



THE HONG KONG  
POLYTECHNIC UNIVERSITY

香港理工大學

Pao Yue-kong Library

包玉剛圖書館

---

## Copyright Undertaking

This thesis is protected by copyright, with all rights reserved.

**By reading and using the thesis, the reader understands and agrees to the following terms:**

1. The reader will abide by the rules and legal ordinances governing copyright regarding the use of the thesis.
2. The reader will use the thesis for the purpose of research or private study only and not for distribution or further reproduction or any other purpose.
3. The reader agrees to indemnify and hold the University harmless from and against any loss, damage, cost, liability or expenses arising from copyright infringement or unauthorized usage.

### IMPORTANT

If you have reasons to believe that any materials in this thesis are deemed not suitable to be distributed in this form, or a copyright owner having difficulty with the material being included in our database, please contact [lbsys@polyu.edu.hk](mailto:lbsys@polyu.edu.hk) providing details. The Library will look into your claim and consider taking remedial action upon receipt of the written requests.

RELATIONSHIP AMONG INTENTION-TO-SEEK-HELP IN DEMENTIA, DEMENTIA  
LITERACY, ACCULTURATION AND SOCIAL NETWORK:  
A MIXED-METHOD STUDY

ADWOA OWUSUAA KODUAH

PHD

The Hong Kong Polytechnic University

2023

The Hong Kong Polytechnic University

School Of Nursing

Relationship among Intention-To-Seek-Help in Dementia, Dementia Literacy, Acculturation  
and Social Network: A Mixed-Method Study

Adwoa Owusuaa Koduah

A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of  
Philosophy

August 2022

## CERTIFICATE OF ORIGINALITY

I herein declare that this thesis is my own work and that, to the best of my knowledge and belief, it reproduces no material previously published or written, nor material that has been accepted for the award of any other degree or diploma, except where due acknowledgement has been made in the text.

---

KODUAH Adwoa Owusuaa

## **Abstract**

### **Introduction**

Africans are a growing minority group in China's megacities, and there are more than 3000 permanent residents and 167,000 African visitors each year to Hong Kong as of 2014. People of African descent have a higher risk of developing dementia. Many Africans seldom use dementia services and mostly rely on their family members to support the persons with dementia in their own homes. The rationale behind such actions is uncertain. Examining factors that may delineate the lack of early help-seeking for dementia among Africans is urgently needed. Cultural belief may be one of the influencing factors, while their mental health literacy level could be another factor. The current study investigates the relationship between dementia literacy, acculturation, social network, and intention-to-seek-help in dementia among Africans in Hong Kong.

**Methods:** This is a three-phase mixed-method design incorporating a scale development (dementia literacy scale), a qualitative study and a cross-sectional survey. Participants were Africans from Sub-Saharan Africa living in various districts in Hong Kong. A semi-structured interview guide was used to collect data for the study. Thematic analysis was used to analysis data from the study. DLS was modified from Mental Health Literacy Scale, considering the items from The Dementia Knowledge Assessment, Alzheimer's Disease Knowledge Scale (ADKS) and based on findings from qualitative study. Content and construct validity were checked by exploratory factor analysis. Quantitative data were collected using questionnaires measuring dementia literacy, acculturation, social networks, intention-to-seek-help, and participants' sociodemographic data. Descriptive statistics, correlation, and path analysis were used.

**Results:** Thirty participants were interviewed individually. Four themes emerged from the study: (a) Navigating cultural identity and contesting social exclusion, (b) changing beliefs and perceptions about dementia, (c) Pluralistic help-seeking for dementia, and (d) factors influencing intention-to-seek-help. Qualitative findings show that despite limited social contact with locals, dementia practices in Hong Kong significantly influenced Africans' perception, knowledge, and help-seeking for dementia. Contextual factors (such as availability of dementia services, health professional attitude, social ties and societal norms, perception, and practices of dementia) influenced dementia help-seeking among Africans in Hong Kong.

A total of 461 Africans aged 18 and above living in Hong Kong were recruited for the survey, with 90% expressing the intent to seek help from health professionals. Survey results also indicated that, contrary to previous literature, the total score of dementia literacy ( $r=.02$ ,  $p=0.609$ ) and acculturation ( $r=.02$ ,  $p=0.621$ ) are not associated with intention-to-seek-help. However, two (risk factors ( $r=-.16$ ,  $p=0.049$ ) and knowledge of how to access dementia information ( $r=-.13$ ,  $p=0.007$ )) out of the five domains of dementia are inversely associated with intention-to-seek-help. Also, of the four acculturation strategies, only the assimilation strategy ( $r=.13$ ,  $p=0.007$ ) showed a significant association with intention-to-seek-help. However, social network ( $r=.11$ ,  $p=0.014$ ) was positively associated with intention-to-seek-help. Path analysis revealed that assimilation had a significant positive mediating effect on the relationship between dementia literacy (Risk factors ( $\beta = 0.025$ ,  $p<0.001$ ) and how to get dementia information ( $\beta = 0.031$ ,  $p<0.001$ )) and intention-to-seek-help. Social networks ( $\beta = -0.011$ ,  $p=0.048$ ) showed a negative and significant mediating effect on the relationship among dementia literacy (information seeking) and intention-to-seek-help.

**Conclusion:** The current findings demonstrate that possession of sufficient dementia literacy does not manifest in higher intention to seek help. Despite a high level of support, the family was identified as a potential barrier to dementia help-seeking. To improve dementia help-seeking efficacy, enhancing social networks and assimilation of Africans into Hong Kong society is imperative. The current study contributed to two main aspects: (1) the development of a validated dementia literacy scale and (2) updating the current theoretical underpinning of the relationship between dementia literacy, acculturation, social network, and intention-to-seek-help for dementia.

### **Publications during the PhD study period**

1. Amoah, P. A., **Koduah, A. O.**, Gyasi, R. M., Nyamekye, K. A., & Phillips, D. R. (2022). Association of health literacy and socioeconomic status with oral health among older adults in Ghana: a moderation analysis of social capital. *Journal of Applied Gerontology*, 41(3), 671-679.
2. Bayuo, J., Abu-Odah, H., & **Koduah, A. O.** (2022). Components, Models of Integration, and Outcomes Associated with Palliative/End-of-Life Care Interventions in the Burn Unit: A Scoping Review. *Journal of Palliative Care*, 08258597221102735.
3. Amoah, P. A., **Koduah, A. O.**, Gyasi, R. M., Nyamekye, K. A., & Phillips, D. R. (2021). Association of Health Literacy and Socioeconomic Status with Oral Health Among Older Adults in Ghana: A Moderation Analysis of Social Capital. *J Appl Gerontol*, 7334648211028391. doi:10.1177/07334648211028391
4. **Koduah, A. O.**, Amoah, P. A., Nkansah, J. O., & Leung, A. Y. (2021). A Comparative Analysis of Student and Practising Nurses' Health Literacy Knowledge in Ghana. *Healthcare*.
5. Amoah, P. A., **Koduah, A. O.**, Anaduaka, U. S., Addae, E. A., Gwenzi, G. D., & Amankwaa, A. (2020). Psychological wellbeing in diaspora space: a study of African economic migrants in Hong Kong. *Asian Ethnicity*, 1-18.
6. **Koduah, A. O.**, Leung, A. Y., Leung, D. Y., & Liu, J. Y. (2019). "I sometimes ask patients to consider spiritual care": health literacy and culture in mental health nursing practice. *International Journal of Environmental Research and Public Health*, 16(19), 3589.
7. **Koduah, A.O.**, Leung, A.Y., Teris C. (2022). Acculturation and Dementia Literacy among Africans Living in Hong Kong: A Qualitative Study. *International Journal of Environmental Research and Public Health*. Under review.
8. Leung, A. Y. M., Parial, L. L., Szeto, S., & **Koduah, A. O.** (2022). Understanding the role of financial health literacy in old age: A scoping review. *Health and Social Care in the Community*. Under review.
9. **Koduah, A.O.**, Leung, A.Y., Teris C. (2022). Dementia Literacy and Its Associated Factors among the General Population: A systematic Review. *Rejected by Journal of Advanced Nursing*. Under Revision.

### Conference Presentations

1. **Koduah, A.O.**, Leung, A.Y., Teris C. (2023). Relationship among Dementia Literacy, Acculturation, Social Network and Help-Seeking Behaviour: A mixed Method Study. The 26<sup>th</sup> East Asian Forum of Nursing Scholars (EAFONS) 2023. 10-11 March 2023. Tokyo, Japan.
2. **Koduah, A.O.**, Leung, A.Y., Teris C. (2022). *Relationships among Help-Seeking Behaviour, Dementia Literacy, Acculturation and Social Network: A Cross-sectional Survey*. [Oral Presentation] The 8<sup>th</sup> Asia Health Literacy Association Conference 27-29 Oct 2022. Chang Hua, Taiwan.
3. **Koduah, A.O.**, Leung, A.Y., Teris C. (2021). *The Role of Acculturation in Dementia Literacy of Africans in an Eastern Society: A Qualitative Study* [Poster Presentation]. Health Literacy Annual Research Conference (HARC) 2021. Virtual Conference.
4. **Koduah, A.O.**, Leung, A.Y., Teris C. (2021). *“Dementia is Not Our Portion”:* *Acculturation and its Impact on Dementia Literacy of Africans in Hong Kong*. [Poster Presentation]. 28<sup>th</sup> Annual Congress of Gerontology 2021. Hong Kong Baptist University, Hong Kong.
5. **Koduah, A.O.**, (2021). *Health Literacy and Coronavirus (COVID-19): A Students’ Perspective*. [Oral Presentation] International Health Literacy Association Webinars (March 2021). Virtual Conference.
6. **Koduah, A.O.**, Leung, A. Y., & Liu, J. Y. (2019). *Nurses Knowledge of and Experience with Health Literacy in Clinical Practice: A Meta-Ethnography* [ Oral Presentation]. 7<sup>th</sup> International Health Literacy Conference 2019. Ho chi Minh City, Vietnam.

### Other Presentations

7. **Koduah, A.O.**, Leung, A.Y., Teris C. (2022). *Africans in Hong Kong: Acculturation, Well-Being, and Health Related-Issues*. [Oral Presentation] African Center’s Service and Exchange Program 2022. Hong Kong.
8. **Koduah A.O.** 2021. Topic: Health Literacy and Covid 19: The Opportunity for Researchers [**Speaker**] Webinar Theme: “Health Literacy Explorers: Opportunity, Innovation, Mindset during Covid-19. 24 March 2021. Virtual Webinar.



## **Acknowledgements**

I want to express my profound gratitude to the Almighty God for his protection and guidance throughout my PhD journey. I am thankful to God for granting me perseverance in moments when I felt like giving up and the strength to be able to complete this tremendously three-years task. I am humbled and grateful for this opportunity.

To Prof. Angela Y.M Leung, thanks for your enthusiastic support, encouragement, and guidance during my PhD program. Your expertise guided me through all the hurdles I encountered during this three years journey. Thanks for not denying anything and instilling in me the perseverance spirit to realise my dream as a researcher. To my co-supervisor, Dr Teris Cheung, it was an honour to share your expertise and knowledge. It is a great pleasure working with you as both supervisors, and I could not have completed this journey without you.

I want to thank the Hong Kong Polytechnic University for the financial assistance and resources to enable this study.

More importantly, I would like to thank all the participants who agreed to be part of this study. Your time and contributions to this study are immensely appreciated.

I am truly indebted to you, my dear husband, Dr Padmore A. Amoah. Thank you for your unyielding support and a keen interest in my academic pursuits. Thanks for taking care of Jayden during those long hours of studying genuinely truly grateful for the emotional support and encouragement during those days when I felt lost. To be born during this journey- thanks for being a wonderful son. I am deeply sorry for all the hours and days we spent apart. I am grateful to my siblings and in-laws for your support and prayers. Thanks for your heavenly blessings, my dear parents (Sampson T. Koduah & Comfort Donkor-Koduah). I hope to continue to make you proud. Special thanks to all my friends and colleagues for your support and encouragement.

## Table of Contents

Certificate of Originality.....	iii
Abstract.....	iv
Acknowledgement .....	viii
List of Tables .....	xv
List Of Abbreviations .....	xvii
<b>Chapter 1: Introduction .....</b>	<b>1</b>
1.1 Background.....	1
1.2 Dementia Literacy.....	2
1.3 Dementia literacy among racial and ethnic minorities .....	2
1.4 Factors associated with dementia literacy of racial and ethnic minorities.....	4
1.5 Problem Statement.....	5
1.6 Research Objectives.....	6
1.7 Research Questions.....	6
1.8 Study Significance and Contributions .....	6
1.9 Thesis Structure .....	7
<b>Chapter 2: Theories And Concepts: Approaches To Understanding The Relationship Between Dementia Literacy, Acculturation And Help-Seeking Behaviour .....</b>	<b>8</b>
2.1 Introduction.....	8
2.2 Dementia Literacy: The Concept.....	8
2.2.1 Exploring definitions of dementia literacy. ....	9
2.3 Dementia Literacy and Its Associated Factors : A Scoping Review.....	11
2.3.1 Background .....	11
2.3.2 Review Objectives.....	12
2.3.3 Methods .....	12
2.3.4 Results .....	14

2.3.5 Discussion.....	34
2.3.6 Conclusion.....	37
2.4 Acculturation and Health Behaviour.....	38
2.4.1 Acculturation: The Concept.....	38
2.4.2 Relationship between Acculturation and Help-Seeking Behaviour .....	40
2.5 Help-Seeking Behaviour: The Concept.....	42
2.5.1 Help-Seeking Theory.....	43
2.5.2 Dementia Help-seeking behaviour .....	43
2.5.3 Factors associated with dementia help-seeking behaviour.....	44
2.6 Research Gap.....	46
2.7 Theoretical Framework .....	47
2.7.1 Sociocultural Health Belief Model (SHBM).....	48
2.7.2 Mental Health Literacy Model .....	49
2.7.3 Conceptual Framework of the Study .....	50
2.7 Summary of Chapter 2 .....	52
<b>Chapter 3: Methodology.....</b>	<b>53</b>
3.1 Introduction .....	53
3.2 Study Purpose.....	53
3.2.1 Aim/Objectives.....	53
3.2.2 Research Questions.....	53
3.3 Methodology .....	53
3.4 Research Design.....	54
3.5 Settings.....	56
3.6 Phase 1: Development of the Dementia Literacy Scale .....	57
3.6.1 Item Generation for the DLS .....	57
3.6.2 Construction of Dementia Literacy Scale.....	58

3.6.3 Assessment of DLS psychometric properties .....	61
3.7 Phase 2: The Qualitative Study .....	64
3.7.1 Study Design .....	64
3.7.2 Sampling and Sampling technique .....	65
3.7.3 Inclusion and exclusion criteria.....	65
3.7.4 Sample Size .....	66
3.7.5 Participants Recruitment.....	67
3.7.6 Data collection method.....	67
3.7.7 Interview guide.....	68
3.7.8 Reflexivity .....	70
3.7.9 Data Analysis.....	72
3.7.10 Rigour .....	73
3.8 Phase 3: Quantitative Study (Cross-sectional Survey).....	75
3.8.1 Study Design .....	75
3.8.2 Sample and Sampling Method.....	75
3.8.3 Inclusion and Exclusion Criteria .....	75
3.8.4 Sample Size Calculation.....	76
3.8.5 Data Collection Procedures .....	76
3.8.6 Measuring Instruments .....	77
3.8.7 Data Analysis.....	81
3.9 Integration of Findings from Both Studies (Data Triangulation).....	83
3.10 Ethical Consideration and Approval for all Three Phases .....	84
3.11 Summary of Chapter .....	85
<b>Chapter 4: Psychometric Properties Of The Dementia Literacy Scale (Dls).....</b>	<b>86</b>
4.1 Item Revision to suit dementia context.....	86
4.2 Content Validity of the Dementia Literacy Scale. ....	86

4.2.1 Face Validity (Qualitative) .....	88
4.3 Dementia literacy scale .....	91
4.3.1 Description of sample .....	91
4.3.2 Exploratory factor analysis of the DLS .....	93
4.3.3 Confirmatory Factor Analysis of the DLS .....	96
4.4 Summary of Chapter .....	98
<b>Chapter 5: Results Of The Qualitative Study .....</b>	<b>99</b>
5.1 Introduction .....	99
5.2 Demographics of the participants.....	99
5.3 Findings of the study .....	101
5.3.1 Navigating Cultural Identity and Contesting Social Exclusion.....	101
5.3.2 Changing in beliefs and perceptions about dementia. ....	107
5.3.3 Pluralistic help-seeking behaviour of Africans .....	113
5.3.4 Factors influencing intention-to-see-help for dementia.....	114
5.4 Chapter Summary.....	117
<b>Chapter 6: Findings From The Cross-Sectional Survey .....</b>	<b>120</b>
6.1 Descriptive Statistics.....	120
6.1.1 Characteristics of Sample .....	120
6.1.2 Dementia Literacy .....	124
6.1.3 Acculturation .....	125
6.1.4 Social Network of Participants .....	127
6.1.5 Intention-to-Seek-Help .....	128
6.2 Results of Correlation Analysis.....	129
6.2.1 Intention-to-Seek-Help and sociodemographic variables.....	129
6.2.2 Intention-to-Seek-Help, dementia literacy, acculturation, and social network .....	129

6.3 Association among Dementia Literacy, Acculturation, Social Network and Intention-to-Seek-Help.....	132
6.3.1 Relationship among total scores of dementia literacy, Acculturation, Social Network, and Intention-to-Seek-Help .....	132
6.3.2 Relationship among the subscales of dementia literacy, acculturation, social network, and Intention-to-Seek-Help .....	133
6.3.3 Relationship among Social Network, Assimilation, Knowledge of risk factors, of how to seek dementia information and Intention-to-Seek-Help.....	134
6.4.1 Dementia literacy mediates the relationship between Acculturation, Social Network, and Intention-to-Seek-Help .....	135
6.4.2 Mediating effect of acculturation (assimilation) and social network .....	136
6.5 Summary of Chapter .....	138

**Chapter 7: Discussion Of Findings From The Study. .... 139**

7.1 Introduction .....	139
7.2 Restating the Study’s Objective and Research Approach.....	139
7.3 Dementia Literacy Scale .....	140
7.3.1 Reasons for developing the DLS.....	140
7.3.2 Features and psychometric properties of DLS .....	141
7.4 Possession of adequate dementia literacy does not always affect intention-to-seek-help .....	142
7.5 Strong familial and African cultural ties as impediment to intention-to-seek-help for dementia. ....	143
7.6 Aligning with Host culture (assimilation) interlink with dementia literacy to influence intention-to-seek-help.....	144
7.7 Poor understanding of key issues about dementia .....	145
7.8 Diverse and inconstant Acculturation strategies among Africans in Hong Kong.....	147
7.9 Sociodemographic characteristics of participants .....	148
7.10 Study Limitation.....	149

7.11 Chapter Summary.....	150
<b>Chapter 8: Study Contribution And Implication .....</b>	<b>151</b>
8.1 Introduction.....	151
8.2 Implication for Healthcare Practice.....	151
8.3 Policy Implications and Recommendations .....	153
8.4 Contributions of the study .....	155
8.4.1 Research and Methodological Contribution.....	155
8.4.2 Theoretical Contribution.....	156
8.4.3 Contribution to Health policies.....	157
8.5 Recommendation for Future Research.....	158
<b>Chapter 9: Conclusion.....</b>	<b>159</b>
References.....	161
APPENDICES .....	165

## List of Tables

TABLE 2. 1. OVERVIEW OF STUDIES INCLUDED IN THE REVIEW. ....	17
TABLE 2. 2. THEMES DERIVED FROM THE INCLUDED STUDIES.....	23
FIGURE 2.1. SOCIOCULTURAL HEALTH BELIEF MODEL .....	48
FIGURE 2.2 CONCEPTUAL FRAMEWORK FOR THE STUDY .....	51
FIGURE 3. 1: EXPLORATORY SEQUENTIAL MIXED METHOD PROCESS FOR THE STUDY .....	55
TABLE 3. 1. OPERATIONAL DEFINITION OF THE SIX SUBSCALES OF THE DEMENTIA LITERACY SCALE.....	57
TABLE 3. 2. INTERVIEW GUIDE .....	68
FIGURE 3. 2. VIGNETTE DESCRIBING SYMPTOMS OF DEMENTIA.....	69
TABLE 3. 3. PSYCHOMETRIC PROPERTIES OF MEASURES USED IN THE STUDY .....	77
TABLE 3. 4. ACCULTURATION STRATEGIES DERIVED FROM THE BRIEF ACCULTURATION ORIENTATION SCALE.....	79
TABLE 4. 1. EXPERT RATING OF THE CONTENT VALIDITY OF THE DEMENTIA LITERACY SCALE .....	87
TABLE 4.2 MINOR REVISION OF THE ITEMS AFTER RECEIVING COMMENTS FROM THE EXPERTS .....	89
TABLE 4.3. CHARACTERISTICS OF THE SAMPLE INCLUDED IN EFA AND CFA .....	91
TABLE 4.4. RESULTS OF EXPLORATORY FACTOR ANALYSIS .....	93
FIGURE 4. 1. CONFIRMATORY FACTOR ANALYSIS OF THE DEMENTIA LITERACY SCALE (DLS)97	
TABLE 4.5. DESCRIPTIVE STATISTICS OF THE DLS AND ITS SUBSCALES .....	98
TABLE 5. 1. DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS INCLUDED IN THE QUALITATIVE STUDY .....	100
TABLE 6. 1 SOCIODEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS. ....	120
TABLE 6. 2. COUNTRY OF ORIGIN OF PARTICIPANTS.....	123
TABLE 6. 3. DESCRIPTIVE STATISTICS OF THE DEMENTIA LITERACY SCALE.....	125
TABLE 6. 4 DESCRIPTIVE ANALYSIS OF THE BRIEF ACCULTURATION ORIENTATION SCALE (BAOS).....	126
TABLE 6. 5. DESCRIPTIVE STATISTICS OF SCORES ON LUBBEN SOCIAL NETWORK SCALE .....	127
TABLE 6. 6. DESCRIPTIVE SCORE FOR INTENTION-TO-SEEK-HELP .....	128
TABLE 6. 7. CORRELATION BETWEEN INTENTION-TO-SEEK-HELP AND SOCIODEMOGRAPHIC VARIABLES.....	130
TABLE 6. 9. REGRESSION ANALYSIS OF SOCIAL NETWORK, ACCULTURATION, DEMENTIA LITERACY, AND ITS RELATIONSHIP TO INTENTION-TO-SEEK-HELP.....	132



TABLE 6.10. REGRESSION ANALYSIS AMONG THE SUBSCALES OF DEMENTIA LITERACY, ACCULTURATION, SOCIAL NETWORK, AND ITS RELATIONSHIP WITH INTENTION-TO-SEEK-HELP.....	133
TABLE 6. 11 REGRESSION ANALYSIS OF SOCIAL NETWORK (TOTAL SCORE), ASSIMILATION, RISK FACTORS AND INFORMATION SEEKING AND INTENTION-TO-SEEK-HELP.....	134
TABLE 6 12. MEDIATING EFFECT OF ASSIMILATION AND SOCIAL NETWORK .....	138
APPENDIX 1: METHODOLOGICAL APPRAISAL OF INCLUDED STUDIES USING JBI CRITICAL APPRAISAL CHECKLIST.....	165
APPENDIX 2: QUALITY APPRAISAL USING MMAT TOOL AND CRITICAL APPRAISAL SKILLS PROGRAMME QUALITATIVE.....	166
APPENDIX 3: ETHICAL APPROVAL FOR THE STUDY.....	167
167	
APPENDIX 4: INFORMATION SHEET .....	168
APPENDIX 5: INFORMED CONSENT .....	170
APPENDIX 6: SURVEY QUESTIONNAIRE.....	171

## List Of Abbreviations

ADKS	Alzheimer's Disease Knowledge Scale
BAOS	Brief Acculturation Orientation Scale
CFA	Confirmatory Factor Analysis
CFI	Comparative Fit Index
DAS	Dementia Attitude Scale
DKAS	Dementia Knowledge Assessment Scale
DL	Dementia Literacy
DLS	Dementia Literacy Scale
EFA	Exploratory Factor Analysis
GHSQ	General Help Seeking Questionnaire
I-CVI	Item Level Content Validity Index
IFI	Incremental Fit Index
IOM	International Organization for Migration
JBI	Joanna Briggs Institute
KMO	Kaiser Meyer Olkin
LSNS-6	Lubben Social Network Scale 6
MHL	Mental Health Literacy
MHLS	Mental Health Literacy Scale
NFI	Normed Fit Index
RA	Research Assistant
RMSEA	Root Square Error Approximation
SN	School of Nursing
SPSS	Statistical Package for the Social Sciences
SRMR	Standardized Root Mean Square Residual
TLI	Tucker Lewis Index

## **CHAPTER 1: INTRODUCTION**

This chapter presents the background to the thesis, with information about Intention-to-seek-help, dementia literacy, and the role of acculturation in dementia literacy. It discusses the study's objectives, questions, and its significance. The last section of this chapter provides a brief description of the thesis outline.

### **1.1 Background**

Over the last two decades, many Africans have migrated to Asia, predominately to China's megacities, including Guangzhou, Hong Kong, Macau, Yiwu, and Beijing (Amoah, Koduah, et al., 2020; Bodomo, 2020; Castillo, 2016). However, there is literature that dates the presence of Africans in China as far back as the Tang Dynasty (618-907, A.D) (Bodomo, 2020). There are estimated more than 500,000 Africans in China, with 100,000 in Guangzhou alone (Bodomo, 2020). A recent study indicated that more than 3,000 African migrants live in Hong Kong, with 167,000 visitors yearly (Amoah, Koduah, et al., 2020). The increasing presence of Africans in China has been attributed to the rapid rise of China as political and economic power and as a significant study abroad destination (Amoah, Koduah, et al., 2020; Castillo, 2016; Hall et al., 2014; Haugen, 2013). Most Africans migrate to various Chinese cities for economic reasons, others as refugees and students (Amoah, Koduah, et al., 2020; Bodomo, 2020). The influx of thousands of Africans into China has added a new dimension to healthcare and medical services. Recent research confirms this in places like Hong Kong (Amoah, Koduah, et al., 2020; Hall et al., 2014). Due to the rapid expansion of the African population in China, the number of older adults in this population is also growing. Many of them are likely to develop dementia in the following decades. Physiological ageing, influenced by societal factors, is a key contributor to early onset of dementia (Alzheimer's Disease Association, 2021).

Dementia is a global epidemic, and the burden brought about by dementia is considerable for those who are affected, their family, friends, and society (Alzheimer's Association, 2019, p. 213). Currently, there are more than 50 million people with dementia worldwide, with nearly 10 million cases of dementia each year, with about 25% of cases in China (Alzheimer's Association, 2019; Annear, Toye, McInerney, et al., 2015). Recent estimates indicate that 9.55 million people in China and Hong Kong have dementia (Wu et al., 2018). The prevalence rate of dementia in Hong Kong is estimated at 5%- 8% among older adults aged 65, and 20%-30% among those older than 80 years (Lam et al., 2019). Due to the increasing number of dementia cases in Chinese societies, dementia is regarded as an essential topic of discussion and has

received greater attention in recent years, which means that more recognition has been paid to the dementia literacy of caregivers, persons with dementia and the general population (Kwok et al., 2011; Kwok et al., 2013; Lam et al., 2019; A. Y. Leung et al., 2018). However, studies about dementia literacy in Hong Kong have focused solely on the local (Hong Kongers) population. In contrast, there has been no research into the dementia literacy of ethnic minority groups, including African migrants, in the city. A recent study indicated that African immigrants living in the United States are 1.71 times more likely to be diagnosed with dementia than Caucasians (Bibio, 2019). Despite this, research shows that Africans migrants often possess limited knowledge and negative attitudes, and delay seeking help for dementia (Berwald et al., 2016; Mukadam et al., 2011).

## **1.2 Dementia Literacy**

Dementia literacy is defined as the understanding of dementia and its treatment, decreasing of dementia-related stigma, knowing when and where to seek help and information on dementia, and developing competencies to improve dementia care and self-management capabilities (Kutcher et al., 2015; S Kutcher, Y. Wei, et al., 2016). Dementia literacy is a construct that has arisen from the domain of mental health literacy. The term ‘dementia literacy’ was first used by Low and Anstey (2009, p. 43), defined as “knowledge and beliefs regarding dementia that aid recognition, management and prevention”. To date, various reviews have reported a significant disparity in dementia literacy among the general population, even in developed countries (Cahill et al., 2015; Cations et al., 2018; Farina et al., 2020; Roche et al., 2021). However, congruent among these studies is that misconceptions, and poor knowledge of dementia risk factors and management was common among people of all races, but even poorer among people of racial and ethnic minority backgrounds (Cahill et al., 2015). Understanding and accessing dementia literacy among racial and ethnic minority groups is imperative.

## **1.3 Dementia literacy among racial and ethnic minorities**

Low awareness and knowledge of dementia abounds among racial and ethnic minorities from different cultures. Culture influences how an individual understands, perceives, approaches, and gives meaning to a particular situation (Qiufen, 2014). Cultural differences exist among various societies and populations regarding understanding and perception of the nature and causes of dementia, which often influence preferred dementia treatment modalities. Inadequate dementia literacy has been reported to correlate with ethnicity and is prevalent among people

of racial and ethnic minority backgrounds (Mehta & Yeo, 2017; Mukadam et al., 2015; Roche et al., 2021; Werner et al., 2014).

Low et al. (2010), in a study focusing on Italian, Chinese, and Greek Australians in comparison with third-generation Australians, identified that most third-generation Australians were more likely to recognise symptoms of dementia than Chinese, Greek, and Italian Australians. The study revealed that these racial and ethnic minority groups were more likely to suggest psychosocial risk factors and ageing as causes of dementia. Third-generation Australians were more likely to suggest brain disease/trauma (Low et al., 2010). Conversely, studies focused on Chinese Americans have reported that most participants believe dementia is a brain disease (Diamond & Woo, 2014; Woo, 2013). Beliefs that dementia could have been avoided and that persons with dementia should be treated as a child is a common belief held by Australian Chinese (Diamond & Woo, 2014; Low et al., 2010; Sun et al., 2021). A recent study identified that these biased beliefs did not change from 2013 to 2017 (Sun et al., 2021). These findings correspond with studies conducted in Mainland China, where participants were identified as holding similar negative beliefs about dementia (Liu et al., 2019).

Among people of African descent (Caribbean ethnic groups and Black Africans), Berwald et al. (2016) identified that most participants reported that dementia was an unfamiliar term to them before migration, and they had poor knowledge of dementia. To some study participants, Africans do not have dementia; instead, it is a disease of Whites or Caucasians (Berwald et al., 2016). These findings are consistent with a recent review among adults of Black, Caribbean and African descent (Roche et al., 2021). According to Roche et al. (2021), religion (faith and spirituality) forms an integral part of the context in which an individual experiences and understands dementia and sources of treatment and support. Similar findings have been reported among South Asian migrants (Hossain et al., 2020). Among Pakistanis, there was a general notion that being diagnosed with dementia helps draw older adults closer to God and deepens their spirituality (Qadir et al., 2013). Some South Asian caregivers perceived dementia as a punishment from God and possession by demons (Hossain et al., 2020; Qadir et al., 2013).

Racial and ethnic minority groups have been identified to delay help-seeking for dementia until a crisis point when family caregivers cannot manage or cope (Mukadam et al., 2011; Mukadam et al., 2015). Lack of awareness and knowledge about dementia often leads to delays in seeking help and, therefore, a delayed diagnosis for persons with dementia (P.W.D.) (Alzheimer's

Association, 2019). A recent review focusing on the pathways to dementia help-seeking identified that British South Asians were of the opinion that dementia is not an illness that requires medical attention, due to the perception that dementia is caused by social or spiritual factors (Mukadam et al., 2011). A sense of filial piety among Asians and familism among people of African descent were also identified. Language barriers, acculturation, and healthcare-related barriers were identified as other barriers that influence help-seeking among racial and ethnic minority groups.

#### **1.4 Factors associated with dementia literacy of racial and ethnic minorities.**

Among people of racial and ethnic minority groups, several factors have been associated with their level of dementia literacy, including cultural, socioeconomic, and psychological factors.

##### *Sociodemographic factors*

Among ethnic minorities, being female, depression, educational status, and ethnicity have been identified as factors associated with adequate dementia literacy. Chinese Americans born outside of the U.S. have been reported to possess higher knowledge and lower biased beliefs than those born in America (Sun et al., 2021). Migration stress often worsens racial and ethnic minorities' psychological status and puts them at risk for depression. Depressive symptoms have been identified by various studies as associated with dementia literacy. Lower levels of depression were reported to be associated with adequate dementia knowledge and lower biased dementia beliefs (Sun et al., 2013; Sun et al., 2021; Zhang et al., 2017a).

##### *Social relationships (social network and family conflicts) and dementia literacy*

Among Chinese Americans, there is an association between social networks, family conflicts, dementia worry and dementia literacy (Sun et al., 2021). A recent review shows that support from informal networks facilitates dementia help-seeking (Parker et al., 2020).

##### *Acculturation*

One of the key factors that influences dementia knowledge, attitude, and help-seeking behaviour globally is the level of acculturation of ethnic minority groups or migrants in the host country (Lee et al., 2010; Mahoney et al., 2005; Mukadam et al., 2011; Schrauf & Iris, 2011). Acculturation has been defined as the complex process by which an individual incorporates a host group's cultural patterns through immigration (Satia-Abouta et al., 2002). The level of acculturation has been associated with various health beliefs and practices among

ethnic minorities and people from low- and middle-income countries (Berry, 2003; Sayegh & Knight, 2013). Studies have suggested that the higher an individual's acculturation level, the more exposure the person has to Western ideologies and information concerning specific health issues, the more likely they are to be knowledgeable about biomedical concepts of dementia (Lee et al., 2010). Various acculturation proxies have been associated with dementia knowledge.

The duration of residence of Chinese Americans in America was compared with their levels of dementia literacy, and it was identified that duration of residence only minimally impacts dementia literacy (Diamond & Woo, 2014). English language proficiency and the use of English print materials have been associated with the recognition of dementia symptoms and knowledge of risk factors (Low et al., 2010)

Research has shown that ethnic minority groups who are less acculturated to Western cultures have inadequate knowledge about dementia, tend to be more unfamiliar with dementia, tend to underutilise dementia services, and have poorer health outcomes (Ciampa et al., 2013; Lee et al., 2010; Nielsen & Waldemar, 2016; Suzuki et al., 2015). A recent systematic review by Cations et al. (2018) has revealed that knowledge of, and attitudes towards, dementia among ethnic minorities living in Western countries had improved over time, due to contact with Western cultural beliefs and practices related to dementia.

Nonetheless, there were primarily cultural and geographical gaps in these studies. The studies mentioned above focus solely on African Americans, Asian Americans, Hispanic/Latin Americans, and other ethnic minority groups living in America and Europe, with no similar studies about ethnic minority groups in Asia (Lee et al., 2010; Xiao et al., 2015; Yong & Manthorpe, 2016; Yuri Jang et al., 2010). Given the homogeneity of various populous countries such as Japan and China, it will be interesting to identify how ethnic minorities acculturate within these societies, and how living in such countries influences their knowledge of various health conditions, including dementia.

## **1.5 Problem Statement**

Literature about Africans in Hong Kong has shown that the majority of Africans suffer from depression, racism, discrimination, and social alienation, all of which directly impact their health status and access to health information and services (Amoah, Koduah, et al., 2020; Hall

et al., 2014; Wong et al., 2017a). It is therefore fair to assume that due to these social difficulties, there may be little room for African migrants to assimilate or integrate into the host country's culture. Therefore, dementia literacy in this population may be relatively low. The majority of dementia literacy-related studies are from the United States of America; it is difficult to ascertain how common these issues are among migrants in other regions, such as Asia, Europe, and Africa. Therefore, further studies must verify the dementia literacy and related barriers in the general population, including racial and ethnic minority groups. Moreover, no study has assessed how acculturation is associated with dementia literacy in Eastern cultures or societies.

### **1.6 Research Objectives**

This study investigates the level of dementia literacy among Africans living in Hong Kong. Further, it explores the relationship between dementia literacy, acculturation, social networks, and the intention-to-seek-help for dementia.

### **1.7 Research Questions**

1. What acculturation strategies do Africans use when they are living in Hong Kong?
2. How much do Africans know about dementia?
3. What factors affect Africans' intention-to-seek-help for dementia?
  - a. Would dementia literacy directly affect their intention-to-seek-help?
  - b. Would acculturation and social network also affect their intention-to-seek-help?
  - c. Would dementia literacy, acculturation and social network interlink and affect Africans' intention-to-seek-help?

### **1.8 Study Significance and Contributions**

This study focused on a growing ethnic minority group in Hong Kong that demands interventions to improve their dementia literacy and acculturation in the host society but has yet to receive sufficient attention from health professionals, policymakers, and researchers. Findings from this study have contributed immensely to literature, policy, and practice.

- Developing a comprehensive scale for dementia literacy has resolved one of the overarching issues in assessing the construct. The scale showed excellent psychometric property and will serve as a valuable tool in evaluating the efficacy of dementia-related interventions and the dementia literacy of other Africans living in Eastern and Western societies.



- Theoretically, findings from the study support the inclusion of various social determinants of health including, acculturation, sociodemographic characteristics, and social networks in an empirically evidence-based model of dementia help-seeking among racial and ethnic minority groups (Sayegh & Knight, 2013). Also, the findings expand our understanding of the association between dementia literacy and intention-to-see-help. Results from this study prove that addressing dementia literacy alone among African migrants might not translate into a positive or higher intention to-see-help for dementia without addressing acculturation issues. These findings emphasise that acculturation of migrants is as crucial as dementia literacy when aiming to promote early help-seeking behaviours, at least among Africans in Hong Kong.
  
- Lastly, this study is motivated as a personal ambition to promote dementia literacy among people of African descent. As a race or group of people whose attitudes and perceptions of mental health issues are often shaped by their cultural ideologies, Africans provide a valuable example to illustrate how one's culture is connected to one's understanding of mental health. Thus, this study has contributed to the discussion and the body of data about dementia literacy, acculturation, social networks, and help-seeking behaviour.

## **1.9 Thesis Structure**

This thesis consists of nine chapters, including this section. Chapter 2 elaborates on the study theoretical and conceptual framework based on the accompanying literature review. Chapter 3 addresses issues related to the methodology (mixed-method design) and includes a description of the significance of the methods, techniques used, and measuring instruments for data collection. Chapter 4 details the results of the psychometric properties of the newly designed dementia literacy scale. Chapter 5 describes findings from the qualitative study and the study's empirical aspect. Meanwhile, Chapter 6 presents the descriptive statistics and examines the relationship between dementia literacy, acculturation, social networks, and intention-to-see-help. Chapter 7 (Discussion) merged and summarise findings from three phases of the research. A discussion of the limitations of the study is also made. The chapter 8 makes recommendations and discusses the study's contributions to research, theory, and practice. The final chapter (9) ends with concluding remarks about the study.

**CHAPTER 2:**  
**THEORIES AND CONCEPTS: APPROACHES TO UNDERSTANDING THE**  
**RELATIONSHIP BETWEEN DEMENTIA LITERACY, ACCULTURATION AND**  
**HELP-SEEKING BEHAVIOUR**

**2.1 Introduction**

The prime focus of this chapter was to review extant literature to examine the relationship between dementia literacy, acculturation, and help-seeking behaviour. The discussions of this chapter are divided into seven sub-sections. Theoretical underpinning and how the three key concepts (dementia literacy, acculturation, and help-seeking behaviour) have been defined and assessed by various researchers are discussed in this chapter. The first section provided an overview of what is known and unknown about the concept of mental health literacy. Secondly, the chapter discussed what is known regarding dementia literacy as a concept. Third section presented a scoping review on dementia literacy and its associated factors among the general population. Section four provided an overview of what is known about the concept of acculturation and its role in dementia literacy and help-seeking behaviour. The fifth section discussed help-seeking behaviour and it correlates with regards to dementia. At the same time, the sixth section analysed the gaps in the literature concerning the association between dementia literacy, acculturation, and help-seeking behaviour. The final section highlights the conceptual framework for the study. By drawing on findings from these reviews, a number of hypotheses were drawn. The chapter ends with a summary of the literature.

**2.2 Dementia Literacy: The Concept**

Dementia is a global health issue that affect over 55 million people and the 7th leading cause of disability and mortality globally (World Health Organization, 2021a). The ability of individuals to recognise, access dementia information, manage health and navigate the healthcare system is imperative. Despite the increasing cases of dementia, knowledge and understanding of the condition remains low (Cahill et al., 2015). Evidence shows that 40% of all dementias may be preventable (Livingston et al., 2020), possession of dementia literacy is desirable among the general population. Dementia literacy is the foundation for the general public, caregivers, and family to recognise dementia symptoms, communicate understanding of risk reduction and preventive measures and seek early diagnosis and treatment (Cahill, 2021). Possession of dementia literacy is perceive to reduce stigma and promote positive attitude towards persons living with dementia (Cahill, 2021).

### 2.2.1 Exploring definitions of dementia literacy.

Currently, there is no consensus on the definition and measurement of dementia literacy. Dementia literacy was a terminology adopted from Mental health literacy (MHL). Although there is a lot of work on mental health literacy, there have been fewer dementia literacy studies. A current review (section 2.3) identified only 16 studies on dementia literacy. There is inconsistent definition of dementia literacy in the literature. To date no study has focused on dementia literacy as a concept and provided a working definition or model. The first definition by Low and Anstey (2009) defined dementia literacy as the beliefs and knowledge regarding dementia that aid recognition, prevention and management.

Although the concept of mental health literacy has gain recognition in the past several decades, but it is not well-researched and known as the main concept health literacy. Different terminologies exist about dementia in the literature. This includes dementia literacy (Aihara & Maeda, 2020; Barak et al., 2022; Diamond & Woo, 2014; Heger et al., 2019; Horst et al., 2021; A. Y. M. Leung et al., 2019; Leung et al., 2020; Loi & Lautenschlager, 2015; Low & Anstey, 2009; Low et al., 2010; Park & Shin, 2021; Sun et al., 2021; Zhang et al., 2017a), Alzheimer's disease literacy (Stansbury et al., 2010; Sun et al., 2013) and mental health literacy of dementia (Carr & Furnham, 2021). Most literature or articles do not provide an explicit definition of dementia literacy but mostly align it with health literacy or mental health literacy (Aihara & Maeda, 2020; Barak et al., 2022; Diamond & Woo, 2014; Heger et al., 2019).

