

Individualised Music Intervention for People with Dementia: A Mixed Methods Implementation Study

Minah Amor Gaviola Bachelor of Nursing; MN (Advanced Practice)

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

October 10, 2019

This research was supported by an Australian Government Research Training
Program (RTP) Scholarship

Statement of Originality

I hereby certify that the work embodied in the thesis is my own work, conducted under normal supervision. The thesis contains no material which has been accepted, or is being examined, for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made. I give consent to the final version of my thesis being made available worldwide when deposited in the University's Digital Repository, subject to the provisions of the Copyright Act 1968 and any approved embargo.

Minah Amor Gaviola

Acknowledgment of Authorship

I hereby certify that the work embodied in this thesis contains published paper/s/scholarly work of which I am a joint author. I have included as part of the thesis a written declaration endorsed in writing by my supervisor, attesting to my contribution to the joint publication/s/scholarly work.

By signing below I confirm that Minah Amor Gaviola contributed significantly to the design; search strategy, including defining the inclusion and exclusion criteria and search terms; conducting the search and assessing retrieved articles for relevance; documenting a summary table of retrieved articles; assessing risk of bias and critically reviewing selected articles; interpretation of findings from the review, and writing of the publication entitled:

Minah Amor Gaviola, Kerry Jill Inder, Sophie Dilworth, Elizabeth G Holliday, Isabel Higgins (2019). *Impact of individualised music listening intervention on persons with dementia: A systematic review of randomised controlled trials*. Australasian Journal on Ageing. 10.1111/ajag.12642

Associate Professor Kerry Inder

Acknowledgments

The road to the completion of my PhD degree was filled with countless trials. I never thought I would make it this far. I am grateful to the people, who in one way or another have helped me through this journey.

Firstly, I would like to express my gratitude to my supervisors: Associate Professor Kerry Inder, Dr. Sophie Dilworth, Professor Isabel Higgins, and Associate Professor Liz Holliday. Kerry, I am blessed to have you as my primary supervisor and it has been a wonderful experience working with you. Your constant presence and guidance motivated me to carry on even at times when the odds were against me. Sophie, apart from your excellent eye for details, I look up to the way you exceptionally managed to juggle career with family. Liz, your brilliant mentorship made working with statistics simple and fun. Isabel, you might not know it but you were instrumental in my PhD undertaking. I guess God had let our paths cross again to remind me to find my calling. Thank you for your words of wisdom and encouragement during the trying times of my studies.

I acknowledge the Australian Government Research Training Program Scholarship for the financial support for my studies and research expenses.

I am thankful to the support from the staff and colleagues from the School of Nursing and Midwifery, to our faculty librarian Debbie Booth, and to health research economist Andrew Searles for advice in the analysis of the cost component of this study.

I will always be indebted to the residential aged care facilities who granted me the opportunity to implement my research. Special thanks to the facility management, staff, older people, and family or guardian who participated in this study.

Having young children while studying was a big challenge for me. Thank you to my family who took turns in looking after the kids so I can work on my research. To my in-laws Baden and Mama Betty thank you. Special thanks to my mother Minda who had to travel from the USA and stay with us for 6 months every year since the commencement of my studies. I would not have gotten this far without your invaluable support and prayers.

To my wonderful husband Ralph, I cannot thank you enough for all your sacrifices and support even at times when you were fighting your own battles. You have been my pillar of strength during my lowest points in this journey. To my beautiful children, Miah and little Ralph, you are my source of joy and inspiration.

Lastly, to my late father Leo, the first person who believed that I could write and my first writing mentor. How I wish you were here to read my work and witness the realisation of the dream that we shared.

Glossary

Assistant in nursing (AIN) – refers to care staff and nursing assistants

Individualised music listening – refers to music listening based on the person's preferences. In the literature this is also described as personalised music listening and preferred music listening

Residential aged care facility (RACF) – in this study this refers to long-term care facilities, nursing homes, assisted living facilities, residential care, residential aged care, and residential aged care facilities

