Expanding access to group singing for people with dementia: implications of music therapy skill-sharing for research and practice

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Abstract

Background: 850,000 people in the UK are estimated to be living with dementia. The importance of supporting people with dementia and their carers through psychosocial interventions is widely acknowledged. The potential of music-based interventions to provide this support is becoming well-recognised, but demand exceeds supply. Group singing is an increasingly popular activity for people with dementia and their carers, and a growing number of community based singing groups are being implemented. However, to date there have been no large-scale studies demonstrating the benefits of community group singing for this population. Music therapy skill-sharing is a way of supporting facilitators without formal therapy training, and increasing capacity to provide singing opportunities, but we need to know how these skills can be communicated most effectively and efficiently. The CHORD (Chorus Research in Dementia) manual has been developed by music therapists to provide guidance to singing group facilitators.

Aims: The aim of this doctoral study is to investigate ways to expand access to singing groups for people with dementia by testing an approach to skill-sharing (the CHORD manual), understanding the perspective of group attendees, and by evaluating commonly-used ways of measuring the benefits of singing.

Methods: The design was conceived as a mixed-methods feasibility study, supported by two complementary literature reviews. A novice singing group facilitator used the CHORD manual to lead 10 weekly singing sessions for people with dementia and their carers. Data was collected from participants using measures of mood, quality of life, and musical engagement, as well as interviews and focus groups. All the sessions were video recorded. Following data analysis, qualitative and quantitative results were synthesised.

Results: The synthesis of the two literature reviews indicated that there were some differences between the outcomes prioritised in music therapy practice and research, with research tending to focus on the reduction of neuropsychiatric symptoms. The feasibility study showed that the novice facilitator found the CHORD manual an effective and accessible tool which enabled her to lead a successful group. Participants reported that the facilitator's openness to sharing her challenges established a point of commonality with the group members. Exploratory analyses of the quantitative data revealed no effects of the singing group on mood and quality of life, but a range of benefits were qualitatively reported, with social benefits being a particularly prominent theme. Synthesis indicated dissonance between quantitative and qualitative results on a case level as well as within groups. Although the research methods were acceptable to the participants, the chosen outcome measures did not detect the changes which were qualitatively described by participants.

Conclusion: Skill sharing initiatives such as the CHORD manual have potential to provide an accessible way of expanding access to music-based interventions, but care must be taken to ensure that the skills which are shared are suitable for dissemination in this way. Response to group singing is complex and individual, and measuring its benefits is a challenge for research. There is a need to develop methodological solutions which provide reliable evidence for the value of the arts at a meaningful level without undermining the flexible and intuitive essence of the intervention which they are designed to evaluate.

Declaration

I certify that this thesis is my own work, except where indicated by referencing. No part of this thesis has been submitted elsewhere for any other degree or qualification.

Elizabeth Rebecca Mary Dowson

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Table of Contents

Abstract i

Declaration iii

Acknowledgements iv

Table of Contents vi

List of Figures xiii

List of Tables xvi

List of Abbreviations xvii

Chapter 1: Introduction 1

1.1 Dementia 1

1.2 Music and dementia 2

1.3 Definitions 3

1.4 Music therapy and dementia 4

1.5 Group singing for people with dementia 6

1.6 The CHORD manual 7

1.7 Aims of this doctoral study 9

1.8 Structure of this thesis 10

Chapter 2: Meta-narrative Review 12

2.1 Introduction 12

2.2 Rationale 12

2.3 Objectives 16

2.4 Inclusion and exclusion criteria 17

2.5 Definitions 18

2.6 Search strategy for identification of studies 19

2.7 Method of Review 21

2.7.1 Selection of studies 21

2.7.2 Assessment of methodological quality 22
2.7.3 Data extraction 22
2.7.4 Synthesis 23
2.8 Results 25
2.8.1 Characteristics of the data 25
2.8.2 Change over time 29
2.9 Research paradigms and outcome measures 30
2.9.1 Quantitative outcome measures 33
2.9.2 Qualitative methods 41
2.10 Developing meta-narratives 43
2.10.1 Changing attitudes to dementia in medicine and society 45
2.10.2 The conceptualisation and management of agitation in dementia 49
2.10.3 The subjective experience of dementia 53
2.10.4 Developments within music therapy practice and research in dementia 58
2.10.5 Group singing and dementia 62
2.11 Discussion 67
2.11.1 Limitations 70
2.12 Conclusion and further work 71
Chapter 3: A Critical Interpretive Synthesis of Music Therapy Case Studies 73
3.1 Introduction 73
3.2 Rationale for this review 73
3.3 Objectives 76
3.4 Methods 79
3.4.1 Inclusion and exclusion Criteria 79
3.4.2 Literature search 79

3.4.3 Analysis 80
3.5 Procedure 81
3.6 Results 82
3.6.1 Characteristics of the data 82
3.6.2 Changes reported in case studies 86
3.7 Discussion 98
3.7.1 Intra- and extra-session outcomes 98
3.7.2 "In the moment" 99
3.7.3 Increasing the positive vs. reducing the negative 100
3.7.4 Causal connections 101
3.7.5 The unknown and unknowable in music therapy 102
3.8 Synthesis with meta-narrative review 103
3.8.1 Developments within music therapy practice and research in dementia 104
3.8.2 The conceptualisation and management of agitation in dementia 105
3.8.3 Changing attitudes to dementia in medicine and society 106
3.8.4 The subjective experience of dementia 108
3.9 Limitations 110
3.10 Conclusion 111
Chapter 4: Methodology 112
4.1 Introduction 112
4.2 Research questions 113
4.3 Epistemology 114
4.4 Methodology 115
4.4.1 Feasibility studies 116
4.4.2 Complex interventions 116
4.4.3 Process evaluation 117

4.5 Operationalisation of research questions 118
4.5.1 RQ1: Is the CHORD manual a useful resource for those wishing to run singing groups for people with dementia? 118
4.5.2 RQ2: How feasible would it be to conduct a full-scale RCT in a similar setting? 119
4.5.3 RQ3: What is the experience of the CHORD group members? What benefits, if any, do they experience from attending the group? 119
4.5.4 RQ4: How can the results of this study be used to inform the theory, practice and research methodology of music in dementia care? 120
4.6 Choice of quantitative outcome measures 121
4.7 Reflections on my position within the study 124
4.8 Conclusion 125
Chapter 5: Methods 127
5.1 Introduction 127
5.2 Study Design 127
5.2.1 Setting 127
5.2.2 Inclusion and exclusion criteria 128
5.2.3 Sample 129
5.2.4 Ethics 129
5.2.5 Recruitment of singing group leader 133
5.2.6 Recruitment of study participants 135
5.2.7 Data collection 135
5.2.8 Development of Manual Adherence Form 139
5.2.9 Data security 142
5.3 Data Analysis 143
5.3.1 Quantitative data 143
5.3.2 Qualitative data 144

5.3.3 Data integration and synthesis 146

5.4 Procedure 147

5.4.1 Setting 147

5.4.2 Recruitment of Participants 147

5.4.3 Consent Process 150

5.4.4 Baseline data collection 151

5.4.5 Planning the group 151

5.4.6 Volunteers 151

5.4.7 Content and structure of sessions 152

5.4.8 Data collection during sessions 152

5.4.9 Focus Groups 152

5.4.10 Post-group data collection 152

5.5 Conclusion 152

Chapter 6: Results 154

6.1 Introduction 154

6.2 Quantitative data analysis 154

6.2.1 Notes on terminology and abbreviations 154

6.2.2 Demographic information 155

6.2.3 Description of data 156

6.2.4 Treatment of missing data 157

6.2.5 Findings from Geriatric Depression Scale Analysis 159

6.2.6 Findings from Quality of Life in Alzheimer's disease analysis 164

6.2.7 Findings from Hospital Anxiety and Depression Scale Analysis 177

6.2.8 Correlations between GDS and QoL-AD scores 180

6.2.9 Findings from MiDAS-SR Scale 183

6.2.10 Discussion 193

6.2.11 Conclusion 199

6.3 Qualitative data analysis 201
6.3.1 Analysis of baseline interviews 201
6.3.2 Themes from baseline interviews 202
6.3.3 Analysis of post-group qualitative data 211
6.3.4 A model for group members' experiences 233
6.4 Feasibility of CHORD Study 235
6.4.1 Results of recruitment procedure 235
6.4.2 Participants 236
6.4.3 Attendance 238
6.4.4 Retention 239
6.4.5 Feasibility and acceptability of outcome measures 240
6.4.6 Implementation and acceptability of qualitative methods 249
6.4.7 Feasibility of manual adherence procedure 250
6.5 Evaluation of the CHORD manual 258
6.5.1 Description and content of sessions 258
6.5.2 Interview with JB 264
6.5.3 JB's post-session notes 270
6.5.4 BD's post-session notes 272
6.5.5 Discussion 275
6.6 Conclusion 277
Chapter 7: Synthesis and Discussion 279
7.1 Introduction 279
7.2 RQ1. Is the CHORD manual a useful resource for those wishing to run singing groups for people with dementia? 279
7.3 RQ2: How feasible would it be to conduct a full-scale RCT in a similar setting? 284
7.3.1 Recruitment and retention 285

7.3.2 Choice of instruments....286
7.3.3 Possible control conditions....287
7.3.4 Treatment fidelity....290
7.4 RQ3: What is the experience of the CHORD group members? What benefits, if any, do they experience from attending the group?....291
7.4.1 Changes in mood....294
7.4.2 Social benefits....295
7.4.3 Case vignettes....297
7.5 RQ4: How can the results of this study be used to inform the theory, practice and research methodology of music in dementia care?....304
7.6 Implications of this thesis....311
7.6.1 Original contribution to knowledge....311
7.6.2 Limitations of this thesis....313
7.6.3 Future directions for research....315
7.7 Conclusion....318
Chapter 8: Conclusion....320
References....326
Appendix 1: Sample pages from CHORD manual....346
Appendix 2: Papers included in meta-narrative review (Chapter 2)....353
Appendix 3: Confirmation of ethical approval....370
Appendix 4: Singing group facilitator recruitment questions....371
Appendix 5: Poster used to advertise the singing group....372
Appendix 6: Interview topic guides for participants....373
Appendix 7: Interview topic guide for facilitator....374
Appendix 8: CHORD manual adherence form....375

List of Figures

Figure 2:1: PRISMA flow chart 25
Figure 2:2: Settings of studies 26
Figure 2:3: Types of music activity 27
Figure 2:4: Number of papers by year 29
Figure 2:5: Visual map of outcome measure domains 35
Figure 2:6: Number of studies with quality of life related outcome measures 48
Figure 2:7: Respondents to outcome measures over time 49
Figure 2:8: Studies using a quantitative measure of agitation 51
Figure 3:1: Outcomes reported in music therapy case studies 87
Figure 3:2: Number of references to outcomes in music therapy case studies 87
Figure 3:3: In their own words 98
Figure 4:1: Operationalisation of Research Questions 121
Figure 6:1: GDS scores at time 0 and time 1 159
Figure 6:2: Change in GDS scores between time 0 and time 1 160
Figure 6:3: Spread of GDS scores at time 0 subdivided by diagnosis 162
Figure 6:4 Spread of GDS scores at time 1 subdivided by diagnosis 162
Figure 6:5: QoL-AD scores at time 0 and time 1 164
Figure 6:6: Change in QoL-AD score between time 0 and time 1 165
Figure 6:7: QoL-AD score for 1M at time 0 and time 1 167
Figure 6:8: QoL-AD score for 16M at time 0 and time 1 167
Figure 6:9: QoL-AD scores for 3M at time 0 and time 1 169
Figure 6:10: QoL-AD scores for 6M at time 0 and time 1 170
Figure 6:11: QoL-AD scores for 7M at time 0 and time 1 170
Figure 6:12: QoL-AD scores for 10M at time 0 and time 1 170
Figure 6:13: Mean change in QoL-AD score by domain for participants reporting clinically significant change 172

Figure 6:14: Spread of QoL-AD scores at time 0 subdivided by diagnosis 174
Figure 6:15: Spread of QoL-AD scores at time 1 subdivided by diagnosis 174
Figure 6:16: HADS depression scores for support members at time 0 and time 1 177
Figure 6:17: HADS anxiety scores for support members at time 0 and time 1 178
Figure 6:18: Change in HADS scores between time 0 and time 1 for support members 179
Figure 6:19: Scatter plot of GDS scores against QoL-AD scores at time 0 181
Figure 6:20: Scatter plot of GDS scores against QoL-AD scores at time 1 181
Figure 6:21: Scatter plot of change in GDS score against change in QoL-AD score between time 0 and time 1 182
Figure 6:23: MiDAS-SR scores for session 1 184
Figure 6:24: MiDAS-SR scores for session 3 184
Figure 6:25: MiDAS-SR scores for session 5 185
Figure 6:26: MiDAS-SR scores for session 7 185
Figure 6:27: MiDAS-SR scores for session 9 186
Figure 6:28: MiDAS-SR Scores for 1M 187
Figure 6:29: MiDAS-SR Scores for 7M 187
Figure 6:30: MiDAS-SR Scores for 8M 188
Figure 6:31: MiDAS-SR Scores for 10M 188
Figure 6:32: MiDAS-SR Scores for 12M 189
Figure 6:33: MiDAS-SR Scores for 13M 189
Figure 6:34: Maximum and minimum MiDAS-SR scores by participant 191
Figure 6:35: Maximum and minimum MiDAS-SR scores by participant (continued) 192
Figure 6:36: Model of interactions between qualitative themes 234
Figure 6:37: Avenues for recruitment of study participants 236
Figure 6:38: Profile of diagnoses of singing group participants 237
Figure 6:39: Attendance at singing group sessions over time 239
Figure 6:40: Missing QoL-AD items by category 241

Figure 6:41: MiDAS-SR form completion over the course of the study.....245
Figure 6:42: Number of complete and incomplete MiDAS-SR forms by session..246
Figure 6:43: Proportion of attempted and completed MiDAS-SR forms.....247
Figure 6:44: Number of MiDAS-SR forms completed by participant.....248
Figure 6:45: Facilitator's manual adherence ratings by session.....254
Figure 6:46: Observer's manual adherence ratings by session 255
Figure 6:47: Cohen's Kappa score for manual adherence ratings by session.....256
Figure 6:48: Chairs arranged ready for a session.....261

List of Tables

Table 2:1: Form used for systematic review data extraction 22
Table 2:2: Frequency of quantitative outcome measures 33
Table 2:3: Summary of studies which focus on singing 65
Table 3:1: Articles and chapters included in the review 83
Table 3:2: Demographic and clinical details of music therapy clients 85
Table 3:3: Domains identified in case studies 88
Table 5:1: Ethical issues identified as relevant to this study 130
Table 5:2: Details of data collection methods used in the study 136
Table 5:3: Examples from CHORD manual analysis 141
Table 5:4: Frequency of codes and categories from analysis of CHORD manual . 142
Table 5:5: Analysis of outcome measure data 144
Table 6:1: Demographic information about participants with dementia and memory problems 155
Table 6:2: Demographic information about support members 156
Table 6:3: Missing data for outcome measures 157
Table 6:4: Distribution of themes from qualitative data analysis 212
Table 6:5: JB's plan for Session Three 259
Table 7:1: Mixed methods matrix 293

List of Abbreviations

AD	Alzheimer's Disease
ADRD	Alzheimer's Disease and Related Dementias
AFMT	Assessment of Functions of Music Therapy
ALS	Amyotrophic Lateral Sclerosis
BAMT	British Association for Music Therapy
BANS-S	Bedford Alzheimer Nursing Severity Scale
BBC	British Broadcasting Corporation
BEHAVE-AD	Behavioral Pathology in Alzheimer's Disease Rating Scale
BPSD	Behavioural and Psychological Symptoms of Dementia
CBS-QoL	Cornell-Brown Scale for Quality of Life in Dementia
CBT	Cognitive Behavioural Therapy
CHORD	Chorus Research in Dementia
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CIS	Critical Interpretive Synthesis
CMAI	Cohen Mansfield Agitation Inventory
COPD	Chronic Obstructive Pulmonary Disease
CSDD	Cornell Scale for Depression in Dementia
DBRS	Disruptive Behaviour Rating Scale
DCM	Dementia Care Mapping
DEFRA	Department for the Environment, Food and Rural Affairs
EBM	Evidence Based Medicine
EBP	Evidence Based Practice
EMBASE	Excerpta Medica dataBASE
FTD	Fronto-Temporal Dementia
GDS	Geriatric Depression Scale
GIM	Guided Imagery in Music
GMT	Group Music Therapy
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
IMIA	Individualised Music Intervention for Agitation
JPND	Joint Programme - Neurodegenerative Disease
LMBS	Lawton's Modified Behaviour Stream
LTC	Long Term Care
MADRS	Montgomery-Åsberg Depression Rating Scale
MAF	Manual Adherence Form
MeSH	Medical Subject Headings
MiDAS	Music in Dementia Assessment Scale
MIDAS-SR	Music in Dementia Assessment Scale - Self-Rated
MMSE	Mini-Mental State Examination

MPES	Menorah Park Engagement scale
MRC	Medical Research Council
MT	Music Therapy
NBD	Need-driven Dementia-compromised Behaviour model
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NPI	Neuro-Psychiatric Inventory
OERS	Observed Emotion Rating Scale
PCC	Person Centred Care
PFC	Paper Folding and Cutting
PLST	Progressively Lowered Stress Threshold
PPI	Public Participation and Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QoL-AD	Quality of Life – Alzheimer's Disease
RAC	Rhythmic Auditory Cueing
RAID	Rating Anxiety in Dementia
RCS	Recreational Choral Singing
RCT	Randomised Controlled Trial
SPSS	Statistics Package for the Social Sciences
STAI	State-Trait Anxiety Inventory
TEMPau	*Test Episodique de Mémoire du Passé*
VAS	Visual Analogue Scale
WHO	World Health Organisation

Chapter 1: Introduction

1.1 Dementia

Dementia is a global health priority; worldwide, an estimated 50 million people were living with the condition in 2017. In the UK, 850,000 people are believed to have dementia; as life expectancy increases, this number is predicted to rise to 2 million by 2050. Dementia is not itself a disease but an umbrella term for symptoms caused by a number of conditions, the most common of which are Alzheimer's disease and vascular dementia. The symptoms caused by dementia include memory loss, confusion, and problems with speech and understanding. There is currently no cure for any form of dementia. Some rarer types of dementia affect people under the age of 65, but the majority of people with dementia are older; the condition affects 1 in 6 people over the age of 80.