Of these definitions, the ones by Low and Anstey (2009) and Jorm (2000) were the most cited definition for dementia literacy. Notably, Low and Anstey (2009) definition of dementia literacy was adapted from Jorm's first definition of mental health literacy (MHL). However, Park and Shin (2021) presented a different definition of dementia literacy that focuses on health literacy and defined it as an individual's ability to access, understand, evaluate, and use dementia information (Organization, 2012). The similarity of this definition is their focus on the individual's knowledge, attitude and beliefs about dementia that aid the recognition, prevention, management, and early diagnosis. All the definitions focused on the individual's capacities and included two main health domains: healthcare (recognition, help-seeking, and management) and prevention.

Table 1. Definitions of Dementia Literacy

Low and Anstey (2009)	“Knowledge and beliefs about dementia that aid recognition, management, or preventions”
Low et al. (2010)	Dementia literacy refers to a person’s knowledge regarding dementia, with greater dementia literacy shown to facilitate help-seeking
World Health Organization (2012)	Dementia literacy refers to the ability to acquire, understand, evaluate, and use information on dementia-related prevention, management, and early treatment.
Lo (2020)	The degree to which older adults, people with cognitive impairment, and their caregivers can understand dementia science has a lot to do with how likely we can effectively translate the state-of-the-art diagnostics and therapeutics into patient care
Horst et al. (2021)	Dementia literacy is one’s beliefs regarding dementia and application of beliefs,

Due to the lack of consensus on the definition of dementia literacy, its assessment also differs significantly in the literature. Various researcher have used different tools to assess dementia literacy, however, like various disease specific literacy tools, the focus is on assessing belief, knowledge and attitude about dementia(Diamond & Woo, 2014; Loi & Lautenschlager, 2015; Low & Anstey, 2009; Noble et al., 2015; Sun et al., 2013; Zhang et al., 2017). Currently, there is no validated comprehensive dementia literacy scale to assess skills needed to access, process, navigate and use dementia services for themselves or family (Doherty et al., 2020).

## **2.3 Dementia Literacy and Its Associated Factors in General Population: A Scoping Review.**

### **2.3.1 Background**

Globally, it is estimated that over 50 million people are living with dementia, and there are nearly 10 million new cases of dementia each year (Alzheimer's Association, 2019). It is predicted that 58% of people living with dementia are from middle and low-income countries (Alzheimer's Association, 2019; Farina et al., 2020). Globally, dementia is a leading cause of dependency and disability among older adults (World Health Organization, 2018). According to the World Health Organization (WHO), the total global cost of dementia as of 2015 was estimated to be U. S\$ 818 billion (World Health Organization, 2017). Dementia affects the individual's memory, behaviour, and cognitive abilities and impacts a person's ability to perform activities of daily living (World Health Organization, 2017). This leads to a significant financial, psychological, social, and physical burden on those with dementia, their families, and society (World Health Organization, 2017, 2018). Despite the current lack of a cure for dementia, there is a need for early recognition, diagnosis, and appropriate treatment and care of persons with dementia (Prince et al., 2015; World Health Organization, 2018; Zhang et al., 2017a).

However, despite these figures, current evidence shows low public awareness, understanding, and knowledge of dementia (Association, 2018; Guerchet et al., 2017; Prince, Comas-Herrera, Knapp, & Guerchet, 2016). Even some health professionals have been identified to possess insufficient knowledge and skills to diagnose and care for people with dementia (Eccleston et al., 2015; Scott et al., 2019). The lack of awareness and knowledge of dementia in most countries leads to stigmatisation, barriers to diagnosis and care, and impacts families and caregivers (World Health Organization, 2018, 2019). This has been attributed to a low level of dementia literacy (Low & Anstey, 2009; Noble et al., 2015). Dementia literacy refers to understanding how to obtain and maintain good mental health, understanding dementia and its treatment, decreasing stigma, and enhancing help-seeking efficacy (knowing when and where to receive evidence-based dementia care and having competencies to improve self-care) (Stan Kutcher et al., 2016; S Kutcher, Y Wei, et al., 2016). Low dementia literacy is associated with a delay in dementia diagnosis and treatment, lack of help-seeking and poor management of dementia and poorer health outcomes for persons with dementia (Berwald et al., 2016; Prince, Comas-Herrera, Knapp, Guerchet, et al., 2016; Reuben et al., 2010). A higher level of dementia literacy contributes to early diagnosis, dementia risk reduction, early treatment and care,

reduced negative attitude (including stigma, discrimination, and abuse) and active preparation for end-of-life care (Cahill et al., 2015; A. Y. M. Leung et al., 2019; Prince, Comas-Herrera, Knapp, Guerchet, et al., 2016; Smith et al., 2014).

### 2.3.2 Review Objectives

This review aims to synthesise existing knowledge on the level of dementia literacy among the general population. Specific objectives include i) exploring the level of dementia literacy among the general population, ii) determining factors influencing dementia literacy.

### 2.3.3 Methods

The Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) guidelines guided this review (Moher et al., 2009). This systematic review aims to provide a comprehensive overview of the current state of dementia literacy and map the challenges and strategies to improve dementia literacy among the general population. A search of the Cochrane database of systematic reviews and Joanna Briggs did not identify any published systematic review on dementia literacy.

#### 2.3.3.1 Search Strategy

An electronic search of CINAHL, PubMed, Psych Info, Scopus, Web of Science and Cochrane Database of Systematic Reviews was conducted to identify articles for inclusion in the study. This search was specific to articles that address dementia literacy published in English with no restrictions on publication date and study settings. Search strategies were tailored to each database and included the Medical Subject Headings (MESH), with the Boolean operators of 'OR' and 'AND'. For instance, in CINAHL, the following search terms were used 'dementia or Alzheimer's disease or vascular dementia, Frontotemporal or cognitive impairment or memory losses AND dementia literacy'. A reference list of all identified studies was also searched and screened to identify articles for inclusion.

#### 2.3.3.2 Inclusion and Exclusion criteria

Articles were included if they were:

- i. Primary data focused on dementia literacy.
- ii. Published in English and peer-reviewed journals.
- iii. Quantitative, qualitative, and mixed-method studies

Studies were excluded if they were:

- i. Interventional studies (Randomized Control Trial (R.C.T.), quasi-experimental, case studies).
- ii. Protocols, letters to the editor, conference abstract and discussion papers.

#### 2.3.3.3 Assessment of methodological Quality

The methodological quality of the included studies was assessed using the Mixed Method Appraisal Tool (MMAT), the Joanna Briggs Institute (J.B.I.) Critical Appraisal tool for Analytical Cross-Sectional Studies and the Critical Appraisal Skills Programme (CASP) Qualitative checklist. The Critical Appraisal Skills Programme (CASP) was used to appraise the quality of qualitative studies included in the review. (Critical Appraisal Skills Programme, 2017). CASP is a very common tool used by various authors to appraise qualitative studies (Campbell et al., 2011; Ho & Chiang, 2015; Schmied et al., 2012) in their various reviews. Therefore, this tool was deemed appropriate for use in this review. The CASP tool consists of three sections: 1) assessment of validity, 2) evaluation of the results and c) the significance of the results to practice. Various literature posit that a qualitative study can achieve validity when researchers report the rigor built into each research process (design, data collection, analysis and interpretation of findings) (Bryman, 2015; Cypress, 2017).

Three independent reviewers appraised the studies using the selected tool above. Discrepancies between the two raters were resolved through discussions and re-assessment by a third rater.

#### 2.3.3.4 Data Extraction

Two independent reviewers assessed and reviewed each article's title, abstract and full text for inclusion in the review. Articles without full texts were therefore exempted from the review. Following the Cochrane guidelines, a data extraction sheet was developed (Higgins, 2011). The following information was extracted from each study; author's names and date aim of the study, sample, data collection method and analysis, and findings. A third reviewer checked the accuracy of the data extracted, and discrepancies were resolved through discussions and consultation with the entire team. Data from each study were extracted to identify emerging themes (Table 2.2).

#### 2.3.3.5 Data Synthesis

Due to the heterogeneity of the quantitative studies, data extracted from the included studies (qualitative, quantitative, and mixed-method studies) were analysed using thematic synthesis.

Descriptive data were reported for all articles included in the research, and relevant quotations related to participants' dementia literacy and aspects influencing their dementia literacy were extracted. Three stages of thematic synthesis were used to identify themes from the findings of studies included in the review (Thomas & Harden, 2008). In the initial step, line-by-line coding of extracted data from each study was conducted, and each finding was assigned a code. Differences and similarities between the generated codes were assessed by the first author and later cross-checked by the second and third authors. Finally, categories and themes were developed per the review objectives.

### 2.3.4 Results

The search yielded 725 results, and sixteen articles met the criteria for inclusion in the systematic review. Table 2.1 shows the characteristics of each individual study. The findings from the search process have been summarised in the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) figure (Liberati et al., 2009). Abstracts were screened, and 340 articles were removed as they did not focus on dementia literacy. Nine pieces were removed based on the inclusion and exclusion criteria as they were interventional studies, editorial and review papers. Sixteen studies were kept for further data extraction.

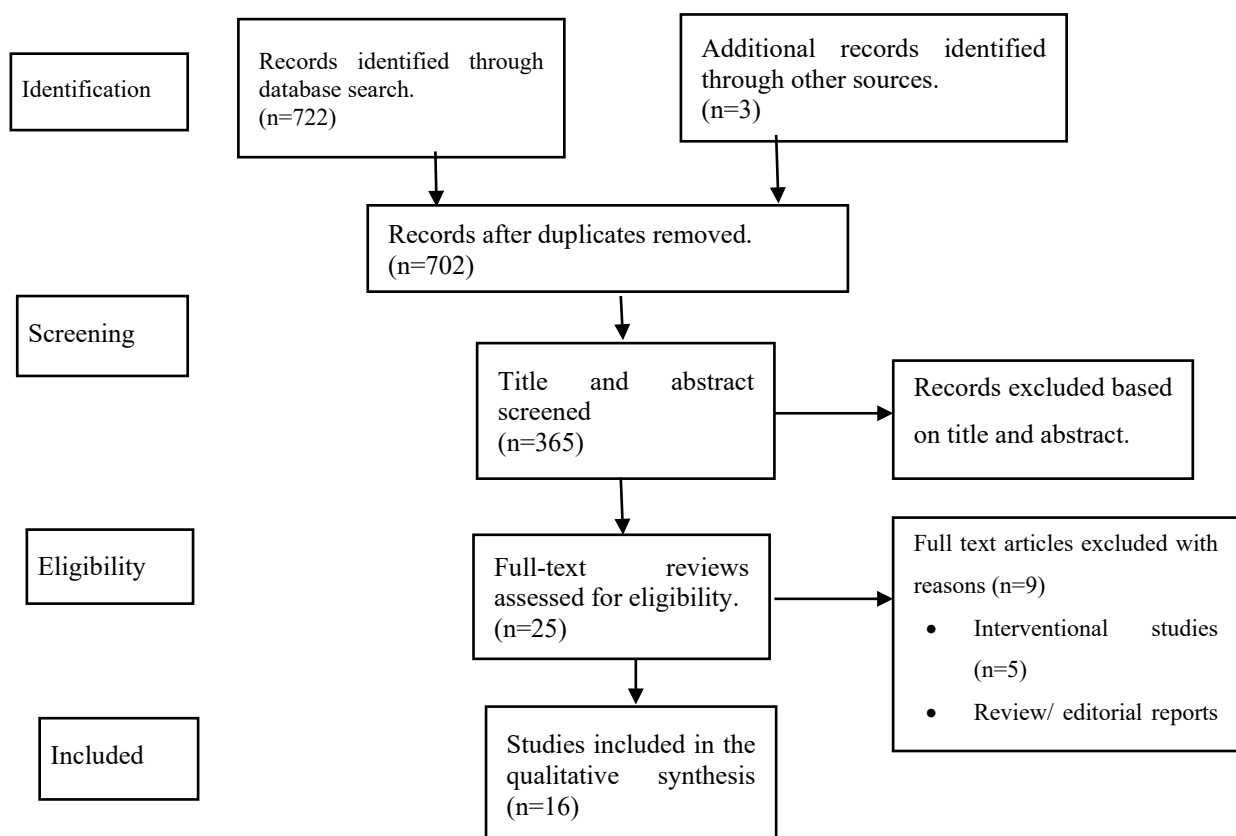


Figure 2.2: PRISMA flow Chart of the search process



Methodological appraisal of the sixteen included studies is presented in the appendix 1&2. The studies were rated as adequate (n=12) and moderate quality (n=4). Most studies were well-designed and adequately reported information on the study's sample, settings, data analysis and results. Most of the studies used standardized tools to measure dementia knowledge, and only three of the studies reported confounding factors in their data analysis. However, all the studies used appropriate statistical analysis for data analysis.

#### 2.3.4.1 Study Characteristics

Most of the included studies (n=14) were quantitative studies (Aihara & Maeda, 2020; Carr & Furnham, 2021; Diamond & Woo, 2014; Heger et al., 2019; Horst et al., 2021; Leung et al., 2020; Loi & Lautenschlager, 2015; Low & Anstey, 2009; Sun et al., 2013; Sun et al., 2021; Zhang et al., 2017a) and the remaining two studies were a mixed method (Angela Yee Man Leung, Sau Fong Leung, et al., 2019) and a qualitative study (Stansbury et al., 2010). With regards to the geographical focus of the studies, most of the studies originated from America (n=4), Australia (n=3) and other European countries (New Zealand, Britain, and Netherland) (n=3), with a significant number from Asia (n=5) (Japan, Korea, Urban China, Greater Bay-Hong Kong Guangzhou, Zhuhai, Macau, West Pacific- Philippines, Fuji, Cambodia). The remaining study was a globally online administered survey. 12,533 participants were included in the studies, with samples in primary studies ranging from 9 to 3007. The mean age of samples ranged from 31 to 78.2, with a predominantly female majority. Majority of the studies focused on the general population (n=8) (Carr & Furnham, 2021; Diamond & Woo, 2014; Heger et al., 2019; Horst et al., 2021; Angela Yee Man Leung, Sau Fong Leung, et al., 2019; Leung et al., 2020; Loi & Lautenschlager, 2015; Low & Anstey, 2009; Low et al., 2010; Park & Shin, 2021), older adults (n=4) (Aihara & Maeda, 2020; Barak et al., 2022; Low & Anstey, 2009). Notably, four studies focused on racial and ethnic minority groups, including Chinese Americans (Diamond & Woo, 2014; Sun et al., 2013; Sun et al., 2021), Italian, Greek and Chinese Australians (Low et al., 2010) and African American clergy (Stansbury et al., 2010).

There is no single validated, comprehensive measure of dementia literacy. Most studies included in the review measured dementia literacy based on the definition of the concept and which domain of dementia literacy was its primary focus. While some studies used a single scale, others used a combination of two scales to measure different concept domains. By defining DL as people's beliefs and explanation of illness from cultural and biomedical models, Sun et al. (2013) assessed dementia literacy based on Alzheimer's disease (A.D.) knowledge

and Alzheimer's disease cultural beliefs. A.D. knowledge was assessed using 24 items scale, which was adapted from two existing scales: the 30-item Alzheimer's disease knowledge scale (ADKS) and the Etiology Disease scale (E.D.S.), which cultural beliefs were assessed using ten items scale with seven items from Family stigma in A.D. scale (Sun et al., 2013). Similarly, Angela Yee Man Leung, Sau Fong Leung, et al. (2019) and Leung et al. (2020) assessed dementia literacy using two scales, ADKS and Dementia Attitude scale (D.A.S.), which measured dementia knowledge and attitude, respectively. Similar findings were observed in Sun et al. (2021) study. However, some studies used a single scale to assess dementia literacy by adapting some questions from the mental health literacy scales (MHLs). Loi and Lautenschlager (2015) adapted the entire scale to measure DL, while two other studies used eight items from the scale (Aihara & Maeda, 2020; Zhang et al., 2017a).

#### 2.3.4.2 Findings

Two main themes were identified after the thematic analysis and included:

- a) Level of Dementia Literacy
- b) Dementia literacy and its associated factors.

##### (a) Level of dementia literacy

Most included studies assessed dementia literacy using two or more concept domains. However, four studies focused on a single domain as a measure of dementia literacy, including knowledge of risk and preventive factors (Barak et al., 2022; Heger et al., 2019; Horst et al., 2021) and recognition of dementia symptoms (Carr & Furnham, 2021). Nonetheless, only one study assessed dementia literacy based on all six domains of the concept using qualitative interviews (Stansbury et al., 2010). Knowledge of self-help interventions available and knowledge of how to seek dementia information was only assessed by one study (Stansbury et al., 2010). Most assessed domains included recognition of symptoms, risk factors and causes and attitudes and beliefs concerning dementia. Sources of help for dementia were also rarely assessed in most of the studies, as only two studies focused on this aspect (Leung et al., 2019; Stansbury et al., 2010).

Table 2. 1. Overview of studies included in the review.

Authors, Date	Objective & Key concept	Settings & Sample	Measures related to DL	Main Findings
Aihara and Maeda (2020) Cross-sectional study	Aim: To assess Dementia Literacy (DL) and explore factors associated with DL and willingness to undergo routine screening DL: dementia knowledge (prevalence, symptoms, nature, and prognosis)	Japan Older adults aged 65 and above (N=775)	DL: an 8-item scale: symptoms, prevalence, nature, and treatment method for dementia. Willingness to undergo regular dementia screening: 2- item questions	Only 1.7 participants answered all dementia literacy correctly. Younger age, those who received dementia information from television/radio/ paper-based sources were willing to undergo regular dementia screening.
Barak et al. (2022) Cross-sectional study	Aim: To assess knowledge about dementia risk and protective factors literacy in a community sample in New Zealand. DL: Risk and protective factors literacy	New Zealand Adults aged 50-74 years (N= 1005)	Modified Lifestyle for Brain Health (LIBRA): 14-item questions: Dementia risk and protective factors.	Inadequate knowledge of dementia risk factors. Three clusters of brain health literacy were identified, including medical health concepts, activities, and psychosocial.
Carr and Furnham (2021) Cross-sectional study	Aim: To investigate the lay theories of three different forms of dementia; Alzheimer's Disease (A.D.), frontotemporal and vascular dementia. Mental health literacy (MHL) of Dementia	Britain Adults 18-69 years (N=167)	Knowledge of Dementia: Six item questions: knowledge of A.D., Frontotemporal dementia, and vascular dementia.	Poor knowledge of frontotemporal and vascular dementia than A.D. Frontotemporal dementia and A.D. were often misdiagnosed as depression. Help-seeking was greater for A.D. than the other two types.
Diamond and Woo (2014) Cross-sectional study	Aim: To assess if the residence duration impacts Chinese Americans' DL. DL: Knowledge (symptoms, causes, treatment and prognosis)	Los Angeles, The U.S.A. Chinese Americans (N=151)	Dementia Knowledge: 11-item question: symptoms, causes, treatment and prognosis	DOR did not have any significant impact on the knowledge of dementia. Participants were the least knowledgeable of dementia symptoms.
Heger et al. (2019)	Aim: To investigate DL and knowledge of modifiable risk and protective factors of dementia.	Province of Limburg, Netherlands	DL: 10-item questions (ten items from the British Social Attitude (B.S.A.) survey and 12 -items from LIBRA;	The majority of the participants were unaware of the link between lifestyle-related risks, protective factors, and brain health. A lower level of

Cross-sectional study	DL: knowledge, personal experience, dementia risk awareness and knowledge of modifiable protective factors.	Midlife adults aged 40-75 years (N=590)	knowledge, personal experience, risk, and protective factors awareness.	education was associated with a lower level of DL.
Horst et al. (2021) Cross-sectional study	Aim: To investigate DL and how demographic characteristics influence dementia perceptions. DL: Perception of the prevention, risk awareness of lifestyle factors.	Globally administered online survey. Adults 18 years and above (N= 598)	<ul style="list-style-type: none"> <li>• One question to assess the perception of the preventability of dementia.</li> <li>• 14 items to determine risk factors</li> </ul>	The general understanding is that lifestyle factors contribute to some risk of dementia. However, scores on the risk factors were generally low. Lower risk scores were found among women, older adults, those with non-post-secondary attainment, below-average income, and white background.
Leung et al. (2020)	Aim: To assess the DL of community-dwelling adults in four cities. DL: Knowledge and attitude	Macau, Guangzhou, Hong Kong, and Zhuhai Community-dwelling adults (N=787).	<ul style="list-style-type: none"> <li>• Knowledge about dementia-Alzheimer's disease knowledge scale (ADKS),</li> <li>• Attitude towards dementia-Dementia Attitude scale (D.A.S.) and</li> <li>• Preferred channels for receiving dementia information.</li> </ul>	There was moderate knowledge of dementia. Unemployed or retired participants had a poor attitude and knowledge about dementia. Middle-aged and unemployed participants prefer receiving dementia information on the television or radio, while younger participants and employed preferred social media.
A. Y. M. Leung et al. (2019)	Aim: To assess levels of knowledge about dementia and attitude toward dementia in low-and-middle-income countries and identify sources to turn to for help. DL: Attitude and knowledge	Philippines, Cambodia, and Fiji. Community-dwelling adults (N=476)	<ul style="list-style-type: none"> <li>• Knowledge of dementia using ADKS</li> <li>• Attitude towards dementia using D.A.S.</li> <li>• Source of help-seeking using a self-developed questionnaire</li> </ul>	Low level of DL; however, participants demonstrated a positive attitude towards persons with dementia. Family members and religious leaders were reported as the first point of source help for dementia.

Loi and Lautenschlager (2015) Cross-sectional study	Aim: To explore DL and current knowledge in a metropolitan city in Australia.  MHL: recognition, the best method of help, treatment.	Melbourne, Victoria, Australia. Older adults (N= 56)	DL: MHL Questionnaire <ul style="list-style-type: none"> <li>• Knowledge</li> <li>• Treatment</li> <li>• Source of help</li> <li>• Prognosis</li> <li>• Risk factors</li> </ul>	The participant had a high level of dementia. Participants endorsed seeking a general practitioner for concerns of dementia as most helpful. However, most of the participants believed that taking vitamins helps treat dementia.
Low and Anstey (2009) Cross-sectional study	Aim: To assess the beliefs and recognition of Australians regarding prognosis, risk factors and causes of dementia.  DL: Recognition, beliefs regarding prognosis and dementia risk reduction, concerns about developing dementia.	Australia Community-dwelling adults (N= 2000)	Dementia knowledge using a researcher-developed questionnaire.	Participants had good knowledge of symptoms of dementia and believed dementia risks could be reduced. Mental and physical exercise, healthy eating and socializing were identified as a method for risk reduction of dementia.
Low et al. (2010) Cross-sectional study	Aim: To investigate recognition, causal beliefs, and attitude regarding dementia in Italian, Greek, and Chinese Australians compared to 3 <sup>rd</sup> generation Australians.  DL: Recognition, attitude and beliefs regarding the cause and contributors to dementia.	Australia Australian migrants; Italian, Greek, Chinese (aged 18 and above) (N= 1701)	Vignette questionnaire	Ethnic minority groups had poor dementia literacy as compared to third-generation Australians. Ethnic minorities were more likely to suggest psychosocial risk factors and old age as causes of dementia.
Park and Shin (2021) Cross-sectional study	Aim: To examine the influence of DL, fear of dementia, internal locus of control and dementia preventive behaviour among middle-aged people with chronic diseases.	Seoul, Korea Adults aged 45 to 65 years (N=123).	16-item Dementia health literacy scale; risk factors, prevention, risk factors, treatment and care services.	Participants with higher DL had a higher level of dementia-preventive behaviours.

	DL: risk factors, prevention, treatment information and care services.			
Stansbury et al. (2010) Qualitative study-Grounded theory	Aim: to examine urban African American clergy's Alzheimer's disease awareness and willingness to provide support to elders, family, and caregivers  MHL: recognition of A.D., risk factors, knowledge of self-help interventions, professional help, and how to seek mental health information.	Central Kentucky, U.S.A.  Baptist African American pastors. (N=9)	Interviews using vignette methodology.  <ul style="list-style-type: none"> <li>• Causes and risk factors.</li> <li>• Self-help interventions</li> <li>• Efficacy of professional help</li> <li>• Stigma</li> </ul>	Pastors had had prior experience with persons with A.D. and were knowledgeable regarding its treatment. Participants were willing to work with their church-based healthcare team with mental health training to improve congregants' knowledge and provide support to persons with Alzheimer's disease and their family.
Sun et al. (2013) Cross-sectional survey	Aim: Examine the roles of and scientific knowledge and cultural beliefs in influencing the perceived threat of Alzheimer's' disease among Chinese American older adults.  Alzheimer's disease (A.D.) literacy: A.D. knowledge and cultural beliefs	Chinese Americans or immigrants from Mainland China aged 55 and above (N=385)	A.D. literacy  <ul style="list-style-type: none"> <li>• The perceived threat of the A.D. scale (9-item scale)</li> <li>• Knowledge of A.D. (24-items scale) adapted from Epidemiology/Etiology Disease Scale and ADKS.</li> <li>• Chinese cultural beliefs of A.D. (10-item scale)</li> </ul>	Cultural beliefs about A.D. and A.D. factual knowledge contributed to a higher perceived threat of A.D. The level of education moderated the association between cultural beliefs, A.D. knowledge and perceived threat of A.D.
Sun et al. (2021) Cross-sectional study with a comparison between 2013 and 2017.	Aim: To examine the change in DL and dementia worry over five years among older Chinese Americans living in Arizona.  DL: Dementia knowledge and dementia beliefs.	Arizona, U.S.A.  Chinese Americans aged 55 and above (N= 703)	<ul style="list-style-type: none"> <li>• Dementia Knowledge (16-item true/false drawn from ADKS)</li> <li>• Dementia beliefs by 10-item scale.</li> <li>• An 8-item scale measures dementia worry.</li> </ul>	Dementia knowledge decreased significantly from 2013 to 2017. No significant change in dementia worry and beliefs from 2013 to 2017.

<p>Zhang et al. (2017a)</p> <p>Cross-sectional study</p>	<p>Aim: To explore nationwide DL among urban China older adults and assess the factors associated with their dementia literacy.</p> <p>DL: nature of dementia, prevalence, appropriate treatment, and intention of treatment.</p>	<p>Urban China</p> <p>Community-dwelling older adults (n= 3007)</p>	<p>Dementia knowledge using eight items from the MHL questionnaire.</p> <ul style="list-style-type: none"> <li>• Nature of dementia</li> <li>• Prevalence</li> <li>• Appropriate treatment personnel</li> <li>• Intention of treatment</li> </ul>	<p>Low level of dementia literacy with inadequate knowledge on prevalence and treatment of dementia. Gender, income level. Education status and depression were significantly associated with the level of dementia literacy</p>
--	---	---	---	--

### *Recognition and knowledge of dementia*

Five studies assessed participants' ability to recognize symptoms of dementia (Carr & Furnham, 2021; Loi & Lautenschlager, 2015; Low & Anstey, 2009; Low et al., 2010; Stansbury et al., 2010). All five studies used a vignette describing symptoms of dementia to assess the ability to recognize dementia. Carr and Furnham (2021) used five vignettes to assess their participants' ability to distinguish Alzheimer's disease, vascular disease and Fronto-temporal dementia from depression and normal ageing symptoms. It was identified that participants could more quickly identify Alzheimer's disease than vascular and frontotemporal dementia, and frontotemporal dementia was often misdiagnosed as depression (Carr & Furnham, 2021). Three studies noted that most participants (Australians and African American Clergy) could recognize lead characters in the vignettes as suffering from dementia (Low & Anstey, 2009; Low et al., 2010; Stansbury et al., 2010). Comparing third-generation Australians to racial and ethnic groups (Chinese, Italians, and Greek Australians) in Australia, it was noted that the formal was more likely to correctly label symptoms of dementia (Low et al., 2010).

It was identified that the misconception of dementia as a normal ageing process was shared among six studies (Leung, Leung, et al., 2019; Loi & Lautenschlager, 2015; Low & Anstey, 2009; Zhang et al., 2017b). There was a perception that persons with dementia can be cured, and almost half of the participants believe there is at least partial recovery (Low & Anstey, 2009). Still, participants from western pacific countries knew dementia is incurable (Leung, Leung, et al., 2019). Notably, when a change in dementia knowledge was examined over five years among older Chinese Americans, it was noted that from 2013 to 2017, beliefs about dementia remained unchanged and knowledge about the condition decline (Sun et al., 2021). A qualitative interview identified that most participants described having insufficient knowledge of dementia and confused dementia with depression (Leung, Leung, et al., 2019).



Table 2. 2. Themes derived from the included studies.

Themes	Meaning and measure of Dementia Literacy (DL)		Domains of DL					Factors influencing DL
Subthemes	What is DL?	Measuring DL	Recognition and knowledge of dementia	Knowledge of risk factors and causes	Attitude towards dementia	Knowledge of treatment and services	Knowing how to seek information	
Aihara and Maeda (2020)	No definition provided	Dementia Knowledge	Memory loss as a symptom of dementia was correctly answered by most participants with the lowest score on the prevalence rate of dementia.	Not assessed	Not assessed	Not assessed	Not assessed	DL was associated with younger age, education status, cohabitating with family members, using more dementia-related information sources, depression, and frequent reading.
Barak et al. (2022)	Not available	Dementia Risk and Protective Factors	Inadequate knowledge of dementia risk and protective factors.	Poor knowledge on risk and protective factors of dementia particularly with regards to cardiovascular risk.	Not assessed	Not assessed	Not assessed	Higher education and urban participants had the highest literacy scores on dementia risk factors.

Carr and Furnham (2021)	“Lay public's attitude and knowledge of dementia”.	Recognition of Alzheimer’s Disease (A.D.), Frontotemporal dementia, and vascular dementia.	Poor dementia knowledge. The majority (60%) of participants were able to identify A.D. correctly than Frontotemporal (11.4%) and vascular (24.6%). Frontotemporal was more likely to be misdiagnosed as depression than A.D. and vascular dementia.	Not assessed	Not assessed	General practitioners (GP) and friends were the preferred source of help for dementia. However, G.P. had the highest ratings.	Not assessed	Not assessed
Diamond and Woo (2014)	None provided	Dementia Knowledge	Poor knowledge of symptoms associated with dementia. High level of stigma towards persons with dementia. Normalization of dementia as an ageing process.	Not assessed	Participants showed stigma towards mental illness.	Not assessed	Not assessed	Chinese Americans with < 20-year duration of stay were unaware that dementia shortens life expectancy.
Heger et al. (2019)	None provided	Dementia risk and protective factors awareness.	Not assessed	Less knowledge on dementia risk and protective factors. Knowledge gaps existed regarding cardiovascular risk factors for dementia.	Not assessed	Not assessed	Not assessed	Not assessed

Horst et al. (2021)	“A person’s beliefs regarding dementia and application of beliefs”.	Researcher developed scale. 1. Perception of dementia prevention 2. Awareness of Risk factors	There was a general belief that dementia is preventable.	The majority (63.9%) correctly identified all risk factors for dementia. Men had higher scores on modifiable risk factors than women.	Not assessed	Not assessed	Not assessed	Women, whites, and participants with income below average reported lower belief that dementia was preventable. Younger adults, secondary education, and being from India were associated with the belief that dementia is more preventable.
Angela Yee Man Leung, Alex Molassiotis, et al. (2019)	“Knowledge of dementia and attitudes towards persons with dementia”.	Dementia Knowledge – ADKS Attitude-D.A.S.	There was inadequate dementia literacy among participants in the Greater Bay area.	Not assessed	Not assessed	Health professionals, family members, friends and religious leaders.	Not assessed	Employment was significantly associated with attitude towards dementia. Students had the highest knowledge in Hong Kong.
Angela Yee Man Leung, Sau Fong Leung, et al. (2019)	“Dementia literacy refers to knowledge and attitude towards persons with dementia”.	Dementia Knowledge – ADKS, Attitude-D.A.S. Interview guide	Moderate dementia knowledge but less knowledge on risk factors, symptoms of dementia, treatment & management of dementia. The belief is that dementia results from a past life or "Karma".	Participants in Cambodia had the lowest knowledge of risk factors of dementia as they perceived dementia as due to "Karma".	Participants felt socially uncomfortable around persons with dementia. Others had a sense of sympathy and helplessness	Health professionals and family were identified as the first source of dementia help-seeking. Dementia treatment and care were associated with religious activities	Not assessed	Knowledge of dementia was associated with attitude, age, marital status, and employment. Seeking help from family was associated with younger people. Help-seeking from health professionals was associated with a

					ss towards dementia.			higher level of education.
Loi and Lautenschlager (2015)	MHL in dementia “Beliefs and knowledge about mental disorders that aid their recognition, prevention and management”.	DL: MHL scale <ul style="list-style-type: none"> <li>• Knowledge</li> <li>• Treatment</li> <li>• People who could help</li> <li>• Prognosis</li> </ul>	Adequate knowledge about symptoms of dementia but moderate understanding of treatment. The perception is that dementia is a normal part of the ageing process—a high level of DL among older adults.	Not assessed	Not assessed	G.P. (94.7%) was endorsed as the preferred source of help. Handling dementia alone was perceived as harmful by 77.2% of participants.		No significant relationship between education level and knowledge of dementia
Low and Anstey (2009)	“Beliefs and knowledge regarding dementia that aid recognition, prevention and management”.	Dementia knowledge using a researcher-developed	Participants had adequate (80%) knowledge of dementia symptoms and risks of dementia. Half of the participants believed dementia patients could attain full recovery.	72% of participants thought risk factors for dementia could be reduced. The majority (80%) of the participants identified stroke, old age, genetics, and brain disease as risk factors for dementia. However, the majority do not know the association between dementia and cardiovascular disease.	Not assessed	Not assessed	Not assessed	Not assessed
Low et al. (2010)	“A person's knowledge regarding dementia”.	The researcher developed questions to assess recognition of symptoms,	Most participants recognised symptoms of dementia. However, racial, and ethnic minorities had	Most participants did not know what caused dementia or that dementia was due to old age. Ethnic minorities attributed the causes of dementia to old age and	Racial and ethnic minorities groups had more negative attitudes	Not assessed	Not assessed	Third-generation Australians were correctly label dementia symptoms than three ethnic minority groups. English language

		attitude, beliefs, cause and risk factors	poorer recognition of dementia than third-generation Australians.	stress and loneliness. In contrast, third-generation Australians attributed cause of dementia to brain disease.	toward persons with dementia			proficiency and use of print materials in English were associated with recognizing dementia symptoms.
Park and Shin (2021)	“Ability to acquire, understand, assess and use dementia information on dementia prevention, management, and early treatment.”	16-item dementia questions Prevention, risk factors, treatment information and care services.	A moderate level of dementia literacy and a higher level of DL was associated with dementia prevention.	Not reported	Not assessed	Not assessed	Not assessed	Not assessed
Stansbury et al. (2010)	MHL in Alzheimer's disease (A.D.). “Knowledge and beliefs about mental disorders aid in their recognition, management or prevention”.	Interview guide assessing recognize A.D.; causes, risk factors; beliefs about self-help and professional assistance; and knowing how to seek for AD information.	All the participants correctly identified A.D. in the vignette and cited forgetfulness, memory loss and impaired memory as A.D. symptoms.	Clergy-identified risk factors of A.D. Commonly cited risks include diet, genetics, age, lifestyle, and diabetes/hypertension.	Dementia was considered a dreaded condition among African Americans. Believe that dementia is incurable. Prayers and reading the Bible were source of spiritual	Clergy adamantly reported that they could not offer anything besides emotional support and therefore endorsed professional help for older adults with symptoms of dementia.	Most of the clergy knew about numerous mental and health agencies but reported challenges and unfamiliarity regarding navigating the mental health system.	Not assessed.

					harmony and comfort to persons with dementia and their caregivers .			
Sun et al. (2013)	“A.D. literacy refers to people's knowledge and beliefs about dementia.	The perceived threat of A.D., knowledge of A.D. (ADKS), Chinese cultural beliefs of A.D.	Significant association between knowledge and perceived threat of A.D.	Not assessed	Not assessed	Not assessed	Not assessed	Worrying about dementia was most prevalent among persons aged 55–64 than those aged 85 or older. Education moderated the effect of knowledge and beliefs on perceived threat of A.D.
Sun et al. (2021)	Dementia knowledge and beliefs regarding dementia.	Dementia knowledge Dementia belief by 10-item scale measuring prevalent cultural beliefs towards dementia.	Participants in 2017 had less knowledge than those in 2013.	Not assessed	Some participants hold stigmatizing views of dementia due to its association with losing cognition and behavioural problems.	Not assessed	Not assessed	Not assessed

Zhang et al. (2017b)	Beliefs and knowledge regarding dementia that aid recognition, prevention and management.	MHLS to assess dementia literacy.	Moderate knowledge of dementia. Most adults knew the symptoms of dementia but perceived dementia as a normal ageing process	Not assessed	Not assessed	The majority (70%) of the participants had the intention to seek help for dementia.	Not assessed	Sex, income level, education, and depression were associated with low DL.
----------------------	---	-----------------------------------	---	--------------	--------------	---	--------------	---

### *Knowledge of risk factors and causes of dementia.*

While some studies reported adequate knowledge of risk factors (Horst et al., 2021; Stansbury et al., 2010), others observed inadequate (Heger et al., 2019; Leung, Sau Fong Leung, et al., 2019). Age, genetics, unhealthy diet, stress, social isolation, and physical inactivity are identified dementia risk factors (Barak et al., 2022; Heger et al., 2019; Horst et al., 2021). It was noted that most people were less knowledgeable on the fact that cardiovascular diseases are major risk factors for dementia (Heger et al., 2019; Horst et al., 2021; Low & Anstey, 2009). Nonetheless, two studies reported that most participants believed one could decrease their risk of dementia (Horst et al., 2021; Low & Anstey, 2009). Australian participants endorsed lifestyle as a modifiable factor (Low & Anstey, 2009); however, in New Zealand, older adults were unaware of the relationship between dementia risks and lifestyle (Barak et al., 2022). Another study in Australia identified that causes of dementia were attributed to biological causes among third-generation Australians and psychosocial causes among Greek, Chinese and Italian Australians (Low et al., 2010).

### *Attitude towards persons with dementia*

In Cambodia, participants believe dementia is because of "Karma", or the consequences of an individual's previous life. One study reported that some participants felt uncomfortable and were afraid of people with dementia, although there was a generally positive attitude towards dementia (Leung, Leung, et al., 2019). In Australia, Greek, Italian, and Chinese participants were observed to have a more negative attitude towards persons with dementia (Low et al., 2010). There was the belief that dementia is avoidable and that persons with dementia cannot enjoy quality of life and should be cared for and treated like a child (Low et al., 2010). In the African American communities, dementia is often described as "getting old", "senility", and "loss of autonomy" and, therefore, often feared and highly dreaded (Stansbury et al., 2010).

### *Knowledge of how to seek dementia information.*

Only one study assessed knowledge of how to seek dementia information (Stansbury et al., 2010). Although participants were informed of mental health agencies in their community, they reported that they face difficulty navigating the mental health system. Key informants like nurses, physicians, social workers, and psychologists associated with their churches were the primary source of information on mental health issues (Stansbury et al., 2010).



### *Preferred mode and source of dementia education*

Only three studies addressed preferences for media types for receiving information on dementia (Aihara & Maeda, 2020; Heger et al., 2019; Leung et al., 2020). Among community-dwelling mid-life (40 to 75 years), there was a high preference for searching online for dementia information and using an internet application to learn more about dementia (Heger et al., 2019). However, there was no significant difference in the preferred source of information among participants from the Greater Bay Area of China (Leung et al., 2020).

### *Help-seeking behavior and knowledge of treatment available*

Three studies assessed help-seeking behavior and preferred source of help for dementia (Carr & Furnham, 2021; A. Y. M. Leung et al., 2019; Loi & Lautenschlager, 2015). Intention to seek help was greater for Alzheimer's disease than vascular and frontotemporal dementia (Carr & Furnham, 2021). Most participants endorsed general practitioners (Carr & Furnham, 2021; Angela Yee Man Leung, Sau Fong Leung, et al., 2019; Loi & Lautenschlager, 2015) and friends (Carr & Furnham, 2021) as a first point or source of help. However, many people also preferred to seek help from friends, family members, and religious leaders (Carr & Furnham, 2021; Angela Yee Man Leung, Sau Fong Leung, et al., 2019). Religious leaders were identified as one of the sources of help for persons with dementia in low and middle-income countries (Angela Yee Man Leung, Sau Fong Leung, et al., 2019).

### *Knowledge of treatment available*

Low literacy about optimal professional care for persons with dementia (Zhang et al., 2017b). Less knowledge was reported about the dementia care services available (Zhang et al., 2017b). African American clergies were knowledgeable that primary care physicians have the skills to conduct physical and neurological exams and provide medications for persons with dementia (Stansbury et al., 2010).

## **b. Factors associated with dementia literacy.**

### *Demographic characteristics*

Female was associated with the recognition of symptoms (Low & Anstey, 2009; Zhang et al., 2017b), higher dementia knowledge (Sun et al., 2021), and lower biased beliefs (Sun et al., 2021)

was associated with recognizing dementia symptoms. However, one study identified an association between males and higher scores on risk factors for dementia (Horst et al., 2021). Age was associated with attitude towards dementia (Angela Yee Man Leung, Sau Fong Leung, et al., 2019; Leung et al., 2020). Younger age was associated with the recognition of modifiable factors (Horst et al., 2021), preference for dementia information from social media and government websites (Leung et al., 2020) and seeking help from family members (Angela Yee Man Leung, Sau Fong Leung, et al., 2019). On the other hand, older participants preferred radio or television and printed materials for information on dementia (Leung et al., 2020).

Higher education was associated with the recognition of symptoms (Loi & Lautenschlager, 2015; Low et al., 2010), higher dementia knowledge (Sun et al., 2021; Zhang et al., 2017b), lower biased beliefs (Sun et al., 2021), attitude (Low et al., 2010), lower dementia worry (Sun et al., 2021), dementia risk factors (Heger et al., 2019; Horst et al., 2021). Additionally, education was associated with help-seeking from health professionals (Angela Yee Man Leung, Sau Fong Leung, et al., 2019). Employment was associated with attitude towards dementia but not knowledge of dementia (Leung et al., 2020). An individual's knowledge of dementia was associated with a attitude towards dementia (Angela Yee Man Leung, Sau Fong Leung, et al., 2019). However, no significant difference was observed between age groups, marital status, ethnicity, education level, cognitive ability, and dementia literacy (Loi & Lautenschlager, 2015; Zhang et al., 2017b). Although Angela Yee Man Leung, Sau Fong Leung, et al. (2019) study identified that marital status was significantly associated with the attitude towards dementia but did not have any effect on overall dementia literacy. Ethnicity was identified to be associated with knowledge of modifiable risk factors and higher preventability beliefs of dementia with Black, indigenous or people of color scoring higher than Whites (Horst et al., 2021).