Contents

Statement of Originality	2
Acknowledgment of Authorship	3
Acknowledgments	4
Glossary	6
Contents	7
Abstract	15
Table of Figures	17
Table of Tables.....	18
Chapter 1 Introduction	20
1.1. Overview of ageing and dementia	21
1.2. Rationale for the study	24
1.3. An overview of the study aim and objectives, research questions, methodology, design and methods	24
1.4. Outline of the thesis.....	27
1.5. The candidate's background and role in the study	28
1.6. Conclusion.....	30
Chapter 2 Background and policy context.....	31
2.1. Introduction	32
2.2. Challenges related to a globally ageing population.....	32
2.3. Prevalence of dementia increases with age	34
2.4. Definition, diagnosis, symptoms and management of dementia.....	35
2.4.1. Symptoms of dementia	37
2.4.2. Management of dementia.....	39
2.5. Music as therapy in modern and historical contexts	46
2.6. Music across the life span.....	47
2.7. Musical memory and dementia	48
2.8. Use of music for people living with dementia	50
2.8.1. Goals of music interventions in dementia care	50
2.8.2. Forms of musical interventions for people living with dementia	51
2.8.3. Evidence supporting the value of music interventions for people living with dementia.....	53

2.9. The benefits of using preferred/individualised music	55
2.10. Individualised music for people living with dementia	56
2.10.1. Theoretical foundation of individualised music for people living with dementia.....	57
2.10.2. Individualised music protocol.....	58
2.10.3. Evidence on the impact of individualised music for people living with dementia.....	59
2.11. Gap between the efficacy and routine implementation of individualised music listening intervention	63
2.11.1. Implementation studies on individualised music listening	63
2.11.2. More research needed to advance implementation of individualised music interventions.....	65
2.12. Addressing the gap between the efficacy of individualised music and routine uptake through implementation research	66
2.12.1. The use of a conceptual model of implementation research.....	68
2.12.2. Implementation strategies	70
2.12.3. The need for implementation research.....	71
2.13. Conclusion.....	73
Chapter 3 Impact of individualised music listening intervention on persons with dementia: A systematic review of randomised controlled trials	74
3.1 Abstract	75
3.2. Introduction	76
3.2.1. Rationale	76
3.2.2. Objectives	79
3.3. Methods	79
3.3.1. Eligibility criteria.....	80
3.3.2. Exclusion	80
3.3.3. Information sources	81
3.3.4. Study selection.....	81
3.3.5. Data collection process	81
3.3.6. Risk of bias in individual studies.....	82
3.3.7. Risk of bias across studies	82
3.3.8. Synthesis of results	82
3.4. Results	82
3.4.1. Study selection.....	82

3.4.2. Study characteristics	85
3.4.3. Risk of bias within studies	89
3.4.4. Results of individual studies	91
3.4.5. Risk of bias across studies	95
3.5. Discussion	95
3.5.1. Summary of evidence	95
3.5.2. Limitations of this review	99
3.6. Conclusion.....	99
Chapter 4 Methodology, design and methods.....	101
4.1. Introduction	102
4.2. Study aim, objectives, and research questions	103
4.3. Pragmatism.....	104
4.3.1. How pragmatism relates to the research topic, the study participants, and the music intervention.....	107
4.4. Methodology and study design: Mixed methods approach.....	116
4.4.3. Application of parallel mixed method design to the study	116
4.4.1. Parallel mixed design.....	119
4.4.2. Rationale for a mixed methods design.....	120
4.5. Study setting	124
4.5.1. RACF1	126
4.5.2. RACF2	128
4.6. Study population.....	130
4.6.1. Eligibility criteria.....	130
4.7. Study outcomes	131
4.7.1. Primary outcome: Implementation outcomes	131
4.7.2. Secondary outcome: Impact of the intervention on older people living with dementia.....	133
4.8. Study procedures	133
4.8.1. Recruitment.....	133
4.8.2. Implementation strategies	137
4.8.3. Training session	141
4.8.4. Study intervention.....	143
4.8.5. Measurement tools.....	150
4.8.6. Data collection	161

4.9. Data analysis.....	169
4.9.1. Quantitative data analysis	169
4.9.2. Qualitative data analysis	171
4.9.3. Integration of inferences	173
4.10. Limitations of the methodology and methods	175
4.10.1. Quantitative component.....	175
4.10.2. Qualitative component.....	176
4.10.3. The candidate	178
4.10.4. Short implementation period	178
4.11. Ethical considerations.....	179
4.11.1. Free and informed consent.....	180
4.11.2. Identifying and managing potential risks.....	189
4.11.3. Privacy and confidentiality	191
4.12. Ensuring the quality of the study	192
4.13. Conclusion.....	194
Chapter 5 Effects of implementation strategies on implementation outcomes – A pre-test post-test study	195
5.1. Introduction	196
5.2. Overview of the study objective and methods	197
5.3. Study participants and recruitment.....	198
5.3.1. Research implementation period	198
5.3.2. Participant flow – older people living with dementia.....	199
5.3.3. Baseline Characteristics.....	201
5.4. Results: Effects of the implementation strategies on the implementation outcomes	204
5.4.1. Adoption	205
5.4.2. Acceptability, appropriateness and feasibility: Staff perceptions from the implementation outcomes questionnaire	208
5.4.3. Feasibility: Evidence from the music intervention logbook.....	219
5.4.4. Fidelity: Evidence from the music intervention logbook	226
5.4.5. Sustainability: Evidence from the music intervention logbook.....	227
5.4.6. Implementation cost.....	228
5.4.7. Fidelity to implementation strategies as planned and adaptation to suit context and preferences	243