Although dementia is progressive, people with a diagnosis may live for many years with the condition. For example, the average life expectancy for someone diagnosed with Alzheimer's disease is eight to ten years. Residential care for people with dementia is common, especially in the later stages, but 61% of people with dementia live in the community, either alone or with support from family or professional carers (Knapp et al., 2014). It is estimated that the 870,000 unpaid carers of people with dementia contribute the equivalent of £11 billion to the UK each year. Many family carers find that their caring role is rewarding, but at the same time it can place a large burden on their physical and mental health. Family carers of people with dementia are at greater risk of developing symptoms of depression and anxiety than the general population (Watson, Tatangelo, & McCabe, 2018). In addition to the cognitive problems caused by dementia, people with dementia also have increased rates of depression and anxiety. Preventing or delaying admission to residential care is important not only to support the

wellbeing of people with dementia but also to reduce the associated cost to both the individual and the state.

1.2 Music and dementia

In the absence of medical cures or treatments for dementia, there is a need to develop and evaluate psychosocial interventions which can support people with dementia and their family carers to live well with the condition. There is increasing recognition among policy makers that the arts can support the wellbeing of the population in general and those with additional needs such as dementia in particular. In the UK, an All-Party Parliamentary Group was established in 2014 and commissioned a report into the state of play in arts and health. The report contained recommendations for embedding the role of the arts into NICE guidelines and NHS policy, and encouraged research councils to target their funding to support the evidence base for the arts and health (All Party Parliamentary Group on Arts Health and Wellbeing, 2017). Subsequently, in June 2019, NICE updated its quality standard for dementia and specifically mentioned music therapy as an activity which should be offered to promote the wellbeing of people with dementia (NICE, 2019). The International Longevity Centre, in partnership with the Utley Foundation, established the world's first Commission on Music and Dementia, which reported that "music can provide a true lifeline for those both with and without dementia by promoting social connection, restoring a sense of self and bringing joy even in the most challenging of times" (Bowell & Bamford, 2018, p. 7). However, they also reported that access to music for people with dementia was sporadic and only available to the few, and that although professionals working in this field were devoted to their cause, there was a need for a more co-ordinated infrastructure to support the delivery of musical interventions. Nurturing the growing evidence base was an area of key importance highlighted by the report. In addition to finding evidence of effectiveness, there is

a need to understand what kinds of music interventions work in which context and for whom, in order to provide relevant support to as many people as possible. Music therapy and group singing are two interventions which have received attention for their potential for improving the lives of people with dementia.

1.3 Definitions

Throughout this thesis various types of musical interventions are described and referenced, but understanding the differences between these interventions can be complex and challenging. More detailed consideration is given to the spectrum of musical interventions in Chapter 2, but since this thesis deals in detail with music therapy skill-sharing, it is important to establish what is meant by music therapy and what forms it may take. Music therapy is a diverse profession practiced in many different ways, but The British Association for Music Therapy has the following definition:

> *Music therapy is an established psychological clinical intervention, which is delivered by HCPC registered music therapists to help people whose lives have been affected by injury, illness or disability through supporting their psychological, emotional, cognitive, physical, communicative and social needs.* (British Association for Music Therapy, 2017)

There are several key features which we can take from this definition. Firstly, music therapy is an "established psychological clinical intervention", meaning that it is supported by a body of scholarship, learning and practice, and is recognised by the state and by other health professions. Secondly, music therapists are HCPC registered, meaning that the profession is regulated and music therapists are required to adhere to certain standards of professional conduct. Thirdly, music therapists help to support the specific needs of their clients. These needs may be

identified through consultation with the client, their relatives or other healthcare professionals, or through the therapist's own assessment. The extent to which therapy is goal-oriented or driven by client needs varies depending on the therapist's orientation and the context of the work, but it is safe to say that the approach taken by the therapist will be guided by the needs of the client in both individual and group settings. This definition only applies directly to music therapy practice in the UK, but the basic model of a regulated profession which is practiced by trained therapists working to meet specific client needs is reflected worldwide, although state regulation and the availability of training courses is not universal.

Although the preceding definition is helpful for identifying what may be designated "music therapy", it does not convey the essence of what actually happens in music therapy sessions. Chapters 2 and 3 contain more in-depth descriptions of what takes place in music therapy sessions, and how therapists think about and approach their work. Other music interventions are not regulated and may be even more difficult to define. In these cases it is helpful to think of the following features and characteristics as a way to define and describe diverse musical interventions (the examples given are not intended to be exhaustive).

- Type of music *(live, recorded, instrumental, vocal)*
- Session format *(invidual, pairs, small group, large group)*
- Type of activity *(receptive/interactive)*
- Activity initiator *(self, carer, staff member, musician)*

1.4 Music therapy and dementia

Music therapy is a recognised area in which evidence of benefit for people with dementia has been established. Qualified music therapists use music therapy to support the wellbeing of people with dementia through interaction based upon

improvised or familiar music and may work with people with dementia at any stage of the condition, in group or individual settings. A recently-updated Cochrane review found evidence that music therapy improves depression and behavioural symptoms of dementia, wellbeing and quality of life, although the duration of these effects is unclear (van Der Steen et al., 2018). Additionally, most research into music therapy and dementia takes place in residential care settings with people at a later stage of the condition, so findings may be less applicable to community-dwelling people whose dementia tends to be milder. Providing individually tailored music therapy sessions is appropriate for those whose dementia has reached the stage where few other interventions are accessible, but people living in the community may benefit from group music sessions which provide social contact as well as meaningful occupation. A recent survey of the approximately 900 music therapists currently practicing in the UK estimated that provision of music therapy to this client group was equivalent to 30 seconds per person with dementia per week (Schneider, 2018). As well as highlighting a need for building capacity within the music therapy profession, the survey results suggest that increasing the provision of music-based interventions which can be delivered by those without music therapy training may enable more people with dementia to access music.

Music therapy in the UK has in previous decades been concerned with trying to establish professional boundaries through development of accredited training courses and establishment of state regulation (Barrington, 2015). The growth of the "Arts in health" movement created tension within the music therapy profession, with some calling for a relaxation of music therapy's tightly controlled boundaries (Hartley, 2008), while others advocated maintaining difference and distance from community music interventions (Barrington, 2008; Wetherick, 2009). Community music therapy was developed as a more context-based form of intervention (Ansdell, 2002). Some music therapists have adapted their practice

along these lines to become more flexible about the way in which they work. This may allow for more dialogue and cross-fertilisation between music therapy and community music, recognising their similarities while preserving their differences.

1.5 Group singing for people with dementia

Group singing is increasingly recognised as a potentially beneficial intervention for community-dwelling people with dementia. In the UK, the Alzheimer's Society provides "Singing for the Brain" sessions which are popular and often over-subscribed, with waiting lists of up to a year. Other organisations and individuals run singing sessions but provision varies geographically. Various providers of singing groups (e.g. organisations such as the Alzheimer's Society and Mindsong) have their own models but independent providers may follow their own path, and there has been little research into the particular characteristics of a supportive and helpful singing session. Some features are common among these groups: most involve people with dementia making music alongside their carers, are based around singing familiar songs and include time for socialising. Initial evidence for the benefits of singing groups is promising but limited, and no large scale randomised controlled trials of community singing for people with dementia have yet been carried out.

Most of the research evidence about the effects of group singing comes from small quantitative studies and evaluations of pilot projects, and the results are mixed and understandably inconclusive, given the scale of the investigations. One study found that group singing could improve mood, lucidity, and focus in people with dementia (Davidson & Almeida, 2014), although other research using standardised measures of mood, quality of life, and behavioural and psychological symptoms of dementia found no change after attending a singing group (Camic, Williams, & Meeten, 2011; Davidson & Fedele, 2011). However, qualitative findings are more

encouraging. Researchers report enthusiastic responses from people with dementia and their carers, who enjoy the experience of singing, trying something new and taking part in an activity which they can do together (Camic et al., 2011). Group singing may also have benefits for couples' relationships, since it provides an accessible experience which may bring them closer together and in which they are equal partners (Unadkat, Camic, & Vella-Burrows, 2016).

Despite the high uptake of groups like "Singing for the Brain" and enthusiastic responses from their members, there is currently little research which has shown evidence of their benefit, as well as a lack of information about what makes an effective singing group and guidance on how to run them. Before larger-scale research can be undertaken, there is a need to develop our understanding of the characteristics of a successful singing group and how we may measure its benefits.

1.6 The CHORD manual

The CHORD (CHOrus Research in Dementia) manual has been developed by Dr Orii McDermott in collaboration with other music therapists to provide guidance to those who wish to run singing groups for people with dementia (McDermott, 2018). The manual contains practical support for setting up a singing group, along with musical advice and ways to approach working with people with dementia. The manual has been developed in consultation with several music therapists using consensus methods with the aim of producing a "replicable evidence-based singing intervention for people with dementia and their carers" (CHORD protocol, p.1, unpub.). The project raises questions about whether music therapy techniques can be successfully shared with non-music-therapists, and whether this approach is beneficial both for the facilitators and for those who attend the groups.

The CHORD manual is not a set of instructions to be rigidly adhered to, but rather a collection of structured hints and tips. It also encourages the facilitator to be reflective and thoughtful about their role. The manual is about 50 pages long and is divided into several sections. The initial part has guidance about how to set up the group and practical considerations, such as how to choose a suitable venue. Subsequent sections have suggestions for a possible session structure, ideas for musical activities, and troubleshooting tips for when things do not go to plan. There is also guidance about how to work sensitively with people with dementia, and throughout the manual, the authors emphasise that when working with this kind of group, *how* you do things is often just as important as *what* you do. Sample pages from the CHORD manual are provided in Appendix 1.

As well as providing a resource for leaders of singing groups, one of the key aims of the CHORD manual is to ensure that sessions are run in a way which is consistent and replicable. Many singing groups rely on the skills and experience of individual facilitators, who use their finely-honed intuition to judge what is appropriate for a certain group in a particular context. The result is that although there may be many facilitators providing excellent singing group experiences, the qualities which make these sessions successful are not documented or well understood. Creating a manual like CHORD, based on the experience and knowledge of people who have run this kind of group, offers a way to define and describe the characteristics which make an effective singing session, with the aim that others will be able to use the manual to replicate these sessions. This approach raises several questions; one is about the limitations of communicating the necessary information through written words only, with no accompanying face-to-face training or audio-visual material. This issue was given extensive consideration by the team who developed CHORD. A second question is about whether it is possible to define and describe the features which make singing groups successful in a way which also preserves the qualities of

a facilitator who uses their intuition to respond flexibly and spontaneously to the needs of the group.

The CHORD manual has already undergone field-testing with a music therapist leading the sessions. The main aim of the present PhD project was to evaluate the manual further, with a view to the future development of a protocol for a randomised controlled trial. Consideration of the CHORD manual in the context of the evidence base for singing and dementia led to further questions about how we measure the benefits of music, and how we decide what to measure. The aims of this doctoral study and the structure of the thesis are outlined in the sections below.

1.7 Aims of this doctoral study

The overall topic of this doctoral study is an exploration of ways to expand access to singing groups for people with dementia. This aim is expressed in three objectives for the thesis:

1. To test the CHORD manual, an approach to music therapy skill sharing, in practice;
2. To understand the experience of singing groups in order to run sessions which are effective and relevant;
3. To assess the feasibility of research methods aimed at empirically demonstrating the value of singing for people with dementia, with a particular focus on outcome measures.

To this end, this doctoral study sets out to situate group singing and the CHORD manual in the context of literature and professional practice with two complementary literature reviews which compare research trends in music and dementia with the realities of music therapy practice. It further aims to assess the

potential of the CHORD manual as a tool for leaders of singing groups by trying it out in a "real-world" setting. Finally, this doctoral study will evaluate the feasibility and understand the specific challenges of research in this area by collecting empirical data on the benefits of group singing and the challenges of capturing them.

1.8 Structure of this thesis

The thesis is divided into eight chapters. Following this introduction, Chapter 2 is a meta-narrative review of outcome measures and indicators which have been used to assess the impact of music-based interventions upon people with dementia. After surveying the papers included in the review, narratives are developed to explore the underlying reasons for choices made by researchers. Chapter 3 presents a Critical Interpretive Synthesis of case studies involving music therapy for people with dementia, exploring what benefits are experienced by the clients in the case studies. The findings from this review are synthesised with the findings from the meta-narrative review, to understand how well research has reflected the realities of practice.

Chapter 4 discusses the underlying methodological considerations which have been taken into account when designing the present study, while Chapter 5 outlines the research questions and the details of the mixed-methods approach which has been taken to answer them. Chapter 6 presents the findings from the qualitative and quantitative components of the study. In Chapter 7, these findings are synthesised and discussed in relation to each of the research questions in turn, before a further discussion of the implications of the research for theory and practice, as well as its strengths and limitations. Chapter 8 summarises the main conclusions of the thesis and suggests directions for future work in this field.

Additional information, such as publicity material for the study, is included in the appendices and referred to within the text.

Chapter 2: Meta-narrative Review

2.1 Introduction

The following chapter presents the methods and findings from a meta-narrative review which investigates the outcome measures and indicators that have been used to assess the impact of music upon people with dementia. The meta-narrative analysis looks for patterns and trends within the choices made by researchers, and considers the influence of underlying factors, such as disciplinary trends and societal attitudes, in shaping these choices. Overall, the review surveys the outcomes which are considered measurable and important in the field, and interrogates the motivation behind these decisions.

2.2 Rationale

Music interventions for people with dementia are gaining in popularity and prevalence, and may take a variety of forms. Music listening activities are common, involving both live and recorded music which is played for people with dementia, in some cases with an element of personalisation (e.g. Playlist for Life). Participatory activities, such as singing or instrumental playing take place in large groups or 1-to-1 settings, or anything in between. Music therapy sessions may be conducted on a group or individual basis and involve a qualified professional who uses interaction through music to support the person with dementia and work towards clinical aims. Each of these interventions may take place in domestic, residential, community or medical settings, and (with the exception of music therapy) may be led by anyone: therapist, paid or family carer, professional or amateur musician. It is clear that these interventions have points of similarity, but vary hugely in their content as well as the resources required to implement them. It has become common to hear that music is beneficial for people with dementia, but such claims often lack contextual information which would help us to

understand more about the factors which mediate the benefits conveyed by a particular intervention.

Furthermore, despite the widespread understanding that music can have beneficial effects for this population, distilling the essence of this phenomenon into something which can be measured is challenging. One reason for this is that the mechanisms involved in the human response to music are complex and not yet fully understood. Another is that musical preference is personal, and what stimulates and moves one person may do nothing for someone else (Schäfer & Sedlmeier, 2009). Finally, the needs met by musical interventions are different for every person (McCabe, Greasley-Adams, & Goodson, 2015). The challenges of empirically measuring outcomes from singing groups are highlighted by Davidson & Fedele (2011). After a six-week singing group programme benefits were reported by people with dementia and their carers, and a set of rich qualitative data were gathered through a questionnaire. However, the chosen validated outcome measure, the Quality of Life scale for Alzheimer's Disease, did not reflect the depth of gains indicated by the study-specific outcome measures.

McDermott, Crellin, Ridder, & Orrell (2013) point out that many quantitative studies of music therapy in dementia focus on reducing neuropsychiatric symptoms. This may be because there are more well-established tools for assessing such symptoms, or because reduction of distressing and disruptive symptoms is a priority for the carers of people with dementia. It may be easier to measure reduction in negative symptoms than it is to notice and quantify improvements in positive aspects, such as quality of life. There are obvious practical advantages of using outcome measures which can be completed through external observation when working with a population with cognitive impairment, though there is evidence that people with quite severe dementia can still answer questions about quality of life (Moyle et al., 2011). In recent years, thanks to the pioneering work

of dementia activists, researchers have begun to understand that integrating views of people with dementia into research design, practice and dissemination is essential, and the inclusion of high-quality Public Participation and Involvement work (PPI) at all stages of the research process is becoming the norm.

The field of music and dementia is still a relatively new one, but it has been approached by researchers from different areas, such as music therapy, psychology, sociology and nursing. The main reason for undertaking this review is to test the hypothesis that researchers from different fields may have different conceptual frameworks for the possible impact of music interventions, and that these differences are reflected in their choices of outcome measures. Unlike other narrative review methods, meta-narrative review is an approach which is specifically designed for inquiries which consider the variety of research approaches to a particular topic. The narratives which are developed from analysis of the data aim not only to describe how researchers have approached a topic, but also to understand what underlying factors influence the difference in approach. The resulting review tells the story of how research traditions develop and are influenced by social, cultural and political forces.

The principle of meta-narrative review is founded on Kuhn's idea that science develops in paradigms which are field-specific. Researchers develop "rules and standards which are considered self-evident by those working in a particular field, but which are not universally accepted" (Greenhalgh et al., 2005, p. 418). According to Kuhn's theory, scientific paradigms differ in four main domains: the conceptual frameworks through which importance is assigned to certain objects of study, the theoretical dimension which is constructed to explain relationships between variables, the methodological approaches used to investigate, and the instruments which are accepted as appropriate tools for measurement. It is this final domain, the instrumental one, which is the focus of this review, but the

intention is that exploration of this domain will also illuminate the underlying principles of concept, theory and methodology which guide the choice of instrument. The meta-narrative review method is ideal for this subject, since it is "designed for topics which have been differently conceptualised and studied by different groups of researchers" and is therefore appropriate "for those reviews where the underlying research goal is to identify and explore the diversity of research approaches to a topic" (Greenhalgh & Wong, 2013, p. 3).

