shares everything with them. Jane was first interviewed in the pilot study phase and was also interviewed a second time as part of the main study.

**Waitwika:** 59-year-old male, married, migrated in 2001 to pursue higher education, and has two adult children both of whom have completed their higher education and are working. Waitwika first undertook tertiary education in Zambia before coming to Australia. Waitwika initially planned to go back to Zambia once he had finished his studies however, he decided to stay permanently. He worked as an accountant in an insurance company before coming to Australia and currently is working for an insurance company in Australia. Waitwika is a Christian and attends church regularly. Waitwika was first interviewed in the pilot study phase and was also interviewed a second time as part of the main study.

**Ted:** 66-year-old male who works as a mechanical engineer at a mineral refinery company. Ted is married to Thandi who also participated in the study, and they have three children and one grandchild. Ted completed his engineering degree in the United Kingdom. Prior to coming to Australia, Ted ran his own business when he was in Zimbabwe. He migrated in 2006 with two of his three children to join both his wife who had migrated six months prior and his first-born daughter who was already in Australia studying. Ted follows traditional African beliefs and practices. He is of the view that Christianity frightens people by talking about hell and that it was introduced to destroy the respect that Africans had for their ancestors.

**NaMbewe:** 55-year-old female who works as a nurse, migrated to Australia in 2002 with her son. She worked as a nurse before migrating from Africa and continues to do the same work in Australia. NaMbewe is a widow who came to Australia to pursue her Master's degree in 1997. After completion, she went back to Malawi but later decided to return to Australia permanently. Her son is currently studying at university. NaMbewe also cares for her niece, her brother's daughter whom she has brought to Australia under the sponsorship visa accommodation. NaMbewe is a Christian who attends church occasionally, when she is able.

**Simbeye:** 67-year-old male who works as an information technology/computer engineer and was previously a businessperson in Zambia. He completed his first degree in Zambia and later went to the United Kingdom to study his Master's degree and completed a PhD. Simbeye came to Australia in 2001 with his wife Tomaida (also a participant in this study). They have five children and seven grandchildren. Simbeye

comes from Chief (royal) lineage in Zambia but has decided to have nothing to do with his heritage. He follows Christian principles.

**Cilla:** 49-year-old female who migrated from Zambia in 2008 to join her husband who had arrived in Australia a year earlier on a work visa. Cilla worked as a primary school teacher before migrating from Zambia, but now works as a support worker for people living with disabilities. Cilla is a mother of four, was widowed in 2017, nine years after migrating. Cilla enjoys living in Australia. She reports that she is a Christian and attends church regularly together with her children, two of whom have completed university and are working, while the other two are still studying at university.

**Tomaida:** 63-year-old female, who came to Australia in 2001 with her husband Simbeye who also participated in the study. They have five children and seven grandchildren. Three of their sons are married to non-African spouses. Tomaida was working as a nurse prior to migrating from Zambia. She worked in the United Kingdom for three years but went back to Zambia before coming to Australia. She currently works in one of the tertiary hospitals in Perth. Tomaida is a Christian and attends church. Tomaida also has two siblings living in Australia.

**Towela:** 55-year-old female, married with three children and one grandchild. Towela worked as an enrolled midwife in Zambia before migrating in 2007 to pursue nursing studies. Her husband and children joined her a year later. Two of her three children have completed university, the third is still studying. Towela works as a nurse in one of the Perth tertiary hospitals. Towela is a Christian, initially she joined a church that had predominantly African members. She since left and joined a 'regular' church.

**NaPhiri:** 60 years old, mother of three and grandmother of one. NaPhiri is married to Hyawo who also took part in the study. NaPhiri worked as an enrolled nurse in Malawi, she migrated to Australia in 2004 as an international nursing student. Her husband and children joined her three years later, one of her children suffers from a chronic health condition. All her children have completed university and are working. One of her daughters recently got married. NaPhiri now works as a registered nurse in one of the Perth government hospitals. NaPhiri is a Christian and attends church regularly and participates in a number of church activities.

**Hyawo:** 70-year-old male, works as an accountant, married to NaPhiri who also participated in the study. Hyawo migrated to Australia from Malawi in 2007 to join his wife, bringing with him their three children. One of his daughters wedded recently, and Hyawo has one granddaughter from his first-born son. Hyawo was working as a chartered accountant in Malawi, the same job he is now doing in Australia. In addition to having worked as an accountant in Malawi, Hyawo was a community leader. He was called upon to lead many community activities. Hyawo reports that he is a devout Christian and attends church regularly with his family.

**Chungu:** 56-year-old male, migrated in 2002. Chungu came to Australia from Zambia as an undergraduate university student and was later joined by his wife and their three children. Before coming to Australia, Chungu was working as a manager in hospitality. Chungu has three children and two grandchildren. All the three children have completed tertiary education and are working. Chungu is an author, who has written three books. He works for the Department of Health in remote Western Australia while his family lives in

Perth. Chungu reports that he is spiritual and takes God's word seriously, and that is why he turns off his mobile phone every evening even when he is away from home.

**Mwada:** 60-year-old female, who came to Australia in 2008 from Zambia and works as a nurse. Prior to coming to Australia Mwada worked as a midwife and ward manager in a hospital managed by a mining company. When Mwada initially came to Australia, she completed the Registered Nurse bridging course to attain the qualification that could be recognised by the Nurses Board of Australia. Mwada migrated with two of her four children and a granddaughter. The two older children were already in Australia studying. All of her children completed tertiary education and are working. Mwada now has five grandchildren. Mwada is a Christian and attends church regularly with her husband Musa who also participated in this study.

**Musa:** 65-year-old male, electrical engineer. Musa attained his first engineering degree in Zambia before completing his Master's degree in the United Kingdom. He worked as an electrical engineer in a mining company in Zambia where he attained the position of station superintendent, prior to migrating. He came to Australia with his wife, two children and a granddaughter in 2008. Two older children were already in Australia studying. He is currently working as a manager for a wind farm electricity producing company. Musa has five grandchildren. Musa is a Christian. He attends church regularly and actively participates in church leadership together with his wife Mwada who is also a participant in this study.



## Category A: Remodelling self

Participants had varied grounds for migrating from MZZ to Australia in search of a better life for themselves and their immediate families. In order to ‘remodel self’, participants figured that if they could migrate from their respective countries, they could achieve their goals. To realise ‘remodelling self’, three means of migration channels to Australia were employed: 1) Tertiary education; 2) work in Australia; and 3) migrating to be free from political interference in their personal affairs. In this category some participants also ‘tested the waters’ with temporary migration prior to completing the process of full migration. These three types of migration are discussed below in relation to this first category of remodelling self.

### Education

Participants described education as a goal and means for migration. They thought of studying in Australia’s tertiary educational institutions as a great opportunity, not just for their children but, for themselves as well. Limited college and university places in all of the source countries (MZZ) led to potential students missing out on enrolments. The practice of adjusting tertiary entry scores depending on how well the students did in their final end of school examinations led many parents to seek out universities in Australia, where the enrolment system was more predictable, as indicated by the excerpt below:

*...we thought of finding a way we could migrate to Australia for the children to get a good education because that would lead to good jobs that would help them stand on their two feet. Enrollments here [Australia] were more predictable, not chopping and changing all the time as happens at home [Malawi] (NaPhiri).*

NaMbewe shared NaPhiri’s sentiments:

*It was a good thing to come here [Australia]. At least I was assured of my son's education because there is a system in place. When one gets good grades, they are assured of a college or university place, and they can do whatever they aspire. Home [Malawi] is different, limited universities means that only a small percentage of students are accepted, and the others miss out which ultimately means, they cannot realise their dreams.*

Chungu also reflected on university study opportunities offered in Australia:

*Unlike back home [Zambia], where after secondary school one is not sure if they would get into college or university because of limited places, here one can be assured of such an opportunity so long you have a desire to study. Back home every year there is an adjustment of entry requirements depending on how well students performed in year 12. Which should not be the case. That is why Australia is better, there is a set standard.*

Education as a reason to migrate was a key factor among the 14 participants in the current study. Participants saw education as key for families becoming self-sufficient in the future, and a gateway out of poverty towards a successful life. In MZZ, families do everything possible to enable a member to attain an education with the view that the individual assisted, would in turn render support to other extended family members. A good education is perceived as the cornerstone for improving not just the concerned individual's life, but for the lives of the extended family as well. This perception of being educated for the good of the whole family, continually plays on migrants' minds, leading to the constant thought about how best participants could assist their extended families back in their respective countries.

*...my husband and I decided to get one family member from each  
[extended family] household to educate them. When they are educated,  
they are to start supporting their own families (Tomaïda).*

Simbeye shared similar sentiments about assisting extended family, with the view that those individuals assisted who are then successful are able to render help to others within the family.

*My hope and wish is that the help offered will result in the recipients  
[extended family in Africa] being able to make it in life and also be  
able to help one or two young ones so that they have a chance of a  
better future (Simbeye).*

For the participants in this study, to achieve their goals of assisting extended family members and helping others and by becoming financially self-sufficient, they needed to improve their skills that would enable them to earn a good income. An overseas tertiary education qualification was perceived as something that placed them in a better position to achieve their goals. Although participants were committed to assisting extended families, education wise, their primary focus was their children.

All participants had adequate education and were working in Africa before migrating. Participants' incomes met their needs at that time; however, they wanted better lives for their children than what they had at the time, which they thought they could not provide while living in their countries of origin. Participants showed determination by sacrificing everything they had to migrate so that they could achieve their goal of the standard of life they envisaged for their children. To reach their goals they figured that firstly, they needed to upgrade their knowledge and skills to enable them to compete in the competitive labour market. With limited university places in MZZ, opportunities for higher education were also limited, as illustrated by NaPhiri:

*We do not have enough universities, that is why I was not able to do university studies there. I did go for the interviews, but I was not selected even though my grades were very good.*

NaPhiri was not alone in missing out on education due to the limited university places. Waitwika expressed similar views when he said:

*I came to study business, as you might be aware, there are not many universities in Zambia...*

Studying overseas was seen as an opportunity that would enable participants to achieve not only the skills and knowledge they require to compete on the international labour market, but also as a way to permanently migrate with their families to provide their children the opportunity for a better life and education. Although this was not common with all participants, one of them traded all that he owned in Zambia to migrate to Australia. This illustrates the importance placed on studying overseas to achieve their goals. Chungu who migrated in 2002 said:

*I was self-sponsored, my wife and I had to sell the car and two houses that we owned in Zambia for me to come to Australia to study.*

NaPhiri who was also self-sponsored, had a similar goal of bringing family over to Australia so that her children could get into the university without the struggles she experienced in Malawi which resulted in her missing out on studying at a university there:

*We could see the potential in these three children, they were very intelligent. My husband said to me, I think we need to do something because, they [children] might struggle as I did with university places. So, when I came here, that was an opportunity as agreed between the two of us.*

Towela also agreed on the fact that she was ready to stay longer in Australia for the sake of her children's education:

*I knew that I would stay longer because my children were very young. I wanted them to have better schooling in Australia, go to university and find jobs. So, I knew that it would be a longer-term stay.*

Coming to study in Australia also took different pathways. Participants identified universities of choice and made applications which were accepted and so, they embarked on their journey to Australia. These participants came as international undergraduate students as illustrated by Chungu and NaPhiri respectively:

*I came as an international student to finish my first degree (Chungu)*  
*I came to Australia as an international student that was in 2004. I enrolled myself into the University to do The Bachelor of Nursing, which I did (Naphiri).*

Towela also migrated to Australia as an international student. She was prompted by the Edith Cowan University's advertisements in Zambia about the advantages of studying in Western Australia. She became interested in Australia and how the university was portrayed and saw this as an opportunity for her and her family to start a new life overseas, something that Towela had desired for a long time.

*I knew about Australia through Edith Cowan University; they came to talk about the university in my country. They marketed about the school, I thought about it especially that they said it was a multi-racial society, it had vibrant schools and there was nice living. As a nurse I thought that I should upgrade my studies and maybe permanently move my children to better schools in Australia.*

Undergraduate overseas students in Australia experienced unique challenges compared to postgraduate students. Overseas postgraduate students' children, when enrolled in Australian local schools, were not subjected to international fees, while children of undergraduate students are. This challenge for the overseas undergraduate student participants resulted in them leaving their families behind until they completed their studies and attained permanent residency before bringing them over.

*I had worked out a plan ... that I needed to, first of all, finish my degree and then along the way, bring my family (Chungu).*

While Chungu did not allude to how expensive the process of bringing his family over while studying as an undergraduate, Towela clearly stated that the fees were unaffordable:

*It was also difficult to come together as a family at the start, we could not afford international school fees for myself as well as for the kids.*

Waitwika's migration to Australia was initiated by his Zambian employer nominating him for overseas studies, however, the choice of where to study was his responsibility. Overseas studying nominated by one's employer required that upon completion of studies the employee must return to the employer and serve an agreed minimum period before the employee is allowed to resign from their job or change employers.

*If I had voluntarily wanted to remain in Australia after my studies, I would have had to pay my employers the total cost I incurred during my studies, every penny they paid for me to get the qualification, which was a substantial amount. But I did not have to pay back because the company was liquidated.*

The practice of nominating employees to study overseas was common in Zambia. It was a way of motivating employees to put in their best when at work, as Waitwika explains:

*I was sponsored by my employers, something that was quite prevalent in my country, to encourage hard work and loyalty from employees. I made several applications to different countries, only Australia responded and so, I made the journey to Australia.*

Sending off several applications to study overseas illustrates the importance placed on overseas studies to acquire skills and expertise. With this type of arrangement, determination and courage were required because although the intent was to study in Australia and upon completion return to Zambia, he was still going to be separated from his extended family for that period, something he needed to adjust to.

Unlike Chungu, NaPhiri and Towela who all planned to stay in Australia permanently after completing their studies, Waitwika's plan was to go back to Zambia as this was the agreement with his employers. However, his situation did not work out as planned nor per the agreement with his employer due to new developments in his organisation, which made him decide to stay permanently: An outcome he has come to appreciate as he was able to stay longer in Australia.

*I should have been here only for four years... the organisation I worked for, got privatized, all employees were laid off so, I became unemployed, ... there was nothing to go back to, which meant that my obligation to serve minimum time after the studies had become null and void (Waitwika).*

Although he has since come to appreciate living in Australia, Waitwika's decision to stay was not an easy one as on one hand, he considered how he was to manage extended

family affairs remotely and on the other, the opportunity to assist extended family better while working in Australia.

*I also love the fact that the pay is good, I can help my folks better,  
although sometimes I kind of think, how will I look after my parents  
when I am here?*

Studying in Australia as an overseas student entails paying expensive university fees for the study participants and also for their children's primary or high school fees. Nonetheless, participants showed determination and commitment even in the face of financial challenges because they were focused on the ultimate goal of completing their studies and bringing their families across to Australia. Towela shared her experience:

*It was difficult to come together as a family at the start, we could not  
afford international school fees for myself as well as for the kids. We  
had to do some planning first so, I had to come alone to begin with.*

Although Mwada's objective for studying was to support her children who were already in Australia, she still faced challenges in payment of her university fees and explained how she managed and what kept her focused:

*I had to work odd jobs to help me pay my university fees for the  
registered nurse conversion course and it was quite expensive, but the  
focus was the children so that kept me going.*

This experience was not unique to Mwada, other participants expressed similar sentiments as Chungu shared his views about the cost of school and living expenses in Australia:

*...when I arrived here, I realised it was much tougher than I thought.  
The amount of money that I was getting for part time employment with  
limited hours, I couldn't afford to sponsor my family to come. It was*



*much harder than I thought, especially adding the demand for university fees. Whatever the case, I had to keep going, to complete the studies so that I could bring my family over.*

The difficulties they faced during their time at university seems to have increased the participants' determination to focus on their goal, that is, to complete their courses and not only bring their immediate family members to Australia but also provide financial assistance to their extended family members back in MZZ: a concern and practice that is generally part of the 'collectivist culture' within which they would have grown up in the respective countries.

While the above participants migrated because of the opportunity to study, others migrated because they wanted to support their children whom they had sent to Australia earlier for tertiary education. A decision to migrate to Australia to financially support children studying at universities was an act reflective of making sacrifices for the betterment of their children's futures amid a 'tug' between the excitement of a life in Australia versus leaving their families in MZZ as narrated by Thandi:

*While I am here with all these benefits and enjoying with my children, my father is over there [Africa], and I don't know what is happening. (Thandi)*

A sentiment shared by Mwada who said:

*It is really a difficult thing to think [extended] family is at home [Africa] where they may be experiencing challenges with life and yet, me and my kids are having this wonderful time here [Australia].*

Chungu also felt that he needed to be with family both in Australia and Africa. He said:

*I want to be in both places that is why when I retire, I will be spending half the year there [Africa] and the other half here.*

For the participants who were parents following their children who were already in Australian universities, it was mainly the financial pressures of paying international university fees with their African currencies which made it difficult to manage their financial obligations, and thus led them to seek work to enable them to settle in Australia.

## **Work**

Participants considered work as a goal and means to settle in Australia. Of the 14 study participants, four, made applications to work in Australia as professionals mainly to get a better education for their children. These four participants reported their need to provide support for their school aged children, which was that they needed to enrol their children in school in Australia and thus be within reach rather than being remote from them back in MZZ. Furthermore, because of the debilitating exchange rates between MZZ and Australia, the parents needed to work in Australia to be able to afford the payment of the local school fees:

*We were paying school fees for her [daughter], ...we couldn't afford to support her with the fees from the meagre Zimbabwean money which we were getting in our country (Thandi).*

Ted lamented about how he had sent his daughter to Australia for studies but later, could not afford her overseas student fees:

*Right in the beginning in 2004, I could afford to send my children to school, so my daughter decided she wanted to be educated in Australia, which was not a problem, but it became a problem two years later; I could not afford it.*

Musa found the exercise of sending children to Australia to study, equivalent to posting packages:

*When the third born finished school, at that point, my wife and I decided that instead of shipping children off to these far places, we should go across and be with them to support them better financially.*

Facing difficulties in paying international fees for their children attending Australian universities while they lived in MZZ, participants decided to apply and pursue employment in Australia to make the financial situation more stable and manageable. Thus, exhibiting determination to achieve what they had set out for their children: a better education. Thandi explains:

*I decided to also apply for work in Australia to support my daughter's schooling, like others were doing... I started working in a nursing home. ... Both of us working was boosting our income...*

Tomaida also thought it to be financially beneficial to support her children's education from within Australia and not from Zambia:

*We wanted to send our children to Australia to further their education. But after looking at the expense, we [with husband] thought it could be financially better if we came too and found work.*

Professional registering bodies were also challenges initially faced by participants in seeking recognition of skills from overseas. These professional registering bodies required an additional Australian university qualification before registration, even though the migrant had been working for many years in their country of origin prior to migration. For Mwada, coming to Australia to support her children who were studying in universities, required her to complete a bridging course as a registered nurse to be able to register with the Nursing Board and to be illegible to work in Australia. The determination to do whatever it took to help the children is clearly demonstrated in pursuing studies too:

*...my son was already studying here, and his immediate younger sister was also coming to study...I visited a few universities to find out about their nursing pathways that would lead up to nurse registration in Australia (Mwada).*

There was one participant who came to work in Australia because of economic hardship. This participant aimed to migrate to Australia because of the good living standards and economic stability. NaMbewe had previously studied for a Master's degree in Australia between 1997-98 then returned to Malawi. Two years later when she was widowed and left to raise her son alone she considered migrating back to Australia:

*Initially, I came to study and went back home. After some unfortunate events in between, that is when I started trying to make sense that maybe going back home, was not the best thing. So, in this case, it was just for economic reasons... it was more the economic side that Australia is more stable economically than Malawi.*

Another participant reported that her husband came to Australia on a work visa which included his immediate family members. The husband was a mining engineer who had been recruited from Zambia by the employer.

*I came with my family. My husband first came on a work visa after being recruited in Zambia (Cilla).*

Cilla's husband took advantage of the work visa to bring his family to Australia and decided to stay permanently for their children's education and wellbeing.

Working overseas for African migrants is a concept that not only serves the migrant's immediate family, but the move is also viewed as a contribution to the whole extended family as they look up to the migrated individual to assist the family financially, as NaMbewe explains:

*...but I top up [assisting family financially] where they require me to. I don't just go in and say, here you are. I wait for them to give me a call. If they call, then I will respond by sending them the needed money.*

Tomaida felt that it was an expectation for her to render assistance to struggling extended family members, especially since she was in Australia:

*Now that I am here, I am expected to chip in [with money] where other family members [in Zambia] are struggling.*

Participants assist the extended family financially when working in Africa however, this assistance is more when working overseas because of the currency strength against the African currencies. The participants still carried the obligation to support extended family members as they work and live in Australia. This is how Simbeye put it:

*I have three nieces and other extended family members whom I am sponsoring [paying school expenses]. There are also times when there are some financial needs, I help out. It is an expectation that when there is a financial need, the family comes together to look at how that need can be met...*

Tomaida also felt similar obligations to family in Africa:

*I participate in solving problems back home and supporting the orphans financially...*

NaMbewe explained further how working in Australia benefits her and her extended family:

*That is one of the privileges of being here because if I had been in Malawi, it could have been harder financially. In Malawi, one has a fixed salary, which sometimes doesn't take you far. But here at least I can manage to work an extra shift when I see the going gets tough, I*

*can pick up some extra shifts. As a result, I have helped to set up a business for one, pay school fees for the others, and managed to bring one here.*

All participants continue to carry the responsibilities, and meeting expectations of helping their extended families in Africa. Now that they are in Australia, the responsibilities grow even larger and so are the expectations from extended family members. Towela explained why her extended family expected more financial assistance from her:

*Family back home also expects more assistance now that I am here [in Australia] because they believe I am getting a huge wage.*

NaMbewe had similar expectations by her extended family members:

*I have got a big family down there [in Malawi]. The expectation for me to render help is greater now that I live here [in Australia].*

While other participants came to Australia straight from MZZ, Jane initially migrated to New Zealand where she lived for 11 years before coming to Australia. Her reason for emigrating from Zimbabwe was economic, she decided to explore where she could live a more comfortable life. Jane reported that the cost of living in New Zealand was very high and had learnt that things were better in Australia so, she and her husband decided to leave New Zealand for Australia:

*At the beginning of 2013, I came here, cost of living in New Zealand was too high, salaries were low, and a lot of people who had come here [in Australia] were telling us that it's much better out here. So, when I looked for a job, I got put in a pool [substitute teacher] for a local school as a teacher.*

Jane has one sister in Zimbabwe but reported that they are not close, only speaking on the phone occasionally. Thus, she is the only participant not providing support to her extended family members back in MZZ. She was more concerned about her life when she retires and thus is working to ensure she achieves a comfortable life in retirement.

*Our [with spouse] plan is to work, try and get some properties here that we can eventually sell and be able to buy something in New Zealand before we retire there. Now we have acquired three houses.*

It was evident in Jane's statement that although she does not have an extended family in mind as she builds her finances, she has the 'toing and froing' going on physically and psychologically as she plans to go back to New Zealand, where she lived previously immediately prior to moving to Australia. She also reported that her husband has two adult sons who live there, which is a contributing factor for planning to retire there:

*...my husband has sons living there [New Zealand], he wants to be near them, and I support him in that.*

In addition to migrating to study and to work, as a goal and means to remodel self, some of the participants in the current study migrated in search of 'freedom from political meddling in personal affairs.

### **Socio-Economic and Political**

Some participants described the reason for migrating to Australia as the socio-economic and political conditions in MZZ, particularly political corruption and persecution affecting the safety and welfare of their families. Two participants from different countries, Zambia, and Zimbabwe, reported experiencing interference from politicians, namely corruption, which affected their ability to run their family businesses. As such, they opted to leave their countries to start afresh in Australia.

Simbeye was not keen to share what kind of ‘political interference’ he had experienced in his business in Zambia, only that it had prompted him to migrate:

*We flew in here, my family and I, we didn't like the political atmosphere back home and our business was not making headway. There was so much interference, politically. We had to leave.*

For Ted, the political interference to his business resulted in him being unable to progress his business which brought about difficulties in paying his daughter's university fees in Australia and this frustrated him. He lamented:

*I was being tormented by the politicians who wanted to get the company for free. ... We sent her [daughter] there [Australia] so that she could get an education. And here I was, getting a big name and so forth. People would invite me to this party and that party, and yet I could not educate my own daughter... So, what really motivated us was that we could not get currency to send to our child. And she was almost at the point of being sent back to Zimbabwe because of non-payment of fees.*

For Ted, the safety of his family and being able to provide for his children's school needs was paramount. Thus, he planned, along with his wife, to migrate to Australia. For Ted, the reason for migration was due to the corruption he experienced and the resulting risk of losing his business and thus not being able to afford his daughter's international student fees in an Australian university. Their migration plan required his wife finding work in Australia and eventually bringing the rest of the family over. Therefore, migration can also be complicated with not just a single problem to manage but several and requiring planning and making big decisions.



Apart from political corruption affecting business, other participants reported being unhappy with the overall political and economic situation in their respective countries.

Jane said:

*The main reason [for migration] it's because our country ..., it's not settling politically. It's not developing, there is nothing. If there was change, if there is a sudden change with the economy, the leadership and, it's peaceful, I can go back home.*

Thandi expressed similar sentiments:

*We realised that...things were going down and the leader of the country was not believing what was happening around and just thought, for us, it was safe to leave and go out of the country and experience some life out there.*

While other participants did not state that they were unhappy with the socio-economic or political situations in their countries of origin, the fact that they decided to migrate was an indication that they were looking for something better than what they were experiencing in their countries. They considered this as an opportunity to remodel self.

### **Testing the waters**

The strategy to achieve migration required in most cases, a forerunner from each family to migrate first, which then enabled the rest of their family members to follow later. This is referred to here as 'testing the waters. The decision to migrate is an enormous undertaking requiring the relocation of family members and taking them to a new environment. The decisions were made, and participants were ready to migrate. However, not all participants came with their families. For many, it was a staggered process with one forerunner, followed later by the rest of the family members. This

testing of the waters allowed for an assessment of the new environment to help with making an informed decision about whether migrating was the right action to take. Cilla and her children stayed behind when her husband initially migrated from Zambia:

*I came with family, my husband came here first, on a work visa, we joined him a year later with the whole family. Four children. It was important for him to come and check out what it was like in Australia before uprooting the whole family to go to an unknown place. He had to do that first.*

Ted also followed a similar plan allowing his wife to migrate first and follow later.

*The plan was that she [wife] works for six months and if she did well and her probation period was over, then I would come with the boys because if I had come first, it was going to be very difficult, there was going to be no income. During those six months, I was preparing to come and eventually, I did. Although our daughter was already here, it was important for my wife to come and assess the living conditions from a worker's perspective, to determine if moving here was the right decision.*

For three participants ‘testing the waters’ was achieved by choice, however, it was not the case for four other participants who, as holders of international student visas, were subjected to different conditions in relation to their families being allowed to join them. The families had to wait for a long period of time before they could migrate, causing uncertainty during the period of waiting, reinforcing the ‘toing and froing’ that participants experienced:

*I overestimated my abilities, because I said to my wife, that when I got settled, became a student, and got a part-time job, I was going to bring*

*her and the family here [Australia]. Instead, they joined me six years later. If I had come together with them [family] at the start, it would have been very stressful and maybe, we could have gone back without accomplishing our objective (Chungu).*

Hyawo's wife migrated first, leaving him behind with the children to follow later:

*After her [wife's] graduation, we [with the children] came to Australia to join her... That was almost four years later. But I do not regret doing that because although it was tough for both her [wife] and myself and the kids, it was better that she was alone at that time. It would have been a disaster if we were all here those years when she was studying. But when she finished, secured a job, and found a place to stay, it was a good time for the family to unite.*

Towela also followed a similar plan:

*I came first, settled down, and secured school, then my family followed and joined me a year later that is, my husband and children. It was a difficult decision to make but, coming to an unknown place, just being told that it was a good place, we felt it was unwise to all [family] come together at the start. I can assure you; it was a good decision.*

These participants held temporary or short-term work visas specifically to come and work, but after a specified period they were allowed to apply for permanent residency and later attained citizenship.

Whatever the reasons for migration were, participants reported that they faced and continue to face challenges. Being away from extended family, most of them for the first time, felt as though family dynamics were being disintegrated.

## **Category B: Disintegrating of family dynamics**

When participants initially migrated to Australia, seven of them thought and felt the disintegrating of family dynamics. Being away from family and the environment they were accustomed to, participants reported feeling a void within them that is, a longing for the familiar things they grew up knowing and being a part of. A feeling of physically being separated from extended family was felt strongly by participants.

### **Physically disengaged**

Participants reported encountering feeling physically disengaged from family and that this was challenging for them. For some, it was the first time they had stayed away from their family units, causing them to feel the rapid disintegration of family dynamics. Participants said that they were feeling physically disengaged from family at the time of migrating, and this affected them negatively causing distress, anxiety, and constant longing for family:

*It affected me so much because that was the first time I lived apart from them, my children, my siblings and my mother ... It was expensive as a student that just came in the country [Australia] to have phone credit all the time or, money to buy phone credit ... it would be days before I could talk to my children (Towela).*

NaPhiri too, found being physically away from her family an enormous challenge:

*I did not come here like a young lady from high school. I was a mature student with a family which was left behind. One of the children suffers from a chronic medical condition. It was very hard not to be with family for three years.*

Hyawo also narrated his struggles in relation to disintegration of family dynamics due to being physically disengaging:

*I must say, although with all the assistance I was getting from extended family members when my wife was here [in Australia] alone, I still struggled to be separated from her for almost four years. It was a difficult time for me. I thought this feeling would go away when we came and joined my wife [in Australia] but, I still feel a void within me when I think about my extended relatives left behind [in Africa]*

Of the 14 participants, four made the decision to face the challenge and chose to be brave to survive as a way of coping. Thandi explained:

*I left my husband with two other kids back home and my youngest was four years old. So, I was brave enough to just turn my back for the sake of attaining something good for the family although being away from them was like excruciating pain for those six months.*

On the other hand, three other participants felt intense emotional disengagement that came with migration and leaving family behind, and at some stage struggled with the decisions of returning home or staying in Australia to complete their studies. Chungu experienced this ‘toing and froing’ in respect of having left his young family behind:

*I left my wife pregnant at the time I came here. I arrived here in February 2002, he [son] was born in August. That time, I did not have a mobile phone, I used to go to the public phone booth to make a call home. So that was a bit of a challenge and the emotions that go with it and sometimes the feeling of wanting to be there with her. In fact, at one stage, I thought to myself, maybe it is better to go back. But I had*

*to endure that long separation for the sake of our future [participant and wife] and the children's future.*

The disintegration of family dynamics affected Towela quite extensively and her academic performance was negatively impacted:

*And you know that mother-child relationship, I was feeling it, and it was not nice. It affected my studies so much, I remember I didn't clear [pass] two of the units in the first semester, I had to repeat them.*

The longing for home was further compounded by the fact that the participants had left behind small children in the care of their spouses with the assistance of extended family members. To continue going forward with their plans of preparing the ground for the rest of the participants' family members to join them in Australia, participants endured stress, anxiety, and loneliness so that the end goal of bringing the family to Australia and having children get a better education could be realised.

The feelings associated with the disintegration of family dynamics did not resolve when participants united with their families in Australia, and most continue to experience this.

### **Losing cultural identity**

The geographical distance between participants and their extended families gave rise to the feeling of being culturally separated. Combined with the disintegration of family dynamics, the loss of cultural identity was expressed as concerning by the participants. For example, this issue related to cultural loss was expressed in relation to the limited availability of African food choices in Australia. Participants reported that food was a big part of their cultures in MZZ, and they tried to find similar foods in the absence of what they were used to eating in Africa. Although African food and cooking ingredients have recently become more readily available in Australia, participants reported still missing

the foods that they ate when they were in MZZ. Cilla explained her experience in relation to the availability of African food:

*When it comes to food, I could not find the ingredients to cook like I did before migrating to Australia, when I managed to get something similar, I found that the taste was quite different. The first couple of years it was difficult for me, I lost weight because I was not eating much.*

Tomaida had similar experiences regarding food but went further to explain how she navigates the challenge:

*Food is also different ... That is why when I travel to Africa or friends go to visit, we always bring back some fish and kapenta [dried small fish], anything that is allowed to be brought back into Australia.*

Reminiscing, Hyawo explained:

*You know, even here, when our Malawian food is being cooked in the kitchen, smelling it reminds me of home and the yester years. Food is a big part of me and a big part of the Malawian culture. When the food that we buy here is being prepared, one can tell that this is not authentic Malawian food, but at least it is close to the real deal.*

Towela also lamented about the lack of availability of the foods she ate while growing up and before migration:

*I do miss Zambian food, like mushrooms that we pick in the bush, not like the artificially grown that we eat here. I also miss kapenta, chikanda and other foods unique to Zambia.*

While African traditional food was an issue, loss of culture among participants' children was a significant concern, with 13 participants reporting on this. Being far from

their countries of origin was challenging to impart their culture to their children leading them to think about what they have lost through migrating from their countries of origin and whether it was worthwhile to do that. Towela bemoaned:

*Sometimes I ask myself if I did the right thing to bring the kids here,  
they have forsaken their culture..*

Tomaida also lamented and explained why she thought her children were not observing her culture:

*Bringing them [children] here when they were still young, meant that  
our culture had not been cemented in them. Maybe if they came when  
they were older, things would be different.*

In an attempt to reinforce and maintain the African culture in their children, participants reported that they take their children along when they attend African-oriented activities being organised by African communities. Participants hoped that by doing so, their culture would be passed on to the younger generation. Hyawo explained his hope in the community groups to promote African cultural growth in his children:

*I think of the Malawian community reinforcing my cultural values in  
my children. When it is a communal thing, there is probably more  
support.*

Waitwika also considered community involvement to be important in passing down culture to the younger generation:

*We encourage them [children] to attend African activities such as  
funerals, baby showers, and weddings, to try and help them understand  
what the [cultural] expectation would be.*

Towela resonated with community involvement as a good strategy for passing on culture to the younger generation:



*... we as Africans support each other culturally, we meet for various African-oriented activities where I encourage my kids to come along, in the hope that they will learn some aspects of my culture.*

Participants also felt that elders in an African community had special responsibilities to guide younger people and pass on the culture to them, something that participants felt lacked in Australia and caused concern:

*...older people would be at the forefront during cultural activities such as marriage negotiations. The younger generation would be alongside to learn the culture... (Tomaida).*

Community support was not only seen as the answer to children learning the African culture, but it was a great support to participants as well, mirroring a community in Africa that participants want to experience. Cilla experienced community support firsthand, entrusting them with the African cultural impartation to her children:

*They [children] have grown up quickly since their father died, thanks to the community around me who have embraced them [children] as their own children, nieces, nephew. They [community] have been marvellous teaching them some Zambian culture. I don't know what I would have done by myself.*

As participants considered the challenges of passing on the culture to their children in Australia, they reported feeling a sense of regret about their decision to stay in Australia, away from processes led by extended families in relation to guiding children. Tomaida lamented:

*I think that maybe they [children] have been shielded so much that they do not know what reality looks like. I know that back home [Zambia],*

*there would be others like aunties and so on, who would take the lead in ensuring culture is being passed on by modelling it to them.*

Towela also mourned over the lack of Zambian culture in her children:

*... regrettably, that's where you find our children follow everything they are told as gospel truth, and totally disregard Zambian culture, calling it old school. The extended family is not here to guide them into our culture, that is what I regret about.*

Although participants are happy living in Australia and feel that they are achieving their objectives of ensuring that they provide a good education for their children, their lives appear to exist in a space somewhere between Australia and Africa – ‘toing or froing’ depending on the situation. For some participants, there was a need to ‘reset the life button’ in order to progress in their endeavours.