#### *Health status and dementia literacy*

Lower levels of depression were reported to be associated with higher dementia knowledge (Sun et al., 2021; Zhang et al., 2017b), lower biased dementia beliefs (Sun et al., 2021) and lower worry about developing dementia (Sun et al., 2013; Sun et al., 2021).

#### *Impact of acculturation*

Five studies assessed the association between various proxies of acculturation and dementia literacy (Diamond & Woo, 2014; Low et al., 2010; Sun et al., 2013; Sun et al., 2021). English language proficiency and English print media used were associated with the recognition of dementia among Italian and Greek Australians (Low et al., 2010). However, among Chinese Australians, none of the acculturation variables (English language proficiency, ethnic diversity of social interactions, use of English language materials) was associated with recognition and knowledge of risk factors and causes (Low et al., 2010). Similarly, two studies found no relationship between acculturation (measured by preferred language, ethnicity, social network and social practice), dementia literacy and perceived risk for dementia among Chinese Americans (Sun et al., 2013; Sun et al., 2021). The duration of residence of Chinese Americans in America was compared with their level of dementia literacy, and it was identified that duration of residence only minimally impacts dementia literacy (Diamond & Woo, 2014). Both participants who have lived in America for more than 20 years and those who have lived less than 20 years all hold misconceptions and stigma against persons who have dementia (Diamond & Woo, 2014). Conversely, one study reported that Chinese Americans born outside of the U.S.A had higher knowledge and lowered biased beliefs than those born in America (Sun et al., 2021). Australian racial and ethnic minority groups were identified to possess more negative attitudes towards persons with dementia (Low et al., 2010). One study identified a positive association between traditional cultural beliefs about Alzheimer's disease and concerns about being at risk for or developing dementia (Sun et al., 2013).

#### *Social relationship (social network and family conflict) and dementia literacy*

One study assessed the relationship between social networks, family conflicts and dementia literacy and identified that among Chinese Americans' family conflict were associated with dementia worry (Sun et al., 2021). Italian, Chinese and Greek Australians have identified social networks (family) are the primary source of help-seeking for dementia (Low et al., 2011).

#### *Dementia literacy and health-related outcomes*

Dementia literacy was associated with concerns of developing dementia (Sun et al., 2013) and higher dementia preventive behaviors (Park & Shin, 2021). Inadequate knowledge was a significant barrier to engagement in preventive behaviours (Heger et al., 2019). Similarly, higher

dementia knowledge was associated with help-seeking in participants from Cambodia and the Philippines but not with those from Fuji (Angela Yee Man Leung, Sau Fong Leung, et al., 2019).

### 2.3.5 Discussion

This is the first review to assess dementia literacy among the general population. Findings from the study prove a lack of literature focused on dementia literacy. The definition of dementia literacy was based on the definition by Low and Anstey (2009), which was adopted from Jorm (2000)'s first definition of mental health literacy (MHL). Jorm et al. (1997) defined MHL as “beliefs and knowledge about mental disorders that aid recognition, prevention, and management. Jorm (2012) has expanded the concept to include knowledge of preventing mental disorders, seeking mental health information, recognising conditions, knowledge of self-help strategies and first aid skills to support others (Jorm, 2012). The construct of MHL is still evolving. Subsequently, Kutcher et al. (2015) redefined MHL as the process of comprehending how to obtain and maintain mental health, knowing mental disorders and treatments, decrease stigma associated with mental disorders, and enhancing help-seeking efficacy. This expanded definition of MHL implies that the construct does not involve knowledge and attitudes about mental illness, but skills in accessing information and promotion of mental health. Therefore, a disease specific construct like dementia literacy should be defined and measured beyond knowledge and attitudes. Specifically, the included studies have conceptualized dementia literacy as mostly dementia knowledge including risk factors, symptoms recognition, treatment, prognosis, beliefs, and attitude.

The studies included in this review used different measuring instruments and outcome measures, making it difficult to compare findings. The commonly used measure of dementia literacy was dementia attitude scale, Alzheimer's disease knowledge scale, and a mental health questionnaire for older adults (Aihara & Maeda, 2020; Zhang et al., 2017b). However, these tools were designed to focus more on knowledge (symptoms, risk factors and causes, prognosis, treatment) and attitude and do not include items that assess knowledge of professional help/services, knowledge of self-help interventions, knowing how to evaluate dementia information, stigma and enhancing help-seeking efficacy (Chao et al., 2020). These findings can be authenticated if future studies compare participants from low and middle-income countries with persons from high-income regions.

Therefore, there is a need for future studies to construct a comprehensive assessment tool for dementia literacy.

Findings from the review showed that the most common method used to assess dementia literacy was a quantitative approach; however, due to the complexity of the construct and lack of a holistic instrument to fully capture all the domains of dementia literacy as defined by S Kutcher, Y. Wei, et al. (2016), a qualitative approach is deemed appropriate (Jorm, 2019). However, recent literature suggests that mental health literacy has evolved and included constructs such as the concept of stigma and help-seeking efficacy (S Kutcher, Y. Wei, et al., 2016). However, the included studies did not assess these concepts in their research. Moreover, findings from the studies proved a negative attitude towards dementia, and help-seeking efficacy is needed among the general population.

Findings from the study proved that across countries and races, the majority of people could recognize symptoms of dementia. However, one study identified Alzheimer's disease as the most recognised type of dementia compared to vascular and frontotemporal dementia. This finding indicates that people with frontotemporal and vascular dementia symptoms may be misdiagnosed by family members, which may hinder early diagnosis and help-seeking. Literature posits that frontotemporal dementia is characterized by early onset (aged 40 to 65); therefore, if this is missed at an early start, it could have an adverse implication on diagnosis and treatment (Carr & Furnham, 2021; Koçoğlu et al., 2022). Future studies should focus on improving public knowledge of the various types of dementia to promote early help-seeking and treatment.

Considerable gaps in dementia literacy exist regarding the relationship between cardiovascular factors and dementia. It was noted that most people were unaware of common dementia risk factors such as heart-related disorders and dementia protective factors. These studies make a strong justification for public health education regarding dementia modifiable, protective and risk factors for dementia. Various institution bodies, including World Health Organization, Alzheimer's Disease International and Lancet Commission on Dementia Prevention, Intervention and Care, have advocated for the need to enhance dementia prevention campaigns in various societies (Alzheimer's Disease Association, 2021; World Health Organization, 2021).

Dementia literacy was generally inadequate among ethnic and racial minorities and participants from developed and developing countries. However, only one study compared dementia knowledge and attitude across racial minorities and their White counterpart and reported poor recognition and pessimistic attitude among the ethnic minority groups (Low et al., 2010). However, studies focused on ethnic minority groups, and people from developing countries reported various cultural beliefs that may hinder early help-seeking. Perception of dementia as 'karma', 'senility' and 'getting old'. A study identified that these cultural beliefs about dementia remained unchanged among Chinese Americans after four years. These may be attributed to a long tradition of ethnic minority's prevalent cultural beliefs concerning dementia which has been left unaddressed in works of literature. Addressing biases concerning dementia is imperative in interventional studies targeting ethnic and racial minority groups and developing countries.

The preferred source of dementia information varied considerably across different age groups. It is worth noting that younger generations prefer online search as a medium for dementia information, while the older generation has more preference for printed materials and T.V. or radio. This is a significant finding to consider when planning an interventional program for the general community. Interventional studies among the population have identified that the use of printed educational materials in the form of fotonovela and comic books effectively improves health literacy and dementia literacy among the Chinese, African Americans, and Latinos (A. Y. M. Leung et al., 2018; Noble et al., 2015; Roche et al., 2018; Rodriguez, 2015). Previous studies have adopted social media (including WeChat, Facebook, and YouTube) to improve dementia literacy (Prins et al., 2020; Wang et al., 2017). However, more studies are needed to assess the preferred source of dementia information among participants from various countries and ethnicity.

Consistent with the previous review, education, females, employment, and ethnicity were common recurring factors influencing various attributes of dementia literacy (Cahill et al., 2015; Farina et al., 2021). Women tend to be primary caregivers of older adults with multiple health conditions in their families. As such, they may pay more attention or interest in health-related issues, including dementia (Adedeji et al., 2022; Sun et al., 2012). Among Chinese living in China and Chinese Americans, higher depression symptoms were associated with lower knowledge of dementia, higher depression worry and higher biased beliefs about dementia (Sun et al., 2013; Sun et al.,

2021; Zhang et al., 2017a). This prompts attention to be paid to people affected with depression. These findings are significant as they highlight potential people to whom dementia health education should pay close attention.

There were inconsistent findings regarding acculturation proxies (English language proficiency and use of English print material), social networks and dementia literacy. However, acculturation measure goes beyond language to include cultural identity and behavioural acculturation (Doucerain et al., 2017; Trickett et al., 2009). Given the fact that cultural beliefs and perception influence dementia literacy, it is imperative for future studies to assess how cultural identity or orientation play a role in dementia literacy among racial/ethnic minority groups and people from developing regions. A higher level of dementia literacy was associated with preventive behaviours, willingness to undergo dementia screening, concerns about developing dementia and help-seeking behaviour. Further studies should examine the relationship between dementia literacy and health outcomes among diverse population groups. These findings also imply that enhancing dementia literacy may lead to early help-seeking for dementia and engagement in preventive behaviours.

### 2.3.6 Conclusion

Findings from this review highlight knowledge gaps about dementia among participants from developed and developing countries. It also highlights the influence of acculturation and various sociodemographic variables in dementia literacy. Further educational studies should not focus on improving dementia literacy alone but on specific population groups such as males, lower education, people with depressive symptoms and ethnicity. Therefore, further research is needed using validated, comprehensive scales or qualitative approaches to assess dementia literacy. Acculturation was identified as key barriers and facilitators of dementia literacy and further understanding of these concepts is imperative. To better understand the relationship between acculturation and dementia literacy, a literature review of acculturation and health related behaviours has been elaborated in the next sections.

## 2.4 Acculturation and Health Behaviour

The first part of this section discusses the concept of acculturation. A literature search identified only two studies focused on the impact of acculturation and dementia help-seeking behaviour. Therefore, the next sub-sections will discuss the concept of acculturation and it's associated with help-seeking behaviours in various other mental health conditions.

### 2.4.1 Acculturation: The Concept

Acculturation is a continues process by which people of a particular cultural group adopt the beliefs and behaviours of another group. Acculturation involves acquiring the dominant society's values, language, behaviours/attitude, and roles and adapting to these changes (Berry, 2005). Although the acceptance or incorporation of these new cultural values varies from one level of acculturation to another, a higher value is typically placed on the collective or group rather than on the individual culture. During the 19<sup>th</sup> century, acculturation, acculturation-which was first described by anthropologists, was described as the outcome of contact between colonized countries and the colonizing society (Boas, 2008). However, although the term 'acculturation' was used during that era, there was no clear definition of acculturation as a concept (Schumann et al., 2020). In 1930, some anthropologists worked together to define a definition (Redfield et al., 1936). Acculturation is *the conversion that emerge from continual, direct contact between two or more people from diverse cultural groups* (Berry, 1997; Redfield et al., 1936). Acculturation was initially defined as a group phenomenon, but the concept was later re-conceptualized to focus on the individual's experiences of changes in behaviour, values, and identity (Schumann et al., 2020). There are different theories on how the process of acculturation occurs.

Park (1928) unidimensional theory posits that acculturation permeates an entire culture through migration and invasion. Acculturation occurs in a continuum in which an individual's relationship with an ethnic culture is lost or broken, thus emancipating the individual to align with the new dominant culture (Fox et al., 2013). In this model, acculturation is seen as a linear process of moving from the individual's original culture to a new culture (Schumann et al., 2020). However, various researchers have advocated for a multidimensional model of acculturation. Most researchers say that cultural changes do not occur as a linear process but must be regarded as changes that might occur in more than a single domain (Berry, 1997; Redfield et al., 1936).



Redfield et al. (1936) suggested that integrating oneself into a new culture or departing from a culture of heritage (assimilation) is simply an aspect of acculturation rather than the only acculturation process. Based on this, many researchers have come up with several multidimensional theories of acculturation (Fox et al., 2013; Schumann et al., 2020).

Among the most widely used and studied concepts of the multidimensional acculturation theory, the most notable is Berry (2003)'s bi-dimensional model of acculturation and its four acculturation outcomes/strategies. In the first fold of acculturation outcome/strategy, 'integration', individuals embrace and maintain their heritage cultural identity and simultaneously seek regular contact with the dominant country/society's culture (Berry, 2003; Fox et al., 2013). This acculturation strategy is called biculturalism (Schwartz & Zamboanga, 2008). In the second acculturation outcome/strategy, 'assimilation', individuals often shun their original culture, forsake their actual cultural identity, and embrace the culture and uniqueness of the dominant country or society (Berry, 2003; Fox et al., 2013). However, in the third acculturation outcome/strategy, 'separation', individuals maintain and uphold their original culture and identity and avoid contact with or reject the culture of the dominant society (Berry, 2003; Fox et al., 2013). In the last acculturation outcome/strategy, 'marginalization', individuals lose all forms of cultural identity. Thus, they reject their original culture and avoid adopting the dominant culture (Berry, 2003; Fox et al., 2013; Schumann et al., 2020). Individuals who choose marginalization often feel like strangers in both cultures as they have gone through a process of de-identification due to their superficial relationship with both cultures (Park, 1928). Such marginalization often results in psychological distress.

In Berry (1997)'s bi-dimensional model, there are four possible strategies/outcomes for migrants regarding the issue of acculturation: assimilation, integration, separation, and marginalization, as shown in Figure 2.4. Berry suggested that migrants vary in their process of acculturation concerning how they respond to two key factors namely, contact and participation and cultural maintenance (Berry, 1997). Cultural maintenance is the importance given to one's cultural characteristics and identity and therefore maintaining these core values is strived for. Contact and participation concern the level of involvement or avoidance of other cultures. These two dimensions are conceptually and empirically independent from each other (Berry, 2005, 2008;

Haugen, 2013). The bi-dimensional model focuses on maintaining traditional beliefs, values, and traditions versus adapting to the host culture as two separate dimensions.

Assimilated migrants often abandon or give up their original cultural beliefs or group and adopt the culture of their host country. Integrated migrants prefer to maintain their own original cultural beliefs while at the same time maintaining contact with the host country's cultural beliefs and practices. However, separated migrants retain their cultural beliefs with limited adaptation or contact with the host country's culture. Finally, marginalized migrants see no value in maintaining their own cultural beliefs or practices nor in engaging with or adapting to the host country's culture (Berry, 2003; Haugen, 2013). Each migrant may choose one acculturation strategy or move from one strategy to the next (Berry, 2003). Studies have found that most migrants prefer integration to the other three strategies, which are influenced by their psychological well-being in the host country (Jasinskaja-Lahti et al., 2003; Nguyen & Benet-Martínez, 2013).

#### 2.4.2 Relationship between Acculturation and Help-Seeking Behaviour

Research has demonstrated that cultural beliefs and practices strongly influence an individual's health status and related behaviour. The influence of these beliefs becomes more complex if an individual's culture of origin and place of abode are not the same. Such outcome is commonly attributed to acculturative change (Fox et al., 2017). The continuous increase in the number of migrants to America, Europe, and Asia has motivated researchers to assess the relationship between acculturation, health (physical and mental) (Campbell & Kaplan, 1997), and the health behaviours of migrants (Buscemi et al., 2012; Cruz et al., 2000).

##### *Impact of acculturation strategy on health outcome*

Research has shown that differences in the level of acculturation can either positively or negatively influence the health and health behaviour of migrants (Buscemi et al., 2012). Several researchers have assessed the relationship between the strategies of acculturation and health outcomes and have suggested that integration often leads to the most adaptive functioning and good health outcomes (Torres, 2010; Wei et al., 2010); while marginalization often leads to poor health outcomes (Berry, 2005; Torres, 2010; Wei et al., 2010). A study by Wei et al. (2010) found that students who adopted the integration strategy experienced fewer depressive symptoms and had

better overall health outcomes than those who adopted other strategies. This finding implies that integration is the ideal strategy for better health outcomes.

Among Norwegian immigrants, a preference to maintain the heritage culture (separation strategy) as acculturation orientation was associated with a high preference for informal and traditional help-seeking sources for depression (Markova et al., 2020). Similar to this study, Korean Americans who were less acculturated to the American culture were identified to possess poorer knowledge (Lee et al., 2010). Although this, scanty literature focuses on the relationship between acculturation and dementia help-seeking. Therefore, there is insufficient data on the relationship between acculturation and help-seeking to establish a clear linear relationship between the two concepts. More studies are therefore needed to explore the relationship among acculturation and dementia help-seeking behaviour among racial and ethnic minority groups.

#### *Language acculturation and health outcomes*

English language proficiency has significantly influenced dementia help-seeking behaviour among racial and ethnic minority groups (Lee, 2022; Low et al., 2011). This study identified inconsistencies in the relationship between acculturation, dementia help-seeking and service utilization (Low et al., 2011) due to the use of different proxies of acculturation.

## **2.5 Help-Seeking Behaviour: The Concept**

According to David Mechanic one of the early researchers to provide a definition of help-seeking conceptualise the concept as a meaning of coping behaviour (Werner et al., 2014). Currently, help-seeking is conceptualised as an active process of seeking help for a disease condition. Help seeking behaviour in mental health context is conceptualised as an adaptive coping process in an individual and family's attempt to seek assistance with mental care and treatment (Rickwood & Thomas, 2012). Seeking help implies that a person communicates with others (commonly family and friends) to gain an understanding, support or care in response to a health condition or distress (Husky, 2018). Studies show that there is a considerable relapse between when symptoms are noticed and when help is sought (Ng et al., 2021). Early and timely diagnosis for dementia promotes early access to dementia care and support and advance care. Timely diagnosis for dementia implies that persons with dementia and caregivers may have ample time to participate in advance care planning process to ensure their wishes are considered (Iliffe et al. 2009). Furthermore, current evidence shows that medications for Alzheimer's disease are more effective if given at an early stage in the disease trajectory (Perry et al. 2008).

Help-seeking behaviour of an individual is dependent on their attitude/beliefs towards help-seeking, the intent to seek help, and actual help-seeking behaviour (Gulliver et al., 2010; Husky, 2018). The act of seeking help evolves from a particular attitudes or beliefs about seeking help for symptoms of dementia and the degree to which this behaviour or action is evaluated as appropriate or inappropriate (Husky, 2018). The motivation or conscious decision to seek help for dementia is reflected as the intentions to seek help. Having an intention to seek help has been identified to be strongly associated with actual help-seeking behaviour. Finally actual help-seeking behaviour refers to seeking help from formal or informal sources.

For a person with dementia symptoms and their family to seek help for dementia, there is a need to recognise symptoms as a health condition. Formal sources of help seeking includes help sought from health professionals (general and mental), helpline, health facilities and resources. Informal sources comprise of help from friends, family members (including parents, spouse, and other family members), religious leaders, healers, community leaders and other non-health

professionals' resources. Help-seeking involves communicating with a potential second party to seek assistance (Husky, 2018).

### 2.5.1 Help-Seeking Theory

Numerous psychosocial models have been developed and applied to assess help-seeking behaviour for various health conditions including mental disorders (Tomczyk et al., 2020). However, to date there is limited models addressing dementia help-seeking behaviour. Most widely used model of help-seeking behaviour includes the health belief model (Rosenstock, 2000) and theory of planned behaviour (Ajzen, 1991) and behavioural health model (Andersen, 1995). The theory of planned behaviour is aimed understanding how subjective norms, attitudes and perceived control over behaviour interact to affect help-seeking intentions and actual help-seeking behaviour. On the other hand, health belief model perceive that an individual's help-seeking behaviour is dependent on their perceived threat of an illness and its severity, the perceived benefits, and barriers of the seeking help. This model has been widely used as a guiding framework to gain an understanding of help-seeking behaviours in various mental health related disorders (Chan et al., 2014; Tomczyk et al., 2020; Werner et al., 2014). Various reviews have attested that various personal characteristics (including, age, gender, ethnicity, lack of knowledge on the particular disease condition), support from social network, problem accessing health system, societal stigma and fear impact help-seeking behaviour (Chan et al., 2014; Mukadam, Cooper, & Livingston, 2011; Parker et al., 2020). Nonetheless, none of these models have addressed the sociocultural factors that influenced help-seeking behaviour, a very significant gap in these theoretical models. To address this gap, Sayegh and Knight (2013) designed the sociocultural health belief model (SHBM) which focused solely on understanding the cross-cultural patterns of dementia help-seeking. Detailed description of this model is given in section 2.7.1.

### 2.5.2 Dementia Help-seeking behaviour

Help-seeking behaviour in this study is conceptualised as intention to seek help for dementia. This is in an effort to capture the intent of general population seeking help in case they or their family member suffers from dementia. Dementia has been classified by World Health Organisation as a global public health priority as such attention has been focused on reducing the burden caused by the disease (World Health Organization, 2012). Dementia is an incurable disease, therefore

attention has been focused on improving early diagnosis, help-seeking and prevention of the disease (World Health Organization, 2021a). Early help-seeking has been identified to be successful in advance care planning given the disease trajectory (World Health Organization, 2021a, 2021b). Early help-seeking may enhance awareness and understanding of the effect of modifiable lifestyle factors on dementia disease process (Devoy & Simpson, 2017). Early and timely help-seeking for dementia is therefore imperative and have received considerable attention in the literatures over the last years. However, an understanding of dementia help-seeking behaviour and its correlates warrants further clarification. The subsequent section elaborates on the dementia help-seeking behaviour, and its correlates.

### 2.5.3 Factors associated with dementia help-seeking behaviour.

#### ***Personal characteristics/ socioeconomic factors***

Education, being ethnic minority and low income were identified as factors that influenced help-seeking behaviour (Werner et al., 2014).

#### ***Attitude/beliefs about dementia***

Denial or inability to recognise symptoms of dementia or possibility of dementia diagnosis was associated with reasons why majority of caregivers do not seek or delay help-seeking for dementia (Parker et al., 2020). Fatalistic and cultural beliefs about dementia was identified as a major barrier to dementia help-seeking behaviour. Practice of filial piety and familism among Asian and African American respectively has been associated with the notion that family members are responsible for care and seeking treatment is regarded as neglect of responsibility or unfilial (Werner et al., 2014). A study by Berwald et al. (2016) identified that among people of Black descent, seeking help from health professionals was regarded as waste of doctor's time as the condition is untreatable.

#### ***Lack of knowledge about dementia***

Poor knowledge of dementia has been directed attributed for delay in help-seeking for dementia. Normalisation of symptoms of dementia as part of aging, lack of awareness and understanding of the nature of dementia are main reasons for delay or lack of help-seeking for dementia (Berwald et al., 2016; Cahill et al., 2015; Chan et al., 2014; Parker et al., 2020). Difficulty differentiating

normal aging and dementia is a common reported challenge faced by caregivers and society at large (Parker et al., 2020; World Health Organization, 2017, 2019).

### ***Social Network Support***

Social support or the lack thereof influenced dementia help-seeking behaviour. Delay or lack of diagnosis or help-seeking for dementia has been attributed to lack of informal network support (Mukadam, Cooper, Basit, et al., 2011; Mukadam, Cooper, & Livingston, 2011; Parker et al., 2020). People often seek affirmation from social network to confirm a certain diagnosis and treatment. More often than not, cognitive impairment, memory and behaviour problems associated with dementia often makes persons with these symptoms unable to make informed decision for themselves leaving the autonomy to their caregivers and family. Depending on the family's level of knowledge, beliefs and perceptions about dementia, this may potentially impact help-seeking behaviour. Often most family feel obliged to provide home care rather than seeking external support if societal stigma is present. In various African cultures, people with dementia are often hidden from public view and often abandon by family due to fear of societal stigma and discrimination (Brooke & Ojo, 2020). In other studies support from social network has been identified as instrumental source of care and support to improve end-of-life care for the person living with dementia (Parker et al., 2020; Sawyer et al., 2019)

### ***Access to help.***

Limited knowledge of where to access dementia health care was identified as one of the practical barriers to dementia help-seeking. Among racial and ethnic minority groups, limited knowledge of resources available, lack of insurance, acculturation issues (immigration and language issues) and distance to dementia clinics were common problems faced in efforts to seek help for dementia (Berwald et al., 2016; Mukadam, Cooper, & Livingston, 2011; Parker et al., 2020; Roche et al., 2018).

## 2.6 Research Gap

Following the discussion from chapters one and two, this study addresses dilemmas in dementia literacy studies.

- Currently, no study has a comprehensive instrument to assess dementia literacy. Thus far, most studies evaluated the construct based on one or two domains mainly focused on assessing knowledge, recognition, risk factors of dementia and attitude towards dementia. Future studies should provide a comprehensive dementia literacy scale that incorporates all seven domains of mental health literacy.
- Less attention has been focused on the distinctive influence of acculturation and dementia literacy on the dementia help-seeking. Besides, most of the studies included in the review were from developed countries, often treating acculturation as a covariate but not an independent variable. Most of the studies focused on acculturation measured the concept using proxies such as English Language proficiency.
- There is a lack of studies evaluating whether and how acculturation in eastern cultures or countries influences dementia literacy of racial and ethnic minority groups in the region. To date, little is known about how acculturation to an eastern society may impact knowledge, attitude, and help-seeking behaviour of a particular disorder.
- The majority of studies cited used quantitative methods, with only two articles using mixed and qualitative methods design. Dementia literacy is a complex construct, and in light of no comprehensive measure, a clearer understanding of the seven domains through qualitative approaches is imperative. Specifically, when assessing issues related to attitude and stigma. A mixed method design may thus help bridge some concerns about the relationship between dementia literacy, acculturation, and dementia help-seeking behaviour.



## **2.7 Theoretical Framework**

To date, there is no theoretical model that form the bedrock for studying the relationship between dementia help-seeking behaviour, acculturation, social network, and dementia literacy. From the literature review, we identified that acculturation affect help-seeking behaviour, but none of the studies have focused on dementia related help-seeking behaviour, dementia literacy, acculturation, and social network. Therefore, this study borrows the tenets of exiting models focused on dementia literacy and dementia help-seeking behaviour to fully understand the interplay between these variables as this study is the first of its kind to study these interactions. To fully understand the complex and intricate process of dementia help-seeking behaviour, and the interplay between socioenvironmental factors (acculturation, social network), dementia literacy and help-seeking behaviour, there was a need to apply other conceptual frameworks to develop a unique framework for this study. Sociocultural health belief model and mental health literacy model were used as a guiding framework to develop the conceptual model for the study.

The mental health literacy model was selected due to its ability to address all aspect of a sensitive health issue like dementia. In various cultures, there is reported low recognition of symptoms, poor knowledge of risk factors and services and negative and stigmatising attitude towards persons with dementia. Therefore, the six domains (see figure 2) of mental health literacy were deem appropriate to assess dementia literacy. However, the MHL model did not account for influencing factors or the outcomes related to possession of adequate dementia literacy. Nonetheless, the therefore addition of sociocultural health belief model was deemed appropriate to provide a complete Among existing models of help-seeking behaviour, the sociocultural health belief model was the sole model focused specifically on decision to seek for dementia and its influencing factors. However, only knowledge was incorporated in the model and did not assess all domains associated with dementia literacy. Therefore, combining this model with the MHL model was deem appropriate to holistically assess the relationship between acculturation, dementia literacy, social network, and intention to seek help. The next section discusses the MHL model, SHBM and finally the conceptual framework of the study.

### 2.7.1 Sociocultural Health Belief Model (SHBM)

The Health Belief Model is a commonly used and well-recognised model to assess factors that may facilitate or hinder help-seeking for dementia (Sayegh & Knight, 2013). The HBM has been criticised for ignoring socio-environmental factors that might contribute to help-seeking behaviour (Kirk Wiese et al., 2019). Additionally, the HBM focused on general help-seeking not dementia specific help-seeking behaviour. To address this concern, Sayegh and Knight (2013) modified H.R.M. by incorporating cultural variables such as acculturation, dementia knowledge and cultural beliefs and family-centred cultural values that may enhance the explanatory role of the model (Sayegh & Knight, 2013). Therefore, the sociocultural health belief model (SHBM) (Sayegh & Knight, 2013) which focused solely on understanding the cross-cultural patterns of dementia help-seeking serves as one of theoretical framework for the study (Figure 2.3). SHBM was obtained from Health Belief Model (Green et al., 2020; Rosenstock et al., 1988).

From figure 2.3, SHBM suggests that family-centred values (familism and filial piety) and acculturation affect knowledge and beliefs about dementia which in turn affect the perception of barriers to dementia care susceptibility to and severity of dementia and the threat associated with not seeking help for dementia care. Cues to action directly influence the

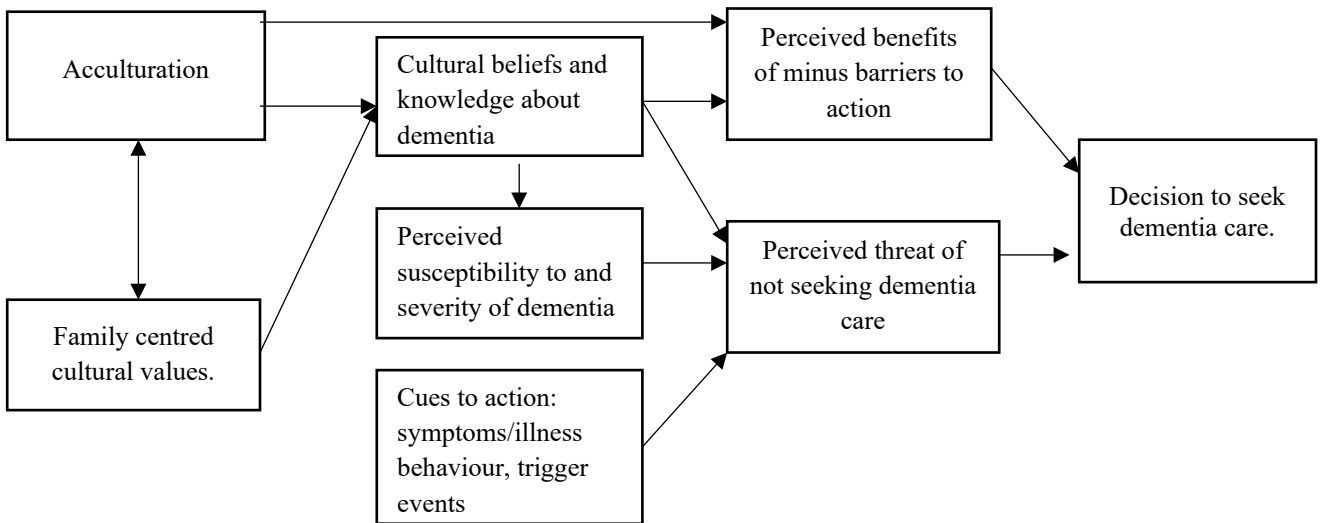


Figure 2.1. Sociocultural Health Belief Model

perceived threat associated with not seeking dementia care. Perceived barriers to action and threats associated with not seeking dementia care are hypothesized to directly impact the decision to

obtain dementia evaluation. Nonetheless, the SHBM does not offer a comprehensive assessment of all domains of dementia literacy as it only focused on dementia knowledge, cultural beliefs about dementia, and perceived susceptibility to dementia and not dementia literacy. Therefore

### 2.7.2 Mental Health Literacy Model

Jorm et al. (1997) in their seminal work on mental health literacy was proposed as a label to draw researchers and policy makers attention to the neglected area of mental health in health literacy research (Jorm, 2012). Since its first definition in 1997, the concept have been expanded and redefined the concept to a more by various researchers (Jorm, 2012; Kutcher et al., 2016). MHL was first used in Jorm et al. (1997) seminal article, where the authors defined the construct as “beliefs and knowledge about mental disorders which aid their recognition, management or prevention” (Jorm et al., 1997, p. 182). The definition was later refined by Jorm (2012) to include knowledge that enhances the mental health of an individual: including recognition of disorders when developing, knowing how to prevent mental disorders, awareness of self-help strategies for mild-to-moderate mental health problems and the first aid skills to assist others.

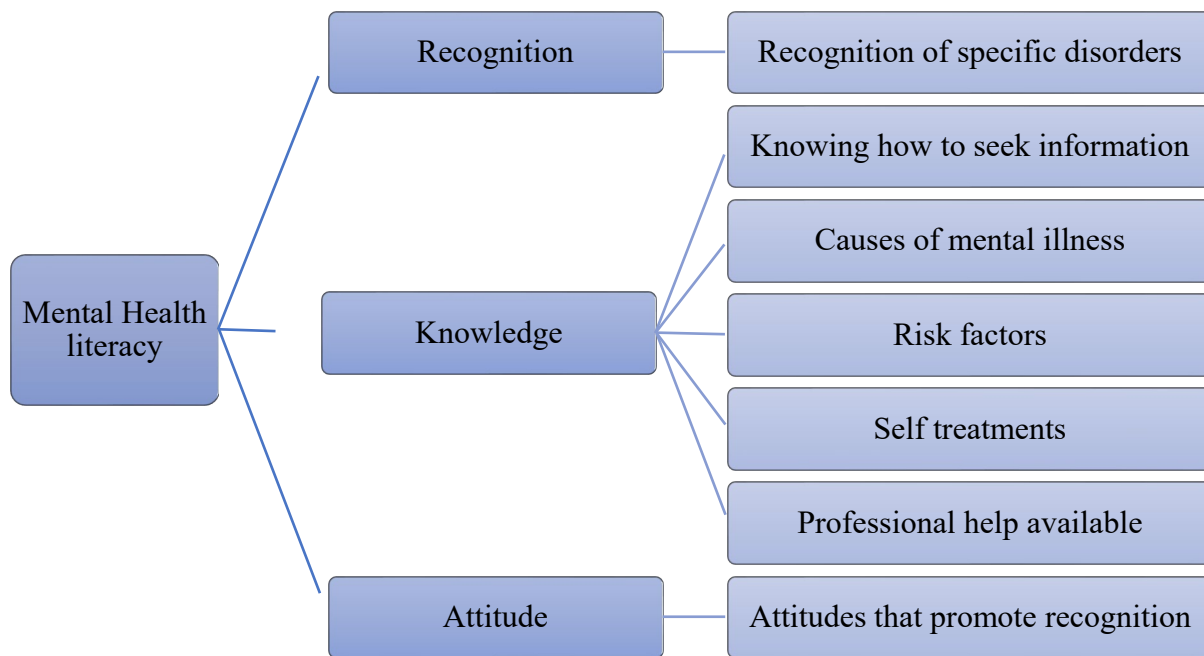


Figure 2. Mental Health Literacy Model

More recently, the concept was redefined as an understanding of mental disorders and treatment, knowledge of how to access and maintain mental health, reduce stigma associated with mental disorders and intensifying help-seeking efficacy (Kutcher et al., 2015; S Kutcher, Y Wei, et al.,

2016). This definition expands the definition of the construct and advances previous notions of mental health literacy as merely knowledge of mental disorders. Jorm (2019) provided seven main domains of MHL including recognition of mental disorders, knowledge of risk factors, understanding of aetiology/causes of mental illness, knowing how to seek mental health information, knowledge of professional help available, knowledge of self-treatment, and attitudes that promote recognition of appropriate help-seeking behaviour. O'Connor and Casey (2015) further integrated the seven domains of mental health literacy into three main domains: recognition, attitude, and knowledge. Measurement of mental health literacy should provide a robust evaluation of all seven components of the construct, as outlined by Jorm (2012).

Despite the advancement of the definition of MHL, conceptualisation and definition of dementia literacy is based on knowledge and attitude alone. Therefore, the subsequent section will examine existing literature to identify what is known about dementia literacy, its measurement, barriers, and facilitators. Later works by Jorm proposed that the definition to include five key components of MHL including: Recognition of symptoms, risk factors, knowledge of self-help strategies, knowledge of help-seeking options.

### 2.7.3 Conceptual Framework of the Study

From the conceptual framework, it is posited that acculturation, social network, and dementia literacy have direct effect on intention to seek help. It is hypothesised that dementia literacy may mediate the effect of acculturation and social network on the intention to seek help for dementia. Moreover, at the individual level, people will vary within their larger cultural group (Africans), as there are significant differences in their country of origin, the local dialect, occupational status, or educational background. Among those of the same country of origin, people will vary according to their gender, marital status, age, and religion. These individual factors (demographic and social variables), which will be treated as covariates in this study, have been identified in collecting and analysing data.

Conceptual Framework of the Study

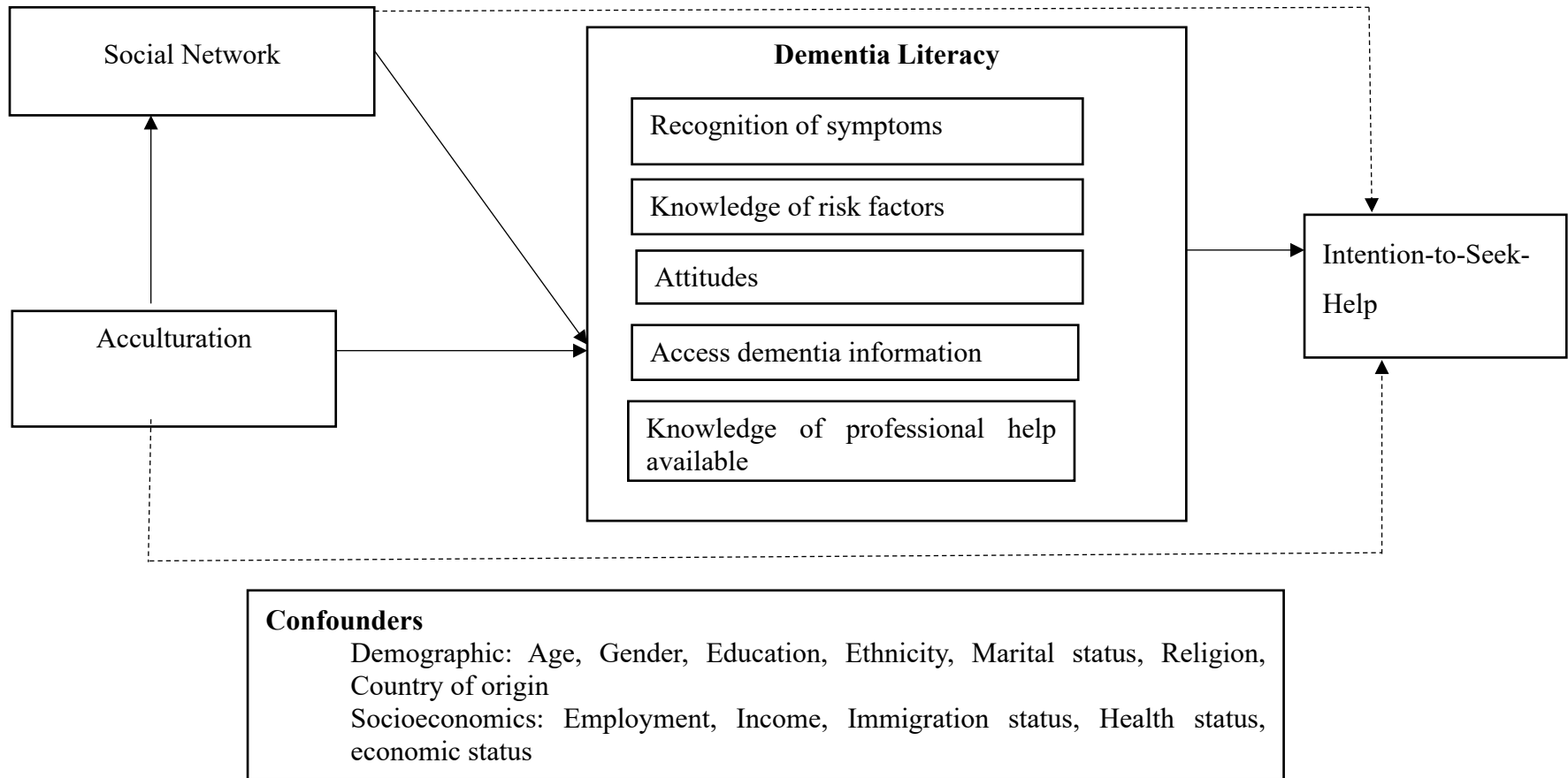


Figure 3.2 Conceptual Framework for the study

In the qualitative aspect of the study, these demographic factors will also help select participants for the investigation to ensure a fair representation of various sub-groups. The conceptual framework points to the fact that an individual's level of dementia literacy may be influenced by their characteristics (e.g., age, sex, marital status, education, ethnicity, and employment status).

## **2.7 Summary of Chapter 2**

Recent evidence suggests that dementia literacy is poor among racial and ethnic minority groups. Factors influencing dementia literacy and help-seeking include acculturation, cultural beliefs, social network, and sociodemographic characteristics. However, findings from these studies are inconclusive. Therefore, there is a need for further studies with robust methodology to assess the relationship between acculturation, social network, dementia literacy and dementia help-seeking. The next chapter will highlight the methodological approach adopted to evaluate the relationship between these main variables.

## CHAPTER 3: METHODOLOGY

### 3.1 Introduction

The chapter discusses the study design. Information about the study design, settings, participants, data collection method, statistical analysis, and ethical approval is presented. The study involves three main phases, and each is discussed in detail in separate sections. A summary will close out this chapter.

### 3.2 Study Purpose

#### 3.2.1 Aim/Objectives

As stated, the study aims to explore the dementia literacy of Africans living in Hong Kong. The study also further examines the relationship between dementia literacy, acculturation, social networks, and intention-to-seek-help for dementia.

#### 3.2.2 Research Questions

The specific research questions are:

- i. What acculturation strategies do Africans use when they are living in Hong Kong?
- ii. How much do Africans know about dementia?
- iii. What factors affect Africans' intention-to-seek-help for dementia?
  - a. Would dementia literacy directly affect their intention-to-seek-help?
  - b. Would acculturation and social network affect their intention-to-seek-help?
  - c. Would dementia literacy, acculturation and social network interlink and affect Africans' intention-to-seek-help?

### 3.3 Methodology

A mixed-methods design (qualitative and quantitative studies) was adopted in this study. Mixed-methods research involves combining or mixing qualitative and quantitative research methods, concepts, and approaches into a single study or series of studies to create a depth and breadth of comprehension and collaboration (Creswell & Plano Clark, 2011). The rationale behind the mixed-methods approach was that a qualitative or quantitative method alone could not fully capture the details and trends of the topic under study. The combination of both paradigms allowed them to complement each other and yielded a more comprehensive analysis (Creswell, 2013; Creswell et

al., 2003; Onwuegbuzie & Combs, 2010). Moreover, this design was appropriate for the study, as the concept of dementia literacy is a complex multi-domain construct, and unfamiliar among most in an African context. To date, no study has examined this concept from the perspective of Africans living in Africa or as part of the African diaspora. Previous studies indicate the term ‘dementia’ was an unfamiliar concept among some Africans, and even health professionals were reported to have limited knowledge of dementia (Brooke & Ojo, 2020; Spittel et al., 2019). Using a mixed-methods approach was appropriate to measure and assess the dementia literacy of Africans, and how contextual factors, such as acculturation and social networks, influence their intention-to-*seek-help* (Dodson et al., 2015). Various studies have indicated the significance of mixed method approaches in reinforcing findings (Amoah, 2017; De Allegri et al., 2015) and even contradicting findings from the same study (Spaetgens et al., 2016). The strength of this design is to provide an in-depth understanding of the relationship between dementia literacy, social networks, and acculturation and intention-to-*seek-help* (Creswell, 2014).