The main aim of this review is to build a picture of the outcome measures used by researchers in the field of music and dementia. This also provides insight into the kinds of outcomes that researchers deem valuable and measurable in this area. A further, separate exploration of case studies is also undertaken to examine the qualitative data contained in this neglected body of information to provide insight into the outcomes which people with dementia, music therapists and musicians experience and observe due to music interventions (see Chapter 3). The decision was taken in the present meta-narrative review to include any paper which focuses on music's impact on the health and wellbeing of people with dementia (a definition of "health and wellbeing" is provided later). This means that, for example, papers which report the effects of dementia pathology on the way the brain processes music are not included. Some studies investigated the effects of combined interventions (for example, an arts programme involving music, painting and drama). In these cases, the studies were only included in the review if the results of the various components of the intervention were treated separately.

Two notes on terminology: throughout this review, the term "music intervention" is used. In some cases, "activity" or "therapy" would be a more accurate description. However, for the sake of conciseness, "intervention" has been chosen as the best catch-all term. This review aimed to include all papers which report empirical research into the use of music to improve the wellbeing of people with

dementia. In the vast majority of papers, the research was interventional in the sense that it involved a change in the usual care or treatment of the people involved. A few papers which did not include an intervention in the study itself were included if they discussed the impact of such interventions (for instance, a paper about the meaning of music to people with dementia could include discussion about which interventions are particularly meaningful). It is important to remember that enjoying, listening to and playing music are part of lots of people's lives, and that many people with dementia continue with their musical activities in the same way as before their diagnosis. "Intervention", although a useful general term, may not be appropriate to describe specific cases, especially where music is already a part of a person's everyday life.

Much consideration has been given to the appropriate terms to use to describe the way in which the results of music interventions are measured or recorded. Where a study uses quantitative methodology, the term "outcome measure" is usually appropriate. However, this review includes studies using qualitative methods, which generally focus on processes rather than outcomes and description rather than measurement. Since outcome measures and qualitative methods are both employed to understand, observe and record the impact which music has on people with dementia, it was important to have a term which could be used that could encompass both these approaches. The word "indicator" was chosen for this purpose; where it is used in this review it refers broadly to the quantitative, qualitative, and mixed methods approaches to examining the effects of music.

2.3 Objectives

The aim of the review is to address the following four questions:

1. How has the impact of music interventions upon people with dementia been evaluated through research?

2. How have different research fields approached this topic?
3. How has the treatment of this area changed over time?
4. How has this area been influenced by changing attitudes to dementia?

2.4 Inclusion and exclusion criteria

Inclusion criteria

- Articles written in English.
- Articles published in peer-reviewed journals
- Studies involving people with dementia, at any stage of the condition
- Studies conducted in any setting: domestic, community, care home or hospital.
- Studies using any kind of qualitative, quantitative or mixed evaluation methods
- Studies concerning any kind of live or recorded music intervention which has the stated goal of promoting health and/or wellbeing.
- Case studies can be included if they use an outcome measure
- Published from 1970 onwards

Exclusion criteria

- Conference/meeting proceedings, posters, letters, editorials, reflective articles, systematic reviews, book chapters, essays
- Studies with a mixed population which do not differentiate the results of people with dementia from the rest of the participants.
- Studies of people with dementia which use a mixed intervention, but do not differentiate the results from the musical component from the rest of the results.
- Studies which measure response to music but do not have a wellbeing/health goal (e.g. enquiries into the cognitive processes involved in musical activities)

- Studies which do not make it clear whether participants have dementia or not
- Studies which focus specifically on dementia caused by Stroke, ALS, Huntington's disease and Parkinson's disease.

2.5 Definitions

Establishing a definition of "health and wellbeing" is important if it is to be used as an inclusion criterion. However, it is a rather nebulous term and is difficult to define. The Department of Health's white paper, *Our Health and Wellbeing Today,* uses "a broad definition of health that encompasses both physical and mental health, as well as wellbeing" (Department of Health, 2010, p. 6), while wellbeing is defined thus:

> *"…a positive physical, social and mental state; it is not just the absence of pain, discomfort and incapacity. It requires that basic needs are met, that individuals have a sense of purpose, that they feel able to achieve important personal goals and participate in society. It is enhanced by conditions that include supportive personal relationships, strong and inclusive communities, good health, financial and personal security, rewarding employment, and a healthy and attractive environment."* (Defra, 2010, p. 68)

Since the former definition includes wellbeing as a facet of health, while the latter includes health as a facet of wellbeing, it appears that the two terms are intrinsically linked. Building on the definition offered by DEFRA, I propose that an intervention be included if it promotes one or more of the following

- Sense of purpose *(occupation, identity)*
- Achieving personal goals *(occupation)*

- Taking part in society *(inclusion)*
- Supporting/strengthening personal relationships *(attachment, comfort, love)*
- Social inclusion *(inclusion, attachment)*
- Physical and mental health *(comfort)*
- Rewarding employment/meaningful activity *(identity, inclusion, occupation)*

It is important to consider the specific meanings that wellbeing may have for people with dementia in particular. For this reason, I have included "meaningful activity" alongside "rewarding employment" as this may be more relevant to a person with dementia who is no longer able to work. The seven domains listed above can each be linked with at least one of the six emotional needs of people with dementia as proposed by Kitwood (1997): love, comfort, attachment, inclusion, occupation and identity.

2.6 Search strategy for identification of studies

Databases included in search

PsychINFO

Medline

CINAHL

EMBASE

Web of Science

British Journal of Music Therapy

Journal of Music Therapy

Nordic Journal of Music Therapy

Search terms and search structure

Search terms for dementia or dementia care settings: dement*, Alzheimer*, "nursing home*", "care home*", hospice or hospital*, AND **search terms for music**: music therapy, music*, sing or sings or singing or singer or singers or song* or choir* or choral*, or listen*, "playing instrument*" or "learning instrument*", or GIM or "guided imagery in music". Relevant topic keywords or MeSH headings were used if the journal search function permitted it. The search strategy was simplified for databases/journals which do not support complex searches.

The following is an example of the search strategy for Medline.

1 exp DEMENTIA/
2 (dement* OR alzheimer*).ti,ab.
3 ("nursing home*" OR "care home*" OR hospice OR hospital*).ti,ab.
4 #1 OR #2 OR #3
5 exp MUSIC/
6 exp MUSIC THERAPY/
7 (music* OR sing OR sings OR singing OR singer* OR song* OR choir* OR choral* OR playlist* OR listen* OR GIM).ti,ab.
8 (guided imagery adj3 music).ti,ab.
9 ((play* OR learn*) adj3 instrument*).ti,ab.
10 #5 OR #6 OR #7 OR #8 OR #9
11 #4 AND #10

The following is an example of the search strategy for Web of Science.

1 TOPIC: (DEMENTIA)
2 TITLE: (dement* OR alzheimer*)
3 TITLE: ("nursing home*" OR "care home*" OR hospice OR hospital*)

4 #1 OR #2 OR #3

5 TOPIC: (MUSIC)

6 TOPIC: (MUSIC THERAPY)

7 TITLE: (music* OR sing OR sings OR singing OR singer* OR song* OR choir* OR choral* OR playlist* OR listen* or GIM)

8 TITLE: ("guided imagery" NEAR/3 music)

9 ((play* OR learn*) NEAR/3 instrument*)

10 #5 OR #6 OR #7 OR #8 OR #9

11 #4 AND #10

2.7 Method of Review

2.7.1 Selection of studies

The initial search was performed, and titles were reviewed for inclusion/exclusion according to the predefined criteria. Information on the database used, the timespan, the search strategy used for each database, the number of references retrieved and the date of searches were recorded for each search. References in relevant papers were searched for papers which may have been missed by the initial search. If systematic reviews were returned by the search, their references were checked for relevant papers. Hand searches were performed in any journals which are not fully indexed by databases (this applies particularly to some music therapy journals). In the first instance, the titles of papers retrieved were screened and clearly irrelevant papers were excluded. Abstracts for papers which pass this first screening stage were retrieved and screened for inclusion. Full texts of papers which are included at abstract level were obtained and examined. The reasons for excluding any paper after examination of the full text were recorded.

2.7.2 Assessment of methodological quality

Quality assessment of the studies was not performed; since the review focuses on the indicators selected by researchers rather than the actual findings, it was considered relevant to include studies of varying methodological quality.

2.7.3 Data extraction

A form was created (using Google forms) to facilitate data extraction. Data was extracted across the domains described in Table 2:1. Explanation of each field is given if necessary and the format of each data field on the form is also provided below. Where "other" is given is as an option, a space was provided to record details. A sample of the form is available here https://goo.gl/forms/PSkAA3qy3YxLB7Zo1.

Table 2:1: Form used for systematic review data extraction

Data field	Explanation	Field format
Author(s)	All named study authors	Free text field
Year	Year of publication	Free text field
Title of paper	Full name of publication	Free text field
Journal	Journal of publication including volume, issue and page numbers	Free text field
Description of intervention	Brief outline of the intervention and study design	Free text field
Category of intervention	Music in health, Music therapy, Music listening, other or not stated	Multiple choice – pick one
Setting	Care home, community setting, hospital, other	Checkboxes – check all that apply
Study methodology	Qualitative, Quantitative, Mixed Methods, Case Study, or other	Multiple choice – pick one

Outcome measure(s)	List of all outcome measures used in the study	Free text
Are the outcome measures used validated?	State whether all, some or none of the outcome measures used in the study are validated.	Multiple choice – pick one
Type of dementia	Alzheimer's, Vascular dementia, Mixed, not stated or other	Multiple choice – pick one
Mean age of participants	Give the mean age if it is stated in the study	Free text field
Severity of dementia	Mild, moderate, or severe	Checkboxes – check all that apply
Sample size	The total number of study participants	Free text field

Once data had been extracted from all included studies, the data were imported into an Excel spreadsheet. Tabulation was used to summarise the data.

2.7.4 Synthesis

Greenhalgh and Wong (2013) outline six underpinning principles for meta-narrative reviews:

1. Pragmatism – it is not obvious what to include/exclude; the intended audience and purpose of the review must be considered when making these decisions.
2. Pluralism – avoid examining the subject from only one perspective or starting from a position of assuming a certain field of enquiry is superior to others. Make sure to include multiple angles.
3. Historicity – having an understanding of how research traditions have unfolded over time helps to build up a picture of their development.
4. Contestation – data from different research traditions which disagree should be scrutinised to reveal underlying reasons for the discrepancies.

5. Reflexivity – the reviewer(s) needs to continuously reflect on the emerging results.
6. Peer review – need to seek and respond to the opinions of external peers on the developing meta-narrative.

These principles were followed when conducting the synthesis of data from this review. In order to develop the meta-narratives, the data extracted from the included papers was reviewed and the outcome measures and/or indicators they used were categorised in terms of the domain they evaluate (e.g. mood, engagement, quality of life etc.). Graphical methods were used to explore the type and frequency of outcome measure usage, as well as changes in the field over time and the kinds of musical interventions that were evaluated. The researcher read additional papers and books not included in the review for background information and socio-historical context , and this information was used to shape the meta-narratives and understand how perspectives on dementia developed over time. Meta-narratives were developed with constant reference to the trends shown by the data from the papers in the review, and developing meta-narratives were discussed with the researcher's supervisors.

2.8 Results

2.8.1 Characteristics of the data

Figure 2:1: PRISMA flow chart

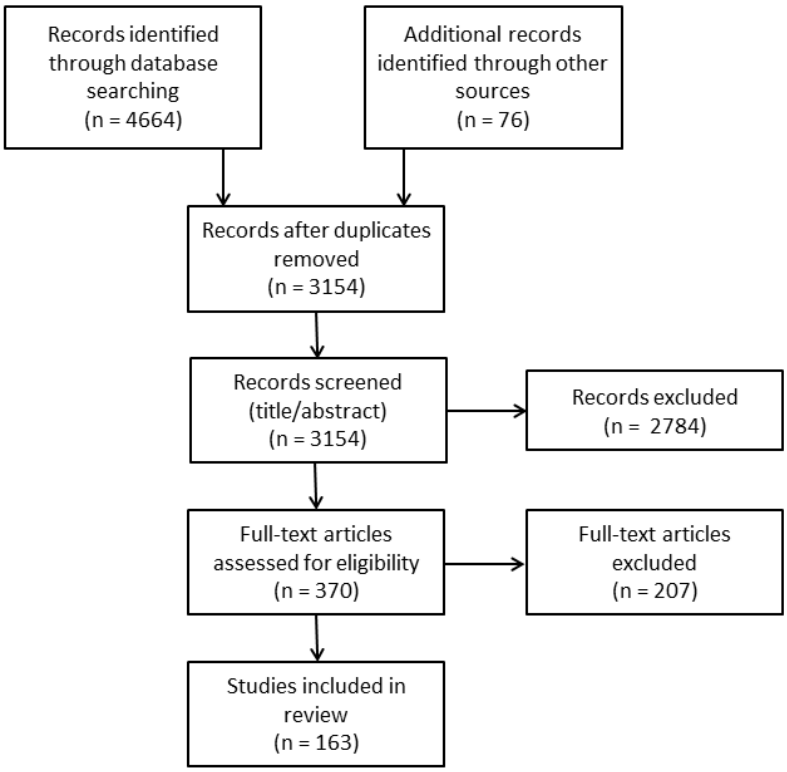


Figure 2:1 shows the flow of articles through the review process. A total of 163 papers were included in the review. These represent the findings of 154 studies. References for the included papers are provided in Appendix 2. In this section the data which was extracted from the included papers is summarised and graphically represented. Some studies were reported in more than one paper; in these cases, the data from each paper were combined so each study is only reported once. Figure 2:2 shows that the majority of studies were conducted in residential care settings. Note that some studies involved more than one setting; this was the case for 13 studies. Some difficulty was encountered in categorising the settings, mainly due to differences in the way healthcare settings are named across cultures. For example, "hospital" is sometimes used to describe a setting which in the UK would

be categorised as residential care. In these cases, when extracting the data, the study was categorised according to the language used by the authors.

Figure 2:2: Settings of studies

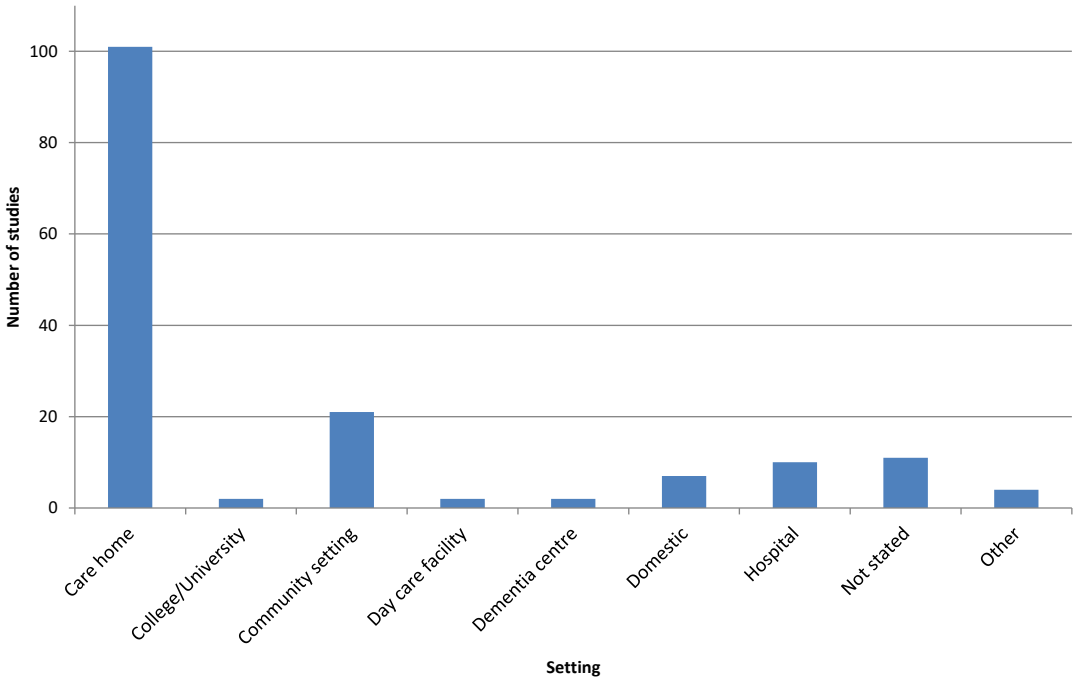
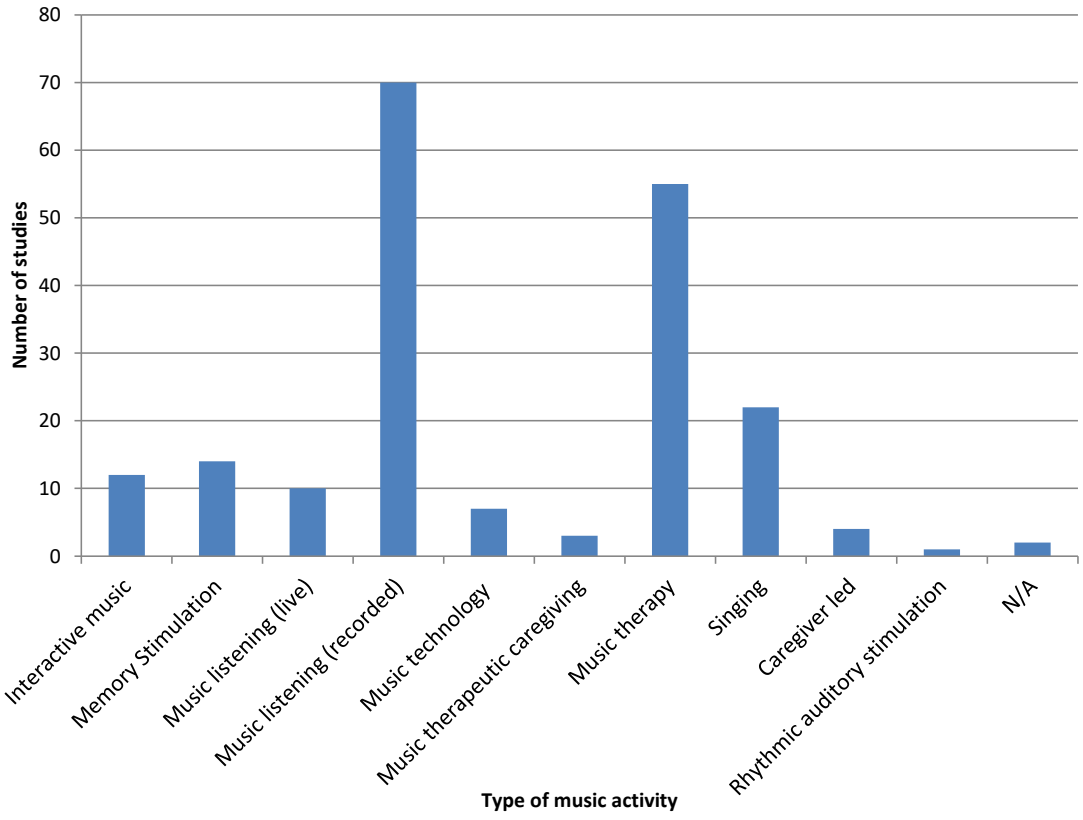