### **Category C: Resetting the life button**

Participants found that Australia was different compared to living in MZZ, and this called for participants to make adjustments and adapt to life in Australia. Facing these challenges was described by many as like ‘resetting the life button’.

#### **Adapting to new environment**

When participants arrived in Australia, it was a start to a new life, leaving behind what was familiar, for a new beginning in a strange environment. Starting a new life in Australia was reported to be a complex experience as participants found differences in the way of life and were constantly referring to what it was like back in their countries of origin, underpinning the concept of ‘toing and froing’. Mwada narrated:

*It was a bit different from the way of life back home [Zambia]. And one thing is, settling in wasn't easy because I had to juggle work, school, and being a mother. I was running around most of the time.*

Towela was more concerned about how different she found things being done in Australia compared to Africa:

*It is different the way they do things here [Australia]. So, it was not easy to imagine the way things are done in my town and the way they are done here. A lot, too numerous to mention.*

NaMbewe also explained her own experiences in trying to find work for which she was qualified:

*I could not work as a nurse when I initially came to study, so I had to work as a carer. What I found most interesting, was that my nursing skills and knowledge were being utilised, but I could not be employed as a nurse.*

When work was found, it usually was requiring to work long hours and balancing work with academic requirements. Public transport was the means by which participants would go from one place to the next, something they were unfamiliar with and meant waiting for bus schedules which had specific running times. NaPhiri reflects on her early days of public transport use.

*Finishing jobs very late in the evening, I still had to catch a bus and connect with trains. It was just draining me, and it was very stressful. On top of that, I had to go back to university, study, and submit assignments on time. As an international student, I had requirements..."*

Waitwika also explained about his experience with the unfamiliar public transport system:

*I think starting a new life all over again was a challenge. I was really confused about the public transport system.*

Although starting life again in Australia was not easy as they thought about home, as reported earlier in the chapter, participants chose to persevere in ‘resetting the life button’ to attain the goal of a good education for their children. Participants also reported that although they faced challenges that they had to work through to settle, they set their eyes on the goal.

### **Settling in**

When participants arrived in Australia being able to settle in was an enormous undertaking especially because they were unfamiliar with the different environment and systems. These challenges always reminding them of their country of origin and the need to reset the life button.

### ***Acquiring essentials***

Finding suitable and affordable accommodation was reported as one of the major issues participants faced during their initial period of settling in Australia. NaPhiri shared her experience in relation to accommodation challenges she faced when she first came to Australia:

*At first, it was a struggle. Housing, was a big issue for me because what I could afford with the money I was getting paid in my job, was not what I would have wanted. The good houses I found were very expensive and the only way I could afford, was by sharing with others.*

*I could not bring myself to sharing a house with people that I do not know, people with different lifestyles.*

Towela referred to the accommodation issue as a nightmare:

*Finding appropriate accommodation to rent was a nightmare. In the first year of my stay, I moved five times because either the house-sharing did not work, or the apartment was too expensive.*

When participants secured accommodation, which was unfurnished, they then had to find basic household items such as saucepans, crockery, cutlery, and furniture.

Furnishing a house as a new migrant was an added challenge for participants. Towela recalls what it was like for her:

*Initially, it was a challenge, trying to get what I needed to have a functional home, having arrived only with a suitcase. Luckily, I was given some [household items] by kind and generous people. I also bought some from the OP (second hand) shops.*

Mwada identified with Towela:

*...one thing is settling in wasn't easy, trying to find items for the home in a strange environment because we initially rented an unfurnished house.*

Thandi also had a similar experience:

*To start with, it was a bit of a challenge, being new here [in Australia] and knowing no one, it was difficult to make a head start. From basic things like pots, plates, beds, and so forth. It was hard.*

### ***Public transport use***

The transport system was also unfamiliar, participants had to learn to catch buses and trains to get to places, something that was unfamiliar to them. Chungu explained his encounter with public transport in his early days of being in Australia:

*Although the beginning was rough, ...Public transport was a challenge to me, catching a bus going the opposite direction, I did that a couple of times.*

Waitwika shared a similar experience:

*I was really confused about the public transport system, I had to always refer to the Trans WA [Western Australia] pamphlets for fear of catching the wrong bus as I had experienced that on a number of occasions.*

NaPhiri also had a similar experience regarding bus routes as she was unfamiliar with the public transport system in Australia:

*... I had to go by bus, I had to find out by myself the bus route, which was easy as I got used, but it was not so at the beginning, catching wrong buses and get off at wrong stations. The scary one was one late night when I got off the bus almost 10 kilometres away from home thinking that I had arrived. I panicked, not knowing what to do. With help from a good Samaritan, I arrived home after midnight.*

Navigating the public transport system in a new country that was unfamiliar required participants to reset the life button.

### ***Change in social status***

Most of the participants were employed in MZZ prior to migration and had attained a certain level of social status which they had to leave behind when they elected to come to Australia. This was not an easily accepted scenario for some and required a resetting of the life button. Participants felt that by coming to Australia, their social status changed significantly; having come from MZZ societies that view the social hierarchy as aspirational and important. NaPhiri lamented about her perceived change in status:

*My status dropped because I just became like a nobody... I never used to run for a bus, but eventually, I was doing such things as running to catch a train or bus because I did not have a vehicle. I really felt the change but what could I have done, I had to keep on.*

Ted also stated his thoughts on his change of status:

*I forfeited my status in Zimbabwe and started at the bottom of the social structure, to survive in Australia. It was a big thing, putting aside the pride in order to start afresh. It was tough but worth it.*

The perception of a change in social status required participants to reset the life button in how they question their reason for migration.

### ***Financial challenges***

Participants reported that they had to financially start afresh after they arrived in Australia with very little or no money at all. Resources that they had worked for in their countries of origin were depleted to support their relocation to Australia. This meant that participants struggled financially in their early days of arriving in Australia. The financial difficulties led them to working any kind of jobs, predominantly, labour intensive jobs

such as cleaning and caring; and not the jobs they were qualified for, as Chungu who was a manager in hospitality before he migrated, reflected:

*...the company I was working for part-time, doing cleaning jobs which were quite demanding physically. I had to do those jobs because I needed money for my upkeep and other essentials.*

Waitwika also shared his own experience about what he did to financially support himself and his family in the early years of arrival in Australia:

*In my early years after moving to Australia, I had to do all kinds of jobs. I was lucky to work as a carer in aged care facilities as well as in disability for a good number of years. The jobs helped me meet my financial obligations in Australia.*

Towela had a similar experience on financial challenges:

*It was not easy financially at the beginning, studying and doing two caring jobs to keep up with bills and everything that comes with living a normal life.*

For participants who initially came to study, it was extra difficult as they had to raise money to pay for their school fees in addition to their daily needs of shelter, food, health insurance, and transport. This meant they had to work two or three jobs in addition to attending to their studies:

*I was also working for my fees and helping out with small things [in Malawi] .... (NaPhiri).*

Mwada also narrated about her payments of university fees:

*I had to work old jobs to help me pay my university fees for the RN conversion course and it was quite expensive.*



The financial challenges around settling in, and loss of social status, reportedly took their toll on participants, who considered going back to MZZ might be a better option. However, they all decided against this return and opted to stay in Australia as explained by three participants:

*...” things got so tough that I thought about going back but I said to myself, if I go back without achieving my goal in Australia, people at home [Africa] will sympathise with me for a short time and then they will laugh at me saying; he has come back with nothing”. (Chungu)*

*“When I arrived in Australia, things were hard, the rent, jobs, just everything was really hard. After about three months of being here I thought it was better to go back home. But that would not have solved the problem, I had already spent so much in school fees, how could I go back with no degree?” (Towela)*

*“The emotional and just being away from everyone [in Malawi] and the hard life that I was experiencing, I thought to myself many times that maybe I should just abandon this school and go back. But then I thought about how difficult it was for me to get into university, I did not want my children to be in the same shoes. I had to endure”. (NaPhiri)*

Attached to the financial challenge was the expectation by the immediate family members to join participants in Australia when they had settled. The settling by participants was thought to be smooth and quick but this was not the case. Finances and Australian student visa requirements could not allow family to join participants unless they produced evidence of sufficient finances, or until they completed their studies and had stable employment:

*At first, I could not bring my family with me because as an undergraduate student the requirement was that I provide evidence of money in my account amounting no less than 100,000 dollars as surety for a family of five to guarantee that we would not become destitute in Australia. I did not have that kind of money. Luckily, I managed to complete my studies and brought my family... (Chungu).*

NaPhiri had a similar experience:

*I could not bring the family with me at that time because of this undergraduate study visa requirement that I needed to provide proof that I had a lot of money in my account to be able to sponsor my family to come with me. So, my family had to wait until I completed school and got a job.*

Although being in Australia had its own challenges and starting a new life was hard, participants persevered to ensure opportunities for themselves such as achieving financial stability as well as for their children, having a good education, and later finding jobs and being independent because they would financially be stable. As Towela explained:

*I wanted them[children] to have better schooling in Australia, go to university, and find jobs.*

Hyawo's thoughts about children's education as a pathway to a better life resonated with Towela's:

*...we thought of finding a way for the children to get a good education because that would lead to good jobs that would help them stand on their two feet.*

Thandi expressed satisfaction for achieving part of her goal to educate her children in Australia:

*Coming here has helped us achieve our goal of providing a good education to our children so that they can be independent, we have achieved that for two of our children so far.*

Participants also saw their potential financial stability in Australia, as an opportunity to financially assist their extended families back in Africa. They envisaged that if they went back to Africa, they would not assist their families in the same way they would if they remained in Australia. Participants were thus constantly thinking about Africa and the needs of the people they had left behind as Simbeye points out:

*I have to make sure I know what is happening there [Zambia] and what I can do to help. There are many needs, not everyone is privileged, that is why I help out, it is very important to me.*

NaMbewe also explained how her financial stability benefits her extended family in Malawi:

*... one cannot stop thinking about the financial hardships that extended family members are going through back home [in Malawi]. I do not think I can have a good sleep when I know there were people, especially kids who had the potential to change family circumstances, were languishing when I had the ability to step in and provide that assistance. That is what makes me African – lending a hand when I can to those in my extended family who are not as privileged as I am.*

### ***Racism***

In addition to financial challenges, participants talked about their negative experiences as African migrants as they faced racism in their Australian communities and became very ‘conscious of being black and African’ in their host society, which is predominately white/European. Jane narrated how she felt about having a different skin tone:

*I am sort of still very conscious of the fact that I am a black African in a foreign land, and sometimes a lot of things make me aware of that, you know, how people from here interact with me, look at me, perceive me. I just have this in the back of my mind that, even though I am here, I don't belong here.*

Waitwika felt like there was stereotyping of people of African descent:

*I remember someone at work showing me a newspaper article about teenagers stealing mobile phones and picnic lunches at a beach in Perth. He concluded that they were of African descent, and according to him, African teenagers were troublesome and needed to go back to their country.*

Simbeye felt as though people take him to be less human:

*Well, I have come across people who have looked at me as though I am not a human being, because of my colour.*

Although participants were facing the challenges identified, they were still keen to persevere, bearing in mind their goal of life in Australia, to achieve a good education for their children. However, financial and racial were not the only difficulties they had to deal with, they also had to adjust to life in Australia. They were also grappling with cultural issues.

### **Acculturating**

Having come from an environment where participants were in a comfortable cultural place, with the community around them having similar cultural values and practices, coming to Australia and finding differences in culture was confronting. Australian culture was unfamiliar to the participants and led them to compare everything with their own

cultures, where for example, there were certain acceptable ways of interacting in society between older and younger people or interacting with strangers, and ways of dressing especially in public.

Participants reported that although they found the culture in Australia different, they felt that assimilation would help them interact with the community better. Cilla recalls how she felt when she first arrived in Australia:

*A lot of differences in terms of the way of life. That gave me [cultural] shock, I realised that for me to be part of my new community and function, I needed to know and be part of the culture of the majority. Not to completely discard mine but adjust in a reasonable way.*

Towela also explained the cultural shock she experienced when she arrived in Australia and what she thought she needed to do to acculturate:

*... for me, it was shocking, asking myself what was going on. I could say hi to people, they just looked somewhere else, even when I sat next to them on the train. So, it shocked me. We dress differently... I had never seen people exposing their big thighs. But since I was in their environment, I told myself that I needed to look at culture from their perspective... Culturally, all things were different, I had a cultural shock.*

NaPhiri also had similar cultural shock experiences as Towela:

*The way people dressed, the way the young people treated older people on public transport, sitting on the chair when someone old was standing up and swinging at every corner the bus made. I thought being thoughtful towards older people was a universal code of conduct.*

*I decided that I was going to familiarise myself with the Australian culture, learn it and see how I could fit in.*

Participants also contemplated abandoning their activities in Australia early on because of the hardships they encountered, but after comparing what their lives would be like back in MZZ, considering what they would achieve if they persevered in their new country, and listening to the reactions from their immediate and extended family members and friends if they abandoned their plans, they all stayed in Australia. Chungu reflected on his initial days in Australia:

*But each time I thought I should go back [to Zambia], I had another thought saying yes, you can go back there. You can tell, your colleagues how hard it was, and that you even did a cleaning job in order to try to make ends meet. But then, our fellow Zambians, they will sympathize with you for the first one hour, two hours and then they will laugh at you for the rest of your life that you went abroad, and you didn't come back with, even with a degree. So that in itself, I used to think, I better persevere.*

NaPhiri also contemplated abandoning her education and returning to Malawi and she shared her reflections:

*Having left a child who had a chronic medical condition, it was very stressful so much that I thought of going back on numerous occasions, especially when I was told that my daughter was unwell or was in a crisis. What kept me going was encouragement from my family and friends who assured me that she was being well cared for.*

The thought of failure was also a significant contributing factor for their persevering in what they were doing as they confronted this tension within themselves and sought

solutions to the hardships. All agreed however that going back to MZZ would have meant missing out on their children getting a better education. Participants considered opportunities that lay ahead of them which they would miss out on if they gave up and returned to MZZ.

### **Realising opportunities**

Opportunities and services available in Australia outweighed the negatives experienced by the study participants as they looked back at where they came from and the difficulties they faced. They were focused on the future as they continued to live in Australia. Participants reported that they saw good opportunities in Australia for themselves and their families, for example with the availability of good medical care.

Participants narrated the challenges with specialised medical treatment stating that patients required being flown abroad to receive quality care, however, this practice was only available to those individuals or families with the financial means. In Australia, with the system of Medicare and affordable priced health care, participants said that they found it was a great opportunity for them to stay:

*Health services here [in Australia] are good, the health support, hospitals are really, really good as compared to the place where I was born. So, one realises that as you age, you start feeling the need to be closer to facilities like that. Not in any way trying to dumb my place of birth. The medical system and facilities are there [in Zambia]. There are doctors, very good doctors, and nurses, unfortunately, the equipment as well as the materials needed to treat patients are nowhere near what you would see here... If anything, when you consider what the businesspeople and politicians do when they become*

*seriously unwell, they fly abroad, probably Johannesburg, or go to India or London to get treatment. When I think of that, I am better off being in Australia (Waitwika).*

Waitwika's observation about availability of medical facilities in Australia, resonated with Hyawo:

*With Australia, there is a set service, that everyone is able to go to the hospital and the government takes care of you. The fact that you do contribution, there is that service. Which is quite different from Malawi.*

Chungu also expressed satisfaction about medical services in Australia:

*...the health support that Australia offers is fantastic, I think it is a great opportunity to be here [in Australia].*

Simbeye experienced first-hand the expert medical system and the government subsidy towards life serving medical procedures in Australia, and he explained:

*"...when my liver was failing, I needed liver transplant. At that time, I was so unwell that I thought I would not survive. One night I just got a call from the hospital telling me that there was a liver available and that I needed to be in the hospital within an hour and into theatre within three hours. I received that liver, and months after that operation, I was closely monitored, having test after test".*

For Tomaïda, being healthy is not only reliant on medical care but also activity that she is involved in as she explained:

*If I were back in Africa at my age, I would be at home, retired. And I would be feeling so much older than I feel here. Because here we work so hard, and we keep ourselves fit.*

### **Finding employment**

In addition to good medical care being available for the participants in Australia, they felt that finding employment in Australia was essential for realising opportunities. The



first priority for participants who came to Australia to study was to gain employment, a pre-requisite for them bringing their families to Australia something they were unable to achieve while studying because of financial constraints. Chungu recalled how he felt when he completed his studies and secured employment:

*...a month before I finished my degree the Director said... ” we are going to offer you this job as the operations manager at the time when your results come out”. It was exciting because now that I had a job, I could arrange for my family to come and join me.*

Hyawo who was left in Malawi with the children when his wife came to study said:

*When an opening came for my wife to be employed in Australia after graduation, we found that as a chance of migrating to Australia.*

Waitwika, whose initial intention was to return to Zambia after his studies, was happy that his accounting skills were in demand in Australia at the time of completing his studies.

*Fortunately, at the time, there was also huge labour demand in Western Australia, and I immediately got five offers, three of which were very good.*

Realising opportunities through finding employment, participants were relieved in relation to concerns about financial burdens they had experienced in their countries of origin. Ted's relief was about the stability of the currency:

*I am earning my money, and my money can buy what I want without any danger of it losing value overnight (Ted).*

Jane was happy that she could achieve whatever dream she had because of working in Australia:

*You can work, get jobs and do something, whatever you dream you can achieve here compared to home, where job opportunities are harder and if you lucky to get a job, it does not pay well enough.*

Simbeye on the other hand was concerned about people's integrity when engaging with them at a business level and was satisfied with how business was conducted in Australia:

*They [customers] might ask me to deliver one phone, I would deliver one phone and the next day, money will be in my account. I do not need to follow up the transaction months on end to be paid.*

Employment opportunities also opened up avenues for a permanent stay, a goal that participants had set out prior to arriving in Australia.

### **Permanent visas**

Participants reported that they were happy to endure the challenges because the endurance led to acquisition of permanent residency in Australia which gave them stability as they felt assured that they would stay for the long term. This meant they could bring their families to join them in Australia. Participants endured the long wait for permanent visa opportunities because of the goal of getting full-time employment and bringing their families to Australia. Chungu stated:

*I thought if I got permanent residence, then I would be able to get full time employment which would be good, then I could bring my family here [Australia]. I got a call from a migration agent that I got permanent residency, that was after nine months of waiting.*

Musa also recalls the time it took for him to get his Australian permanent residency:

*At the end of the four years, we had taken on residency here. It was a long wait, but it was worth it.*

Towela had a similar experience as she narrates:

*After completing my three years of university training, I was offered a job and permanent residency shortly after that. I felt something lifted off my shoulders, I did not have to think about international school fees for my children.*

Thandi reported to have had a different experience about getting permanent residency in Australia and explained the benefit:

*I came in as a permanent resident which was good because I did not have to stay in Australia for two years or so, before getting it together with my husband and kids. I was fortunate as I was given a Medicare card within days after my arrival in Australia.*

An experience shared with NaMbewe:

*I applied and got my permanent residency while still in Malawi. It was good to find that the country was waiting for me on my arrival. I did not need to wait for long to get my Medicare card.*

Participants reported that they intended to stay in Australia for the long term, they were aiming to become citizens of Australia, something they felt of great benefit to them and their families:

*...after they [children] had finished school, we thought we would go back home [Zambia] but ended up staying and ended up becoming citizens, I feel more at peace, not worrying about my status in Australia and that of my family (Mwada).*

Like Mwada, Hyawo also felt that there was benefit in acquiring Australian citizenship:

*So, we sought residence and citizenship in Australia, and we are citizens of Australia now, something that ensures that one has peace of mind not worrying about the risk of being evicted and deported from the country.*

Cilla felt indebted to Australia for her citizenship:

*It took about four more years [after getting permanent residency] when we were granted citizenship, the opportunity I really appreciate.*

Participants value Australian citizenship over their countries of origin and were willing to forfeit citizenship from their birthplaces. Simbeye who migrated due to political reasons felt that Australia was his new home:

*This is my home. When I left Zambia, I told myself that I was going to find a new home, and this is my new home. I might go there [Zambia] to visit when I decide to, but just a visit not staying there, and I am very happy with that decision.*

Musa also felt that Australian citizenship was of greater value especially when travelling overseas:

*When we [Musa and family] got Australian citizenship, we decided to relinquish the Zambian one because we did not see the benefit of keeping it.*

Relinquishing their citizenship was only found to be evident amongst those from Zambia. Those from Malawi and Zimbabwe had dual citizenship. Regardless of whether participants were dual citizens or had relinquished their initial citizenship, they all wanted to leave a legacy for their children.

## **Leaving a legacy**

Migrating from Africa was perceived as a big achievement in that, children migrating to Australia at a tender age had an opportunity to attain a good education. The move also brought about undesired outcomes as there was a sense of anxiousness in participants that the next generation would not maintain the cultural values of their parents thereby losing their identity. Participants reported wanting to leave a legacy behind for their children and grandchildren but were at a loss with the lack of identity that their children had attained. However, participants were looking back and drawing from their culture in their countries of origin to pass that on to their children. For these participants, legacy was, if their children could carry on the culture and not let it die with the participants' generation. Waitwika felt that taking his children along to cultural functions and activities would benefit him leave a legacy:

*I feel it is very important for me to introduce my kids to activities unique to the Zambian way of life. Because of this, I make sure that whenever I am invited to such activities, I take my son along so that he gets an idea of what being among Zambian men was like and learn the issues discussed at “insaka” [men’s meeting place].*

Hyawo shared similar sentiments about leaving cultural legacy with Waitwika to their children when he stated:

*I think it’s very important ... to instil what I want in my children to help them in the future, ... reinforcing my cultural values in my children.*

Leaving a legacy was not only related to culture. Participants also talked about leaving acquired properties or finances for their children as Thandi pointed out:

*I will review whatever can be shared [possessions] amongst my children and tell them, make all arrangements before I go [die] so that I leave everything in place.*

NaMbewe agreed with Thandi about passing on acquired properties to the children as inherited assets that are viewed as a steppingstone in life:

*...even if I don't have to live in [the house], it will still be there for my son and his family, if he wants to visit, he will know that their stepping stone is there.*

Simbeye also carried the same thought although for him, he was concerned about children inheriting the business he owns and how they would manage it:

*And when I die, I want my properties and business to be still standing, and I would like them to be taken over and managed well after my demise.*

Ted, on the other hand, was more concerned about passing on his thoughts and stories to the next generation, for them to be informed of why he undertook the journey to Australia:

*I don't want my children to imagine, I want my grandchildren to read and possibly listen to my voice, telling them of where we came from, our stories, and the reasons why we came. Have I achieved what I wanted as I was aspiring to come here? I would say on the overall, yes, and I would tell them my story, and I would tell them how I would want to be treated through the story. And it will be in written form.*

While other participants were primarily concerned about what the next generation would inherit from them, NaMbewe was also concerned about what onlookers would be thinking about her achievements:

*I want to go to my own place, even as a dead person, it will give me some respect that she did this, this is what she achieved and accomplished.*

Legacy was all about belonging, especially for the next generation, and yet, belonging was one thing the participants were grappling with as migrants.

### **Belonging**

Participants in this study found it challenging to ‘belong’ post-migration. There were feelings of loneliness among all participants in this study. Participants came from a place where they had large extended families and community, to a place where they found themselves alone with no community around them, as Waitwika explains:

*I came from a much bigger and noisier family, but here it was sort of like more quieter, not in a good way because I started feeling lonely even though I had my wife and children with me, which I found a bit weird.*

NaMbewe fondly described the community she left behind in Malawi and how she belonged:

*... from my side and from my late husband's side, it is a massive family. My late husband was one of nine, I was one of seven. That means it is really extended and everyone is considered an important member of the family.*

She also expressed being lonely as she compared the size of the extended family in Malawi to what family she has in Australia:

*...when I see families gathering...for us, it's not a family gathering as such, it is a small unit of us. So, it is basically three of us for all the events, so that becomes lonesome.*

Sense of belonging was challenging to achieve for some participants as there are varied factors that influence the feeling of belonging such as people, the culture and new environment. Participants therefore turned to churches, as a source of support because they were familiar with how churches operated and how they would fit in and have a sense of belonging:

*...church has become our family; we [with husband] are much closer to our church family. We feel that sense of belonging which is very important for support (Jane.)*

Mwada felt a sense of belonging by attending church when she first arrived in Australia:

*The church we went to when we first arrived in Australia was so welcoming and I felt that sense of belonging. I still go to the same church.*

NaPhiri felt that church offered a sense of community:

*I didn't have much socialization apart from the church, that was my social and spiritual support. Otherwise, I had few friends, Malawian friends but, I found that everybody minded their own business ... my time was spent going to church....*

Although churches became a source of strength and support, there were some difficulties in truly belonging because of the differences in culture and how spiritual matters were conducted in Australia compared to Africa. Cilla explained her experience:



*When we first came, we found a church that was similar to one we went to back home. I felt a sense of being a part of a community right away although there were some differences in the way church was conducted here [Australia] compared to Zambia.*

Towela also expressed her disappointment on how churches were different from what she was used to:

*I would go to church, it was all different, even as a Christian. Things are different the way they do them here. The way the [church] service and everything is conducted is so different from the way things are done in Zambia.*

For Waitwika, the difference between churches in Africa and Australia, was about the extent to which the church leadership involved itself in a church member's life:

*The church here [in Australia] gets involved just minimally. And sometimes, even if you are a member of a church, it is almost like booking your own church, paying for the minister or whoever is going to do the service. Whereas back home [Zambia], if you are a regular attendee at a church, the offering, tithe, and other contributions made are enough. That is the part that I feel should be debated whether to have our own African church with leadership that understands us or, we try and integrate.*

While participants found church was conducted differently compared to their experiences in MZZ, they continued attending those churches. However, as a result of their sense of belonging not being fully met, they sought to find communities of fellow Africans where they thought they would be more comfortable because they would have similar cultural practices. These community groups have become sources of support for

participants in every way, supporting each other and ensuring that during significant events like weddings, illnesses, births and funerals, cultural activities are done just like in MZZ as Chungu explained:

*When we held a traditional pre-marriage function for our daughter, the community of Africans not just from Zambia, came to support us in a big way. It was as though I was back in Africa.*

Cilla recalled how she felt a sense of belonging to her community here in Australia through the support she received when her husband died in Australia:

*What I have been through because my husband died here... The Zambian community was very supportive. I felt like I was back in Zambia. My family back home was also surprised to learn that I was so well supported. Initially, they were concerned about how I would manage alone with just my four children. But when my two sisters arrived, they saw that community spirit. They were very relieved.*

Mwada also experienced similar community spirit when she participated in providing the support to an African family:

*Coming from Africa, we live as a community, whereas here, you are virtually on your own, but we have built a lot of strong relationships with fellow Africans, and we formed a community. For instance, when one of the Zambian men was very sick, we all rallied behind the wife and the children.*

The community groups are important not only during significant events in the life of the members but also as an ongoing support for the participants as their families grew larger in Australia.

## **Growing families**

Having migrated with their children, participants reported that their families were growing larger in Australia, and they felt it to be inconceivable to go back to MZZ and leave their children and grandchildren in Australia. Thandi's words portrayed her deep thoughts about the matter:

*My daughter got married, she now has a kid. And then my son, he will be wedding soon here in Australia, and he is marrying someone from here. This means our family here is getting bigger, something I am looking forward to.*

NaPhiri also felt that her family was the reason to stay in Australia:

*All the children are here, three of them. They have all finished their university studies, they are now independent, and we have one grandchild so far, home is here.*

Towela also felt that she would be torn between being with her children in Australia and returning to Zambia.

*...my husband and I were thinking of going back [returning to Zambia]. But now, circumstances have changed. Looking at our children having their own children, the family is growing, and my kids need me here.*

Before migrating, participants were accustomed to larger families which included extended family members. Being away from their original countries, participants were attempting to simulate the extended family scenario by identifying themselves with African cultural groups in Australia which functioned as extended family. For participants, family in Australia was not just applicable to biological relatives, but close friends that form their community in Australia. Chungu said:

*I am constantly building quality relationships because these relationships turn to be like family, especially for me who is so far away from my own relatives. My relationships, friends that I have here were of great support. I believe I have 'family' members, those that can do things that our family back home would do. In other words, we have a surrogate family, a community of close friends here in Australia.*

Mwada went further to explain that these new linkages were considered more like family:

*We have built good friendships that are much closer than family. I would say that in some instances they have replaced family that is in Africa.*

Cilla also agreed that African community members she had come to know in Australia were like family to her in providing support when she needed it. She explained:

*It is quite difficult when there are no older family members to provide guidance and support. But I thank God, having lived here, and made friends who became family, they were of great help.*

Although participants considered it inconceivable to go back to MZZ because of their growing families in Australia, they were nonetheless torn between remaining with their children and grandchildren in Australia or returning to MZZ to be with extended family when considering their EOL period. This was a dilemma for participants and was mainly due to lifestyles in MZZ being different from Australia. For example, extended family members would gather around someone unwell in MZZ, but it is not so easy for this to happen in Australia, relying instead on an immediate family member who may need to take leave from their jobs to assist them. This feeling of being torn between here and

there, led to participants wanting to be in both places, referred to here as ‘shuttling back and forth’.

### **Category D: Shutling back and forth.**

Participants reported that they found it good living in Australia, but they were also constantly reflecting on what was taking place in MZZ, in the communities which they left behind, to help where needed because they understood the difficulties the communities in their countries of origin faced.

All participants reported feeling a void, in relation to their countries of origin, and found that they were constantly referring to their original countries as home. However, when they visited their countries of origin, they called Australia home. Participants calling both places, ‘home’ is evidence of their feelings of ‘shuttling back and forth’ as they talked about longing for home, a reflection of the DPTF that they were experiencing.

#### **Longing for home**

Migrating to a new country is a complex phenomenon because participants continue to relate with and actively think about their countries of origin. Although participants were endeavouring to settle and carry on with their new lives in Australia, they continued to exist in both worlds. Participants reported a longing for home and wanting to get involved in the countries where they have migrated from regardless of the length of time spent in Australia:

*But there’s always that aspect, where you always feel I wish I was home [Zimbabwe] (Ted).*

NaMbewe affirmed her sense of belonging towards Malawi when she said:

*...there is that uncertainty in the sense that I still love Malawi. Malawi is my home...*

To uphold their sense of belonging to their country of origin, participants continued to invest financially in businesses in their countries of origin. They were building houses for themselves, and fully participating in community activities remotely, despite seeing themselves as strangers when they went back to visit. However, they still viewed themselves as part of those communities in MZZ because they still had parents or siblings and/or extended family members, as NaMbewe explains:

*I also keep the channel to home [Malawi] open because, ... the majority of the family is back home. ... Still, I have relatives back home... I suppose it is also the pride, the fact that I have lived in Australia for so long. So, to go to my own place [in Malawi], ... Yes, like I said, that little house I have built, it is my place...*

Chungu also viewed investing in his original country as beneficial to him as he explains:

*That project is for generating income for the future so that when we travel there [Zambia], we are not worried about how we are going to manage financially. Apart from the Zambian government bonds that I have invested in, I also have some real estate that I think will generate good income for me.*

While Thandi is not financially investing in Zimbabwe, she strongly felt she was a part of her extended family in Zimbabwe and expressed real concern for restricted travel during the COVID-19 pandemic:

*I can't even go overseas to meet or see my dad and if anything were to happen to him today, I still can't go now with this COVID which would be a very sad thing for me and my family over there.*

While other participants were explicit about the need to call both worlds home through strengthening connections with the extended families in Africa and had strategies to maintain those connections, Ted strongly stated that home was still in Africa:

*... but truly home is home, and that's the reason why I think I will never be settled here in Australia.*

Similarly, Chungu shared the longing for family:

*I like the idea of enjoying ... networking with family and that aspect of making sure that I don't forget my roots.*

For Mwada, she was undecided, but was open to the idea of returning to Zambia:

*I wouldn't mind going back if that opportunity availed itself... I don't know, I haven't really thought that much about it. I have thought about going back and if the opportunity arose, I think I would. But at the moment I haven't decided yet.*

Jane was sure of what would lead her to go back to Zimbabwe:

*If there was change, if there was a sudden change of the economy, the leadership, and it's peaceful, I will be more than happy to go back home. So, the only reason why we would stay here with New Zealand is because of the situation in our country. Otherwise home for us is Africa. But with everything there happening it's not the best option at the moment.*

Although Mwada stated that if opportunity arose, she would go back to Zambia, she was unable to identify what opportunities would determine or prompt her to go back. At

the same time, she acknowledged that her growing family would need her in Australia. This further reveals the uncertainty that participants were going through in relation to choosing the ‘world’ they wanted to live in.

*...like I spoke about family support; I think they [children] need me around here (Mwada).*

Musa also presents this dilemma in choice when he says:

*I would say yes, I am settled both here [Australia] and in Africa.*

Among the participants there was a strong desire to stay in Australia, and yet despite being resolute about this, participants reported wanting to go back to Africa to experience the culture and community because they viewed Australia as being too individualistic.

