

**The experiences and perceptions of illness, care and
the use of traditional, complementary and
integrative medicine for dementia and other chronic
illnesses in older adults: A qualitative study of carers
and ethnic health workers in Korean and Chinese
communities in Sydney**

By Josephine Chidinma Agu

BSc, PGDip, MPH

Thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy, Public Health

Under the supervision of Distinguished Professor Jon Adams, Professor Yun-Hee Jeon and
Yvonne Santalucia

University of Technology Sydney, Faculty of Health

September, 2020

CERTIFICATE OF ORIGINAL AUTHORSHIP

I, Josephine Chidinma Agu declare that this thesis is submitted in fulfilment of the requirements for the award of Doctor of Philosophy in the School of Public Health, Faculty of Health at the University of Technology Sydney. This thesis is wholly my own work unless otherwise reference or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis. This document has not been submitted for qualifications at any other academic institution. This research is supported by the Australian Government Research Training Program.

Signature:

Production Note:
Signature removed
prior to publication.

Date: January 6th, 2020

ACKNOWLEDGEMENTS

I want to thank and acknowledge everyone who assisted, supported and encouraged me during the process of completing this thesis. Firstly, I would like to thank the Australian Research Centre in Complementary and Integrative Medicine (ARCCIM) for awarding me with a PhD scholarship as part of the ARC Future Fellowship Project under Distinguished Professor Jon Adams. Secondly, thank you to the University of Technology Sydney who also awarded me with an International Research Scholarship (IRS) for the duration of my candidature. Both scholarship awards made it financially possible to commence and complete this doctoral research.

I would like to express my most profound appreciation to the supervisory team including; My primary supervisor, Distinguished Professor Jon Adams whose invaluable and expert guidance, consistent support and constant encouragement not only empowered me and facilitated the completion of this thesis but also helped shape and improve my skills as an academic and a researcher; My auxiliary supervisor, Professor Yun-Hee Jeon thank you for the generous contribution of your time, qualitative insights, methodological prowess and constructive comments and suggestions throughout; Yvonne Santalucia whose field expertise and well-respected connectedness within the study's target communities allowed for seamless access to all the necessary organisations; and a special thank you to Desiree Leone, whose mentoring and expert counsel provided early and ongoing insights that helped launch and guide accessing and engaging with the multicultural community targeted in this thesis study. The supervisory panel has, in more than one respect, enabled me to cross the finish line, and I am beyond grateful.

Thank you to my friends, partner and fellow PhD colleagues for providing me with ongoing social, personal and intellectual support. I would particularly like to thank my loving parents and siblings who have patiently supported and prayed with me throughout this process, encouraging me to persevere even in seasons of doubt. Above all, thank God, for counting me worthy of such a unique opportunity in life to attain this educational level and meet great people along the way that have made a life away from my country of origin enjoyable and played a significant role in making Australia feel like home.

THESIS PUBLICATION AND PRESENTATIONS

1. Agu, J (2019). Use of Traditional, Complementary and Alternative Medicine (TCAM) amongst CALD communities for dementia and self-care: some insights from a qualitative study. 14th International Congress on Complementary Medicine Research, Brisbane, Queensland. **Oral Presentation**
2. Agu, J (2019). Traditional medicines must be integrated into health care for culturally diverse groups. **The Conversation** (Academic and research website).
<https://theconversation.com/traditional-medicines-must-be-integrated-into-health-care-for-culturally-diverse-groups-114980>
3. Agu, J (2019). Traditional, Complementary and Alternative Medicine use amongst Ethnic Minority Populations: A systematic review and some thoughts on a future agenda. 14th International Congress on Complementary Medicine Research, Brisbane, Queensland. **Poster Presentation**
4. Agu, J. C., Hee-Jeon, Y., Steel, A., & Adams, J. (2018). A systematic review of traditional, complementary and alternative medicine use amongst ethnic minority populations: a focus upon prevalence, drivers, integrative use, health outcomes, referrals and use of information sources. *Journal of immigrant and minority health*, 1-20.
5. Agu, J (2018). Traditional, Complementary and Alternative Medicine use amongst Ethnic Minority Populations: A systematic review and some thoughts on a future agenda. UTS Faculty of Health Research Students Conference, Ultimo, Sydney. **Oral Presentation**
6. Agu, J (2017). Complementary and Alternative Medication in People Living with Dementia from Culturally and Linguistically Diverse Communities. 15th World Congress on Public Health 2017, Melbourne, Victoria. **Digital Poster Presentation**