Figure 2:3 shows the different types of music intervention in the included studies. Some studies used music in more than one way, for example if they were comparing music therapy sessions with group singing. If a study described a musical approach which could be placed into two categories, it was recorded in both. For example, a music therapy approach which was explicitly described as singing-focused was recorded under "music therapy" and "singing". The category "memory stimulation" was created to represent the use of music with the explicit aim of improving recall of information or memories. Listening to recorded music was the most widely used intervention in the included studies (n=69), which is perhaps indicative of the ease with which it can be administered. 55 studies fell under the "music therapy" category, representing an established research

tradition. 22 studies involved singing; the other categories are populated by small numbers of studies. Occasionally, there was uncertainty over whether the description of a study as involving music therapy was accurate, as some authors use the term to refer to any use of music with therapeutic intent, and regulations regarding the term vary across the world. When there was uncertainty, descriptions of the training and qualifications of the person(s) leading the intervention were checked, and the study was classified as music therapy if the said person was described as a qualified or accredited music therapist.

Figure 2:3: Types of music activity



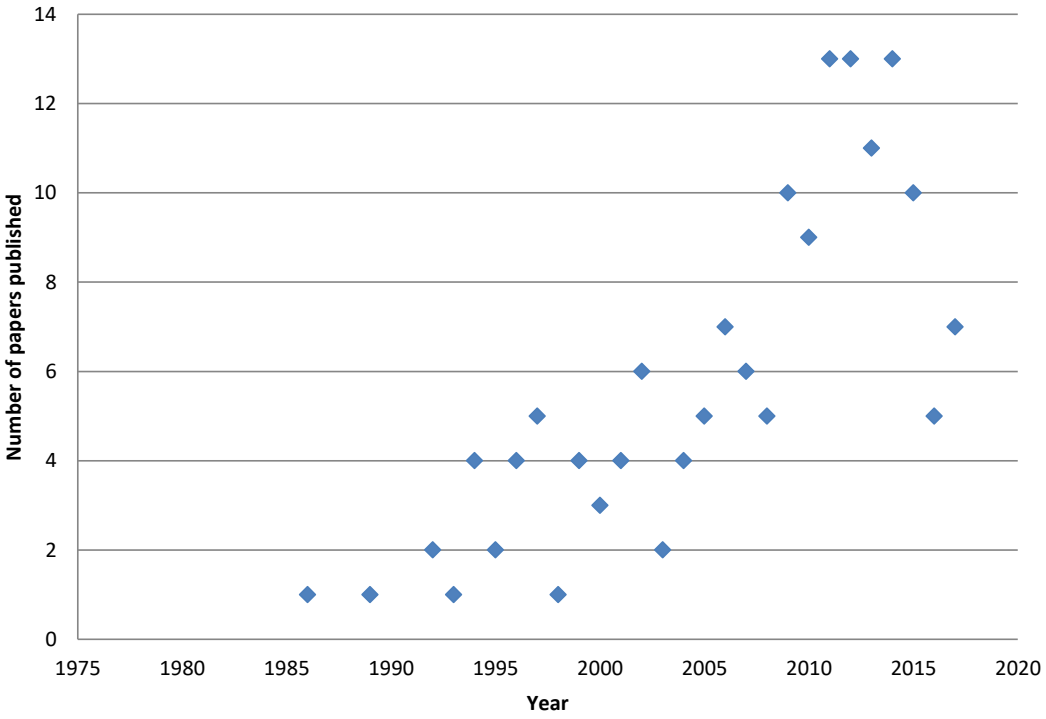
A majority of the studies (83%) used quantitative methodology, whilst 7% of studies were qualitative and 7% were mixed methods. Two case studies were included (1%). The remaining 2% of studies were categorised as "multi methods"

meaning that they used some qualitative and quantitative methods, but did not integrate them.

One interesting aspect of the data is the types of dementia experienced by the people in the studies and the way these are reported by authors. 38% of studies stated that participants all had diagnosed or probable Alzheimer's disease, whilst 23% reported a mixture of different types of dementia and clearly stated this in the article. Two studies focused exclusively on fronto-temporal dementia, and one on three different named types, but the remaining 40% did not report the type of dementia at all. This may be because study authors felt that the severity of dementia was more relevant than the type, due to the difficulty of conclusive diagnosis and the prevalence of mixed dementia. Dementia severity was frequently reported, either by describing it as mild, moderate or severe, or through mean/standard deviation and range of MMSE scores.

2.8.2 Change over time

Figure 2:4: Number of papers by year



The approach to meta-narrative review described by Greenhalgh and Wong (2013) emphasises the importance of historicity: considering how research traditions have unfolded over time. Figure 2:4 shows how the number of papers (NB. not studies) published per year has gradually increased the past 40 years, from very few in the 1980s to more than ten per year in recent years. This graph indicates a trend towards increased research interest in this field, although other factors may be at play, such as the wider availability of publishing outlets. The factors influencing the development of publications in this field over time will be explored in more detail at a later stage.

2.9 Research paradigms and outcome measures

The preceding section has described the characteristics of the studies which were included in the review and has summarised and graphically represented them. The following section outlines the approach which was adopted for analysis of the data and for developing meta-narratives, and includes the rationale for focusing on outcome measures and indicators in order to focus the inquiry.

The main reason for undertaking this review was to test the hypothesis that researchers from different fields may have different conceptual frameworks for the impact of music interventions upon people with dementia, and that these differences are reflected in their choices of indicators. In reviewing the indicators chosen by researchers from different fields, the aim is to gain insight into the outcomes which have been considered important within the various paradigms, and to investigate the indicators which might be appropriate for research which occupies the unclear territory between music therapy and "therapeutic music".

Meta-narrative review is founded on Kuhn's idea that science evolves in paradigms which are field-specific. Researchers develop "rules and standards which are considered self-evident by those working in a particular field, but which are not universally accepted" (Greenhalgh et al., 2005, p. 418). According to Kuhn's theory, scientific paradigms differ in four main domains: the conceptual frameworks through which importance is assigned to certain objects of study, the theoretical dimension which is constructed to explain relationships between variables, the methodological approaches used to investigate, and the instruments which are accepted as appropriate tools for measurement (T. S. Kuhn, 1962).

The studies included in this review proved more difficult to classify in terms of paradigms than initially anticipated. Researchers do not always make their

ontological and epistemological positions (or "conceptual frameworks") clear. Relationships between variables are implied but not necessarily explored, and methods are described while underlying methodological considerations are not. One reason for this is the "self-evident" nature of the rules and standards followed by each research paradigm (Greenhalgh et al., 2005, p. 418); they are not explored because they are assumed to be understood by the intended audience. This makes comparison of different research paradigms difficult. There are also problems over terminology and with categorising interventions in this review. For example, "music therapy" is frequently used to describe therapeutic uses of music in the literature which would not be considered music therapy according to the UK definition. This may be because music therapy is not clearly understood or defined, or because of differences in terminology which exist between countries. The uses of music captured by this review are diverse, and even within a seemingly straightforward category such as "Music Listening (Recorded)" there is a world of difference between, for example, playing some classical music as background during mealtimes and engaging someone in a listening activity with personally significant music.

The approach taken in the following section of the review is based upon Kuhn's fourth "domain": the instruments which are accepted as tools for measurement (T. S. Kuhn, 1962) We can take the instrument as a starting point and ask "What does the choice of an indicator tell us about the researcher's position on the potential of music?" For example, if a study uses the Cohen-Mansfield Agitation Inventory as an outcome measure, one might reasonably assume that the authors of the study hypothesised that music could affect agitation. It may or may not have features in common with other studies that use an instrument to measure agitation. Examining the studies in this way may lead to insight into the differing theoretical perspectives on the mechanisms which operate to bring about change through music. This approach places Kuhn's fourth domain, the instruments used for

measurement, as the paradigm at the centre of the review. The following section describes and summarises the outcome measures and qualitative methods which have been used in the studies included in this review.

2.9.1 Quantitative outcome measures

Table 2:2: Frequency of quantitative outcome measures

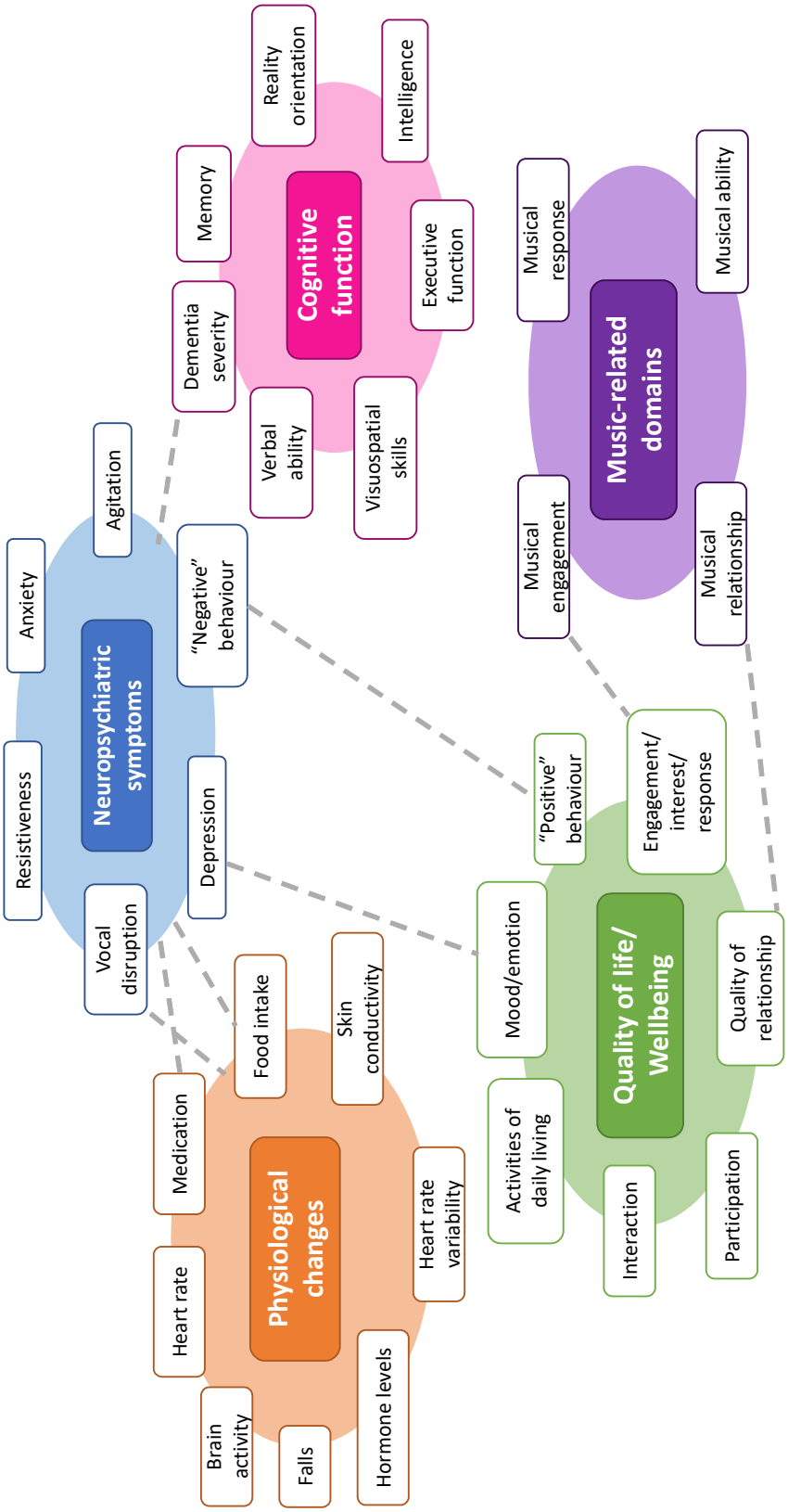
Outcome measure	Stands for	Relates to domain	Times used
CMAI	Cohen Mansfield Agitation Inventory	Agitation	30
MMSE	Mini-Mental State Examination	Cognitive function	16
NPI	Neuro-Psychiatric Inventory	Neuropsychiatric dementia symptoms	12
CSDD	Cornell Scale for Depression in Dementia	Depression	6
DCM	Dementia Care Mapping	Quality of life	5
RAID	Rating Anxiety in Dementia	Anxiety	5
GDS	Geriatric Depression Scale	Depression	4
Barthel Index		Activities of Daily Living	3
BEHAVE-AD	Behavioral Pathology in Alzheimer's Disease Rating Scale	Behaviour	3
OERS	Observed Emotion Rating Scale	Mood	3
QoL-AD	Quality of Life - Alzheimer's Disease	Quality of life	3
TEMPau	Test épisodique de mémoire du passé	Memory	3
BANS-S	(Bedford Alzheimer Nursing Severity Scale	Dementia severity	2
CBS-QoL	Cornell-Brown Scale for Quality of Life in Dementia	Quality of Life	2
DBRS	Disruptive Behaviour Rating Scale	Behaviour	2
LMBS	Lawton's Modified Behaviour Stream	Mood	2
MADRS	Montgomery-Åsberg Depression Rating Scale	Depression	2
MiDAS	Music in Dementia Assessment Scale	Musical engagement	2
MPES	Menorah park engagement scale	Engagement	2
PFC	Paper Folding and Cutting	Cognitive function	2
STAI	State-Trait Anxiety Inventory	Anxiety	2

Table 2:2 shows all the standardised quantitative outcome measures which were used more than once in the included studies, the domain to which they relate, and the number of times that each was used. They are arranged in descending order of frequency. The CMAI, MMSE and NPI were used more than ten times each, while the next most frequently used measure (CSDD) was used only six times. The wide use of these three most popular measures perhaps reflects their status as well-established and tested tools. This theory is supported by the relative lack of other tools which were used to quantify these domains: agitation is only measured by

one other tool, cognitive function by five other tools each only used once. No other tools are used which measure the full spectrum of neuropsychiatric symptoms of dementia, and the popularity of the NPI may be due to the fact that it encompasses a range of other domains (agitation, anxiety, depression etc.) which may be measured in more detail with more specific tools.

Figure 2:5 visually represents the domains measured by all the standardised tools and how they relate to each other. The domains were derived by compiling a list of the variables targeted by each of the outcome measures and grouping them together in related categories. There are five main domains with a number of sub-domains: neuropsychiatric symptoms, cognitive function, physiological changes, quality of life, and music-related measures. Dotted lines represent clear links across the domains; for example, depression and mood are strongly related, although there may be a paradigmatic difference between a tool which measures depressive symptoms and one which records indicators of positive mood. These five domains provide a framework for thinking about the potential of music which the studies' authors have identified and deemed worthy of investigation. It is possible that they may represent separate but related research paradigms. These five domains were used as a framework for investigating the shared characteristics of studies which use each of them as the variable of interest. In order to do this, I returned to the full texts and examined them for the motivations underlying the choice of these measures. It is important to note that some studies fall into more than one domain; this allows insight into which domains are often considered together and draw links between them. The results from the quantitative studies were compared with those from the studies which use qualitative methods, to ascertain whether qualitative methods are being used to investigate the same domains or to address completely different questions. Quantitative studies which used study-specific measures were included in this analysis; they were assigned to a domain based on the description of the measure.

Figure 2:5: Visual map of outcome measure domains



The following section examines the full texts of studies which used quantitative outcome measures for each of the five domains, in order to explore the underlying theoretical and methodological assumptions which guide the choice of instrument. Variation in use of these measures over time is also described.

Quality of life/Wellbeing

The domain "quality of life/wellbeing" refers to studies which use direct measures of quality of life and wellbeing, as well as studies which address factors that affect quality of life, such as ability to carry out daily tasks and relationships with other people. Studies using a measurement of what has been loosely termed "positive behaviour" are included in this domain; "positive" in this sense refers to measurement of behaviours which are an indicator of wellbeing (e.g. engaging with music, being social with others). 28 studies (18%) were categorised only in the "quality of life" domain, while a further 22 (14%) include quality of life among other measures. Papers measuring quality of life in the 1990s are often associated with music therapy; later, other types of intervention appear as well. The earlier music therapy papers do not used standardised QoL scales, but instead create behavioural checklists or inventories which are specific to each study. For example, Pollack and Namazi (1992) designed a checklist to record the frequency of social and non-social behaviours of participants, while Clair and Bernstein (1990) measure the duration of specific responses such as singing, communicating and interacting with a musical instrument. In these papers, music is hypothesised to promote social engagement and purposeful activity which may be compromised by cognitive impairment; the checklists are intended to show that music can affect behaviour in a desirable way.