Towela lamented about her children neglecting their (her) culture:

*For instance, our children are becoming very individualistic instead of our communal way of living and helping one another. In our culture, no one suffers alone, we are always together.*

Mwada shared Towela’s feelings about Australia having an individualistic culture when she said:

*Coming from Africa, we live as a community, whereas here [Australia], you are virtually on your own...*

Participants thought that they would go back to Africa right away if a situation availed itself. This is a constant battle and a tension within the minds of migrants from Malawi, Zambia, and Zimbabwe, where on one hand, they are happy and want to stay in Australia while on the other, culture and family seem to be pulling them back to their origins. For these migrants, settling in Australia appears far-fetched, and thinking about preparing for EOL was not even remotely in their minds because their thoughts were preoccupied with



this tension of not being able to nominate where they consider home. Participants were also considering their EOL and being cared for by their family in their country of origin:

*I would go back to Malawi, and I would be going with the aim of being looked after by my extended family (NaMbewe).*

Towela was also inclined to return to Zambia to be cared for by extended family, citing the collectivist culture for her reasons:

*Sometimes I think, maybe I should just go back to my people, hopefully because we are family oriented, hoping that I can stay there and maybe have a peaceful ending once I am with my people.*

The thought of going to be looked after by extended family, emphasises the strong connections that participants still had with their extended families which they found difficult to disconnect themselves from. Nonetheless, while participants still have strong ties to their countries of origin, they also still want to feel settled in Australia and achieve this through seeing the results of their hard work in for example the acquisition of real estate, as Chungu explained with excitement:

*Now that we bought some properties and we are still paying mortgages, at some point we are going to finish. When we finish paying off, at some point we are going to just be receiving rentals.*

NaMbewe also felt the need to purchase properties:

*So, at this moment, we are still paying a mortgage for this house. The thing is, if I was not thinking of living in Australia for good, I could have said, I don't need a mortgage.*

Participants have bought houses in Australia as a sign of wanting to stay for the long term however, thoughts about going back to Africa or staying for the long term seem to change every so often, and participants reported that situations at any given moment were

what would determine the action to take at that specific time, evident of ever-changing thoughts and the DPTF.

### **Ever-changing thoughts**

Participants were longing to be in MZZ as much as they enjoyed and wanted to live in Australia; they are torn between two worlds but feel compelled to make a choice for their own families. However, they continued to long for Africa, they felt as though they were being torn between Africa and Australia, as NaMbewe explained:

*...I am happy to take what life brings to me. But not to be hundred percent certain that I would not go back to Malawi, because Malawi did not wrong me, I just came for these opportunities, so, I value Malawi, I respect Malawi with all my heart. And because of that, whatever comes, I am happy to go back to Malawi if need be.*

Chungu felt that he needed to make deliberate plans to share time between Africa and Australia when he would no longer be in regular work:

*My plan is retirement will be a combination of living in Australia for some months of the year and the other months living in Zambia... with my children here and now a grandchild, I will definitely be spending more time here to help out with that.*

Waitwika agreed with spending time in both places when he said:

*Obviously, my long-term plan is that, towards my retirement, in these last 10 years, have a much more involvement in both continents [Australia and Africa].*

There was tension in participants' minds as they thought about their growing families in Australia and yet still having extended family back in MZZ. Participants reported that

they were happy to stay in Australia and yet, they also expressed challenges they faced, as illustrated by NaPhiri:

*Another challenge is that I cannot just go back to Africa, it is not easy, I have family there, but my children are here. It is not something that I would just say, let us go back home. Even the children, now say that we cannot go back.*

Although Chungu stated that he was staying in Australia for the long term, he reported that he has invested substantially in Africa as he explained:

*...but also, I try to work on some projects back home [Zambia] during this time that I've still got the energy, and I've got the income. I am involved in at least two investment projects back home... I am also part of a cooperative...*

NaMbewe is building in Malawi because she wants a place to call home:

*Because of that, I know it is a late project, but I am in the process of building a small house. Not a mansion, but just something to call home.*

The participants are constantly looking back to the situation in their original countries while at the same time looking forward to the new life they have come to embrace.

Providing financial assistance to their extended family members back in MZZ is a way of remaining connected, yet the DPTF in terms of being indecisive about where they call 'home' has resulted in settlement and concentrating on life in Australia remaining elusive.

### **Category E: Finding equilibrium**

Participants found themselves in a 'muddled' state as they attempt to settle in Australia while at the same time feeling separated from their culture and extended

families. They were living in two worlds as they strive to live in Australia as well as be connected to their birthplaces: an ongoing journey. Therefore, for the purposes of this research to then be asked about how they are preparing for their EOL in Australia, added another level of complexity to their lives in terms of thinking about the future, which is a convoluted rather than a linear progression. Mwada shared her thoughts after deep reflection:

*...seeing myself getting older but not wanting to think about where to, from here. It is just impossible for me to do that, maybe because I have not been brought up in that kind of environment where people plan for such kind of things. We do not, others do the planning on the person's behalf when the situation arises...I don't think I've really paid much attention to it, but it does come up, it's something that is always pushed away.*

Musa shared in Mwada's opinion about the need for planning for EOL:

*There is no plan. It will be what it will be. I suppose these things cross one's mind, but otherwise I have not really seriously been thinking about it.*

NaPhiri's opinion was that things should be left until the time comes:

*This is for the future. I have not thought about planning my end-of-life, I leave that for when the time comes.*

Participants are clearly 'toing and froing' as they attempt to remodel their lives, 'reset the life button', manage their feelings associated with the disintegration of family dynamics, as they shuttle back and forth, aiming to find a balance between their two worlds, this is when participants started to consider the question of preparations for EOL.

Participants indicated that they value financial stability more than anything else as they aim to set themselves up for staying at home (in Australia) for their EOL, accessing required care to maintain their comfortable environment. They felt that having adequate money was the key to accessing the care they desired. Jane explained her plan:

*...we [participant and husband] are working, saving money, trying to have assets that will make us survive when we retire, or should something happen that we can't work anymore. We are trying to build some security, something that can look after us when we grow old.*

Simbeye resonated with financial planning as essential:

*I have prepared a good base [financial] for when my energy levels can no longer support me as much as now.*

According to Thandi, financial planning was a way of preparing for EOL and thus engaged a professional to guide her through the processes:

*... not too long ago, I hired a financial advisor ... she has been helping me reorganize my finances.*

While participants were content with migration to Australia, it was not all well and good for them as they thought about what they had lost by moving to Australia.

### **Living with regret**

Living with regret was another concept that participants needed to deal with before reaching a state of equilibrium. Living with regret can lead to undesirable consequences bringing about anxiety and heartaches. Two main regrets were expressed by participants: loss of culture and managing the dying process.

### ***Loss of culture***

Participants migrated in their adult years when their culture had already been inculcated in them, while their children were young at the time of migration to Australia. Because the children were young, they had not been immersed in the culture of the community where they were born, making it easy for the children to adapt to the Australian culture. Waitwika lamented:

*At this point in time, I can't see my children picking one culture or the other. They are half-baked Australians. They don't even understand what an Australian funeral would be like because they hardly go to Australian funerals. They all just post on Facebook over a friend about something that has happened.*

Towela agreed that the children have lost the culture:

*I think they have somehow lost it [culture], in that the Australian way of doing things has taken over them. For them, it is normal, and they question of the cultural practices, or things I do myself as a parent. In schools, they are taught, do this or report this. Whereas in my culture, some things are unheard of, and you can't do that. So maybe that's where you find our children follow everything they are told as gospel truth and totally disregard our culture, calling it old school. For instance, our children are becoming very individualistic instead of our communal, collective way of living and helping one another.*

Participants reported being satisfied about the education their children attained and other opportunities that Australia offers. However, Tomaida expressed living with regret at her children's limited grasp of her culture and attributed that to the ages at which the children were brought to Australia:

*I came here when I was already an adult which means that I have  
Zambian cultural values in me, my children were young and so, were  
not as conversant as I was in culture.*

### ***Managing the dying process***

Regret about managing the dying process was a concern for one participant who lost her husband in Australia. Given the situation she went through, Cilla stated that she felt she failed to protect her husband during the dying process, at the time when he was most vulnerable. She wanted to ensure the same did not happen to her and so, she has started to write down what her preferences are for EOL.

*My late husband was actually exposed to more people. And I think  
going through that experience, I could see he had people that he was  
connected with, but I could also see that he had people that he really  
didn't know, standing by his bedside. That used to stress him a lot. And  
that is something that I did that I have regretted because I knew he  
would say, no, I don't want too many people in my room. Coming from  
a culture where when someone is sick, everyone just goes to visit. So  
that's one thing I regret. I would have followed his wish because he  
didn't want that [strangers visiting], but somehow, I allowed that, and  
he was at that stage where he could not speak for himself. That is one  
thing I have actually regretted. My husband used to say, I don't want  
people that I do not know coming to see me. I do not want, please do  
not allow them.*

Simbeye also reflected on living with regret on his daughter dying in hospital:

*My daughter died in hospital. Maybe if I had talked to her about where she*

*wanted to be at the end of her life, she may have chosen to be here, at home. She loved her room which had been redone just before she went into hospital. Maybe she would have enjoyed that. I always think about that, I do not know why I had not thought about it then, it would have been a good thing if she was in her own bed, in her own room, with everyone around her.*

Finding equilibrium does not conclude the DPTF because even when participants find a place of comfort and start to think about EOL, the ‘toing and froing’ seems to continue, throwing them back into the convoluted process. Therefore, finding equilibrium is not a sustained state for participants but it provides them a steppingstone to pursue the horizon.

### **Category F: Pursuing the horizon**

Finding equilibrium in an unfamiliar environment can be a challenge with so many things to consider that would eventually lead to participants prepare for their EOL in Australia. It was difficult initially for participants to talk about EOL, as they found it easier to talk about death as observed in Waitwika’s statement:

*I have been thinking about the possibility of buying a plot or grave site while I am still alive to make things easier. Pay for it now rather than making decision when on your deathbed or, someone making that decision when you are dead. If that is locked in now, then nothing would change because then everything is in the will.*

Thandi was also concerned about her dying when she said:

*Let's say, people have discovered that this could be my last moments or something. I would love to have a priest called in to come and to bless*



*me or whatever or have some prayers with me. And also, I wouldn't mind if it is being done again after I'm gone.*

As a result, participants were reminded that the interview was about EOL and not death, and they were able to talk about EOL. Participants were happy that they were living in Australia where health care services were available and that they were accessible when in need. Waitwika explained:

*...the health support, and hospitals are really, really good as compared to a place where I was born. So, one realises that as you are aging, you start feeling the need to have appropriate services and live closer to facilities like that.*

Hyawo shared with Waitwika thoughts about availability of medical services in Australia:

*With Australia, there is a set service, one is able to go to the hospital and the government takes care of you. The fact that you do contribution, there is that service. Which is quite different from Malawi because the service is normally from the community. If you got to go to hospital, it is the community which works on that. So possibly there is that little difference that there is already a service available in Australia, which minimises the burden on the whole family as such because they use that service.*

Availability of medical care resonated with NaMbewe as well:

*I know that Australia has good, better resources than Africa, for example, painkillers, one would have access to better painkillers here than there are available in Africa...If maybe morphine infusion is required, they may not be able to access a supply of that medication which may have to be bought from here [Australia] and sent over there [Malawi] to ensure I am comfortable. That is if I went back [to Malawi]. Very important to consider what I can*

*have here, good medical services.*

However, the decision-making process was a concept that migrants from MZZ found themselves caught between the western practice of an individual being at the centre of the decision-making process, leading, actively participating and providing preferences of care, and the African concept of collective decision-making where participants were happy to sit back and let families make EOL decisions for them. Participants showed willingness to learn the Australian health care system but also wanted to practice the collective decision-making concept from Africa. To manage this tension between individualistic and collective decision-making processes, participants needed to find a balance.

Culture is an important aspect of the way people live and influences all aspects of life including EOL practices. Religion or spirituality is closely linked to culture because culture encompasses one's entire lifestyle. While spirituality and culture maybe different, culture and ethnicity have great influence on how communities practice spirituality; it equates to the totality of human existence and experience. Ethnicity is the shared cultural background while culture is the way a community or society lives. This includes their values, beliefs, artifacts, institutions, codes of conduct, dress, rituals, language, and religion. Culture is perpetuated by one generation passing it on to the next through cultural practices, and as such culture is always evolving.

### **Cultural practices**

Participants struggled with new cultural practices that were different from those in their original countries. Hyawo found the different culture a challenge as he talked about his family:

*While in Australia, there are some differences with that because the culture in Australia is different from that of my home [Malawi]. It is a challenge for me when I compare, sometimes I do not know what to do about it, things are so different. Even funerals are different. But the family would still look at how best we can now carry value for our father and things of that nature.*

For NaPhiri, EOL planning is a cultural issue that although she is ready to embrace, it is not a norm in her country of origin, Malawi. She explains:

*So, growing old in a different country with different culture, difference systems are not easy, and you don't plan forward to say this is what I will do. But because of the Western culture, one has to plan for death. Though sounds silly, back home, we don't plan for death. Because of extended family, even if I die now, people still come and, they will put me in the grave anyway. But there is a lot of support and everything, all the systems. But here, we have to start preparing for our own deaths.*

Waitwika elaborated on cultural practices regarding family communications and decision-making and the rationale behind the practice:

*I don't think, based on seniority and respect, I would ever raise that issue with my father about my end-of-life care and funeral plans. That will be seen to be disrespectful. Now, when my father is dead, when I am with my brothers and sisters, then I can tell them because then I will be the senior person in authority.*

However, these practices seem to be getting eroded even in participants' countries of origin as Towela lamented:

*I go home [Zambia] every two years, and each time I go back, I find that families living together and helping one another is getting less. Some families just want to be close to their children and not extended families as we knew it. It is so sad.*

NaMbewe shared a similar experience when she said:

*I do not know what is happening in Malawi, it should be this global village phenomenon where people what to behave like those in western countries. Whenever I go home [Malawi], which I do at least every two years, except during the pandemic [COVID-19], I notice that the dressing changes, the behaviour of people changes, there is no longer that spirit of helping your neighbour. It is so sad that we now have each one for himself and God for us.*

Tomaida also expressed this concern as she questioned:

*We don't do things in the same way. They [non-Africans] have things that they value which may not be my values. We are totally different; how can they understand me? I find the same thing when I go back home to visit. I notice that things are always different in a space of two to three years. Everyone everywhere is becoming Western, even at home, it is just me and my immediate family, no thought for the neighbour. What kind of world is this? The cultural fabric is just falling apart.*

In addition to culture, spirituality was also an area that was considered different by study participants.

## Spirituality

Spirituality is considered to be integral to a person regardless of their religious status. Although spirituality is used interchangeably with religiosity, spirituality is the practice by an individual while religion refers to an organised set of beliefs (Shaw et al., 2016). To be spiritual for migrants from MZZ may mean different things to different individuals, dependant on what the individual values more, and depending on the influence of the 'triple heritage' that indigenous Africans from MZZ experience, consisting of African traditional beliefs, Christianity, and Islam. All these, in the context of colonisation which brought with it a foreign European culture, and an education system that demonised traditional African cultures, impacting the continent long after political independence was achieved for each nation. Ted questions the effects of the triple heritage on the African population:

*Christianity brought in the idea of Satan, they brought the idea of going to heaven and going to hell, and therefore it brought in fear. It's inevitable, people are going to die, but because it brought in fear, it brought negative feelings. So, people cry, and you will find that Africans are the ones that cry most at funerals, as if by so doing, you're going to change things, instead of being practical and say, well, this has happened. Probably the person was 98 or, a hundred years old, what would you expect? They were going to die.*

Ted also has strong negative feelings about what he considered the effect of colonisation. His thoughts are illustrated in the following excerpt:

*I think as Africans, the way we live now with a history of colonization, it brought in corruption, bad feelings, and so forth. People are now looking at what they can get out of that death. Whereas before, the idea*

*of my wife remaining in the family, was not to be remarried, it was to ensure that my children will be looked after, and they would continue living without them feeling the heavy pain of having lost their father (Ted).*

Spirituality which at times may be referred to as faith, gives individuals a sense of purpose, and is said to guide decision making when faced with difficult situations and in many circumstances is used as a coping mechanism. This was evident among participants in this research as they were guided in their decision making through their culture and spirituality as Chungu explains:

*It just shows how God listens to our prayers and guides us every day by bringing the right people in our paths and right resources to us. I believe all this is God helping me to make informed choices. Sometimes people think that they are doing things by themselves and making great achievements. I do not share that view; God is always orchestrating things...*

Cilla shared Chungu's view about prayer and how her decisions are influenced by her faith in God:

*I am a Christian and I believe in prayer. My faith is very important when I am making decisions. I always pray about it until I know that God is telling me to decide in a certain way.*

MZZ migrants have similar cultural practices in relation to EOL. Collective decision-making is practiced in the communities where these migrants come from. The interpretation of collective decision-making raises questions about afro-communitarianism, that is to say, where community is more important than the

individual. On the contrary, the individual is an important unit of community therefore, the individual or the idea of a person's wellbeing takes precedence. It is this culture of caring by community that positions an individual at ease when it comes to preparing for EOL. The following excerpt from Jane illustrates this point:

*You know in Africa, maybe not the whole of Africa, not sure but, in Southern Africa, we don't normally talk about any issues relating to dying until we are dead. The family comes together to decide what is better for the care of a sick family member and even allocates who should provide the care. But here, it is different, and it is very challenging to start to think about that, something very foreign and unfamiliar.*

It is not customary to plan what would be needed when experiencing EOL. That responsibility is left to the family. The other reason why EOL care wishes are not documented is the concept that these preferences would be overridden by influential family members not just during illness but concerning funeral arrangements as well. Thandi was concerned that the practice would override her preferences.

*Well, the problem with the end of life wishes, it's a bit contrary because the end of life wishes here, it's a bit different with our culture. Because in our culture, when you are married to someone, even when you die, that's the end. Whatever happens afterwards, they have got the right to suggest to you, and they can even say, I want my wife to be buried there. Where let's say because in the African context we don't arrange things in advance, we don't say our wishes or say, it's an accident, before you have even made the arrangement. So, the people who*

*remain, they can just make decisions for you. So, I'm afraid there are times when such can happen.*

There is also an element of entrusting family to make those decisions as seen with NaMbewe and Chungu;

*Very important to consider what I can have here [Australia], what I can have there [Malawi], and what the family can decide whether it is better here or there (NaMbewe).*

*In my view, if my wife is around, culturally is, what she feels comfortable with. Luckily for us, we come from the same tribe. So culturally, she would know what needs to be done. I am comfortable with that aspect. It would have been tricky if I had married a non-Zambian (Chungu).*

The dependence on collective decision-making is enhanced by participants' continued close interactions with family in Africa. Participants explained that African family settings are not nuclear but extended therefore, participants were contributing to the wellbeing of the family back in Africa with the expectation that if they went back to their countries of origin, they would be welcomed and looked after by those extended family members, as illustrated by NaMbewe:

*I wish I could go back home because the reason being if I go back home, when I have retired and aged, people will still look after me because back home, it is not a nuclear type of family arrangement. We have extended type of families. Of course, I would also need to help those around me financially. Even in that situation, at least there will be someone, even little ones who might want to clean the house or do some other chores for me. There would be people around.*



However, some participants are planning their own lives and making decisions independently. This is not usual within MZZ cultural practices thus it demonstrates a shift from the norms and customs practiced in Africa. One participant started this shift while in Africa because he was unhappy with what he saw as adverse outcomes of collective decision making within his own family.

*I started writing my ideas of how I think we should go about it when I was still in Zimbabwe. And I said, I own nothing, my wife owns nothing. We have a family trust where everything goes because there is a tradition where if I were to die, all my clothes get distributed to my relatives. I don't mind that, but I say, you should stop there. You can't go and distribute my wealth that I built with my wife. Likewise, when she dies, people might distribute cups and utensils and so forth (Ted).*

Place of care and death also brings about cultural practice challenges. Most participants want to be cared for in their own home. There are varied reasons for the preference to be cared for at home. Reasons range from concerns about racial issues, wanting to maintain a routine and desiring to be in a familiar environment, and wishing to maintain control over their situation and their care:

*Going to a government place one rarely receives proper care. I would rather, I have a good room myself in my home and if I need medical care from time to time, the doctors can come to visit me in my private environment. I would like to stay in a familiar place with my family around me (Simbeye).*

*I would want to be at home. Having that financial stability will allow me to access services when required. I will be able to call on my son to organise a nurse to come and visit me, I will pay for the services. I am*

*sure my son will be very quick to organise because the money is not coming from their pocket (Chungu).*

*I would rather be at home and have some people come in to help. If the situation becomes too complex for my husband and the ladies from church, then maybe those nurses that help people in the homes could come and help. The goodness with that is that it is my home, and I can choose who to let in and who not to. If someone is like those who don't seem interested in my welfare, I mean the people that look at black people like they are not equal humans, I would not let them in. That is why getting admitted in an institution is a bit tricky for me. It is a big concern (Jane).*

### **Place of care**

Place of care was the second aspect of EOL preparation that participants were concerned about and had preferences for. A familiar environment was the preferred place of care, citing comfort, being in control and choosing who would come into the home and provide the required care as the reasons for the preference. Hyawo stated:

*For me, unless my home is taken away, I would prefer my home to be my place of care. It is a place I am familiar with, and I have control over. In my home, I am not being introduced to, and also dependant on other people's routine. It is my environment, and my family can be around unlike an institution where either you adhere to visiting hours or, if allowed to visit anytime, there maybe one or two allowed to visit at any given time. Home is better.*

To be cared for at home during EOL also resonated with Tomaida stating:

*Nursing home is definitely out of question. If I have saved enough money, which I hope I will by the time I retire, I will need to find some carers and nurses that I can hire. I know that the government provides packages for care, so I can use some of that. But I will need to choose who comes in my home to give me that care. That is the main reason why I want to stay home, so that I can choose who cares for me, something I would not be able to if I went in an institution.*

Jane reported that her preference for being cared for at home was to foster a sense of belonging which she thought would be absent if she went into a facility for her EOL care. She also expressed her dislike for institutional settings for her care where she believed that being of CaLD background would disadvantage her:

*I am afraid that if in a care facility, I may feel out of place, not belonging. I have seen that happen to me now, what more when I am dependent on others for care? I wouldn't like to be in a hospice. I would rather be at home and have some people come in to help. If the situation becomes too complex for my husband and the ladies from church, service providers can come in to help. I would feel more comfortable that way.*

NaMbewe reported wanting to be in a familiar environment so that she could continue to experience 'life until the end':

*... You feel alive, the dogs barking... the smell of flowers and the cooking, it gives one that sense of being alive until death comes. I do not think this would be possible in a place other than home. If it could be possible, the smells would not be familiar, so, there is a difference there; you see what I mean?*

Being in control was profound as it was not just being in control of what would be happening around the participants but also who would be allowed to provide the care. Some chose only family members to care for them and others accepted specialised services to be involved but with family overseeing the care for fear of racial discrimination. Participants were aware of domiciliary services that were available in Australia however, they still preferred family members taking the lead in the provision of care. Participants reported that to achieve being cared for at home during EOL, they needed to have sufficient money at that time, a goal towards which they were working through business ventures, retirement planning, and superannuation contributions. While place of care preference was established by participants, the idea of home was not as straight forward because participants referred to home in Australia and home in Africa which demonstrated this continuous ‘toing and froing’. The ultimate decision to resolve the ‘toing and froing’ did not seem to lie in the participants but externally, in the children extended family members as expressed by participants:

*“...my children will be able to make those decisions when time comes. It is the cultural responsibility that they will need to carry with the help of other [extended] family members in Africa”. (Musa)*

*If something happened here, my children will need to step up to make sure all [care] is done well. It will be their turn to grow up and take up the mantle of being adults especially boys, who are supposed to lead the family. Their uncles will be there to guide them”. (Towela)*

*Well, I know about the forms [AHD/ACP], but we generally do not write down our wishes. It is for those people close to someone; they are the ones who are*

*given authority to provide guidance in decisions being made by adult children”*  
(Mwada)

*“Like I said before, these children do not want to learn the culture. When things get tough and I cannot manage to care for myself and also make decisions, they will be the ones making those decisions. We participant and husband] have been there and now it will be their [sons] turn to be in the forefront”. (Tomaida*

### **Place of death**

There was an overwhelming preference for dying at home, in an environment that was familiar and surrounded by family members and friends. Participants reported that the preference for dying at home was also to ensure as many family members and friends or church members as possible were around, something they thought may not be possible in an institutional setting like a nursing home or hospice which may impose a limit of how many people allowed around the patient at any given time. The practice in MZZ is that as many people who know the individual as possible should gather around and within the vicinity when death is eminent, something that is unfamiliar in Australia where closeness refers to immediate family and sometimes very close friends, not a large crowd. This further demonstrates that although participants have been in Australia for a considerable period of time, the aspect of cultural practice takes them back to the African way of viewing the dying process. The dying process that takes the natural cause and surrounded by loved ones as Simbeye stated:

*I want to die at home not in a noisy place like a health institution. The issue is that, in that place, I have no control of what happens, while in my home, I have.*

Towela, Jane and NaMbewe also resonated with the idea of dying at home surrounded by family:

*I would rather be here [Australia] and die in here with my children and grandchildren around me. I think it is good and comforting to be in my own place, hearing the normal conversations and seeing the home, familiar activities. Maybe open the windows and curtains, hear the outside noise and smell some flowers or smell the ground when the first rains hit the ground. I think, I would feel that I am still a part of the family and taking part in the family activities even if not physically (Towela).*

*I prefer to die in my own house because I would be with my husband and surrounded by my church family. That would be so comforting to me. Like I said before, I don't like the hospice and care homes or hospital...I truly am working so hard to save money so I can afford services in my own home when I get old, and I am dying (Jane).*

*...definitely home is more user friendly, more conducive. You hear the same birds. The birds that have been singing before, you hear the cars passing by it gives you a sense of belonging and a sense of life. You feel alive, the dogs barking, you know, those little things. You know, the smell of flowers and the cooking, it gives one that sense of being alive until death comes (NaMbewe).*

Waitwika had a different preference from Jane and Towela:

*I would want to fly home [Zambia] and die there. But at the same time, I realise the longer I've been here, those people that knew me, a lot of*

*them have also died. If I went there [to Zambia], I would feel out of place. As you can see, this is causing a dilemma.*

Although Towela reported that her preferred place of death was her home in Australia surrounded by her family, she also reported a desire to go back to Zambia to die:

*...because we are family oriented, I can go back [to Zambia] and maybe have a peaceful ending once I am with my people...And I thought about it, here I am with my husband, if he went first, would I be able to cope living here or I may be better off going back. Those are the thoughts that kept coming in my mind, questioning to say maybe I need to go back. Because here there are very few family members. I feel like my children will not be able to look after me, they will be very busy.*

As noted from Waitwika and Towela's preferences, it is evident that there is confusion in the participants' minds about their preferred place of death, emphasising the continued search for finding equilibrium in order to arrive at a decision. Some participants reported that they preferred to have a quick and peaceful but natural death.

### **Voluntary Assisted Dying**

Voluntary Assisted Dying (VAD) was considered an unnatural dying process to which participants did not subscribe. The subject of VAD was raised by participants without being prompted. Participants understood VAD to be a form of suicide by an individual who has sought assistance from other people to end their life, in this case, medical professionals, the latter of whom can make mistakes in their predictions about how much time someone has before they die. For these participants, whatever came their way in life in relation to severe life limiting conditions, VAD was not the solution, and that things must take their natural course. Culture and spirituality were the main influencers in

forming that unshakable view, which may change with time if cultural and spiritual convictions capitulated. Tomaida explained about her views on VAD:

*I do not mean suicide or voluntary assisted dying. It is a figurative speech meaning that I dislike that idea so much. I would not think of being assisted to die because I am in an unpleasant situation. God gives life and God decides when to take it. This means that when I am at end-of-life or old, I am not demanding that doctors and nurses go out of their way to make sure that I continue living. What for? Others ought to die, to leave space for those being born. Simple equation. We all will die one day.*

NaMbewe also thought VAD was not appropriate:

*I am not talking about voluntary assisted dying, I am just saying that I do not want to be resuscitated only to be of no use to people rather, a burden. Let nature take its course, do not kill me, also do not keep me on life-sustaining measures when it is clear life is fading away. Let nature take its course.*

NaPhiri reported being open minded to VAD, but she was not considering it at present:

*If I am in a vegetative state, I would say, do not bother resuscitating me, let me just die as it is. Maybe voluntary assisted dying is not there yet, but if they just let me die a natural death, that would be much better. Depending on what incapacitation I will have, I might revisit in future. Because as I said, being a nurse myself, I am seeing what is happening with patients. Sometimes you would wish the family would make a decision to do this, instead of letting someone suffer, because*



*sometimes it is just suffering for no point. And there is no reason why I should suffer when I can just rest in peace and forget about it. Those are the things that probably might consider when I reach a point where this is the end of me. If I am unable to do a lot of things for myself, there is no point of living.*

Simbeye was rather implicit in talking about assisted dying as shown in the following excerpt:

*...if I am about to go or have a condition that is persistent, let me go. Although I had a situation [liver transplant] that required major and heavy treatment, which I did get. In those circumstances, you would count it as negligence if I was not provided with treatment. And refusing treatment on the other hand, would not have been considered planning death on my part. So, I would not like to take God's place.*

### **Advance Health Directive/Advance Care Planning**

The participants in this study were able to outline their preferences about place of care and death and thus appeared to have clear preferences for their EOL. This should have led them to consider documenting their EOL wishes, however, most of them had not previously thought about putting in place a directive to guide the family and health practitioners on how to care for them during EOL.

During the first interview phase, participants were introduced to the Advance Health Directive (Appendix 12) and Advance Care Planning information (Appendix 13) for consideration. Most of the participants had never heard of the documents and their uses. During the second interview phase, I followed up with the participants in relation to the information supplied to them in the first interview. Participants then began thinking about

writing down their EOL plans, thus diverting from their traditional MZZ cultures that rely on extended family members to make decisions about EOL care on their behalf. However, participants who expressed wanting to utilise the documents still looked to other family members to contribute to the document. This highlights the 'toing and froing' between Australia and MZZ in relation to their decision-making processes. Cilla was one of those who made a decision to utilise the information provided to her because she had already experienced the process of dying in Australia when her husband passed away.

*People that are not close to me have no need of being with me at that time. People that I hold dearly to my heart and very comfortable with, those are the people that I would want to be around me, because I've got that connection. I think even as I am leaving them, these are the people that I know as they surround me, that they have my interest at heart. They will pray with me. I would rather have people that connect my family and the friends that have become family, that are connected to me to be around. I don't actually believe for the sake of just being there, you don't know them, no connection and all that. It's like they've just come to us to watch you. So, I'd rather have that circle around me.*

Because of her experience during the EOL of her husband, she resolved:

*I learned quite a lot. I looked into care when I get to that stage. Yes. So, I got a bit of knowledge from what we talked about...I would love to transfer the information from the book to the proper document [ACP] as soon as possible because you just never know what comes around. I think it's better to put things in my order, I am already in middle age. I would love to do it as soon as possible.*

While Cilla said that she learnt from the interviews and decided to put in place an ACP, Tomaida was not keen to transition her thinking:

*Although I am a nurse, I have not really thought about such things. You know, documenting what I would like when I am old and frail or, when I am at the end-of-life. My husband and I have discussed, and we both feel it is important to have a document that will guide those caring for me. I want to talk to my children to let them know my thoughts. But documenting is somehow daunting. I think my kids would know what to do. I will leave it as it is.*

For Waitwika, participating in the study enabled him to think through what his culture meant to him:

*This is a difficult question. Basing on the upbringing in terms of my culture, if a family member is requiring care, it was assumed that he or she is going to be taken care of by either the children or the spouse. The entire life that I've lived, looking at my family, even the passing on of my mom, she had cancer. We managed to look after her until her death.*

While he acknowledges that talking about death in his culture is taboo, he also understands that times have changed:

*Yes, but in our culture it is kind of taboo to talk about such things until the time comes. The family knows their responsibility when it comes to terminal illness and death of a family member but, things are now changing especially for people like us who have migrated. There isn't that extended family to manage the process. So, I have to look at how best to manage the situations here with just my wife and two children.*

Having the opportunity to think about the topic, Waitwika's second interview resulted in how he wanted to proceed with preparing for EOL:

*It [EOL] is something I have deeply thought about, especially after a mishap two weeks ago. It is something that I would like to explore. I also want to explore the Advance Care Plan, to put in place what I consider important for my care so that my family do not have to guess what to do and also they will know what my preferences are.*

## **Overview of findings**

Culture was one of the major concepts that participants had concerns with when considering EOL preparation and negotiating in a new place such as Australia, so that life may have a sense of normality. Cultural values that participants wanted their children to mirror were hoped would also assist to maintain identity, the latter, which was being lost through for instance, disintegration of family. Participants were keen to introduce and help their children realise their cultural identity, which was of critical importance to participants. To navigate through the actions to reach a state of equilibrium, participants forged new friendships, some of which turned into surrogate family relationships, to establish community support networks, a lifestyle that they were familiar with. Church attendance also established similar relationships of support and surrogate families and played a vital role in fostering belonging and care for one another. In addition, spirituality was also an important aspect in finding a balance in life. While these participants sought to find spiritual groups like churches to belong to for support and nurturing, some found that these were different in the way activities were conducted. For instance, invitations to attend church member funerals was one thing participants found difficult to understand and grasp. To find equilibrium, therefore, required working towards a balance in the

convoluted process of ‘toing and froing’ whereby ‘resetting the life button’ and ‘pursuing the horizon’ would assist in stabilising participants opportunities and choices, allowing the individual to move forward.

It is a difficult process to navigate for this cohort of migrants from MZZ. The constant ‘shuttling back and forth’ and quest to ‘finding equilibrium’ can often remain elusive as some participants continue to go back and forth, starting all over again when they encounter new challenges when thinking about extended families that are left behind. There are family expectations that need to be met for both the immediate family members in Australia and the extended family members in MZZ. This challenge often drew participants back to their countries of origin. However, participants had embarked on this new journey which changed the way they thought about some of the cultural practices in MZZ.

While they lived in MZZ, participants had different ways of conducting family affairs with heavy involvement of extended family. Now that they were in Australia, they adopted new ways of thinking, questioning the traditional way of looking at situations.

Culturally in MZZ when a spouse died, extended family came together after the funeral to decide how to manage the family of the deceased, his or her children and property. Participants began thinking differently about this especially since they migrated to Australia, in part due to the group of traditional elders not being on hand to attend to such matters because they are in MZZ.

Some participants reported that they were relieved that they were in Australia because their families would not be exposed to such practices and that even if someone from Africa were to be present at such a time, they would not reinforce that because Australia has clearly laid out laws that can intervene on behalf of the deceased family to protect them. Some participants began to question those practices before migration, deciding to

question their families in relation to the consequences of such vices on the bereaved family. For these participants, moving to Australia enhanced their thinking in that direction to protect their families. Participants who had arrived at that level of thinking, appeared to have reached a place of balance however, equilibrium may remain elusive depending on for example, the disintegration of family dynamics.

## **Summary**

This chapter has presented the findings of the study commencing with information about each of the 14 participants. Presentation of the findings of the study was shaped using the three steps of data analysis as per constructivist grounded theory design: initial coding, focused coding, and theoretical coding. The data depicts the experiences of the study participants going through the DPTF in planning for EOL. The findings generated from the interviews with participants were shaped by constructivist grounded theory design. The data analysis using the constant comparative technique, identified six categories: A) Remodelling self; B) disintegration of family dynamics; C) resetting the life button; D) shuttling back and forth; E) finding equilibrium; and F) pursuing the horizon. These six different categories were discussed in detail in relation to the experiences of migrants from MZZ and their EOL planning. The emergent model of the Dynamic Process of Toing and Froing (DPTF) in preparation for EOL by migrants from MZZ in Australia was introduced above in relation to the 'toing and froing' of participants struggling to settle in Australia and belong between two worlds, both considered home. Chapter 5 will present the process undertaken for development of the substantive dynamic process of 'toing and froing theory'.