TABLE OF CONTENTS

Chapter 1- Introduction to TCIM, CALD Communities and Dementia	1
1.1 Definitions of TCIM.....	1
1.1.1 Traditional Medicine	2
1.1.2 Complementary Medicine	3
1.1.3 Integrative medicine and Integrative healthcare	5
1.1.4 Research working definition of TCIM	6
1.2 TCIM Consumption and Practice	7
1.2.1 Prevalence of Traditional Medicine and Complementary Medicine.....	10
1.2.2 Prevalence of Integrative Medicine	14
1.2.3 Prevalence of Integrative Health Care	15
1.3 The mainstreaming of TCIM- a global review	16
1.3.1 Case Study- The mainstreaming trajectory of TCIM in the United States.....	16
1.3.2 Integrative Strategies in other countries	18
1.3.3 TCIM in the Australian health care setting.....	20
1.4 CALD Communities	26
1.4.1 Definition of the term CALD	26
1.4.2 CALD communities in Australia	27
1.4.3 Health of CALD populations	31
1.4.4 CALD communities' access to Mainstream Healthcare services in Australia.....	33
1.5 The use of TCAM in CALD communities- Literature review	37
1.5.1 Review Abstract.....	38
1.5.2 Review Introduction	39
1.5.3 Review Methods.....	40
1.5.4 Review Results.....	43
1.5.5 Review Discussion	66
1.5.6 Key findings and contribution of the review to the wider-thesis.....	68
1.6 The Ageing population and Dementia.....	68
1.6.1 Dementia Synopsis	69
1.6.2 Dementia in Australia	72
1.6.3 Dementia in Australian CALD communities	79
1.6.4 TCIM approaches to Dementia Management in Australian CALD groups	82
1.7 Health Services Research Agenda	83
1.7.1 Interdisciplinary efforts of HSR.....	83

1.7.2 Contributions of HSR to policymaking.....	83
1.7.3 HSR for the current research.....	84
1.7.4 Research problem statement/Research question	84
1.7.5 Significance and niche of the study.....	86
1.7.6 Aim and Objectives.....	87
1.8 Summary of Chapter 1.....	88
Chapter 2 Methodology.....	89
2.1 Research paradigm – Qualitative research	89
2.1.1 Qualitative Research Strategy in Health Services Research.....	89
2.1.2 Pragmatic approach for Descriptive Qualitative Research	90
2.1.3 Rationale for Methodology	92
2.2 Setting and Sample recruitment	95
2.2.1 Research setting	95
2.2.2 Sample rationale.....	96
2.2.3 Sampling technique	97
2.2.4 Sample size and inclusion criteria	98
2.2.5 Recruitment procedure and summary.....	99
2.3 Data Collection	101
2.3.1 Focus group discussions for carers and ethnic health workers.....	101
2.3.2 One-on-one In-depth interviews for carers and ethnic health workers	104
2.3.3 Data Collection summary	105
2.3.4 Data collection guide.....	106
2.3.5 Field Notes.....	107
2.3.6 Pilot testing.....	107
2.3.7 Translators and Interpreters	108
2.3.8 Data Analysis – Framework approach.....	113
2.4 Limitations of the study methodology	121
2.5 Ethical Considerations	122
2.6 Summary of Chapter 2.....	123
Chapter 3- Results	124
3.1 Looking at dementia through a cultural lens	124
3.1.1 A normal part of Ageing	125
3.1.2 Cultural stigma hindering discussion.....	127
3.1.3 “Everyone is affected”: The circle of people impacted by dementia.....	131
3.1.4 Cultural Obligation to care	146
3.2 Experiences of TCIM and alternative approaches for health and wellbeing	149