5.5 Discussion	252
5.5.1. Effects of implementation strategies.....	252
5.5.2. Implementation highlights from the music intervention logbook data.....	256
5.5.3. Costs of the music intervention and its implementation by participating staff	259
5.5.4. Limitations related to implementation outcomes.....	263
5.6. Conclusion.....	264
Chapter 6 Impact of individualised music listening on older people living with dementia – A pre-test post-test study.....	266
6.1. Introduction	267
6.2. Overview of the study objective and methods	267
6.3. Results	269
6.3.1. Effects on agitation, quality of life, and level of engagement: Comparison between implementation sites.....	269
6.3.2. Effects on agitation, quality of life and level of engagement: Comparison between data collection points of the pooled sample	276
6.3.3. Effects on the use of psychotropic medications.....	280
6.4. Discussion	286
6.4.1. Agitation	286
6.4.2. Quality of life.....	287
6.4.3. Level of engagement during the intervention	289
6.4.4. Psychotropic medication use	291
6.4.5. Limitations	293
6.5. Conclusion.....	294
Chapter 7 The perceptions and experiences of staff and family or guardians of the individualised music intervention	296
7.1. Introduction	297
7.2. Overview of the study objectives and methods.....	297
7.3. Results from the qualitative data sets: interviews, implementation questionnaire, and progress notes	300
7.3.1. Transcendental reminisces, the calm, the joy and the elation.....	301
7.3.2. Optimism, excitement, and the snowball effect.....	310
7.3.3. Pitching in for the older person, it's not rocket science, and the hurdles	318
7.3.4. Music beyond the intervention	329
7.4. Discussion of qualitative findings	333

7.4.1. Effects of the music intervention on the participating older people, staff, and family or guardian.....	333
7.4.2. Implementing the individualised music intervention.....	334
7.4.3. Considerations and recommendations for music delivery and music selection	337
7.4.4. Limitations	338
7.5. Conclusion.....	340
Chapter 8 Integration of findings, discussion, and conclusion	341
8.1. Introduction	342
8.2. Revisiting the study aim, objectives and research questions, research design and methods	344
8.2.1. Study objectives.....	344
8.2.2. Study design, outcomes, and methods.....	345
8.2.3. Implementation strategies used.....	347
8.3 Impact of the strategies used for the implementation of the music intervention on the implementation outcomes.....	349
8.4. Facilitators to the implementation of the music intervention.....	356
8.5. Barriers to the routine implementation of the music intervention.....	359
8.5.1. Barriers relating to the older person	359
8.5.2. Barriers relating to the use, maintenance, and storage of the music intervention equipment	360
8.6. Secondary outcomes: Impact of individualised music listening on older people living with dementia	361
8.7. Discussion	363
8.7.1. Evaluation of the strategies used to promote the implementation of the music intervention: what worked and what did not	365
8.7.2. Effects of implementation strategies on implementation outcomes: adoption, acceptability, appropriateness, feasibility, fidelity, sustainability, and implementation costs	368
8.7.3. Utility of the music intervention: an intervention and a leisure activity	372
8.7.4. Factors that promote routine utilisation of the intervention	373
8.7.5. Barriers to the routine implementation of the intervention.....	379
8.7.6. Effects of the music intervention on older people: study findings addressing the secondary outcomes	383
8.7.7. Future directions for sustainability of and individualised music program for older people living with dementia in a residential aged care facility	385
8.8. Methodological considerations.....	391