# **Chapter 5: Theory Development**

## **Introduction**

The previous chapter four presented the findings of the study. This chapter five progresses these findings into the substantive theoretical development of the Dynamic Process of Toing and Froing (DPTF), which emerges from the six categories as discussed above. This chapter articulates the step-by-step process of constructing the grounded theory using the core categories identified from the analysis of data, based on the experiences and voices of MZZ migrants living in WA, Australia in relation to their preparations for EOL care. The chapter commences with introduction of the DPTF followed by an explanation of its elements as an emergent theoretical model. The chapter concludes with a summary,

## **The Dynamic Process of Toing and Froing**

The culmination of the findings of this study brings together the six categories that emerged from the data, re-modelling self, the disintegrating of family dynamics, resetting the life button, shuttling back and forth, finding equilibrium, and pursuing the horizon. Participants were navigating through each of the identified categories as they sought to settle in Australia and make meaning of their past, present and future lives.

It was clear from the data above that although these individuals made the decision to settle in Australia, they never really ‘left’ their home countries, vacillating between thoughts of their home country and plans for their families and homes in their new country of settlement, Australia. The DPTF was evident at every level of their lives, decisions and plans, all ultimately affecting their ability to plan for EOL in Australia, away from their traditional collective cultures and extended families.

The six categories identified in this study were examined separately, but as demonstrated above they are interrelated and intertwined. For instance, the ‘disintegrating of family dynamics’ causing loss of culture also filters into the ‘shuttling back and forth’, and the ‘shuttling back and forth’ as a result of the ‘disintegrating of family dynamics’, and the resulting adaptations to new cultures and having to start again, directly connect to ‘resetting the life button’. At the start of the whole DPTF is the remodelling self. If there was no migration to Australia, there may not have been disintegrating of family dynamics or the need to reset the life button. If no migration occurred, participants would not be shuttling back and forth because they would be in the midst of their own people, practicing their collectivist culture. These six categories, including remodelling self, disintegrating of family dynamics, resetting the life button, shuttling back and forth, finding equilibrium and pursuing the horizon are all segments of a single story. These categories consist of the properties that were constantly evolving in relation to preparing for EOL in Australia and illustrate the journey each individual was engaged in as they immersed themselves in the DPTF.

The reasons why each participant came to Australia in the first place varied to some extent, such as, for work or study, or to join family members by way of migration. Nonetheless, these six categories were at the core of the model. Condensing the identified properties into one model may be interpreted that there was a defined set of elements that the process assumed which individuals followed as they navigated through the concepts to arrive at starting to plan for EOL in Australia. However, this study asserts that preparing for EOL in a new country did not follow a set process and was more-so a DPTF. The ‘toing and froing’ reflected the tension within the individual as they navigated to get to a position of equilibrium to enable them start to plan for EOL in Australia. The process of ‘toing and froing’ was very dynamic, that is, it was ever-changing in relation to finding personal equilibrium and thus in resetting the life button, and in how through the perceived disintegrating of family dynamics,



they could pursue the horizon. It was a balancing act between concentrating on life in Australia and differentiating themselves from the everyday situations happening among their extended families in MZZ. It was also in the coming to terms with the fact that culture changes and would not be as they left it when they migrated from MZZ, and it was a constant and evolving journey for the participants as well.

The study findings above illustrate that participants were ‘toing and froing’ between culture, food, connections, and being ‘homesick’ for MZZ; periodic returns not helping. ‘Toing and froing’ was evident throughout the findings, not just in relation to EOL care planning when this was discussed.

Notably, participants were unaware that they were engaged in the ‘toing and froing’ process until they were asked about how they were preparing for EOL in Australia. They had to consider their roles in their families here in Australia as well as in their extended families in their countries of origin. Participants were concerned for their families in MZZ, with how their parents and/or extended family members were managing with life and what kind of needs they had. In addition, participants were also apprehensive about how extended family members in Africa such as nieces, nephews, uncles and others were managing their needs.

The DPTF (Figure 5.1) illustrates the tensions that individuals experienced through the categories of ‘resetting the life button’, the ‘disintegrating of family dynamics’, and ‘shuttling back and forth’. The properties of the disintegrating of family dynamics category denote a constant feeling of being detached from their culture and extended families. The collectivist nature of their communities in MZZ, a concept the participants grew up with, was challenging to let go of because they depended a great deal on it, not only for the process of decision-making but also for keeping the connections alive with their extended family members in MZZ. The category ‘resetting the life button’ exemplifies the process of beginning a new life in a different environment, something that was challenging for

participants on all fronts, particularly the different cultures and other social connections. Participants needed to step out of what they knew and were comfortable with, into a new environment, and the process if completed would enable them to find equilibrium. However, the findings above revealed that participants kept going back and forth from what they knew before, into the new environment and back into the old. This category of ‘shuttling back and forth’ illustrates the vacillation between two geographical locations where study participants participated in both of their communities and were unable to detach themselves from their extended families. Participants were seen to engage with life in Australia and continued to fully participate in all its opportunities and be interested in activities taking place back in MZZ, especially special events such as births, deaths, weddings, and other significant occasions. As with the ‘disintegrating of family dynamics’ and ‘resetting the life button’, ‘shuttling back and forth’ denotes an unsettledness that individuals had found themselves experiencing, but which required settling, in order to find equilibrium. The category of ‘finding equilibrium’ explains the state of comfort experienced by individuals when they reached a point of acceptance that minimised the tension within them vis-à-vis the ‘disintegrating of family dynamics’, the ‘resetting the life button’ and the ‘shuffling back and forth’, to the point that they were able to move forward in ‘pursuing the horizon’, a point at which they were then able to start preparing for EOL in Australia.

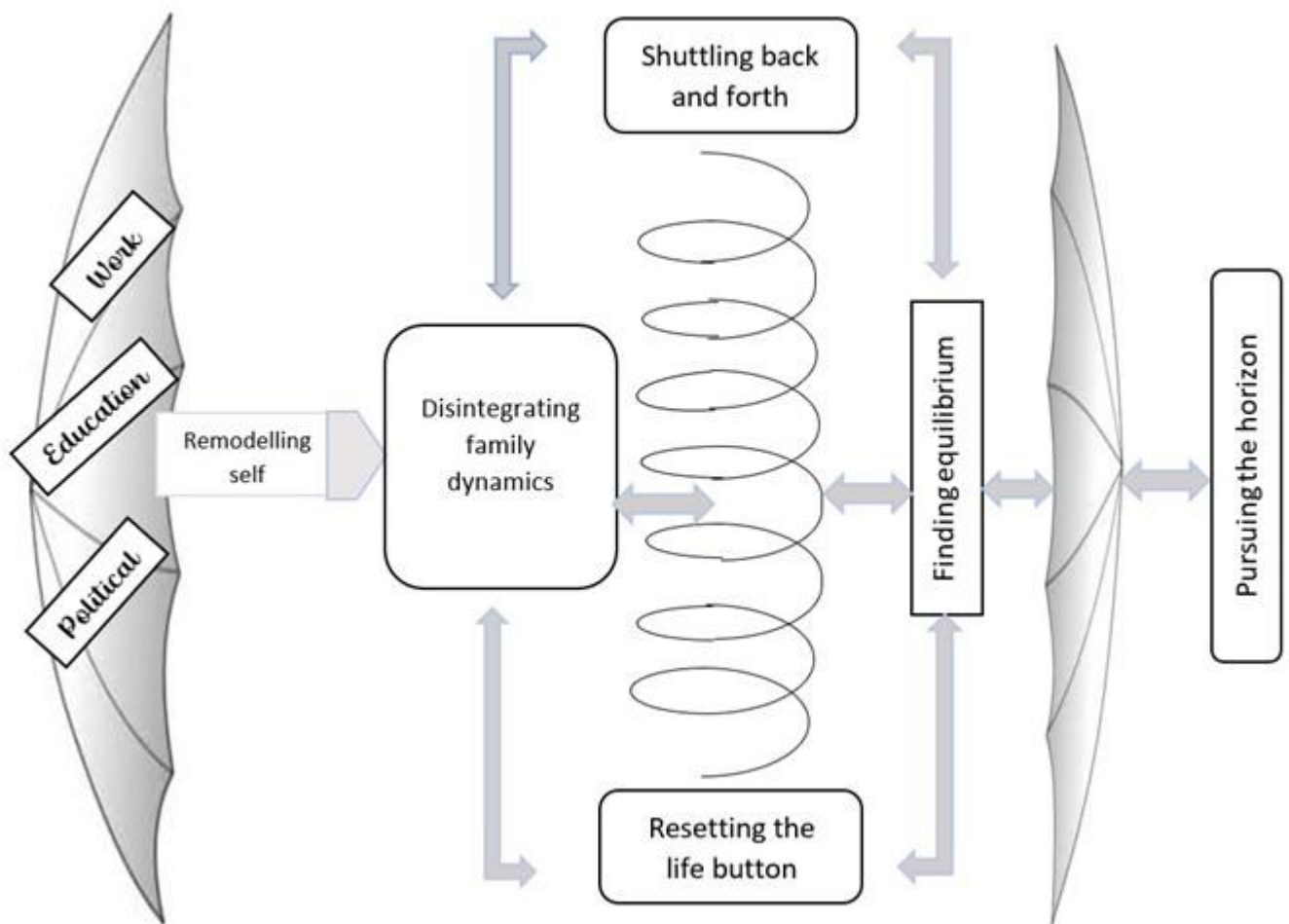


Figure 5.1 Emergent Theoretical Model: The Dynamic Process of Toing and Froing

In Figure 5.1 illustrating the emergent theoretical model of the DPTF, the umbrella on the left represents the starting point of remodelling of self, the migration from MZZ and the avenues that facilitated migration: Education as a goal to attain the desired remodelling of self and a means to gain employment in Australia which otherwise they would not have if they had remained in their countries of origin. The gaining of employment was viewed as an enabler for participants to bring their families into Australia, which would benefit their children by attending schools and tertiary education which were considered to be better than those in MZZ. Additionally, gaining employment in Australia was also of financial benefit to the extended family members left in the countries of origin because participants were able to regularly send monetary assistance. Work as a goal and a means was also considered in the

same way as migrating for education except for those coming to Australia primarily to work: Their first priority was to access permanent visa opportunities which promised benefits such as access to health care and lower school fees. The third avenue used by participants was migrating due to socio-economic or political reasons. These participants were concerned with the corruption and interference of political leaders in their personal business ventures, prompting them to migrate to Australia, a place they envisaged would facilitate and support freedom to engage in legitimate business. As participants embarked on remodelling self, they began to feel separated from their communities that they knew from childhood and cultures with which they were familiar. They began to experience the disintegrating of family dynamics because of their migrating. This disintegrating of family dynamics continued to unfold in their lives and affected their ongoing settlement in Australia.

Resetting the life button represents the sense of a fresh start experienced by participants, the joy of having great opportunities such as well remunerated jobs and realising their goal of their children receiving education in Australia and being in a position to support extended family in MZZ. While participants felt happy with opportunities they found in Australia, there was a sense of loss, resulting from disintegrating of family dynamics that made participants feel that they were ‘shuttling back and forth’ because they wanted to feel relevant in both geographical locations, their countries of origin and Australia. ‘Finding equilibrium’ is what participants needed to then be able to begin considerations of EOL preparations. Participants were found to be on a continuum in all concepts, requiring making progress to a point of comfort which would then lead to pursuing the horizon.

In Figure 5.1 above, the spiral in the centre of the figure illustrates the constant ‘toing and froing’ of participants, as individuals sought to ‘find equilibrium’ by coming to terms with the ‘disintegration of family dynamics’ from their culture and extended family and about being able to perpetually ‘reset the life button’. In addition, participants were searching for

equilibrium in the ‘shuttling back and forth’, a state that continued to challenge them as they endeavoured to be present and relevant in both geographical locations of Australia and Africa.

The process of migration and settlement was convoluted and does not follow a straight, step-by-step process. Rather, participants found themselves dealing with one or more of the four concepts that were pertinent at a particular time. As such, the individual could move between the ‘disintegrating of family dynamics’ to ‘resetting the life button’ and back to the ‘disintegrating of family dynamics’ or ‘shuttling back and forth’ to the ‘disintegrating of family dynamics’ or vice versa’, as they sought to find equilibrium. The arrows pointing ‘to and fro’ represent the notion of this back-and-forth motion for individuals, relating to all concepts, the process did not follow a set route to finding equilibrium, the process took them back and forth, and was dependent on prevailing circumstances at any given time.

There were enablers and inhibitors for finding equilibrium. Participants found that they started to think about EOL preparation when they no longer were rigid about their culture, when they accepted that culture was changing even in MZZ, when they did not worry about their children as having half-baked culture, and when the separation from extended family was no longer impacting their lives. The opposite of the above was found to inhibit going forward into pursuing the horizon. Permanent visas and stable work were facilitators however, these did not appear to have a bearing on how participants leaped from finding equilibrium to pursuing the horizon.

In Figure 5.1 above, the second umbrella at the right represents the bridge that participants needed to cross from the DPTF to commencement of ‘pursuing the horizon’ which was the starting point for preparing for EOL in Australia. This bridge could only be crossed when individuals reached a state of equilibrium in relation to the ‘disintegrating of family dynamics’, ‘resetting the life button’, and ‘shuttling back and forth’. Indeed, as quoted at the

start of this thesis, “You cannot swim for new horizons until you have courage to lose sight of the shore” (Faulkner, 1966).

The DPTF should be regarded as an emergent theoretical model in relation to preparing for EOL in Australia by migrants from MZZ. The model illustrates the interplay of processes of remodelling self, the disintegrating of family dynamics, resetting the life button, shuttling back and forth, finding equilibrium, and pursuing the horizon all of which interplay with each other and need to be understood by not just the migrants from Malawi, Zambia, and Zimbabwe, but also to those providing palliative and EOL care.

### **Summary**

This chapter discussed the theory development process undertaken to generate the emergent theory of the Dynamic Process of Toing and Froing that the participants go through as they prepare for end-of-life in Australia. The chapter discussed the construction of the theory of the Dynamic Process of Toing and Froing and described the concepts and categories of the process, and how they clearly exemplify how the substantive theory of Dynamic Process of Toing and Froing was developed, grounded in data. In this study, a pattern emerged from the data in relation to how participants were dealing with the issues that they face. Preparing for EOL in Australia for these participants appeared far-fetched as they struggled to find a place of comfort, finding equilibrium, to start the EOL preparation process. Finding equilibrium was therefore, found to be an important milestone to reach, as it marked the completion of the Dynamic Process of Toing and Froing and being able to step into ‘pursuing the horizon’, the place which marks the start of EOL preparation.



# Chapter 6: Discussion

## Introduction

Chapter Five presented the emergent DPTF substantive theory grounded in the data. The purpose of this Chapter Six, is to discuss and interpret the study findings and situate these findings within the existing body of literature, as introduced and discussed above in Chapter Two, based on Charmaz's (2014) assertions that prior to a study, constructivist grounded theorists conduct a moderate literature review, to gain some understanding about the subject to be researched. Hence, the literature incorporated in this chapter will be examined in more depth and relate specifically to the findings identified in this current study.

This chapter commences with an overview of the study, followed by a brief exploration of Lee's (1966) and Duncan and Perrucci's (1976) seminal sociological theories of migration to help understand some of the migration issues identified in the current study. The chapter then explores the elements of the DPTF and discusses it as a theoretical model, followed by the provision of an evaluation of the model to exemplify its rise from the conceptual status to the theoretical level. In doing so, the chapter briefly discusses the theory of ambiguous loss and the process of navigating cultural spaces, both of which highlight similar concepts to those identified in this study. To further explicate the challenges of migrants, transitional theories from nursing science are discussed.

The chapter then discusses what migrants bring to the palliative care situation and the need for the co-designing of education resources, strategies to introduce palliative care and planning for EOL to this community, and the need to use the public health approach to facilitate palliative and EOL care information dissemination. It is contended that the results of this study consolidate, confirm, and contribute to the approaches that have been previously



advanced concerning migrants and preparation for EOL in Australia while at the same time, articulating the newly generated substantive theory of the DPTF. The chapter concludes by tying together synthesised key elements of remodelling self, the disintegrating of family dynamics, resetting the life button, shuttling back and forth, finding equilibrium, and pursuing the horizon, to generate the substantive DPTF, and confirm that constructivist grounded theory was the appropriate methodology for this study.

## **Study Overview**

This constructivist grounded theory study was conducted to address the gap identified through personal and professional experience, and an introductory literature review undertaken prior to commencing. Past studies in relation to migrants and access to palliative and EOL care, identified barriers such as culture and communication, spirituality, collective decision-making and family carer preference (Bullock, 2011; Hiruy & Mwanri, 2014; Shanmugasundaram & O'Connor, 2009; Sneesby et al., 2011).

This study was undertaken to address the question ‘why?’: Why is there an underutilisation of palliative and EOL care services in relation to preparing for EOL by migrants in Australia? The above research and data show that it was because these individuals were unsettled within themselves as they continued ‘toing and froing’ between their original home country and notion of extended family, and their new settled home in Australia and their immediate but growing families. Secondly, this study aimed to address the ‘how?’: That is, how does the experience of migration impact on the individual’s ability to deal with the difficult questions of life and death, in particular planning for EOL care.

Data collection and analysis were conducted through the theoretical perspective of the science of nursing (Fjelland & Gjengedal, 1994). As both a trained nurse and a migrant from MZZ living in Australia, as a researcher I am in a unique position; professionally to research

this topic, to collect and analyse the data from a palliative care professional perspective; and personally, as an insider within the MZZ diaspora living in WA, Australia, to empathise with and understand participants' points of view. However, to ensure that the data analysis and findings were not influenced by my position as a nurse and MZZ migrant, the research included the application of reflexivity and theoretical sensitivity, as discussed above in Chapter Three.

This research was generated from my journey as an MZZ migrant in Australia and working as a nurse, and the process of decision-making that I observed within the African communities living in Australia, particularly when individuals were faced with EOL situations and death. I noticed a recurring pattern in the decision-making for EOL and palliative care: It was left to not only the individual's children living in Australia but also to extended family members who are living in MZZ, which resulted in frequent phone or video calls with extended family members, often causing distress among these relatives. In some cases, it was the EOL patients themselves having long phone conversations with extended family members back in MZZ and seeking guidance on how to proceed with their situations of ailing health and impending death.

This study began with a pilot study which involved one interview with each of the three participants recruited (Appendix 8). The results of this pilot study revealed that participants did not have insight into the subject of preparing for EOL in Australia until they were asked the question during their interview. Building on the outcomes of the pilot study, the main study was able to adapt its protocol to provide participants with time to think about this difficult and sensitive subject. Thus, it was decided that each participant be interviewed twice. Participants were provided with information about making decisions for EOL care during the first interview. The second interview focused on participants sharing their thoughts

about the information they were provided with in the first meeting. A richer data set was collected, and more was learnt through these two interviews.

The analysis revealed that participants were engaged in a convoluted DPTF that continued to perpetuate the barriers CaLD migrants experience in accessing palliative and EOL care. Addressing the barriers, therefore, required understanding the experiences of DPTF. There was consistency across the participants about the DPTF however, before I discuss the substantive theory and what it means to migrants from MZZ, I will consider the sociological theories of migration. This will help grasp an understanding of migration issues which also impact on these study participants' thinking about their future care needs while being away from their extended family members.

## **Migration**

Migration is a phenomenon that has been going for many hundreds of years and it is predicted to continue and, as a matter of fact, to increase. As African migrants from MZZ make valuable contributions to the skills, economic and otherwise, of the society that has become their new home, Australia ought to prepare for receiving more of these migrants, in palliative care settings as they get older and deal with life-limiting illnesses. This preparation will enable healthcare workers to be ready to provide care to migrants including providing guidance for EOL planning. Additionally, the migrant community would feel freer to engage with healthcare workers to access information about timely preparations for EOL care.

The following section will thus briefly consider the sociological theories of migration and compare these with the study participants' own migration stories. The working definition of migration in this study is the relocation of an individual or individuals from one geographical location, to a distant one, beyond the borders of their countries (Bartram et al., 2014).

Floodgates for migration opened wide in the 1980s due to globalisation, a phenomenon that

defined the world as one global village (International Organisation for Migration, 2020; Triandafyllidou, 2018). The push factors for migration relate to leaving one's location because of unfavourable conditions, while pull factors relate to the attraction of another particular location (Krishnakumar & Indumathi, 2014; Lee, 1966; Urbański, 2022).

Theories of migration are discipline-based and can be identified in the literature such as economic, geographical, unifying, or sociological (Wickramasinghe & Wimalaratana, 2016). Sociological theories of migration highlight the issues that impact migration across the board, regardless of the migrant's origin or destination. While there are several theories of migration advanced in the literature, Lee (1966) and Duncan and Perrucci (1976) were selected here for the purposes of understanding the factors that led the present study participants to migrate from their countries of origin to Australia and how this ultimately influences their planning for EOL care. The two theories examined here each have their similarities however, they also have different applications (Lee, 1966; Duncan & Perrucci, 1976).

Choosing to migrate from one location to another is a mammoth decision that takes numerous factors into account (McAuliffe et al., 2022). While there are other external factors that influence migration, such as government policies, leadership, power, and politics in the country of destination (International Organisation for Migration, 2020), the migrant is the final decision maker on whether to migrate or not (unless the migration is forced due to war or conflict and thus humanitarian factors). Both Lee (1966) and Duncan and Perrucci (1976) posit theories that agree on the fact that there are influencers that facilitate arriving at a decision to migrate.

Duncan and Perrucci (1976) consider that the catalyst for migration across borders includes: population growth in agricultural sectors, economic, technical, social and personal causes. The economic and technical causes relate to changes within the structures in the

operations of agriculture such as production, and price for the produce. Social causes of migration on the other hand, relate to changes such as population growth, policies relating to land and agricultural production, and family maintenance changing needs (Duncan & Perrucci, 1976). Another cause of migration identified by Duncan and Perrucci (1976) is related to personal factors such as wanting to gain more knowledge and have access to good health care.

Lee's (1966) theory also discusses the causes of migration but sums them up into 'push and pull' factors. The push factors are features that motivate individuals to leave their countries of origin to other locations, such as dissatisfaction with situations in political administrations and economic challenges. While the pull factors are those desirable elements in the country of destination such as education and employment opportunities (Krishnakumar & Indumathi, 2014; Urbański, 2022). Lee (1966) thus concludes that the push factors either push the migrant out of their country of origin or the pull factors pull them into the country of destination. Although Lee (1966) and Duncan and Perrucci (1976) may label the causes differently, they are essentially pointing to the same factors that participants of this study felt as their push to leave their countries of origin, and their pull to migrate to Australia.

### **Push Factors**

The areas of origin can serve as the push factors that motivate individuals to migrate from their country of origin (Krishnakumar & Indumathi, 2014; Lee, 1966; Urbański, 2022). The push factors leading to the migration among participants were the conditions that they felt were unfavourable for their continued stay in their countries of origin. These included economic hardships and also political reasons which were identified in the literature to be common in MZZ. Maguchu (2019) for example, cited corruption, and physical human rights abuses perpetuated by lack of comprehensive justice frameworks in Zimbabwe.

The hardships identified in this study were political interference into privately owned businesses, and not being paid sufficient wages to support their families. Private businesses in MZZ, often face over-regulation from the regulatory bodies, and also interference from political figures. In Zambia for example, the lack of specific policies is also a problem (Siwale & Okoye, 2017). Interference by politicians in private businesses for two of the participants here meant that they were unable to conduct their business affairs in a manner that was profitable for them. The inability to conduct businesses in a profitable manner resulted in participants not being able to provide for their families to their satisfaction. Interferences can emanate from political appointments to economic regulatory bodies that result in corruption (Chilunjika, 2021). Participants reached a point where they felt needed to migrate to a more stable environment, where business rules for operating businesses were clear. For these participants, migration enabled them to cater for their children's needs such as schooling which meant that they were achieving their financial and life goals. Additionally, they were taking themselves and their families away from environments that were considered unfavourable. It was a push that had their children at the front of their minds, to provide them with better education that would set them up for their future.

Migration was a big step to take, especially because the participants here were accustomed to the collectivist culture in which they were brought up and then faced the challenges of moving to and living in a place far away from their extended families; away from older family members who would normally assist them with making significant decisions. Nonetheless, participants continued to rely on that process, which was familiar to them, frequently consulting families in MZZ and sometimes accepting decisions made on their behalf by extended family members. This emphasises the tension within the participants' minds between the 'joy' of being in a country that was meeting their needs and helping in realising their life goals, and the 'void' of the familiar culture that they had left behind.

Although the participants expressed feeling financially safe in their host nation of Australia, they continued to think about and often returned to their countries of origin whenever possible; some ritualistically returned every two years. Relocating geographically and finding a new home did not result in being detached from their extended families in MZZ because, as evidenced through this study, participants continued to be a part of the everyday life situations in their countries of origin. Thus, supporting the theory of the DPTF.

Migrating to Australia, a developed country, meant that participants could gain employment and provide for their children as well as extended family members in MZZ, who expected to be assisted. Connections with extended families were kept alive because of the collectivist culture which relies heavily on the community for support, both financially and culturally (Afulani et al., 2016). It was this cultural connection and collectivist culture that had the greatest impact on how participants considered their EOL needs.

In addition to the issues identified about the area of origin in relation to the push factors in the decision to migrate, the migrant's destination can be as equally important and is referred to as the pull factors.

### **Pull Factors**

The pull factors for migration are based in the areas of destination and thus what attracts individuals to the countries they migrate. For example, these pull factors include employment and/or education opportunities (Krishnakumar & Indumathi, 2014; Urbański, 2022). Among these pull factors, Lee (1966) considers the intervening obstacles or factors that facilitate migration, such as selectivity, distance, ethnic barriers, cost of movement, and technological advances. For all participants in this study, they chose to migrate to Australia because there were opportunities available to them.

The factors that push individuals to leave their countries of origin are often the same factors that pull them to the area of destination. That is, the area of destination offers those elements that the area of origin does not. Some participants described that they selected to migrate to Australia to attain tertiary education because it was unattainable in MZZ. The participants considered the opportunity for education to be better in Australia than their country of origin, and the opportunity to gain employment after graduation also better. The participants also reported that their goal was to bring family into Australia to enable their children to also gain an education. Thus, the opportunity to study in Australia was perceived by participants, as a dream come true, to enable them to realise their long-term aspirations of a better life for themselves, their immediate family units, and also extended family members.

The collectivist cultural values also continued to play in participants' minds, and they thought settling in Australia would not just benefit their immediate family, but also their extended family members. For participants, migrating to Australia meant that they were not only going to have opportunities for education and employment but also to improve the lives of their extended family members by being able to support them financially. The financial support would enable extended family members to send their children to school, thus breaking the poverty chain, so prevalent in numerous families and communities in MZZ (Battersby & Watson, 2019; De La Fuente et al., 2017; Rock et al., 2016).

Although Lee (1966) discusses ethnic barriers in the area of destination as an obstacle to migration, this did not seem to have a negative impact on participants' plans to migrate to Australia. The combination of push and pull factors was sufficient to reach the decision to migrate. For example, while education was considered a push factor in the cause of migration, it also was a pull factor because the country of destination had what the country of origin did not have.



Education is considered something vital in MZZ. Since its introduction by the European missionaries in the British protectorates of Malawi and Zambia, and the colony of Zimbabwe (Oldham, 1929), western education has been perceived as of paramount importance by the populations in those localities (Kudakwashe & Richard, 2011; Michelo, 2018; Mwalimu, 2014). The introduction of education for ‘natives’, which the British saw as their responsibility to facilitate as colonial masters, was seen primarily as an advancement of the natives which would result in prosperity. Education for natives was also viewed as a pathway to establishing a world free from evils that beset humans such as “prejudice, fears, and wasteful competitions” (Rawson, 1931; Wallbank, 1934). In addition to fostering civilisation through education, there was a substantial economic benefit for the British, whose main interest was in the vast material resources on the continent which they thought educated natives would be beneficial in being trained as workers to extract the material resources for their economic gain and that by using health propaganda in schools, the natives would be more productive (Lugard, 1929).

This notion that education was the solution to all human problems, still is at play today, as found in this study that participants migrated in search of better education for their children which they perceived to be unavailable in their countries of origin. In addition, education obtained overseas is considered superior to one locally acquired, as students become globally mobile with the aim of having an employability advantage (Brux & Fry, 2010; Gaulee et al., 2020) thus alleviating poverty (Durstun & Nashire, 2001; Kapungwe, 2004; Mutasa, 2015; Thengela & Hendricks, 2020).

The findings of this study, confirm the existing literature in relation to how the participants perceive the role of education in an individual’s life and the assumption that an overseas education, was superior, to studying in their countries of origin. The participants who migrated to study can be considered as ‘globally mobile’ students, and it was clear they were

determined to acquire an education in Australia and provide similar opportunities for their children.

In Australia, when there are skills shortages, industries such as mines and health periodically conduct overseas skilled labour recruitment drives, including in MZZ (Department of Home Affairs, 2018). Skilled migrants can bring their families with them to Australia, unlike international students who cannot, at least until they have completed their degrees and found stable employment. Therefore, migration usually involves the individual migrating with their spouse and/or children (Lee, 1966), the goal of many migrants with the aim that the whole family unit would benefit from living, studying, and working in the selected country of destination, in this case, Australia.

### **Other factors**

Lee (1966) also explores another factor that leads to migration. Lee refers to this as sequential migration. That is, the children and spouses of migrants who are perceived to have little to no role in the decision-making for migration. According to Lee (1966), this factor for migration is significant in relation to further decisions being made while the family lives in the host country but not before migration.

In the current study, all participants came with their spouses, and all except one, came with their children. In contrast to Lee (1966), the decision to migrate for each of the participants was agreed upon by the entire family. For the seven participants who had one family member migrate first, with the rest of the family following later, it was evident that those left behind were anxiously waiting for the time when they would join their family member in Australia, which does indicate that they were part of the decision-making process of migrating to Australia. For 13 of the study participants, it meant that their children could experience a good life in Australia, attend school, and be able to enrol in tertiary education,

enabling them to be qualified to gain suitable employment and hopefully become financially independent. Both the 'push factor' from their country of origin and the 'pull factor' (Lee, 1966) towards Australia were experienced by all of the study participants.

While the participants were satisfied that they were in stable employment and thus able to financially assist the extended families in MZZ, they did not expect their children to do the same when they gained stable employment. This view about their children's level of responsibility towards extended family members was contrary to the participants' levels of responsibility, which to some extent indicates that they are in the process of moving away from their collectivist culture. Participants may have found it difficult to assume a non-collectivist cultural position because they did not know any other way of dealing with cultural situations and so, they chose to perpetuate what they were familiar with but did not force their children to continue with their culture. It also indicates that having lived in Australia for some time, participants understood the challenges of being present in both worlds and therefore, did not want their children to be in a similar position to theirs. However, there was an acknowledgment by these migrants that parenting in Australia was challenging, resulting in children not being raised according to their culture, thereby leading to a break in cultural expectations (Mugadza et al., 2021). The other possible reason for children following different values in relation to rendering assistance to extended family members may be as a result of acculturation which is usually more effective in individuals who migrated at a younger age (Van Hook & Glick, 2020). This meant that participants were uncertain about how to continue assisting their extended families back in MZZ, thus emphasising the DPTF that they were experiencing.

The Lee (1966) and the Duncan and Perrucci (1976) theories of migration are robust and provide general insight into the causes of migration however, these sociological theories do not address difficult issues of life such as what migrants were to do when faced with illness

or impending death. While confirming the Lee (1966) and the Duncan and Perrucci (1976) theories to be applicable in this current study, this study extends the migration theories by connecting them to grief and loss experienced by migrants. This study conducted through nursing and African migrant lenses illuminated the issues that migrants' exemplar MZZ, experience and how migration in itself impacts preparation for EOL. While the Lee (1966) and the Duncan and Perrucci (1976) theories of migration provide insight into the complexities of migrating in search of a suitable environment in which to settle, they do not go far enough. The two theories do not address issues of what happens to migrants once in the area of destination and the many challenges in relation to health, EOL, and death. This study went further by discussing not just complexities of the process of migration but, also the situations that migrants face in the host country, addressed issues that are difficult, issues that cannot be avoided as EOL and death are everyone's natural progression. The nursing lens applied in this study was beneficial because the sociological perspective has not identified the issues of EOL that this study presents. It is therefore contended that this study extended the migration theories by contributing on how migrants consider preparation for EOL while living in their new home as they engage in the DPTF. In relation to migration theories, there are other theories that highlight the plights and struggles of migrants attempting to fit in their new environment such as the nursing transition theories developed in nursing science.

### **Transition theories**

Transitions are said to be complex and multifaceted; they could be social or economic (Messias, 1997). These participants, who often shifted from professional status to student and from middle class to lower class, and facing limited employment opportunities, viewed transition from different perspectives which also affected how they viewed preparing for EOL. Individuals recognise that the transitions were stepping stones to achieving their goal, as was with the study participants. The current study was consistent with the temporality of

where participants were, at a given time in the DPTF. Messias (1997) identified that the transition was impacted by the congruency between what was known about the process individuals were going through and how they responded to what was expected. Participants had expected to have a continued type of lifestyle as they knew it in MZZ but that was not the case, accepting to move to what they perceived as lower status. The number of years spent in Australia had no impact in the participants' transition experience. Regardless of the period spent in Australia, they were all experiencing this temporal equilibrium on and off, hindering their planning for EOL. Messias et al. (1995) recognised that allocation of timeframe for transition was not possible because of the temporality of the phenomenon. Meleis et al (2000) also assert that migrants would periodically experience being in transition, consistent with the findings of the current study which found that participants' state of equilibrium was a temporal experience. The duration of equilibrium depended on how serene the situation was with the extended family in MZZ and the immediate family in Australia. This unstable state of equilibrium was capable of causing stress or a crisis.

The family stress and adaptation theory, which considers when individuals are in a crisis and stressful situation, offers further strategies for dealing with hardship (LoBiondo-Wood, 2008). While participants in this study did not view themselves as being in a crisis, the disintegrating family dynamics demonstrated participants being in a crisis experience. Therefore, it required developing competencies to aid them in recovery that is; reconceptualizing normal (Greif, 2014). While this theory calls for nurses to understand how families adjust to illness, it can help palliative and EOL care providers understand the DPTF and where the migrants are at, in self-transcendence and in the DPTF as a whole.