Many later papers use standardised outcome measures but also cite music's potential to engage cognitively impaired and under-stimulated individuals in

meaningful activity, especially by providing a means for making social contact with others (Cevasco, 2010; Cohen-Mansfield, Marx, Thein, & Dakheel-Ali, 2011; Engstrom, Hammar, Williams, & Gotell, 2011; Melhuish, 2013; van der Vleuten, Visser, & Meeuwesen, 2012). Several studies draw an explicit link between boredom resulting from lack of stimulation, and disruptive behaviour (Cheong et al., 2016; Cohen-Mansfield et al., 2011). Two studies concerned a music-based technology which people with dementia were intended to operate themselves, which was hypothesised to have beneficial effects on their wellbeing by increasing self-reliance (Lancioni et al., 2013, 2014). The phrase "promoting wellness" is used by one study (Clements-Cortes, 2013), whereas many of the others seem to explicitly link quality of life with the absence of behavioural and psychiatric symptoms. This raises questions about whether quality of life is represented by the presence of a positive state of being, or whether it is merely the absence of negative symptoms which detract from wellbeing. It is also worth noting that later papers included ratings of QoL which are given directly by people with dementia, rather than through observation or caregiver report (Davidson & Fedele, 2011; Särkämö et al., 2014).

Physiological Variables

11 studies (7%) measure only physiological variables. Four of these focused on nutrition, one on brain activity, three on aspects of motor functioning and two on hormone levels. A further ten studies (6%) include measurement of a physiological variable alongside other measures, commonly neuropsychiatric symptoms. In several cases an explicit link is drawn between reduction of neuropsychiatric symptoms and a favourable physiological outcome. For example, Gill & Englert (2013) link agitation levels in people with dementia to an increased risk of falls, so music is explored as a means of reducing agitation and therefore reducing falls. The four studies which focus on nutrition draw similar links; Thomas & Smith (2009), Ragneskog et al. (1996) and Wong et al. (2008) hypothesise that playing

background music at mealtimes could improve the environment and decrease stress and anxiety, while McHugh et al (2012) investigated whether pre-meal music therapy would lead to improved functioning that "carries over" into mealtimes. The study which measures brain activity using Near Infra-Red Spectroscopy links increased prefrontal lobe activity to "effective brain rehabilitation" but does not clearly define what this means (Tanaka & Nogawa, 2015; Tanaka, Nogawa, & Tanaka, 2012). Clair and O'Konski (2006) explore Rhythmic Auditory Cueing (RAC) to improve gait, linking falls and decreased mobility resulting from unsafe walking to decreases in physical health and QoL, while Wittwer et al. (2013) also use RAC and associate improved gait with decreased cost of care and increased life quality. Finally, Fukui et al. (2012) investigate whether music therapy can increase levels of hormones which are thought to have a preventative effect on progress of Alzheimer's disease.

Music-related outcomes

Only seven studies (5%) use any kind of music-related quantitative outcome measure, most of these in conjunction with other measures, so these studies were all considered together. Generally, these studies used music-related measures to support the evidence provided by other outcome measures, or to explain the mechanisms by which such outcomes occur. Ceccato et al. (2012) used rating scales for evaluating musical competencies and relationship with the music therapist. They predicted that if the musical relationship improved, a decrease in neuropsychiatric symptoms would be noted, which was not in fact the case. Similarly, Raglio et al. (2015) assessed change in the musical communication of a subset of patients involved in a larger trial which was primarily investigating neuropsychiatric symptoms and quality of life, and Belgrave (2009) evaluated the participants' rapport with the music therapist as part of a study which also measured behavioural changes. Sambandham and Schirm (1995) explore music's potential to improve communication, social behaviour and memory for people

with dementia, using the Music Therapy Assessment Tool, which assesses memory as well as response to music. In a study of small-group music therapy, Keough, King and Lemmerman (2017) used items from the Assessment of Functions of Music Therapy for Persons with ADRD in Adult Day Healthcare Settings (AFMT) to monitor progress across a wide range of domains; although the tool has been developed for music therapy, it does not just focus on musical responses.

Two papers (McDermott, Orgeta, Ridder, & Orrell, 2014; McDermott, Orrell, & Ridder, 2015) report stages in the development of a tool to address the "lack of client-specific, clinically appropriate, and psychometrically evaluated outcome measures" in music therapy (McDermott, Orgeta, et al., 2014). The resulting measure (MiDAS) is intended to capture change which is individual and focused on what matters to the client, rather than just on reducing neuropsychiatric symptoms. The importance of individual preferences also underpins the study by van der Geer et al. (2009). The researchers interviewed staff at a randomly selected sample of nursing homes to find out how these homes used music with people with dementia experiencing agitation, and whether the musical preferences of the person in question played a role in determining the choice of music.

Cognitive Function

18 studies (12%) focused exclusively on the measurement of cognitive function using quantitative methods. Of these, some evaluated different types of memory (e.g. autobiographical recognition, verbal) some measured overall cognitive performance using measures such as the MMSE, and some focused on specific aspects of cognitive function such as visuospatial and language skills. From these studies, three mechanisms can be identified through which enhanced cognition from music may result in positive outcomes for people with dementia. Firstly, a decrease in neuropsychiatric symptoms brought about by music is postulated to have a positive effect on cognitive function (Bruer, Spitznagel, & Cloninger, 2007).

Secondly, music as a memory enhancer has practical applications for improving performance of activities of daily living which may enhance quality of life (Moussard, Bigand, Belleville, & Peretz, 2012; Simmons-Stern et al., 2012). Thirdly, music may be used to preserve autobiographical memories and maintain sense of identity, which also has implications for quality of life (El Haj, Antoine, Nandrino, Gely-Nargeot, & Raffard, 2015; El Haj, Clement, Fasotti, & Allain, 2013; Meilan Garcia et al., 2012).

Several studies imply that improving cognitive function is a desirable outcome for people with dementia without much discussion of why such improvement may occur (Basaglia-Pappas et al., 2013; Hong & Choi, 2011; Moussard, Bigand, Belleville, & Peretz, 2014; Simmons-Stern, Budson, & Ally, 2010). One study focused on comparing the performance of AD patients with healthy older adults; positive outcomes for the AD patients seemed to be a welcome side effect (El Haj, Postal, & Philippe, 2012). 15 out of the 18 studies involved people with AD; this may imply that improvement of cognitive performance is considered of particular importance in this population. On the other hand, it may be because research practices in these studies called for a sample with a homogenous diagnosis (in contrast with other studies in which the mixed sample is more reflective of a real-world situation).

Neuro-psychiatric Symptoms

71 studies (46%) used quantitative outcome measures to evaluate various neuropsychiatric symptoms of dementia. Of these, 58 took place in residential care settings, suggesting that the reduction of neuropsychiatric symptoms is considered to be of importance in this context. 35 studies measured agitation, 30 of these using the Cohen-Mansfield Agitation Inventory (CMAI). The extensive prioritisation of agitation is perhaps explained by the burden it places on caregivers, and the fact that decrease in agitated behaviours is fairly

straightforward to observe and measure using standard tools. Additionally, the fact that early, trial studies using CMAI produced encouraging results laid a foundation which may have encouraged future researchers to conduct larger studies using this measure (Gerdner, 2000; Gerdner & Swanson, 1993; Goddaer & Abraham, 1994). Many studies cite caregiver burden (e.g. Park & Pringle Specht, 2009) or the need to develop non-pharmacological interventions (e.g. Sung, Lee, Li, & Watson, 2012) as their reason for targeting neuropsychiatric symptoms of dementia. In other studies, decrease in neuropsychiatric symptoms is correlated with improvement in quality of life, both for people with dementia and their caregivers (e.g. Ledger & Baker, 2007).

2.9.2 Qualitative methods

11 studies (reported in 16 papers) used purely qualitative methods (7% of the total). The most commonly used methods were interviews either with caregivers and people with dementia or with caregivers alone, and qualitative analysis of video or audio material. Another 14 studies integrated qualitative methods as part of a mixed methods approach. Overall, the studies which used qualitative methods were those in which the aim of the research was not only to show whether a particular intervention worked, but to explore the underlying reasons for its success or failure and the mechanisms at play. For instance, studies which focused on the pilot stage of novel interventions (Bannan & Montgomery-Smith, 2008; Camic et al., 2011; Harris & Caporella, 2014) or the development of new technology prototypes (Peeters, Harbers, & Neerincx, 2016; Riley, Alm, & Newell, 2009; Topo et al., 2004) gathered qualitative data providing information about participants' experience which can be integrated into the development of future versions.

The nature of qualitative data means that findings of studies using qualitative methods cannot be directly compared with those using quantitative outcome

measures, as the former is more concerned with the processes while the latter focuses on the end result. However, these two forms of data may complement and inform each other. Where studies use mixed methods, synthesis of qualitative and quantitative data may show points of convergence or divergence between the data, highlighting potentially fruitful avenues for future research. Qualitative data collection may also be the first stage in the development of new quantitative outcome measures, as in the case of McDermott et al. (2015), who conducted a qualitative study as the first phase of the development of Music in Dementia Assessment Scales (MiDAS) which aim to assess how people with dementia respond to music therapy. Analysis of interviews and focus groups with people with dementia, their family members, carers and music therapists led to the development of a theoretical model for music and dementia, which describes how complex psychosocial variables interact to mediate a person's response to music. Other studies have also focused on the development of theories or models which can explain the value of music to people with dementia, and consequently represent in-depth inquiries into musical experiences (McDermott, Orrell, & Ridder, 2014; Osman, Tischler, & Schneider, 2014; Sixsmith & Gibson, 2007).

Other qualitative studies investigate the mechanisms at play in various kinds of musical interactions and interventions. One particularly in-depth inquiry reports qualitative findings across six papers from a study into the effects of "music therapeutic caregiving" (caregiver singing during personal care situations). Transcripts of conversation during care are used to explore the influence of music (Götell, Brown, & Ekman, 2002) Video analysis is used to examine vocally expressed emotion (Götell, Brown, & Ekman, 2009), verbal/non-verbal communication (Hammar, Emami, Engström, & Götell, 2011a) and the physical responses of participants (Götell, Brown, & Ekman, 2003). Finally, qualitative content analysis of interview transcripts explored the caregivers' own experiences (Hammar, Emami, Engström, & Götell, 2011b) and their perception of the

experiences of people with dementia (Hammar, Emami, Engström, & Götell, 2010). Other papers also consider the mechanisms of action within specific musical interventions such as individualised music (Johnston, Rasmusson, Foyil, & Shopland, 2017), music and dance therapy (Melhuish, Beuzeboc, & Guzmán, 2017) and live music concerts in care homes (Shibazaki & Marshall, 2017).

2.10 Developing meta-narratives

The meta-narrative review method is based upon Kuhn's idea of scientific paradigms (Kuhn, 1962). The concept is that science develops in paradigms, which guide the assumptions and decisions made by scientists. Within a paradigm, the commonly understood views and assumptions are called "normal science" by Kuhn. When a paradigm will no longer fit the evidence, it is discarded and replaced by a new paradigm, which then becomes "normal science". Drawing upon this idea, meta-narrative review examines the possibility that different disciplines have investigated the same topic from different angles, each paradigm bringing its own set of assumptions, without there necessarily being much interplay and cross-fertilisation between the fields.

Kuhn suggests that in the period before the first commonly held paradigm of any field of enquiry is established, many different and conflicting schools of thought exist, without any holding sway over the others. Using the field of optics as an example, Kuhn writes:

> *"Being able to take no common body of belief for granted, each writer on physical optics felt forced to build his field anew from its foundations. In doing so, his choice of supporting observation and experiment was relatively free, for there was no standard set of methods or of phenomena that every optical writer felt forced to employ and explain."* (1962, p. 13)

In other words, the lack of an underlying established theoretical framework means that pioneers in a field must start from the ground up. Kuhn also writes that "in the absence of a paradigm or some candidate for paradigm, all of the facts that could possibly pertain to the development of a given science are likely to seem equally relevant" (1962, p. 15). This implies that it is hard to be selective about what to include or what information is most pertinent in the absence of an established shared understanding or hierarchy of data.

Although the concept of "senility" (cognitive impairment related to old age) has been around for centuries, it is only in recent decades that we have begun to conceptualise dementia as something distinct from the normal course of human ageing, and to understand the neurological processes responsible. The central premise of this review is that understanding of both music and dementia has changed rapidly over the past four decades, and that this is reflected in the way researchers have studied and evaluated the effects which music has for people with dementia. Conceiving of this phenomenon in terms of paradigms is a way of understanding the preconceptions which may influence academic perspectives on dementia, and outcome measures represent a lens through which to focus the enquiry. The choice of outcome measure tells us what domain the researcher thought it would be possible, desirable or interesting to measure; how they believed music might effect change; who they deemed relevant to ask, and what kind of change might be observed.

Since music and dementia is still a relatively new field, and understanding of dementia itself has changed radically over the past decades, it seems possible that Kuhn's suggestion of how early work in a field may develop is relevant here, with researchers feeling the need to build their field "anew from its foundations". There are also a number of backgrounds from which researchers might be approaching this topic: medicine, psychology, nursing, social care and music therapy, to name a

few. Although a unifying underlying theoretical framework may not yet exist for music and dementia, these disciplines have their own theoretical backgrounds which researchers in this newly-emerging field may have drawn upon.

The following meta-narratives have been developed based on an overview of the papers included in the review, and upon other relevant literature from the 1970s onwards.

2.10.1 Changing attitudes to dementia in medicine and society

A prevailing view of dementia until the 1980s was that it was a normal part of getting older; that nothing could be done to help those with the condition, save for meeting their basic physical needs and keeping them comfortable. Dementia might be seen as a "death that leaves the body behind" and conceived of as an unstoppable disease which progressively strips away the essence of a person. A paper from 1979 describes the progression of dementia thus: "the personality disintegrates and the qualities that constitute a personality recede. Persons at the end of this recession appear remarkably similar" (Ropper, 1979). The understanding that dementia was in fact not an inevitable part of the ageing process led to a new interest in research focused on understanding the aetiology of dementia and developing possible drug treatments which could reverse or halt the effects (e.g. Alexander, 1972). The medical research community worked to define and classify the different types of brain disease, and there was some difficulty distinguishing between what we would now call dementia and other psychiatric illnesses which involve psychosis. In the U.S., many people with dementia were committed to mental asylums in the first part of the 20th century, and later when this practice was abandoned, nursing homes designed for the care of frail elderly people without dementia were ill-resourced to cope. There is little evidence from this time of research involving the care (as opposed to the medical treatment) of people with dementia.

Changing attitudes to care evolved alongside deeper scientific understanding of the disease process. The realisation that dementia was neither a natural part of getting older nor directly comparable to mental illness may have contributed to this change (Lyman, 1989). The biomedical model legitimised research into dementia because it "countered the longstanding ageist assumption that senility is an inevitable condition of old age"; however, it also stifled research into the psychosocial forces at play in dementia (Lyman, 1989, p. 599). In the UK, the work of Tom Kitwood was instrumental in challenging the received wisdom around care practices. Kitwood describes how he "came to believe that much more could be done to help people with dementia than was commonly assumed" (p.3). His theory was that the brain damage caused by dementia was frequently compounded by the "malignant social psychology" which pervaded dementia care; a systematic undermining of the person with dementia's rights, freedom and dignity. Kitwood's work in this field culminated with the book "Dementia Reconsidered: The person comes first", which holds that good dementia care strives to uphold "personhood" even in the face of severe cognitive impairment (Kitwood, 1997). The book is strongly critical of the "biomedical model" of dementia care, which may explain why it received a one-star review in the British Medical Journal upon its release (Flicker, 1999). Nevertheless, it has been hugely influential on care practices in the UK and upon the development of other theories of dementia care.

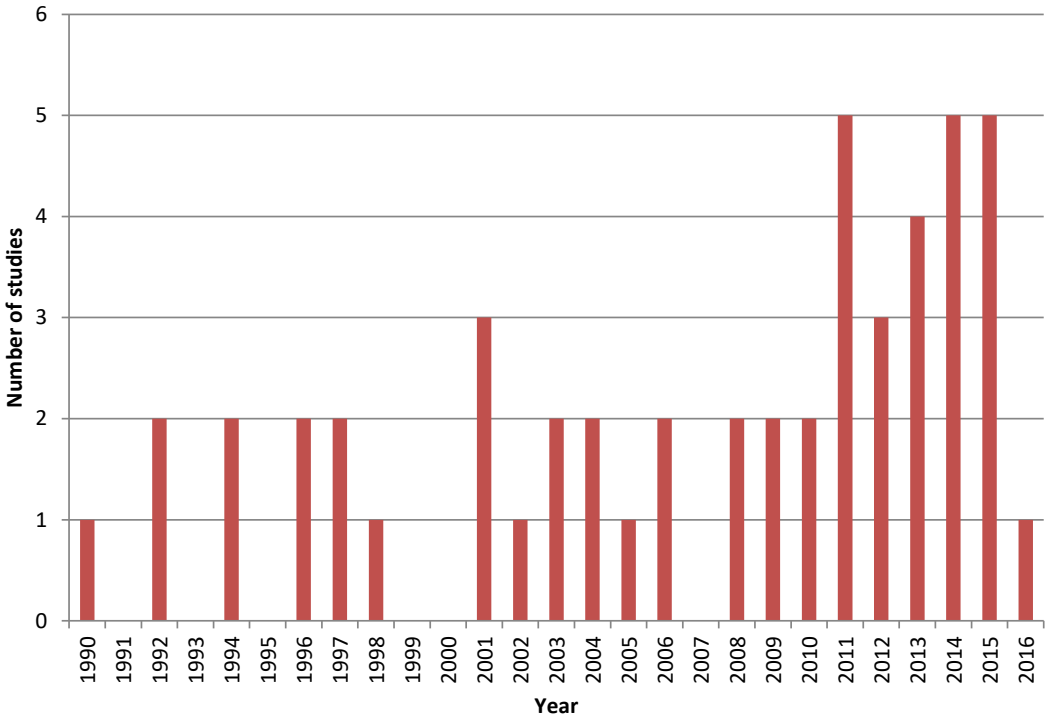
More recently, Spector and Orrell amalgamated existing psychosocial models of dementia into a revised biopsychosocial model, drawing on the biopsychosocial model of illness proposed by Engel (1977). This model suggests that there are biological and psychosocial factors involved in dementia, both fixed and tractable in each case, and aims to understand the relationship and interplay between the two (Spector & Orrell, 2010). The move away from perceiving people with dementia as hopeless victims and towards the understanding that society

contributes to their disempowerment has clear parallels with the social model of disability. This model was pioneered in the 1970s but was mainly focused on physical impairment and its relevance to dementia was not explored until the late 90s (Gilliard, Means, Beattie, & Daker-White, 2005).