8.8.1. Study design and sample size	391
8.8.2. Outcome measures and data collection.....	393
8.8.3. Duration of the research implementation.....	394
8.8.4. The candidate's role and influence	395
8.9. Summary of the integrated findings	396
8.10. Recommendations for future research.....	398
8.11. Clinical practice implications	400
8.12. Conclusion.....	401
Appendices.....	403
Appendix 1 – Published systematic review.....	403
Appendix 2 - Systematic Reviews and Meta-analyses (PRISMA) statement.....	404
Appendix 3 – Medline search details	406
Appendix 4 – Research poster/advertisement	407
Appendix 5 – Information statements and consent Forms	408
5.1. Information statement for staff – RACF1	408
5.2. Information statement for older people and their family or guardian – RACF1	413
5.3. Consent form for staff – RACF1 and RACF2	419
5.4. Consent form for family or guardian – RACF1.....	420
5.5. Consent form for older person – RACF1	422
5.6. Consent for the residential aged care facility – RACF1	423
5.7. Information statement for staff – RACF2.....	425
5.8. Information statement for older people and their family or guardian – RACF2	430
5.9. Consent form for family or guardian – RACF2.....	436
5.10. Consent form for older person – RACF2	438
5.11. Consent form for the residential aged care facility – RACF2	439
Appendix 6 – HREC approval letters.....	441
6.1. HREC expedited approval	441
6.2. HREC expedited approval – variation 1	442
6.3. HREC expedited approval – variation 2	443
6.4. HREC expedited approval – variation 3	444
Appendix 7 – Laminated card	445
Appendix 8 – Anonymous feedback form.....	446

Appendix 9 – Staff training session preferences	447
Appendix 10 – Correspondence to authors	448
10.1. Gerdner	448
10.2. Baker.....	448
10.3. Lyon.....	449
10.4. Young.....	449
Appendix 11 – Assessment of music preferences: Gerdner.....	450
Appendix 12 – Implementation outcomes questionnaire	451
12.1. Pre-implementation.....	451
12.2. Post-implementation	457
Appendix 13 – Resident’s music intervention logbook	462
Appendix 14 –CMAI.....	463
Appendix 15 – DEMQOL	464
15.1. Patient version.....	464
15.2. Carer version.....	465
Appendix 16 – HoME-S.....	466
Appendix 17 – PAS.....	467
Appendix 18 – GDS scale	468
Appendix 19 – Educational material for all staff	469
Appendix 20 – Assessment of music preferences – modified version.....	471
References	472

Abstract

Background: Evidence demonstrates the promising impact of individualised music listening for people with dementia, however there is paucity of research on its implementation and uptake.

Objectives: To evaluate the impact of strategies utilised to improve the adoption, acceptability, appropriateness, feasibility, fidelity and sustainability associated with implementing an individualised music listening intervention, costs and effects of the intervention on older people with dementia.

Methods: A parallel mixed methods design was used involving a pre-test-post-test study and focus group and individual interviews. Trained staff and family or guardians implemented the individualised music intervention for older people with dementia in two residential care settings in NSW, Australia. The music intervention involved individualised music listening based on the person's music preferences as determined by the older person with dementia where possible and their family or guardian.

Strategies used to promote the implementation of the music intervention by staff and family or guardian included: training and education of staff, family and guardians regarding the music intervention, identification of program champions, providing and obtaining feedback about the implementation of the intervention, and reminders to prompt staff to implement the intervention. Application of the music intervention was recorded in a logbook over the 3-month research implementation period.

Measurements: At baseline and at the end of the 3-month research implementation, agitation, quality of life, and psychotropic medication use were measured using the Cohen-Mansfield Agitation Inventory, Dementia Quality of Life Questionnaire, and

medical records respectively. The Homecare Measure of Engagement Staff-Questionnaire was administered during each month of implementation. Qualitative interviews were conducted with staff and a guardian during the third month of research implementation.

Results: Of the 32 older people with dementia who consented to the study, 22 completed the individualised music intervention. Fourteen staff and seven family members or guardians participated in the training and implemented the music intervention. A total of 331 entries of individualised music listening implemented to participating older people were documented throughout the 3-month research implementation period. The total annual cost of the music intervention and its implementation for 32 older people across implementation sites was AU\$6,623.76. There were significant improvements in quality of life and the people with dementia's engagement during the intervention increased throughout the implementation period. Findings from the qualitative interviews revealed positive responses from older people with dementia and the simplicity of the intervention. Barriers to routine uptake of the intervention by participants included discomfort from headphones, and care and storage of equipment.