Self-transcendence, a concept theory that refers to expanding self (Reed, 2008), participants' decision to migrate and remodel self was a way of self-transcendence as they fused the past and the future to accomplish what was meaningful to them at present that is;

educate their children in Australia and help their extended families in MZZ. Yet the aspirations were not without hardships. They were vulnerable but chose to persist, trusting that the path they were taking was leading them to well-being for themselves and their families both in Australia and MZZ. In light of the DPTF, transition theories can illuminate further complexities faced by migrants and also guide to better strategies for care provision by healthcare providers.

This study therefore confirms these theories of migration and transition from study participants' experiences and reasons for choosing to migrate to Australia and demonstrates why participants experience the DPTF. To help fully appreciate the DPTF, it would benefit to first consider its elements in relation to the six categories that emerged from the data.

## **The Dynamic Process of Toing and Froing**

### **The Elements**

The DPTF is found in the six categories identified through the data as described in chapter four above: 1) remodelling self; 2) the disintegrating of family dynamics; 3) resetting the life button; 4) shuttling back and forth; 5) finding equilibrium; and 6) pursuing the horizon. Each of these categories is summarised below in relation to the findings above and the DPTF.

#### ***Remodelling self***

Remodelling self represents the shift that participants made in their personal lives to achieve the goals. Migration has played a role for migrants who wanted to remodel self. For migrants to achieve the goals they set out for themselves and their families, they needed to firstly set themselves up for migration. This has provided them an opportunity to live in

geographically distant locations from their original countries. However, to remodel self, required participants to leave their homes and get an education in Australia.

An overseas education is perceived as better than local education by many people in MZZ, and thus is considered as a way to remodel self: When acquired international credentials can in turn open many employment opportunities in the international labour market (Kamwendo, 2013; Masaiti, 2018). Thus, participants in this study viewed education in Australia to be their gateway to remodelling self, although it also required lifestyle changes and included challenges because of feeling detached from extended family.

### ***Disintegrating of Family Dynamics***

The disintegrating of family dynamics as identified in the current study depicts the feeling of losing the roots of culture in relation to behaviours, food, interactions with extended family, and not being able to engage in activities that were familiar to migrants. Half of the participants were separated from their families when they initially migrated to Australia. Whenever family members were separated there were feelings of disintegrating within the family unit, a phenomenon evidenced in the literature (Constant & Zimmermann, 2013; Prinz, 2019). For the participants, the disintegrating was also related to being separated from extended family members. Participants in this study came from collectivist cultures, which fostered community living. This supported the current literature which states that there are normally feelings of being separated not only from culture but also from family and that both the extended family members left behind and the migrants experience a sense of separation (Antman, 2013; Wali & Renzaho, 2018). Participants demonstrated attempts to maintain the same level of culture as at the time they emigrated from their countries of origin. However, this proved a challenge as they observed that their children were at different cultural levels because of assimilation into the Australian culture, further disintegrating family dynamics.

Separation is based on the feeling of loss and grief in the sense that it is based on how strong the person's attachment was with their family (Gindling & Poggio, 2012; Rusch & Reyes, 2013). For individuals who left their countries because of war, the feelings of separation may not be as strong compared to those experienced by individuals who migrated voluntarily (Doan et al., 2023; Gindling & Poggio, 2012), such as the participants of this study. However, the findings of this study are contrary to the available literature because all the study participants reported feelings of separation even though none of them were forced to migrate. The culture in which these participants were brought up, is such that the relationships with extended family are strong and these relationships are a means of support to them, something that is not available in Australia. The relationships with extended family are vital in that cultural setting because support is readily available when required, in relation to helping with children in the full sense of the African proverb - *It takes a village to raise a child*. That support with raising their children is not available in Australia, with participants relying on friendships formed in their new home country. However, this could not be relied on entirely because of differences in cultures, and the friends did not have as much time as required to assist in the lives of their children, resulting in raising, as Waitwika explained above, 'culturally half-baked' children who neither practice African culture nor Australian culture because they knew neither of the cultures. This results in frustration and disappointment and was evidence among nine of the participants. Additionally, the strong attachment with the extended family, combined with being away from them caused the feeling of wanting to go back to be with them, therefore there was the 'toing and froing' – the struggle between living away from extended family and pull factor of a desirable socioeconomic status offered by migration to Australia.

Migration for these participants was about their socioeconomic status, simply because remaining in their countries of origin, they had insufficient socioeconomic capabilities to



supply for their needs to live independent lives. Even though there was this strong attachment with extended family members, there was still the tension within participants between the strong bonds they had with their extended family members in MZZ and the desired ideal economic status. Because of this tension, participants were in a state of uncertainty which made it challenging for them to contemplate about planning for the future, thus emphasising the DPTF. There was also the issue of financially supporting extended family members in order to try and salvage the disintegrating relationships, to remain connected. These findings here confirm what has previously been identified in the body of literature in relation to financially supporting extended families not just in Africa, but also in Asia, to maintain connections and feel relevant (Baak, 2015; Ratha, 2016; Singh et al., 2012).

However, connections between the disintegrating of family dynamics and the challenges migrants from MZZ experience about forward planning for EOL has not been discussed in the literature before. The literature has demonstrated that culture is not static but evolves (Mesoudi, 2016; Whiten et al., 2011). Participants also realised that while they wanted to maintain the culture which they grew up with, they found themselves lost when they visited their countries of origin as they always found that things were different from the previous time, they visited due to the constant evolution of culture (Spencer-Oatey & Franklin, 2012; Whiten et al., 2011). Although participants had this desire to maintain their culture, they also felt that they needed to start afresh by *resetting the life button*.

### ***Resetting the Life Button***

Resetting the life button embodies the notion of starting life all over again in a new environment. Participants felt they had a life in Africa which they left behind to start a new one. Having arrived in Australia, participants began to focus on settling down to get a head start with life, to what migrants look forward to (Hugo, 2009; Jacubowicz, 2009). This

entailed finding a reasonably comfortable place to live, getting children into school, getting a mortgage, and buying a house as demonstrated in numerous studies (Glick, 2010; Jacubowicz, 2009; Murry & Fry, 2010). All participants found challenges with restarting their lives in Australia. Finding a comfortable place to live, at times sharing accommodation with one or two people, something they had never experienced before. Difficulties finding a place to live when a migrant first arrives in Australia are not unique to MZZ migrants. Other migrant communities from other African countries and, those from continents such as Asia, face similar challenges (Udah et al., 2019; Renzaho, 2019; Murry & Fry, 2010). Migrants find difficulties in the new environment after migration making it challenging to start a new life in an unfamiliar environment. Participants had to share a house with strangers to enable them to be able to afford rent. Financial burdens of paying education fees while paying rent was something these participants grappled with, forcing them to work long hours and often work two or three jobs to meet their financial obligations.

Settling was also challenging in relation to perceived change in social status. For instance, seven participants were using public transport during their initial months of arriving in Australia, although they were accustomed to driving a vehicle everywhere while in their countries of origin. Change in social status for migrants comes as a shock as they seek to adjust to a new way of living (Gatwiri et al., 2021; Glick, 2010; Rashid & Gregory, 2014). Participants also reported finding difficulties with working as well as managing their home chores because they relied on home helpers in their countries of origin, which was generally unavailable in Australia.

All participants reported experiencing cultural challenges, especially in relation to respect for elders and clothing choices. This confirms the literature that states that migrants find cultural challenges and experience cultural shock when they first arrive in the host country (Oji, 2013; Tabor & Milfont, 2011; Vergalli & Moretto, 2005; Wali & Renzaho, 2018). The

challenges were also evident in the current study. The challenges faced by participants in this study included the finding of appropriate work for the qualifications they possessed as well as parenting challenges in relation to different cultural values they were experiencing in Australia. Previous studies have also examined these issues of employment (Mwanri et al., 2012; Renzaho et al., 2011; UDAH et al., 2019) and cultural challenges (Renzaho et al., 2011).

Resetting the life button in Australia was dependant on reasons for migration for the participants and also not wanting to go back to the same reasons that motivated them to migrate in the first place. This meant that participants were ready to face any challenges in Australia and were determined to succeed. The beginning was challenging but participants were willing to continue to face those difficulties until they achieved their objectives for migrating to Australia, confirming previous studies which identified that migrants go through hardships while settling in the host society (Klokgieters et al., 2020; Rashid & Gregory, 2014). Resetting the life button was also determined by what was prevailing here in Australia. Bonds with family in Africa were still strong but there were also strong bonds here in Australia.

Participants migrated with their children, these children were now older and having families of their own. This created a pull and push within the minds of participants therefore, they required choosing between extended family members and children and grandchildren. The resetting of life button was not an easy task for participants, how do these participants see themselves in the future? There was a sense of not knowing which way to proceed with the future because the extended family bond was present while the participant was active and making meaningful financial contributions to the extended family. Once financial assistance ceased to flow, relationships could be strained, and the strong bonds weakened due to dissatisfaction by the extended family members, even to the point of rejection.

Resetting the life button was also challenging for participants as they reported that they were seen and treated differently compared to other people around them. The issue of racial profiling in Australia is well documented (Gatwiri & Anderson, 2022; Gatwiri et al., 2021; Mapedzahama & Kwansah-Aidoo, 2013; Udah, 2023). Sustained awareness for the whole community on the effects of racism and discrimination and appreciating that the other person is a member of the society, equally contributing to its wellbeing, maybe effective in altering people's perceptions. This requires determination and a concerted effort by the community to help shift the recent portrayals of African migrants as criminals operating in gangs (Majavu, 2020). Instead, to have the community consider the high number of African professionals of CaLD background across industries including health and palliative care, who are making a significant contribution (Fozdar, 2023). However, as noted from the current literature, the issue continues to exist with no end in sight. Participants reported that while they enjoyed living in Australia, they would not want to be cared for anywhere else apart from their own home, due to fear of racial discrimination. They also reported wanting to enjoy the best of both their original home and Australia, evidence of the shuttling back and forth between the two geographical locations.

### ***Shuttling back and forth***

Shuttling back and forth represents the constant moving back to MZZ and coming back to Australia mentally, emotionally, and physically as a result of the feeling of disintegrating from extended family. Migration is a complex phenomenon as migrants are 'torn away' from their familiar environment and communities and have settled far away from what they knew (Li, 2009). As participants sought to 'reset the life button', they stated that they felt a void within them in relation to extended family and culture. This void is the feeling of grief. Grief about what was lost as a result of migrating to Australia such as extended family members

and culture, confirming literature which identifies profound grief experienced by individuals who for one reason or another become separated from their culture (Lester, 2000). Although there was a sense of achievement that all participants reported having realised, grief was very evident in the way they expressed it. It was no longer easy to rely on extended family for physical assistance except monitory, conversations, and decision-making which assumes a different form; through technology such as mobile phones, emails and zoom. The loss and grief experienced through migration, may lead to complicated grief and loss like that identified among African refugees settled in Australia (Bryant et al., 2020): A grief and loss that may be associated with the lack of preparation for EOL care.

As indicated earlier, participants maintained strong bonds of attachment with extended families in Africa. However, the bond for their growing families in Australia placed them in an uncertain position where they have to consider which bonds were stronger and required more attention. Participants were still very attached to family in Africa therefore, deciding to invest their time and resources in both areas signifies a state of being unsettled, being unsure of how to plan for their future. Additionally, they were attempting to maintain relevance with extended families in MZZ by remitting money, building houses, starting up businesses, and participating in decisions being made in MZZ. All this was being carried out because of cultural beliefs that participants had about the significance of extended family in their lives.

Although participants felt secure in Australia in relation to their children's education, lifestyle and health, they were still attached to their extended families in their countries of origin because of the strong bonds that exist, forming transnational communities and families (Baldassar et al., 2014). As a result, participants were maintaining high levels of participation in both their countries of origin and Australia, being available to participate in decision-making for families back in MZZ, and the families in MZZ also participating in making decisions for participants living in Australia.

Participating in affairs in MZZ also involved financial assistance to extended family members in need, such as parents, siblings as well as uncles, nieces, and other more extended, and remotely participating in caring for the sick extended family members. The caring on the transnational level confirms what previous studies have found about maintaining relevance by assisting extended family members economically (Kilkey & Merla, 2014; Singh et al., 2012). Therefore, transnational families' setup plays a significant role in migrants' lives because when planning their lives here in Australia, they also consider their extended families in MZZ. Further evidence of the DPTF being at play.

In addition to being remotely available to assist extended families in MZZ, participants travel back to their countries of origin to keep the connections with culture and with the extended family members. Participants found themselves in an unbalanced state mentally and culturally, a state that gives rise to potential complex responses to terminal diagnosis and planning for EOL. Moreover, they face the challenges of the 'disintegration of family dynamics', 'resetting the life button', and the 'shuttling back and forth' which they need to overcome before they can start to contemplate EOL preparations in a state of equilibrium.

### ***Finding Equilibrium***

The state of equilibrium is when the individual feels settled within themselves, when they no longer feel the 'disintegrating of family dynamics' and they no longer view themselves as existing in both worlds that is; 'shuttling back and forth' but felt there was less need to struggle with culture because culture evolves (Whiten et al., 2011) meaning that even in MZZ, culture was not as it was at the time of their migration.

This core-category represents the state of comfort that participants are searching for, to feel settled after coming to terms with the new environment and the disintegration of family dynamics, which denotes a separation from extended family. The participants also felt a

disintegration from the culture that they were familiar with, the culture of communal living, collective decision-making, and cultural activities. Additionally, they needed to let go of high expectations for their ‘culturally half-baked’ children to practice their culture.

Migrants tend to visit their countries of origin every so often because they still have family back in Africa and have a special bond with them. They miss the people and culture, so they go back to experience the relationships and culture (Huang et al., 2013; Marschall, 2017). However, every time they go back, they find change, such as some family members may have died and there is a change in culture. Thus, the migrants find themselves in the middle between their original country and Australia, as they try to adjust between learning to live in Australia and still attempt to be a part of their original country’s culture; a confusing place to be in. This can lead to a new grief because of the perceived losses due to changing culture back in Africa (Solheim & Ballard, 2016).

In all that confusion, participants were constantly attempting to find equilibrium in community engagements and spiritual groups. Finding equilibrium is an important milestone to achieve in the DPTF. While the equilibrium stage allows participants to start thinking about how they would like to die well, reaching this stage does not imply that the DPTF is complete, and they could go forward in their planning. It just implies that participants could begin to think about preparing for EOL. However, this was dependent upon circumstances prevailing with their families in Australia and in MZZ, the thinking process would easily be abandoned when more immediate and pressing issues to attend to arose, necessitating reverting back into the DPTF. If a state of equilibrium can be sustained long enough, participants can find a place of comfort in relation to culture and collective decision-making, and about their ‘culturally half-baked’ children and any regrets about whether they made the right decision to migrate to Australia. At this level, pursuing the horizon becomes possible.

### *Pursuing the Horizon*

Pursuing the horizon represents a stage where the migrant has found an equilibrium in their emotional state. They are then able to see beyond their responsibilities in MZZ and in Australia that they can begin to consider their EOL vision.

Finding equilibrium in a place that is unfamiliar can be challenging with many factors to consider that can eventually lead the participants to prepare for their EOL in Australia. Talking about dying, was difficult at the beginning of the interviews with participants. Participants had to be constantly reminded that the topic was about dying. Many African cultures consider discussing death to be taboo (Burger et al., 2023; Ekore & Lanre-Abass, 2016) as a result, participants showed an unwillingness to complete an ACP for their EOL choices. Participants left the matter to their children, demonstrating the horizontal collectivist culture which uses community decision-making, at times, without the patient's involvement, a feature that is common with communities that practice such a culture (Ekore & Lanre-Abass, 2016; Hiruy & Mwanri, 2014).

These collectivist cultures mainly draw from the filial piety values that considers younger family members such as the individuals' children to be responsible for the care of elderly parents and other close extended family members (Chen et al., 2016; Li, 2009). However, such collectivist practices occur even in western culture when individuals get very old and frail, especially in cognitive impairment situations, although in most cases the process is planned and the decision makers are officially appointed as proxy or surrogate (Morrison et al., 2021; Spalding, 2021). Although participants were clear in their minds where they wanted to be cared for, and who should care for them when they were dying, they had not discussed with their loved ones because they considered it unnecessary to talk about such matters or even to write down their preferences. For these participants, they were still holding on to their culture of not worrying about what is to come because others would make those decisions for



them at the time. This demonstrates the continued DPTF that participants were going through as they still wanted to hold on to their culture where older family or community members make those decisions at the time, when the situation is at play. This process is contrary to expectations of the palliative and EOL care systems which emphasises that the individual actively participates in decision making for such important matters as EOL. The five elements come together to create the DPTF.

### **An Emergent Theoretical Model**

The inherent and extraneous elements embedded in the DPTF are discussed here, to give rise to a new understanding of the realities of participants in relation to preparing for EOL in Australia. This DPTF, represents the convoluted thought processes, the psychological, and social factors that impact migrants, which may act as a deterrent for thinking about the future. The enormity of these factors permits migrants to only focus on the present and the immediate future. It is an unstable process with no clear pattern or direction therefore, it is unpredictable and changing.

The evidence presented in this study demonstrates the multi-faceted tensions in the process of preparing for EOL in Australia for migrants from MZZ. When observed from an external position, the true reflection of the multi-faceted challenges may not be fully appreciated as these migrants struggle to assimilate while at the same time remain committed to their culture which comes with some responsibilities. While African migrants in Australia do not necessarily have insight into this DPTF, they acknowledge the starting and stopping, going back, and racing forward at times, as they attempt to start their lives all over again in a new environment. It is truly dynamic because it is not a linear process with a starting and finishing points; it is a convoluted, iterative process.

The DPTF distinguishes elements that interconnect participants' realities when considering how to prepare for EOL in Australia. To date, there has been an emphasis for cultural awareness for health care service providers, and migrants with CaLD background, to facilitate understanding of other cultures by health care workers, and of the health care system expectation by the migrants. Yet, culture and communication continue to be barriers to accessing palliative and EOL care by migrants (Clark, 2012; Department of Health and Aged Care, 2018; Palliative Care Australia, 2018). While there is an acknowledgment of the barriers, there have been no studies to illuminate the deep-rooted, unsettling situation within the CaLD migrant communities that plays a significant role in how they respond to palliative and EOL challenges.

Although there is limited research about how MZZ migrants prepare for EOL in Australia, this study clearly finds it to be interconnected with participants' culture. This study, therefore, addresses a gap in the literature in relation to complex perspectives of African migrants ageing and preparing for EOL in Australia, and contributes to the body of literature on the subject. Research has identified collectivist cultural practices among many indigenous communities around the globe (Hiruy & Mwanri, 2014; Shanmugasundaram & O'Connor, 2009; Uda et al., 2019) but has not linked the practice to EOL preparation. This study has found a link between the collectivist culture practiced by participants in the current study, and barriers to accessing palliative care. The collectivist cultural practice also acts as an impediment to objectively plan for EOL by study participants. Additionally, racism or fear of racism, also contributes to wishing to maintain low engagement with health care professionals, with most participants (12 out of 14) expressing a strong desire to depend heavily on family, that is children or extended family in MZZ.

The impact of the collectivist culture within which all participants were brought up in MZZ has enormous influence on how they view preparation for EOL. Collectivist values

prioritise family or community well-being over an individual's interests (Krassner et al., 2017). Arguably, it is suggested that collectivism is the force that exacerbates the disintegration of family dynamics participants are feeling about their culture and extended families, the struggle with resetting the life button, and the constant shuttling back and forth. Although the collectivist culture was attributed to be at the core of the impact of the disintegration of family dynamics, there was no congruence in the actions taken by participants in relation to migration. While on one hand there was great value placed in collective decision-making, it is not absolute, because not all decisions were made collectively. This suggests that there were levels of decision-making and different levels of family involvement. For instance, the decision to migrate, mainly concerned the nuclear family, while decisions about marriage or EOL are discussed with members beyond the nuclear family. Participants were unaware of this personal change of their own individualistic behaviours until they were asked if they consulted extended families on every decision they made about their lives such as, purchasing a new vehicle or, which school to send their child to. This might mean that the abstract decision-making which involves the basic decisions, are made subconsciously and at an individual level. The core decisions around death and dying are well tied to the cultural collective decision-making. Therefore, the participants are to a certain degree individualistic as they chose to migrate and live separately from their extended families, demonstrating a lack of insight and reflection on the changes. Consequently, choosing to leave their culture behind, resulted in raising 'culturally half-baked' children, an undesirable outcome. This was an indication of lack of personal insight which led to a belief that there was collectivism at play which would ensure that when faced with EOL, the family would come along and provide support.

The disintegrating of family dynamics causes stress, depression, and family dysfunction because of being away from extended family and familiar culture (Bullock, 2011; Mugadza et

al., 2021; Shavitt & Cho, 2016). This feeling also affects how individuals start their new lives in a new country. Additionally, it affects how migrants relate on a trans-national level, in relation to decision-making, and caring for extended family members left in MZZ, duties which they continue to perform as expected by their extended families. Participants of this study continued to avail themselves to their extended families in MZZ, suggesting that they were trying to bridge the disintegration of family dynamics and that they were still part of the community in MZZ.

There is a body of literature that discusses separation from extended family as being profound among migrant populations in relation to assimilation into a new culture and the stress that goes with it (Burholt et al., 2018; Rusch & Reyes, 2013). The feeling of disintegration can also suggest that the participants were brought up by extended family members, reinforcing the collectivist culture in participants, such as an obligation to return the favour by continuing to be part of the community.

While the sample in this study were well-educated with no language barriers, culture remained an issue as all participants reported missing culture and being worried about their children who have embraced the Western culture and apparently discarded theirs. The cultural orientation of participants' children raised questions in that participants did not expect that their children would or, should carry the same level of responsibility as their parents towards extended family members in MZZ. Although there was concern about participants' children losing culture, the emphasis was on these children setting up a future for themselves, suggesting that participants were 'toing and froing' on the issue of children as well. They were not sure about what they really wanted to see in their children in as far as culture was concerned. Interestingly, no literature was found relating to parents' cultural practice expectations of their children, indicating that it is an area that would benefit from investigation. However, there is literature that discusses migrants' children who migrate as

young children, toddlers or teenagers having no connections to their countries of origin because they assimilate effectively in the host country (Cunningham & King, 2018; Rumbaut, 2015). This is evident in this current study as participants reported that their children questioned them when participants attempted to reinforce their culture, which included connections with extended family members in MZZ.

This study found that ‘finding equilibrium’ was an essential milestone to reach before commencing preparation for EOL in Australia. However, even when participants found equilibrium, the ‘toing and froing’ continued, dependent on prevailing circumstances at the time, in relation to their immediate family members in Australia, as well as the situation with extended family members in MZZ. The state of equilibrium, therefore, is unstable because participants go in and out depending on the situation prevailing at a given time. Migration literature presents this instability as activities on the social field whose activeness are dependent on what is transpiring both in the country of origin and host country (Baldassar, 2016; Baldassar & Merla, 2015). Only one participant clearly demonstrated ‘equilibrium’ as he had embraced community in Australia as family. However, this participant still exhibited the ‘toing and froing’ by declining to plan for his future, wanting his children to take responsibility. All other participants reported wanting family to take responsibility for their care and decisions for EOL.

### *Similar Theories*

In comparison to the reasons for this study’s participants’ migration stories, it was clear that they were faced with some ‘push’ and ‘pull’ factors precipitating events for migration. This study resonates with both Lee’s (1966) and Duncan and Perrucci’s (1976) theories of migration in relation to participants’ reasons for migrating, as discussed above. In addition to the sociological theories of migration, a search for theories that would explain this ‘dynamic

process of toing and froing', clearly exhibited by the participants in relation to preparing for EOL in Australia, found two theories that resonate with this study, although not in totality. They are Nayar et al.'s (2012) navigating cultural spaces substantive theory, and Solheim et al.'s (2016) ambiguous loss theory. These two similar theories will be explained in brief.

**Navigating Cultural Spaces.** The theory of navigating cultural spaces Nayar et al., 2012) is one that sheds some light on the challenges migrants face in a new environment. Although this theory relates to women finding occupations and being able to fit in the society they had come to embrace, there are still differences, so much that these women navigate the spaces with caution (Nayar et al., 2012). The theory highlights the challenges Indian women migrants in New Zealand face in the workplace as they try to fit in. While the women were keen to identify with the local population, they faced challenges as they endeavoured to maintain a balance between New Zealand culture and Indian culture. As the Indian migrants navigated cultural spaces, they constantly moved between four dimensions of the Indian and New Zealand cultures which are the Indian, the New Zealand, the private, and the public dimensions (Nayar et al., 2012). Additionally, the migrants also considered appropriate ways to engage in private and public places as they participated in occupations in their host country. While these cultural dimensions were not obvious in this study, there are similar aspects such as cultural issues, a desire to associate with African migrants to create a community to the extent of surrogate families (Fozdar, 2023; Gatwiri & Anderson, 2021). The Indian dimension is consistent with study participants missing their culture and wanting to practice it at every opportunity.

**Ambiguous Loss.** The ambiguous loss theory possesses a framework that explains the complex and unique realities of transnational families (Solheim et al., 2016) which identifies

loss due to events such as death, as concrete and clear. On the contrary, the loss that results from cross-border separation from family is not clearly defined although it affects individuals' psychological well-being (Solheim & Ballard, 2016). This theory concentrates on the phenomenon of transnational families in relation to families in diaspora voluntarily separating from extended families in their countries of origin. The sense of loss from separation is so intense that migrants do everything in their power to maintain connections with family members in their countries of origin. The ambiguous loss concept identifies stress, emotional toll, and boundary ambiguity experienced by transnational families. The sense of loss is consistent with cumulative grief which impacts on individuals, leading to chronic stress (Bryant et al., 2020; Nyen & Tveit, 2018). This indicates that the adverse experiences affect both the migrant, and the extended family left behind. The feeling of loss in the migrant has implications for mental health.

### **End-of-Life Planning**

Having discussed the DPTF and its properties, considered the theories of migration (Duncan & Perrucci, 1976), the navigation of cultural spaces (Nayar et al., 2012), and the ambiguous loss (Solheim & Ballard, 2016) theories, it is evident that migrants and the process of adaptation need to be understood first, to be able to provide an acceptable palliative and EOL care service to them. Involving migrants of CaLD background at the strategic planning level is what is required to ensure the services being planned are culturally appropriate similar to strategies being implemented in indigenous primary health care (Smith et al., 2017).

Migrants go through a lot of situations in order to get where they are now, evidence of absolute commitment to having a better life for their families. Having come thus far, they now would like to die well in Australia, but they have some challenges to overcome, as

discussed above before they can consider how their preferred EOL care. These migrants come to the palliative and EOL care situation with the communal collectivist culture which emphasises caring for extended family, and they view the important decision-making process to be a family responsibility (Bullock, 2011; Hiruy & Mwanri, 2014) and not just the individual concerned. For that reason, participants find it perplexing to be asked about preparing for EOL because culturally for them, matters about death and dying are left to the people who are supporting the individual. In the absence of those extended family members, participants were left wondering how things might turn out when they were at the EOL stage. Others consider going back to Africa as a better option, to be looked after by their extended family members, where they believed they would be better understood. If they are unable to go back to Africa to be looked after by family, participants prefer to be cared for by church members or for those who had siblings in Australia, to be cared for by a sibling, to escape perceived racial prejudice when in institutional care. This is also confirmed by earlier studies that found that CaLD patients prefer family carers because of racial profiling (Eckemoff et al., 2018; Shanmugasundaram & O'Connor, 2009; Smith et al., 2009). Additionally, the current mainstream palliative and EOL care services on offer, do not adequately address the migrants' cultural needs due to limited awareness of the DPTF that migrants experience. There is need therefore to evaluate the current palliative and EOL care educational and intervention strategies to ensure they appropriately address the needs of the migrants.

Therefore, the emergent theoretical model of the DPTF advanced in this study through the use of grounded theory, elucidates and fuses together the complex elements of this model. The DPTF represents all of the linked together facets, that require to be accomplished in order to arrive at a starting point in preparations for EOL in Australia, for migrants from MZZ. Participants developed an awareness of this during their participation in this study, highlighting their actions and interactions in relation to the phenomenon of preparing for



EOL in Australia. The level of awareness and perspectives of preparing for EOL appeared to be highly influenced by participants' cultural backgrounds, the latter of which is unfamiliar to many palliative and EOL care providers.

Therefore, migrants come to the palliative situation with their culture, beliefs, spirituality, and how they have managed the transition to a new country overall. To provide person-centred care for these migrants means knowing and understanding their perspectives in relation to care for the dying. To open up the service, it requires being able to incorporate their culture in the care model which can be achieved by including the migrants as part of the stakeholders formulating the required strategies to achieve quality care provision.

It is, therefore, important to start from how health professionals are educated about culture and culturally appropriate care in the first place. Although there currently are issues being addressed by educators and healthcare providers (Bellamy & Gott, 2013; Clark, 2012; de Voogd et al., 2020), more needs to be done to adequately address the gap in knowledge and understanding of cultural principles. Educators of healthcare professionals need to be equipped with appropriate materials for education to address these cultural issues. Appropriate educational resources can be achieved by co-designing the curriculum with the concerned cultural groups.

### **Codesigning Educational Resources**

Healthcare professionals are expected to provide high-quality, person-centred care to all patients that seek their service, including palliative and EOL care (Department of Health and Aged Care, 2018). However, there are instances when this high-quality person-centred care is not achieved even in mainstream health care. This is compounded by the cultural diversity that exists in Australia (ABS, 2021), which makes it challenging to provide such care. From this study, it is contended that limited or lack of awareness by healthcare workers of the

DPTF that migrants experience needs to be understood to facilitate person-centred care during palliative and EOL care, including providing guidance for EOL preparation. A major challenge that participants faced was dealing with a health care system that is perceived to be unfriendly, a system that challenges their thinking in relation to decision-making about health-related choices and preferences. These challenges were a result of difficulties in assimilating into the Australian culture.

In considering co-designing educational resources for healthcare workers, it would be unachievable if professionals were expected to learn about every culture represented in Australia through the curriculum. Instead, the resources would be more of benefit if the emphasis were on cultural awareness and cultural competence which considers firstly, being aware of one's own culture (Berger, 1998; Oumlil & Balloun, 2017) and secondly, recognising that other people including patients may not share that culture (Alper, 2018; Payne et al., 2005). Therefore, simply asking migrants of CaLD background what help they need and how to provide the help, would ensure educational resources are tailored accordingly. This position facilitates respect for other cultures, prevents judging other cultural practices as being inferior, and maintains an openness to ask patients how they would like to proceed with their care culturally or spiritually. The education could therefore concentrate on building skills to identify patients with different cultures and equipping staff in how to proceed with cultural awareness while attending to patients with CaLD backgrounds. Recognising that migrants were in a process of adaptation is an important aspect to consider while co-designing educational resources because, migrants also need to develop an awareness of their responsibility to speak up about preferences so that healthcare professionals can provide appropriate care. Healthcare professionals' awareness of needs for cultural competency and migrants' realisation of their responsibility to speak up, is an ideal place of collaboration which needs to be encouraged.

The complexities of the DPTF reflects the ongoing shifting of thoughts, feelings, and actions which African migrants find necessary to proceed with the process. Migrating to Australia required a commitment to establish a new life in an unfamiliar environment, central to which was their desire to provide a better education for their children. Participants needed to settle and become established which required acculturation and adaptation (Nayar et al., 2012). The process of assimilation was hampered by cultural issues even though this cohort migrated by choice. Tabor and Milfont (2011) laid out the model of the psychology of the migration process and called it a behaviour change that precedes actual migration, explaining that the migrant starts to think and contemplate about migration in a precontemplation phase. This is followed by contemplation time when serious thought is given to the issue of possible migration, followed by action which leads to departure, and then acculturation which is the process resulting from intercultural contact in the host country (Eun-Hye, 2019). However, for participants in this study, this was not a linear process and though they made intercultural contact, it did not result in assimilation as they continued to miss their culture and extended families back in MZZ: Always looking back and wishing to be there and here at the same time.

Acquiring skills on how to address the barriers is key to opening accessibility to services by migrants. Once the healthcare workers acquire appropriate cultural knowledge and skills, they will be in a better position to provide quality care (Alper, 2018; Long, 2011).

Codesigning care intervention strategies will enhance the provision of quality person-centred care because it will be strategies that migrants will be familiar with. This in turn could bring harmony between palliative care workers and migrants and lead to better and increased access to palliative and EOL care services by the migrant community. On the other hand, migrants would be more likely to utilise/access services because they are part and parcel of the architectural work of the identified strategies for care. It could also be

anticipated that treatment and care will be accepted and adhered to because it will be care that the migrants are familiar with which in turn will be more acceptable to them.

Effective education on cultural matters would be more valuable and effective if resources in the curriculum were designed not only by educators tasked with reading research and applying it to curriculum development but also by involving the marginalised groups (Brand et al., 2021). Involving cultural groups to participate in curriculum development could enhance understanding issues faced by migrants and also what constitutes a better understanding of what to include, and equally, what to exclude in the curriculum to impart knowledge that would enable healthcare workers provide culturally appropriate care (Brand et al., 2021). The Virtual Roundtable for Collaborative Education Design model has shown that curriculum development involving all stakeholders including service users, yields better outcomes (Sbait et al., 2021). The roundtable discussions facilitate an understanding for both professionals and CaLD communities of the intertwined complexities related to migrants' perspectives of the Australian medical and palliative care services set up, and how to engage in a beneficial way with the healthcare system respectively. The understanding would provide a platform for cultural knowledge sharing which would be fundamental in creating educational materials.

### **Codesigning Service Interventions**

In addition to co-designing educational resources, is codesigning service interventions with service users, such as, migrant communities. Enabling migrants to be a part of the care intervention strategies team ensures that there are relevant strategies put in place (Mohamed Nazri et al., 2012; NSW Gov, 2023) using visualisation in participatory programmes (VIPP), a well-known participatory methodology. Codesigning interventions is important as seen with mental health lived experiences where participants in Bell et al.'s study reiterated "nothing

about us without us” (2023, p. 9). Therefore, codesigning interventions with service recipients results in usage of the designed service because stakeholders including service users, have brought their situations to the table and provided solutions. These service users also own those interventions which results in access and usage of the service because users feel the complexities of their situation are acknowledged and understood. Involving the concerned communities to achieve better outcomes is well documented (Sbait et al., 2021; Schwoerer et al., 2022). There are participatory methodologies that have been found very effective involving community to be part of the project that concerns them (Mohamed Nazri et al., 2012). In codesigning interventions, a number of cultural options for palliative EOL care could be made available to the migrants who could then pick and choose from the options. These culturally appropriate intervention strategies could then be made easily and readily available to migrants to introduce them to thinking about EOL early, which would enable them to identify where they are in the DPTF. By identifying that they were within this ‘toing and froing’ process, migrants could then be prompted to seek for information earlier, to not only assist them consider EOL preparation but examine their level of assimilation and acculturation.