### **3.4 Research Design**

This study is an exploratory sequential mixed-method design conducted in three phases using qualitative and quantitative methods (Creswell & Clark, 2011). According to Creswell (2014), an exploratory sequential mixed method is usually helpful when there is limited knowledge about a concept or phenomenon, or there is a need to develop a scale when there are no available measures or scales to measure a variable. Although an exploratory sequential mixed-method design was used, the data collection comprises three main phases. Figure 3.1 provides a summary of the flow of the study’s three phases. The first phase was the development and validation of the dementia literacy scale, the second phase was a qualitative study, and the final phase (phase 3) was a cross-sectional survey, as shown in Figure 4.1 (Creswell & Clark, 2011). Phase 1 involved two main phases, categorised as phases “1a” and “b”. Phase 1a involved a literature review on dementia literacy and its influencing factors, and a search for standardised existing measures or instruments to assess dementia literacy, acculturation, social networks, and help-seeking behaviour among African migrants. Phase 1b involved the development and validation of a dementia literacy scale. To date, there has been no comprehensive single-factor scale to measure dementia literacy. Therefore, a comprehensive dementia literacy scale was developed and validated in the study’s first phase.



In the second phase, the study aimed to assess dementia literacy and the help-seeking behaviour of Africans living in Hong Kong, and how certain contextual factors, such as acculturation strategies, impact their dementia knowledge, attitudes, and help-seeking behaviour. The qualitative method was used to gain an in-depth understanding of Africans' ability to recognise symptoms of dementia, knowledge of how to seek dementia information, risk factors and causes, attitudes, knowledge of professional help available, and dementia help-seeking. The qualitative study also aimed to assess factors that influence their dementia literacy.

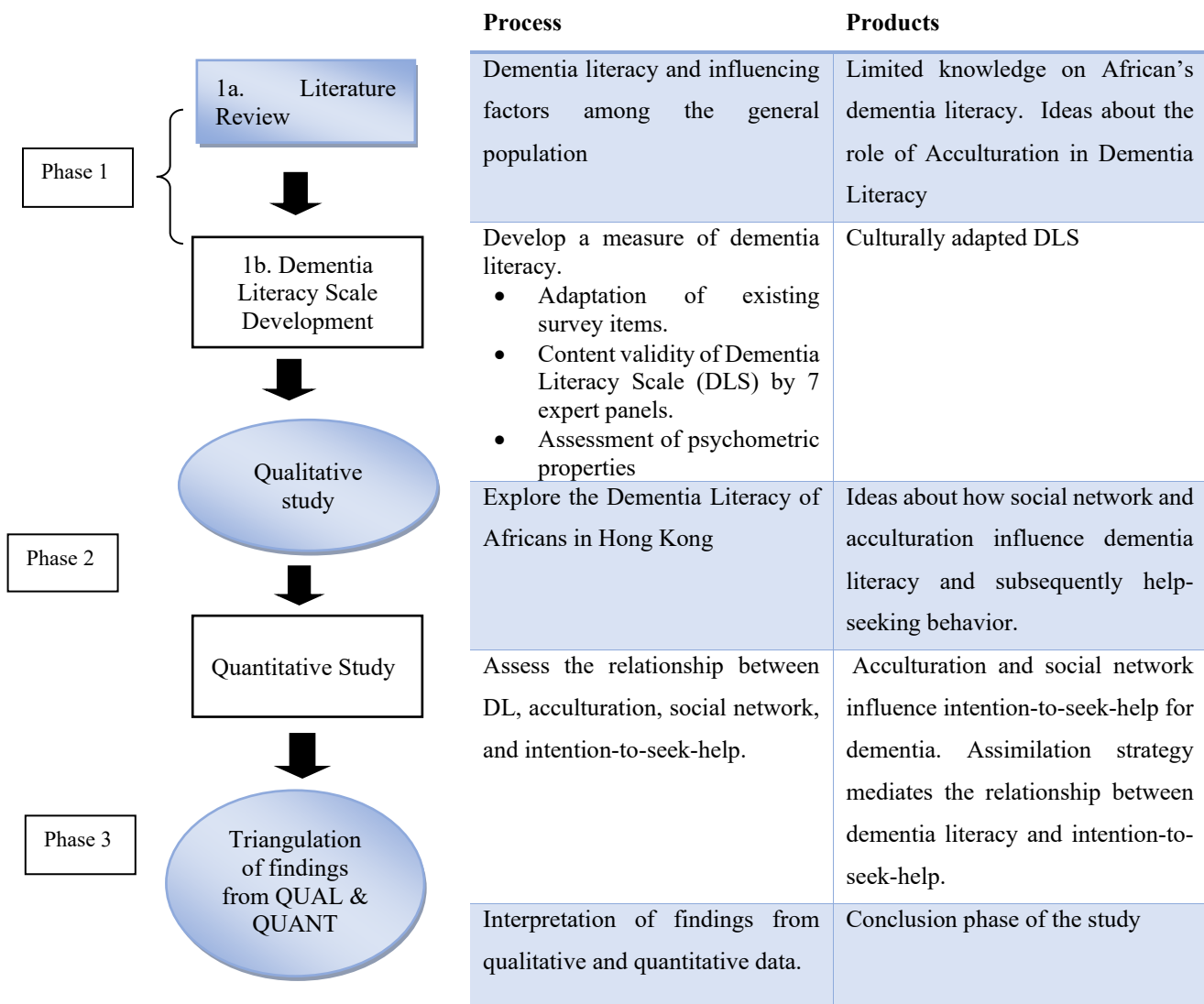


Figure 3. 1: Exploratory Sequential Mixed Method Process for the Study

Building on the findings from qualitative data, social networks were identified as a new factor that might influence the help-seeking behaviour of Africans in Hong Kong. The quantitative method was also used to assess the association between dementia literacy, acculturation, social networks, and help-seeking behaviour. An actual cross-sectional study was used to assess the association between dementia literacy, acculturation, social networks, and the intention-to-see-help, and to generalize qualitative findings from the study (Bryman et al., 2008; Creswell, 2014)

### **3.5 Settings**

Both the qualitative and quantitative studies occurred in the 18 districts and various communities in Hong Kong, a special administrative region of China. Public places, such as churches, mosques, various African restaurants and shops, parks, and African centres were the main study recruitment centres. These places were selected because a significant number of Africans socialise and ply their trade in these locations (Amoah, Koduah, et al., 2020). Africans are a small ethnic minority group in Hong Kong. There are no official statistics on the exact number of Africans in Hong Kong; however, some estimates place the figure at more than 3,000 (Amoah, Koduah, et al., 2020; Bodomo, 2015; Zheng & Leung, 2018).

### 3.6 Phase 1: Development of the Dementia Literacy Scale

Results from the qualitative study were used to adapt and write new survey items from the mental health literacy scale (MHLS) to assess dementia literacy (Bryman, 2015; Creswell, 2014). This modification was necessary as, to date, there is no validated, comprehensive measure for dementia literacy (DL). This phase aimed to develop a comprehensive and psychometrically robust measure for dementia literacy based on the definition and attributes of mental health literacy (MHL), Dementia Knowledge Assessment Scale (DKAS) and Alzheimer's disease knowledge scale (ADKS). The validation of the dementia literacy scale involved three stages: generation of items for the scale, content validity, and assessment of the psychometric properties of the newly developed Dementia Literacy Scale (DLS).

#### 3.6.1 Item Generation for the DLS

Subscales of the DLS were based on the six attributes of the MHL (O'Connor & Casey, 2015). Questions from the MHLS, DKAS, ADKS and findings from the qualitative study were pooled as questions for the DLS. After several revisions, items were generated for each of the six subscales of DLS. The final item comprised 42 items with six subscales. The six subscales include the ability to recognise dementia symptoms, knowing how to seek information, risk factors and causes, awareness of self-treatment, knowledge of professional help available, and an attitude that promotes recognition and care. The operational definition of these six subscales and decisions made regarding each question's generation are outlined in Table 3.1 below. These definitions were developed by O'Connor and Casey (2015) after a comprehensive consultation with psychologists (n=7) and clinical experts (n=10). The following sections detail the processes in validating the psychometric properties of the newly designed DLS.

Table 3. 1. Operational definition of the six subscales of the Dementia Literacy Scale

Subscale	Operational definition
Ability to recognize dementia signs and symptoms	Ability to correctly identify symptoms associated with various types of dementia.

Knowing how to seek dementia information	Knowing where to access dementia related information and the ability to access available health information from various sources.
Causes and risk factors	This includes awareness and knowledge of genetic/biological, social, and environmental factors that increases the risk of dementia. This includes knowledge of protective and modifiable risk factors for dementia.
Self-treatment and care	Possession of adequate information to manage symptoms associated with dementia as recommended by health professionals and activities that a person with dementia can conduct.
Professional help available	Awareness of various dementia services available and health professionals that provide such care and services. This includes information on interventions available for persons with dementia.
Attitudes that promote recognition and appropriate help-seeking	An attitude that influences the recognition of disorders minimizes the stigma and treatment of persons with dementia.

### 3.6.2 Construction of Dementia Literacy Scale

The initial phase of developing the dementia literacy scale for Africans in Hong Kong involved reviewing existing DL measures. The operational definition of DL was based on the definition of MHL, which consist of six subscales. MHL is defined as beliefs and knowledge about mental disorders that aid in the recognition, prevention, and management of disorders (Jorm, 2012). In this study, dementia literacy is defined as the ability to recognise symptoms of dementia, causes and risk factors, knowing how to seek information and of risk factors and causes, awareness of self-treatment and professional help available, and possession of an attitude that promotes recognition of dementia. Questions for the dementia literacy scale were referenced from the following sources: the MHLS, ADKS, DKAS, and findings from the qualitative data.

### *Mental Health Literacy Scale*

The MHLS is a single-factor scale comprising six subscales and 35 questions (O'Connor & Casey, 2015). Questions 10, 12, 15, and 20-28 are reverse scored. The six subscales include (1) recognition of specific disorders, (2) causes and risk factors, (3) knowing how to seek information, (4) awareness of self-treatments, (5) awareness of professional help available, and (6) an attitude that facilitates recognition and appropriate help-seeking. Ability to recognise disorders consists of eight questions measured on a 4-point Likert scale (1-very unlikely to 4 very likely). This subscale refers to “the ability to identify signs and symptoms of a disorder correctly”. The knowing how to seek information was measured with four questions using a 5-point Likert scale (strongly disagree (1) to strongly agree (5)). The subscale measures participants’ knowledge of where to access information and skills. The knowledge of risk factors subscale comprises two questions using a 4-point Likert scale (very unlikely (1) to very likely (4)). This subscale refers to awareness of biological or familial, social, and environmental factors that increase a person’s risk of developing a particular illness. Knowledge of self-treatment was used to assess participants’ knowledge of treatment recommended by health professionals and activities that a person can conduct. This subscale was measured using two questions on a 4-point Likert scale (very unhelpful (1) to very helpful (4)). Knowledge of professional help available was measured using three questions on a 4-point Likert scale (very unlikely (1) to very likely (4)). The subscale measures knowledge of the availability of health services and mental health professionals. Lastly, the attitudes that promote recognition or appropriate help-seeking behaviour consist of 16 questions using a 5-point Likert scale (strongly disagree (1) to strongly agree (5)).

Notably, none of the 35 questions were related to dementia (O'Connor & Casey, 2015; Zhang et al., 2017a). Then, based on the O'Connor and Casey (2015) six attributes of the MHLS, an initial six-attribute dementia literacy questionnaire was developed. A review of the MHLS showed that the questions on knowing how to seek information and attitudes that promote recognition domains were generic, and could be applied to all forms of mental illness. Therefore, these questions were revised to measure dementia literacy and the remaining four domains were adapted from other measures (ADKS and DKAS). Scores are obtained by summing all individual correct answers; the lowest score is 35, with the highest score being 160. A higher score is an indication of higher MHL

status. Various studies have used this scale and demonstrated high internal consistency ( $\alpha = 0.79$  to  $0.93$ ) (Chao et al., 2020; Loureiro et al., 2013; Nejatian et al., 2021; O'Connor & Casey, 2015).

#### *The Alzheimer's Disease Knowledge Scale (ADKS)*

The ADKS comprises a 30-item scale made up of true/false questions. One mark is given for each correct answer. The total score is calculated by summing the correct scores for each item, yielding a score ranging from 0 to 30. This tool was selected because it has excellent psychometric properties (reliability coefficient =  $0.81$ ,  $P < .001$ ) and has widely been used by various researchers (Leung et al., 2020; Leung, Leung et al., 2019; Low & Anstey, 2009; Smyth et al., 2013). The ADKS conceptually comprises seven domains, namely: symptoms (items 19, 22, 23, and 30), life impact (items 1, 11, and 28), diagnosis and assessment (items 4, 10, 20, and 21), risk factors (items 2, 13, 18, 25, 26, and 27), treatment and management (items 9, 12, 24, and 29), caregiving (items 5, 6, 7, 15, and 16), and disease course (items 3, 8, 14, and 17). This tool has excellent psychometric properties and has widely been used by various authors (Carpenter et al., 2009; A. Y. Leung et al., 2019; Leung et al., 2020; Low & Anstey, 2009; Smith et al., 2014; Sun et al., 2013). The ADKS, despite its good psychometric properties, only assessed the knowledge domain of dementia literacy and did not fully capture all six components of dementia literacy. To identify items to include in the DLS, the operational definition of each subscale of the DLS was compared with the ADKS, and the items that correspond with each subscale were selected.

#### *Dementia Knowledge Assessment Scale*

The DKAS is a true or false 25-item scale developed to assess dementia knowledge. The scale consists of four subscales: health promotion and risks (6 items), characteristics and causes (7 items), behaviour and communication (6 items), and care considerations (6 items) (Annear, Toye, Eccleston, et al., 2015). The scale is a 5-point Likert scale (false, probably false, probably true, true, and I don't know). Some items from the scale were reverse coded. The total score was 50. The scale had good reliability with Cronbach's alpha of  $0.85$  and acceptable subscale internal consistency with Cronbach's alpha of  $0.65 - 0.76$  (Annear, 2020; Annear et al., 2017; Annear, Toye, Eccleston, et al., 2015; Robinson et al., 2014)

### 3.6.3 Assessment of DLS psychometric properties

Following item generation, the preliminary version of the DLS with 42 questions was compiled and subjected to content and construct validity, discussed in detail in subsequent sections.

#### 3.6.3.1 Content Validity.

Both quantitative and qualitative content analysis was conducted by experts in dementia care, management and research, mental health promotion, African migrant studies, and scale development and validation, who were invited to be a part of the study. A seven-member expert panel was invited and provided both qualitative and quantitative content validity. An invitation email was sent to the seven experts. An information sheet detailing the study objectives was provided. Expert panel members were informed that participation was voluntary, and they could leave the scale evaluation at any time. Each panel member had to sign a consent form before the content validity. After recruitment and consent forms were returned, a link (using Qualtrics software) was sent to participants. A one-month deadline was allocated to complete the questionnaire. In the initial phase, the expert panel was asked to comment on the scale content, reading the items one by one and providing ratings.

#### *Quantitative method to check Content Validity*

Item-level content validity (I-CVI) was used to analyse data from the expert review. CVI is often used when researchers want to evaluate whether a question needs to be deleted, retained, or revised (Korhonen et al., 2019; Polit, 2015; Polit, 2018). To calculate the content validity index of the scale, experts were asked to assess each of the 42 questions on a 4-point Likert scale (where 1= very irrelevant, 2= irrelevant, 3= relevant, and 4= very relevant). The expert was also asked to determine the importance and clarity of the scale using 3-point and 2-point Likert scales, respectively. Demographic data, including country of origin, working experience, gender, education, age, and profession, were also gathered. The CVI score for all 42 items was calculated and found to be satisfactory, with scores ranging from 0.71 to 1. Using a 4-point Likert scale, the best overall item score is 1.00 (Polit, 2015). A cutoff point score of 0.79 is an indication of an acceptable question.

### *Qualitative method to check Content Validity (Item-CVI)*

For the qualitative content validity, experts were asked to evaluate the scale for grammatical errors, item allocation, and wording. After gathering expert opinions on each item, essential changes were made to the scale (see Chapter 5, section 5.2.1). Five questions were deleted, four items were revised due to grammatical errors, and an additional three questions were culturally adapted.

### 3.6.3.2 Construct validity of the provisional version of DLS

Following content analysis, the provisional version of DLS with 37 questions was subjected to psychometric evaluation. Construct validity of the dementia literacy scale (DLS) was evaluated using exploratory and confirmatory factor analysis. Internal consistency analysis was used to assess the scale reliability. The detailed processes involved are described below.

### *Design and participants*

A cross-sectional study was conducted on a purposive sample of Africans living in Hong Kong. Participants were recruited from various districts, including East-Tsim Sha Tsui, Mong Kok, Yuen Long, Central, Wan Chai, Sham Shui Po, etc. Eligibility criteria for study inclusion were as follows: persons 18 years and above, having stayed in Hong Kong for at least a year, an African, and able to read and write in English. A total of 400 participants was estimated for the study based on the rule of thumb of 10 samples per number of items in the questionnaire (Harrington, 2008; Kline, 2013; Kline, 2015). In total, 461 participants were recruited for the study. The sample was split into two groups for the analysis using the split sample approach. For the EFA, 223 samples were included, while 238 were included in the CFA.

### 3.6.3.3 Data Analysis (Construct validity and internal consistency)

Social Package for Social Scientists (SPSS) software version 21 (IBM Corporation, 2013) was used for data analysis. CFA was evaluated using SPSS AMOS version 23 (Arbuckle, 2012)

### *Exploratory Factor Analysis*

An exploratory factor analysis was conducted to assess the construct validity of the DLS. Using the force response function on the Qualtrics software and face-to-face interviews for data collection ensured there were no missing data. A principal axis factor analysis was conducted on the 37 items of the dementia literacy scale with orthogonal rotation (varimax). Eigenvalues greater



than 1, a minimum factor loading of 0.4, a maximum of 25 rotation iterations, and a scree plot were used to determine the number of underlying factors of the DLS (Field, 2013; Osborne, 2008). Additionally, the rotation of the factor analysis converged at eight iterations. Bartlett's Test of Sphericity and Kaiser-Meyer-Olkin (KMO) were used to ascertain the sample appropriateness for data analysis.

#### *Confirmatory factor analysis*

The theoretical fit of the DLS model was assessed using confirmatory factor analysis (CFA). CFA was carried out with the findings from the exploratory factor analysis using the maximum likelihood estimation method and covariance indexes. The model's goodness-of-fit indexes were assessed using the Comparative Fit Index (CFI), Root Mean Square Error of Approximation (RMSEA), Tucker Lewis Index (TLI), Incremental Fit Index (IFI), model chi-square ( $\chi^2$ ), and the Standardized Root Mean Square Residual (SRMR). For goodness-of-fit indexes, acceptable values included  $\chi^2/df \leq 2$ , RMSEA < 0.08,  $p > 0.05$ , CFI > 0.9, IFI > 0.9, SRMR < 0.08, and TLI > 0.9 (Meyers et al., 2016; Thakkar, 2020).

#### *Internal Consistency*

Internal consistency of the whole scale and subscales was assessed using Cronbach's alpha coefficient. A Cronbach's alpha coefficient of 0.70 was considered an acceptable scale (Field, 2013; Meyers et al., 2016; Thakkar, 2020).

## 3.7 Phase 2: The Qualitative Study

### 3.7.1 Study Design

An interpretive description research design was used to explore the role of dementia literacy and acculturation on the intention-to-seek-help. According to Polit (2018), qualitative design is the most appropriate for exploring a phenomenon about which little is known. This study was used to uncover, describe, explain, and understand whether dementia literacy and acculturation play a role in the dementia help-seeking among Africans living in Hong Kong (Thorne, 2014, 2016). Various studies have highlighted the significant impact of higher levels of acculturation, social networks, and health literacy on different disease-specific context and health outcomes (Kim et al., 2012; Kim & Chen, 2011; Sagong & Yoon, 2021; Valencia-Garcia et al., 2012). However, little is known about the relationship between dementia literacy, acculturation, and help-seeking behaviour.

Interpretive description is an inductive approach that facilitates the examination and generates knowledge of a clinical phenomenon, based on human health experiences as they are explained by those affected by it in their embedded context (Thorne, 2016; Thorne et al., 1997). The interpretive description, also called a “non-categorical” research methodology, implies this qualitative methodology does not fit with a conventional approach (Thorne, 2016). Interpretive description, according to Thorne (2016) is:

*“A research approach that requires an impartial purpose deriving from three sources; 1) an understanding of known and unknown knowledge based on the existing empirical evidence (from multiple sources), (2) an actual real-world question, and (3) an appreciation for a contextual and conceptual realm within which a targeted audience is positioned to receive an answer generated” (Thorne, 2016, p. 40)*

Interpretive description is a suitable design to explore a new concept (dementia literacy) among Africans. Interpretative researchers expect their researchable questions to shift throughout a study (Thorne, 2016). The interpretive description also aids in gaining insight into informants’ ways of understanding and life experiences. Therefore, the aim is to remain closely attuned to what the participants say and how they say it (Thorne, 2016; Thorne, 2008).

### 3.7.2 Sampling and Sampling technique

A total of 30 participants was recruited in the study using purposive and snowball sampling. There is no fixed sampling design in an interpretive description study, and a researcher could adopt a purposive, convenience, theoretical, or snowball sampling approach (Burdine et al., 2021; Thorne, 2016). Purposive sampling helped in selecting participants who met the inclusion and exclusion criteria. The term Africans, in this study, refers to people who originate from Africa and identify as Africans. These countries cover the regions of West Africa, Central Africa, East Africa, and Southern Africa. Africans in Hong Kong include asylum seekers, refugees, students, businesspeople, traders, and economic migrants (Amoah, Hodzi, et al., 2020; Bodomo et al., 2020). Although recent reports indicate that the number of African traders in the city may be decreasing, their representation is kept intact by an influx of student populations (Amoah, Hodzi, et al., 2020). Recent figures show that in the past decade, the proportion of Africans studying in China has been growing more than in other regions. Factors such as gender, immigration status, and country of origin were considered to ensure a balanced sample (Crang & Cook, 2007). Although a qualitative sample may not be a meaningful representation of the general population, it may reflect a “certain kind of perspective built from an auditable set of angles of vision whose nature and boundaries we can acknowledge and address” (Thorne, 2016). Purposive sampling entails recruiting informants who fit the study’s objectives and research questions (Bryman, 2015). Recruiting Africans for the study was a struggle due to the emergence of the Coronavirus disease 2019 (COVID-19) pandemic and the social distancing measures in place during data collection. Therefore, a purposive sampling approach was supplemented with snowball sampling to help in tracing hard-to-reach Africans living in Hong Kong. Snowball sampling made it easier to identify Africans living in Hong Kong (Bryman, 2015).

### 3.7.3 Inclusion and exclusion criteria

Subjects with different immigration status, including permanent residents, asylum seekers, refugees, students, people with working visas, and those with diplomatic passports, were invited. Among these groups of people, those who met the criteria below were invited to participate in the study:

- i. Africans aged 18 and above.
- ii. Persons who had lived in Hong Kong for at least a year.

- iii. People who can communicate in English.
- iv. People who are legally able to give consent to take part in the study.

Exclusion criteria include:

- i. People with severe difficulty in communicating (i.e., those who are deaf, blind, or have aphasia).
- ii. Those who have a severe mental illness (e.g., schizophrenia, mania, bipolar disorder).

People from North Africa.

### 3.7.4 Sample Size

Interpretive descriptions can be conducted on any sample size. However, it suits smaller-scale qualitative investigations (Thorne et al., 2004). According to Morse (2000), data quality is linked to the study's method and sample size selected. According to Morse (2000) using a sample of 20-30 participants is enough to obtain a rich and in-depth data. However, there is lack of consensus about what is considered an ample sample size in qualitative studies; therefore, numerous researchers have proposed that the nature of the topic should guide the sample size, the data quality, and the study design; or by using the concept of "data saturation" (Mason, 2010; Sandelowski, 1995). A significant concern of qualitative researchers is determining whether a sample is too small or too large to support claims of having achieved data redundancy or theoretical saturation (Bryman, 2015; Lincoln & Guba, 1985; Sandelowski, 1995).

However, Sandelowski (1995) has simplified the issue highlighting how a researcher can judge the adequacy of the sample based on the quality of the information/data gathered and how it addresses the research objectives and questions. As such, researchers are encouraged to aim to produce what Geertz (1973) recount as a 'thick description', which simply means producing a rich account of the details of results from the study. Therefore, to derive at a desirable sample, attention should be paid to data saturation and strategies to gather a rich and thick data (Bryman, 2015). The principle of data saturation forms the basic principle for the sample size for this study. Data was deemed saturated when there was the realisation that a rich and thick information had been gathered to replicate the research, and the chance of gathering new information have been exhausted and further coding was not feasible (Fusch & Ness, 2015; Guest, Bunce, & Johnson, 2006; O'Reilly, O' Reilly, Rosato, & Connolly, 2007; Walker, 2012). Therefore, data was saturated

when the sample size was 27, but an additional three interviews were conducted to confirm saturation.

### 3.7.5 Participants Recruitment

Participant recruitment was done in the various communities in Hong Kong with the support of the president of the African Community Hong Kong. The president provided the names and contacts of eight country-specific association presidents in Hong Kong, namely, from Nigeria, Ghana, Uganda, South Africa, Cameroon, Kenya, Guinea, and Zimbabwe. Names of leaders, including executives of the African community, Chairman of the African Elders in Hong Kong, and the leader of the African Businessmen Association were also provided by the president. These individuals were approached, and permission was sought to recruit their members as study participants. After the study advertisement appeared on various countries' social media platforms (WhatsApp and Facebook), some participants signed up to be part of the study. Potential participants were contacted on WhatsApp before recruitment, to encourage dialogue and trust between the potential participants and me, to facilitate a relaxed environment for sharing ideas during the interview sessions.

### 3.7.6 Data collection method

Data collection was done from the 1<sup>st</sup> to the 30<sup>th</sup> of January 2020. Data collection was conducted through individual in-depth interviews with Africans living in Hong Kong. Interviews were performed using a semi-structured interview guide (Table 3.1). Primary data are a researcher's self-constructed data that have not been subjected to manipulation (Bryman, 2015; Koduah, 2018). Due to the social distancing measures (stay at home) and time constraints for most participants, it was deemed more appropriate and practical to conduct individual interviews. Zoom and WhatsApp were used to conduct the interviews with participants, based on their individual preferred times. All interviews were recorded with a voice recorder and the built-in recording function in Zoom and WhatsApp.

The lead researcher moderated the discussions—while a research assistant (RA) assisted the moderator and oversaw the taping of all sessions. The RA also observed and recorded the participants' non-verbal clues and gestures. After informed consent was sought from participants,

a date for the in-depth interview was scheduled. Interviews were conducted in English and lasted approximately 25 to 60 minutes. Memos and field notes were kept during the data collection process.

### 3.7.7 Interview guide

A semi-structured interview guide (see Table 3.2) was used to interview participants. The questions were developed after a comprehensive review of the literature on acculturation, dementia literacy, and help-seeking behaviour. The semi-structured interview guide helped in producing in-depth data on the topic, as the participants were encouraged to express their views freely, without restrictions (Bryman, 2015; Smith et al., 2013). Using a semi-structured interview guide also promoted dialogue between the researcher and the participants and allowed room for the interview questions to be modified based on the responses received. Additionally, it aided the researcher in probing further when important ideas or responses arose (Smith et al., 2013). A vignette (Figure 3.2) describing a person with dementia symptoms was used as part of the interview guide to solicit answers to questions about dementia literacy. Table 3.2 summarises the interview guide. The questions for this study centred on the experiences and knowledge of Africans in terms of dementia literacy, acculturation, and help-seeking behaviour. Using a semi-structured interview guide enabled participants to express themselves freely without restrictions, but within the confines of the research questions (Bryman, 2008).

Table 3. 2. Interview Guide

<b>Questions</b>	
<b>Acculturation</b>	1. How do you describe your experience migrating to Hong Kong? i. What are some of the challenges you faced after migration?
	2. Could you elaborate on your self-identity?
	3. As a result of your experiences living here, do you feel more connected to the Hong Kong culture or your heritage culture? i. Do you feel like part of Hong Kong society? ii. Which group of people do you usually socialise with in Hong Kong?
	4. In your opinion, what is wrong with Ms Annika?

<p><b>Dementia Literacy</b></p>	<ul style="list-style-type: none"> <li>i. How do you describe/call this condition in your local dialect?</li> <li>ii. Tell me what you know about dementia?</li> <li>iii. In your opinion, does this condition exist in Hong Kong?</li> </ul> <p>5. In your opinion, what do you believe is/is the cause of her condition?</p> <ul style="list-style-type: none"> <li>i. What can be done to prevent getting dementia?</li> </ul> <p>6. Tell me how you receive information about dementia?</p> <ul style="list-style-type: none"> <li>i. Where or whom do you often seek health information from?</li> </ul> <p>7. When you think about dementia, how do you describe people with the condition?</p> <ul style="list-style-type: none"> <li>i. How should persons with such conditions be treated?</li> </ul>
<p><b>Intention-to-Seek-Help</b></p>	<p>1. If you suspect that your parents or any acquaintances have dementia, how will you deal with it?</p> <ul style="list-style-type: none"> <li>i. Who will you consult/contact when faced with a similar condition like Ms Annika? Give reasons.</li> <li>ii. Do you know any facilities available for people with such conditions in Hong Kong?</li> </ul>

Vignette

Madam Annika is a 65-year-old woman who lives in Umlazi with her children. She has lost her husband and four of her eight children in three years. Currently, she often wakes up at night and starts to pray fervently, mentioning the names of her deceased family. She often forgets conversations and keeps repeating herself. She misplaces her items and often blames others for taking or moving them. She cannot remember familiar places and people and has gotten lost countless times in her neighbourhood, where she has resided for over 20 years. Her children are worried and not sure what to do.

Figure 3. 2. Vignette describing symptoms of dementia.

### *Questions about participant demographics*

Age, gender, ethnicity, religion, educational status, marital status, immigration status, duration of stay, and country of origin were collected before the interview. Therefore, this study will gather information on the participants' demographic characteristics.

### 3.7.8 Reflexivity

Reflexivity is the continuous process of internal discourse and self-critique of a researcher's positioning and active and explicit awareness that this position may influence the research process and outcome (Berger, 2015; Rettke et al., 2018). Therefore, there was a need to recognise how the primary researcher's situation may have impacted the study settings, participants, research questions, data collection, and data interpretation (Berger, 2015; Tinker & Armstrong, 2008). In this study, relevant researcher positioning includes personal characteristics such as age, gender, immigration status, personal experiences, duration of stay, beliefs, and linguistic traditions. Taking an outsider or insider position is a conscious decision qualitative researchers must adopt to conceptualise observations and interpret findings objectively (Amoah, 2013; Tinker & Armstrong, 2008). Various qualitative researcher has posited that positioning oneself as an outsider or insider during the research process impacts how results are interpreted.

The primary researcher is an African who relocated to Hong Kong in 2016 as a research student and started her study on African migrants in Hong Kong three years later. During data collection, she encountered discrimination and racial profiling and learned to cope with linguistic barriers. This shared immigrant experience with study participants positioned her as an 'insider' and offered some advantages during the data collection and analysis. Various studies have reported how having shared experiences with study participants gave researchers a head start regarding knowledge about the research topic and an understanding of nuanced reactions from their study participants (Ahmed et al., 2011; Berger, 2015; Rettke et al., 2018).

Being an African immigrant greatly facilitated participant recruitment and data collection. Participants, especially the males, were very receptive and cooperative, and expressed their joy in knowing there is an African researcher in Hong Kong who will help change the narrative of the African plight in the city. Being an African made it easy for participants to discuss issues their



experiences, and the challenges they face in their new society, openly. Being an African also boosted my confidence and comfort level in establishing rapport during the interviews. Participants expressed their joy and relief at meeting an African researcher in Hong Kong. A researcher's awareness of their status (whether as an outsider or insider) between themselves and their study participants enables the researcher to genuinely understand participants' experiences (Cloke et al., 2004; Tinker & Armstrong, 2008).

Being a female student also influenced the data collection process and analysis, as my status allowed me to approach the study with cultural knowledge and insights on the subject matter. Sharing a common background also diminished the cultural distance and enhanced my willingness to go to places (e.g., Chungking Mansion) that I otherwise would not have. Being African, I was familiar with potentially sensitive questions and familiar with common language used by Africans in the city. Awareness of cultural nuances made me sensitive to non-verbal cues, able to probe in-depth and ferret out hints that a non-African might miss.

However, my being an insider also influenced participants' responses, due to their perceptions of sharing common experiences. There were instances where participants left sentences incomplete, as they assumed that I had first-hand knowledge of their experiences. Therefore, there was a state of being conscious and constantly alert as to how my identity may have influenced responses. To address this dilemma, participants were made aware that although we may share a similar ethnic identity, some experiences may be unique to them, and I would like to learn more and understand this.

Notably, while I might share similar immigration status with some participants, there were also significant differences in certain demographic characteristics such as duration of stay, sex, education, and country of origin and acculturation process. There was a conscious effort to separate my experiences from theirs, and to avoid overlooking certain aspects of their subjective experiences (Berger, 2015). Researchers who assume an 'Outsider' position more often than not are criticised for failing to accurately interpret the participants' experiences. At the same time, insiders are prone to overlooking significant differences within and between groups due to familiarity (Tinker & Armstrong, 2008). Therefore, with the assistance of supervisors acting as

second and third independent coders, similarities and differences among participant experiences and knowledge of dementia were observed and recorded. Tinker and Armstrong (2008) specified that researchers always alternate between insiders and outsiders in every research context, based on observed similarities and differences. This approach will promote the researcher's role as a seeker of knowledge, without tarnishing the study objectives and data collection process (Amoah, 2017).

### 3.7.9 Data Analysis

All individual interviews were audio recorded and transcribed verbatim in English by the primary researcher and two independent research assistants. NVivo 11 software was used to manage all transcribed data, the codes, and the coding structure. Inductive thematic analysis using a constant comparative method was used to analyse data from the study (Braun & Clarke, 2006; Thorne et al., 2004). A constant comparative approach was used to identify similarities and differences in participants' experiences and knowledge regarding dementia literacy and acculturation (Glaser et al., 1968; Nowell et al., 2017; Thorne, 2016). We repeatedly read and re-read the transcripts to gain a sense of the data. Codes were generated from the transcribed data, and a meaning was assigned to each code (Burdine et al., 2021; Thorne, 2008). Codes from the interviews and reflective journals were contrasted and compared with each other. The codes generated were synthesised based on their relevance to dementia literacy, acculturation, and help-seeking for dementia. A coding template was developed, applied to subsequent transcripts, and revised and refined based on codes identified from the new transcripts. This was to ensure that new data or information was not missed and to develop themes more extensively (Burdine et al., 2021).

#### *Data Saturation*

After the 28<sup>th</sup> interview was transcribed, we discovered that no new information was generated. To ensure data has been saturated, two interviews were conducted to authenticate whether any new thematic expressions would be formed. Nevertheless, no new codes were identified; therefore, the data was saturated. In this study, data collection stopped after the realisation that all interview questions had been answered exhaustively and no new information was forthcoming.

Theoretical interpretation of the data was formed by grouping different codes to create patterns. The research team (the student and the two supervisors) met via Zoom to discuss and share independent interpretations of the data. After consensus on the coding pattern, the primary researcher (the student) amassed them into main themes and described the theoretical connection between the themes using a diagram. The team met again to refine and confirm the organisation of the themes identified. Efforts were made to ensure that the main themes that were developed reflected participants' interpretations. The discussions also focused on how the findings fit or expanded the existing literature on the role acculturation and dementia literacy play in the help-seeking behaviours of African migrants. Disagreements among the team members were resolved through discussions and re-examining the data until a consensus was reached. An independent scholar who was not part of the research team reviewed the themes and subthemes generated. This step was necessary to establish the rigour of the data analysis process.

#### 3.7.10 Rigour

The following subsections explain how credibility, dependability, confirmability, and transferability were employed in this study.

*Credibility:* Credibility refers to a reliable account of the participants' experiences during the data collection process (Koch, 2006). At the outset, the design, research questions and method, were formulated based on a systematic review and refined based on expert assessments. The interview guide was carefully developed, and pilot tested with three Africans in Hong Kong to ensure wordings suit the context and participants. Individual interviews were conducted to reduce doubt, by asking participants to clarify the accounts of their experiences. To ensure credibility of the analytical process, three coders independently read the data transcripts several times to capture the essential features of the data and develop trustworthiness. Credibility was also established by emphasising data saturation—a process of obtaining a comprehensive understanding of a phenomenon under study by continuing the sampling process until no new substantive data is produced (Miles & Huberman, 1994; Palinkas et al., 2015). This study records all observations, and data obtained during the fieldwork was documented in a field notebook to addendum audio recordings. Attention was also paid to the participants' mannerisms, including their body language and tonation in responding to questions.

*Dependability:* Dependability refers to the reduction of idiosyncrasies in interpreting the data. The data obtained from participants was even and theoretically inclusive among the participants, thus not conflicting (Amoah, 2013; Koch, 2006). The opinion of an experienced qualitative nurse researcher was gathered to ascertain coherence in the methodology and interpretation of the findings from the study. In this process, a reflection on the theoretical, methodological, and analytical decisions was made throughout the study. More specifically, an external audit was conducted, which confirmed the rationale and the dependability of decisions made.

*Confirmability:* Confirmability was achieved when the findings from the study were produced through a consensus interpretation of data by the primary researcher, reflecting the opinion and experiences of participants and not from the researcher's perspectives (Gatrell & Elliott, 2014; Polit-O'Hara & Beck, 2006). Analytical patterns from the data were examined during the data collection process to ascertain whether they 'ring true' to the narratives of other participants. More specifically, data triangulation confirmed the interpretations, with some participants asked to provide feedback to certify the confirmability of the findings and its interpretations.

*Transferability:* Transferability is the fitness of a study's findings to the actual study context (Bryman, 2015). The study results were compared to other studies focused on assessing acculturation, mental health literacy or health literacy-specific disease conditions. In other words, the data gathered 'fit' in the context of a deeper understanding of the relationship between dementia literacy, acculturation, and help-seeking behaviour were discussed. In addition, direct quotations from participants that exemplify the researcher's interpretation are presented in the findings chapter (see Chapter 5) for readers to authenticate transferability.

### **3.8 Phase 3: Quantitative Study (Cross-sectional Survey)**

Given the findings from the qualitative study, a follow-up survey study was deemed appropriate to learn more about the nature of key themes discovered. In this study, social network was added to dementia literacy and acculturation, to assess how these three variables impact the intention-to- seek-help. This section will discuss the study design, sample and sample size, data collection methods, measuring instruments, and data analysis plan.

#### **3.8.1 Study Design**

A descriptive cross-sectional survey was conducted to examine the relationship between dementia literacy, acculturation, social networks, and dementia help-seeking among Africans living in Hong Kong.

#### **3.8.2 Sample and Sampling Method**

Study participants are Africans currently living in Hong Kong, including students, asylum seekers, refugees, businessmen/women, traders, economic migrants, permanent residents, and those with diplomatic visas. A convenience sampling approach was used to recruit participants for the study. This sampling approach was helpful for the practicality of data recruitment, as data were gathered during the third wave of the COVID-19 pandemic and social distancing measures were in full force. Although this sampling approach may not be helpful for a heterogeneous population, efforts were made to ensure that the participants recruited were diverse in terms of country of origin, immigration status, education status, and gender (Bryman, 2015; Lo, 2020; Nardi, 2018). Using a snowball strategy, acquaintances of Africans already recruited were invited to participate in the study. Africans in Hong Kong are difficult to reach, as their numbers and exact location in the city are unknown. Recruitment using convenience and snowball sampling approaches was suitable for this population group. Invitation letters were also sent to various countries' and African students' WhatsApp platforms.

#### **3.8.3 Inclusion and Exclusion Criteria**

The criteria for participant inclusion were:

- i. Africans were aged 18 and above.
- ii. Persons who have lived in Hong Kong for at least one year.

iii. Those who speak and understand English.

It was anticipated that after two years, participants would have integrated into society to a certain point and forged some social networks.

The exclusion criteria were:

- i. People with severe difficulties in communicating (e.g., those who are deaf, blind, or have aphasia).
- ii. People with severe cognitive impairment (dementia).
- iii. People who have severe mental illnesses (e.g., schizophrenia, mania, bipolar disorder).

#### 3.8.4 Sample Size Calculation

The sample for the study was calculated using the sample size calculator.net, based on a confidence level of 95%,  $\pm 5\%$  margin of error, with a population proportion of 50% and a population size of 4,000. The calculated results indicate a minimum total sample size of 351. Considering a 30% attrition rate, the total sample size was 456. A total of 461 participants was recruited for the study.

#### 3.8.5 Data Collection Procedures

This study gathered data from Africans. Efforts were made to ensure that participants involved in the qualitative study were not included in the survey. Participants included Africans who had completed at least a two-year stay in Hong Kong. Online and face-to-face interviewing techniques were adopted in administering the survey questionnaire. Face-to-face interviewing was favoured for various reasons. First, it was anticipated that some participants might possess low English language proficiency and literacy levels, and self-administered questionnaires would have produced many mistakes. Some Africans are from non-English speaking countries, and the ability to accurately read and interpret the questions and instructions may be limited. Lastly, using face-to-face interviewing and the force command function in Qualtrics prevented incomplete data and ensured a higher response rate (Bryman, 2015).

A link to the online survey was distributed on various social media platforms (WhatsApp and Facebook). Information sheets and informed consent forms were added to the questionnaire, and participants must consent to participate before gaining access to the questionnaire. Face-to-face

interviews were conducted in restaurants, the African centre, churches (including the Vine Church, Vision first, Pentecost Church, Catholic and Adventist churches), mosques, Chung King Mansion, Mirador building, and shops and parks in Central, Wan Chai, Sham Shui Po, and East Tsim Sha Tsui and various university campuses. For face-to-face interviews, 400 questionnaires were dispatched, of which 328 were completed and deemed valid. This gives an overall response rate of 82%.