3.2.1 Alternative Management of Dementia	150
3.2.2 Multiple health issues benefitting from TCIM-use.....	167
3.2.3 Preventive and curative uses of TCIM.....	170
3.2.4 Understanding of TCIMs - what they contain and how they work	172
3.2.5 The power of ‘word of mouth’ TCIM information dissemination	173
3.2.6 Communication about TCIM use.....	175
3.2.7 Qualification as a Consideration When Choosing TCIM Practitioners	180
3.3 Factors influencing decisions towards TCIM and/or conventional medicine for overall health ...	181
3.3.1 Severity and nature of the illness.....	181
3.3.2 TCIM as a culturally familiar choice.....	184
3.3.3 TCIM use determined by past experiences	188
3.3.4 Preference for integration.....	195
3.3.5 Financial considerations	197
3.3.6 The safety Factor	198
3.3.7 Recommendations for evidence-based TCIM research and information	204
3.4 Summary of Chapter 3.....	206
Chapter 4- Discussion	207
4.1 Cultural connotations as barriers to dementia diagnosis and help-seeking - understanding Korean and Chinese participants’ perspectives of dementia and its effect on health help-seeking (Objective 1).	208
4.1.1 Reasons for denial in dementia.....	208
4.1.2 Cultural obligations to care hindering help-seeking	210
4.2 Unfamiliarity of TCIM-use for dementia- To gain insight into the perceived effectiveness and benefits of using TCIM in managing dementia and other age-related health conditions from the perspectives of carers and workers (Objective 4).....	213
4.3 TCIM preferred for acute conditions by CALD groups -To gain insight into what health issues are commonly managed with TCIM and the motivations for use/non-use of TCIM for dementia and other illnesses (Objective 2).....	215
4.4 Reasons why TCIM was considered more beneficial and safer than conventional medicine - To understand how TCIM use may influence CALD help-seeking by exploring the factors considered when deciding whether to use conventional medicine (Objective 3)	218
4.4.1 Adverse drug-drug interactions as a consequence of TCIM safety notion	219
4.4.2 Perceived toxicity of conventional medicine	220
4.4.3 The natural, non-invasive and extended duration of the TCIM consultation process.....	221
4.5 Divergent views regarding TCIM-use for overall health between workers and carers- Examining the different perceptions of conventional health service delivery to understand how TCIM use may influence conventional health help-seeking (Objective 3).....	223
4.5.1 Perceptions on the extent of conventional medicine use for illnesses.....	224
4.5.2 The impact of cultural attachments and acculturation on TCIM-use	226

4.5.3 (Non)Disclosure of TCIM use to conventional medicine providers and workers.....	227
Chapter 5- Conclusion, implications from research and future directions.....	232
5.1 Significance of the research findings.....	233
5.2 Implications of the research and future research directions.....	236
5.2.1 Implications for PWD and their carers from CALD groups.....	237
5.2.2 Implications for service providers and workers.	237
5.2.3 Implications for policymakers.....	239
5.3 Limitations of the research.....	240
5.4 Contributions and strengths of the research.....	241
5.5 Conclusion.....	242
References.....	245
Appendices.....	271

LIST OF TABLES

Table 1: Inclusion and exclusion criteria for articles in the review.....	41
Table 2: Guidelines for quality appraisal.....	42
Table 3: Quality appraisal of qualitative research Higginbotham, Albrecht [238].....	46
Table 4: Quality appraisal of quantitative research: McMasters critical appraisal tool Law, Steinwender [239].....	46
Table 5: Description of included studies on TCAM use amongst ethnic minorities.....	52
Table 6: Description of Key themes from studies on TCAM use amongst ethnic minorities.....	59
Table 7: Research methodology summary.....	92
Table 8: Inclusion criteria for family carers and ethnic health workers.....	99
Table 9: Recruitment sites and organisations.....	100
Table 10: Data Collection Summary.....	105
Table 11: Checklist for methodological recommendations for cross-language qualitative research.....	111
Table 12: Excerpt of preliminary codes from the familiarisation stage.....	116
Table 13: Categories that formed the thematic framework.....	119
Table 14: Study objectives and representative themes.....	119
Table 15: Common words used to describe emotions experienced when caring for or providing services to people with dementia from both CALD groups.....	131
Table 16: Conditions managed with different TCIM modalities according to Korean and Chinese carers and workers.....	167
Table 17: Linking study objectives to themes and research implications.....	236