### **Public Health Approach**

A public health approach is one that has been echoed by many writers including Kolcaba (2003) who asserted that synthesising community nursing principles with a community-based approach yields better outcomes. Comfort care is a holistic approach which reduces power struggle in the care patients seek from healthcare workers because the patient is at the centre of the decision-making process (Kolcaba, 2003). In light of that, using the comfort theory and DPTF theoretical model together, would ensure that the power that healthcare professionals often have over patients, is significantly reduced especially, during the decision-making

process about EOL preparation. Healthcare professionals need to understand where patients are at on the process so that they can assist them better.

A public health approach is thus recommended to reach migrants about the need to prepare for their EOL. Many programs have used this approach to get through to the target populations with the targeted message and it has been successful. Examples can be drawn from campaigns about smoking (Lizama et al., 2019; Vardoulakis et al., 2020), children's vaccinations (VanderEnde et al., 2017), and more recently COVID-19 vaccinations (Nemati-Anaraki et al., 2021), and infection prevention. Preparing for EOL by MZZ migrants in Australia can also benefit from public health campaigns with targeted messages for migrants. While the objective will not be to prevent death, it will be important for migrants from MZZ to hear the message about preparing for EOL. Health education is a "planned combination of learning experiences designed to predispose, enable, and reinforce voluntary behaviour decisions conducive to health in individuals, groups, or communities" (McKenzie et al., 2013, p. 219).

An integrated framework for assessing the value of community-based prevention proposes influencing norms and values through an informational environment. While the aim would not be for participants to change their values, CaLD communities would benefit from information transmitted through this way to inform them of the benefits of EOL planning which would help alleviate burdens left for their children to carry out any planning on behalf of their parents. This strategy can be used in the palliative care arena to sensitise and encourage the CaLD community to think about the years ahead and plan so that the burden of planning is not left to the children who may not have the same thoughts and preferences on how to care for their ageing and ailing parent. Health promotion in the area of palliative care for migrants can shift their thinking from the perception that the palliative care approach is solely a medical problem to understanding that the patient and their family are the unit of

care. Behaviour is heavily embedded in an individual's belief, therefore, to facilitate change (Evans et al., 2011), there needs to be a deliberate effort to understand the migrants' beliefs about preparing for EOL and formulate strategies to provide information, and that it is not aimed at changing their values.

## **Summary**

This Chapter 6 has discussed the emergent theory of the DPTF in light of the previous barriers experienced by MZZ migrants in accessing palliative and EOL care. This research has contributed to the existing literature on CaLD access to the latter through establishing a direct link to collectivist culture and the role it plays in discussions of death and dying, and not preparing for EOL in destination countries such as Australia. This study found this connection through the 'toing and froing' that participants were engaged in, which blocked their ability to plan for EOL.

It is therefore important for palliative care professionals to be aware of the DPTF that migrants from MZZ or elsewhere may be going through to be able to approach the participants with understanding and be able to assist in providing appropriate services for EOL preparation. Participants also need to gain an insight into their own cultural and identity changes, and not assume that they still hold on to the collectivist cultural foundations to the same degree as when they left MZZ: their positions have long since transitioned without their notice. The need for codesigning education resources and interventions is of paramount importance if palliative and EOL service users are to be comfortable with service utilisation. Professionals need to understand and be equipped with appropriate skills to enable them to provide person-centred care when attending to patients of CaLD backgrounds. Migrants would then be comfortable to access the services and get assistance in starting to plan for their EOL.

The study limitations and strengths, recommendations for future research, implications for education and policy, and application to clinical practice will be discussed in Chapter Seven.



# **Chapter 7: Recommendations and Conclusion**

## **Introduction**

The previous chapter focused on the interpretation of the study findings, linking the generated DPTF substantive theory to existing literature. This chapter brings the thesis to a close by presenting the recommendations and implications specifically for the support of migrants from MZZ regarding palliative and EOL care. This is followed by suggestions for future areas of research, implications for policy and practice, followed by an overview of the strengths and limitations of the study.

## **Recommendations**

Migration is a phenomenon that has been going on for many hundreds of years and is likely to continue as Australia, like other developed countries attracts international students, skilled migration (d'Aiglepierre et al., 2020) and demonstrates its humanitarian responsibility by providing a place for refugees to settle from around the globe (Ziaian et al., 2023). As migrants from MZZ make valuable economic and skills contributions to the society which has become their new home, and also as the population of migrants from other African countries increases, Australia must prepare for these migrants, as with the general population ageing, experience life-limiting and threatening illnesses, and potentially require palliative and EOL care services.

The findings of this study present challenges and many opportunities in areas of practice and research in relation to palliative and EOL care for migrants of CaLD background in general and specifically those from MZZ. The Australian government's commitment to providing culturally appropriate palliative and EOL care is evident (Palliative Care

Australia, 2018). However, the application of the DPTF in conjunction with established care strategies would enhance palliative and EOL care preparation by this population.

The DPTF substantive grounded theory generated in this study firstly, provides a roadmap to guide palliative care providers on how to proceed with supporting migrants from CaLD backgrounds in accessing services when needed and in seeking information and assistance on planning for EOL. It emphasises that care providers ought to first understand the DPTF that migrants are experiencing before they can render appropriate assistance. The DPTF substantive theory also provides the migrants with an eye-opener about the process they are engaged in. Understanding the process, they are in, as well as the importance of preparing for EOL, the migrants can seek assistance from palliative care services to start planning for their EOL. Secondly, there may be instances that migrants may require mental health services to work alongside palliative and EOL services to fully benefit from the assistance rendered to prepare for EOL.

Migration in itself is an enormous undertaking as migrants move from familiar environments to unfamiliar countries, with different cultures that are foreign to them. EOL planning is not an easy task when the migrants are required to forsake their culture, assimilate in the Australian culture, and seek assistance from institutions with EOL care values that are uncomfortable for them.

### **Future areas of research**

The current study focused on investigating how migrants from Malawi, Zambia, and Zimbabwe were preparing for the EOL in Australia and provided a basis for future studies. There is need to widen the participant pool to include other migrants of CaLD backgrounds to test and refine the DPTF theory. Additionally, the study also offers opportunities to explore how spouses influence each other in planning for EOL. This study included four couples

whose views of preparing for EOL were all different from their spouses. An exploration of couples on the impact such relationships have on preparing for EOL would be beneficial for palliative care professionals and the participants.

### **Implications for Policy**

As evidenced in this study, there are policies related to the provision of palliative and EOL care for people from CaLD backgrounds. The implication of the DPTF theory for policy is to adequately address the needs of migrants of CaLD background. It calls for those with the responsibility of designing or reviewing policy to understand this going and finding that migrants struggle with, and also, that the DPTF is a convoluted process that requires the sensitivity of policymakers and care providers. Policies and strategic plans specifically related to palliative and EOL care such as, the National Palliative Care Strategy, the National Palliative Care Standards, and the Western Australian EOL and Palliative Care Strategy would benefit from the study. These policies relate to ensuring culturally appropriate palliative and EOL care is delivered by healthcare professionals however, it is currently blurry as to what this care is all about, and how to provide it in a population with over 300 languages spoken in households (ABS, 2021).

The argument being presented here is that while there are some specifics in cultural appropriateness documented in relation to some cultures that have been in Australia for a much longer time and their populations are significant in number, the same cannot be said about others such as, migrants from MZZ. As with the codesigning of educational resources and healthcare interventions, policy would also benefit from the codesigning model. Community bodies such as the OACWA, the African Professionals of Australia, and other CaLD organisations, working hand-in-hand with for example, in WA the Office of Multicultural Interests, are well placed to represent the African community in the area of

healthcare policy development and review. The representation by the African CaLD community organisations would ensure that the element of cultural appropriateness is well articulated as they seek to review policies, strategic plans and guidelines for an eclectic approach to EOL and palliative care in Australia. The DPTF shows that each person is in a different place in their process of blending the old and new cultures. Therefore, care needs to be flexible to accommodate the changing needs and responses of the migrant who may soon be planning for (and facing) the EOL.

This study found that participants were far from starting to think about preparing for EOL in Australia. The involvement of African representatives would highlight ways in which African migrants would see the benefits and consider starting to plan and prepare for EOL early on, before they get to a stage where they have to make decisions in haste or a situation where they must leave decision-making for their EOL to their children or significant others. These proxy decision-makers may have different opinions, which sometimes leads to decisions made that are contrary to patients' preferences. A clear policy on what is required to provide culturally appropriate care to migrants from MZZ would help professionals care with confidence because they will know that they are providing appropriate care to all their patients. The findings of this study suggest that to be culturally appropriate, goes beyond knowing what palliative care patients of CaLD backgrounds would require in relation to what they prefer during care. It entails understanding where the patient is at, on the pendulum of the dynamic process of toing and froing and providing tools for professionals to use in supporting patients. There should also be a provision in the policy to encourage migrants to discuss and document Advance Health Directives/Advance Care Plans as soon as they can, and not wait until when they are unwell, to make decisions in a panic state.

## **Implications for practice**

Professionals attending to patients from CaLD backgrounds in particular those migrants from MZZ would be assisted to ensure the care provided is of high standard when guided by policy that acknowledges the DPTF theory. Professionals such as general practitioners as primary health care custodians, should provide palliative and EOL information to their patients and encourage them to think about the issue. The substantive theory generated in this study is one that can facilitate the provision of knowledge and information about available services and professionals that are available to assist the migrants with clarifying the process. It is therefore important for healthcare providers to be open to other cultures and to learn patients' preferences when in their care and not assume that there is one universally accepted culture that needs to be followed. The dynamic process of toing and froing substantive theory and other findings from other studies on palliative care related to CaLD background migrants needs to be used to provide much more tailored and nuanced policy and practice.

## **Limitations**

The study was designed to be rigorous and consistent with Charmaz's (2006) method of constructivist grounded theory. In addition, each study participant was required to participate in two interviews based on the findings of the pilot study. However, the planned two-week gap between the two interviews was not consistent due to the COVID-19 pandemic.

The COVID-19 pandemic brought about movement restrictions in Australia from 2020 to 2021. Recruitment of participants impacted the study as data collection occurred during the COVID-19 pandemic period. Western Australia experienced much longer travel and group gathering restrictions compared to other states. Depending on the number of daily COVID-19 infections, travel, and socialising restrictions were updated accordingly within the state. Restrictions were necessitated by the fast spread of the COVID-19 infections (Government,

2023). Western Australia experienced lockdowns in March to May 2020 and February to May 2021. During these lockdowns, only services deemed essential as per the Western Government's criteria were permitted to provide services, all other businesses were closed.

The COVID-19 situation brought challenges to the data collection because individuals were concerned about contracting the infection which would have meant they had to stay away from work for 14 days, a situation seen as financially challenging especially if they were casual employees. There were potential participants who because of fear of contracting COVID-19, stated that they would have participated if there was no risk of infection in the community. However, those who participated were happy that they were provided with an opportunity to talk about the issue of preparing for EOL in Australia. Some interviews had to be rescheduled for participants who experienced flu-like symptoms on their scheduled interview appointment day. One first interview was cancelled and could not be rescheduled because the potential participant, living in a household of five had contracted COVID-19 twice. It was difficult to determine when the household was to be free of COVID-19 infection. The rescheduling of interview appointments meant that some participants' second interviews were conducted more than two weeks after the initial interview, giving them more time to reflect on the subject of preparing for EOL. It is unclear if this variation in time between the first and second interviews had an impact on responses by study participants.

Another unexpected aspect of recruitment was that the study participants consisted of couples as well as the expected individuals. Sometimes these couples had completely different views about preparing for EOL in Australia. The variations in couples' views, added to the diversity and complexity of thinking about the subject and demonstrated that, although an individual may be in a close relationship such as having a spouse, they could still have a different way of looking at EOL matters. The couples that participated in the study were treated as individuals therefore, a decision was made not to investigate the couples in order to

fully explicate the grounded theory for individuals, as a person-centred approach. Another limitation was about the study having a small cohort, being limited to three African countries, MZZ, with close historical and cultural ties, and all participants were from professional backgrounds. Therefore, the findings of this study are not a representation of the voices of all African migrants across Australia. Additionally, professionals' perspectives on EOL may not represent the experiences of all African migrants even from MZZ. Lastly, being a novice grounded theorist was considered a limitation, but this was addressed by memo writing, supervisory meetings, and interactions with fellow research candidates as well as senior researchers who acted as research critical friends.

### **Strengths**

Despite some limitations, this study has many strengths which support the findings and conclusions presented. The professionalism with which this study was conducted, applying reflexivity by being aware and acknowledging my role in the process concerning prior experiences, assumptions, and beliefs that would influence the research process. In addition to reflexivity, theoretical sensitivity was also vital in maintaining an analytical stance which facilitated insights into what was meaningful. Theoretical sensitivity helped recognise and extract from the data relevant elements in the development of the theory of the dynamic process of toing and froing. Memoing my thoughts, feelings, ideas, and analytical insights as they emerged throughout the research process of data collection, coding, and analysis, was paramount. Memoing also enabled me to answer the question about what was happening in the data. Knowledge of the culture enabled me to relate well with study participants. Additionally, being an African migrant like the participants helped gain their trust. This enabled study participants to be open and genuine in their responses to the interview questions. Being aware of the study participants' cultures also enabled me to converse with

them in a culturally appropriate manner as I could understand cultural references and was able to respond promptly when required. The accent with which I spoke was another strength as I did not have to be frequently asked to repeat myself, nor did I request participants to repeat themselves because of not understanding their word pronunciations. Being able to clearly understand the participants' accents was a strength in trust and relationship building because they narrated their stories without many interruptions thereby, maintaining their thought processes.

Secondly, even though initially, the topic of preparing for EOL was not an easy one to discuss because it was new, something study participants had not thought about before, the pilot project enabled me to perceive that, participants needed more time to reflect on the subject. Therefore, to provide study participants with the time needed for reflection, it was decided that two interviews be conducted instead of one. Conducting two interviews, enabled participants to think deeply about the subject, which led to meaningful discussions in the second interview. Additionally, reflecting on the subject of EOL preparation, resulted in a degree of intervention as some participants decided to consider documenting their EOL wishes following the interview. These strengths give confidence that the findings of this study can be relied on.

Using the Constructivist grounded theory approach as the methodology in this study was another strength as the approach explored participants' different beliefs. The exploration of the phenomenon of preparing for EOL in Australia by MZZ migrants was complex but was made possible because of the constructivist approach which made it possible to look at data from different standpoints. The different participant perspectives on the phenomenon were important in understanding multiple realities, as they applied differently to each participant and were co-constructed with the participants through the constant comparative approach. Reaching such an understanding through a constructivist grounded theory methodology



approach helped me appreciate that each study participant was different and understand that participants had varied views and perceptions of reality.

## **Conclusion**

The purpose of this study was to explore perceptions of MZZ migrants in Australia in relation to preparing for EOL by asking the question, ‘How are migrants from Malawi, Zambia, and Zimbabwe preparing for end-of-life in Australia?’ The study objectives were; 1) describe the experience of migration and settling in Australia in relation to preparing for EOL; 2) examine family relationship structures and their impact on preparation for EOL; 3) describe the social processes of African migrants as they prepare for EOL; and 4) develop a substantive theory on preparing for EOL by migrants from MZZ living in Australia.

This constructivist grounded theory study explored the process of preparing for EOL by migrants from MZZ in Australia. Previous studies on palliative and EOL for people from CaLD backgrounds in Australia, focused on barriers that migrants have in accessing care when needed. There has been no time and resources allocated to exploring why the identified barriers continue to exist. This study has identified the Dynamic Process of Toing and Froing theory which explains the experiences of migrants and that which prevents them from settling, and accessing care, and, therefore, prevents them from starting planning for EOL.

The collectivist culture and collective decision-making was determined as a significant factor among study participants in relation to EOL planning. The migration experience, including the pull and push factors, plays an important role in how EOL preparation is viewed. Loss of culture and being away from extended family continues to play in their minds causing stress. Cumulative losses may lead to complicated grief; that is, living in a culture that is different from their own. This grief is also felt about children not adhering to the culture of the parents. The DPTF theory demonstrates the struggle that study participants

have, where they are satisfied with being in Australia, but at the same time, they are missing MZZ. The study participants were able to think and reflect deeply about their losses and what impact that had on their preparation for EOL, because of the opportunity provided to them by the second interview.

Modifying the traditional qualitative methodology by conducting two interviews, allowed study participants to reflect on the difficult, often considered taboo topic of EOL, exposing their position on the matter, and revealing how deeply rooted and loyal to extended family members study participants were. These issues result in the feeling of being unsettled by migrants and the need to be understood by care providers so as to better assist these migrants identify where they were in relation to the dynamic process of toing and froing. Once they identified where they were at in the toing and froing, migrants could be assisted to move forward and progress into considering EOL. This may require specialised healthcare services such as mental health, especially if the migrants were dealing with grief due to cumulative loss.

Migrants may need mental health support in addition to palliative and EOL care as they plan for their EOL. There is a need, therefore, to integrate more mental health, understanding, and skill into palliative care to assist with the impact of migration such as chronic grief, and chronic stress which result in poor quality of life, reduced life expectancy, and increased pain. A palliative care team whose members with a psychiatrist or psychologist would benefit patients with mental health symptoms and would help in relieving the identified symptoms of stress and pain, resulting in a better quality of life (Breitbart et al., 2000).

Codesigning educational resources for healthcare workers to help them appreciate and understand how CaLD background palliative and EOL patients would seek services because the approach would be acceptable to the service users. Additionally, codesigning care strategies and implementing them using the public health approach which is more focused on

prevention. However, in the palliative and EOL, the public health approach would not be on preventing death but, on ensuring that the patient's preferences were carried out because the individual would have prepared their EOL plan and laid down their preferences. This in turn would lift the burden of decision-making from children in Australia and extended family members in MZZ. Additionally, the family would be provided with written instructions on what to do, thereby preventing differences of opinion and in turn preventing family conflicts.

The dynamic process of toing and froing substantive grounded theory describes the process that migrants from MZZ were experiencing. One may be able to navigate through the process from disintegrating family dynamics, resetting life button, shuttling back and forth, finding equilibrium, to pursuing the horizon. While pursuing the horizon is the point where once achieved, the migrant is able to consider EOL matters, reaching that point is not a guarantee that they will not go backward. The process is not linear but convoluted and it takes migrants back and forth, between MZZ and Australia, depending on what was prevailing at any particular time in Australia and in MZZ in relation to family.

This study has demonstrated that qualitative researchers need to think beyond the traditional single-study participant interviews when exploring topics that are difficult and/or considered taboo. Conducting two interviews enabled participants to reflect deeply on the issue of preparing for EOL and think about their journey toward EOL, revealing to study participants and researcher the dynamic process of toing and froing that was in progress, and enabled a better understanding of the issues that have a bearing on planning for EOL.

Therefore, the dynamic process of toing and froing offers a way of understanding the African migrants' progress in their migration journey, and adaptation to a new way of life in Australia. This substantive grounded theory provides an explanation why the palliative and EOL care access barriers continue to exist, even though they have been identified through research projects over a substantial period of time. I argue that understanding the Dynamic

Process of Toing and Froing is the missing piece of the puzzle for migrants' timely access to palliative and EOL care services.

# References

- Afulani, P. A., Torres, J. M., Sudhinaraset, M., & Asunka, J. (2016). Transnational ties and the health of sub-Saharan African migrants: The moderating role of gender and family separation. *Social Science & Medicine*, 168, 63-71. <https://doi.org/10.1016/j.socscimed.2016.09.009>
- Allik, J., & Realo, A. (2004). Individualism-collectivism and social capital. *Journal of Cross - Cultural Psychology*, 35(1), 29-49. <https://doi.org/10.1177/0022022103260381>
- Alper, J. (2018). *A proposed framework for integration of quality performance measures for health literacy, cultural competence, and language access services : proceedings of a workshop*. The National Academies Press. <https://doi.org/10.17226/24918>
- Ancestry. (1895). *The Randall / Martin families and the first fleet*. Ancestry.com.
- Antman, F. M. (2013). The impact of migration on family left behind. *International Handbook on the Economics of Migration*(p 293).
- Australian Bureau of Statistics. (2021). *Population: Census*. <https://www.abs.gov.au/statistics/people/population/population-census/2021>.
- Australian Government the Treasury and Department of Home Affairs (2018). *Shaping a nation: Population growth and immigration over time*. Commonwealth of Australia, Canberra. [https://population.gov.au/sites/population.gov.au/files/2021-09/shaping\\_nation.pdf](https://population.gov.au/sites/population.gov.au/files/2021-09/shaping_nation.pdf)
- Australian Healthcare Associates. (2019). *Exploratory analysis of barriers to palliative care – Issues report on people from culturally and linguistically diverse backgrounds*. <https://www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-people-from-culturally-and-linguistically-diverse-backgrounds>
- Australian Institute of Health Welfare. (2022). *Suicide & self-harm monitoring: Deaths by suicide in Australia*. Australian Institute of Health and Welfare.
- Australia, P. C. (2018). National palliative care standards. *Canberra: Palliative Care Australia*.
- Baak, M. (2015). Transnational families, remittances, cieng and obligation for Dinka women in Australia. *Emotion, Space and Society*, 16, 123-129. <https://doi.org/10.1016/j.emospa.2014.08.001>
- Baldassar, L. (Ed.). (2016). *Mobilities and communication technologies: Transforming care in family life*. Palgrave Macmillan. <https://doi.org/10.1057/978-1-137-52099-9>.
- Baldassar, L., & Merla, L. (2015). Transnational families, migration, and the circulation of care. *family, life*.

- Baldassar, L., Kilkey, M., Merla, L., & Wilding, R. (2014). Transnational families. *The Wiley Blackwell companion to the sociology of families*, 155-175.
- Bartram, D., Poros, M., & Monforte, P. (2014). *Key concepts in migration*. Sage.
- Battersby, J., & Watson, V. (2019). *Urban food systems governance and poverty in African cities*. Routledge, Taylor & Francis Group.
- Bell, J., Lim, A., Williams, R., Girdler, S., Milbourn, B., & Black, M. (2023). 'Nothing about us without us': co-production ingredients for working alongside stakeholders to develop mental health interventions. *Advances in Mental Health*, 21(1), 4-16.  
<https://doi.org/10.1080/18387357.2021.2020143>
- Bellamy, G., & Gott, M. (2013). What are the priorities for developing culturally appropriate palliative and end-of-life care for older people? The views of healthcare staff working in New Zealand. *Health & Social Care in the Community*, 21(1), 26-34.  
<https://doi.org/10.1111/j.1365-2524.2012.01083.x>
- Benson, M., & Osbaldiston, N. (2014). New horizons in lifestyle migration research: Theorising movement, settlement and the search for a better way of life. In *Understanding lifestyle migration: Theoretical approaches to migration and the quest for a better way of life* (pp. 1-23). Springer.
- Berger, J. T. (1998). Culture and ethnicity in clinical care. *Archives of Internal Medicine*, 158(19), 2085-2090. <https://doi.org/10.1001/archinte.158.19.2085>
- Birks, M., & Mills, J. (2011). *Grounded theory: a practical guide*. SAGE Publications.
- Brand, G., Sheers, C., Wise, S., Seubert, L., Clifford, R., & Griffiths, P. (2021). A research approach for co-designing education with healthcare consumers. *Medical Education*, 55(5), 574-581. <https://doi.org/10.1111/medu.14411>
- Breitbart, W., Chochinov, H. M., & Passik, S. D. (2000). Psychiatric symptoms in palliative medicine. In G. H. D. Doyle, N. Cherny and K. Calman (Ed.), *Oxford Textbook of Palliative Medicine* (3rd ed., pp. 746-771). Oxford University Press.
- Brux, J. M., & Fry, B. (2010). Multicultural Students in Study Abroad: Their Interests, Their Issues, and Their Constraints. *Journal of Studies in International Education*, 14(5), 508-527.
- Bryant, A., & Charmaz, K. (2019). *The SAGE handbook of current developments in grounded theory*. SAGE Publications Ltd.
- Bryant, R. A., Edwards, B., Creamer, M., O'Donnell, M., Forbes, D., Felmingham, K. L., . . . Van Hooff, M. (2020). A population study of prolonged grief in refugees. *Epidemiology and psychiatric sciences*, 29, e44.
- Bullock, K. (2011). The Influence of culture on end-of-Life decision making. *Journal of Social Work in End-Of-Life & Palliative Care*, 7(1), 83-98.  
<https://doi.org/10.1080/15524256.2011.548048>

- Burger, H., Venter, M., Wearne, N., & Krause, R. (2023). Advance care planning in South Africa. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen*.
- Burholt, V., Dobbs, C., & Victor, C. (2018). Social support networks of older migrants in England and Wales: the role of collectivist culture. *Ageing and Society*, 38(7), 1453-1477. <https://doi.org/https://doi.org/10.1017/S0144686X17000034>
- Buzasi, K. (2016). Linguistic situation in twenty Sub-Saharan African countries: A survey-based approach. *African Studies*, 75(3), 358-380.
- Charmaz, K. (2000). Grounded theory in the 21st century: Applications for advancing social justice studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Handbook of Qualitative Research* (2nd ed., pp. 509-535). Sage
- Charmaz, K. (2006). *Constructing grounded theory: a practical guide through qualitative analysis*. Sage Publications.
- Charmaz, K. (2014). *Constructing grounded theory* (2nd edition. ed.). Sage.
- Chen, W. W., Wu, C. W., & Yeh, K. H. (2016). How parenting and filial piety influence happiness, parent-child relationships and quality of family life in Taiwanese adult children. *Journal of Family Studies*, 22(1), 80-96.
- Chilunjika, A. (2021). Revamping the Zimbabwe Anti-Corruption Commission (ZACC). *African Journal of Business & Economic Research*, 16(2).
- Chuang, E., Hope, A. A., Allyn, K., Szalkiewicz, E., Gary, B., & Gong, M. N. (2017). Gaps in provision of primary and specialty palliative care in the acute care setting by race and ethnicity. *Journal of pain and symptom management*, 54(5), 645-653. <https://doi.org/10.1016/j.jpainsymman.2017.05.001>
- Clandinin, D. J. (2007). *Handbook of narrative inquiry: Mapping a methodology*. SAGE Publications.
- Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. Jossey-Bass.
- Clark, D. (2012). Cultural considerations in planning palliative and end of life care. *Palliative Medicine*, 26(3), 195-196. <https://doi.org/10.1177/0269216312440659>
- Clarke, A. E. (2005). *Situational analysis: Grounded theory after the postmodern turn*. Sage Publications.
- Clarke, A. E. (Ed.). (2019). *Situating grounded theory and situational analysis in interpretive qualitative inquiry*. SAGE Publications Ltd.
- Cobbing, J. (1988). The Mfecane as Alibi: Thoughts on dithakong and mbolompo1. *The Journal of African History*, 29(3), 487-519.
- Constant, A. F., & Zimmermann, K. F. (2013). 14 Immigrants, ethnic identities and the nation-state. *International Handbook on the Economics of Migration*, 259.

- Corbin, J. M., & Strauss, A. (2007). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. SAGE Publications.
- Corbin, J. M., & Strauss, A. L. (2015). *Basics of qualitative research: techniques and procedures for developing grounded theory* (Fourth edition. ed.). SAGE.
- Creswell, J. W. (1998). *Qualitative inquiry and research design: choosing among five traditions*, Sage Publications.
- Creswell, J. W. (2009). *Research design: qualitative, quantitative, and mixed methods approaches* (3rd ed. ed.). Sage.
- Creswell, J. W. (2013). *Qualitative inquiry & research design: choosing among five approaches* (Third edition. ed.). SAGE Publications.
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: qualitative, quantitative, and mixed methods approaches* (Fifth edition. ed.). SAGE Publications, Inc.
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry & research design: choosing among five approaches* (Fourth edition. ed.). SAGE.
- Crotty, M. (1998). *The foundations of social research: meaning and perspective in the research process*. Allen & Unwin.
- Cunningham, U., & King, J. (2018). Language, ethnicity, and belonging for the children of migrants in New Zealand. *SAGE Open*, 8(2), 2158244018782571.
- Currie, T. E., Meade, A., Guillon, M., & Mace, R. (2013). Cultural phylogeography of the bantu languages of sub-Saharan Africa. *Proc Biol Sci*, 280(1762), 20130695. <https://doi.org/10.1098/rspb.2013.0695>
- d'Aiglepierre, R., David, A., Levionnois, C., pielvogel, G., Tuccio, M., & Vickstrom, E. (2020). *OECD social, employment and migration working papers*. OECD.
- de Filippo, C., Bostoen, K., Stoneking, M., & Pakendorf, B. (2012). Bringing together linguistic and genetic evidence to test the Bantu expansion. *Proc Biol Sci*, 279(1741), 3256-3263. <https://doi.org/10.1098/rspb.2012.0318>
- De La Fuente, A., Rosales, M., & Jellema, J. R. (2017). The impact of fiscal policy on inequality and poverty in Zambia. *World Bank policy research working paper* (8246).
- de Voogd, X., Oosterveld-Vlug, M. G., Torensma, M., Onwuteaka-Philipsen, B. D., Willems, D. L., & Suurmond, J. L. (2020). A dignified last phase of life for patients with a migration background: A qualitative study. *Palliative Medicine*, 34(10), 1385-1392. <https://doi.org/10.1177/0269216320948708>
- Denzin, N. K., & Lincoln, Y. S. (2000). *Handbook of qualitative research* (2nd ed. ed.). Sage Publications.



- Denzin, N. K., & Lincoln, Y. S. (2005). *The SAGE handbook of qualitative research* (3rd ed. ed.). Sage Publications.
- Department of Health and Aged Care. (2018). *The national palliative care strategy 2018*. Australian Government. <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>
- Department of Home Affairs (2018). *Shaping a nation: Population growth and immigration over time*. The Treasury, Australian Government, Canberra, [https://population.gov.au/sites/population.gov.au/files/2021-09/shaping\\_nation.pdf](https://population.gov.au/sites/population.gov.au/files/2021-09/shaping_nation.pdf)
- Doan, T., Nghiem, N., & Doan, N. (2023). Free versus regulated migration: Comparing the wages of the New Zealand-born, other migrants and the Australia-born workers in Australia. *International Migration*, 61(2), 297(231).
- Drescher, S. (2010). *Econocide: British slavery in the era of abolition*. Univ of North Carolina Press.
- Duncan, R. P., & Perrucci, C. C. (1976). Dual occupation families and migration. *American Sociological Review*, 41(2), 252-261.
- Durston, S., & Nashire, N. (2001). Rethinking poverty and education: an attempt by an education programme in Malawi to have an impact on poverty. *Compare: A Journal of Comparative and International Education*, 31(1), 75-91.
- Eckemoff, E. H., Sudha, S., & Wang, D. (2018). End of life care for older Russian immigrants - Perspectives of Russian immigrants and hospice staff. *Journal of Cross-Cultural Gerontology*, 33(3), 229-245. <https://doi.org/10.1007/s10823-018-9353-9>
- ECU Research Data Management Policy, (2017).
- Edhlund, B. M., & McDougall, A. G. (2019). *NVivo 12 essentials: your guide to the world's most powerful data analysis software*. Form & Kunskap, AB.
- Ekore, R., & Lanre-Abass, B. (2016). African cultural concept of death and the idea of advance care directives. *Indian Journal of Palliative Care*, 22(4), 369-372. <https://doi.org/10.4103/0973-1075.191741>
- Elliott, M. (2019). No. 1 / Slavery, Power and the Human Cost 1455 - 1775. (SpecialSections). *The New York Times*, 5(L).
- Erikson, E. H., & Erikson, J. M. (1997). *The life cycle completed* (Extended version / ed.). W.W. Norton.
- ESV Bible. (2008).
- Eun-Hye, G. Y. (2019). Does acculturation matter? End-of-life care planning and preference of foreign-born older immigrants in the United States. *Innovation in Aging*, 3(2). <https://doi.org/10.1093/geroni/igz012>

- Evans, D. R. N., Coutsaftiki, D., & Fathers, C. P. (2011). *Health promotion and public health for nursing students*. Learning Matters.
- Fang, X., Kothari, S., McLoughlin, C., & Yenice, M. (2020). The economic consequences of conflict in Sub-Saharan Africa.
- Faulkner, W. (1966). *The sound and the fury*. Chatto & Windus.
- Feldman, R. S. (2019). *Development across the life span* (Ninth Edition. ed.). Pearson.
- Fjelland, R., & Gjengedal, E. (1994). A theoretical foundation for nursing as a science. *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness*, 3-25.
- Flick, U. (2018). Doing grounded theory. *Doing grounded theory*, 1-176.
- Fozdar, F. (2023). Belonging in the land down under: Black Africans in Australia. *International Migration*, 61(1), 23-38.
- Frayser, D. W., Wolpoff, M. H., Thorne, A. G., Smith, F. H., & Pope, G. G. (1993). Theories of modern human origins: The paleontological test. *American Anthropologist*, 95(1), 14. <https://doi.org/10.1525/aa.1993.95.1.02a00020>
- Fulton, R., & Fulton, J. (2019). A psychosocial aspect of terminal care: Anticipatory grief 1. in *caring relationships* (pp. 87-96). Routledge.
- Gatwiri, K., & Anderson, L. (2022). *Afrodiasporic identities in Australia: Articulations of blackness and Africanness*. Springer.
- Gatwiri, K., Mwanri, L., & McPherson, L. (2021). Afro-diasporic experiences of highly skilled Black African immigrants in Australia. *Australian Social Work*, 74(4), 480-491.
- Gaulee, U., Sharma, S., & Bista, K. (2020). *Rethinking education across borders : emerging issues and critical insights on globally mobile students*. Springer. <https://doi.org/10.1007/978-981-15-2399-1>
- Gergis, J., Brohan, P., & Allan, R. (2010). The weather of the first fleet voyage to Botany Bay, 1787–1788. *Weather*, 65(12), 315-319.
- Ghosh, B. N. (2002). *Scientific method and social research* (Revised ed.). Stirling Publishers Pvt. Ltd.
- Gibbons. (1916). *New Map of Africa (1900-1916): A History of European colonial expansion and colonial diplomacy*. Unspecified.
- Gindling, T. H., & Poggio, S. (2012). Family separation and reunification as a factor in the educational success of immigrant children. *Journal of Ethnic and Migration Studies*, 38(7), 1155-1173. <https://doi.org/10.1080/1369183X.2012.681458>

- Glaser, B. G. (1978). *Theoretical sensitivity: advances in the methodology of grounded theory*. Sociology Press.
- Glaser, B. G. (1992). *Emergence vs forcing basics of grounded theory analysis*. Sociology Press.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research* (8th pr. ed.). Aldine.
- Griffiths, I. (1986). The scramble for Africa: Inherited political boundaries. *The Geographical Journal*, 152(2), 204-216.
- Grollemund, R., Branford, S., Bostoen, K., Meade, A., Venditti, C., & Pagel, M. (2015). Bantu expansion shows that habitat alters the route and pace of human dispersals. In *Proceedings of the National Academy of Sciences* (Vol. 112, pp. 13296-13301).
- Guba, E. G. (1990). *The Paradigm dialog*. Sage Publications.
- Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Sage Publications.
- Hallberg, L. R. (2006). The “core category” of grounded theory: Making constant comparisons. *International Journal of Qualitative Studies on Health and Well-being*, 1(3), 141-148.
- Han, H., Jung, Y. M., & Xiong, X. (2019). *The ageing of Australian ethnic minorities*. Palgrave Pivot. <https://doi.org/10.1007/978-981-13-2796-4>
- Healey, J. (2007). *Immigration and citizenship*. Spinney Press.
- Heger Boyle, E., & Ali, A. (2010). Culture, structure, and the refugee experience in Somali immigrant family transformation. *International Migration*, 48(1), 47-79.
- Hirschman, C. (2004). The Origins and demise of the concept of race. *Population and Development Review*, 30(3), 385-415.
- Hiruy, K., & Mwanri, L. (2014). End-of-life experiences and expectations of Africans in Australia: cultural implications for palliative and hospice care. *Nursing ethics*, 21(2), 187-197. <https://doi.org/10.1177/0969733012475252>
- Huang, W.-J., Haller, W. J., & Ramshaw, G. P. (2013). Diaspora tourism and homeland attachment: An exploratory analysis. *Tourism Analysis*, 18(3), 285-296.
- ILO. (2021). *ILO Global estimates on international migrant workers - Results and methodology*.
- Immigration and citizenship. (2021). *Parliamentary library: Student visa, guide for overseas students*. Department of Home Affairs.
- International Monetary Fund. (2022). *African century*. <https://www.imf.org/en/Publications/fandd/issues/2023/09/PT-african-century>

- International Organisation for Migration. (2020). *World migration report* (PUB2019/006/L WMR 2020). U. Nations. [https://www.un.org/sites/un2.un.org/files/wmr\\_2020.pdf](https://www.un.org/sites/un2.un.org/files/wmr_2020.pdf)
- Jakubowicz, A. (2009). Australia's migration policies: African dimensions [Background paper for AHRC African Australians Project]. 1-18.
- Janssens, M. J. P. A. (2001). *Palliative care: Concepts and ethics*. Nijmegen: Nijmegen University Press.
- Jensen, L. A. (2015). *The Oxford handbook of human development and culture: an interdisciplinary perspective*. Oxford University Press.
- Jeon, Y. (2004). The application of grounded theory and symbolic interactionism. *Scandinavian Journal of Caring Sciences*, 18(3), 249-256.
- Jovanovic, M. (2012). Cultural competency and diversity among hospice palliative care volunteers. *The American journal of hospice & palliative care*, 29(3), 165-170. <https://doi.org/10.1177/1049909111410415>
- Kamwendo, G. (2013). Malawi: Contemporary and critical issues. *Education in Southern Africa*, 103.
- Kapungwe, A. (2004). Poverty in Zambia: Levels, patterns and trends. *Development Southern Africa*, 21(3), 483-507.
- Khoo, S.-E., McDonald, P. F., & Hugo, G. (2005). *Temporary skilled migrants in Australia: Employment circumstances and migration outcomes*. Canberra: DIMIA.
- Kilkey, M., & Merla, L. (2014). Situating transnational families' care-giving arrangements: the role of institutional contexts. *Global Networks*, 14(2), 210-229.
- Klokgieters, S. S., Van Tilburg, T. G., Deeg, D. J. H., & Huisman, M. (2020). The linkage between aging, migration, and resilience: Resilience in the life of older Turkish and Moroccan immigrants. *The Journals of Gerontology: Series B*, 75(5), 1113-1123.
- Koekkoek, J. A., Chang, S., & Taphoorn, M. J. (2016). Palliative care at the end-of-life in glioma patients. *Handbook of clinical neurology*, 134, 315-326.
- Kolcaba, K. (2003). *Comfort theory and practice: a vision for holistic health care and research*. Springer Pub. Co.
- Krassner, A. M., Gartstein, M. A., Park, C., Dragan, W. L., Lecannelier, F., & Putnam, S. P. (2017). East-west, collectivist-individualist: A cross-cultural examination of temperament in toddlers from Chile, Poland, South Korea, and the U.S. *European Journal of Developmental Psychology*, 14(4), 449-464. <https://doi.org/10.1080/17405629.2016.1236722>
- Krishnakumar, P., & Indumathi, T. (2014). Pull and push factors of migration. *Global Management Review*, 8(4).