One clear way that the changing attitude to dementia is reflected in the papers included in this review is simply the large increase in the number of papers about music and dementia. Papers focus on dementia as distinct from problems faced by people who are elderly, and the increase in the number of papers indicates perhaps a growing sense that something can be done for people with dementia, beyond meeting basic physical needs. The development of measures of quality of life for people with dementia reflects an acknowledgement that people with cognitive impairment may still experience a good quality of life. Starting in the early 1990s it is given a higher priority in dementia research; Whitehouse and Rabins (1992) suggest that it should be "the central goal of our professional activity". Logsdon et al. (1999, 2002) and Trigg, Skevington and Jones (2007) both developed measures of QoL designed to be used for self-report for people with dementia, with both measures exhibiting a move away from concepts of QoL which are strongly linked to health and disability. Since the 1990s, the use of QoL as an outcome measure for studies of music and dementia has increased (see Figure 2:6). Concepts of QoL in dementia and their measurement may have become more nuanced, and more inclined to include the perspectives of people with dementia. For example, the earliest QoL paper in this review measures participation and response by recording the frequencies of different behaviours; these behaviours are associated with purposeful activity and therefore deemed to contribute to quality of life (Clair & Bernstein, 1990). By contrast, a later study (Davidson & Fedele, 2011) draws on literature about the wellbeing benefits of singing for the general population and older people, before considering neurological reasons why singing may be especially relevant to people with dementia. In this way, people with dementia are

treated as a sub-set of the population who have the same needs as everyone else, but may require extra support to meet those needs. This study includes both self- and proxy-rated quality of life measures.

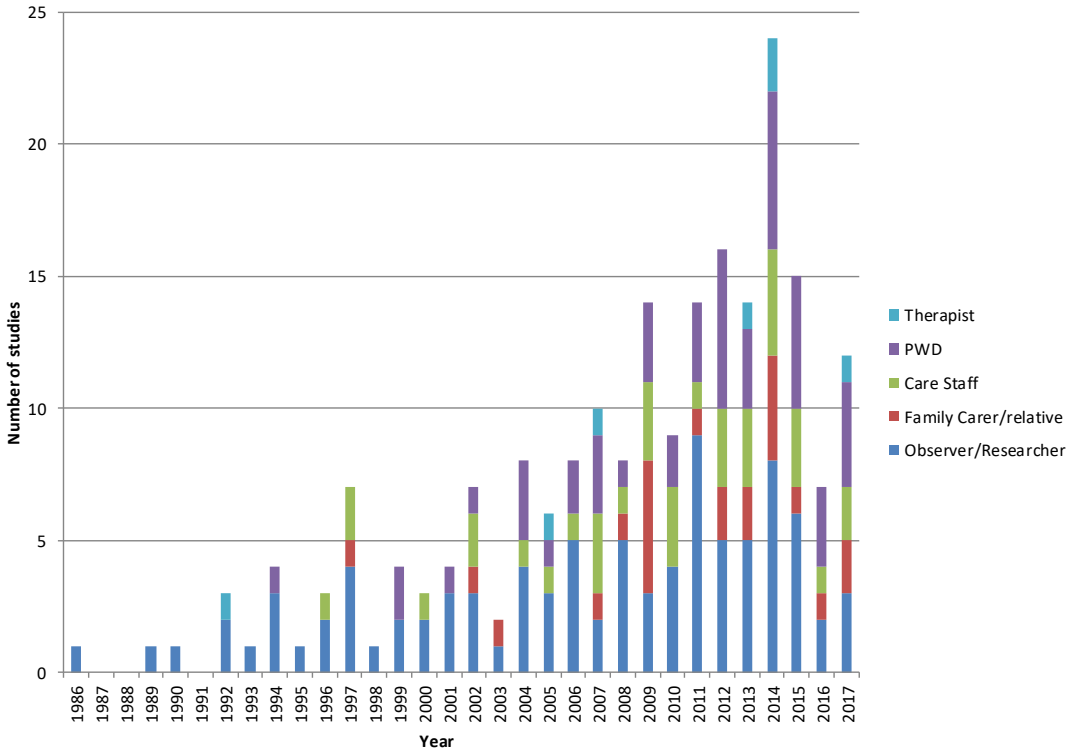
Figure 2:6: Number of studies with quality of life related outcome measures



Changing attitudes may also be reflected in the way data is collected in studies. Figure 2:7 shows the change in who responds to outcome measures and indicators over time. As the number of studies published grows, so does the proportion which included data collected directly from people with dementia, beginning in the mid to late 1990s. This may reflect growing recognition that asking people with dementia to provide direct responses is both possible and worthwhile. The need for this change is identified by Cotrell and Schulz who write that "our understanding of AD has become increasingly biomedical, with an accompanying tendency to attribute the experience of persons with dementia exclusively to a disease process" which in turn means that "the person with dementia is often relegated to the status of object rather than legitimate contributor to the research

process" (1993, p. 205). For instance, they argue that behavioural disturbances, rather than being just a symptom of disease, are shaped by the individual, their life, personality and coping strategies. They emphasise that people with dementia are "important actors responding and adapting to the disease, rather than passive individuals who are succumbing to deficits" (Cotrell & Schulz, 1993, p. 206).

Figure 2:7: Respondents to outcome measures over time



2.10.2 The conceptualisation and management of agitation in dementia

Many studies relating to music and dementia have as their focus the reduction of symptoms of agitation. Agitation is defined by Cohen-Mansfield and Billig as "inappropriate verbal or motor activity that is not an obvious expression of need or confusion" and many papers in the music and dementia literature have cited this definition (Cohen-Mansfield & Billig, 1986). The Cohen-Mansfield Agitation Inventory (CMAI), an observational tool developed for measuring the severity and frequency of agitated behaviour is the most frequently used outcome measure

among the papers included in this review. Agitation falls under the category of "behavioural and psychological symptoms of dementia" (BPSD) and "challenging behaviour", terms which are often used. In earlier literature, behavioural problems are characterised as a symptom of dementia which is not just caused by cognitive impairment but by other changes in the brain (Jellinger, Caplan, & Esiri, 1997). Agitation is understood to cause significant problems in the care of people with dementia, leading to the use of medication and restraints, and causing stress and burden to family and professional caregivers (Forbes, 1998; Nasman, Bucht, Eriksson, & Sandman, 1993). In earlier literature there is not much consideration of what experiencing agitation is like for the person with dementia. Since behavioural problems are assumed to originate from organic changes in the brain, psychosocial factors involved in agitated behaviour are not explored (Cotrell & Schulz, 1993).

Kitwood challenges what he calls the standard paradigm: "that the mental and emotional symptoms are a direct result of a catastrophic series of changes in the brain that lead to the death of brain cells – and nothing more than that" (Kitwood, 1997, p. 40). He puts forward the idea that agitation arises from unmet emotional needs, and that meeting these needs is possible even where cognitive impairment is very severe. The "Unmet Needs Model" and "Needs-Driven, Dementia-Compromised Behaviour model" have much in common with Kitwood's ideas; they suggest that dementia affects people's ability to communicate and therefore they are unable to express their needs verbally, so these needs are expressed through agitated behaviour instead (Algase et al., 1996; Cohen-Mansfield, 2000). However, the "unmet needs" model appears to have developed independently of Kitwood's theory. This change in the conceptualisation of agitated behaviour might be regarded as a paradigm shift, since it moves from an understanding of agitation which is purely based on the disease process, to one which takes into account the needs and experience of the person with dementia which are

considered relevant, despite the disease. Agitated behaviour can then be understood as an attempt to communicate, rather than a manifestation of disease pathology (Caspi, 2013). Caspi argues that characterising these behavioural expressions as "symptoms" of dementia may be misleading and "could imply that these behaviors are an inevitable and direct consequence of dementia, which in the majority of situations is not the case" (2013, p. 768).

Figure 2:8: Studies using a quantitative measure of agitation

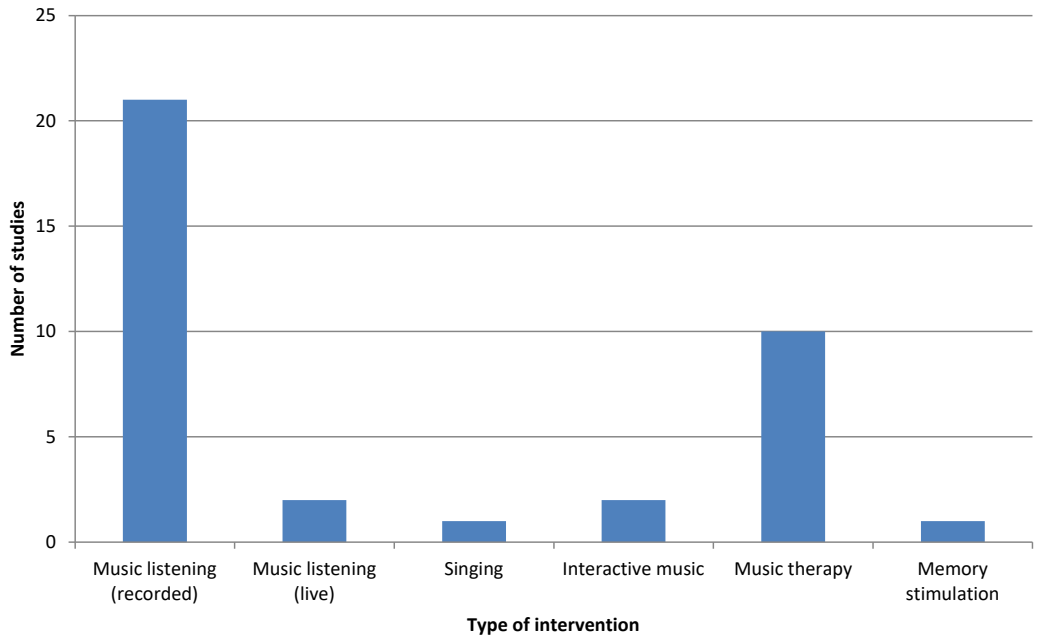


Figure 2:8 shows the breakdown of studies which measure agitation quantitatively, and the type of intervention they involve; music therapy and recorded music listening feature prominently. Among early studies of recorded music listening and agitation, two contrasting theoretical frameworks can be identified. Gerdner (1997, 2000; Gerdner & Swanson, 1993) developed the Individualised Music Intervention for Agitation (IMIA) based upon the Progressively Lowered Stress Threshold Model (PLST) (Hall & Buckwalter, 1987). The PLST model theorises that people with dementia exhibit agitation when the stressors in their environment exceed their capacity to cope, which is lowered due

to cognitive impairment. The IMIA model proposes that when individualised music is provided for people with dementia before the peak agitation level is reached, positive memories will be elicited which will have a soothing effect and reduce agitation; more personally relevant music is suggested to have a greater effect. Individualised music is also proposed to have a calming effect because it invokes feelings of familiarity and safety (Thomas, Heitman, & Alexander, 1997). Other studies do not use individualised music, but instead choose pieces which are deemed to have certain relaxing qualities. For example, Goddaer and Abraham (1994) investigate whether music played at mealtimes can reduce agitation. They suggest that relaxing music can act as a "buffer" for the kind of disturbing background noise which can pervade the mealtime environment and may contribute to raised agitation levels. Relaxing music is defined thus: "a slow tempo; a slow, irregular, and unpredictable rhythm; the absence of sound impulses, evocations, or variations in intensity; a linear melody; a certain homogeneous monotony throughout; and in the register of bass frequencies" (1994, p. 152). Above all, they state that relaxing music should not contain any recognisable tunes as these may have a stimulating effect. However, these characteristics are not universally accepted. Tabloski, McKinnon-Howe and Remington (1995) share the view that calming music should be slow in tempo, but they use Pachelbel's "Canon in D" as the relaxing music in their study, which is a well-known piece. These theoretical frameworks seem to suggest two different mechanisms by which music may reduce agitation: one prioritises music's familiarity and personal relevance, while the other relies on inherent musical characteristics producing similar effects in different people. Furthermore, these contrasting theoretical frameworks are still in evidence in more recent studies. Sanchez et al. (2016) compare multi-sensory stimulation environments with individualised music, citing Gerdner's IMIA model as their basis for choosing this intervention, while Ho et al. (2011) investigate the effects of researcher-composed music at mealtimes; the music in question shares many qualities with the definition provided by Goddaer and Abraham (1994).

Studies involving music therapy vary in how they conceptualise its potential to reduce agitation, and some earlier studies do not describe a theoretical framework (e.g. Brotons & Pickett-Cooper, 1996). Some studies reference music's perceived capacity to bypass or compensate for areas of the brain which are damaged (Jennings & Vance, 2002; Ridder, Stige, Qvale, & Gold, 2013). Ray and Mittelman (2017) use the need-driven, dementia-compromised behaviour model (NBD) as the theoretical framework for their study, with music therapy postulated as a possible way of meeting those needs which if left unfulfilled could lead to agitation. However, several studies do not align themselves with a particular theoretical framework, but cite the findings of other studies (Ceccato et al., 2012; Ledger & Baker, 2007; Vink et al., 2013). Most of these citations focus on other music therapy studies, although some music listening studies are mentioned. This may be a sign that researchers in music therapy are keen to define it as unique and separate from other types of music intervention.

2.10.3 The subjective experience of dementia

Including subjective experiences of dementia in research

There is a growing understanding of the importance of listening to and understanding the thoughts, feelings and opinions of people with dementia in research and policy-making. Historically, it was felt to be impossible to include people with dementia directly in research, either because they could not communicate their thoughts, or because cognitive problems made any reports unreliable (Bond & Corner, 2001). Preoccupation with disease progress also contributed to this deficit; Hubbard, Downs and Tester (2003) suggest that until the 1990s, "the subjective experiences of and inner feelings of people with dementia were overshadowed by a concentration on charting their cognitive and functional decline" (p.351). Nygard (2006) explores the possibilities for accessing the experiences of people with dementia with an "adjusted, ethnographically

inspired" approach. This suggestion shows understanding of a need to adapt research methodologies so that they can include people with dementia, rather than excluding people with dementia from research because they cannot access the conventional methodologies. Sabat calls into question the value of exclusively measuring "objective" parameters relating to dementia, such as cognitive function, arguing that accessing subjective experience is essential in understanding how dementia affects the person, and how their quality of life people may be improved (Sabat, 2003). He goes on to advocate studying "the person as a whole in the natural social world", as an alternative to standard neuropsychological tests of cognitive ability (2003, p.6).

Starting in the late 1980s, care practice also evolved to incorporate deeper understanding of the subjective experiences of people with dementia. Tom Kitwood drew on the ideas of Carl Rogers to develop the idea of person-centred care (PCC), an approach that emphasises the importance of psychosocial factors in supporting or undermining the personhood of someone with dementia (Kitwood, 1988, 1990; Kitwood & Bredin, 1992; Rogers, 1957). The VIPS model was then developed to define the four key components of person-centred care; one of these is "looking at the world from the perspective of the person with dementia" (Brooker, 2003, p. 216). Dementia Care Mapping (DCM) is a structured observation tool which was developed by Kitwood and Bredin (1992) primarily to evaluate quality of care by focusing on the state of well-being or ill-being of a person with dementia. Kitwood describes it as "a serious attempt to take the standpoint of the person with dementia, using a combination of empathy and observational skill" (1997, p. 4). DCM has also been used as an outcome assessment tool in research as the following section describes; such methods may be especially helpful for understanding the perspective of people with severe dementia, who may not be able to provide self-report (Kuhn, Ortigara, & Kasayka, 2000).

Outcome measures accessing subjective experience

The changing value placed upon the subjective experience of dementia may be reflected in the choice of outcome measures and indicators, and especially in the use of qualitative methods. In part, this change is reflected in Figure 2:7 which shows the increase in the number of studies which seek direct responses from people with dementia. However, some of these studies do not necessarily focus directly on the subjective experience of dementia, because they are concerned with testing of cognitive function, for example, which necessarily requires direct self-report from the subjects but is concerned with their performance rather than their experiences. Bond writes of cognitive testing "to describe this as 'participation' is undoubtedly a travesty, since the participant has a limited role as the provider of test material, 'as a passive vessel of answers'" (2001, p. 96). Furthermore, some people with severe dementia may not be able to respond directly to questions, but their perspective can still be taken into account through the use of outcome measures like DCM and reports from people who know them well. The following section will focus on studies which use DCM and those which seek the perspective of people with dementia and their carers about musical experience.