LIST OF FIGURES

Figure 1: CAM Out-of-Pocket Spending: Self-Care* vs. Practitioner Costs.....	9
Figure 2: Registration percentage by principal place of practice [147].....	22
Figure 3: Total Industry sales of TCIM from 2003 to 2017.....	26
Figure 4: Proportion of Non-English Speaking Background (NESB) population in each state [176].....	29

Figure 5: Bi-dimensional Model of Acculturation	33
Figure 6: Flowchart of study review and selection process	45
Figure 7: Estimated number of Australians with dementia, by age group, 2010 to 2030 [171]	72
Figure 8: NAATI interpreter knowledge, skills and attributes (KSA)	110
Figure 9: Flow Chart for theme 1- Looking at Dementia through a cultural lens.	125
Figure 10: Participants' explanation of reasons for using or not using TCIM for dementia care.	157

Abbreviations

AIHW	Australian Institute of Health and Welfare
BPSD	Behavioural and Psychological Symptoms of Dementia
CAM	Complementary and Alternative Medicine
CALD	Culturally and Linguistically Diverse
CM	Complementary Medicine
GP	General Practitioner
HSR	Health Services Research
IM	Integrative Medicine
IHC	Integrative Health Care
NCCAM	National Centre for Complementary and Alternative Medicine
NESB	Non-English Speaking Background
PWD	People/Person with Dementia
TCAM	Traditional, Complementary and Alternative Medicine
TCIM	Traditional, Complementary and Integrative Medicine
TCM	Traditional Chinese Medicine
TGA	Therapeutic Goods Administration
TM	Traditional Medicine
US	United States

ABSTRACT

Background

Culturally and linguistically diverse (CALD) populations have been identified as high users of traditional, complementary and integrative medicine (TCIM). Koreans and Chinese make up a well-established and relatively large proportion of the CALD communities in Sydney. As a significant health care resource amongst these aforementioned populations, there is an increased likelihood of employing TCIM approaches before or alongside their use of conventional medicine. Dementia, an illness highly stigmatised due to negative cultural connotations, is projected to have a three-fold increase amongst CALD groups in the next decade and the perceptions of dementia amongst the CALD community is under researched and poorly understood. To date, no research has provided an examination of any non-conventional approach used for dementia and other illnesses amongst older adults or the wider cultural understandings of illness, caring and treatment approaches for the elderly amongst the Korean and Chinese CALD communities in Australia. Given the increasing acceptance and popularity of TCIM and non-pharmaceutical options in managing several chronic diseases, this thesis aims to provide empirical data, using a pragmatic health services research approach, on cultural understandings of dementia, aspects of caring, treatment and perceived benefits from the use of TCIM amongst Korean and Chinese CALD populations from the perspectives of their family carers and ethnic health workers for dementia and other chronic and acute conditions.

Methods

A qualitative research design employing one-on-one in-depth interviews and focus group discussion sessions were undertaken with individuals from two CALD (Korean and Chinese) groups. Participants targeted for this inquiry were ethnic health workers providing services to people with dementia (PWD) and their loved ones, and family carers of PWD. Both target groups (workers and carers) were interviewed from each of the CALD communities to explore different perspectives of lived experiences between CALD groups (Korean and Chinese) and within each CALD group.

Results

A considerable level of TCIM use was observed amongst both CALD groups usually attributed to its perceived safe and natural properties. CALD groups predominantly used and preferred TCIM concurrently with conventional medicine and mainly utilised it for illnesses considered to have historical and cultural significance with remedies that have been passed down through generations. However, the cultural stigmatisation of dementia hinders open discussion and hence the absence of any known and accepted

TCIM for the explicit management of dementia. Although TCIM was highly prevalent amongst CALD groups, workers' and carers' perspectives of usage and disclosure differed. Disclosure to conventional medicine providers was minimal and analysis suggests that overall people from CALD groups have a preference to disclose TCIM usage to conventional providers of the same ethnicity.

Conclusion

A substantial level of TCIM integration with conventional medicine is common practice amongst these CALD groups, and the lack of disclosure about TCIM use raises an essential area for further research inquiry. Research into TCIM and distinct CALD groups helps practitioners, researchers and policymakers to contribute to providing safe, effective and patient-centred care to these diverse populations on a more ethnicity focused and tailored level.