- Kudakwashe, M. A., & Richard, B. (2011). Education for all: Issues and challenges: The case for Zimbabwe. *International Journal of Social Sciences & Education*, 1(4).
- Lally, M., & Valentine-French, S. (2019). *Lifespan development: A psychological perspective* (Second edition. ed.). College of Lake County.
- Lee, E. S. (1966). A theory of migration. *Demography*, 3(1), 47-57.
- Lester, J. C. (2000). *Strangers in their own land: Culture loss, disenfranchised grief, and reentry adjustment*. Graduate School.
- Li, J. (2009). Forging the future between two different worlds: Recent Chinese immigrant adolescents tell their cross-cultural experiences. *Journal of Adolescent Research*, 24(4), 477. <https://doi.org/10.1177/0743558409336750>
- Lugard, F. D. (1929). *The dual mandate in British Tropical Africa* (Vol. 60). Blackwood & Sons.
- MacCulloch, M. (1951). *The Southern Lunda and related peoples: (Northern Rhodesia, Belgian, Congo, Angola)*. International African Institute.
- Majavu, M. (2020). The ‘African gangs’ narrative: Associating blackness with criminality and other anti-black racist tropes in Australia. *African and Black Diaspora: An International Journal*, 13(1), 27-39.
- Mapedzahama, V., & Kwansah-Aidoo, K. (2013). Negotiating diasporic black African existence in Australia: A reflexive analysis. *Australasian Review of African Studies*, 34(1), 61-81.
- Marschall, S. (2017). Transnational migrant home visits as identity practice: The case of African migrants in South Africa. *Annals of Tourism Research*, 63, 140-150.
- Masaiti, G. (2018). *Education in Zambia at fifty years of independence and beyond: History, current status and contemporary issues*. Unza Press.
- Masaiti, G., & Chita, J. (2014). Zambia: An overview of formal education. *Education in East and Central Africa*, 423, 1-10.
- Mason, R. (2013). Remembering the family home: emotions, belonging, and migrant men in multicultural Australia. *Journal of Australian Studies*, 37(3), 378-389.
- Mayaux, P., Bartholomé, E., Fritz, S., & Belward, A. (2004). A new land-cover map of Africa for the year 2000. *Journal of biogeography*, 31(6), 861-877.
- Mazrui, A. A. (1986). *The Africans: a triple heritage*. BBC Publications.
- McAuliffe, M., Abel, G., Ocho, L. a., & Sawyer, A. (2022). 7 International migration as a stepladder of opportunity: What do the global data actually show? *World Migration Report*, 2022(1). <https://doi.org/10.1002/wom3.28>

- McGovern. (2017). *Capturing the lived experience: Getting started with interpretive phenomenology research*. Sage Publications Ltd.  
<http://methods.sagepub.com/case/capturing-lived-experience-interpretive-phenomenology-research>
- McKenzie, J. F., Neiger, B. L., & Thackeray, R. (2013). *Planning, implementing, and evaluating health promotion programs: a primer* (6th ed. ed.). Pearson.
- Massoudi, A. (2016). Cultural evolution: a review of theory, findings and controversies. *Evolutionary biology*, 43, 481-497.
- Michelo, S. (2018). How Zambia's social protection services and programmes helped mitigate inequality and reduce poverty.
- Mintz, S. (2022). Historical context: Facts about the slave trade and slavery. *The Gilder Lehrman Institute of American History*. Retrieved on, 20.
- Mohajan, D., & Mohajan, H. (2022). Classic grounded theory: A qualitative research on human behaviour.
- Mohamed Nazri, M., Sulastri, S., Nur Afni, A., Sazaroni, M., Haslina, H., Maizurah, O., . . . Ahmad Shalihin, M. (2012). Role of Visualisation in Participatory Programme (VIPP) in Engaging Youth and School Children in Health Promotion Activities: A Four-Year Experience in Malaysia. International Social Work Conference. Malaysia,
- Morrison, R. S., Meier, D. E., & Arnold, R. M. (2021). What's wrong with advance care planning? *Jama*, 326(16), 1575-1576.
- Morse, J. M., & Clark, L. (Eds.). (2019). *The nuances of grounded theory sampling and the pivotal role of theoretical sampling*. SAGE Publications Ltd.
- Morse, J. M., & Field, P.-A. (1995). *Qualitative research methods for health professionals* (2nd ed. ed.). Sage Publications.
- Mugadza, H. T., Akombi, B. J., Tetteh, V. W., Stout, B., & Renzaho, A. M. N. (2021). Engaging sub-Saharan African migrant families in Australia: broadening definitions of family, community, and culture. *Community, Work & Family*, 24(4), 435-454.
- Mutasa, F. (2015). The future of the basic education assistance module: A poverty alleviation strategy in Zimbabwe. *Journal of Public Administration and Governance*, 5(3), 155-164.
- Mwalimu, M. (2014). Education and the economy: Achievements and shortfalls in independent Zambia, 1964–2014. *Journal of Southern African Studies*, 40(5), 1091-1108.
- Mwanri, L., Hiruy, K., & Masika, J. (2012). Empowerment as a tool for a healthy resettlement: a case of new African settlers in South Australia. *International Journal of Migration, Health and Social Care*, 8(2), 86-97.

- Nayar, S., Hocking, C., & Giddings, L. (2012). Using occupation to navigate cultural spaces: Indian immigrant women settling in New Zealand. *Journal of Occupational Science*, 19(1), 62-75. <https://doi.org/10.1080/14427591.2011.602628>
- New South Wales Government (2023). Co-design toolkit: Agency for clinical innovation. Retrieved from: <https://aci.health.nsw.gov.au/projects/co-design>
- Ngcobo, S. (1953). The Bantu peoples. In *The South African way of life: Values and ideals of a multi-racial society* (pp. 48-69). Columbia University Press. <https://doi.org/doi:10.7312/calp94192-007>
- Nyen, S., & Tveit, B. (2018). Symptoms without disease: Exploring experiences of non-Western immigrant women living with chronic pain. *Health Care for Women International*, 39(3), 322-342. <https://doi.org/10.1080/07399332.2017.1370470>
- Oji, K. (2013). *Managing culture shock and conflict: Creative strategies of African immigrants in the city of Philadelphia* [Fielding Graduate University].
- Oldham, J. H. (1929). Report of the commission on the closer union of the Eastern and Central African Dependencies. *Journal of the Royal Institute of International Affairs*, 8(3), 227-259.
- Omer-Cooper, J. D. (1993). Has the Mfecane a future? a response to the Cobbing critique. *Journal of Southern African Studies*, 19(2), 273-294. <https://doi.org/10.1080/03057079308708360>
- Oumlil, A. B., & Balloun, J. L. (2017). Cultural variations and ethical business decision making: a study of individualistic and collective cultures. *The Journal of Business & Industrial Marketing*, 32(7), 889-900. <https://doi.org/10.1108/JBIM-08-2016-0194>
- Pakenham, T. (1992). *The scramble for Africa: 1876-1912*. Abacas.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3 ed. ed.). Sage Publications.
- Payne, S., Chapman, A., Holloway, M., Seymour, J. E., & Chau, R. (2005). Chinese community views: Promoting cultural competence in palliative care. *Journal of Palliative Care*, 21(2), 111-116.
- Phillips, J., & Spicks, H. (2012). *Skilled migration: Temporary and permanent flows to Australia; Parliament of Australia: Canberra, Australia*
- Phiri, G. G., Muge-Sugutt, J., & Porock, D. (2023). Palliative and end-of-life care access for immigrants living in high-income countries: A scoping review. *Gerontology and Geriatric Medicine*, 9, 1-13 DOI: 10.1177/23337214231213172
- Pink, S., Fors, V., Lanzeni, D., Duque, M., Strengers, Y., & Sumartojo, S. (2022). *Design ethnography: research, responsibility, and futures*. Routledge. <https://doi.org/10.4324/9781003083665>



- Polit, D. F., & Beck, C. T. (2006). *Essentials of nursing research: methods, appraisal, and utilization* (Sixth edition. ed.). Lippincott Williams & Wilkins, a Wolters Kluwer Company.
- Polit, D. F., & Beck, C. T. (2013). *Essentials of nursing research: appraising evidence for nursing practice* (8th ed. ed.). Wolters Kluwer/Lippincott/Williams & Wilkins Health.
- Porock, D., Pollock, K., & Jurgens, F. (2009). Dying in public: The nature of dying in an acute hospital setting. *Journal of Housing for the Elderly*, 23(1-2), 10-28. <https://doi.org/10.1080/02763890802664521>
- Prinz, A. (2019). Migration, cultural identity and diasporas an identity economics approach. *IZA Journal of Development and Migration*, 10(1).
- Pybus, C. (2002). Black Caesar [Our first bushranger was a six-foot African man who arrived on the First Fleet.]. *Arena Magazine (Fitzroy, Vic)* (57), 30-34.
- Rashid, R., & Gregory, D. (2014). 'Not giving up on life': A holistic exploration of resilience among a sample of immigrant Canadian women. *Canadian ethnic studies*, 46(1), 197-214.
- Ratha, D. (2016). *Migration and remittances factbook 2016* (3rd ed. ed.). World Bank Publications.
- Ratnapalan, S. (2019). Qualitative approaches: Variations of grounded theory methodology. *Canadian Family Physician*, 65(9), 667-668.
- Rawson, W. T. R. (1931). *Education in a changing Commonwealth: Report of a British Commonwealth education conference held in London in July, 1931*. New Education Fellowship.
- Redman-MacLaren, M., & Mills, J. (2015). Transformational grounded theory: Theory, voice, and action. *International Journal of Qualitative Methods*, 14(3), 1-12. <https://doi.org/10.1177/160940691501400301>
- Renzaho, A. M. N., Green, J., Mellor, D., & Swinburn, B. (2011). Parenting, family functioning and lifestyle in a new culture: the case of African migrants in Melbourne, Victoria, Australia. *Child & family social work*, 16(2), 228-240.
- Robert, O. C. (1967). The Southern Lunda and related peoples [The Zulu aftermath: A nineteenth-century revolution in Bantu Africa, J. D. Omer-Cooper]. *The American Historical Review*, 72(2), 661-662. <https://doi.org/10.2307/1859394>
- Rock, A., Barrington, C., Abdoulayi, S., Tsoka, M., Mvula, P., & Handa, S. (2016). Social networks, social participation, and health among youth living in extreme poverty in rural Malawi. *Social Science & Medicine*, 170, 55-62.



- Rosberg, C. G. (1956). The federation of Rhodesia and Nyasaland: Problems of democratic government. *The ANNALS of the American Academy of Political and Social Science*, 306(1), 98-105. <https://doi.org/10.1177/000271625630600115>
- Rumbaut, R. G. (2015). Assimilation of immigrants. *James D. Wright (Ed.), International Encyclopedia of the Social & Behavioural Sciences*, 2, 81-87.
- Rusch, D., & Reyes, K. (2013). Examining the effects of Mexican serial migration and family separations on acculturative stress, depression, and family functioning. *Hispanic Journal of Behavioral Sciences*, 35(2), 139. <https://doi.org/10.1177/0739986312467292>
- Rutzou, T. y., & Steinmetz, G. (2018). *Critical realism, history, and philosophy in the social sciences*. Emerald Publishing.
- Sbait, M., Streule, M. J., Alhaffar, M., Pilkington, V., Leis, M., Budhathoki, S. S., . . . Abbara, A. (2021). Whose voices should shape global health education? Curriculum codesign and codelivery by people with direct expertise and lived experience. *BMJ global health*, 6(9), e006262. <https://doi.org/10.1136/bmjgh-2021-006262>
- SBS. (2020). Did you know there were 12 Africans on the first fleet? <https://www.sbs.com.au/news/the-feed/article/did-you-know-there-were-12-africans-on-the-first-fleet/v01kw8xi8>
- Schutz, A. (1962). Concept and theory formation in the social sciences. In *Collected papers I* (pp. 48-66). Springer.
- Schutz, A. (1972). *The phenomenology of the social world*. Heinemann Educational.
- Schwoerer, K., Keppeler, F., Mussagulova, A., & Puello, S. (2022). CO-DESIGN-ing a more context-based, pluralistic, and participatory future for public administration. *Public Administration*, 100(1), 72-97. <https://doi.org/10.1111/padm.12828>
- Serrant-Green, L (2011) The sound of ‘silence’: a framework for researching sensitive issues or marginalised perspectives in health. *Journal of Research in Nursing*. 16(4):347-360. doi:10.1177/1744987110387741
- Shanmugasundaram, S., & O'Connor, M. (2009). Palliative care services for Indian migrants in Australia: experiences of the family of terminally ill patients. *Indian Journal of Palliative Care*, 15(1), 76-83. <https://doi.org/10.4103/0973-1075.53589>
- Shavitt, S., & Cho, H. (2016). Culture and consumer behaviour: the role of horizontal and vertical cultural factors. *Current opinion in psychology*, 8, 149-154.
- Shaw, R., Gullifer, J., & Wood, K. (2016). Religion and spirituality: A qualitative study of older adults. *Ageing International*, 41(3), 311-330. <https://doi.org/10.1007/s12126-016-9245-7>
- Singh, S., & Estefan, A. (2018). Selecting a grounded theory approach for nursing research. *Global Qualitative Nursing Research*, 5. <https://doi.org/10.1177/2333393618799571>

- Singh, S., Robertson, S., & Cabraal, A. (2012). Transnational family money: Remittances, gifts and inheritance. *Journal of Intercultural Studies*, 33(5), 475-492.
- Siwale, J., & Okoye, N. (2017). Microfinance regulation and social sustainability of microfinance institutions: The case of Nigeria and Zambia. *Annals of Public and Cooperative Economics*, 88(4), 611-632. <https://doi.org/10.1111/apce.12165>
- Slatyer, S., Pienaar, C., Williams, A. M., Proctor, K., & Hewitt, L. (2015). Finding privacy from a public death: a qualitative exploration of how a dedicated space for end-of-life care in an acute hospital impacts on dying patients and their families. *Journal of Clinical Nursing*, 24(15-16), 2164-2174. <https://doi.org/10.1111/jocn.12845>
- Smith, A. K., Sudore, R. L., & Perez-Stable, E. J. (2009). Palliative care for Latino patients and their families: whenever we prayed, she wept. (Case study). *JAMA, The Journal of the American Medical Association*, 301(10), 1047(1011).
- Sneesby, L., Satchell, R., Good, P., & van der Riet, P. (2011). Death and dying in Australia: perceptions of a Sudanese community. *Journal of Advanced Nursing*, 67(12), 2696. <https://doi.org/10.1111/j.1365-2648.2011.05775.x>
- Solheim, C. A., & Ballard, J. (2016). Ambiguous loss due to separation in voluntary transnational families. *Journal of Family Theory & Review*, 8(3), 341-359.
- Solheim, C., Zaid, S., & Ballard, J. (2016). Ambiguous loss experienced by transnational Mexican immigrant families. *Family Process*, 55(2), 338-353. <https://doi.org/10.1111/famp.12130>
- Spalding, R. (2021). Accuracy in surrogate end-of-life medical decision-making: A critical review. *Applied Psychology: Health and Well-Being*, 13(1), 3-33.
- Spencer-Oatey, H., & Franklin, P. (2012). What is culture. *A compilation of quotations. GlobalPAD Core Concepts*, 1(22), 1-21.
- Strauss, A. L., & Corbin, J. M. (1990). *Basics of qualitative research: grounded theory procedures and techniques*. Sage Publications.
- Strauss, A. L., & Corbin, J. M. (1998). *Basics of qualitative research: techniques and procedures for developing grounded theory* (2. ed. ed.). SAGE.
- Strauss, A., & Corbin, J. (1994). Grounded theory methodology: An overview. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 273–285). Sage Publications, Inc.
- Tabor, A. S., & Milfont, T. L. (2011). Migration change model: Exploring the process of migration on a psychological level. *International Journal of Intercultural Relations*, 35(6), 818-832. <https://doi.org/10.1016/j.ijintrel.2010.11.013>
- Thengela, N., & Hendricks, E. A. (2020). The role of education in alleviating poverty, inequality and promoting economic development in South Africa. *African Journal of*

*Development Studies (formerly AFFRIKA Journal of Politics, Economics and Society)*, 10(3), 215-234. <https://doi.org/10.31920/2634-3649/2020/10n3a11>

Thomas, H. (1997). *The slave trade: The story of the Atlantic slave trade, 1440-1870*. Simon & Schuster.

Thornberg, R., & Charmaz, K. (2014). Grounded Theory and theoretical coding. In U. Flick (Ed.), *The SAGE Handbook of Qualitative Data Analysis* (pp. 153-169). SAGE Publications, Inc. <https://doi.org/10.4135/9781446282243>

Thorne, A. G., & Wolpoff, M. H. (1992). The multiregional evolution of humans. *Scientific American*, 266(4), 76-83.

Triandafyllidou, A. (2018). *Handbook of migration and globalisation*. Edward Elgar Publishing.

Turaki, Y. (2000). *Africa traditional religious system as basis of understanding Christian spiritual warfare*. <https://www.lausanne.org/content/west-african-case-study>

Udah, H. (2023). Anti-black racism and othering: an exploration of the lived experience of black Africans who live in Australia. *Social Identities*, 1-20.

Udah, H., Singh, P., Hiruy, K., & Mwanri, L. (2019). African immigrants to Australia: Barriers and challenges to labour market success. *Journal of Asian and African Studies*, 54(8), 1159-1174.

Urbański, M. (2022). Comparing push and pull factors affecting migration. *Economies*, 10(1), 21.

Van Hook, J., & Glick, J. E. (2020). Spanning borders, cultures, and generations: A decade of research on immigrant families. *Journal of Marriage and Family*, 82(1), 224-243.

Van Manen, M. (1997). *Researching lived experience: human science for an action sensitive pedagogy* (Second edition. ed.). Althouse Press.

Vansina, J. (1984). Western Bantu expansion. *The Journal of African History*, 25(2), 129-145.

Vergalli, S., & Moretto, M. (2005). *Migration dynamics* (49). University of Brescia.

Wali, N., & Renzaho, A. M. N. (2018). “Our riches are our family”, the changing family dynamics & social capital for new migrant families in Australia. *PLoS ONE*, 13(12), e0209421.

Wallbank, T. W. (1934). The educational renaissance in British tropical Africa. *The Journal of Negro Education*, 3(1), 105-122.

Whiten, A., Hinde, R. A., Laland, K. N., & Stringer, C. B. (2011). Culture evolves. *366*(1567), 938-948.

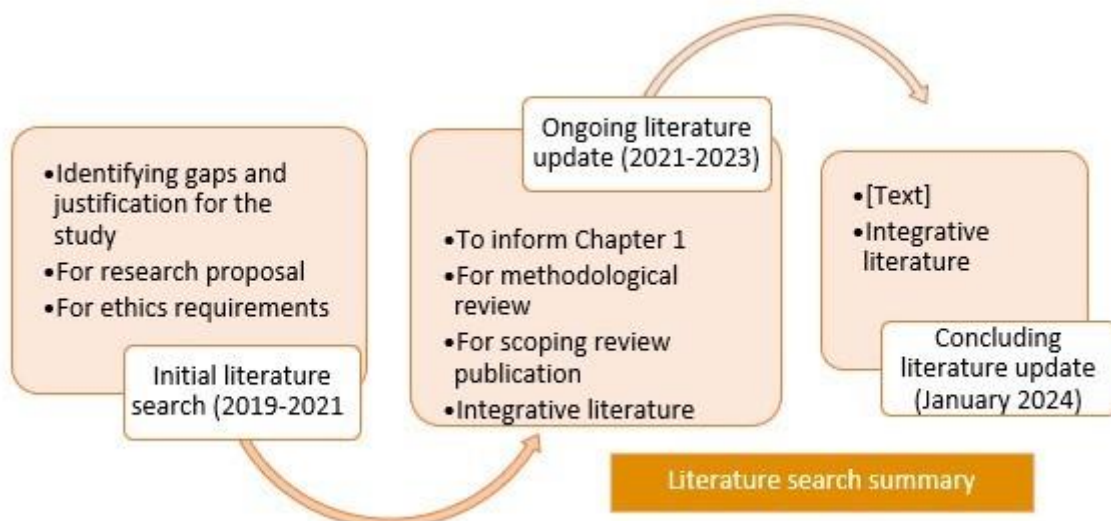
- WHO. (2018). *Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers* (9241514477).
- Wickramasinghe, A., & Wimalaratana, W. (2016). International migration and migration theories. *Social Affairs*, 1(5), 13-32.
- Willard, M. (1967). *History of the white Australia policy to 1920*. Psychology Press.
- Woodward, R. (2009). *The organisation for economic co-operation and development (OECD)*. Routledge.
- Worldometer. (2024). *Population of Africa (2024)*. <https://www.worldometers.info/world-population/africa-population/>
- Wright, J. (2006). Beyond the “Zulu aftermath”: Migrations, identities, histories. *Journal of Natal and Zulu History*, 24(1), 1-36.  
<https://doi.org/10.1080/02590123.2006.11964135>
- Yin, R. K. (2009). *Case study research: design and methods* (4th ed. ed.). Sage.
- Ziaian, T., Puvimanasinghe, T., Miller, E., Augoustinos, M., Esterman, A., Baddeley, M., . . . Stewart-Jones, T. (2023). Rebuilding life after migration: Research protocol of a mixed methods study on settlement experiences of refugee and migrant youth. *PLoS ONE*, 18(4), e0285023.
- Żółkoś, M., & Kavaliski, E. (2008). *Defunct federalisms: critical perspectives on federal failure*. Ashgate.

# Appendices

## Appendix 1

### Literature search details

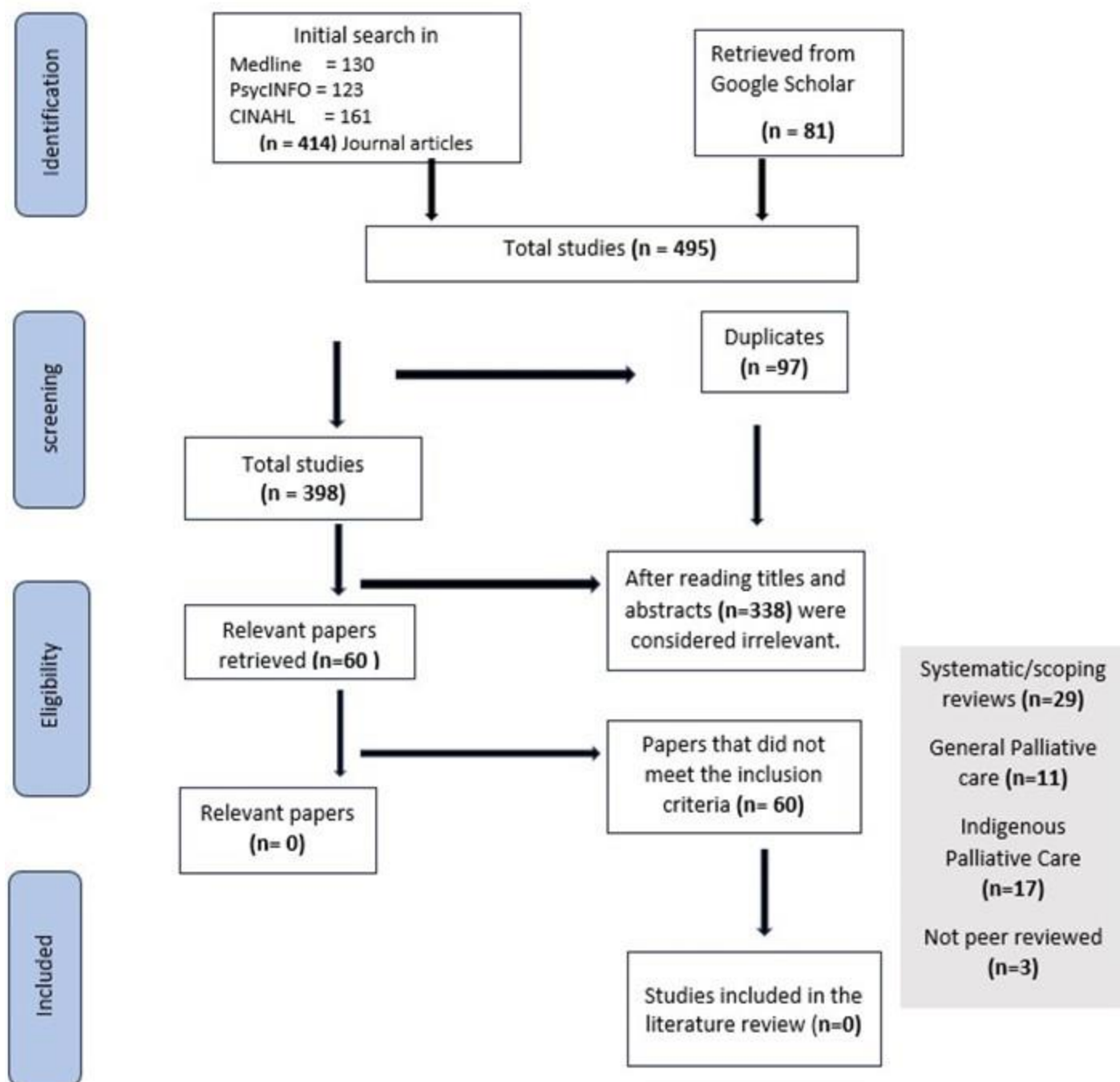
The literature search was undertaken throughout the life of the study, commencing with the preliminary search to situate the study, followed by ongoing conferring with the data obtained, and later for conferring with the study's findings. The search was carried out systematically from multiple databases while documenting each search to ensure an audit trail was maintained. The audit trail was also essential for refining the literature search as the study progressed. The initial literature search provided a broad view of the research topic and was instrumental in identifying gaps, justifying the need for the study, and fulfilling the university ethics committee's ethical approval requirements. This initial literature search was reviewed in its broad sense and published as a scoping review as exhibited in Chapter 2. The published scoping review focused on palliative and end-of-life care access by CaLD migrants in OECD countries (Phiri et al., 2023). Additionally, the initial literature was essential for setting the scene for the research in the introductory chapter. Below is an illustration of the literature search summary during the entire period of the study.



Data extraction was carried out for the included scholarly articles. These data were recorded on a spreadsheet which identified the Authors, Year Published, Study aims, Sample and Methods, Location where the study was conducted, and Key findings.

The final literature search was undertaken near the conclusion of the study to capture scholarly articles published between December 2021 and January 2024. There were no recently published articles related to the topic identified in the final search.

The literature search was conducted using the same search terms as the initial search; palliative care, end-of-life care, culture\*, African migrant\*, immigrant, emigrant, Malawi\*, Zambia\*, Zimbabwe\*, and Australia\*. The following databases were searched Google Scholar, CINAHL, MEDLINE, and PsycINFO. The pre-planned inclusion and exclusion criteria were applied to ensure consistency was maintained. Articles included were primary research studies from 2009 to 2021, with full text, written in English, peer-reviewed, and contained search terms. The exclusion criteria were Systematic/Scoping reviews, articles without an abstract, not written in English, did not contain search terms, and were not peer-reviewed. The concluding literature update in January 2024 yielded no results as there were no articles that met the pre-planned inclusion criteria of primary research peer-reviewed studies published between December 2021 and January 2024. Below is the PRISMA chart illustrating the January 2024 literature search.