In DCM, a trained observer monitors an individual over a period of several hours. The observer records the person's mood and engagement and categorises their behaviour. At the end of the process a total score indicating the person's well- or ill-being is produced. In contrast to other measures, DCM was developed primarily as a means for care homes to assess the quality of care they were providing, not as a metric for research or a clinical tool; however, it has been adopted for this purpose. Five studies in total use DCM or elements from the method to examine the effects of music, in a variety of ways. In a study of music therapy's effect on depression levels in a nursing home, Myskja and Nord (2008) use DCM if there is doubt over a resident's depression score, in order to reach a consensus. Holmes et

al. (2006) use DCM as the main outcome measure in a study which compares the effects of live and recorded music. However, they examine only Category E of DCM, which monitors the subject's engagement with a creative activity. Clare (2014) observed residents before, during and after a live music performance to map its effects on levels of wellbeing. Interestingly, the stated goal of the intervention is to reduce agitation, yet DCM is chosen as the outcome measure. The care home where the research took place describes itself as having a person-centred approach, and an understanding that challenging behaviours are communicative, so the choice of DCM is perhaps reflective of a care philosophy that focuses on improving wellbeing as a route to reduction of agitated behaviour. Sherratt, Thornton and Hatton (2004) use codes adapted from DCM to assess the effects of live music listening. This study explicitly identifies its theoretical perspective as based on Kitwood's theory of personhood since it "aims to integrate neurological findings with social psychological principles and theories of interpersonal processes, moving away from the traditional medical view of dementing illness" and prioritises the subjective experiences of people with dementia (Sherratt et al., 2004a). Finally, Hsu et al. (2015) use DCM alongside other outcome measures including NPI in a study of music therapy's effects on neuropsychiatric symptoms. The inclusion of DCM in this recent study is perhaps indicative of a move towards a paradigm in which the links between subjective wellbeing and neuropsychiatric symptoms are better understood and explored.

Qualitative enquiry into musical experience

Among the 11 qualitative studies included in this review, five directly seek the perspective of people with dementia through interviews. Of these, two studies focus not on responses to a particular intervention or activity, but on the meaning and value of music to people with dementia. Sixsmith and Gibson (2007) conducted interviews with 26 people with dementia in a variety of settings to investigate the role that music played in their everyday lives. In some cases, a

carer was present during the interview and made some contribution, but the investigation is primarily into the views of people with dementia themselves. The interviews focused on the role and importance of music in their lives, its benefits for them, and any difficulty they had engaging with music or using music-playing devices. The theoretical framework of the research is an ecological model of wellbeing, informed by Kitwood, in which personal and contextual factors are understood to influence the activities a person takes part in. Their ability to derive meaning from these activities in turn affects their wellbeing. Therefore, the research sought to understand what the facilitators and barriers to taking part in meaningful musical activities might be. This study was part of a larger project exploring the potential of technology to improve the lives of people with dementia.

McDermott, Orrell and Ridder (2014) also conducted a qualitative study as the initial phase in the development of a music therapy outcome measure. The aim of their study was to explore the meaning and value of music to people with dementia, as well as the perceptions of family carers and care staff, in order to develop a theoretical model of music and dementia. Influenced by the biopsychosocial model of dementia (Spector & Orrell, 2010), the "Psychosocial Model of Music and Dementia" was developed from the thematic analysis of the qualitative data. It is interesting to note that both of these qualitative studies focus on well-being, not on symptom reduction or memory enhancement or other parameters which are prioritised by quantitative studies. This may reflect the paradigm shift away from the medical model of dementia noted above, but in addition there appears to have been a simultaneous prioritising of the subjective experience of people with dementia; the two phenomena may not be unrelated. We also see, especially in the later study, a new interest in understanding why and how music has benefits for people with dementia. Although clinicians and practitioners have always had insight into how music "works", it is only relatively

recently that this insight has been articulated and published. This change may show that more effort being made to understand the mechanisms involved in response to music, but also that the value of qualitative forms of evidence is being understood, challenging the positivist medical model which has dictated that only quantitative measures demonstrating effectiveness are of value. Where quantitative measures are used, an interpretivist epistemological stance demands that researchers develop outcome measures which are based on the experiences of people with dementia, not only what researchers think is important.

2.10.4 Developments within music therapy practice and research in dementia

Music and dementia have been researched by various fields, including medicine, nursing and psychology. However, music therapy has from its inception been concerned with the impact of music upon health and wellbeing, whereas music's potential to have a direct effect on health (as opposed to simply providing entertainment) has been acknowledged more recently within fields such as medicine and psychology. The following section considers how the research paradigms associated with music therapy have evolved, and how this may have affected research into music therapy and dementia. Music therapy authors writing in the 1990s provide insight into the history and state of play in music therapy research. In 1991, Kenneth Aigen reviewed the existing field and criticised it on the grounds that "music therapy research was guided more by pragmatic commercial concerns than by a pure desire to learn more about the intrinsic mechanisms of music therapy processes" (2015, p. 14). A paper published in 1994 gives an overview of music therapy research which has appeared in medical journals to date; the author states that "until recently there has been no established research tradition" (Aldridge, 1994, p. 204) although the practice of music therapy had been established in the 1960s. Aldridge also warns against music therapy research restricting itself to a medical ontology (1993).

In the early 2000s, the Evidence-Based Medicine (EBM) movement began to demand higher standards of evidence for medical care. As a profession allied to medicine, Evidence-Based Practice (EBP) presented a new challenge for music therapists in general and especially for music therapy research. Jane Edwards outlines how music therapy posts may be supported by EBP, but anticipates some of the issues which may arise; for example, music therapy cannot be administered in consistent "doses" as though it were a drug (Edwards, 2002). In the hierarchy of EBP, systematic reviews and randomised controlled trials hold sway, and although Edwards argues for plurality in research methods, the positivist paradigm of EBM may well have affected the types of research which would be considered worthwhile and would attract funding. Considering music therapy's response to the demands of EBM, Tia De Nora in 2006 felt the profession was "too willing to bow to presumptions about evidence hierarchies" perhaps because it felt "somewhat nervous about its own professional standing and about its continued welcome in medical and mental health settings" (DeNora, 2006). Aigen has criticised the EBP hierarchy thus: "In seeking a firm foundation for knowledge claims, rigid standards are often employed regardless of whether those standards are reasonable in a particular context" (2015, p. 14). He emphasises that he is not criticising any particular type of research design in music therapy, but is arguing against the uncritical application of this model since "EBP tenets cannot accommodate all that music therapists do in their work" (Aigen, 2015, p. 15)

Within the framework of EBP, music therapy studies have been criticised in systematic reviews for low methodological quality (e.g. Vink & Birks, 2013). Although some of these criticisms are no doubt justified within the scientific paradigm they inhabit, they highlight the difficulties of designing music therapy studies so that they comply with the "normal science" of a positivist medical research tradition. For example, it is almost impossible to blind participants to the fact that they are receiving music therapy. Others have called for pluralism in

music therapy research because of the multidisciplinary nature of the field (Hillecke, Nickel, & Bolay, 2005). Hillecke et al. identify six fields which are related to music therapy and from which music therapy research might borrow: physics, biology, psychotherapy, psychology, sociology and musicology. These different fields could be seen as paradigms through which music therapy researchers have conceptualised their work. Because music therapy is a relatively new field with an interdisciplinary nature, research in this field may have borrowed from other paradigms; consequently, researchers within the same field could have very different ideas about what constitutes "normal science". Writing in the late 90s, Aldridge identified a conceptual binarism in music therapy research in which "factions identifying themselves as creative or receptive, qualitative or quantitative are claiming a universal knowledge that is misplaced and unsupported" (1999, p. 28). He also suggests that as well as showing that music therapy does work, we need to be able to describe how it works and the processes involved, even though we cannot expect the experience to translate directly into words. This, he claims, is the domain of current qualitative research methods in music therapy.

In the current review, 55 studies include some form of music therapy (they may also include other forms of music intervention). Of these, 49 (89%) are quantitative; 53% of these quantitative studies include some measure of neuropsychiatric symptoms, while 45% include a measure of well-being/quality of life. In general, earlier studies have smaller sample sizes and, although they use quantitative measures, have an almost descriptive quality; they use study-specific outcome measures to count and categorise types and frequencies of behaviour. By contrast, later studies tend to have larger sample sizes, use psychometrically validated and standardised outcome measures, and seem more likely to include measures of neuropsychiatric symptoms. The dominance of quantitative studies and of neuropsychiatric symptom outcome measures may reflect the trend

towards an Evidence-Based Medicine approach in the 1990s and 2000s. Qualitative and mixed methods studies of music therapy and dementia do not appear until the mid-2010s. In a mixed methods feasibility study, Hsu *et al.* (2015) interviewed care staff to provide additional data about their perception of the effects of music therapy upon care home residents and their own caregiving. As discussed previously, McDermott, Orrell and Ridder (2015) explored the meaning of music to people with dementia as the initial stage in the development of a new outcome measure. Two purely qualitative studies have also been conducted: Dassa and Amir (2014) transcribed music therapy sessions which were based around familiar songs, and used content analysis to investigate the relationship between these songs and the conversations which took place among participants with dementia. Melhuish, Beuzeboc and Guzmán (2017) interviewed care staff at a facility where people with dementia attended music and dance therapy groups, and used Interpretative Phenomenological Analysis to discover how the sessions affected the staff members' attitudes and responses to the residents.

To sum up, research in the field of music therapy and dementia has mainly focused on quantitative studies with outcome measures that measure neuropsychiatric symptoms or well-being. Qualitative studies are a relatively recent addition to the evidence base, a fact which may be related to the influence of EBM's evidence hierarchy upon the profession. Qualitative studies are used to explore the mechanisms at play in music therapy, offering in-depth insight into the functioning of the triadic interaction between therapist, client and music. It should be emphasised that for many years, music therapists have written reflectively about why and how music therapy actually works, and that work with people with dementia is included in that. However, this kind of reflective enquiry has not been translated into qualitative research until recently, meaning that when examining the music therapy evidence base, quantitative studies dominate.

2.10.5 Group singing and dementia

This final meta-narrative examines studies which focus on group singing for people with dementia, as a kind of case study. Group singing is particularly relevant to the PhD study of which this review forms part. Furthermore, singing and dementia have been approached by different research paradigms, so these studies offer insight into how researchers have treated the same topic differently. For this section, the 11 studies which focus on singing alone have been examined. Their publication dates range from 1989 to 2016, but nine of them have been published in the last ten years. Four of these studies are quantitative, three are qualitative and four use mixed methods. The even methodological spread is interesting in light of the fact that overall this review is dominated by quantitative studies. Additionally, there is a high proportion of mixed methods studies, given that across all included studies only ten use mixed methods. This indicates that mixed methods designs lend themselves to the kinds of research questions asked in studies of group singing. Four of the studies involve music therapy (i.e. the group singing takes place as part of a music therapy session) whereas most of the others might be characterised as community music, although one takes place in a care home. It is very common for music therapy to include singing, especially when work takes place in dementia care settings; the difference here is that the researchers have specifically focused upon singing as a key component of the therapy.

Table 2:3 summarises the 11 studies of group singing. The outcome measures used in quantitative and mixed methods studies reveal a wide range of target variables, including quality of life, cognitive function, mood, behaviour, nutritional intake, neuropsychiatric symptoms, engagement, energy levels and activities of daily living. Three of these studies use only standardised instruments, but four use measures which have been created specifically for the study in question, either on their own or alongside other standardised measures. This might suggest that the

researchers felt the range of standardised tools available were not suitable for their purposes, or were unlikely to show any change. For example, although Davidson and Almeida (2014) survey the literature relating to music and dementia and identify areas where music has been shown to have an effect, they do not base their choice of outcome measure upon those used in other studies. Instead, they created five-point bipolar rating scales, which carers used to provide a rating across four domains: Confused – Lucid, Negative Mood – Positive Mood, Agitated – Relaxed, and Unfocused – Focused. They based this approach upon "behaviours commonly reported as difficulties experienced by people with dementia and their caregivers" (2014, p. 6). Using study-specific measures naturally limits the generalisability of the results, but as this was intended as an exploratory study, the authors may have considered it better to use these scales which encompass a range of domains than standardised scales which may take longer to complete and probe one area in more detail than necessary. By contrast, Camic, Williams and Meeten (2011) select a battery of standardised tests which are used alongside observational scales created specifically for the study. The focus of this study is on wellbeing, improving daily function and reducing social isolation; these changes are thought to be evidenced by increases in quality of life, reduced psychological distress, and increased social inclusion. In the literature review, the authors note that quality of life can be difficult to measure for people with dementia, and that increased behavioural and psychological symptoms are associated with low QoL, and so there is a sense that the other measures (such as the Geriatric Depression Scale and the Neuropsychiatric Inventory) may have an explanatory function for any changes in QoL.

Of the four mixed methods studies which are described in this part of the review, only two are explicitly described as such. None of the papers reporting these studies spend much time describing the underlying epistemology guiding this choice of methodological approach. However, they all have fairly broad research

questions (or study aims where a research questions is not stated). For instance, Davidson and Fedele ask "How do people with dementia respond to carer–caregiver group singing activity?" and "What, if any, aspects of overall quality of life are affected by the singing activity?" (2011, p. 405). As well as addressing specific changes in the variables pain, mood and energy in the research questions, Clements-Cortes (2015) also asks what aspects of the choir participants with dementia and their carers find beneficial. Since all these studies involve small samples and only in one case a control group, they represent preliminary, exploratory work, and therefore it makes sense that they tend to use a broad range of outcome measures (to identify areas amenable to change) as well qualitative methods (to find out why and how this change might occur).

Table 2:3: Summary of studies which focus on singing

Year	Author(s)	Title of paper	Setting of intervention	Methodology	Outcome Measure(s) & Indicators
1989	Olderog Millard & Smith	The Influence of Group Singing Therapy on the Behavior of Alzheimer's Disease Patients	Care Home	Quantitative	Behaviour mapping
2006	Lesta & Petocz	Familiar Group Singing: Addressing Mood and Social Behaviour of Residents with Dementia Displaying Sundowning	Care Home	Quantitative	Mood-Behaviour Assessment Chart (MBAC)
2008	Banman & Montgomery-Smith	'Singing for the Brain': reflections on the human capacity for music arising from a pilot study of group singing with Alzheimer's patients	Community Setting	Qualitative	video analysis, audio analysis, questionnaires
2011	Davidson & Fedele	Investigating group singing activity with people with dementia and their caregivers: Problems and positive prospects	Care Home, Community Setting	Mixed Methods	QoL-AD, HDS, study-specific questionnaires, anecdotal feedback, observational data, video analysis
2012	McHugh et al	The Effect of Pre-meal, Vocal Re-creative Music Therapy on Nutritional Intake of Residents with Alzheimer's Disease and Related Dementias: A Pilot Study	Care Home	Quantitative	nutritional intake
2013	Camic, Williams & Meeten	Does a 'Singing Together Group' improve the quality of life of people with a dementia and their carers? A pilot evaluation study	Community Setting	Mixed Methods	GDS, DEM-QoL, DEM-QoL proxy, BADL, NPI, observational scale for engagement and participation, semi-structured interviews
2014	Dassa & Amir	The Role of Singing Familiar Songs in Encouraging Conversation Among People with Middle to Late Stage Alzheimer's Disease	Care Home	Qualitative	Content analysis of session transcripts
2014	Davidson & Almeida	An exploratory study of the impact of group singing activities on lucidity, energy, focus, mood and relaxation for persons with dementia and their caregivers	Community setting, Care home	Mixed Methods	Scales for lucidity, energy, focus, mood and relaxation; interviews with PWD and carers
2015	Clements-Cortes	Singing for health, connection and care	Care Home	Mixed Methods	FLACC, AD-ACL, DMAS, interviews
2015	Satoh et al	Music Therapy Using Singing Training Improves Psychomotor Speed in Patients with Alzheimer's Disease: A Neuropsychological and fMRI Study	Hospital	Quantitative	MMSE, RCPM, RBMT, test for construction ability, frontal function assessment, NPI, Barthel index, IADL, DAD, ZBI
2016	Osman, Tischler & Schneider	'Singing for the Brain': A qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers	Community Setting	Qualitative	Thematic analysis of semi-structured interview transcipts

Singing groups for people with dementia are often attended by family carers as well, especially if they take place in the community. Two of the four qualitative studies include a focus on the effect which the singing group has on the relationship between care partners. Osman, Tischler and Schneider (2014) investigated the experience of participating in "Singing for the Brain" groups by interviewing people with dementia and their family carers together, and three of the themes they identify relate to social inclusion and relationship improvements. Unadkat, Camic and Vella-Burrows (2016) looked at how the relationship between couples was affected by attending different kinds of choirs and singing groups. Additionally, Dassa and Amir (2014) use content analysis of session transcripts to describe the effect of singing familiar songs on encouraging conversations between people with dementia in a singing group. They identify increased social interaction as one factor which can improve quality of life in people with Alzheimer's disease. Finally, in their evaluation of pilot study of "Singing for the Brain", Bannan and Montgomery-Smith (2008) include "How might participation in group singing contribute to the social relationship between people with dementia and their carers?" as one of the research questions which they believe should be addressed by future studies, based on their findings in the evaluation.

Among these qualitative studies, there seems to be a sense that attending a singing group can have positive effects upon social inclusion and especially on the relationship between care partners. It is interesting, then, that although many of the quantitative and mixed methods studies include outcome measures for both people with dementia and carers, none target the relationship between the care partners. In fact, among all the studies included in this review, only one standardised quantitative measure of relationship quality is used, in the study by Baker, Grocke and Pachana (2012), who use the Mutual Communal Behaviours Scale to assess the effect of a caregiver-directed music intervention.