### 3.8.6 Measuring Instruments

Scales used in the study showed good psychometric properties, with Cronbach's alpha ranging from 0.66 (General help seeking questionnaire) to 0.96 (Dementia Literacy) (Table 3.3).

Table 3. 3. Psychometric properties of measures used in the study.

Scales		No. of items	Range	M	SD	Cronbach's $\alpha$
Brief acculturation Orientation Scale (BAOS)	Total scale	8	8 - 40	20.58	5.696	0.79
	Home orientation	4	4 - 20	9.79	3.87	0.91
	Host orientation	4	4 - 20	10.79	4.01	0.91
Lubben Social Network Scale-6 (LSNS-6)		6	0 - 30	14.59	4.45	0.68
Dementia Literacy Scale (DLS)		37	41 -160	87.27	36.13	0.96
General Help-Seeking Questionnaire (GHSQ)		8	16 - 40	32.25	4.035	0.66

#### 3.8.6.1 Dementia Literacy

This study measured dementia literacy using the newly developed dementia literacy scale (DLS) (see Chapter 4 for details). The DLS scale was the first to provide a comprehensive measure for all attributes of dementia literacy based on the conceptual definition of the concept of mental health literacy. The DLS scale is a 5-point Likert scale consisting of 37 items with five subscales. The five subscales include (a) recognition of dementia symptoms, (b) Causes and risk factors, (c) knowing how to seek dementia information, (d) Awareness of professional help available and (e)

attitudes that promote dementia recognition. The knowledge of professional services available subscale was rated on a five-point scale, namely ‘fully aware (5)’, ‘aware (4)’, ‘not aware (3)’, ‘fully not aware (2)’, and ‘don’t know (1)’. However, the remaining subscale was rated on a 5-point Likert scale: ‘strongly agree (5)’, ‘agree (4)’, ‘disagree (3)’, ‘strongly disagree (2)’, and ‘don’t know (1)’.

In the scoring of the scale, ‘don’t know’ answers were given a score of zero, strongly disagree= 1, disagree=2, agree = 3, and strongly agree = 4. Summing of all individual scores on each question was used to compute for the dementia literacy total score. Eight of the questions were reverse scored. Three new values were summed in computing for the different levels of dementia literacy using the median and percentile values (33, 66, and 100 percentiles). Scores below 17 were labelled as 1 (inadequate dementia literacy), scores from 17.00001 to 76 were labelled as 2 (problematic dementia literacy), and scores from 76.00001 to 123 were labelled as sufficient dementia literacy.

#### 3.8.6.2 Acculturation

The brief acculturation orientation scale (BAOS) is a bi-dimensional scale used to measure acculturation (Demes & Geeraert, 2014). BAOS uses four indicators, including the value of cultural friendships, traditions, actions, and characteristics, to assess acculturation (Demes & Geeraert, 2014; Palladino et al., 2020). The BAOS consists of two independent subscales (orientation to home and host cultures). This study adapted the host culture subscale to refer to Hong Kong culture. The scale is an 8-item questionnaire where the central indicators of acculturation are presented twice (e.g., “It is important for me to have [Hong Kong] [African] friends”). Responses were rated on a 5-point Likert scale, ranging from “Extremely important (5)” to “Not at all important (1)”. The scale has been used to assess Italian ethnic minority adolescents (Palladino et al., 2020), Erasmus students in Croatia (Demes & Geeraert, 2014), Greek migrants (Petkanopoulou et al., 2021), and migrant workers (Ozer & Schwartz, 2021). The scale had an acceptable internal consistency with  $\alpha = 0.90$  (African culture) and  $\alpha = 0.91$  (Hong Kong culture). The Cronbach's alpha of the 8-item Brief Acculturation Orientation Scale (BAOS) in this study was 0.79. A total score was obtained by summing all scores on eight items. The higher the score, the higher the acculturation level. There is no cut-off point for the scale. In computing for the acculturation strategies, the average score of each subscale was computed with scores  $\geq 2.5 = 2$



and  $\leq 2.5 = 1$ . Acculturation strategies were derived from the scores obtained from Hong Kong and African/Home subscales, as shown in Table 3.4.

Table 3. 4. Acculturation strategies derived from the Brief Acculturation Orientation scale

Strategies	Hong Kong culture score	African/Home culture score
1. Integration	2	2
2. Assimilation	2	1
3. Separation	1	2
4. Marginalization	1	1

### 3.8.6.3 Social Network

The Lubben Social Network Scale-6 (LSNS-6) was used to assess participants' social networks. The LSNS was developed to evaluate the social engagement of older adults (Chang et al., 2018; Lubben et al., 2006). The LSNS-6 consisted of six questions assessing interactive and structural dimensions of social networks that were summed and equally weighted. Friends and Family networks were evaluated, with each having three questions. The questions include (a) “How many relatives do you see/hear from at least once a month?”, (b) How many relatives do you feel close enough to that you could call on them for help? (c) How many relatives feel at ease with whom you can talk about private matters? These questions were repeated to assess friends’ networks. Responses to the question ranged from 0 (none) to 5 (nine or more). Scores from the questions were combined to form a total score. LSNS-6 has been used and translated into a variety of languages (Chinese, Korean, Vietnamese, and Spanish), and each reported excellent psychometric properties (Chang et al., 2018; Grace et al., 2016; Jang et al., 2022; Vilar-Compte et al., 2018). The internal consistency of the scale was  $\alpha=0.68$ . The total score was an equal sum of the six questions. Scores ranged from 0 to 30, with higher scores indicating high social support and lower scores indicating social isolation. Scores below 12 indicated a participant with a minimal social network and a high risk for isolation.

#### 3.8.6.4 Intention-to-Seek-Help

Intention to seek help was assessed using the General Help-Seeking Questionnaire (GHSQ) (Wilson et al., 2005). The GHSQ consists of eight items on a 5-point Likert scale to assess participants' tendency to seek help from various individuals. Data from this scale were analysed as a total score and then based on individual items. The GHSQ was used to explore the likelihood that participants would seek help if they or a family member exhibited early signs of dementia. The help-seeking sources include a spouse, friend, parent, other family members, religious leaders (pastors, imam, and traditional healers), and psychiatrist/general health professionals. Two additional questions were added: one question assessed whether participants would avoid or delay seeking help if they thought that they (or other family members) had early signs of dementia. The second question assesses whether they would seek help immediately or delay seeking help or not seek help at all. The response options for the instrument are comprised of a 5-point Likert scale, with options ranging from 'extremely unlikely' to 'extremely likely'. Questions indicating a delay in seeking help and no intention to seek help were revised and coded. Total scores were computed by summing all responses from each item. Higher scores indicated a higher help-seeking behaviour and low scores, vice versa.

#### 3.8.6.5 Covariates: Socio-demographic variables

A systematic review of data on dementia literacy (Chapter 2) showed inconsistent results on potential factors influencing the dementia literacy of individuals (Cahill et al., 2015; Cations et al., 2018; Farina et al., 2020). These factors include age (participants included were 18 years and above), gender (both males and females were selected), ethnicity, religion (Islam, Christianity, traditional, Buddhism, no religious affiliation), educational status (measured from no education to tertiary school), marital status (single, married, divorced, cohabitating, separated and widowed), and length of stay (minimum eligibility of two years, measured in years). Others were immigration status (permanent residents, Hong Kong residents, asylum seekers, refugees, and diplomatic visa holders) and employment (employed, unemployed, student, retired, and homemaker). Additionally, country of origin (all 46 countries in subSaharan Africa were included), country of birth (participants were asked to write their country of birth), estimated monthly income, and district of residence were also ascertained.

The Health Days Core Module scale measures two kinds of health status (physical and mental health) (CDC, 2012; Control & Prevention, 2019). Self-perceived general health rating, the first question of the scale, was used as a specific measure of physical health status. Various studies have affirmed that the one-item self-perceived health status measure is accurate in predicting the onset of disability in a diverse population (Harris et al., 2011; Kawachi & Kennedy, 1999; Nieminen et al., 2013; Savatt et al., 2020). Using a single item, participants were asked, “In the past three months, how would you rate your physical health, which includes physical illness and injury?” This item was rated on a 5-point Likert scale (excellent to very poor). The second question was related to mental health using a similar question. The data were dichotomised as good physical or mental health (excellent, very good, and good) and poor physical or mental health (poor and very poor) (Kawachi et al., 1999). Lastly, the self-perceived economic and social status of a participant’s household – as perceived by the participants, compared to other households in Hong Kong. The social and economic status of participants’ households was rated on a scale of 1 to 10, with 1 being the lowest and 10 being the highest.

### 3.8.7 Data Analysis

Statistical analyses will be performed using IBM’s Statistical Package for the Social Sciences (SPSS) version 25.0 (IBM Corporation, 2013) and AMOS (Arbuckle, 2012). Different descriptive statistics, including percentages, sums, and univariate analysis, were used to examine the sample and establish the state of dementia literacy, acculturation, social networks, and help-seeking behaviour (intention to seek help). Two correlation analyses were conducted. The first analysis was conducted to assess the association between dementia literacy, acculturation, social networks, and help-seeking behaviour. The second was conducted to ascertain the correlation between help-seeking behaviour, dementia literacy, acculturation, social networks, and sociodemographic variables.

Three-step multiple hierarchical regression analysis (Chapter 6) was conducted using SPSS to examine the influence of the total scores of dementia literacy, acculturation, social networks, and help-seeking behaviour. Three multiple hierarchical regression analyses were performed. None of the sociodemographic variables correlated with the dependent variable (help-seeking behaviour); therefore, none of these variables was controlled for in the model. Social network total score was

entered in step one of the models, followed by acculturation in step two and dementia literacy in step three. For issues of multicollinearity, variance inflation factor (VIF) < 10 and Tolerance > 0.3 were acceptable scores (Field, 2013).

In the second regression analysis, all subscales of the main variables were used for the regression analysis and followed the same order stated earlier. Based on the results of the two hierarchical models discussed previously, a third regression model was conducted to assess the effect of assimilation, causes and risk factors, knowing how to access dementia information, and help-seeking. Social networks were entered in model 1, followed by assimilation in model 2 and lastly, knowing how to access information and causes and risk factors.

Structural equation models were developed to examine the relationships among sociodemographic indicators, dementia literacy, acculturation, social network, and intention to seek help. Two main path models were developed using the significant predictors identified from the hierarchical regression models. The maximum likelihood method was used to estimate the model parameters. In the path model, standardised regression coefficients were utilised to evaluate the effect of dementia literacy, acculturation, and social networks on the intention to seek help in the path model. The overall fitness of the model was evaluated using the model chi-square ( $\chi^2$ ), comparative fit index (CFI), Tucker Lewis Index (TLI), Chi-square ratio to the degree of freedom ( $\chi^2/df$ ), root means square error of approximation (RMSEA), the Normed Fit Index (NFI), and the standardized root mean square residual (SRMR).  $\chi^2/df \leq 2$ , RMSEA < .08,  $p > 0.05$  and SRMR < .08, and the CFI, IFI, and TLI cut-off scores should be above 0.9 were considered acceptable values to ascertain the goodness-of-fit indexes (Meyers et al., 2016; Thakkar, 2020). Insignificant paths were trimmed to alter the path model until the goodness-of-fit indexes showed that the final model fit the data appropriately. The indirect and direct effects of the main variables were also examined. SPSS AMOS was used to estimate path coefficients and the assessment of the overall fit of the structural model. All  $p$ -values were two-tailed, and the significance level was set at a  $p$ -value less than 0.05.

#### *Analysing sociodemographic data*

Participants' ages were categorised into five groups, 18-24 years, 25-34 years, 35-44 years, 45-59 years, and 60 years and above. These groups showed stages of maturity, from young adults (18 to

34 years) to older adults (35 to 59 years) and the elderly (60+). Sex was categorised as male and female. The duration of stay in Hong Kong was arbitrary, categorised as two to five years, six to 10 years, 11 to 15 years, 16 to 20 years, and 21 years or above. This was undertaken to estimate the mean duration of stay. Additionally, income (measured in Hong Kong dollars, HKD) of participants were from: <4,000, 15,000 to 39,999, 40,000- 79,999 and 80,000 and above. The participants' marital status was categorised as single/never married, married (married and cohabitation), and previously married (divorced, separated, widowed). Employment was also classified as employed, unemployed (housewives/homemakers, and retired/pensioners) and students. Participants' self-rated social and economic status was categorised into three groups, namely, high= 8-10, medium= 5-7, and low= 1-4.

### **3.9 Integration of Findings from Both Studies (Data Triangulation)**

Merging of findings from both qualitative and quantitative study occurred at the discussion phase (See Chapter 7). Data from both studies were analysed separately as specified in the previous subsections. Using data triangulation design, findings from the qualitative study and quantitative statistical findings were further compared and interpreted (Creswell, 2014; Flick, 2016). Findings from both studies were further interpreted and data compared for similarities and differences. Data triangulation approach was used to interpret findings from both qualitative and quantitative study. According to Creswell (2014), to assess the validity of mixed method findings, there is a need for mixed method researchers to compare of findings from the different data set based on the same topic. The aim of using triangulation approach is to provide a comprehensive understanding of the association between dementia literacy, acculturation, social network, and help-seeking behaviour. The merging of data was used to answer the research question 3:

1. What factors affect Africans dementia help-seeking behaviour?
  - a. Would dementia literacy directly affect help-seeking behaviour?
  - b. Would acculturation and social network affect their help-seeking behaviour?
  - c. Would dementia literacy, acculturation and social network interlink and affect Africans help-seeking behaviour?

### **3.10 Ethical Consideration and Approval for all Three Phases**

Before data collection, ethical approval was sought from the Human Subjects Research Ethics Committee of the Hong Kong Polytechnic University (Reference Number: HSEARS20200907003). Permission and consent were also sought from the president of the African community of Hong Kong and various presidential heads of the country-specific communities in Hong Kong (e.g., The Ghanaian Community Hong Kong, The Nigerian community Hong Kong, Ugandan community Hong Kong, the Cameroonian Community Hong Kong, etc.). Participants' consent was also sought before recruitment in all three study phases. An information sheet explaining the aims and objectives of each study phase was also provided to all participants. Emphasis was placed on the confidentiality of the information provided and on voluntary participation. Each participant was assured they could withdraw from the interviews (qualitative and quantitative) whenever they felt uncomfortable, without giving a reason. Efforts were also made to ensure that participants felt comfortable in all circumstances by requesting permission for audiotaped sessions (qualitative study).

The participants were also informed that data from the study would be published and presented at academic conferences. The audiotapes and completed questionnaires have been kept in a locked locker at the primary researcher's office and will be destroyed after the study has been completed. According to the Council for International Organizations of Medical Sciences, this study adheres to the principles of conducting health research among human subjects (Organization & Council for International Organizations of Medical Sciences, 2016). A sample of the information sheet and consent form has been attached in Appendix 4&5.

### **3.11 Summary of Chapter**

This chapter presented the methodology of this study. The study involves three phases: (1) development of the dementia literacy scale; (2) qualitative study and (3) cross-sectional study. The dementia literacy scale was developed based on a relevant literature review, the mental health literacy scale, the Alzheimer's disease scale, the Dementia Knowledge Assessment scale, and later refined based on findings from the qualitative data. A qualitative study was initially conducted to understand the relationship between dementia literacy, acculturation, and intention-to-seek-help among Africans living in Hong Kong. This is the first study of its kind to be conducted in a non-Western society and among African migrants, therefore, a qualitative research design was deemed appropriate. The quantitative study (cross-sectional survey) was conducted to test the hypotheses that were generated by the findings from the qualitative data and to assess the relationship between social networks and intention-to-seek-help for dementia. There, the quantitative study aimed to examine the association between intention-to-seek-help, dementia literacy, acculturation, and social networks. Dementia literacy, acculturation, and social networks were the independent variables, with intention-to-seek-help as the dependent variable.

## **CHAPTER 4: PSYCHOMETRIC PROPERTIES OF THE DEMENTIA LITERACY SCALE (DLS)**

This chapter presents the validation study findings of the Dementia Literacy Scale (DLS), which was modified from the Mental Health Literacy Scale (MHLS). The following will be covered: face and content validity and report the psychometric properties of the DLS. Finally, the chapter ends with a summary of the psychometric properties and significance of the DLS scale.

### **4.1 Item Revision to suit dementia context.**

DLS consists of three scales:

1. The Alzheimer's Disease Knowledge Scale (Carpenter et al., 2009). The ADKS comprises a 30-item scale made up of true/ false questions. Seven items (Q1, 6, 9,10,11,17,18) were selected from this scale and used to modify the MHLs.
2. Dementia Knowledge Assessment Scale (Annear et al., 2017). This is a 25-item, with four subscales with true/false questions. Eight items (Q3,4,5,7,8,14,16 &20) were adapted from this scale and used to modify the MHLs.
3. The MHLS (O'Connor & Casey, 2015) is a single factor measure with 35 questions and six domains measured using a 4-point Likert scale. MHLS was designed to examine knowledge and attitude in different aspects in mental health and help-seeking and, therefore, not specific to dementia. Therefore, using items adapted from ADKS and DKAS, various MHLS questions were modified to assess dementia literacy. The final scale consists of 42 items with six main sub-domains which reflect the original attributes of the MHLS, which include 1) recognition of dementia, (2) causes and risk factors (3) awareness of dementia treatment/management, (4) awareness professional help available, (5) knowing how to access information and (6) Attitude towards dementia.

### **4.2 Content Validity of the Dementia Literacy Scale.**

The content validity of the DLS was assessed with scale content validity index average (SCVI-Av) and item content validity index (I-CVI) as recommended by Polit and Beck (2006). The content validity of the 42 items was scored by seven experts from various universities in Ghana (n=3), Hong Kong (n=2), Ethiopia (n=1) and Uganda (n=1). There were five females and two male



experts. Three experts were nurses with expertise in dementia care, management, and research, two psychiatrists and the remaining two were experts in public health. Their expertise ranged from dementia care (n=4) and mental health (n=2), health literacy (n=1), African migrants' studies (n=2), scale development and validation (n=2). All these experts reported they knew of the mental health literacy scale, but only three have used it in their work. Table 4.1 shows that all the 42 items demonstrated a positive I-CVI ranging from 0.714 to 1, indicating that items were built with a good conceptualisation.

Table 4. 1. Expert rating of the Content validity of the Dementia Literacy Scale

Subscales	Item	Expert agreement	I-CVI	Universal Agreement (UA)
1. Recognition of dementia symptoms	Item 1	7	1	1
	Item 2	6	0.857	0
	Item 3	7	1	1
	Item 4	7	1	1
	Item 5	6	0.857	0
	Item 6	7	1	1
	Item 7	6	0.857	0
	Item 8	6	0.857	0
2. Knowledge of risk factors and causes	Item 9	7	1	1
	Item 10	7	1	1
	Item 11	7	1	1
	Item 12	7	1	1
	Item 13	7	1	1
	Item 14	7	1	1
	Item 15	7	1	1
	Item 16	7	1	1
3. Knowledge of treatment and management	Item 17	7	1	1
	Item 18	6	0.857	0
	Item 19	7	1	1

	Item 20	7	1	1
	Item 21	7	1	1
	Item 22	7	1	1
	Item 23	7	1	1
	Item 24	7	1	1
4. Knowledge of professional help available	Item 25	7	1	1
	Item 26	7	1	1
	Item 27	7	1	1
	Item 28	7	1	1
5. Knowledge of where to access dementia information	Item 29	7	1	1
	Item 30	7	1	1
	Item 31	7	1	1
6. Attitude that promotes recognition and help seeking	Item 32	5	0.714	0
	Item 33	7	1	1
	Item 34	7	1	1
	Item 35	7	1	1
	Item 36	7	1	1
	Item 37	7	1	1
	Item 38	7	1	1
	Item 39	7	1	1
	Item 40	7	1	1
	Item 41	7	1	1
	Item 42	7	1	1
Proportion of relevance		Sum of I-CVI	42	Sum of UA
		Scale-level-CVI (S-CVI) Average	0.976	S-CVI Relevance

#### 4.2.1 Face Validity (Qualitative)

According to the experts' comments, five questions were removed because one question was redundant compared to another question, and the other four were deemed irrelevant to dementia

literacy or too technical for the general population (see table 4.2). Three items were revised during the cultural adaptation process based on the recommendation by experts to adopt words commonly used in the African context (for example, curses and spiritual illness) and to avoid using technical or medical jargon (Table 4.2). Four questions with grammatical problems were revised with examples.

Table 4.2 Minor Revision of the items after receiving comments from the experts.

Revisions	Original item	Comments	Revised item
Cultural adaptation to suit participants	High cholesterol levels increase the risk of developing dementia.	Cholesterol is not an everyday language in some African settings. High fat intake seems more appropriate	High fatty food intake increases the risk of developing dementia.
	Heredity or genetic factors could contribute to one's risk of developing dementia.	Genetics may not be well understood by your participants why do not your simple words like family history.	A family history of dementia could contribute to one's risk of developing dementia.
	People can recover from the most common type of dementia.	I think it would be better if one or two questions talked about some cultural beliefs and perceptions of dementia among Africans, like belief in spiritual causes.	People with dementia are often witches or people who have been cursed.
Grammatical revision	People with dementia find it difficult to learn new skills.	Instead, you can write, "people with dementia have difficulty learning new skills.	People with dementia have difficulty learning new skills.
	Dementia may lead to premature death	Please revise this statement	Dementia may shorten the lifespan of the person.

	In Africa, women are more likely to suffer from dementia of any kind as compared to men	I suggest deleting Africa so that the scale could be used in the future by other populations	Women are more likely to suffer from dementia of any kind compared to men.
	Dementia is a category of mental illness.	Revise this statement; dementia is a brain disorder, not a mental illness.	Dementia is a disease of the brain.
Deleted items	Making some lifestyle changes may slow down the progression of dementia.	This statement does not reflect dementia literacy	Item deleted
	People with dementia might experience depression.	This statement might be more suited for health professionals than the general population. I advise you to remove this item	Item deleted
	Dementia is not an actual medical illness; it is a normal part of ageing	This statement is like the statement in the knowledge domain, "Dementia is a normal part of ageing" You might consider deleting it.	Item deleted
	Confusion among older people is always due to dementia	Dementia does not always lead to confusion, and confusion among older adults is not always due to dementia but other conditions. This statement is controversial, and I advise you to delete this item (Expert 2)	Item deleted

		That is not always the case. I think it would be better to omit this question (Expert 4)	
	Reality orientation and reminiscence therapy are effective in improving the cognitive functions of people with dementia	This question may be a bit overwhelming for the lay participants. I suggest you delete this or revise it.	Item deleted

**4.3 Dementia literacy scale**

After the above revision, the dementia literacy scale consists of 37 items. In the following steps, the sample was randomly divided into two to ensure mutually independent variables were obtained for both exploratory and confirmatory factor analysis.

**4.3.1 Description of sample**

All observations were used in the analysis as there were no missing values, resulting in 461 participants in total. Characteristics of the two randomly split samples used in the exploratory (sample 1), and confirmatory factor analyses are shown in Table 4.3. The randomisation results revealed 223 samples for EFA and 238 samples for CFA. There was no significant difference in the samples regarding gender, age, education, marital status, duration of stay, employment, and immigration status. A detailed description of the sample can be seen in Table 4.3. Approximately majority of the participants were males, stayed 1 to 5 years and were Hong Kong residents (Students and working visas).

Table 4.3. Characteristics of the Sample included in EFA and CFA

Characteristics		Sample 1 n (%)	Sample 2 n (%)
Sample size		223	238
Gender	Male	160 (71.7)	171 (71.8)

	Female	63 (28.3)	67 (28.2)
Age	18 – 24 years	27 (12.1)	25 (10.5)
	25 – 34 years	108 (48.4)	114 (47.9)
	35 – 44 years	60 (26.9)	74 (31.1)
	45 – 59 years	27 (12.1)	25 (10.5)
	60 years and above	1 (0.4)	0 (0.0)
Education	Primary school	2 (0.9)	1 (0.4)
	JHS/JSS/Middle school	6 (2.7)	6 (2.5)
	SHS/SSS/Vocational school	28 (12.6)	33 (13.9)
	A 'level/ Diploma	26 (11.7)	29 (12.2)
	Bachelor's degree	140 (62.8)	141 (59.2)
	Doctorate	21 (9.4)	28 (11.8)
Marital status	Married	108 (48.4)	120 (50.4)
	Divorced/ Widowed	11 (4.9)	13 (5.5)
	Single	104 (46.6)	105 (44.1)
Employment	Employed	118 (52.9)	147 (61.8)
	Unemployed	26 (11.6)	20 (8.4)
	Student	79 (35.4)	71 (29.8)
Duration of stay	1-5 years	132 (59.2)	143 (60.1)
	6 – 10 years	56 (25.1)	54 (22.7)
	11 – 15 years	17 (7.6)	13 (5.5)
	16 – 20 years	12 (5.4)	21 (8.8)
	21 years and above	6 (2.7)	7 (2.9)
Immigration status	Permanent residents	65 (29.1)	69 (29.0)
	Hong Kong residents	137 (61.4)	143 (60.1)
	Asylum seeker	11 (4.9)	17 (7.1)
	Refugees	9 (4.0)	8 (3.4)
	Diplomatic visa	1 (0.4)	1 (0.4)

#### 4.3.2 Exploratory factor analysis of the DLS

The Kaiser-Meyer-Olkin measure confirmed the sampling adequacy ( $n=223$ ) for the analysis as indicated by the value of  $KMO = 0.93$ ,  $df: 666$  and Bartlett's Test of Sphericity  $p < 0.001$  (Field, 2013). An initial analysis was conducted to obtain the eigenvalue of each factor. Each factor had an eigenvalue greater than Kaiser's criterion of 1, and all these factors explained 73.2% of the variance in the DLS. The scree plot showed inflexions that justified retaining five factors; therefore, five factors were retained due to the Kaiser's criterion on the values and the scree plot's convergence (see table 4.4 for the rotated matrix). Based on the items that cluster on the same factor, factor 1 was labelled as 'attitude towards dementia and care', factor 2 as 'recognition of signs and symptoms of dementia', factor 3 represents knowledge of risk factors and causes, factor 4 represents 'knowledge of professional help available, and factor 5 represents knowledge of where and how to access to dementia information. Factors comprised of 12 questions and explained 49% of the variance, the second factor with eight questions explained 9.1% of the variance, the third factor with eight questions explained 6% of the variance, factor four with five questions explained 5% of the variance and lastly the fifth factor with four questions explained 4% of the variance. In the end, the DLS was completed with 37 items and five factors.

Table 4 4. Results of Exploratory Factor Analysis

	Items	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
		Attitude towards dementia	Recognition of dementia symptoms	Knowledge of risk factors and causes	Knowledge of professional help available	Knowledge of where to access information
At1	I would be willing to socialise with someone with dementia.	.803				
At2	I would be willing to move next door to someone with dementia.	.801				
At3	Dementia is a sign of personal weakness.	.775				
At4	I would be willing to marry into a family with a history or someone with dementia.	.767				

At5	It is best to avoid people with dementia, so you do not develop this condition.	.752	.420			
At6	People with dementia are dangerous.	.743				
At7	People with dementia are often witches or people who have been cursed.	.716	.424			
At8	People with dementia could return to their old selves if they want to.	.668				
At9	When someone has dementia, using reminders can worsen the condition.	.576	.428			
At10	When a dementia patient repeats the same story several times.	.520				
At11	A person with a worse case of dementia may need 24-hours care and monitoring.	.507	.492	.424		
At12	When a person with dementia is distressed, it may be helpful to talk to them about their feelings.	.504	.481	.441		
K1	People with dementia find it difficult to learn new skills.		.800			
K2	Dementia affects a person's memory, thinking, emotion and behaviour.	.408	.795			
K3	People with dementia generally have problems making decisions.		.793			
K4	Dementia is a disease of the brain.		.789			
K5	People with dementia often misplace personal belongings and believe other people are stealing them		.768			
K6	Dementia is a normal part of ageing.		.657			
K7	Dementia may shorten the lifespan of people suffering from the condition.		.640	.418		



K8	Difficulty drinking and eating generally occur when the dementia condition gets worse.		.524	.415		
R1	Having high fat (cholesterol) levels increases the risk of developing dementia.			.832		
R2	Having high blood pressure increases the risk of developing dementia.			.820		
R3	Excessive smoking increases one's risk of developing dementia.			.719		
R4	Lack of exercise may increase the risk of developing dementia.			.694		
R5	Women are more likely to suffer from dementia of any kind compared to men.			.654		
R6	Alcohol abuse may increase one's risk of suffering from dementia.			.641		
R7	Dementia can affect both young and older adults.			.604		
R8	A family history of dementia may contribute to one's risk of developing the condition.	.414		.503		
PH1	Government-subsidised residential care homes and day-care centres.				.839	
PH2	Day rehabilitation training programs and centres.				.826	
PH3	Drugs that are effective for improving cognitive function.				.825	
PH4	Hospitals for people with dementia in Hong Kong.				.801	
PH5	Service - Online self-assessment for dementia				.744	
In1	I can locate health facilities for persons with dementia in Hong Kong.					.828

In2	I can use online tools to seek factual information about dementia.					.827
In3	I know where to seek information about in dementia.					.826
In4	I can attend face-to-face appointments with health professionals for information about dementia.					.813
	Eigenvalues	18.14	3.4	2.2	1.9	1.5
	% Of variance	49.0	9.1	6.0	5.0	4.0

#### 4.3.3 Confirmatory Factor Analysis of the DLS

A CFA was conducted on a sub-sample 2 (n=238) specifying the five factors identified from the exploratory factor analysis. The model fit indices including, CMIN/DF=2.138, CFI =0.93, TLI =0.92, IFI= 0.93, RMSEA =0.06 and SRMR =0.05. Based on existing literature, the CFI, IFI and TLI cut-off scores should be above 0.9 (Meyers, Gamst, & Guarino, 2016). The RMSEA achieved a value of 0.06, indicating an acceptable fit (Meyers Lawrence, Glenn, & Guarino, 2013; Meyers et al., 2016). These indices are an indication of a good or acceptable model fit. The DLS showed good internal consistency with a Cronbach's alpha of 0.964 and a Split-half Spearman-Brown coefficient of 0.890. Cronbach's alpha for the five factors of the DLS ranged from 0.85 to 0.96 (Table 4.4). The standardised regression weights (factor loadings) for the 37 items ranged from 0.61 to 0.97 (Figure 4.1). Only two items had factor loadings lower than 0.70, with the lowest factor loading being item K8 (0.61) 'Difficulty drinking and eating generally occur when dementia condition worsens'. The final version of the DLS included five attributes ability to recognise dementia symptoms (7 items), causes and risk factors (9 items), awareness of professional help available (5 items), knowing where to access dementia information (4 items), and attitudes that promote recognition (12 items) (Table 4.4).

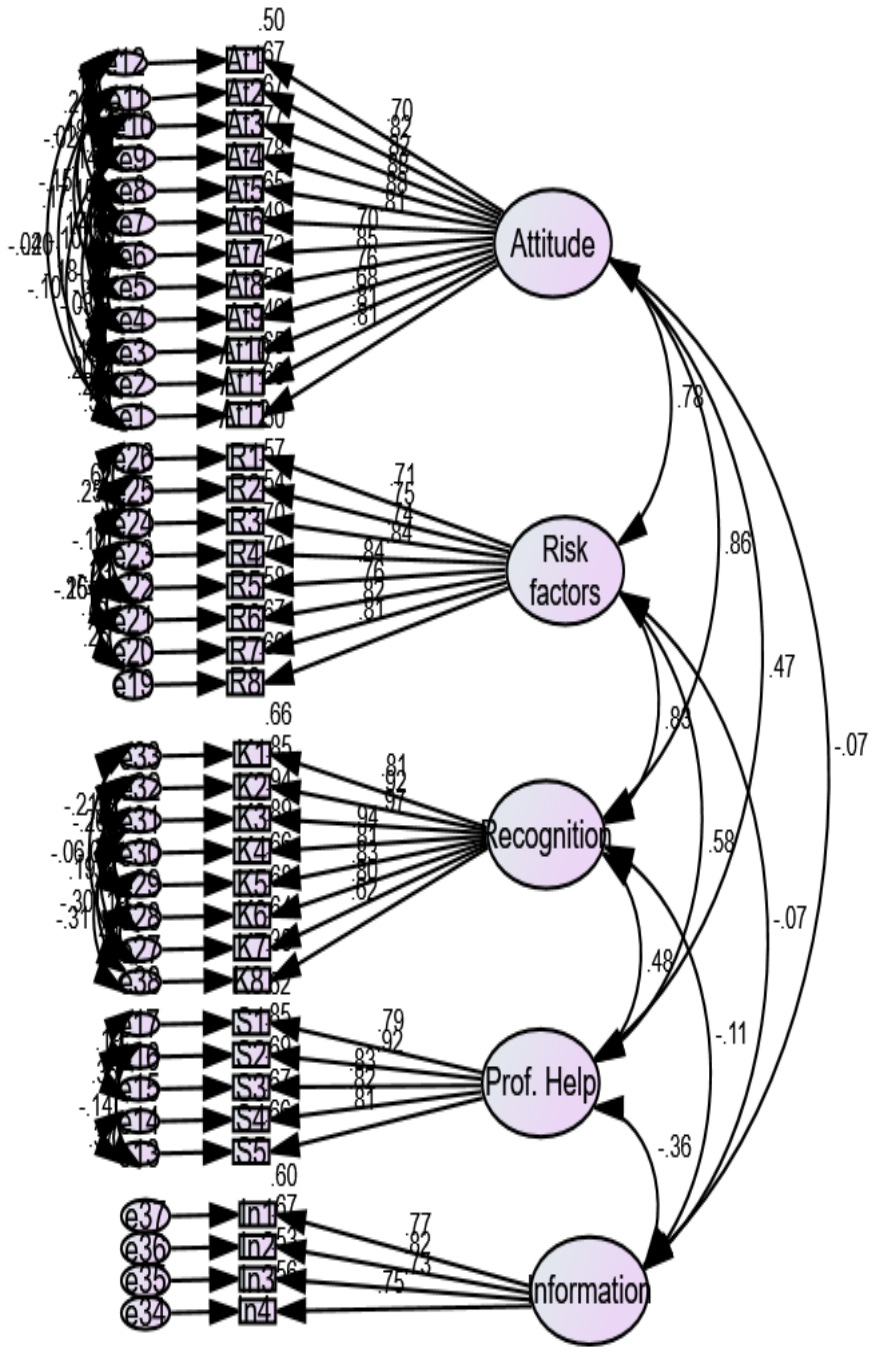


Figure 4. 1. Confirmatory factor analysis of the Dementia Literacy Scale (DLS)

Table 4.5. Descriptive Statistics of the DLS and its subscales

Subscales of DLS	Item	Minimum	Maximum	Mean	SD	Cronbach's alpha
Recognition of dementia symptoms	8	8.0	39.0	18.68	11.07	0.95
Knowledge of risk factors and causes	8	8.0	40.0	16.81	10.06	0.93
Knowledge of professional help available	5	5.0	25.0	10.09	3.54	0.90
Knowledge of where to access dementia information	4	4.0	20.0	9.50	3.82	0.85
An attitude that promotes recognition or appropriate help-seeking	12	12.0	59.0	29.72	15.95	0.96

#### 4.4 Summary of Chapter

This chapter provided an overview of the psychometric properties of the DLS. The findings largely support that DLS, and its five subscales are a valid and reliable tool to assess dementia literacy. The DLS scale is the first comprehensive scale covering all dimensions of dementia literacy. Due to the ease of use and self-administrative nature, this scale can assess dementia literacy among English-speaking African populations. The next chapter focus on the interactive and independent associations between dementia literacy, acculturation, social network, and dementia help-seeking behaviour.

## **CHAPTER 5: RESULTS OF THE QUALITATIVE STUDY**

### **5.1 Introduction**

This chapter presents the findings from the qualitative study. This qualitative study aimed to explore the role of acculturation and dementia literacy in intention-to-seek-help for dementia. Therefore, as stated in the previous chapter, the research question that the study addressed was:

1. What acculturation strategies do Africans use when living in Hong Kong?
2. How much do they know about dementia?
3. What factors affect Africans' intention-to-seek-help for dementia?

The analysis focused on participants' intention-to-seek-help by initially exploring their dementia literacy and acculturation from their lived experiences. The study explores how their acculturation experiences and dementia literacy impact their help-seeking behaviour. After the first four interviews, it was identified that dementia was an unfamiliar concept to most participants; therefore, a vignette describing someone with early-stage dementia was used to elicit more responses from participants.

The chapter begins with a description of the demographics of the participants included in the study. It follows with a presentation of the findings. Verbatim quotes from participants were used to demonstrate how sub-themes emerged from the data and were further condensed into main themes. This step was to assist in establishing the reliability and trustworthiness of the findings.

### **5.2 Demographics of the participants**

A total of 30 participants was recruited and interviewed individually. Of these, 19 (63.3%) were males, and the remaining 11 (36.7%) were females. Education levels ranged from secondary to tertiary (including Bachelor's, Master's, and PhD degrees). Participant ages ranged from 25 years to 60 years. Regarding employment, 22 participants were employed, five unemployed, and three were students. Sixteen of the participants were permanent residents, 11 Hong Kong residents (including working visa and student visa holders), and the last three participants were asylum seekers. Christianity (n=24) and Islam (n=6) were participants' predominant religions. Participants originated from West Africa (Ghana, Nigeria, Togo, and Guinea), East Africa (Ethiopia, Uganda), and Central Africa (Cameroon). Participants' duration of stay in Hong Kong ranged from two to 30 years. Table 4.1 summarises participant demographic characteristics.

Table 5. 1. Demographic characteristics of participants included in the qualitative study.

Demographic characteristics (n=30)		Frequency	Percentage
Gender	Male	19	63.3
	Female	11	36.7
Age	26-30years	4	13.3
	31-40years	10	33.3
	41-50years	10	33.3
	51-60years	6	20
Occupation	Employed	22	73.3
	Unemployed	5	16.7
	Student	3	10
Country of Origin	Ghana	15	50
	Nigeria	7	23.3
	Cameroon	3	10
	Togo	1	3.3
	Uganda	2	6.7
	Ethiopia	1	3.3
	Guinea	1	3.3
Education level	Secondary/Vocational	10	33.3
	Tertiary	20	66.7
Marital status	Married	24	80
	Single	5	16.7
	Divorced/Separated	1	3.3
Religion	Christian	24	80
	Muslim	6	20
Duration of Stay	2-5 years	11	36.7
	6-10 years	7	23.3
	11-15 years	8	26.7
	16-20 years	3	10

	21-30 years	1	3.3
Type of migrant	Permanents residents	16	53.3
	Asylum seeker	3	10
	Working visa (n=8)	11	36.7
	Students (n=3)		

**5.3 Findings of the study**

Four main themes were identified from the qualitative study:

1. Navigating Cultural identity and Contesting Social Exclusion
2. A Change in beliefs and perception about dementia
3. Pluralistic help-seeking for dementia
4. Factors influencing intention-to-seek-help for dementia.

5.3.1 Navigating Cultural Identity and Contesting Social Exclusion.

The acculturation of Africans in Hong Kong is a process rife with barriers, including perceived discrimination and racism. The acculturation of Africans in Hong Kong occurs through the following main themes:

- a. Expectations versus reality of the migration dream: The feeling of cultural shock
- b. Navigating cultural identity
- c. Forming social ties within and beyond an ethnic network: Barriers and opportunities
- d. Factors influencing the acculturation of Africans.

The following paragraphs discuss the different themes.

5.3.1.1 Expectation versus reality of the migration dream: The feeling of cultural shock

Before arriving in Hong Kong, Africans reported having optimistic expectations about their personal and professional lives in the host society (Hong Kong (HK)). Migrating to flee prosecution, torture, or tribal war, for a better chance of educational or job opportunities and joining family members already living in Hong Kong, were the joint driving forces for Africans to leave their countries. With the exception of asylum seekers and refugees, most participants reported having secured a job or an educational opportunity in Hong Kong before arriving.

*"I moved to Hong Kong to escape persecution and torture by the government in Uganda. I fled to Kenya, then to China, and when I arrived in North Korea, I got rejected and sent back to China, which later advised me to come to Hong Kong". (Male, aged 55, six-year stay in Hong Kong, Uganda).*

Most participants reported experiencing culture shock when they first encountered people in the host society. Their image of Hong Kong as a cosmopolitan and multicultural society was shattered by both active and passive racial discrimination. According to the participants, locals staring at them, avoiding physical contact, (inside buses and trains) and pinching their noses when they see an African, was a common experience. The post-immigration experiences in Hong Kong were not in line with participants' expectations. Participants reported feeling like a spectacle and humiliated in public.

*"I thought Hong Kong, a metropolitan city mixed with many foreigners and having experienced colonisation, would be more accommodating to newcomers. However, I realised they are not accommodating to black people; you feel like a daily spectacle in the city. People are constantly staring, holding their noses when they see you, and refusing to sit on the same seat with us. However, I am used to it now. They would not change, so I must adapt". (Female, age 58, six-year stay in HK, Nigeria)*

Although participants worked, were schooled, and lived among locals, they reported experiencing a cultural and social distance between locals and themselves. Notably, some participants reported a dwindling in cases of discrimination and racism when the number of African workers and students increased in the new environment (Hong Kong).

#### 5.3.1.2 Navigating cultural identity.

With continuing efforts to associate with the host culture, Africans navigated their cultural identities in the new environment. This was a continuum, as some participants reported changing their identity going from one strategy to another. Thus, over the course of a few years' stay, some participants preferred to keep their heritage culture, with no effort to adapt to the host culture. However, with time, there was the realisation that to fit into the work environment and society,



there was a need to adopt some or all aspects of Hong Kong culture. Some participants combined their heritage culture with that of the host culture. Others felt more connected to Hong Kong culture than their heritage culture. Others felt the need to maintain their heritage cultural identity, with little or no adaptation to the host culture. The main factor contributing to the host culture's adoption was connecting with locals and economic gain. However, it was noted that this phase is not static, and participants continued to navigate their cultural identity as time passed. The duration of stay, marrying a local, and a change in immigration status (student to the work environment) causes a drastic change in participants' cultural identity. Participants developed various means of adapting to fit into their new society, and this includes:

#### *Practising both heritage and host (Hong Kong) culture*

Based on the participant narratives, it was identified that most Africans had made a conscious decision to retain their cultural beliefs and practices, while simultaneously adopting the host culture. There are two variations to this adaptation approach, including maintaining heritage culture, but adopting only some aspects of the host culture and the practice of both cultures holistically.