PRISMA Diagram of the January 2024 literature search strategy



## Appendix 2

### Studies included

Author	Year	Title	location
Australia Bureau of Statistics.	2021	Population: Census	Australia
Afulani, P. A., Torres, J. M., Sudhinaraset, M., & Asunka, J.	2016	Transnational ties and the health of sub-Saharan African migrants: The moderating role of gender and family separation	France
Alper, J.	2018	A proposed framework for integration of quality performance measures for health literacy, cultural competence, and language access services: proceedings of a workshop.	USA
Barron, I., & Abdallah, G.	2017	Field trial of a complicated grief psychosocial program for adolescents in occupied Palestine.	Palestine
Bartram, D., Poros, M., & Monforte, P.	2014	Key concepts in migration	UK
Battersby, J., & Watson, V.	2019	Urban food systems governance and poverty in African cities. Routledge, Taylor & Francis Group.	Kenya & Zambia
Bell, J., Lim, A., Williams, R., Girdler, S., Milbourn, B., & Black, M.	2023	'Nothing about us without us': co-production ingredients for working alongside stakeholders to develop mental health interventions.	Australia
Bellamy, G., & Gott, M.	2013	What are the priorities for developing culturally appropriate palliative and end-of-life care for older people? The views of healthcare staff working in New Zealand.	New Zealand
Berger, J. T.	1998	Culture and Ethnicity in Clinical Care.	USA
Bhugra, D., & Becker, M. A.	2005	Migration, cultural bereavement, and cultural identity	Britain
Brand, G., Sheers, C., Wise, S., Seubert, L., Clifford, R., & Griffiths, P.	2021	A research approach for co-designing education with healthcare consumers.	Australia
Bryant, R. A., Edwards, B., Creamer, M., O'Donnell, M., Forbes, D., Felmingham, K. L., . . . Van Hooff, M.	2020	A population study of prolonged grief in refugees.	Australia
Bullock, K.	2011	The Influence of Culture on End-of-Life Decision Making.	United States of America
Burger, H., Venter, M., Wearne, N., & Krause, R.	2023	Advance Care Planning in South Africa.	South Africa
Chen, W. W., Wu, C. W., & Yeh, K. H.	2016	How parenting and filial piety influence happiness, parent-child relationships and quality of family life in Taiwanese adult children	Taiwan
Chilunjika, A.	2021	Revamping the Zimbabwe Anti-Corruption Commission (ZACC)	Zimbabwe
Clark, D.	2012	Cultural considerations in planning palliative and end of life care	Zimbabwe
Czaika, M., & Reinprecht, C.	2022	Migration drivers: why do people migrate. Introduction to Migration Studies: An Interactive Guide to the Literatures on Migration and Diversity	Netherlands
De La Fuente, A., Rosales, M., & Jellema, J. R.	2017	The impact of fiscal policy on inequality and poverty in Zambia. World Bank Policy Research Working Paper.	World Bank

de Voogd, X., Oosterveld-Vlug, M. G., Torensma, M., Onwuteaka-Philipsen, B. D., Willems, D. L., & Suurmond, J. L.	2020	A dignified last phase of life for patients with a migration background: A qualitative study	Netherlands
Department of Health	2018	National Palliative Care Strategy.	Australia
Doan, T., Nghiem, N., & Doan, N.	2023	Free versus regulated migration: Comparing the wages of the New Zealand-born, other migrants and the Australia-born workers in Australia	Australia
Duncan, R. P., & Perrucci, C. C.	1976	Dual Occupation Families and Migration.	United States of America
Durston, S., & Nashire, N.	2001	Rethinking Poverty and Education: an attempt by an education programme in Malawi to have an impact on poverty.	Malawi
Eckemoff, E. H., Sudha, S., & Wang, D.	2018	End of Life Care for Older Russian Immigrants - Perspectives of Russian Immigrants and Hospice Staff.	United States of America
Ekore, R., & Lanre-Abass, B.	2016	African cultural concept of death and the idea of advance care directives.	Africa
Erdal, M. B., & Ezzati, R.	2015	'Where are you from' or 'when did you come'? Temporal dimensions in migrants' reflections about settlement and return.	Norway
Esipova, N., Pugliese, A., & Ray, J.	2018	More than 750 million worldwide would migrate if they could.	World Economic Forum
Eun-Hye, G. Y.	2019	Does Acculturation Matter? End-of-Life Care Planning and Preference of Foreign-born Older Immigrants in the United States.	United States of America
Evans, D. R. N., Coutsaftiki, D., & Fathers, C. P.	2011	Health promotion and public health for nursing students.	Sage - Book
Gatwiri, K., Mwanri, L., & McPherson, L.	2021	Afro-diasporic experiences of highly skilled Black African immigrants in Australia.	Australia
Gaulee, U., Sharma, S., & Bista, K.	2020	Rethinking education across borders : emerging issues and critical insights on globally mobile students.	Book Chapter
Gindling, T. H., & Poggio, S.	2012	Family Separation and Reunification as a Factor in the Educational Success of Immigrant Children.	Central America & Mexico
Government, A	2018	Shaping A Nation: Population growth and immigration over time.	Australia
Hiruy, K., & Mwanri, L.	2014	End-of-life experiences and expectations of Africans in Australia: cultural implications for palliative and hospice care	Australia
International Organisation for Migration.	2020	World Migration Repot (PUB2019/006/L WMR 2020).	Geneva
Kapungwe, A.	2004	Poverty in Zambia: Levels, patterns and trends.	Zambia
Kudakwashe, M. A., & Richard, B.	2011	Education for All: Issues and Challenges: The Case for Zimbabwe.	Zimbabwe
Lee, E. S.	1966	A Theory of Migration.	Book
Liu, B. S., & Huang, H. C.	2009	Family care for the elderly and the importance of filial piety.	Taiwan
Lugard, F. D.	1929	The Dual Mandate in British Tropical Africa.	Britain
Marschall, S.	2017	Migrants on home visits: Memory, identity and a shifting sense of self.	South Africa
Masaiti, G., & Chita, J.	2014	Zambia: An overview of formal education.	Zambia

McAuliffe, M., Abel, G., Ocho, L. a., & Sawyer, A.	2022	7 International Migration as a Stepladder of Opportunity: What do the Global Data Actually Show?	World Migration Report
McKenzie, J. F., Neiger, B. L., & Thackeray, R.	2013	Planning, implementing, and evaluating health promotion programs : a primer	Book
Michelo, S.	2018	How Zambia's Social protection services and programmes helped mitigate inequality and reduce poverty.	ambia
Mohamed Nazri, M., Sulastri, S., Nur Afni, A., Sazarani, M., Haslina, H., Maizurah, O., . . . Ahmad Shalihin, M.	2012	Role of Visualisation in Participatory Programme (VIPP) in Engaging Youth and School Children in Health Promotion Activities: A Four-Year Experience in Malaysia. International Social Work Conference.	Malaysia
Morrison, R. S., Meier, D. E., & Arnold, R. M.	2021	What's wrong with advance care planning?	Australia
Mutasa, F.	2015	The future of the Basic Education Assistance Module: A poverty alleviation strategy in Zimbabwe.	Zimbabwe
Mwalimu, M.	2014	Education and the economy: Achievements and shortfalls in Independent Zambia, 1964–2014.	Zambia
Nayar, S., Hocking, C., & Giddings, L.	2012	Using Occupation to Navigate Cultural Spaces: Indian Immigrant Women Settling in New Zealand.	New Zealand
Nyen, S., & Tveit, B.	2018	Symptoms without disease: Exploring experiences of non-Western immigrant women living with chronic pain.	Norway
Oldham, J. H.	1929	Report of the Commission on the Closer Union of the Eastern and Central African Dependencies.	England
Oumlil, A. B., & Balloun, J. L.	2017	Cultural variations and ethical business decision making: a study of individualistic and collective cultures.	United States of America
Payne, S., Chapman, A., Holloway, M., Seymour, J. E., & Chau, R.	2005	Chinese community views: Promoting cultural competence in palliative care.	United Kingdom
Perng, A., & Renz, S.	2018	Identifying and treating complicated grief in older adults.	United States of America
Rawson, W. T. R.	1931	Education in a Changing Commonwealth: Report of a British Commonwealth Education Conference Held in London in July, 1931.	London
Renzaho, A. M. N., Mansouri, F., Counted, V., & Polonsky, M.	2021	The Influence Region of Origin, Area of Residence Prior to Migration, Religion, and Perceived Discrimination on Acculturation Strategies Among Sub-Saharan African Migrants in Australia.	Australia
Rock, A., Barrington, C., Abdoulayi, S., Tsoka, M., Mvula, P., & Handa, S.	2016	Social networks, social participation, and health among youth living in extreme poverty in rural Malawi.	Malawi
Rumbaut, R. G.	2015	Assimilation of immigrants.	United States of America
Rusch, D., & Reyes, K.	2013	Examining the Effects of Mexican Serial Migration and Family Separations on Acculturative Stress, Depression, and Family Functioning.	United States of America
Sbait, M., Streule, M. J., Alhaffar, M., Pilkington, V.,	2021	Whose voices should shape global health education? Curriculum codesign and	Australia

Leis, M., Budhathoki, S. S., . . . Abbara, A.		codelivery by people with direct expertise and lived experience.	
Schultz, H. J.	1971	English liberalism and the state : individualism or collectivism?	United States of Ameica
Schwoerer, K., Keppeler, F., Mussagulova, A., & Puello, S.	2022	CO-DESIGN-ing a more context-based, pluralistic, and participatory future for public administration.	United States of America, Germany, and Singapore
Shanmugasundaram, S., & O'Connor, M.	2009	Palliative care services for Indian migrants in Australia: experiences of the family of terminally ill patients.	Australia
Shelley, M. R.	2017	Talking about the Taboo Topic of Death: State and Federal Initiatives to Reach Informed Consent at the End of Life through Advance Care Planning.	Australia
Siwale, J., & Okoye, N.	2017	Microfinance Regulation and Social Sustainability of Microfinance Institutions: The Case of Nigeria and Zambia	Africa
Sneesby, L., Satchell, R., Good, P., & van der Riet, P.	2011	Death and dying in Australia: perceptions of a Sudanese community.	Australia
Solheim, C., Zaid, S., & Ballard, J.	2016	Ambiguous Loss Experienced by Transnational Mexican Immigrant Families.	United States of America
Spalding, R.	2021	Accuracy in Surrogate End-of-Life Medical Decision-Making: A Critical Review	United States of America
Thengela, N., & Hendricks, E. A.	2020	The role of education in alleviating poverty, inequality and promoting economic development in South Africa.	South Africa
Thulesius, H. O., Scott, H., Helgesson, G., & Lynøe, N.	2013	De-tabooing dying control - a grounded theory study.	United States of America
Triandafyllidou, A.	2018	Handbook of migration and globalisation.	Italy
Triandis, H. C., & Gelfand, M. J.	1998	Converging measurement of horizontal and vertical individualism and collectivism.	United States of America
Urbański, M.	2022	Comparing push and pull factors affecting migration.	Polland and Romania
Van Hook, J., & Glick, J. E.	2020	Spanning borders, cultures, and generations: A decade of research on immigrant families.	United States of America
Wali, N., & Renzaho, A. M. N.	2018	“Our riches are our family”, the changing family dynamics & social capital for new migrant families in Australia.	Australia
Wallbank, T. W.	1934	The Educational Renaissance in British Tropical Africa.	Britain
Ward, C.	2020	Models and measurements of acculturation.	Singapore
Wickramasinghe, A., & Wimalaratana, W.	2016	International migration and migration theories.	Sri Lanka
Wise, J.	2012	Dying remains a taboo subject for patients and GPs, finds survey.	Britain
Ziaian, T., Puvimanasinghe, T., Miller, E., Augoustinos, M., Esterman, A., Baddeley, M., Stewart-Jones, T.	2023	Rebuilding life after migration: Research protocol of a mixed methods study on settlement experiences of refugee and migrant youth.	Australia

## Appendix 3

### Supporting letter from OACWA



11 Patrick Court GIRRAWHEEN, WA 6064.  
Mailing Address: PO Box 58 Dianella  
Contact: 0401 166 201, 0430 582 314  
info@oacwa.com.au, www.oacwa.com.au  
ABN. 29 845 428 718

Monday, 18 January 2021 Dear Gertrude,

I would like to inform you that the Organisation of African Communities in WA (OACWA) has agreed to assist you to disseminate information about your current research to its members for the purpose of research participant recruitment.

Yours sincerely,



Joe Tuazama

President - Organisation of African Communities in WA

***Inspire, Engage, Consult and Promoting Unity***

## **Appendix 4**

### **Invitation Letter to potential study participants**

Dear Sir/Madam,

I am a PhD student at Edith Cowan University undertaking research. I am looking for volunteers to participate in a study intitled “Preparing for end of life in a new country: A grounded theory study of African migrants living in Australia”. The researcher will ask you some questions about how you anticipate preparing and experiencing end-of-life in Australia when that time comes. This research will explore how migrants from Malawi, Zambia and Zimbabwe prepare for end-of-life in a new country, Australia. The objectives of the study are to:

- a) Describe the migration experience and settling in Australia in relation to planning for end-of-life.
- b) Examine relationship structures and their impact on preparing for end-of-life for migrants from Malawi, Zambia and Zimbabwe,
- c) Describe the social processes of African migrants from Malawi, Zambia and Zimbabwe as they prepare for end-of- life in Australia.

I am looking for individuals from Malawi, Zambia or Zimbabwe of non-Caucasian descent who are 45 years old and above to participate in this research. Please contact the undersigned if you would like to participate in the study. I am available to provide more information and explain the planned research to interested individuals by phone. A face-to-face meeting will be arranged with interested individuals to explain in detail the research, provide the information letter, answer questions and obtained informed consent if they chose to participate. A second interview will be arranged at the first interview session.

I look forward to hearing from you.

Kind regards

Gertrude Phiri

Chief investigator

Tel: +61 519 385 162

Email: [gphiri0@our.ecu.edu.au](mailto:gphiri0@our.ecu.edu.au)

## Appendix 5

### Participant information letter

Chief Investigator: Gertrude Phiri  
School of Nursing and Midwifery  
Edith Cowan University  
270 Joondalup Drive  
JOONDALUP WA 6027  
Phone: [REDACTED]  
Email: gphiri0@our.ecu.edu.au



### Participant Information Letter

**Project title:** Preparing for end-of-life in a new country: A grounded theory study of African migrants living in Australia.

**Approval Number:** 2021-02929-PHIRI

**Principal Investigator:** Gertrude Phiri and supervisors Professor Davina Porock and Dr. Caroline Vafeas

#### An invitation to participate in research.

You are invited to participate in a project titled 'Preparing for end-of-life in a new country: A grounded theory study on African migrants living in Australia which seeks to explore African migrants' perceptions of how they prepare for end-of-life away from their country of origin. You are being asked to take part in this project because you are a migrant from Malawi, Zambia or Zimbabwe and over 45 years of age. To participate in the study, you must have migrated to Australia in the past four years or more, and are comfortable to talk about death and dying.

This research project is being undertaken for an Integrated PhD at Edith Cowan University.

Please read this information carefully. Ask questions about anything that you do not understand or want to know more about. Before deciding whether to take part, you might want to talk about it with a relative or friend.

If you decide you want to take part in the research project, you will be asked to sign a consent form. By signing it you are telling us that you:

- Understand what you have read;
- Agree to take part in the research project;
- Consent to the use of your personal information as described.

#### What is this project about?

This project aim is to explore African migrants in relation to preparing for end of life in a new country, Australia. The African migrant population in Australia has been growing in the last two decades, yet little is known about their palliative and end-of-life care needs. You will be asked questions about your migration story, how you are preparing for your end-of-life and how you hope what you have put in place can be achieved. This project aims to shed some light on the subject to enable health workers gain understanding of this population's end-of-life care needs and also encourage a conversation amongst African migrants about end-of-life planning.

#### What does my participation involve?

Your participation in this research project will involve, two interview sessions 2 weeks apart each lasting 45-60 minutes. The interviews will be conducted by the researcher at your home or a suitable

place you may nominate which offers a comfortable environment and some distance from other people to ensure confidentiality is maintained. The researcher will contact you by mobile phone to arrange the day, time and venue for the interview.

The interview will be digitally recorded so that nothing is missed for the analysis.

### **Do I have to take part in this research project?**

Taking part in this research project is completely voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project prior to data analysis.

If you do decide to take part, you will be asked to sign a Consent form and you will be given a copy of this information letter to keep. Your decision to take part, or to take part and later withdraw, will not affect your relationship with the research team and ECU.

### **Your privacy**

By signing the consent form, you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Pseudonyms will be used in all reports so that no one will know what you have said or that you have taken part in the study, interview recordings will be deleted once transcribing is complete and all data collected will be stored in a secure place at Edith Cowan University Joondalup.

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

In accordance with relevant Australian and Western Australian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this letter if you would like to access your information.

All data collected will be kept in accordance with ECU's Data Management Policy. Electronic data will be stored on a secure Microsoft SharePoint site provisioned by ECU's IT Services and physical records will be stored as required in ECU's Records as per Management Policy. The data will be retained for a period of seven years as required by research ethics governance after which it will be destroyed securely by the process set out by the university if appropriate under the State Records Act. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

### **Possible Benefits**

We cannot guarantee or promise that you will receive any benefits from this research, however possible benefits may include facilitating discussions on African migrants' end-of-life needs in Australia.

### **Possible Risks and Risk Management Plan**

You may wish to bring along a family member or friend to the interview if you feel you may need support.

You may feel uncomfortable with some of the questions you will be asked during the interview. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. You may want to talk to the researcher or to the family member/friend in attendance about the uncomfortable feeling. The researcher is a registered nurse who has dealt with various situations of similar nature in individuals and families during her many years of nursing. You will also



be encouraged to make an appointment with your regular doctor or contact Beyond Blue, a free counselling service. If there was discomfort experienced during the interview session, the research will contact you by phone for a wellness check, 24 hours following the interview.

For information relating to the University's research participant insurance coverage, please go to: <https://intranet.ecu.edu.au/staff/centres/strategic-and-governance-services/our-services/risk-and-assurance/insurance/practicum-work-experience-or-volunteer-activities>

### **What happens when this research study stops?**

We will advise you of the outcomes via email.

### **Has this research been approved?**

This research project has received the approval of Edith Cowan University's Human Research Ethics Committee, in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research 2007 (Updated 2018)*. The approval number is **2021-02929-PHIRI**.

### **Contacts**

If you would like to discuss any aspect of this project, please contact the following people.

#### **Chief Investigator**

Gertrude Phiri

PhD student

Edith Cowan University

P: [REDACTED]

F: 6304 2323

E: [gphir0@our.ecu.edu.au](mailto:gphir0@our.ecu.edu.au)

#### **Supervisors**

Professor D. Porock and Dr. C. Vafeas

School of Nursing and Midwifery

Edith Cowan University

P: 6304 3482

F: 6304 2323

E: [c.vafeas@ecu.edu.au](mailto:c.vafeas@ecu.edu.au)

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact:

#### **Independent Person**

Research Ethics Support Officer

Edith Cowan University

P: 6304 2170

E: [research.ethics@ecu.edu.au](mailto:research.ethics@ecu.edu.au)

If you wish to participate in this research, please sign the Consent Form and return to: [gphir0@our.ecu.edu.au](mailto:gphir0@our.ecu.edu.au)

[REDACTED]

Gertrude Phiri

Chief Investigator

## Appendix 6

### Participant Consent Form

Chief Investigator: Gertrude Phiri  
School of Nursing and Midwifery  
Edith Cowan University  
270 Joondalup Drive  
JOONDALUP WA 6027  
Phone: [REDACTED]  
Email: gphiri0@our.ecu.edu.au



### Participant Consent Form

**Project title:** Preparing for end-of-life in a new country: A grounded theory study of African migrants living in Australia

**Approval Number:** 2021-02929-PHIRI

**Principal Investigator:** Gertrude Phiri, supervisors Professor Davina Porock and Dr. Caroline Vafeas

I, \_\_\_\_\_ have read the Participant Information Letter. By signing this consent form, I acknowledge that I:

- have been given a copy of the Participant Information Letter, explaining the research study
- have read and understood the information provided
- have been given the opportunity to ask questions and have had questions answered to my satisfaction
- can contact the research team if I have any additional questions
- understand that participation in the research project will involve:
  - participation in two 45 – 60-minute interviews 2 weeks apart.
- understand that the information provided will be kept confidential, and that my identity will not be disclosed without my consent
- understand that I am free to withdraw from further participation at any time, without explanation or penalty
- freely agree to take part in the project
- The data collected for the purposes of this research project may be used in further approved research projects provided my name and any other identifying information is removed.

I agree to have my conversations audiotaped

Yes ☐ No ☐

Participant  
name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date \_\_\_\_\_

Approval to conduct this research has been provided by the Edith Cowan University's Human Research Ethics Committee, approval number 2021-02929-PHIRI, in accordance with its ethics review and approval procedures.

## Appendix 7

### COVID-19 Symptom Checklist

Participant's pseudonym.....

Date- -- / -- / ----.

	Question	Yes/No
1	Do you have a fever?	
2	Do you have a cough and/or runny nose?	
3	Is anyone in your household experiencing flu-like symptoms?	
4	Have you travelled to Western Australia from elsewhere in the past 2 weeks?	
	If yes to question 4, please state where you have travelled from	
5	Do you have someone in your household who has arrived in Western Australia from elsewhere?	

## **Appendix 8**

### **Pilot Study Interview Questions**

**Project title:** Preparing for end-of-life in a new country: A pilot study on cultural perspectives of African migrants living in Australia.

#### **Research question:**

What are the cultural perspectives of migrants from Africa preparing for end-of-life in Australia?

#### **Interview questions.**

1. What does it mean to be an African migrant in Australia?
2. Tell me your thoughts about preparing for end-of-life in a country away from your place of birth.
3. What concerns if any, do you have when thinking about preparing for end-of-life in Australia?
4. Tell me about who you would prefer to look after you when you are at the end-of-life stage and why.

#### **Prompts to guide the conversation.**

- Can you tell me more about that?
- Can you give an example?
- Is it okay for us to go back and talk about that?
- What springs to mind?
- Family circumstances?
- Is this a personal experience?

## **Appendix 9**

### **First Interview Questions**

#### **Research questions:**

How do migrants from Malawi, Zambia and Zimbabwe prepare for end-of-life in Australia?

#### **Interview questions:**

1. Tell me about how you came to be living in Australia.
2. Tell me about your experience of migrating and settling in Australia.
3. Tell me what it is like living in Australia. Are you planning to stay in Australia for the long term?
  - a) If they are planning to go back permanently at some stage – why?
  - b) If they are planning to stay, why? How do you foresee your life going forward?
4. What are your thoughts about growing old and eventually dying in Australia?
5. Do you have any concerns about being able to die according to your wishes while in Australia?
6. Tell me about your preferences in preparing for end-of life in Australia.
7. Are there any cultural, religious or spiritual practices you would like to take place during this time?
8. How do you ensure that those close to you know your preferences that you have just described?
9. How do you think the health care providers would be of assistance to ensure your preferences are achieved?

#### **Prompts to guide the conversation.**

1. Can you tell me more about that?
2. Can you give an example?
3. Is it okay for us to go back and talk about that?
4. What springs to mind?
5. Family circumstances?
6. Is this a personal experience?

## **Appendix 10**

### **Second Interview Questions**

#### **Research question:**

How do migrants from Malawi, Zambia and Zimbabwe prepare for end-of-life in Australia?

#### **Interview questions**

1. Tell me what your thoughts are since our last interview
2. Have your thoughts on preparing for end-of-life changed after giving the topic some consideration?  
If they have not changed, why?

If they have changed, could you tell me more about how your thoughts have changed and why?

#### **Prompts to guide the conversation**

7. Can you tell me more about that?
8. Can you give an example?
9. Is it okay for us to go back and talk about that?
10. What springs to mind?

## Appendix 11

### Ethics Approval Letter

Research Ethics Cloud Services <svc\_RE\_Cloud\_Services@ecu.edu.au>

**Sent:** Wednesday, 10 November 2021 1:42 PM

**To:** Gertrude PHIRI <GPHIRIO@our.ecu.edu.au>

**Cc:** Research Ethics <research.ethics@ecu.edu.au>; GRS student support <GRSstudentsupport@ecu.edu.au>; Research Assessments <researchassessments@ecu.edu.au>; Davina POROCK <d.porock@ecu.edu.au>; Caroline VAFEAS <c.vafeas@ecu.edu.au>

**Subject:** HUMAN RESEARCH ETHICS APPROVAL - HDR STUDENT - HREC

Dear Gertrude PHIRI,

**RE: HREC - Full Review**

**PROJECT NAME: Preparing for end-of-life in a new country: A grounded theory study on African migrants living in Australia**

**REMS NO: 2021-02929-PHIRI**

**Student No: 10162175**

The ECU Human Research Ethics Committee (HREC) has reviewed your application and has granted ethics approval for your research project. In granting approval, the HREC has determined that the research project meets the requirements of the National Statement on Ethical Conduct in Human Research.

The approval period is from 10/11/2021 to 31/07/2023.

The Research Assessments Team has been informed and they will issue formal confirmation of candidature (providing research proposal has been approved). Please note that the submission and approval of your research proposal is a separate process to obtaining ethics approval and that no recruitment of participants and/or data collection can commence until ethics approval has been granted, your research proposal has been approved and formal confirmation of candidature has been received.

All research projects are approved subject to general conditions of approval as outlined below.

### 1. Monitoring of Approved Research Projects

Monitoring is the process of verifying that the conduct of research conforms to the approved ethics application. Compliance with monitoring requirements is a condition of approval.

The National Statement on Ethical Conduct in Human Research indicates that institutions are responsible for ensuring that research is reliably monitored. Monitoring of approved projects is to establish that a research project is being, or has been, conducted in the manner approved by the HREC. Researchers also have a significant responsibility in monitoring, as they are in the best position to observe any adverse events or unexpected outcomes. They should report such events or outcomes promptly to the Research Ethics Team and take prompt steps to deal with any unexpected risks.

All projects approved by an ECU Human Research Ethics Committee are approved subject to the following conditions of approval:

- If the research project is discontinued before the expected date of completion, researchers should inform the Research Ethics Team as soon as possible, giving reasons;
- An annual report (for projects that are longer than one year) and a final report at the completion of the research will be provided to the Research Ethics Team, for review by the HREC. You will also be notified when a report is due. To complete an annual or final report you can visit your [REMS Portal](#), select the report icon for the relevant project and complete the report online; and
- Researchers must also immediately report anything that might warrant review of the ethical approval of the protocol, including:
  - Any serious or unexpected adverse effects on participants; and
  - Any unforeseen events that might affect continued ethical acceptability of the project.
- Reporting an adverse event can also be completed by visiting your [REMS Portal](#), clicking on the report icon and selecting the 'Adverse Event' tab in the reporting portal.

The HREC retains the right to require a more detailed and/or more frequent report if the research is deemed to be of high risk, and to recommend and/or adopt any additional appropriate mechanism for monitoring including random inspections of research sites, data and signed consent forms, and/or interview, with their prior consent, of research participants.

## **2. Changes and amendments**

Compliance with the approved research protocol is a condition of approval, and any changes to the research design must be reported to the Research Ethics Team. Amendments to the research design that may affect participants and/or that may have ethical implications must be reviewed and approved by the HREC before commencement.

Any changes to documents and other material used in recruiting potential research participants, including advertisements, letters of invitation, information sheets and consent forms, or data management intentions should also be approved by the HREC.

To request approval for a change, please visit the [REMS Portal](#), click on the report icon for the relevant project and select the 'amendment' tab once in the [REMS Portal](#).

## **3. Extension of ethics approval**

All research projects are approved for a specified period of time – from the date of approval until the date of completion provided in the ethics application. If an extension of the approval period is required, a request must be submitted to the Research Ethics Team. Please ensure that requests for extension of approval are submitted before the original approval expires.

To request an extension of ethics approval, please visit the [REMS Portal](#), click on the report icon for the relevant project and select the 'extension' tab once in the [REMS Portal](#).

## **Additional Information**

### **Data Management**

Your responses in Element 4 now form your Data Management Plan. A unique Microsoft Team folder will now be created which will include a SharePoint digital data storage space for your research records and data in the 'Files' tab.



To access the Teams folder, open the Microsoft Teams Desktop application, select the 'Teams' tab on the left navigation panel, open your Team which should be titled [REMSNumber] and select the 'Files' tab at the top centre of the screen (below the search bar).

You can add any other members of your research team who may also require access to the information.

#### Work Health And Safety (WHS) Hazard Risk Assessment

In addition to the risk assessment completed in REMS, it is also **mandatory** for you to complete a work health and safety (WHS) hazard risk assessment for your research project in the WHS Risk Register module of Riskware. Information on how to complete a Work Health and Hazard risk assessment can be found here. Your WHS hazard risk assessment must be submitted for **approval** to your Research Supervisor/Line Manager in the first instance, if the level of risk is outside their scope of approval, they will redirect it for approval in accordance with the ECU risk acceptance criteria. Further approvals may be required after completing the WHS Hazard Risk Assessment, such as approval to use radiation, biosafety and hazardous substances (RBHS) or undertake fieldwork, events or travel (FET). Further information on other approvals and Enterprise risk assessments can be found here.

Students - your main source of support is your **Research Supervisor**. For further advice and support please contact the Graduate Research Student Support Co-ordinators – GRS@ecu.edu.au or 6304 2628.

Should you have further questions regarding any of the Riskware modules please contact the Safety and Employment Relations (SER) Team – osh@ecu.edu.au , Radiation, Biosafety and Hazardous Substances Committee – RBHSC@ads.ecu.edu.au or call (08) 6304 2302.

Regards,

Chair

Human Research Ethics Committee

## Appendix 12

### Advance Health Directive



XY310580

If hospital inpatient  
affix Patient ID  
Label here

## Advance Health Directive

### Notes:

- To make an advance health directive, you must be 18 years of age or older and have full legal capacity.<sup>1</sup>
- A person who makes an advance health directive is called “the maker”.

This advance health directive is made under the *Guardianship and Administration Act 1990* Part 9B on the \_\_\_\_\_ day of \_\_\_\_\_ 20\_\_\_\_

by \_\_\_\_\_  
(maker’s full name)

of \_\_\_\_\_  
(maker’s residential address)

born on \_\_\_\_\_  
(maker’s date of birth)

This advance health directive contains treatment decisions in respect of my future treatment.

A treatment decision in this advance health directive operates in respect of the treatment to which it applies at any time I am unable to make reasonable judgements in respect of that treatment.

### Notes about treatment decisions:

- Treatment is any medical, surgical or dental treatment or other health care (including palliative care and life sustaining measures such as assisted ventilation and cardiopulmonary resuscitation).<sup>2</sup>
- A treatment decision is a decision to consent or refuse consent to the commencement or continuation of any treatment.<sup>3</sup>
- A treatment decision operates only in the circumstances that you specify.<sup>4</sup>
- Treatment to which you consent in this advance health directive can be provided to you.
- Treatment to which you refuse consent in this advance health directive cannot be provided to you.
- Your enduring guardian or guardian or another person cannot consent or refuse consent on your behalf to any treatment to which this advance health directive applies.<sup>5</sup>

<sup>1</sup> Guardianship and Administration Act 1990 s. 110P

<sup>2</sup> Guardianship and Administration Act 1990 s. 3(1), definitions of “life sustaining measure”, “palliative care” and “treatment”

<sup>3</sup> Guardianship and Administration Act 1990 s. 3(1), definition of “treatment decision”

<sup>4</sup> Guardianship and Administration Act 1990 s. 110S(2)

<sup>5</sup> Guardianship and Administration Act 1990 s. 110ZJ

MR00H ADVANCE HEALTH DIRECTIVE

### 1. Treatment decision

In the following circumstances:

I consent/refuse consent (cross out and initial one of these) to the following treatment:

### 2. Treatment decision

In the following circumstances:

I consent/refuse consent (cross out and initial one of these) to the following treatment:

### 3. Treatment decision

In the following circumstances:

I consent/refuse consent (cross out and initial one of these) to the following treatment:

Notes for maker about signing and witnessing:

- If you are physically incapable of signing this advance health directive, you can ask another person to sign for you. You must be present when the person signs for you.<sup>6</sup>
- Two (2) witnesses must be present when you sign this advance health directive or when another person signs for you.<sup>7</sup>
- Each of the witnesses must be 18 years of age or older and cannot be you or the person signing for you (if applicable).
- At least one of the witnesses must be authorised to witness statutory declarations. For a list of people who are authorised to witness statutory declarations, see the *Oaths, Affidavits and Statutory Declarations Act 2005*.<sup>8</sup>
- The witnesses must also sign this advance health directive. Both witnesses must be present when each of them signs. You and the person signing for you (if applicable) must also be present when the witnesses sign.<sup>7</sup>

Signed by:

\_\_\_\_\_  
(maker's signature)

Witnessed by a person authorised to witness statutory declarations:

\_\_\_\_\_  
(authorised witness's signature)

\_\_\_\_\_  
(authorised witness's full name)

\_\_\_\_\_  
(authorised witness's address)

\_\_\_\_\_  
(occupation of authorised witness)

\_\_\_\_\_  
(date)

and by another person:

\_\_\_\_\_  
(other witness's signature)

\_\_\_\_\_  
(other witness's full name)

\_\_\_\_\_  
(other witness's address)

\_\_\_\_\_  
(date)

<sup>6</sup> Guardianship and Administration Act 1990 s. 110Q(1)(c)

<sup>7</sup> Guardianship and Administration Act 1990 s. 110Q(1)(d) and (e) and (3)

<sup>8</sup> Oaths, Affidavits and Statutory Declarations Act 2005 s.12(6) and Sch. 2

## Optional statement about legal or medical advice

### Notes about statement:

- You are encouraged (but are not required) to seek legal or medical advice before making this advance health directive.<sup>9</sup>
- If you wish to indicate that you have obtained legal or medical advice and wish to identify the person who gave you the advice, complete the relevant part of the statement.
- If you wish to indicate that you have obtained legal or medical advice but do not wish to identify the person who gave you the advice, cross out and initial the relevant part of the statement.
- If you do not wish to indicate whether or not you have obtained legal or medical advice, you may (but do not have to) cross out and initial the statement.
- If you do not wish to obtain legal or medical advice, you may (but do not have to) cross out and initial the statement.
- You do not have to say anything in this advance health directive about whether or not you have sought or obtained legal or medical advice. You can leave the statement blank and do not have to cross out or initial any part of it.

Before making this advance health directive, I obtained legal advice about making it.  
I obtained that legal advice from (details of person who provided legal advice):

Before making this advance health directive, I obtained medical advice about making it.  
I obtained that medical advice from (details of person who provided medical advice):

## Optional statement about enduring power of guardianship

### Notes about statement:

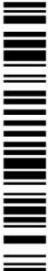
- If you wish to indicate that you have made an enduring power of guardianship, put a tick (✓) or cross (✗) in the box next to the statement.
- You do not have to say anything in this advance health directive about whether or not you have made an enduring power of guardianship. You can leave the box next to the statement blank.


I have made an enduring power of guardianship ☐

<sup>9</sup> Guardianship and Administration Act 1990 s. 110Q(1)(b) and (2) and 110QA

## Appendix 13

### Advance Care Fact Sheet for Individuals

  
XY000240



Government of Western Australia  
Department of Health  
WA Cancer and Palliative Care Network

Affix patient ID label here

# My Advance Care Plan

Last name: \_\_\_\_\_

First name: \_\_\_\_\_ Date of birth \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Address: \_\_\_\_\_

My Advance Care Plan is a record of your advance care planning discussion and a way of informing those who are caring for you of your preferences. Your preferences may not necessarily be health related but will guide your treating health professionals, Enduring Guardian and or family as to how you wish to be treated including any special requests or messages.

Please note: Should you wish to make legally binding treatment decisions, it is recommended that you record these decisions in an Advance Health Directive. You may also wish to give consideration to appointing an Enduring Guardian to make personal, lifestyle and treatment decisions on your behalf. See the Guide for further detail.

I have given a copy of my Advance Care Plan to:

Full name	Telephone	Mobile	Relationship to me

MR00H.01 MY ADVANCE CARE PLAN

health.wa.gov.au1

Preferences for my future care

Affix patient ID  
label here

These are my preferences, in relation to my future care.  
Please refer to the *Advance Care Planning Guide for Patients*.

Other outcomes of the Advance Care Planning conversation:

For example, you may have considered completing other relevant legal documents such as an Advance Health Directive or Enduring Power of Guardianship or you may have decided to become an organ donor.

Outcome	Description



**I have completed one or more of the following:**

Affix patient ID  
label here

**Advance Health Directive**

**Yes/No (please circle)**

I have stored a copy at: \_\_\_\_\_

A copy can also be obtained from:

Name: \_\_\_\_\_

Telephone: \_\_\_\_\_

---

**Enduring Power of Guardianship**

**Yes/No (please circle)**

I have stored a copy at: \_\_\_\_\_

A copy can also be obtained from:

Name: \_\_\_\_\_

Telephone: \_\_\_\_\_

---

**Enduring Power of Attorney**

**Yes/No (please circle)**

I have stored a copy at: \_\_\_\_\_

A copy can also be obtained from:

Name: \_\_\_\_\_

Telephone: \_\_\_\_\_

---

**Will**

**Yes/No (please circle)**

I have stored a copy at: \_\_\_\_\_

A copy can also be obtained from:

Name: \_\_\_\_\_

Telephone: \_\_\_\_\_



**If I have lost capacity or am approaching end of life, where practical and appropriate, I would prefer to be cared for:**

Initial the option you prefer:

- ☐ In my usual home: \_\_\_\_\_
- ☐ At a family member's home: \_\_\_\_\_
- ☐ At a hospice or palliative care unit
- ☐ In hospital
- ☐ On country (for Aboriginal and Torres Strait Islanders)
- ☐ At another place: \_\_\_\_\_

**I would like to leave the following message(s)**

For example: I am a carer for my partner/family member or I would like the following person to care for my pet, or I would like a particular song played or I would like a particular complementary therapy to be used or I would like my family to respect my preferences to be an organ donor etc.

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Signed: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

This document can be made available  
in alternative formats on request for  
a person with disability.

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