Conclusion: Regular implementation of an individualised music listening intervention in residential care for older people with dementia by staff and family or guardian is feasible. The music intervention is perceived as appropriate for older people with dementia by older people, family and staff. Findings of this study support the promising impact of individualised music listening as a low-cost, simple, and meaningful non-pharmacological intervention for older people with dementia.

Table of Figures

Figure 2.1. Conceptual model of implementation research (Proctor, 2009)	70
Figure 3.1. Preferred Reporting Items for Systematic Reviews and Meta-analyses flow diagram of the study selection procedure for reviewing the impact of individualised music listening intervention on persons with dementia	84
Figure 4.1. Application of parallel mixed design (Teddlie, 2009)	119
Figure 4.2. The continuum of implementation research	123
Figure 4.3. iPod shuffle	147
Figure 4.4. Headphones	148
Figure 5.1. Flow of participating older people living with dementia	200
Figure 5.2. Flow of participating staff, family, and guardian	207
Figure 5.3. Comparison of logbook observations between implementation sites	220
Figure 5.4. Comparison of logbook observations per month between implementation sites	227
Figure 5.5. Consumer registry flow chart	229
Figure 6.1. Differences in the pre-implementation and post-implementation agitation scores between implementation sites	270
Figure 6.2. Differences in the pre-implementation and post-implementation scores between implementation sites	273
Figure 6.3. Differences in the level of engagement scores between implementation sites across the three time points	274
Figure 6.4. Differences between pre-implementation and post-implementation agitation scores (pooled sample)	277
Figure 6.5. Differences between pre-implementation and post implementation quality of life scores (pooled sample)	278
Figure 6.6. Differences in the level of engagement scores between time points of data collection (pooled sample)	279

Table of Tables

Table 3.1. Summary of included randomised controlled trials in systematic review of impact of individualised music listening intervention on persons with dementia	87
Table 3.2. Risk of bias summary.....	90
Table 4.1. Evidence-based protocol of individualised music for elders with dementia	144
Table 4.2. Modified version of the evidence protocol for individualised music for older people living with dementia	145
Table 4.3. Summary of data collection and analysis.....	174
Table 5.1. Comparison of baseline characteristics between implementation sites (n=32)	202
Table 5.2. Profile of staff who completed the implementation questionnaire	209
Table 5.3. Training/practice acceptability, feasibility, and appropriateness.....	212
Table 5.4. Measure of disseminability - Pre implementation	215
Table 5.5. Measure of disseminability - Post implementation.....	218
Table 5.6. Details of the music logbook observations	222
Table 5.7. Reasons for implementing the intervention of the pooled sample (n=346 entries).....	223
Table 5.8. Breakdown of reasons per implementation site (n=346)	223
Table 5.9. Effects of the intervention on the pooled sample of people living with dementia (n=351 entries)	224
Table 5.10. Frequencies of other effects (n=26)	225
Table 5.11. Breakdown of effects per implementation site (n=351 entries).....	226
Table 5.12. Data inputs for the operating costs.....	231
Table 5.13. Total cost of the individualised music playlist creating for the study participants	232
Table 5.14. Data inputs for the music intervention equipment.....	233
Table 5.15. Total cost of music intervention equipment and iTunes download	234
Table 5.16. Data inputs for the staff training and education costs	235
Table 5.17. Total staff training and education cost (labour and non-labour).....	238
Table 5.18. Data inputs for the implementation of the music intervention.....	240
Table 5.19. Total cost of implementing the music intervention to the study participants over the 3-month period	241
Table 5.20. Summary of total annual cost.....	242
Table 6.1. Comparison between implementation sites on CMAI (agitation), DEMQOL (quality of life), and HoME-S (engagement during the intervention) scores	271
Table 6.2. Frequency and duration of implementation as documented in the HoME-S assessment	275
Table 6.3. Effects of individualised music listening intervention on agitation and quality of life: comparison of pre-implementation and post-implementation scores in the pooled sample.....	276
Table 6.4. Effects of individualised music listening intervention on level of engagement: comparison between points of data collection	279

Table 6.5. Comparison of the number of people living with dementia with psychotropic medication prescriptions between implementation sites.....	282
Table 6.6. Number of PRN (as needed) psychotropic medications administered	283
Table 6.7. Comparison of the pre-implementation and post-implementation psychotropic medication prescription within each implementation site	284
Table 6.8. Comparison of the pre-implementation and post-implementation psychotropic medication prescription across both implementation sites (pooled sample)	285
Table 7.1. Interview guide questions for focus group and individual interviews	299
Table 7.2. Outline of participants participating in interviews.....	300