*"Cultural heritage is a vital aspect of life. If that aspect of my life is broken, I feel like part of me is lost...there is no way I will give up that aspect of my life to embrace a new culture entirely. Yes, I have adapted to some aspects of a new culture. I looked for the good in the Hong Kong culture and added it to mine... I speak Cantonese, eat more vegetables like them, and drink tea with meals. So, I can say some aspects of my life fit with Hong Kong's way of life, while the larger part is Guinean culture". (Male, age 44, 11-year stay in Hong Kong, Guinea)*

#### *Adopting host (Hong Kong) culture and abandonment of heritage culture*

Notably, some participants showed a sense of belonging and specified that they no longer practice their heritage culture but have adopted the host country's cultural practices. These participants felt more like Hong Kong locals by culture, and no longer aligned with their original culture.

*"... I consider myself a Hong Konger. Even though I am a black person by race, I consider myself a Hong Konger because of my contributions to this society. I left my country years ago and no longer practise my culture... I regard myself as a Hong Konger or Chinese*

*rather than a Ghanaian. I consider myself a Ghanaian by birth and Hong Konger by culture..." (Male, age 42, 16-year stay, Ghana)*

*Preference to maintain heritage culture with no contact with the host culture.*

Irrespective of their length of stay, some participants felt no connection to the host culture and were still strongly connected with their original culture. Disparate cultural beliefs impeded the development of social relations and integration into society. As one female participant recounted:

*"I do not think I will ever feel part of Hong Kong or Chinese society as an African or Ghanaian. Their culture is very different from my Ghanaian background. I cannot mix my Ghanaian beliefs with the Hong Kong culture. We are different in our music, language, food, and cultural beliefs. I cannot speak Cantonese and still speak English... All my friends are other Africans. I live in Hong Kong, just like I used to do back home". (Female, age 41, 15-year stay in Hong Kong, Ghana)*

*5.3.1.3 Forming social ties within and beyond ethnic network: Barriers and opportunities.*

It was identified from participants' narratives that migration significantly impacts social networks, particularly in making new friends. It was observed that the social network of Africans in the city was partly made up of other Africans, and only a few participants reported having succeeded in making local friends. Findings revealed that most participants reported having adopted Hong Kong culture (assimilated), and those who practise both their heritage culture and that of Hong Kong (integrated) reported having more local friends and limited interactions with African friends and family back home.

*"... I have lived in this city for 27 years and have spent all my adult life here. I am Chinese now... I see myself as part of this land (Hong Kong) ...I have many Chinese friends and only two African friends. Except for my brother in Nigeria, I hardly even talk to any of my relatives there. I consider my friends here my family". (Male, age 55, 27- year stay, Nigeria)*

Consistently, participants who reported practising their heritage culture with little to no contact with the host culture reported having no or few local friends and maintaining frequent contact with other Africans and family back home.

*"I do not think I can regard people I know here as my friends... I still call my family and friends back home every day. So, in the big picture, I have no friends in Hong Kong, just classmates". (Female, age 31, three-year stay, Ghana)*

However, these participants were quick to note that most of their friendships with locals seldom extended beyond work and school relationships to tight-knit connections or ties. Most locals were very private, and relationships were surface level. Therefore, they receive support from family and friends in their home country:

*"I have few local friends, but we only say hi or hello and sometimes go out together, but none of us has tried to practise each other's culture. Our friendship is limited to the workplace, although I have known them for over five years. So, if I have problems here, I call my family and friends back home to ask for advice". (Female, age 41, 15-year stay, Ghana)*

#### *5.3.1.4 Factors influencing the social integration of Africans.*

##### *Language barrier: Cantonese versus English*

Language embodies an essential experience of Africans in their effort to integrate into Hong Kong society and realise their "migration dream". In the context of Hong Kong, a multilingual society, Africans must navigate their linguistic identities around English, Cantonese, and Putonghua. While participants from anglophone (English speaking) countries found it easy to adjust to living in Hong Kong, it was challenging for those from francophone, Arabic and Portuguese speaking countries to communicate with Hong Kong locals. These Africans prefer to speaking English rather than Cantonese, because of the ease of learning English, and the fact that most locals can speak a bit of English. One participant described his struggles:

*"... It was a real struggle as a West African, and from a country where we do not speak English but French as a national language. Coming to Hong Kong, which is not only an English-speaking country, but a country where Cantonese is the national language... I had to learn English to cope with life here... Then I realised not all locals could speak English, so I had to start learning Cantonese. Nevertheless, I speak English more often, as Cantonese is difficult to master...." (Male, age 38, seven-year stay in Hong Kong, Togo)*

Notably, learning to speak Cantonese, or even Mandarin, was seen as a steppingstone to significant opportunities in the city, and facilitated socialisation with locals. Therefore, some participants have made a conscious effort to be proficient in Cantonese, to fit into their new environment. A Nigerian noted:

*"...If you can speak and understand Cantonese, you get things done quickly and fit in with the locals. I can speak Cantonese, so it was easy for me to find a job... my wife speaks the language better than I do, and whenever she goes to the market, she always gets free stuff and discounts. So, when you learn their language, they (locals) like you and are friendly with you". (Male, age 55, 27-year stay, Nigeria)*

#### *Social distance and dominance*

According to the participants, a broader social distance exists between Africans and locals, limiting their ability to fully integrate into society. This may be attributed to Hong Kong's culture and political dominance over Africans. Some suggested that immigrants, particularly Africans, are associated with lower socioeconomic status, so locals avoid contact and have a negative attitude towards them. Social dominance in this context refers to the degree of equality (domination or subordination) between Hong Kong and African culture. An asylum seeker expressed this concern:

*"...If you are African, you are of lower social status, and most locals will not associate with you. Europeans and other ethnic minorities have a higher status than Africans in Hong Kong. Locals prefer to socialise with them, making it easier for them to integrate. Therefore, for most Africans, particularly asylum seekers, social circles comprise other Africans. So, it is difficult for us to integrate into the Hong Kong culture". (Male, age 40, 12-year stay, Cameroon)*

All participants unanimously experienced language-related stress to varying degrees. African migrants with no Cantonese proficiency faced higher challenges than those who reported some fluency in Cantonese. Language created a barrier to employment, socialisation, and daily activities (shopping and ordering food in restaurants).

*"I can say I have partially integrated into Hong Kong society because I cannot speak the language. If I can speak the language, it will be easy to mix with them and know more about them. For instance, if you are an African and want to get a job, most employers will require fluency in Cantonese or Mandarin. Because you do not speak the language, you*

*will not be able to get that job. The inability to speak Cantonese always makes you feel like an outsider, and not a local". (Male, age 39, 11-year stay, Nigeria)*

Out of fear of losing their self-identity, some participants decided not to learn about Hong Kong culture. One participant commented as follows:

*"Cultural heritage is a vital aspect of life. If that aspect of my life is broken, I feel like part of me is lost. So, there is no way I will give up that aspect of my life to embrace a new culture". (Male, age 44, 11-year stay in Hong Kong, Guinea)*

#### *Multicultural nature of the Hong Kong society*

To most participants, Hong Kong society is merged with various cultures. Elements of Western cultural influences, traditional Cantonese/Chinese culture, and South Asian cultures arguably influence every facet of Hong Kong society. Identification of authentic Hong Kong culture is a struggle for migrants.

*"The main issue with integration in Hong Kong is the nature of the society... Hong Kong is a melting pot of cultures (Chinese, European and South-eastern Asia), so most people who want to be aligned with European culture speak English... Second, they try to behave more like Westerners, even though that is not their culture. Most of them struggle with self-identity and which culture to embrace. This makes it difficult for immigrants to learn their culture. I am unfamiliar with local songs, as I often hear Western music in most pubs and restaurants. Not familiar with their pop culture". (Female, age 58, four-year stay in Hong Kong, Nigeria)*

### 5.3.2 Changing in beliefs and perceptions about dementia.

Dementia literacy of Africans is elaborated in the following five sub-themes.

#### 5.3.2.1 Recognition and awareness of dementia

Dementia was an unfamiliar term to most participants, and those who have heard about the condition reported having poor knowledge about it. The term dementia was non-existent; therefore, there was no equivalent word in the various African dialects and languages. A significant number of participants (n=17) reported hearing about dementia; however, only five could correctly identify symptoms described in the vignette as dementia.

*"I think this woman has dementia. Dementia is a state where one tends to forget things like your name and relations, and mostly happens to older adults". (Female, age 31, 3-year stay in Hong Kong, Ghana)*

However, the some of the participants attributed the symptoms in the vignette as witchcraft, a severe form of depression, menopause, madness/craziness, childlike behaviour, acting like a "fool", and forgetfulness associated with ageing. One participant commented:

*"Growing up in Nigeria, I have witnessed people with similar symptoms to the woman you described. People like this woman are called witches or crazy people". (Male, age 39, 11-year stay, Nigeria)*

Others reported they were unsure what dementia is, or the symptoms associated with it, as they have never had a first-hand encounter with someone with the condition. Others reported only briefly hearing the word dementia on television or radio.

#### 5.3.2.2 Dementia is not my portion: Beliefs about causes and risk factors.

Participants reported various perceived causes of dementia, which have been grouped into four clusters. The first cluster is biological or medical concepts. Participants reported multiple causes of dementia, including brain damage or failure, head injury, depression, anxiety, substance abuse, and genetics. One participant reported:

*"Dementia can be hereditary, which means it is in the family. When you get older, they lose their memories. Some can also have it through accidents and brain injuries". (Female, age 58, four-year stay in Hong Kong, Nigeria)*

Participants also cited various psychosocial factors as causes of dementia, including poverty, letting go of oneself, loneliness, marital problems, stress, lack of support or neglect from family, and lifestyle (excessive drinking and smoking) during one's youth.

*"If family members are not supportive, it can lead to this condition. Also, someone who is not financially stable or lonely can have this condition". (Male, age 52, 14-year stay in Hong Kong, Ghana)*

The most cited cluster is the spiritual cluster, where the majority believed that dementia is caused by punishment for wrongdoings, witchcraft, and possession by a spirit (Jinn).

*“In Islam, we have something called "Jinn" (supernatural creature or spirit), which can see human beings, but we cannot see them with our naked eyes. These "Jinn" can enter an individual's body and even marry that person. This Jinn causes all the abnormal behaviours that this woman is exhibiting. They can make the person forget about their family and their past life. This person can go out and forget how to return home”. (Male, age 42, 16-year stay in Hong Kong, Ghana)*

There was a notion among some participants that dementia does not affect Africans but is only a "white man's" condition. One female participant reported, *"... I have heard and seen only white people with dementia. Africans do not have dementia"*. Due to this perception, there was a general notion that Africans cannot be at risk of developing the condition, as can be seen from the statement of one male participant:

*“Most Africans do not suffer from mental illnesses. I do not smoke and have not offended anyone to receive curses. Therefore, I am free from this woman's condition (a reference to the vignette)”. (Male, age 38, seven-year stay in Hong Kong, Togo)*

A lack of social interactions, limited support from family and friends, and an inability to handle stressful situations or hardships were reasons why white people had dementia. Among Asians, eating reptiles like snake, and a higher rate of depression and stress, were some of the perceived causes of dementia among this race. This may imply that Africans ascribe racial attributes to dementia based on whether they have encountered it in their surroundings and who is more represented or associated with it.

#### *5.3.2.3 Stigmatising and negative attitude towards dementia*

Participants acknowledge that having a relative with symptoms of dementia is perceived as a "stain" on the family's image and reputation, which results in stigma towards other family members. Dementia is perceived as witchcraft, craziness, madness, acting like a fool, and returning to a childlike state, which all contribute to the societal stigma associated with persons with dementia.

*"...In Nigeria, people believe that most family conditions are hereditary, especially mental conditions. So, if a family member has dementia, it is difficult for the younger generations to get married. In Nigerian culture, before one gets married into a particular family, there*

*is a background check on illnesses in the family from both sides. So, the idea that older women in the family have dementia - usually perceived as witchcraft or going crazy - will tarnish the family's image. So, family members always hide people like this from society or the community". (Female, age 32, four-year stay in Hong Kong, Nigeria)*

Due to societal stigma associated with mental illness in most African societies, participants reported that people with dementia are often hidden at home, sent to prayer camps and mosques, physically abused, and neglected by family members. However, most participants reported they would support and care for a family member with dementia and shield them from societal stigma.

*"...Everyone in my community said he was a wizard. His family neglected him, and even his children did not want anyone to see him. But if he were my father, I would care for him at home and would not allow anyone to bully him". (Male, age 45, three-year stay in Hong Kong, Ghana).*

#### 5.3.2.4 Limited awareness of dementia-specific treatment and services in Hong Kong

All participants acknowledged that dementia was an "incurable condition" and believed it is a typical experience for older adults who experience a degree of hardship and stressful life and curses. Participants were aware of various mental health facilities and agencies that could treat and cater to dementia patients in Hong Kong. However, only a few participants were aware of dementia-specific care centres and facilities in Hong Kong. Although the majority were unaware of dementia-specific services in Hong Kong, they were confident these services exist in Hong Kong, as this statement shows:

*"I do not know any hospital for dementia in Hong Kong, but I do know there are many health facilities and nursing homes for older people in Hong Kong (Male, age 39, 11-year stay in Hong Kong, Nigeria)"*

#### 5.3.2.5 Low prioritisation and ability to appraise dementia related information.

Interestingly, most participants were not keen to search for information about dementia. The lack of interest was attributed to the fact that they never perceived themselves as at risk for dementia, the stigma associated with psychiatric help-seeking in their heritage culture, and poor knowledge of where to seek help:



*I do not look for information on dementia because I do not think I will get it (Male, 38 years old, seven-year stay in Hong Kong, Togo)*

Among the four female participants who have researched dementia information reported that there is dementia Infodemic, and they find it difficult to understand and appraise factual information from myths.

*“There is much information online about dementia, but the issue is identifying authentic or factual information. It isn’t easy to verify if I am getting accurate information”. (Female, age 29 years, four-year stay in Hong Kong, Nigeria)*

Religious leaders and social networks (family and friends) were the primary sources of information on mental illness, as there is a societal stigma associated with seeking dementia information from mental health hospitals.

*“I always rely on family and friends for mental health advice and information. I do not consult anybody, as I do not want to be stigmatised as mentally ill”. (Male, age 44, 11-year stay in Hong Kong, Guinea)*

#### 5.3.2.6 Factors that impact dementia knowledge and attitude.

##### *Facilitators of dementia knowledge and attitude*

From the narrative, most participants reported hearing about dementia through their friend’s network in Hong Kong. However, exposure to dementia information was gained after migration. Some stated their experiences hearing about dementia:

*“I first heard dementia from a local PhD student in Hong Kong who was researching about dementia. I did not know about dementia when I was in Ghana... After she explained what it was, I told her these are witchcraft behaviours, but she explained dementia is not witchcraft, but a medical condition.” (Male, age 30, six-year stay, Ghana)*

*“I had never heard of dementia in Ghana because such behaviours in older adults are associated with witchcraft... My best friend’s (a local) mother suffers from this condition, so I asked her about it, and she educated me about this disease”. ((Female, age 45, 15-years stay, Ghana)*

Availability of resources, such as free Internet access (e.g., free Wi-Fi) and the Department of Health website privileged them to access dementia-related information. One participant recounted how she accidentally learned about dementia through YouTube.

*“I was informed about dementia by chance through YouTube... I watched my favourite YouTuber when she mentioned that her father had been diagnosed with dementia. Information and knowledge of health issues come with access to the Internet... Even Internet subscriptions are expensive and unstable in Ghana. I do not think I would have used my Internet data to search for dementia information in Ghana, because it is costly. After watching that YouTube video, I searched for more information about dementia on the Department of Health website”. (Female, age 37, six-year stay in Hong Kong, Ghana)*

The benefit derived from being able to speak Cantonese was a recurrent theme among participants. Speaking Cantonese helped some participants fit into their new society and improve their knowledge and awareness of dementia and the services available in Hong Kong. One participant who has assimilated into Hong Kong society reports:

*“I heard about dementia on a television programme in Hong Kong. I love to listen to health news because I understand Cantonese... During the talk, they also mentioned elder centres and government hospitals that can manage people with this condition. I was able to refer an older Pakistani man in our mosque who suffered from this condition, and his son took him to the Adventist Hospital. I don't think I would have known about this condition if I couldn't speak Cantonese”. (Male, age 54, 12 year-stay, Ghana)*

#### 5.3.2.7 Barriers to dementia knowledge and attitude

Most participants had limited awareness of dementia issues in Hong Kong, mainly since most health education materials and media outlets are written and communicated in Cantonese. This deters them from learning anything about health issues in the city. However, some participants also reported that most Africans had not cultivated the habit of reading about health issues. Verbal or face-to-face education on health issues is preferred over written materials.

*“Most Africans do not like to read and want verbal information or want to receive information from someone. With this kind of attitude, if the government even translated a book online, people like me will not have access because they won’t read it. They must educate Africans face to face. I think this is one of the main problems Africans in Hong Kong experience”. (Male, age 45, 20-year stay in Hong Kong, Cameroon)*

### 5.3.3 Pluralistic help-seeking behaviour of Africans

From participants' narratives, three clusters of help-seeking for dementia were identified: those who endorsed home care for their parents, those who will seek medical care, and those who favour pluralistic care (combining prayers with medical treatment). Notably, participants were unanimous in their assertion that dementia facilities and services were non-existent in their countries. Prayers, support, and love from family and friends were believed to be the best approach to caring for persons with dementia. Caring for a person with dementia in the family was seen as a responsibility or obligation. However, these participants reported they would also consult their religious leaders, as exemplified below:

*“If this affects my parents, I will take care of them. I will show them love and support them... I know dementia cannot be cured or treated in a hospital. Therefore, no need to take them to a hospital. I would take care of them myself and ask my pastor to pray for them. It is my responsibility as their daughter”. (Female, age 28, eight-year stay in Hong Kong, Nigeria)*

Conversely, four participants reported they would take their family members to see a doctor if they started showing signs of dementia. However, this approach would be taken only if their family member was with them in Hong Kong and treatment was affordable.

*"... I will go to Sha Tin hospital or Alice Ho's hospital if a relative has dementia and is with me here. I know these two places, because my friend's (Hong Kong local) mother has dementia. However, I do not think we have hospitals for people with dementia in Ghana". (Female, age 45, 15-year stay in Hong Kong, Ghana)*

Interestingly, a majority also endorsed pluralistic help-seeking, as they will consult religious leaders for spiritual and emotional support while they approved going to doctors for physical care, evaluation, and medication:

*"As a Christian, I know prayer works, so I will back the hospital treatment with consultations with my pastor. However, the hospital will be the first point of call to treat dementia". (Female, age 31, four-year stay in Hong Kong, Ghana)*

#### 5.3.4 Factors influencing intention-to-seek-help for dementia.

##### 5.3.4.1 Facilitators to dementia help-seeking

###### Impact of social ties on help-seeking behaviour

Participants' awareness of dementia also had an impact on their help-seeking behaviour. Having local friends who have been caregivers for persons with dementia significantly influenced some participants' intention to seek help for dementia. One participant reported recounting her experience:

*"...Two of my friends' (Hong Kong locals) parents have Alzheimer's disease... One is in a nursing home, and the other is in Sha Tin or Alice Ho's hospital...Experiencing how people with dementia are cared for in the hospitals, I have decided to take my mother or advise any other family member with memory problems to see a doctor instead of a pastor". (Female, age 45, 15-year stay in Hong Kong, Ghana)*

###### *Influence of Host society's dementia beliefs and practices*

Hong Kong's cultural perception and attitudes towards dementia and dementia care encouraged some participants to change their previous beliefs and attitude towards dementia care and treatment:

*"My first recommendation will be to take my relative to the hospital to seek medical treatment. Hong Kong has influenced how I will handle such a relative, because they treat older people with dignity and give them all necessary medical care and assistance. However, if I were in Ghana, I would have thought of dementia as witchcraft and mistreated my relative. Visiting nursing homes in Hong Kong changed my beliefs on how to handle my parents when they begin to experience memory loss or a change in their behaviour". (Male, age 30, six-year stay, Ghana)*

##### 5.3.4.2 Barriers to dementia help-seeking

*Cultural context: the impact of geographical locations' dementia beliefs, attitude and practices*

Help-seeking behaviour was identified to be based on physical location and the contextual beliefs and practices with regards to dementia. According to participants in most African societies and cultures, placing older adults suffering from various ailments in nursing homes and under psychiatric care was socially unacceptable. However, some participants were open to accessing and accepting health care for their family members with dementia. For these participants, Hong Kong culture supports formal health-seeking for dementia, especially as services are readily available and the social norm of taking persons with dementia to elder centres and nursing homes. This is exemplified by the statement below:

*“If I take the person to a psychiatric hospital in Ghana, people will say my family member is mad, so I will not take my family member there. Some will also shame my family for neglecting our responsibility. Even if I explain dementia as a health condition, people will not understand, but conclude that my mother or relative has gone mad. I will not send my relative to the psychiatric hospital in Ghana because of the stigma attached to dementia. However, if I can afford to bring my mother to Hong Kong, I will take her to a hospital or elder home for her to be treated. Nobody will stigmatise her here”. (Female, age 37, six-year stay, Ghana).*

#### *Limited ability to recognise symptoms of dementia.*

Other participants also reported the inability to recognise dementia symptoms, and limited knowledge of where to seek dementia information as factors that might hinder their help-seeking for family members with dementia, as this statement illustrates:

*“You just asked me about this condition, and I do not know much about it... For example, when I have a runny nose, I think I am about to have a cold. However, I know nothing about this condition, so I will only take my mother to see our pastor for prayers, or care for her at home. Old age makes people forget; I do not think I will immediately consider this as a condition to be treated in hospital”. (Male, age 38, seven-year stay, Togo).*

#### *The practice of familism*

Although some participants were open to the idea of medical treatment for persons with dementia, there were reports of perceived resistance from family members due to the cultural practice of familism and societal stigma.

*“In Ethiopia, the extended family decides on treatment and care for a sick person. Taking care of older adults with various health conditions is seen as a family responsibility. People will criticise me and my family members if we cannot take care of our mother, who has forgetfulness, at home. This act can only bring curses on the younger generation, so I will take care of my parent at home if they suffer from this type of condition”. (Male, age 32, three-year stay in Hong Kong, Ethiopia).*

#### *Negative experience with the health system*

Some participants reported neglect and discrimination towards Africans by health professionals in Hong Kong as the main reason they will not seek help from mental health facilities in Hong Kong.

*“I do not know any specific hospital that treats people with dementia in Cameroon, but Hong Kong has a lot of special homes for older people, so they will have one for dementia. I will not personally take my mother - or another family member there - because I think they will not treat her well. I have been neglected and experienced rude behaviour from nurses in various instances when admitted to a hospital. I will instead take care of my parents myself or take them back to Cameroon for other family members to provide care”. (Male, age 45, 20 year-stay, Cameroon).*

One participant also reported her lack of trust in medical professionals as the reason why she might not seek help for dementia:

*“Taking my parent with dementia to the healthcare centre is not a bad idea, but I know how to care for them more than the health professionals. I cannot trust health professionals with someone I love, like my parents. They are not doing a good job there, but I prefer to care for them at home”. (Female, age 28, eight-year stay, Nigeria).*

## 5.4 Chapter Summary

This chapter presented the results of the qualitative study. Themes identified from the study have established that in addition to dementia literacy, an array of social determinants including acculturation (social integration), social ties/network, availability and access to dementia services and care, societal norms, and practices with regards to dementia (social and community context) and the health system influenced help-seeking behaviour of Africans in Hong Kong. At the same time, social ties/networks proved to be a double-edged sword in promoting appropriate help-seeking behaviour among Africans in Hong Kong. To the best of the authors' knowledge, this study is the first to examine the role of acculturation and dementia literacy on help-seeking behaviour among Africans in Hong Kong.

Notably, participants had diverse explanatory beliefs models including biopsychosocial, biomedical, and spiritual/Faith models. This finding is consistent with previous studies about African migrants (Berwald et al., 2016; Roche et al., 2021). However, this study's overarching perception of dementia as mysterious and witchcraft was less pronounced than in previous literature (Berwald et al., 2016; Brooke & Ojo, 2020; Spittel, Maier, et al., 2019b). Changing perceptions of dementia was due to the adoption of 'host culture's attitude and practices concerning dementia care and management and intercultural contact/exchange (van Wezel et al., 2018).

Per the cluster of causation of dementia, preferred sources of help for dementia were equally diverse. Three significant help-seeking clusters were identified among participants included in the study: Faith/spiritual care, homecare/ family care and pluralistic help-seeking (combination of medical care with spiritual care). However, a combination of faith healing and biomedical treatment was the most cited preferred source of help and care for dementia. The pluralistic framework for help-seeking behaviour is a well-documented preferred approach to dementia and mental disorders treatment over traditional health care or medical treatment and services (Daniel et al., 2018; Hughes et al., 2009; Koduah et al., 2019; Mukadam et al., 2011; Mushi et al., 2014). All participants included in the study were religious, and religion has been identified as an integral part of various African cultures as most people draw strength and support from faith and prayers in times of ill-health (Brooke & Ojo, 2020; Koduah et al., 2019; Roche et al., 2021).

Reliance on family members or preference to care for a parent or family members with dementia was also an integral part of managing dementia. Africans experience less emotional burden in caring for older adults with various forms of illness due to the practice of familism (Adedeji et al., 2022; Roche et al., 2021). Caregiving was considered a responsibility, and participants tended to find more satisfaction in providing care for a family member than in relying on health professionals. Studies have identified that African Americans have a solid attachment to their family member diagnosed with dementia right from diagnosis through the disease trajectory. A finding which is uncommon among their White counterparts (Ross & Dagley, 2009).

Although the impact of acculturation on dementia literacy of African migrants was minimal, it highlights how even with limited social interactions, there were observable changes in dementia perception and attitude and help-seeking behaviour of Africans. However, these changes were not attributed to acculturation alone but the influence of various social determinants of health. Although some Africans find it challenging to achieve acculturation in Hong Kong, some societal and structural agents in the Hong Kong support the growth of some aspects of their dementia literacy (access to information and services). Public and clinical health professionals and government institutions can utilise these platforms to educate, promote and empower the mental health literacy of Africans in Hong Kong. It is worth noting that cultural beliefs and practices overshadowed medical or biomedical concepts about dementia treatment, management, and help-seeking behaviour among Africans. However, this study provides an insight into how dementia awareness and education may change certain cultural beliefs about the condition.

The study findings show that integration, assimilation, and separation are the acculturation strategies adopted by Africans in Hong Kong. The study also identified various factors that impact Africans' ability to integrate into their new society. Subsequently, the study identified cultural misconceptions and negative attitudes among some study participants. However, there was a change in the beliefs and practice of other participants due to intercultural exchanges or social contact. Nonetheless, there was pluralistic help seeking behaviour among participants, due to the fact that religion and spirituality forms an integral part of the African culture.



The most interesting finding was how a social network was a recurring theme that influences dementia knowledge, attitudes and acculturation, and help-seeking behaviour of Africans in Hong Kong. A further assessment of the association between dementia literacy, social networks, acculturation, and help-seeking behaviour is suggested for future studies. There were various facilitators and barriers to Africans' help-seeking behaviour, and these results could guide the development of interventions to improve the help-seeking efficacy of Africans in Hong Kong and other locations.

## CHAPTER 6: FINDINGS FROM THE CROSS-SECTIONAL SURVEY

This chapter discusses the findings from the cross-sectional survey. The first section provides a descriptive overview including the characteristics of the sample of findings from the survey. The chapter also shows the results of correlation, regression and path analysis used to show the relationship among dementia literacy, acculturation, social network, and help-seeking behaviour.

### 6.1 Descriptive Statistics.

#### 6.1.1 Characteristics of Sample

Four hundred and sixty-one African adults participated in the survey with a mean age of 33.6 (SD=8.15) (see Table 6.1). Majority of the participants were males (331/461, 71.8%). Most of the participants holds a bachelor's degree (281/461, 61%) followed by senior high school certificate (61/461,13.2%), diploma (55/461, 11.9%), doctoral degree (49/461, 10.6%) while the remaining three participants (0.7%) had only primary school education. Over half (57.5%) of the participants were employed, 32.5% of them were students (PhD, masters and undergraduate) and remaining 10% reported that they were unemployed.

Almost all the participants (439/461, 95.2%) were foreign-born (born in various countries in Africa). However, sixteen (3.5%) of the participants were born in Hong Kong. Remaining others were born in the United States of America (N= 3, 0.7%) and Italy (N=2, 0.4%) and France (N=1, 0.2%). With regards to immigration status, 60% of the participants are Hong Kong residents (working or student visa), 29.1% are permanent residents, 6.1% are asylum seekers, 3.7% are refugees and 0.4% holding diplomatic visas. The duration of stay of Africans in Hong Kong range from 2 to 30 years, with an average stay of 6.6 years (SD=5.42). Over three-quarters (72.5%) of the participants are Christians, 22.8% are Muslims and the remaining 4.8% have no religious affiliation.

Table 6. 1 Sociodemographic characteristics of participants.

Demographic characteristics		Frequency	Percentage
Gender	Male	331	71.8
	Female	130	28.2
Age	18 - 24 years	52	11.3

	25 – 34 years	22	48.2
	35 – 44 years	134	29.1
	45 - 59 years	52	11.3
	60 years and above	1	0.2
Education	Primary school	3	0.7
	Junior Secondary School	12	2.6
	Senior Secondary School + Vocational Training	61	13.2
	Diploma/ associate degree	55	11.9
	Bachelor's degree	281	61.0
	Doctoral Degree	49	10.6
Marital status	Married	228	49.5
	Divorced	24	5.2
	Single/Never married	209	45.3
Employment	Employed	265	57.5
	Unemployed	46	10.0
	Students	150	32.5
Country of birth	Africa	439	95.2
	France	1	0.2
	Hong Kong	16	3.5
	Italy	2	0.4
	USA	3	0.7
Income (HK) (n=265)	< 4000 – 14,999	42	9.1
	15,000 – 39,999	181	39.3
	40,000 – 79,999	40	8.7
	80,000 and above	2	0.4
Duration of stay	2 – 5 years	275	59.7
	6 – 10 years	110	23.9
	11 – 15 years	30	6.5
	16 – 20 years	33	7.2

	21 years and above	13	2.8
Immigration status	Permanent resident	134	29.1
	Hong Kong residents	280	60.7
	Asylum seekers	28	6.1
	Refugees	17	3.7
	Diplomatic Visa	2	0.4
Religion	Christian	334	72.5
	Muslim/Islam	105	22.8
	No religion	22	4.8
Perceived Status		Mean	SD
Physical Health status	Good	398	86.3
	Poor	63	13.7
Mental health status	Good	192	41.6
	Poor	269	58.4
Economic status	Low	148	32.1
	Medium	278	60.3
	High	35	7.6
Social status	Low	142	30.8
	Medium	268	58.1
	High	51	11.1

Abbreviations: SD, Standard deviation; JHS, Junior High School; JSS, Junior Secondary School; SHS, Senior High School; SSS, Senior Secondary School; HKD, Hong Kong dollar.

Physical health, mental health, social and economic status were assessed on a scale of 1 to 10 with 1 being low and 10 being highest.

Majority (86.3) of the participants reported having good physical health with only 13.7% of the participants reported having fall sick in the past one month. More than half (58.4%) of the participants rated their mental health status as poor while 41.8% of the participants reported having good mental health. In general, more than half of the participants were likely to rate their social (58.1%) and economic status (60.3%) as of medium status in comparison with locals. A significant

number of them rated their economic (32.1%) and social (30.8%) status as low while only 7.6% and 11.1% rated these as high respectively.

Table 6.2 shows the country of origin of participants involved in the study. These participants come from 43 different countries in Sub-Saharan Africa, with top 2 countries with most participants being Ghana (137/461, 29.7%) and Nigeria (87/461, 18.9%).

Table 6. 2. Country of origin of participants

Country of Origin (n=43)	Frequency	Percentage
1. Angola	4	0.9
2. Benin	3	0.7
3. Botswana	2	0.4
4. Burkina Faso	2	0.4
5. Burundi	3	0.7
6. Cabo Verde	1	0.2
7. Cameroon	23	5.0
8. Central African Republic	1	0.2
9. Chad	1	0.2
10. Comoros	1	0.2
11. Congo, Democratic Republic of	3	0.7
12. Congo, Republic of	7	1.5
13. Cote d'Ivoire	7	1.5
14. Equatorial Guinea	3	0.7
15. Eritrea	1	0.2
16. Ethiopia	15	3.3
17. Gabon	6	1.3
18. The Gambia	11	2.4
19. Ghana	137	29.7
20. Guinea	8	1.7

21. Kenya	14	3.0
22. Lesotho	1	0.2
23. Liberia	5	1.1
24. Madagascar	4	0.9
25. Malawi	4	0.9
26. Mali	8	1.7
27. Mauritania	1	0.2
28. Mauritius	1	0.2
29. Mozambique	2	0.4
30. Namibia	3	0.7
31. Niger	5	1.1
32. Nigeria	87	18.9
33. Rwanda	3	0.7
34. Senegal	3	0.7
35. Sierra Leone	6	1.3
36. Somalia	8	1.7
37. South Africa	16	3.5
38. Sudan	3	0.7
39. Tanzania	14	3.0
40. Togo	3	0.7
41. Uganda	10	2.2
42. Zambia	10	2.2
43. Zimbabwe	11	2.4

### 6.1.2 Dementia Literacy

Half of the participants (N=235, 51.0%) were unfamiliar with dementia and had not heard of this word before the survey. The mean score on the dementia literacy scale for the study's participants was found to be 87.27 (SD=36.14). One third of the participants (N=152, 33%) had sufficient dementia literacy, remaining participants had problematic (N=133, 28.9%) and inadequate (N=176, 38.2%) dementia literacy. Scores on the various subscale were 16.72 (SD=10.09), 18.78 (SD=11.09), 9.49 (SD=3.83), 12.56 (SD=4.35), 29.72 (SD=15.94) for ability to recognise

dementia symptoms, knowledge of risk factors, knowledge of how to seek information, knowledge of professional help available and attitude that promote recognition of dementia respectively (Table 6.3).

Table 6. 3. Descriptive Statistics of the dementia literacy scale

Variables		Frequency	Percent	
Dementia literacy levels	Inadequate	176	38.2	
	Problematic	133	28.9	
	Sufficient	152	33.0	
Variables		Range	Mean	Standard Deviation
Dementia Literacy	Total score (37 items)	37-185	87.27	36.14
Subscales of Dementia Literacy Scale	Recognition of dementia symptoms (8 items)	8-40	10.68	11.08
	Risk factors (8 items)	8-40	8.81	10.08
	Information seeking (4 items)	4-20	5.50	3.82
	Professional help available (5 items)	5-25	7.55	4.34
	Attitude (12 items)	12-60	17.72	15.96

*Note.* Evaluations were made on a 5-point scale (1= “strongly disagree” to 5 = “Strongly agree”)

Notably more than half of the participants reported “Strongly disagree” on recognition of symptoms of dementia, knowledge of risk factors and attitudes that promotes recognition and appropriate help seeking subscales.

### 6.1.3 Acculturation

The mean score for acculturation was 20.38 (SD=5.70). Acculturation has two domains: acculturation orientation (orientation to home culture and host culture) and acculturation strategies (integration, assimilation, separation, and marginalization).

Table 6. 4 Descriptive analysis of the Brief Acculturation Orientation Scale (BAOS)

Variables		Range	Mean	Standard deviation
Acculturation	Total score (8 items)	8-40	20.58	5.70
Acculturation subscales	African Culture (4 items)	4-20	9.79	3.88
	Hong Kong Culture (4 items)	4-20	10.79	4.01
Orientation to African Culture	Have African friends	1-5	2.19	1.01
	Take part in African traditions/ceremonies	1-5	2.42	1.02
	Hold on to African beliefs and norms	1-5	2.48	1.16
	Do things the African way	1-5	2.70	1.18
Orientation to Hong Kong culture	Have local (Hong Kong) friends	1-5	2.35	1.01
	Take part in Hong Kong festivals/ceremonies	1-5	2.69	1.08
	Hold on to Hong Kong beliefs and norms	1-5	2.87	1.20
	Do things the Hong Kong way	1-5	2.89	1.21
Variables			Frequency	Percent
Subscales of Acculturation	Integration		137	29.7
	Assimilation		123	26.7
	Separation		102	22.1
	Marginalization		99	21.1

Evaluations were made on a 5-point scale (1= “Not at all important” to 5 = “extremely important”).

### 6.1.3.1 Acculturation orientation

Acculturation orientation can be categorised into two types: 1) orientation to host (Hong Kong) culture and 2) orientation to home (African) cultures. Table 6.5 shows that orientation to Hong Kong culture subscale has a mean of 10.79(SD=4.0) and orientation to African culture was 9.79 (SD=3.88).

#### *Acculturation strategies*

Table 6.4 shows the acculturation strategies used by the African migrants: integration (29.7%), assimilation strategy (26.7%), separation strategy (22.1%) and marginalisation (21.5%). Integration is the dominant acculturation strategy for African migrants in Hong Kong, followed by assimilation.



#### 6.1.4 Social Network of Participants

Mean score on the total score of social networks was 14.59 (SD= 4.45), Friends' subscale was 6.26 (SD=3.25), Family subscale was 8.33(SD=2.67). Using score of less than 12 as a cut point for the LSNS-6, we identified 35% of Africans as socially isolated (table 6.5).

Table 6. 5. Descriptive statistics of scores on Lubben Social Network Scale

Variables		Range	Mean	Standard deviation
Social Network	Total score (6 items)	0-30	14.59	4.45
Social Network Subscale	Family (3 items)	0-15	8.33	2.67
	Friends (3 items)	0-15	6.26	3.25
Family Social Network	How many family members do you see or hear from at least once a month?	0-5	3.87	1.13
	How many family members do you feel at ease with that you can talk about private matters?	0-5	2.15	1.07
	How many family members do you feel close to such that you could call on them for help?	0-5	2.31	1.11
Friends Social Network	How many friends do you see or hear from at least once a month?	0-5	2.91	1.39
	How many friends do you feel at ease with that you can talk about private matters?	0-5	1.45	1.29
	How many friends do you feel close to such that you could call on them for help?	0-5	1.89	1.71
Variables		Range	Frequency	Percent
Level of Social network	Social isolation	0-12	162	35.1
	Social integration	12-29	299	64.9

Evaluations were made on a 6-point scale (0= none, 1= one, 2= two, 3= three or four, 4= five thru eight, 5= nine and above). Lubben Social Network Scale-6 (LSNS-6) was used to assess social network.

### 6.1.5 Intention-to-Seek-Help

Mean score for intention-to-see-help was 32.25 (SD=4.03). An indication that participants were likely to seek help if they thought they were experiencing early signs and symptoms of dementia (Table 6.6). Participants indicated that they were most likely to seek help from health professionals with mean score of 4.57 (SD=0.93), followed by parents mean= 4.54 (SD =0.87) and partners with a mean score of 4.35 (SD=0.94). Only a few people reported that they would delay seeking help (8%) and not seek help from anyone (2.8%).

Table 6. 6. Descriptive score for Intention-to-Seek-Help

Items	Range	Mean	Standard deviation
Total score (range: 16-40)	16-40	32.25	4.03
Sources of help			
1. Partner (spouse, boyfriend, girlfriend) (range: 1-5)	1-5	4.35	0.94
2. Friend	1-5	3.16	1.35
3. Parents	1-5	4.54	0.87
4. Other family members	1-5	3.64	1.27
5. Health professionals (psychiatrists, general doctors, nurses, social workers, psychologists)	1-5	4.57	0.93
6. Ministers/Religious leaders (Pastor, Imam, Chaplain, traditional healer)	1-5	3.57	1.44
7. Delay seeking help for as long as possible	1-5	3.93	1.29
8. I would not seek help from anyone	1-5	4.49	0.94

Note: The items of this scale were modified from General Help-Seeking Questionnaire to fit the context of dementia. Evaluations were made on a 5-point scale (1= “Extremely unlikely” to 5 = “extremely likely”). Items 7 and 8 were reversed coded.

## 6.2 Results of Correlation Analysis

Bivariate analysis (correlations) was conducted to test which variables are related to help-seeking. The first section will discuss the correlation between help-seeking and sociodemographic. The second correlation analysis was among help-seeking and acculturation, social network, and dementia literacy.

### 6.2.1 Intention-to-Seek-Help and sociodemographic variables.

In Table 6.7, none of the sociodemographic variables was significantly correlated with help-seeking behaviour.

### 6.2.2 Intention-to-Seek-Help, dementia literacy, acculturation, and social network.

This section elucidates the relationship between acculturation, dementia literacy, social network, help-seeking and sociodemographic variables. Two spearman's correlation analyses were conducted as the main variables were not normally distributed. The first analysis examines the relationship between the main dependent variables (dementia literacy, acculturation, social network) and their various subscale and help-seeking (Table 6.8).

#### 6.2.2.1 Intention-to-Seek-Help and dementia literacy.

Table 6.8 shows no statistically significant relationship between help-seeking and dementia literacy total score ( $r=.02$ ,  $p=0.609$ ). However, knowledge of how to seek dementia information was inversely associated with help-seeking ( $r=-.13$ ,  $p=0.007$ ). None of the remaining subscales showed no correlation with help-seeking behaviour.

#### 6.2.2.2 Intention-to-Seek-Help and acculturation.

Assimilation ( $r=.13$ ,  $p=0.007$ ) was the only subscale of acculturation that had a significant positively associated with help-seeking. The analysis revealed no significant association between total score for acculturation ( $r=.02$ ,  $p=0.621$ ), Hong Kong culture orientation ( $r=.08$ ,  $p=0.080$ ) and African culture orientation ( $r=-.06$ ,  $p=0.241$ ). Integration ( $r=-.03$ ,  $p=0.553$ ), separation ( $r=-.04$ ,  $p=0.376$ ), and marginalization ( $r=-.06$ ,  $p=0.182$ ) strategies showed no correlation with help-seeking.

Table 6. 7. Correlation between Intention-to-Seek-Help and Sociodemographic variables.

Variables	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.
1. Help seeking	1	-.002	.017	.002	.011	-.060	.075	.010	.029	.037	.023	.046	.032	-.032
2. Gender		1	-.226**	.096*	.012	.008	-.265**	-.068	-.007	-.092*	-.167**	-.070	.031	.014
3. Age			1	-.544**	-.108*	-.439**	.325**	.340**	-.199**	.084	.023	-.147**	-.097*	-.124**
4. Marital Status				1	-.087	.308**	-.277**	-.137**	.191**	-.040	.038	.065	-.029	-.036
5. Education					1	.097*	.182**	-.347**	.080	-.045	.022	.100*	.190**	.285**
6. Employment						1	-.391**	-.414**	.321**	-.168**	.081	.195**	-.013	.032
7. Income							1	.160**	-.289**	.204**	-.036	-.139*	.147*	.139*
8. Duration of stay								1	-.590**	.157**	-.055	-.148**	.013	-.066
9. Immigration									1	-.050	.110*	.042	-.211**	-.126**
10. Religion										1	-.014	-.098*	-.025	-.016
11. Physical health											1	.549**	.056	.140**
12. Mental health												1	.155**	.164**
13. Economic status													1	.516**
14. Social status														1

\*\* p-value < 0.01, \* p-value < 0.05 level

Table 6. 8. Correlation between Dementia Literacy, Acculturation, Social Network, and Intention-to-Seek-Help.

	HS	DL	DL1	DL2	DL3	DL4	DL5	SN	SN1	SN 2	ACC	ACC1	ACC 2	ACC3	ACC4	ACC5	ACC6
HS	1	.024	.054	.029	-.126**	.042	.059	.114*	.045	.112*	.023	-.055	.082	-.028	.125**	-.041	-.062
DL		1	.885**	.901**	.033	.588**	.878**	.043	-.037	.121**	.092*	-.119*	.260**	.130**	.156**	-.232**	-.079
DL1			1	.823**	-.131**	.469**	.788**	.163**	.076	.203**	.117*	-.053	.223**	.151**	.088	-.193**	-.067
DL2				1	-.121**	.538**	.786**	.055	-.006	.104*	.075	-.106*	.206**	.112*	.143**	-.201**	-.075
DL3					1	-.307**	-.080	-.140**	-.155**	-.050	-.027	-.201**	.181**	.033	.184**	-.208**	-.025
DL4						1	.439**	-.002	-.011	.001	.105*	.077	.059	.094*	-.019	-.034	-.050
DL5							1	.096*	.006	.158**	.101*	-.126**	.283**	.153**	.134**	-.239**	-.073
SN								1	.701**	.806**	-.020	.037	-.055	-.002	-.022	.028	-.001
SN 1									1.	.195**	-.025	.052	-.082	-.029	-.035	.071	-.002
SN 2										1	.023	.020	.028	.053	-.005	-.036	-.017
ACC											1	.680**	.708**	.655**	-.011	-.032	-.685**
ACC 1												1	.026	.511**	-.524**	.486**	-.496**
ACC 2													1.	.441**	.515**	-.467**	-.574**
ACC 3														1	-.392**	-.347**	-.340**
ACC 4															1	-.322**	-.315**
ACC 5																1	-.279**
ACC 6																	1

\*\* p-value < 0.01, \* p-value < 0.05 level

Abbreviations: HS=Help-Seeking, DL= Dementia Literacy; SN= Social Network.

Dementia Literacy refers to the total score of the Dementia Literacy Scale (DLS); Acculturation refers to the total score of the Brief Acculturation Orientation Scale (BAOS); Social network refers to the total score of Lubben Social Network scale-6 (LSNS-6).

D1= recognition, D2= risk factors, D3= Information Seeking, D4= Professional help, D5= Attitude, SN1= Family subscale of Social Network, SN2= Friends subscale of Social Network, ACC1= Home Culture subscale of acculturation, ACC2= Host culture subscale of acculturation, ACC3= integration, ACC4= Assimilation, ACC5= Separation, ACC6= Marginalisation.

### 6.2.2.3 Intention-to-Seek-Help and social network.

Findings demonstrated that social network was positively associated ( $r=.11, p=0.014$ ) with intention-to-seek-help. Similarly, friend's subscale was positively associated ( $r=.11, p=0.016$ ). However, family network showed no significant relationship with the intention-to-seek-help ( $r=.05, p=0.331$ ).

## 6.3 Association among Dementia Literacy, Acculturation, Social Network, and Intention-to-Seek-Help.

This section empirically examines the probing question if acculturation, social network, dementia literacy and intention-to-seek-help are interconnected? Before conducting hierarchical multiple regression and path analysis among the main variables, a correlation analysis was conducted and the findings revealed that knowledge of how to seek information, knowledge of risk factors (Dementia literacy subscales), assimilation strategy (acculturation) and social network were the only independent variables that correlated with intention-to-seek-help. Three different hierarchical regression analysis were conducted (see Tables 6.9 to 6.10).

### 6.3.1 Relationship among total scores of dementia literacy, Acculturation, Social Network, and Intention-to-Seek-Help

Table 6.9 showed the relationships among intention-to-seek-help, dementia literacy, acculturation and social network of Africans living in Hong Kong. Since no demographic factors correlated with intention-to-seek-help (Table 6.7), none of the demographic factors was added to the regression model. Social network was entered in the first block followed by acculturation in model 2. Finally, dementia literacy total score was added in the final model (model 4).

Table 6. 9. Regression analysis of Social Network, Acculturation, Dementia Literacy, and its relationship to Intention-to-Seek-Help

Variables	Model 1			Model 2			Model 3		
	B (95% CI)	Standard error	p-value	B (95% CI)	Standard error	p-value	B (95% CI)	Standard error	p-value
Social Network	.097 (.014, .180)	.042	.022	.098(.015,.180)	.042	.021	.094 (.011, .178)	.042	.026
Acculturation				.028 (-.036, .093)	.033	.387	.026 (-.39, .091)	.033	.431

Dementia Literacy							.004 (-.007, .014)	.005	.475
Adjusted R <sup>2</sup>	.009			.009			.008		

The bold emphasis is to highlight p value <0.05. Dependent variable: Intention-to-Seek-Help

In model 1, social network contributed significantly to intention-to-seek-help with  $F(1,46) = 5.09$ ,  $p < 0.022$ ) and accounting for 0.9% of the variation in help-seeking. The addition of the acculturation explained an additional 0.8% of the variation in intention-to-seek-help, and this change in R<sup>2</sup> was insignificant  $F(1,46) = .751$ ,  $p = 0.387$ ). lastly, addition of the dementia literacy to the regression model explained an additional 0.7% variation in dementia help-seeking, and this change in R<sup>2</sup> was also insignificant  $F(1,46) = .514$ ,  $p = 0.475$ ). Social network was identified as the only factor affecting intention-to-seek-help among Africans in Hong Kong.

### 6.3.2 Relationship among the subscales of dementia literacy, acculturation, social network, and Intention-to-Seek-Help

Investigation was made on the relationship among the subscales of dementia literacy, acculturation, social network, and intention-to-seek-help. A three-stage hierarchical multiple regression analysis was conducted (Table 6.10).

Table 6.10. Regression analysis among the subscales of dementia literacy, acculturation, social network, and its relationship with intention-to-seek-help.

Variables	Model 1			Model 2			Model 3		
	B (95% CI)	Standard error	p-value	B (95% CI)	Standard error	p-value	B (95% CI)	Standard error	p-value
SN1=Family	.062 (-.045, .233)	.071	.182	.065 (-.040, .237)	.070	.163	.057 (-.082, .197)	.071	.420
SN2= Friends	.077 (-.018, .210)	.058	.100	.078 (-.017, .210)	.058	.095	.073 (-.042, .189)	.059	.213
ACC1= Integration				.040 (-.683, 1.392)	.528	.502	.261 (-.781, 1.302)	.530	.623
ACC2= Assimilation				.162 (.420, 2.540)	.540	.006	1.685 (.617, 2.753)	.544	.002
ACC3= Separation				.039 (-.734, 1.482)	.564	.507	.174 (-.937, 1.285)	.565	.759
DL1= Recognition							.035 (-.028, .098)	.032	.270
DL2= Risk factors							-.070 (-.133, -.007)	.032	.030

DL3= Information seeking							-.159 (-.263, -.055)	.053	.003
DL4= Professional help							.023 (-.083, .128)	.054	.674
DL5=Attitude							.015 (-.025, .056)	.021	.459
Adjusted R <sup>2</sup>	.007			.020			.041		

Note: SN= Social Network, ACC= Acculturation, DL= Dementia Literacy. Bold

In model 1, none of the subscales of social network was significantly associated with intention-to-  
seek-help. In model 2, assimilation strategy ( $\beta = 0.162$ ,  $p < 0.006$ ) was the only acculturation  
strategy that was significantly associated with intention-to-  
seek-help. Model 2 explained an  
additional 2% of the variation in intention-to-  
seek-help, and this change in  $R^2$  was significant  $F(3,46) = 3.01$ ,  $p < 0.030$ ). In model 3, only risk factors ( $\beta = -.070$ ,  $p < 0.030$ ) and information seeking  
( $\beta = -.159$ ,  $p < 0.003$ ) subscales were significantly inversely associated with intention-to-  
seek-help. Model 3 explained an additional 4% variation in help-seeking, and this change in  $R^2$  was  
significant  $F(5,45) = 3.07$ ,  $p < 0.010$ ).

### 6.3.3 Relationship among Social Network, Assimilation, Knowledge of risk factors, of how to seek dementia information and Intention-to-Seek-Help

Table 6.11 showed the results of the hierarchical regression model. In model one, the social  
network contributed significantly to the regression model,  $F(1,46) = 5.09$ ,  $p < 0.024$ ) and  
accounting for 0.9% of the variation in help-seeking. The addition of the assimilation subscale of  
acculturation explained an additional 3% of the variation in the intention-to-  
seek-help, and this  
change in  $R^2$  was significant  $F(1,46) = 8.50$ ,  $p < 0.004$ ).

Table 6. 11 Regression analysis of social network (total score), assimilation, risk factors and  
information seeking and intention-to-  
seek-help.

Variables	Model 1			Model 2			Model 3		
	B (95% CI)	Standard error	p-value	B (95% CI)	Standard error	p-value	B (95% CI)	Standard error	p-value
Social Network	.097 (.014, .180)	.042	.022	.099 (.017, .181)	.042	.018	.085 (.003, .167)	.042	.042
Assimilation				1.223 (.399, 2.048)	.420	.004	1.509 (.670, 2.348)	.427	.000



Risk factors							-.014 (-.048, .019)	.017	.396
Information seeking							-.165 (-.263, -.067)	.050	.001
Adjusted R <sup>2</sup>	.009			.025			.044		

Lastly the introducing risk factors and information seeking (Dementia literacy subscales) explained an additional 4% variation in the intention-to-seek-help, and this change in R<sup>2</sup> was significant  $F(1,46) = 5.56, p < 0.004$ . Social Network, assimilation, and information seeking were identified as the significant factors of intention-to-seek-help. Risk factors was insignificant factor of intention-to-seek-help ( $p < 0.396$ ).

#### 6.4 Path Analysis

Structural equation models were developed to examine the relationships among socio-demographic indicators, dementia literacy, acculturation, social network, and intention-to-seek-help. Two main path models were developed using the significant predictors identified from the hierarchical regression models (refer to Table 6.11).

##### 6.4.1 Dementia literacy mediates the relationship between Acculturation, Social Network, and Intention-to-Seek-Help

Figure 6.1 illustrates path analysis for each independent variables on intention-to-seek-help, holding all sociodemographic variables constant. The model demonstrated a good model fit (CMIN= .723; NFI= 0.99; TLI=1.00; CFI=1.00; RMSEA=0.001,  $X^2/df=.723$ ;  $P=0.395$ ;  $df=1$ .) Acculturation (assimilation) ( $\beta = 0.17, p < .001$ ) and social support ( $\beta = -0.11, p < .014$ ) demonstrated a significant and positive and negative relationship respectively with knowledge of risk factors dementia literacy. Assimilation exhibited a significant relation with knowledge of risk factors ( $\beta = 0.13, p < .005$ ) however, social network had an insignificant effect on knowledge of risk factors ( $\beta = 0.06, p < .167$ ). Acculturation (assimilation) ( $\beta = 0.10, p < 0.001$ ) and social network ( $\beta = 0.10, p < 0.051$ ) exhibited positive significant direct relationship with intention-to-seek-help.

Only knowledge of how to get dementia information (dementia literacy) ( $\beta = -0.16, p < 0.001$ ) exhibited a direct negative significant relationship with help-seeking. Knowledge of risk factors and causes exhibited an insignificant negative relationship ( $\beta = -0.04, p < 0.395$ ) with intention-to-

seek-help. The mediating effect of dementia literacy (knowledge risk factors and information-seeking) on the relationship between acculturation (assimilation) and social network and intention-to-see-help.

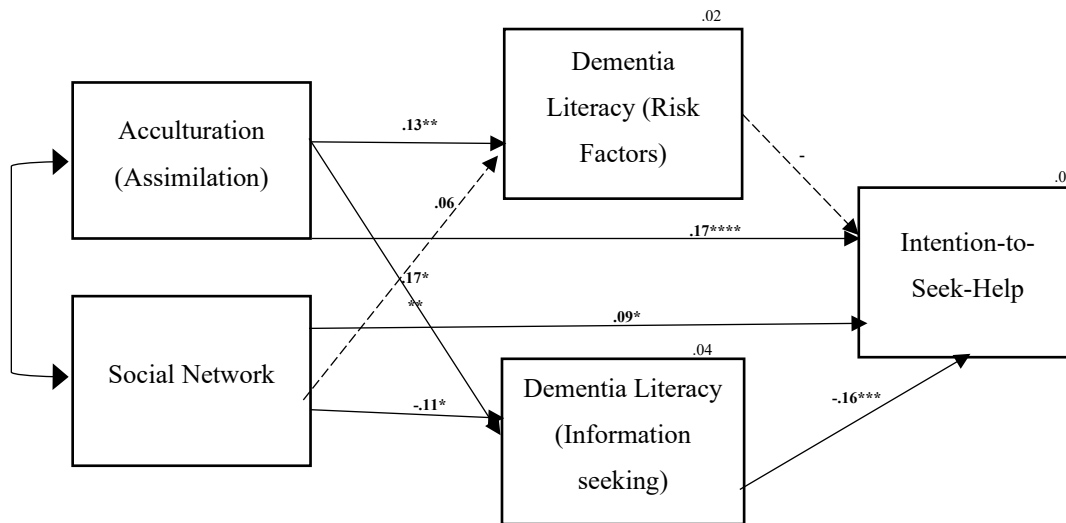


Figure 6.1 Relationship among social networks, acculturation, dementia literacy and intention-to-see-help.

Knowledge of how to get dementia information showed a significant negative mediative effect on the relationship between, assimilation ( $\beta = -0.014, p=.027$ ) and help-seeking. Risk factors also negatively mediated the relationship between acculturation and intention-to-see-help ( $\beta = -0.020, p=.036$ ).

#### 6.4.2 Mediating effect of acculturation (assimilation) and social network

A final optimal model was conducted for the study where social network and acculturation mediated the relationship between dementia literacy (knowledge of risk factors and knowledge of how to get dementia information) and intention-to-see-help. The final model exhibited a good fit, CMIN= 1.577; NFI= 0.98; RFI=0.94; CFI=1.000; RMSEA<0.001,  $X^2/df=0.526$ ; P=0.665; df=3. Figure 8.2 showed that assimilation ( $\beta = 0.16, p<0.001$ ) and social network ( $\beta = 0.09, p=0.021$ )

exhibited positive significant relationships with intention-to-seek-help. Knowledge of how to get dementia information ( $\beta = -0.16, p < .001$ ) showed a direct significant negative relationship with intention-to-seek-help. Conversely, knowledge of risk factors ( $\beta = -0.04, p = 0.368$ ) showed a negative insignificant direct relationship with intention-to-seek-help. Knowledge of how to get dementia information showed a direct positive significant effect on assimilation strategy ( $\beta = 0.19, p < 0.001$ ) however, showed a direct negative significant effect on social network ( $\beta = -0.16, p < 0.011$ ). Knowledge of risk factors showed a positive direct relationship with assimilation ( $\beta = 0.16, p < 0.001$ ), but negative insignificant relationship with social network ( $\beta = -0.04, p = 0.368$ ).

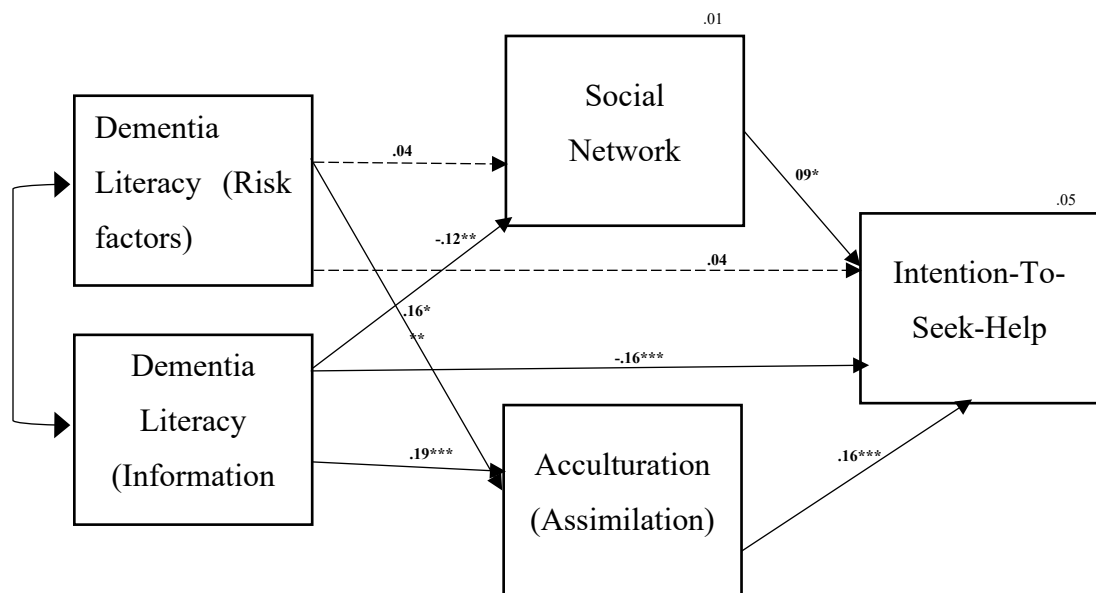


Figure 6.2. Optimal path model for the study

Note: estimates are standardized estimates. \* $p < .001$ , \*\*  $p < 0.01$ , \*  $p < 0.05$ .-----►Non-significant path.

The mediating effect of recognition, risk factors and information-seeking subscales of dementia literacy is shown in Table 6.12. Assimilation had a significant positive mediating effect on the relationship between knowledge of risk factors and causes ( $\beta = 0.025, p < 0.001$ ) and knowledge of how to get dementia information ( $\beta = 0.031, p < 0.001$ ). Social network ( $\beta = -0.011, p = 0.048$ ) showed a negative significant mediating effect on the relationship between information seeking and intention-to-seek-help.

Table 6 12. Mediating effect of assimilation and social network

Indirect Path	Unstandardized Estimate	Lower	Upper	p-Value	Standardized Estimate
Risk factors --> Assimilation-->Intention-to-seek-help	0.010	0.005	0.019	0.001	0.025***
Information seeking --> Assimilation --> Intention-to-seek-help	0.032	0.017	0.062	0.001	0.031***
Information --> Social Network --> Intention-to-seek-help	-0.012	-0.027	-0.002	0.048	-0.011*

Significance of Estimates: \*\*\*  $p < 0.001$ , \*\*  $p < 0.010$ , \*  $p < 0.050$ .

## 6.5 Summary of Chapter

Findings from the study have established the presence of different levels of dementia literacy, acculturation, social network, and help-seeking intentions among Africans in Hong Kong. The findings showed that social network was significantly related to the intention to seek help for dementia. However, total dementia literacy score and acculturation showed an insignificant relationship to help-seeking behaviour for dementia. Nonetheless, assimilation strategy was positively significant with the intention to seek help, while knowledge of risk factors and how to seek help (subscale of dementia literacy) was inversely significantly related. This was the first study to assess dementia literacy, acculturation, social network, and help-seeking intentions among the understudied migrant population: African migrants living in Hong Kong. Findings from the study demonstrate that participants who have assimilated and those with a higher social network had more intention to seek help for dementia. Notably, possessing adequate dementia literacy did not necessitate a higher intention to seek help for dementia. This finding was surprising given the fact that adequate mental health literacy has been described as a foundation for mental help-seeking (Gorzynski et al., 2017; Jorm, 2012; Kutcher et al., 2016; O'Connor & Casey, 2015; Smith & Shochet, 2011; White & Casey, 2016). Therefore, various factors such as social networks and acculturation may be in place and may prevent the intention to seek help for dementia.

## **CHAPTER 7: DISCUSSION OF FINDINGS FROM THE STUDY.**

### **7.1 Introduction**

This chapter provides an interpretation of findings from the three main phases of the study (development of the Dementia Literacy Scale (DLS), the qualitative study and cross-sectional survey). Interpretation of the findings will be based on the results and existing literature. Findings from the study have established the presence of different levels of dementia literacy, acculturation strategies, social network, and help-seeking behaviour among Africans in Hong Kong. This chapter comprises of five sub-sections. The first section will discuss a recapitulation of the study's objectives, research question and methods utilised in the study. The section discusses the findings and contributions of the Dementia literacy scale (DLS). The third section gives an insight into how the study addressed the research questions and supported or refuted the initial hypothesis. The strength and limitation of the study is addressed in the fourth sub-sections of the chapter. The final section summarised the challenges faced during the data collection.

### **7.2 Restating the Study's Objective and Research Approach**

This study addressed dementia literacy, acculturation, social network, and help-seeking behavior among Africans in Hong Kong. The purpose of the exploratory sequential mixed method design was to sort answers to the research questions:

1. What acculturation strategies do Africans use when they are living in HK?
2. How much do Africans know about dementia?
3. What factors affect Africans' intention-to-seek-help for dementia?
  - a. Would dementia literacy directly affect their intention-to-seek-help?
  - b. Would acculturation and social network affect their intention-to-seek-help?
  - c. Would dementia, acculturation, social network interlinks and affect Africans' intention-to-seek-help?

This study is the first to assess the association among dementia literacy, acculturation, social network, and intention-to-seek-help. It is also the first to determine how these variables are interlink among migrants in a non-western society (Hong Kong).

Three concepts - Berry's acculturation model, mental health literacy and sociocultural health belief model - were used to conceptualize the main variables in the study. A conceptual framework was

generated from previous empirical studies that addressed similar concepts (health literacy, mental health literacy, acculturation and social network and disease-specific outcomes). The framework steered the data collection, analysis, and outline of the study. Findings from the literature informed the two-hypothesis generated for the study.

- a. Acculturation strategies, social network and dementia literacy will directly affect intention-to-seek-help.
- b. The relationship between acculturation, social network, and intention-to-seek-help will be mediated by level of dementia literacy.

### **7.3 Dementia Literacy Scale**

One of the innovations in this thesis is the development of the Dementia Literacy Scale (DLS). This was the first attempt to develop and psychometrically evaluate a comprehensive scale to measure dementia literacy among African migrants. A robust methodological process was used to develop this scale that assesses all attributes of dementia literacy. This scale was designed based on the review of all existing measures of dementia literacy in the literature, taking the reference of the definition of dementia literacy in the mental health literacy framework proposed by Jorm (2012). In the process of development of the DLS in this study, qualitative interviews were made with the stakeholders (African migrants) to assess their understanding and perceptions of dementia literacy (Chapter 4). This strategy ensures the coverage of the concepts of dementia literacy perceived by the Africans.

#### **7.3.1 Reasons for developing the DLS.**

The existing literature shows the unavailability of comprehensive instrument for measuring dementia literacy. Most of the previous studies measured dementia literacy by using a combination of two or more scales (A. Y. Leung et al., 2019; A. Y. Leung et al., 2020; Loi & Lautenschlager, 2015; Sun et al., 2013; Sun et al., 2021), while other studies used a single non-validated scale to assess dementia literacy, with most of the scales adopting from the Mental Health Literacy Scale (MHLS). Most of these existing dementia literacy instruments did not measure and reflect broader constructs such as knowing how to seek dementia information and awareness of professional treatment and services available. The Consumer Access, Appraisal and Application of Services and Information for Dementia (CAAASI-Dem) is a validated scale to assess dementia literacy;

however, this scale is suitable for people with dementia and their caregivers and cannot be used in general population (Doherty et al., 2020). Carr and Furnham (2021) and Zhang et al. (2017b) had used two non-validated dementia literacy scales which were constructed based on the MHL scale. However, both scales did not provide a comprehensive measure of all the subscales of the MHL framework. The scale used by Zhang et al. (2017b) was an 8-item scale which assessed symptoms, prevalence, nature, and treatment method for dementia. But no item was used in this scale for measuring knowing how to access dementia information, attitudes that promote appropriate help-seeking, risks factors and causes of dementia. Similarly, Carr and Furnham (2021) dementia literacy scale only focused on assessing recognition and knowledge of three types of dementia (Frontotemporal, vascular, and Alzheimer's disease). This newly developed DLS fills the knowledge gap of dementia literacy instruments in the field of dementia research. DLS is a comprehensive and reliable assessment scale to measure all the subscale of dementia literacy among Africans in Hong Kong. Adaptation and modification of the MHL make it suitable to measure dementia literacy in English-speaking populations, including the Africans who speak English in this study.

### 7.3.2 Features and psychometric properties of DLS

DLS is a 37-item scale with five subscales that can be used to assess different aspects of dementia literacy including knowledge, attitude towards dementia, and help-seeking ability. The scale has been validated and is reliable. In term of comprehensiveness, DLS covers the measurement of a person's ability to recognised signs and symptoms of dementia, causes and risk factors, knowing how and where to seek information, awareness of professional help available and attitudes towards persons with dementia. One of the critical features of the DLS is its meaningful theoretical structure which is obtained by the coalition of all scores of individual subscales to provide a total score.

This study assessed the structure of the DLS with 461 Africans living in Hong Kong using both exploratory and confirmatory factor analysis. The EFA's results identified five subscales of factorial structure for this questionnaire. However, these results are slightly different from O'Connor and Casey (2015) six subscales of the MHL scale. The MHL scale's subscales which were adopted from Jorm's framework consisted of six subscales namely, recognition of disorders,

knowing how to seek mental health information, causes and risk factors, knowledge of self-treatment, awareness of professional help available, and attitudes that promote recognition (Jorm, 2012; O'Connor & Casey, 2015). However, as mentioned previously in chapter 6, EFA analysis revealed five factors for the DLS. Knowledge of self-treatment domains were moved to the knowledge of causes and risk factors and attitudes that promotes recognition seeking domains. As majority of the participants completed the scale in about 10 mins, we believe that this self-administered scale is an easy-to-use questionnaire.

However, a few of the items required modification and revision to suit the cultural background of participants and make items comprehensible and clear. After evaluating the scale, five questions were removed, and the DLS with 37 items and five subscale was confirmed. Previous studies which utilised MHLS to assess a specific mental disorder have reported Cronbach's alpha above 0.70 (Nejatian et al., 2021; Noroozi et al., 2018). Therefore, the DLS showed excellent reliability.

#### **7.4 Possession of adequate dementia literacy does not always affect intention-to-seek-help.**

This section addresses the research question, “*Would dementia literacy directly affect their intention-to-seek-help for dementia?*”. Quantitative finding suggest that possession of adequate dementia literacy was not directly associated with intention-to-seek-help. However, possession of limited or low knowledge of how to seek dementia information and knowledge of risk factors was influential factors in the intention-to-seek-help for dementia. Data from the qualitative injury suggest that participants who recognise dementia as a medical condition instead of witchcraft or as normal part of aging were likely to seek medical care or support. A recent review has identified normalisation of dementia symptoms and association of cognitive problems as psychosocial causes were factors that hinder help-seeking (Hill et al., 2021).

Although in the quantitative study, attitude towards dementia was not statistically significant with help-seeking behaviour, qualitatively, societal attitude towards persons with dementia, dementia management and treatment were the most influential factors in help-seeking behaviour. These findings are consistent with Werner et al. (2014) review which identified stigmatising beliefs and poor knowledge as main barriers to help-seeking for dementia. Most Africans were willing to seek professional help for dementia in Hong Kong due availability of dementia services and lack of



societal stigma associated with utilising these services. According to Alzheimer's Disease Association (2021) access to dementia care services is one of the main influencing factors in engaging in dementia preventive services and early diagnosis and care.

### **7.5 Strong familial and African cultural ties as impediment to intention-to-seek-help for dementia.**

This section addresses the research question, “*would acculturation and social network affect intention-to-seek-help?*”. Qualitative data suggest that African cultural belief strongly belief in the practice of familism where persons with symptoms of dementia are often cared for by family members. Some participants reported that accessing medical care for dementia in a health institution is something their family members will prevent. Some participants went as far to report that they will hide such actions from their extended family members. Caregiving for dementia among people of African descent is often a collective responsibility and decision with regards to source of treatment are often made by the entire family (Guerchet et al., 2017; Roche et al., 2021). Findings from the quantitative study suggest that Africans in Hong Kong with stronger ties with family network do not engage in help-seeking behaviour. However, those with stronger friends' social network in Hong Kong were more likely to engage in help-seeking behaviour. From the qualitative study, it was identified that participants with local friends were more informed about dementia services and treatment and more willing to seek medical care in future if a family member shows symptoms of dementia.

Notably, both studies also highlight how upholding African beliefs serves as a barrier to help-seeking for dementia. Quantitatively, the data suggest that participants who orient themselves to the host (Hong Kong) culture were more likely to seek help for dementia whereas those who orient to African culture alone (Separation) or some aspect of African culture with Hong Kong culture (Integration) were less likely to seek help for dementia. Various studies have highlighted how integration to host culture (either linguistically or culturally) not only improve access to health information and services but also improve early help-seeking behaviour (Lee, 2022). Most of the participants during qualitative inquiry reported how Hong Kong culture always approach dementia from biomedical perspective and from spiritual or psychosocial perspective among Africans. Therefore quantitatively, it was not surprising that aligning with Hong Kong culture (assimilation)

was directly associated with help-seeking behaviour. These findings highlight the significant role of social ties/network and specific cultural beliefs and practices on help-seeking for dementia.

### **7.6 Aligning with Host culture (assimilation) interlink with dementia literacy to influence intention-to-seek-help.**

The acculturation strategy of migrants may be a potential factor for the differences in help-seeking behaviour among African migrants and South Asian migrants in Hong Kong. Quantitatively, the findings indicated that assimilation strategy is directly associated with higher intention to seek help for dementia. These findings are consistent with previous research that ascertain that acculturation into a new society or culture (either linguistically or culturally) improves access to health information and services and early help-seeking behaviour (Lee, 2022; Markova et al., 2020; Sayegh & Knight, 2013). The study by Lee et al. (2010) among Korean Americans also identified acculturation as a robust predictor of dementia care seeking. These findings imply that assimilated Africans may be knowledgeable of dementia care and services in Hong Kong, which may have influenced participants' decision to seek help from health professionals. A study among caregivers in Hong Kong identified that due to fear of 'losing face,' most people refuse to rely on their social network for support but seek help from community dementia service providers, such as NGOs or other health professionals (Au et al., 2012). Family caregivers of persons with dementia in Hong Kong have been reported to show positive attitudes toward formal help-seeking for dementia in a new society, a phenomenon often absent in their native countries (Yiu et al., 2020). This may partly explain why highly acculturated Africans in this study tended to seek help from health professionals for dementia.

Findings from the quantitative study shows that acculturation (specifically assimilation) interlink with dementia literacy to affect Africans help-seeking behaviour. This finding addresses the research question: "*Would dementia literacy, acculturation and social network interlink to affect intention-to-seek-help?*". Assimilation mediates the relationship between knowledge of how to seek information, risk factors, and intention to seek help. This finding broadens our understanding of the context of help-seeking behaviours for dementia and provides information on what should be highlighted in dementia help-seeking promotion education. Assimilation was the most robust predictor across acculturation strategies, with Africans who orient themselves with Hong Kong

culture having a higher help-seeking behaviour. In this study, adopting an assimilation strategy was a protective factor against low knowledge of risk factors and of how to seek dementia information associated with help-seeking for dementia. This finding was inconsistent with the sociocultural health belief model which posit that knowledge and awareness of dementia mediated the relationship between acculturation and decision to seek help for dementia (Sayegh & Knight, 2013).

Although this question was addressed quantitatively, there are subtle findings from the qualitative data that might expand our understanding of this relationship. It was noted from the qualitative data that irrespective of poor knowledge of dementia, some participants recount how they will open to the idea of taking their family members with cognitive problems to the hospital due to societal acceptance of such behaviours in Hong Kong. Participants were open to behave as locals with regards to help-seeking for dementia.

### **7.7 Poor understanding of key issues about dementia**

This section addresses the research question, *“how much do Africans know about dementia?”*. It was identified from both studies that dementia literacy is inadequate among Africans in Hong Kong. Both studies reported that half of the Africans in Hong Kong have never heard of dementia. The findings revealed that 51-69% (N= 236-319) of the participants did not know any functional and cognitive symptoms associated with dementia. Qualitative findings shows that dementia symptoms were often associated with depression, menopause, and witchcraft. This finding was inconsistent with studies among other population groups that identified that most participants could recognise dementia symptoms (Loi & Lautenschlager, 2015; Low & Anstey, 2009; Nagel et al., 2021). Majority of participants (N= 223,72%) agreed that "dementia is a normal part of ageing", a belief shared by Latino Americans, African Americans, Chinese Americans, and community-dwelling Japanese (Aihara & Maeda, 2020; Dai et al., 2015; Gray et al., 2009; Hinton et al., 2005; Loi & Lautenschlager, 2015; Mahoney et al., 2005). Inability to recognise dementia symptoms has severe implications as studies have identified that ability to detect dementia symptoms is associated with early help-seeking behaviours, diagnosis, and treatment among persons with dementia and their carers (Lang et al., 2017; Leung et al., 2011; Rossor et al., 2010). The low recognition rate implies that symptoms of dementia may be overlooked and possibly

explain findings from previous studies that there is a lack of early detection and help-seeking for dementia among the African population (Brooke & Ojo, 2020; Spittel, Kraus, et al., 2019).

Similar to previous studies, there was the misconception that dementia is a white man's disease (Berwald, Roche, Adelman, Mukadam, & Livingston, 2016). Dementia remains an unknown or foreign term in most African countries and cultures (Brooke & Ojo, 2020; Mkhonto & Hanssen, 2018). Therefore, to an African, dementia is a label only assigned to a white man or Caucasian as various African cultures identify dementia as a normal part of ageing or a spiritual illness (Mkhonto & Hanssen, 2018). It is worth noting that cultural beliefs and practices overshadowed medical or biomedical concepts about dementia treatment, management, and help-seeking behaviour among Africans. The lack of interest in dementia and the perception that Africans are immune to dementia served as significant deterrents in influencing their willingness to learn more about dementia in society. The language barrier and lack of social interaction between locals (Chinese-speaking people) and Africans worsen acculturation's impact on dementia literacy for these new migrants. This implies that dementia literacy can only be improved when these barriers have been addressed and full integration has been achieved.

Quantitative findings clearly showed that most Africans in Hong Kong did not know the relationship between lifestyle-related and biological risk factors for dementia. Considerable knowledge gaps exist regarding common dementia risks such as high blood pressure, high cholesterol (hypercholesterolemia), alcohol and smoking abuse. Qualitative most participants reported not knowing the cause or risk factors of dementia while others were of the notion that Africans are not at risk for dementia and dementia is a condition of “White and Asians”. These findings align with previous studies that reported poor knowledge and awareness of risk factors associated with dementia (Heger et al., 2019). Poor knowledge on risk factors and causes has detrimental implications, given that people of African descent are twice as likely to have Alzheimer's disease than Caucasians (White people) (Fazeli et al., 2022; Kulisevsky et al., 2001; Potter, 2009). The connection between Blacks or people of African descent and dementia has mainly been attributed to the high prevalence rate of high blood pressure, diabetes, strokes, lack of exercise, and limited knowledge of dementia (Akinyemi et al., 2022; Guerchet et al., 2017). Systemic hypertension and peripheral arterial disease have been associated with the high

prevalence rate of dementia in West and Central Africa, with high cholesterol levels and risk of Alzheimer's disease among Nigerians (Akinyemi et al., 2022; Hall et al., 2006; Ojabemi, 2020). These findings implies that the limited knowledge of Africans on modifiable risk factors of dementia implies that there would be lack of engagement in preventive measures for dementia thereby increasing risk of developing the condition. Efforts to improve dementia literacy among Africans by public health officials should include measures aimed at controlling vascular disorders and diabetes as well as education and significance of exercise among this population.

### **7.8 Diverse and inconstant Acculturation strategies among Africans in Hong Kong**

This study sought to address the research question, “*What acculturation strategies do Africans use when they are living in Hong Kong?*”. The study identified that all four acculturation strategies, as specified by Berry (2019), exist among Africans living in Hong Kong. This finding contrasted with previous studies among Africans living in western societies where separation and marginalization strategies were limited or non-existent. A plausible explanation may be attributed to the nature of the community, social determinants (social class, immigration status) and exposure to various acculturation stressors (social isolation, perceived discrimination, and racism). It was also observed that acculturation was a continuous process for Africans – subjected to change – and often determined by social or employment status. For instance, when some African students join the workforce, they often change their integration or separation strategy to assimilation or integration. Acculturation strategy changes were a survival approach to be accepted and fit into society and the workforce. Some Africans increased their tolerance and normalizing subtle negative and racial attitudes toward them to integrate into their new environment.

Findings shows that among participants, 29.7% adopted integration (29.7%), 26.7% assimilation, 22.1 % separation and lastly, 21.5% adopted marginalisation strategy. An indication that there was no predominant acculturation strategy among Africans in Hong Kong. Previous studies have reported that integration and separation are the commonly adopted strategies among African migrants (Adegboyega et al., 2021; Onyigbuo et al., 2018; Swarts et al., 2021). Marginalisation strategy was often absent or non-existent (Adegboyega et al., 2021; Onyigbuo et al., 2018; Swarts et al., 2021). Although branded as a multicultural and Asia's world city, is it an assimilation-oriented absorbing society.

Quantitative study proves that Africans with higher educational status and older adopted the integration strategy. At the same time, assimilation was associated with people with lower education, low income, asylum seekers, and those with good physical health status. Separation was adopted by those who reported poor physical and mental health status and females. Interestingly male participants and those with a more extended stay, with higher income, adopted the marginalisation strategy. The results showed a strong acculturation orientation toward one's heritage culture (separation). This represents a risk for African migrants as studies have associated separation and marginalisation strategies with low mental health literacy and limited access to mental health services and care (Horyniak et al., 2016; Yoon et al., 2013). Integration and assimilation have been favoured as the ideal strategies for mental health and improved health outcomes (Berry, 2017, 2019; Swarts et al., 2021).

### **7.9 Sociodemographic characteristics of participants**

Congruent with the Institute of Medicine's (IOM) recent reports on migration (Hennebry et al., 2021; Newland et al., 2020), the majority of the participants in the study were males (71.8% of 461). A higher number of males has been attributed to the increasing demand for male migrant workers (Hennebry et al., 2021). There was no significant difference in participants in terms of age; however, only one participant was above 60 years in the survey. These findings affirm the IOM 2020 report that 74% of the migrant population are of the working-age group (Newland et al., 2020). The educational attainment among the participants was considerably high as more than half (61%) of the participants hold a bachelor's degree, 10.6% hold a doctorate, and only a mere 0.7% have primary education. This is also affirmative to report that migrants with tertiary education are five times more likely to migrate than those with primary education.

Most of the participants were born in Africa. However, a small number (3.5%) were born in Hong Kong, indicating second-generation immigrants among the sample. Second-generation immigrants may experience various competing and opposing forces in their everyday life to adapt to society's norms and values than their migrant parents (Kalmijn & Kraaykamp, 2018). The findings affirm the existence of different generational migrants in the study context. The majority of studies about Africans in Hong Kong only highlight African asylum seekers, refugees (Mathews, 2011; Wong

et al., 2016; Wong et al., 2017b) and first-generation migrants (Amoah, 2017a; Amoah, Koduah, et al., 2020; Chow-Quesada & Tesfaye, 2020). The study's sample was heterogeneous; therefore, there are expected differences and diversity in social network, acculturation, and dementia literacy levels. Asylum seekers and refugees may possess different acculturation and social network than Hong Kong residents (students and those with working visas), permanent residents and participants with diplomatic passports. A blend of these unique experiences may provide a holistic understanding of their dementia literacy, acculturation strategies, social network, and help-seeking behaviours, which aid public and health professionals in developing a comprehensive intervention plan to meet their unique needs.

Although findings from this study affirm the "health migrant syndrome", 58.4% of participants reported poor mental health status (McAuliffe & Khadria, 2019; United Nations International Organization for Migration, 2020). Africans in Hong Kong have been identified to have exhibited depression symptoms with a prevalence rate of 36.1%, which is higher when compared to the general population of Hong Kong (10.7%).

### **7.10 Study Limitation**

Findings from the study highlight the significant role of acculturation and social network in intention-to-seek-help among Africans living in Hong Kong. However, several shortcomings were observed:

- However, there are numerous limitations of this scale. First, it was adapted to suit African cultural backgrounds and beliefs. Secondly, words or terminologies used in the questions in the various domains are specific to Africans. Therefore, future studies should exercise caution when adopting this scale among other ethnic minority groups. Adaptation of the scale to the culture and context of participants might be necessary. Additionally, the self-reported nature of the scale responses may be subjected to response bias if the participants did not wish to disclose their poor or low dementia knowledge, attitude or beliefs and knowledge of where to seek information. Lastly, this scale was not subjected to a test-retest assessment and therefore may question or judge the stability of the reliability test of the scales.

- The study's cross-sectional design restricts the study's ability to infer a causal relationship between dementia literacy, acculturation, social network, and help-seeking behaviour. A limitation of cross-sectional designs is their inability to observe changes in variables over time. Variables such as acculturation strategies, social network, mental health status, age and dementia literacy could change during the one year before the study, affecting the proposed model's effectiveness. Therefore, caution should be taken in making conclusive associations regarding some findings from the survey. The study also used self-assessment instruments to elicit participants' dementia literacy, acculturation, social network, and help-seeking behaviour. Therefore, it is anticipated that some participants may have modified their responses. However, the combination of qualitative and quantitative designs helps to effectively capture salient influences of dementia literacy, acculturation, and social network on dementia help-seeking behaviour.
- Second, Covid19 social distancing measures and challenges in locating Africans in the city led to a more significant proportion of Ghanaian, Nigerians, Cameroonians, South Africans, and Ethiopian participants being recruited from purposive and snowball sampling. However, the sample was deemed representative of the African community as there was a representative from all 46 countries.

### **7.11 Chapter Summary**

To a significant extent, the findings above illustrate that possessing adequate dementia literacy does not always necessitate a higher help-seeking behaviour among African migrants in Hong Kong. However, contextual factors such as social networks, acculturation and its stressors and specific social determinants influence the impact of dementia literacy on intention-to-see-help.



## CHAPTER 8: STUDY CONTRIBUTION AND IMPLICATION

### 8.1 Introduction

This chapter summarises the study's contribution to the literature. The first section reiterates the study implications for healthcare practice. The next two sections discuss the implications for research and healthcare policies. Finally, the last sections discuss the study theoretical, research, and methodological contributions.

### 8.2 Implication for Healthcare Practice

- The DLS is a self-administered instrument that can be used in both clinical settings and population-based studies of racial and ethnic minority groups. Works of literature posit that dementia literacy is generally low or inadequate among the general population, but notably lower in ethnic and racial minority groups (Low et al., 2010; Selten et al., 2020), which has led to misdiagnosis, delayed help-seeking, and underutilisation of dementia services. Therefore, an understanding or knowledge of specific domains of poor dementia literacy may assist health professionals in designing interventions to address the specific needs of these groups. The development of DLS reinforces the first step in assessing dementia literacy levels among Africans diasporas. It can be used in interventional studies to collect baseline data and follow-up data among African migrants. Using the newly designed Dementia Literacy Scale (DLS), health professionals can identify Africans' dementia literacy levels, which may help to support further education, intervention, and support.
- Public health approaches, such as dementia literacy campaigns, may positively affect early help-seeking and diagnosis. However, the extent of such effect and the processes involved significantly depend on an individual and, by amplification, each minority group's assimilation into society, and the quantity and type of social networks involved. Therefore, efforts to improve the help-seeking behaviour of Africans, without recourse to their social networks and assimilation into the community, may be challenging to implement and sustain. Health practitioners, including clinicians, allied health professionals, and public health officials, should engage with the public – those accessing curative and preventive health services – as if there were reaching out to an entire African population group at each level. This is according to the study findings that identified that Africans are active

advocates and potential resources for other members in their social network in matters relating to health knowledge, as they are the primary source of help.

- For health professionals, researchers, and policymakers to create sustainable and effective interventions and services for Africans, they should be aware of their conceptualisation of mental health disorders and related treatment. From the study, it was identified that Africans understand dementia from the biopsychosocial and spiritual perspectives. Therefore, there is a need for health professionals in Hong Kong to be aware of this and approach education and care accordingly. Health educators can provide accurate information on dementia by dispelling spiritual myths that often lead to the abuse, stigma, and neglect of persons with dementia. Health professionals should provide up-to-date information about risk factors (including modifiable and non-modifiable factors) and present data on how dementia can affect anyone, irrespective of race. Interventions targeted at improving dementia help-seeking behaviour and promoting risk reduction and dementia awareness among Africans should be done through video-based, talk/lecture-based interventions instead of print-based or app-based interventions. This may ensure easy accessibility and understanding of dementia-related information for Africans.
- Health professionals need to be made aware of the negative experiences of Africans in the city, which has led to a lack of trust in health professionals, poor treatment, and a negative influence on future help-seeking behaviour. There is a need for a culturally sensitive educational workshop to train health professionals on how to communicate and provide culturally sensitive care to African migrants in the city.
- Any intervention promoting help-seeking behaviour should acknowledge Africans' needs for emotional and spiritual support from religious leaders, and a sense of family obligation to provide care and support for their loved ones. Adopting a holistic and pluralistic approach in addressing help-seeking behaviour may appeal more to the African population. Various works of literature have explored the potential role of spiritual leaders in promoting dementia awareness and help-seeking behaviour (Camacho-Montaña et al., 2021; Daly & Fahey-McCarthy, 2014; Epps et al., 2021; Willis et al., 2018). Therefore, a

collaborative effort with African religious leaders to promote dementia literacy and help-seeking behaviour in the city is recommended.

### **8.3 Policy Implications and Recommendations**

- Findings from this study prove that Africans experience health disparities in access to information. Although community-based interventions exist to improve dementia literacy among community members in Hong Kong, evidence from this study indicates this does not include Africans in the city. There is a need for a collective inclusion of Africans and other ethnic minority groups in future public health campaigns. The Department of Social Welfare should extend its "Dementia Friendly Campaigns" to Africans in Hong Kong.
- However, given the complexities in designing educational interventions that address help-seeking behaviour through social networks, a socially friendly approach should be adopted. Given this dilemma, the Department of Health and Social Welfare department could collaborate with various African leaders to develop a suitable intervention to improve the dementia literacy and mental health literacy of this population. These organisations can select and train specific people from each African region with a similar national language. The trainees could include persons with acclaimed expertise or knowledge of health matters within the various countries' organisations. Religious leaders, research students, and country executives could be trained to carry out these responsibilities. Country or region-based representatives can be supported with health-related skills, logistics, and finances to provide education on various health-related issues, including dementia and mental illness.
- Africans are ethnically and linguistically diverse, making it highly complex for health officials in Hong Kong to tailor health information to overcome the language barriers faced by this population. Africa is a multilingual continent, with more than 2,000 spoken languages (Gut, 2012) that co-exist with colonial language, which often forms part of the national language or languages spoken and written in school (Mesthrie et al., 2021). Most Africans maintain colonial languages as an official language or as one of their numerous official languages in which primary affairs of the country - in government, schools, courts,

and media - are conducted (Mesthrie et al., 2021; Yameogo, 2020). In print materials and the spoken word, translation of health materials into one of these non-indigenous or official languages (English, French, Swahili, Somalia, Arabic, and Portuguese) will facilitate access to health-related information. The Department of Health has already implemented this initiative, where health-related pamphlets in various hospitals have been translated into Hindi, Nepali, Urdu, Bahasa Indonesian, Tagalog, and Thai. This initiative can be extended to the African community as well.

- Assimilation into Hong Kong culture was identified as a significant predictor of help-seeking for dementia and as a mediator between dementia literacy and help-seeking behaviour. Therefore, efforts to integrate Africans into Hong Kong society are imperative. However, evidence shows that most Africans have faced racism, discrimination, and stereotyping in their efforts to acculturate into their host society. Media representation and reports about Africans in Hong Kong have been identified as one of the main culprits for the social isolation, and the perception of Africans as inferior, among Hong Kongers (Chow-Quesada & Tesfaye, 2020; Zheng & Leung, 2018). Notably, it was identified that the majority of Africans reported poor mental health status. Studies have reported the poor mental health and loneliness of Africans in Hong Kong (Amoah, Hodzi, et al., 2020; Amoah, Koduah, et al., 2020; Wong et al., 2017b). Africans' poor mental health status has been significantly associated with a lack of social support, and reports of discrimination and social isolation (Wong et al., 2016; Wong et al., 2017b). Loneliness and depression have been associated with the risk of developing dementia in later life (Kessing, 2012; Saczynski et al., 2010; Zhou et al., 2018). Therefore, the Hong Kong government has a moral and ethical obligation to provide a social and community support system for Africans to improve their social networks, and assimilation is of utmost importance.

## 8.4 Contributions of the study

This study finding has significantly contributed to research, methodology, theory, and practice.

### 8.4.1 Research and Methodological Contribution

- The study makes an essential contribution to the development of a comprehensive and disease-specific instrument that measures all domains of the concept of dementia literacy. The Brief acculturation orientation scale was also adopted from the Demes and Geeraert (2014) study and adapted to fit the cultural background of participants and the study context. Existing measures of dementia literacy only assess a single domain (Knowledge, attitude, risk factors) or a combination of two scales to evaluate dementia literacy (Aihara & Maeda, 2020; Annear et al., 2017; Carr & Furnham, 2021; A. Y. Leung et al., 2018; Leung et al., 2020; Loi & Lautenschlager, 2015; Low & Anstey, 2009). This approach solved one of the researchers' significant challenges with a dementia literacy assessment. The dementia literacy scale is meant to elicit the ability to recognise dementia symptoms, causes and risk factors, knowing how to access dementia information, understanding of professional help available, and attitudes that promote recognition. The DLS showed good internal consistency and, therefore, can be a good tool for assessing the dementia literacy of the general population.
- This study deviates from usual practice, in which dementia literacy is methodologically and conceptually measured by one or two different domains/attributes, such as knowledge, attitude, and knowledge of risk factors (Aihara & Maeda, 2020; Horst et al., 2021; A. Y. Leung et al., 2018; Low & Anstey, 2009). Study findings prove that dementia encompasses not only knowledge, attitude, and risk factors, but also extends to knowledge and skills in accessing dementia information and the expertise of available professional help. Using the DLS provided a comprehensive understanding of the dementia literacy of Africans in Hong Kong.
- Research about Africans and Black people is often carried out within an environment that more often than not makes assumptions about ethnic and racial identities, and often homogenises Black people in data analysis and reports. For example, studies from the U.K and the United States often classify Black people as Africans from various parts of the continent, Caribbeans from other islands, British Africans, and African Americans. Moreover, the context in which

these studies are conducted often makes assumptions about racial identities and categories. However, this study was analysed from an African perspective. The primary data collector assumes an insider and outsider role in each study phase. Adopting the insider role ensured and created an atmosphere allowing participants to freely share their experiences and views without discrimination. The insider role also facilitated communication and understanding of meaning and nuances that may be foreign to an outsider.

#### 8.4.2 Theoretical Contribution

- The findings from this study expand on the scanty empirical literature on issues relating to dementia literacy, acculturation, social networks, and help-seeking behaviour in the study context. Notably, this is the first study within the field of dementia literacy that has attempted to strategically examine dementia literacy as a key determinant of dementia help-seeking behaviour. By examining the association between dementia literacy and help-seeking behaviour, the study extends how various contextual factors, such as acculturation and social networks, might influence dementia literacy and thereby impact the help-seeking behaviour. Qualitatively, the study expands our understanding of how social determinants, such as the availability of dementia services and facilities and societal attitudes towards biomedical care, impact help-seeking behaviour. Furthermore, the findings explain the relationship between social networks, acculturation, dementia literacy, and help-seeking behaviour.
- The study has discovered how assimilation into an Eastern society (Hong Kong) and social networks directly impacts the help-seeking behaviour. It broadens our understanding that promoting dementia literacy alone may not substantially lead to a higher preference to seek help for dementia without addressing issues of acculturation and social isolation.
- Additionally, the study explained the mechanism and pathways through which an assimilation strategy moderates the relationship between dementia literacy (knowledge of causes and risk factors, and of how to access dementia information) and help-seeking behaviour.
- This study makes a significant contribution to the literature by expanding knowledge on acculturation in an Eastern society and its association with help-seeking behaviour.

Acculturation to Western societies and its impact on health outcomes have been documented (Adegboyega et al., 2021; Bilal et al., 2020; Ciampa et al., 2013; Kim & Chen, 2011; Kimbro et al., 2008). The study also provides valuable insights into acculturation and related stressors in Hong Kong.

- Mental health literacy from a reductionist standpoint could be seen as focused on the individual's beliefs and knowledge about specific disorders, which aids in recognition, management, and prevention. But this conceptualisation removes the individual from a broader array of social forces, which influences health outcomes (help-seeking). To address the issue of appropriate help-seeking behaviours, there is a need for future studies to expand the concept of mental health literacy to integrate social factors, such as acculturation, social networks, and social determinants of health.

#### 8.4.3 Contribution to Health policies.

- The increasing number of Africans in Hong Kong calls for a change in health policies and healthcare. The study highlights the need for health policymakers to extend and tailor educational outreach programmes to meet the needs of Africans in the city. There is a need for the Department of Health and Social Welfare to work in unison with African leaders and researchers to develop and implement sustainable interventions that incorporate social elements, such as social networking and cultural assimilation.
- The study also projects how Africans in Hong Kong are disadvantaged in terms of unequal access to health information, social isolation, and poor mental health status. In Hong Kong, interventions, and policies to promote Africans' and other ethnic minorities' access to health information and mental health status are imperative. Promoting intercultural activities in the city is essential to encourage interactions between locals and ethnic minority groups, foster easy integration, and expand social networks.
- Assimilation was identified as the most positive approach to dementia literacy and help-seeking among the four acculturation strategies. The Hong Kong government should implement social policies and schemes to successfully assist Africans in adopting

elements of Hong Kong culture. Issues of racism and discrimination should be addressed by the government and media agencies. Cultural exchange programmes between locals and Africans should also be implemented. Learning about both cultures may reduce stereotypes and promote understanding of cultural norms and taboos, which both cultures may misinterpret as negative attitudes.

### **8.5 Recommendation for Future Research**

This study has examined the association among dementia literacy, acculturation, social network, and help-seeking behaviour. It has also made an innovative contribution by designing a comprehensive single scale for dementia literacy. However, there is a considerable and yet significant contributions that could still be made through further studies.

- Qualitatively, it was identified that Africans do not prefer print materials, therefore there is a need for further studies to explore effective ways to disseminate health information to Africans in Hong Kong. An awareness of this medium may prove effective for interventional studies aimed at improving dementia literacy among this population.
- Findings from the qualitative study highlights various familial and cultural factors associated with help-seeking behaviour among Africans in Hong Kong. There is therefore a need for further studies in examining these interpersonal factors and how they impact help-seeking behaviour.
- Assimilation and social network proved as influential factors in dementia help-seeking. Therefore, future studies should explore how to incorporate these factors in dementia literacy interventions aimed at improving help-seeking efficacy among Africans in the city.
- Further studies are needed to examine ways to motivate Africans in Hong Kong to utilise available dementia care services.
- Findings from the study showed that although majority of participants endorsed the willingness to seek help from health professionals, qualitatively health professionals' attitude was seen as an influential barrier to help-seeking. Future studies should examine actual help-seeking behaviour among participants as intentions may not translate into actual help-seeking.



## CHAPTER 9: CONCLUSION

Most participants were willing to seek help from health professionals if they experienced memory problems. This finding was inconsistent with previous empirical studies that posit that religious leaders and family are often the most highly endorsed source of help-seeking among people of African descent (Berwald et al., 2016; Mukadam et al., 2011; Roche et al., 2018). It is, therefore, essential to increase general awareness and recognition of dementia as a medical condition and to promote access to dementia information. Efforts should be made to address barriers that hinder appropriate help-seeking behaviour of Africans in Hong Kong. An assimilation strategy was identified among the four acculturation strategies as playing a significant role in directly impacting the level of dementia literacy and help-seeking behaviour. However, dementia literacy did not directly influence the help-seeking; adopting an assimilation strategy significantly mediated the relationship between the two concepts. This makes the assimilation strategy a double-edged sword in addressing the issues of dementia literacy and help-seeking behaviour. Moreover, according to the study findings, knowledge of risk factors, and knowledge of how to seek dementia-related information, does not necessarily always need to be high to have a positive effect on help-seeking behaviour. Therefore, the study suggests that adopting an assimilation strategy can interactively or directly impact help-seeking behaviour due to various factors, including the availability of dementia services/facilities, societal perceptions of biomedical care, and the attitude of health professionals towards Africans.

The study also proposes that not every form of social network helps promote the dementia help-seeking. Among Africans in Hong Kong, friends' social networks were more beneficial in promoting help-seeking behaviour than family networks. However, considering its apparent role in promoting the dementia help-seeking behaviour among African migrants, it has proven to be equally as significant as acculturation and social determinants of health. Therefore, a tactical approach, for health professionals and government agencies in charge of promoting a dementia-friendly community and awareness in Hong Kong, to promote social interactions between locals and African migrants in the city, is strongly advocated. Not only do social interactions aid in reducing negative attitudes and discrimination against Africans, but they also promote awareness and knowledge of health-related issues in the city. Nevertheless, this study has ingrained

assimilation and social networks as critical determinants of positive help-seeking behaviours and overall mental health status among African migrants in Hong Kong.

## References

- Ajzen, I. (1991). The theory of planned behavior. *Organizational behavior and human decision processes*, 50(2), 179-211.
- Andersen, R. M. (1995). Revisiting the Behavioral Model and Access to Medical Care: Does it Matter? *Journal of health and social behavior*, 36(1), 1-10. <https://doi.org/10.2307/2137284>
- Au, A., Shardlow, S. M., Teng, Y. U. E., Tsien, T., & Chan, C. (2012). Coping strategies and social support-seeking behaviour among Chinese caring for older people with dementia. *Ageing & Society*, 33(8), 1422-1441. <https://doi.org/10.1017/S0144686X12000724>
- Berwald, S., Roche, M., Adelman, S., Mukadam, N., & Livingston, G. (2016). Black African and Caribbean British communities' perceptions of memory problems: "We don't do dementia". *PLoS One*, 11(4).
- Brooke, J., & Ojo, O. (2020). Contemporary views on dementia as witchcraft in sub-Saharan Africa: A systematic literature review. *Journal of Clinical Nursing*, 29(1-2), 20-30.
- Bryman, A. (2015). *Social research methods* (Fifth ed.). Oxford university press.
- Cahill, S. (2021). Personhood, dementia literacy, and the causes and consequences of Alzheimer's disease fear. *International Psychogeriatrics*, 1-3. <https://doi.org/10.1017/S1041610220003750>
- Cahill, S., Pierce, M., Werner, P., Darley, A., & Bobersky, A. (2015). A systematic review of the public's knowledge and understanding of Alzheimer's disease and dementia. *Alzheimer Disease & Associated Disorders*, 29(3), 255-275.
- Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R., . . . Donovan, J. (2011). Evaluating meta-ethnography: systematic analysis and synthesis of qualitative research. *Health Technol Assess*, 15. <https://doi.org/10.3310/hta15430>
- Chan, L., Lai, C., Werner, P., Segel Karpas, D., & Goldstein, D. (2014). Help-seeking for Dementia: A systematic review of the literature. *Alzheimer disease and associated disorders*, 28(4), 299-310. <https://doi.org/10.1097/WAD.000000000000065>
- Critical Appraisal Skills Programme. (2017). CASP(Qualitative Research) Checklist. . <http://www.casp-uk.net/#!/checklists/cb36>
- Cypress, B. S. (2017). Rigor or reliability and validity in qualitative research: Perspectives, strategies, reconceptualization, and recommendations. *Dimensions of Critical Care Nursing*, 36(4), 253-263.
- Devoy, S., & Simpson, E. E. A. (2017). Help-seeking intentions for early dementia diagnosis in a sample of Irish adults. *Ageing & mental health*, 21(8), 870-878.
- Diamond, A. G., & Woo, B. K. (2014). Duration of residence and dementia literacy among Chinese Americans. *International Journal of Social Psychiatry*, 60(4), 406-409.
- Doherty, K. V., Nguyen, H., Eccleston, C. E., Tierney, L., Mason, R. L., Bindoff, A., . . . McInerney, F. (2020). Measuring consumer access, appraisal and application of services and information for dementia (CAAASI-Dem): a key component of dementia literacy. *BMC geriatrics*, 20(1), 1-10.
- Gorczynski, P., Sims-Schouten, W., Hill, D., & Wilson, J. C. (2017). Examining mental health literacy, help seeking behaviours, and mental health outcomes in UK university students. *The Journal of Mental Health Training, Education and Practice*.
- Gulliver, A., Griffiths, K. M., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review [journal article]. *BMC Psychiatry*, 10(1), 1-9. <https://doi.org/10.1186/1471-244x-10-113>

- Ho, K. H., & Chiang, V. C. (2015). A meta-ethnography of the acculturation and socialization experiences of migrant care workers. *Journal of advanced nursing*, 71(2), 237-254.
- Horst, B. R., Furlano, J. A., Wong, M., Ford, S. D., Han, B. B., & Nagamatsu, L. S. (2021). Identification of Demographic Variables Influencing Dementia Literacy and Risk Perception Through a Global Survey. *Frontiers in Public Health*, 9, 711.
- Husky, M. (2018). Help-Seeking. In R. J. R. Levesque (Ed.), *Encyclopedia of Adolescence* (pp. 1747-1754). Springer International Publishing. [https://doi.org/10.1007/978-3-319-33228-4\\_285](https://doi.org/10.1007/978-3-319-33228-4_285)
- Jorm, A. F. (2012). Mental health literacy: empowering the community to take action for better mental health. *American psychologist*, 67(3), 231.
- Jorm, A. F., Korten, A. E., Jacomb, P. A., Christensen, H., Rodgers, B., & Pollitt, P. (1997). "Mental health literacy": a survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. *Med J Aust*, 166(4), 182-186.
- Kirk Wiese, L., Galvin, J. E., & Williams, C. L. (2019). Rural stakeholder perceptions about cognitive screening. *Aging & mental health*, 23(12), 1616-1628.
- Kutcher, S., Wei, Y., & Coniglio, C. (2016). Mental health literacy: past, present, and future. *The Canadian Journal of Psychiatry*, 61(3), 154-158.
- Lee, E. (2022). Perceptions of caregiving for people living with dementia and help-seeking patterns among prospective Korean caregivers in Canada. *Health & social care in the community*.
- Lee, S. E., Lee, H. Y., & Diwan, S. (2010). What do Korean American immigrants know about Alzheimer's disease (AD)? The impact of acculturation and exposure to the disease on AD knowledge. *International journal of geriatric psychiatry*, 25(1), 66-73.
- Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., . . . Cooper, C. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, 396(10248), 413-446.
- Lo, R. Y. (2020). Uncertainty and health literacy in dementia care. *Tzu-Chi Medical Journal*, 32(1), 14.
- Loi, S. M., & Lautenschlager, N. T. (2015). Dementia literacy in older adults. *Asia-Pacific Psychiatry*, 7(3), 292-297.
- Low, L.-F., & Anstey, K. J. (2009). Dementia literacy: recognition and beliefs on dementia of the Australian public. *Alzheimer's & Dementia*, 5(1), 43-49.
- Low, L.-F., Anstey, K. J., Lackersteen, S. M., Camit, M., Harrison, F., Draper, B., & Brodaty, H. (2010). Recognition, attitudes and causal beliefs regarding dementia in Italian, Greek and Chinese Australians. *Dementia and geriatric cognitive disorders*, 30(6), 499-508.
- Markova, V., Sandal, G. M., & Pallesen, S. (2020). Immigration, acculturation, and preferred help-seeking sources for depression: comparison of five ethnic groups. *BMC Health Services Research*, 20(1), 1-11.
- Mukadam, N., Cooper, C., Basit, B., & Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics*, 23(7), 1070-1077.
- Mukadam, N., Cooper, C., & Livingston, G. (2011). A systematic review of ethnicity and pathways to care in dementia. *International journal of geriatric psychiatry*, 26(1), 12-20.
- Ng, C. K., Leung, D. K., Cai, X., & Wong, G. H. (2021). Perceived help-seeking difficulty, barriers, delay, and burden in carers of people with suspected dementia. *International Journal of Environmental Research and Public Health*, 18(6), 2956.

- Noble, J. M., Hedmann, M. G., & Williams, O. (2015). Improving Dementia Health Literacy Using the FLOW Mnemonic: Pilot Findings From the Old SCHOOL Hip-Hop Program. *Health Education & Behavior, 42*(1), 73-83. <https://doi.org/10.1177/1090198114537063>
- O'Connor, M., & Casey, L. (2015). The Mental Health Literacy Scale (MHLS): A new scale-based measure of mental health literacy. *Psychiatry Res, 229*(1-2), 511-516. <https://doi.org/10.1016/j.psychres.2015.05.064>
- Parker, M., Barlow, S., Hoe, J., & Aitken, L. (2020). Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia. *International Psychogeriatrics, 32*(5), 611-634.
- Rickwood, D., & Thomas, K. (2012). Conceptual measurement framework for help-seeking for mental health problems. *Psychology research and behavior management, 173-183*.
- Roche, M., Mukadam, N., Adelman, S., & Livingston, G. (2018). The IDEMcare Study—Improving Dementia Care in Black African and Caribbean Groups: A feasibility cluster randomised controlled trial. *International journal of geriatric psychiatry, 33*(8), 1048-1056.
- Rosenstock, I. M. (2000). Health Belief Model.
- Sawyer, J. M., Sallnow, L., Kupeli, N., Stone, P., & Sampson, E. L. (2019). Social networks, social capital and end-of-life care for people with dementia: a realist review. *BMJ open, 9*(12), e030703.
- Sayegh, P., & Knight, B. G. (2013). Cross-cultural differences in dementia: the Sociocultural Health Belief Model. *International Psychogeriatrics, 25*(4), 517-530.
- Schmied, V., Olley, H., Burns, E., Duff, M., Dennis, C.-L., & Dahlen, H. G. (2012). Contradictions and conflict: A meta-ethnographic study of migrant women's experiences of breastfeeding in a new country [journal article]. *BMC Pregnancy and Childbirth, 12*(1), 163. <https://doi.org/10.1186/1471-2393-12-163>
- Smith, C. L., & Shochet, I. M. (2011). The impact of mental health literacy on help-seeking intentions: Results of a pilot study with first year psychology students. *International Journal of Mental Health Promotion, 13*(2), 14-20.
- Sun, F., Gao, X., & Coon, D. W. (2013). Perceived threat of Alzheimer's disease among Chinese American older adults: the role of Alzheimer's disease literacy. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, gbt095*.
- Tomczyk, S., Schomerus, G., Stolzenburg, S., Muehlan, H., & Schmidt, S. (2020). Ready, willing and able? An investigation of the theory of planned behaviour in help-seeking for a community sample with current untreated depressive symptoms. *Prevention Science, 21*(6), 749-760.
- Werner, P., Goldstein, D., Karpas, D. S., Chan, L., & Lai, C. (2014). Help-Seeking for Dementia: A Systematic Review of the Literature. *Alzheimer Disease & Associated Disorders, 28*(4), 299-310. <https://doi.org/10.1097/wad.0000000000000065>
- White, M., & Casey, L. (2016). Helping older adults to help themselves: the role of mental health literacy in family members. *Aging Ment Health, 1-9*. <https://doi.org/10.1080/13607863.2016.1206513>
- World Health Organization. (2012). *Dementia: a public health priority*. World Health Organization.
- World Health Organization. (2017). *Global action plan on the public health response to dementia 2017–2025*.

- World Health Organization. (2019). Risk reduction of cognitive decline and dementia: WHO guidelines.
- World Health Organization. (2021a). Global status report on the public health response to dementia.
- World Health Organization. (2021b). Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives (DFIs).
- Yiu, H. C., Zang, Y., & Chau, J. P. C. (2020). Barriers and facilitators in the use of formal dementia care for dementia sufferers: A qualitative study with Chinese family caregivers in Hong Kong. *Geriatric Nursing*, *41*(6), 885-890. <https://doi.org/https://doi.org/10.1016/j.gerinurse.2020.06.018>
- Zhang, H., Loi, S. M., Zhou, S. a., Zhao, M., Lv, X., Wang, J., . . . Wang, H. (2017). Dementia literacy among community-dwelling older adults in urban China: A cross-sectional study. *Frontiers in Public Health*, *5*, 124.

## APPENDICES

Appendix 1: Methodological Appraisal of included studies using JBI Critical Appraisal Checklist

Questions	Aihara and Maeda [23]	Barak, Rapsey [24]	Carr and Furnham [25]	Diamond and Woo [26]	Heger, Deckers [27]	Horst, Furlano [28]	Leung, Molassiotis [37]	Loi and Lautenschlager [31]	Low and Anstey [12]	Low, Anstey [32]	Park and Shin [33]	Sun, Gao [35]	Sun, Wang [36]	Zhang, Loi [6]
Were the criteria for inclusion in the sample clearly defined?	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Were the study subjects and settings described in detail?	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Was the exposure measured in a valid and reliable way?	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes
Were objective, standard criteria used for measurement of the condition?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Were confounding factors identified?	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
Were strategies to deal with confounding factors stated?	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
Were the outcomes measured in a valid and reliable way?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was an appropriate statistical analysis used?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Total score	8	7	6	5	7	8	8	6	6	8	7	8	7	8

Appendix 2: Quality Appraisal using MMAT Tool and Critical Appraisal Skills Programme Qualitative

Study design	Methodological quality criteria	Responses
Mixed Methods Leung, Leung [20]	Is there an adequate rationale for using a mixed methods design to address the research question?	Yes
	Are the different components of the study effectively integrated to answer the research question?	Yes
	Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Yes
	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Yes
	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	Yes
TOTAL SCORE		5/5
Stansbury, Harley [34]	Was there a clear statement of the aims of the research	Yes
	Is a qualitative methodology appropriate	Yes
	Was the research design appropriate to address the aims of the research?	Yes
	Was the recruitment strategy appropriate to the aims of the research?	Yes
	Was the data collected in a way that addressed the research issue?	Yes
	Has the relationship between researcher and participants been adequately considered?	No
	Have ethical issues been taken into consideration?	No
	Was the data analysis sufficiently rigorous?	No
	Is there a clear statement of findings?	Yes
How valuable is the research?	Yes	
TOTAL SCORE		7/10



## Appendix 3: Ethical Approval for the Study

---



To Leung Yee Man Angela (School of Nursing)  
From Choi Kup Sze, Chair, Departmental Research Committee  
Email thomasks.choi@ Date 16-Sep-2020

### **Application for Ethical Review for Teaching/Research Involving Human Subjects**

I write to inform you that approval has been given to your application for human subjects ethics review of the following project for a period from 02-Nov-2020 to 02-Aug-2021:

**Project Title:** Examining the role of acculturation in dementia literacy of Africans in a Chinese Society: A Mixed Method Study  
**Department:** School of Nursing  
**Principal Investigator:** Leung Yee Man Angela  
**Project Start Date:** 02-Nov-2020  
**Reference Number:** HSEARS20200907003

You will be held responsible for the ethical approval granted for the project and the ethical conduct of the personnel involved in the project. In case the Co-PI, if any, has also obtained ethical approval for the project, the Co-PI will also assume the responsibility in respect of the ethical approval (in relation to the areas of expertise of respective Co-PI in accordance with the stipulations given by the approving authority).

You are responsible for informing the Human Subjects Ethics Sub-committee in advance of any changes in the proposal or procedures which may affect the validity of this ethical approval.

Choi Kup Sze

Chair

Departmental Research Committee (on behalf of Human Subjects Ethics Sub-Committee)

#### Appendix 4: Information Sheet

##### Relationship Among Intention-To-Seek-Help in dementia, Dementia Literacy, Acculturation, and Social Network: A Mixed-Method Study

You are cordially invited to participate in the above project conducted by Adwoa Owusuaa Koduah, a post-graduate student at the School of Nursing in The Hong Kong Polytechnic University. She is currently under the supervision of Dr Angela Y.M Leung and Dr Teris Cheung. The project has been approved by the Human Subjects Ethics Sub-committee (HSESC) of The Hong Kong Polytechnic University (HSESC Reference Number: HSEARS20200907003)

This study examines how the nature and processes of acculturation affect their dementia literacy among Africans living in Hong Kong.

You are invited to take part in an in-depth individual interview. The individual interview will last approximately 45 minutes to an hour. You will then be asked to participate in a survey after the interview. However, you can refuse participation. The surveys will not be administered on the same day as the interviews. You will be contacted a month later through a phone call. You will be asked to complete four questionnaires, which will take you approximately 45 minutes to an hour.

There is no risk in participating in the study. However, you have every right to withdraw from the study without penalty of any kind. Interviews will be audio-recorded, and you will be asked a series of questions and follow-up questions to share your experiences and knowledge on the topic. Efforts will ensure that no personal identifiers are obtained, and information will remain confidential and kept in a locker at the primary researcher's office and destroyed after the research is completed. You will also be assigned a fictitious name to hide your identity. All information received will be used for academic purposes only and destroyed after the study is complete. Responsible members of The Hong Kong Polytechnic University may be given access to monitor and audit the research. The Hong Kong Polytechnic University takes reasonable precautions to prevent the loss, misappropriation, unauthorized access or destruction of the information you provide.

If you have any complaints about the conduct of this study, please do not hesitate to contact Miss Cherrie Mok, Secretary of the Human Subjects Ethics Sub-Committee of The Hong Kong

Polytechnic University in person or writing (c/o Research Office of the University or email: [cherrie.mok@](mailto:cherrie.mok@) ), stating clearly the person and department responsible for this study.

If you would like more information about this study, please contact Adwoa Owusuaa Koduah telephone number: +8529711 or via email: [owusuaa.koduah@](mailto:owusuaa.koduah@) .

Thank you for your interest in participating in this study.

Dr Angela Y.M Leung, PhD

(Principal Investigator)

Associate Professor

School of Nursing

The Hong Kong Polytechnic University.

## Appendix 5: Informed Consent

### Relationship among Intention-To-Seek-Help in Dementia, Dementia Literacy, Acculturation, and Social Network: A Mixed Method Study

I \_\_\_\_\_ consent to participate in the above research conducted by Adwoa Owusuaa Koduah under the supervision of Prof Angela Y.M Leung and Dr Teris Cheung. This study examines the extent to which your acculturation and social relationships in Hong Kong influences your knowledge of dementia. The study targets Africans 18 years and above and who have lived in Hong Kong for at least one year.

I understand that information obtained from this study may be used in future research and published. However, my right to privacy will be retained by the researchers, i.e., my identity will not be revealed by the researchers.

I understand that participating in this study will not involve any risks. My participation in the project is voluntary. I acknowledge that I have the right to question any part of the study and can withdraw without penalty of any kind.

Yes, I consent.

No, I don't consent.

## Appendix 6: Survey Questionnaire

Relationship among Intention-to-Seek-Help in Dementia, Dementia Literacy, Acculturation, and Social Network: A Mixed Method Study

### A. Demographic

1. What is your sex?
  - a. Male
  - b. Female
2. What is your age? (Indicate in years, for example, 18, 38, 58) \_\_\_\_\_
3. What is your marital status?
  - a. Single
  - b. Married
  - c. Separated
  - d. Divorced
  - e. Widowed
  - f. Cohabiting
4. What is the highest educational level you have attained?
  - a. Never been to school.
  - b. Primary school
  - c. JHS/JSS/Middle school
  - d. SSS/SHS/Vocational/Technical
  - e. A' level/Polytechnic/Diploma
  - f. Tertiary (bachelor's & Masters)
  - g. Doctorate
5. Employment status
  - a. Full-time Employee
  - b. Part-time employee
  - c. Unemployed looking for work.
  - d. Unemployed not looking for work
  - e. Retired/Pension
  - f. Student /Apprentice
  - g. Housewife
6. What is your estimated monthly income/profit? (If employed) \_\_\_\_\_
  - a. Less than HKD4000
  - b. 4,000 – 5,999 HK\$
  - c. 6,000 – 7,999 HK\$
  - d. 8,000 – 9,999 HK\$
  - e. 10,000 – 14,999 HK\$

- f. 15,000 – 19,999 HK\$
- g. 20,000 – 24,999 HK\$
- h. 25,000 – 29,999 HK\$
- i. 30,000 – 34,999 HK\$
- j. 35,000 – 39,999 HK\$
- k. 40,000 – 49,999 HK\$
- l. 50,000 – 59,999 HK\$
- m. 60, 000 – 69,999 HK\$
- n. 70,000 – 79,999 HK\$
- o.  $\geq 80,000$  HK\$
- p. Not applicable

7. What is your country of origin? \_\_\_\_\_

8. Country of birth? \_\_\_\_\_

9. How long have you lived in Hong Kong? specify in years or months.

\_\_\_\_\_

10. Which district in Hong Kong do you live in (select from the list below)?

- a. Central and Western district
- b. Wan Chai
- c. Eastern
- d. Southern
- e. Yau Tsim Mong
- f. Sham Shui Po
- g. Kowloon City
- h. Wong Tai Sin
- i. Kwun Tong
- j. Kwai Tsing
- k. Tsuen Wan
- l. Tuen Mun
- m. Yuen Long North
- n. Tai Po
- o. Sha Tin
- p. Sai Kung
- q. Islands

11. Immigration status

- a. Permanent resident
- b. Hong Kong resident (working and student visa)
- c. Asylum seeker
- d. Refugees
- e. Diplomatic Visa
- f. Dependent Visa

12. What is your religion?

- a. Christian
- b. Muslim/Islam
- c. Traditionalist
- d. Buddhism
- e. No-religion.
- f. Others (specify) \_\_\_\_\_

13. Current Health status

	Excellent	Good	Fair	Poor	Very poor
In the past three months, how will you rate your physical health?					
In the past three months, how will you rate your mental health?					

14. On a scale of 1=very low and 10=very high, how would you rate your economic and social status in Hong Kong?

How would you rate your household's economic status compared to other households in your community in Hong Kong?	1	2	3	4	5	6	7	8	9	10
How would you rate your household's social status (in terms of respect, prestige, or honour) with other households in your community in Hong Kong?	1	2	3	4	5	6	7	8	9	10

**B. Acculturation:** Questions 15 to 20 are to collect information about your life and cultural identity in Hong Kong.

15. How well do you speak Cantonese?

- a. Extremely well
- b. Very well
- c. Moderately well
- d. Slightly well
- e. Not well at all

16. How often do you speak the following language at home?

	Always	Often	Sometimes	Rarely	Never
Native language					
Cantonese					
English					

17. How often do you speak the following languages outside your home?

	Always	Often	Sometimes	Rarely	Never
Native language					
Cantonese					
English					

18. The following questions are about your sense of belonging.

	Very strong	Strong	Weak	Very weak	No opinion
How would you describe your sense of belonging to people with the same ethnic or cultural background as you?					
How would you describe your sense of belonging to Hong Kong society					



**Acculturation orientation**

19. While living in Hong Kong, to what extent are these statements important to you?

	Extremely important	Very important	Moderately important	Slightly important	Not at all important
Have African friends					
Take part in African traditions/ceremonies					
Hold on to African beliefs and norms					
Do things the African way.					
Have Hong Kong friends					
Take part in Hong Kong festivals/traditions.					
Develop Hong Kong characteristics					
Do things the way local Hong Kongers do.					

20. Think about living in Hong Kong; how often have you felt...

Questions	Always	Often	Sometimes	Rarely	Never
Excited about being in Hong Kong.					
Out of place, like you do not fit into the Hong Kong culture					
Lonely without your African family and friends around you.					
Sad to be away from your country in Africa.					
Nervous about how to behave in certain situations					
Homesick when you think of your country in Africa.					

Frustrated by difficulties adapting to Hong Kong society.					
Happy with your day-to-day life in Hong Kong.					

**Social Network:** The following questions (21& 22) will ask about your relationship with family and friends in Hong Kong.

21. Please indicate how often you talk to or see your relatives.

- a. How many relatives in Africa do you hear from at least once a month?
- b. How many relatives in Africa do you feel at ease with that you can talk about private matters?
- c. How many relatives in Africa do you feel close to such that you can call on them for help?

22. Consider all your friends (Africans and local Hong Kongers) in Hong Kong.

- a. How many of your friends do you see, visit or hear from at least once a month
- b. How many of your friends do you feel at ease with that you can talk about private matters?
- c. How many of your friends do you feel close to such that you can call on them for help?

**D. Questions related to Dementia Literacy**

Questions 23 to 31 are about your knowledge and understanding of a condition called dementia.

23. Have you heard about dementia?

- a. Yes
- b. No
- c.

24. If yes, where did you first hear about dementia? Select as many as applicable to you.

- a. Friend
- b. Relative
- c. Internet search
- d. Health professionals
- e. Newspaper/magazine article
- f. At a conference/Workshop/Training program
- g. Taught in school.
- h. Social media platforms (Facebook, YouTube, Twitter, IG, WeChat, TikTok)
- i. Television/Radio

25. Would you mind indicating to what extent you agree with the following statement about dementia?

Statement	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly disagree
a. Dementia is a normal part of ageing					
b. Dementia is a disease of the brain					
c. Dementia affects a person’s memory, thinking, emotion and behaviour.					
d. People with dementia generally have problems in decision making.					
e. People with dementia find it difficult to learn new skills					
f. Misplacing personal belongings and believing other people are stealing them is one of the symptoms that persons with dementia have.					
g. Dementia may shorten the lifespan of people suffering from the condition					

26. Would you please indicate to what extent you agree with the following statements?

Statement	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly disagree
Having high blood pressure increases the risk of developing dementia.					
Having high fat (cholesterol) levels increase the risk of developing dementia.					
Women are more likely to suffer from dementia of any kind compared to men.					
Heredity/family history could contribute to one's risk of developing dementia.					
Alcohol abuse increases one's risk of developing dementia					
Smoking increases one's risk of developing dementia					
Lack of exercise can increase one's risk of developing dementia					
Dementia can affect both young and older adults.					

27. The following sentences focus on your knowledge of caring for or managing persons with dementia. Would you please indicate to what extent you agree with the following statements?

Statement	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly disagree
When someone has dementia, using reminders (notes) can worsen the condition.					

When a dementia patient repeats the same story several times, it is helpful to remind them that they are repeating themselves.					
Eventually, a person with a worse case of dementia may need 24-hour care and monitoring.					
When a person with dementia is distressed, it may be helpful to talk to them about their feelings.					
Difficulty drinking and eating generally occur when dementia condition gets worse.					

28. To what extent are you aware of the following services available for dementia patients in Hong Kong.

Statement	Fully aware	Aware	Neutral	Not aware	Fully not aware
Hospitals for people with dementia in Hong Kong.					
Day rehabilitation training programs for people with dementia in Hong Kong.					
Government-subsidised residential care homes and day-care centres for people with dementia in Hong Kong.					
An online self-assessment for dementia.					
Drugs that are effective for improving cognitive function in people with dementia in Hong Kong.					

29. The following statements will assess your confidence in searching for information about dementia. Please indicate to what extent you agree with the following statements:

Statement	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly disagree
I am confident that I know where to seek dementia information					
I am confident in using online tools (google, social media platforms, health databases) to seek factual information about dementia					
I am confident attending face to face appointments to seek information about dementia from health professionals.					
I am confident I can locate health facilities for persons with dementia in Hong Kong.					

30. The following statements will assess your perception or beliefs about persons with dementia:

STATEMENT	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
PEOPLE WITH DEMENTIA COULD RETURN TO THEIR OLD SELVES IF THEY WANT.					

DEMENTIA IS A SIGN OF PERSONAL WEAKNESS.					
PEOPLE WITH DEMENTIA ARE DANGEROUS					
IT IS BEST TO AVOID PEOPLE WITH DEMENTIA, SO YOU DO NOT DEVELOP THIS CONDITION.					
I WOULD BE WILLING TO SOCIALISE WITH SOMEONE WITH DEMENTIA.					
WOULD BE WILLING TO MOVE NEXT DOOR TO SOMEONE WITH DEMENTIA					
I WOULD BE WILLING TO MARRY INTO A FAMILY WITH A HISTORY OR SOMEONE WITH DEMENTIA					

PEOPLE WITH DEMENTIA ARE OFTEN WITCHES OR PEOPLE WHO HAVE BEEN CURSED DUE TO THEIR PAST EVIL LIFESTYLES.					
---	--	--	--	--	--

31. Below is a list of people you might seek advice or help from if you are experiencing memory problems or forgetfulness. Please indicate to what extent you agree with the following statements.

Statement	Extremely Likely	Likely	Neutral	Unlikely	Extremely unlikely
Partner (e.g., spouse, boyfriend, or girlfriend)					
Friend (someone not related to you)					
Parents					
Other family members					
Health professionals (e.g., psychiatrist, general practitioner, nurse, social worker, psychologist)					
Minister or Religious leader (e.g., Pastor, Imam, Rabbi, Chaplain, traditional healer, herbalist).					
Delay seeking help for as long as possible.					
I would not seek help from anyone					



There is a gift coupon for all participants who completed this survey. Please leave your address and contact below. Thank you.

---

---