In summary, studies which focus on group singing for people with dementia use a wide range of outcome measures targeting different domains, and qualitative and mixed methods seem relatively common compared with other sub-fields in this research area. Several qualitative and mixed methods studies look at social improvements which may be brought about by group singing, but this is not reflected in the choices of quantitative outcome measure, perhaps because it is difficult to find appropriate measures. Although the results of the studies are not the focus of this review, it is interesting to note that for three of the four mixed methods studies, the qualitative results show more compelling evidence of the benefits of group singing than the quantitative ones (Camic et al., 2011; Davidson & Almeida, 2014; Davidson & Fedele, 2011). Within this strand of music and dementia research, then, there is a clear need for outcome measures which reflect the benefits that are reported qualitatively. The tendency for studies in this area to mention social inclusion, bonding and relationship improvements among their outcomes more than other studies in this review perhaps indicates that group singing has specific effects on these areas which are worthy of further review and research.

2.11 Discussion

The preceding sections developed meta-narratives – storylines about research traditions – following a review of studies about music and dementia which focused on outcome measures and indicators. These storylines discuss how the outcomes which researchers think are relevant for these studies are influenced by social, medical and political developments in the perception of dementia, as well as growing interest in the potential of music for health and wellbeing. The following discussion section brings the main points from these meta-narratives together and summarises their effects on music and dementia research.

Society's attitude to dementia has changed substantially in the past few decades, but there is still more work to be done to ensure that people with dementia receive the respect and dignity they deserve. In an article entitled "Overcoming the social death of dementia through language", Daniel R. George writes of a need to alter the language we use about dementia in order to reduce the stigma and sense of hopelessness that a diagnosis may confer (2010). Emotive and provocative language which evokes warfare and a complete "loss of self" may be an effective way of gathering money to fund dementia research, but it does nothing to promote the personhood of people with dementia. George's description of the linguistic dichotomy underpinning the way we think of dementia has clear parallels with the way evolving paradigms have affected music and dementia research. The language of the "war on Alzheimer's", where dementia "victims" are "ravaged by a singular marauding disease" ties in with the medical model of dementia, while George's suggestions for more humane language reflect the theory of personhood. Compare, for example, the difference between the "death that leaves the body behind" and the idea of "living well with dementia", which is the title of the 2009 National Dementia Strategy for England (Banerjee, 2010; Sweeting & Gilhooly, 1997). The purpose of this is example about language is to highlight the fact that even when assumptions about dementia are not made explicit, they are implicit in the way we talk and write about dementia. The same is true of the methodological decisions made in research.

Underlying all the studies involving music and dementia included in this review are beliefs and assumptions about dementia: what it is, what aspects of it are amenable to change, what should research focus on. Three developments in particular have had a profound effect on research paradigms: the realisation around 1980 that dementia was not an inevitable part of the ageing process, the related conceptualisation of dementia primarily in terms of disease pathology, and

the more recent understanding of the importance of social factors. These developments appear to have had three main effects upon music and dementia research:

1. The initial recognition of dementia as a condition separate from normal ageing led to the development of interventions, including musical ones, specifically for people with dementia.
2. The medical model of dementia meant that symptom reduction was often prioritised as an outcome.
3. Better understanding of social factors has led to more consideration of quality of life and wellbeing, recognition of the contribution that the perspectives of people with dementia can make to research.

This is not to say that reduction of behavioural and psychological symptoms, which can cause great distress to both people with dementia and carers, is not a valuable outcome. However, addressing these symptoms is only one part of improving the lives of those affected by dementia. This is reflected in the fact that in recent years studies have tended to combine outcome measures for neuropsychiatric symptoms with other domains, such as quality of life. Kitwood's theory of person-centred care, the "Unmet Needs" model and the "Progressively Lowered Stress Threshold" model are all examples of a paradigm shift. However, although the importance of these ideas is recognised, they may be used less in research simply because they are more difficult to measure objectively. It is perhaps considered easier to document the instances of a particular behaviour than it is to gather self-reports about quite abstract concepts from people with dementia.

We also see differences in the outcomes targeted by studies across different research paradigms. For example, music therapy has been heavily influenced by Evidence Based Medicine's hierarchy which prioritises randomised controlled

studies. Music therapy researchers have quite probably been influenced by the struggle to be recognised as a "profession auxiliary to medicine", and so it is important to note that the issues which form the basis of music therapy research in this field may not reflect the real-world practice of music therapists and the way they think about their work. By contrast, studies of community singing (for example) seem more likely to be thought of in terms of social inclusion and ecological models of wellbeing.

2.11.1 Limitations

A limitation of this review is that the geographical locations of the studies have not been considered. Clearly, this may have an influence on the outcome measures and indicators chosen, because attitudes to dementia are not the same throughout the world, and research is influenced by policies around health and social care which vary from place to place. However, the vast majority of the studies took place in Europe or the USA.

A further limitation is that only peer-reviewed studies of music and dementia were included in this review, which is not a standard approach in the meta-narrative review method although it is normal in other types of systematic review. This decision was taken to ensure a reasonable standard of methodological quality; however, it is possible that relevant information to support the meta-narratives was missed due because of this. Additionally, in some cases the full text of studies which might have been included could not be found. This was especially true of earlier studies, which were less likely to be available online. Therefore it is possible that more recent studies are overrepresented. However, the review's intention was to develop narratives rather than to paint a completely comprehensive picture of every study conducted in this field. It seems likely that the rigorous search strategy and the 163 papers included in the review are sufficient to ensure that the resulting meta-narratives are representative.

2.12 Conclusion and further work

This chapter has discussed the method and findings of a meta-narrative review of outcome measures and indicators which had been used in music and dementia research. The review categorised the quantitative outcome measures into five domains: neuropsychiatric symptoms, quality of life, cognitive function, physiological changes and music-related outcomes. Measures of neuropsychiatric symptoms dominated the list, with much of this research taking place in care homes. The review presented five meta-narratives, considering how the various disciplines investigating this area might have approached it differently, and how developments in society and medicine's understanding of dementia might have influenced research. The meta-narratives suggested that a shift in society's attitude to dementia had impacted upon the way research was conducted. Instead of being seen as an inevitable part of ageing which resulted in destruction of an individual's personality, dementia was understood as a number of distinct conditions, and care practice developed to reflect the idea that people could be supported to live well with dementia even in the face of cognitive decline. For instance, this change can be seen in the conceptualisation of agitation in dementia. Agitation was previously understood to be a symptom of dementia, but more recent developments in understanding have conceived of agitated behaviour as communicative of unmet psychosocial needs. Overall, the plurality of methods and lack of unifying theories about music in this field may be indicative of its relative newness, and more work into understanding the meaning of music for people with dementia is suggested as a way to develop pertinent theories.

The studies included in this review are not easy to categorise neatly into research paradigms; instead there is cross-fertilisation between these paradigms, and some of the studies described fit into more than one of the meta-narratives. This perhaps

reflects the fact that this is still a relatively new and developing field. In section 2.10 Kuhn's ideas regarding the development of new fields were discussed; they seem pertinent in light of the findings of this review, since the plurality of approaches indicates a field which is not underpinned by a single unifying theory. The outcome measures and indicators which have been chosen give us an idea of the domains which are considered important by researchers; however, these may not be an accurate reflection of the outcomes which are important to people with dementia, their carers and those who work closely with them. In the following chapter, a complementary review will use Critical Interpretive Synthesis to examine case studies of music and dementia, to identify the areas of change which are described by those closely involved in the work. The first part of the present review is published in the journal *Maturitas* (Dowson, McDermott, & Schneider, 2019).

Chapter 3: A Critical Interpretive Synthesis of Music Therapy Case Studies

3.1 Introduction

The preceding chapter reviewed studies which evaluate the impact of music upon people with dementia. This approach helped to illuminate the benefits of music which researchers have deemed important, and the outcomes which they have endeavoured to measure. But how can we gain knowledge of the realities of practice, and examine how well these realities align with the priorities of research? The present review addresses this challenge by using music therapy case studies as a means of gathering and synthesising evidence about what music therapy can offer to people with dementia. The chosen review method, Critical Interpretive Synthesis (CIS) (Flemming, 2010), was devised for working with diverse and complex literature. The findings from the Critical Interpretive Synthesis were synthesised with the results from the meta-narrative review described in Chapter 2. The integration of data from these two reviews provides insight into whether the outcomes which are the focus of research reflect the benefits of music therapy as perceived by stakeholders, especially people with dementia themselves.

3.2 Rationale for this review

> *"What is it that we want evidence of when we do research in music therapy? There are many things in which researchers are interested: (1) that clients are satisfied with music therapy services; (2) that other individuals (e.g., professionals, family members, caregivers, etc.) are satisfied with music therapy services; (3) that music therapy benefits clients' lives in some way; (4) that music therapy benefits the institutions, agencies, and communities where it is offered; and (5) that music therapy*

> *achieves what its advocates claim for it. And, of course, the concern that most people probably think of, (6) that music therapy works—that it is effective as a treatment modality."* (Aigen, 2015, p. 15)

Music therapy research has for many years been grounded in a positivist tradition which sought to produce evidence for the effectiveness of the intervention (McFerran, Hense, Medcalf, Murphy, & Fairchild, 2017). However, as Aigen points out above, there are many other avenues which researchers might choose to explore. This positivist trend can be linked to the dominance of Evidence Based Practice (EBP), and the preoccupation of the music therapy profession with developing research methods and producing the kind of evidence which is prioritised in EBP's hierarchy. The impact of EBP upon music therapy practice and research has been described in section 2.10.4 and critiqued in detail elsewhere (Aigen, 2015; DeNora, 2006; Edwards, 2002; Wigram, 2002) and it is not the intention of this review to weigh in on the debate, but rather to draw upon a different kind of evidence: using critical interpretive synthesis to explore music therapy case studies, with a focus on work with people living with dementia.

A complementary meta-narrative review has investigated the outcome measures and indicators which have been used in research involving music and dementia and has used these outcome measures as a way of exploring how the field has changed over time. The findings of this review represent a picture of the outcomes which researchers think are important - and possible - from music for people with dementia; however, they do not necessarily reflect the outcomes and experiences which are valuable to people with dementia themselves, their family, carers, and the music therapists who work with them and who use their clinical judgement to decide whether music therapy is worthwhile. Quantitative studies such as randomised controlled trials necessarily aim to recruit large samples and to produce results which can be generalised to the population. This approach, while

important for generating evidence which will gain scientific acceptance, looks for change on a group level and might therefore be seen as focusing on the similarities between participants, while neglecting individual differences.

A body of case studies exists within the music therapy literature which are under-exploited resources. These case studies provide detailed descriptions of real clinical work, the individual client's responses to music therapy and the effects which it may have had on their life. These case studies also represent "real-world" music therapy work, rather than work which has been carried out in the context of research. Examined individually, case studies represent insights into a particular piece of work which can have relevance for other therapists' practice, but they may be seen as anecdotal evidence in the context of research. However, review methods involving synthesis offer the chance to compare case studies and critically examine similarities and differences between them. One previous paper has used Critical Interpretive Synthesis to examine a particular theme within music therapy case studies (Medcalf & Skewes McFerran, 2016), but the present review is the only known synthesis of a body of case studies with a particular focus on the results of therapy.

It should be noted that this review focuses on music therapy case studies because the music therapy profession has a tradition of writing and publishing case studies. Case study methodology is sometimes employed in music therapy research, but case studies are also written as a way of sharing clinical practice with other therapists. Preliminary searches have not revealed any case studies of music-based work with people with dementia which was not music therapy. Furthermore, although this review focuses on music therapy, the spectrum of practice is very broad, and it is anticipated that included case studies will range from individual psychodynamically-informed therapy to group sessions following a community music therapy model. In other words, the music therapy case studies are expected

to provide data about the value of music to people with dementia in a wide variety of settings and contexts.

A note on terminology: within the preceding meta-narrative review, the term "outcomes" was used to describe the desired results of music interventions when measured quantitatively, while the term "indicators" was used to encompass the results of both quantitative and qualitative studies. Both these terms have a teleological quality which reflects the preoccupation, especially in quantitative research design, with the end result. Music therapy is often described by its practitioners as process- rather than goal-oriented, and thus it is apparent at the outset that one of the difficulties in comparing the findings of these two reviews is the tension between the language which is used to describe them. Nevertheless, it is productive to compare their findings since process and outcome are intrinsically linked. Within the following review, the terms "outcome" and "indicator" are sometimes used as shorthand to describe the results of therapy; but where possible these are described using terms such as benefit, change and response as applicable to each case.

3.3 Objectives

The chosen review method, Critical Interpretive Synthesis, has been developed for use when working with complex and varied literature, including both qualitative and quantitative studies. While conventional review methods use aggregative techniques, pooling and summarising data, interpretive reviews "see the essential tasks of synthesis as involving both induction and interpretation" (Dixon-Woods et al., 2006). The processes involved in conducting Critical Interpretive Synthesis are described as "iterative, interactive, dynamic and recursive rather than as fixed procedures to be accomplished in a predefined sequence" (Annandale, Harvey, Cavers, & Dixon-Woods, 2007, p. 445). The approach to CIS which is deployed in

this review has been informed by that of Medcalf and Skewes McFerran (2016), who used CIS to examine therapeutic boundary themes in the context of contemporary music therapy practice. The present review seeks to identify music therapy case studies describing work with people living with dementia which are as diverse as possible, including different settings for the work, different theoretical orientations of the author, and individuals with different types and stages of dementia. The questions it asks may be linked to Aigen's first three points quoted at the start of this chapter:

1) What is the value of music therapy to people with dementia, and what benefits does it have for them?
2) What value and benefits of music therapy do carers, family members, music therapist perceive for people with dementia and for themselves?

These questions have been formulated using the words "value" and "benefit", and these are considered not to be synonymous, although there may be overlap between them. For example, one might consider the aesthetic experience of creating music to have value for a person with dementia, but it could be difficult to translate this aesthetic value into a concrete benefit. The two questions separate the experiences of people with dementia from other stakeholders, since it is not necessarily the case that their perceptions will align, although they may do. For example, reduction of wandering behaviour might be an outcome which is perceived as a benefit by a carer, but not by the person with dementia themselves. Therefore, this review also aims to reveal whether there are differences between the benefits of music therapy as they are perceived by people with dementia and other stakeholders, and to investigate the subjective experience of dementia with respect to music therapy. The questions used in CIS are described by Flemming (2010) as similar to "the meta-ethnographic approach, with the posing of a question which does not represent a specific hypothesis and which may be refined

during the review process" (p.202). Therefore, these questions are akin to the meta-ethnographic approach of "identifying an intellectual interest that qualitative research might inform" and are subject to change and refinement throughout the review process (Noblit & Hare, 1988, p. 26).

The CIS review method draws strongly on meta-ethnography (Noblit & Hare, 1988). CIS was developed as a method of synthesising qualitative and quantitative research, while meta-ethnography is focused on qualitative studies. One might argue, therefore, that meta-ethnography is a better approach for the kind of purely qualitative synthesis which is proposed here. The main reason that CIS has been chosen over meta-ethnography is the difference in the kind of synthesis which each method uses. Meta-ethnography uses a "line of argument synthesis" grounded in the findings of separate studies, whereas CIS develops "synthetic constructs" from the "transformation of the underlying evidence into a new conceptual form" and the creation of a "synthesising argument" (Flemming, 2010, p. 202). Since the results from analysis of the case studies will be synthesised with the results from the meta-narrative review, it is felt that a "synthesising argument" will be more useful for generating comparisons and triangulating results with the meta-narratives developed in the first review.

The present review aims to uncover what benefits, changes and responses people with dementia, music therapists, professional and unpaid caregivers, and family members look for from music therapy. It identifies similarities and differences between the themes which emerge from case studies, and looks for factors which may influence the responses which are considered important. These may include (but are not limited to) the country, setting and context in which the work takes place; the age, diagnosis, and personal history of the client; the theoretical orientation of the therapist; the input of the family members, staff and carers; and the reasons for referral to therapy. The sampling methods and search strategies

used aim to examine the greatest possible range of different case studies, and to examine enough studies that theoretical saturation is reached, without necessarily aiming to include all case studies involving people with dementia (depending on how many there are). In order to facilitate the analysis, categories generated from the meta-narrative review were used for this review (quality of life, BPSD, physiological changes, music-related behaviour, and cognitive function) and other categories were developed to accommodate themes which do not fit into these.

3.4 Methods

3.4.1 Inclusion and exclusion Criteria

Any case study which describes music therapy work with people with dementia, in a group or individual context, was considered for inclusion in the CIS, provided that it was of sufficient length to allow detailed discussion of the work. Case studies describing non-music therapy work were excluded, as were those where the client did not have dementia. The search was limited to work written in English, and there was no date limit.

3.4.2 Literature search

Since case studies may appear both in journal papers and books, both of these media were included in the search. The preceding chapter's meta-narrative review employed a search strategy which used broad terms relating to music and dementia to find the widest possible range of papers. Case studies in the field of music therapy and dementia which have been published in journals are likely to have been detected in this previous search. Therefore all the papers which were found in during this systematic review were searched for references to case studies, using reference management software. International music therapy journals were also electronically searched.

Since it did not prove possible to obtain a copy of each potentially relevant music therapy text, books containing case studies were identified using online resources. The contents pages were then searched for case studies. Efforts were made to obtain full-text copies of books containing case studies. Maximum variation sampling (Patton, 1990) was used, with the aim of ensuring that diversity is present in the included case studies. At the outset, it was not clear how many papers would be identified in the search, so the decision about how many papers to include in the review and when to stop searching was based on the total number which were identified and the need to maximise diversity among the included papers.

3.4.3 Analysis

The strategy for analysis was adapted from the approaches of Dixon-Woods et al (2006), Flemming (2010) and Medcalf & Skewes McFerran (2016). The following process were used as a guide:

1. **Understanding the case study in relation to itself.** Reading through each case study to understand its context and to identify potential outcomes which are described (Flemming, 2010).
2. **Categorical data collection.** Collecting descriptive data about the studies into a spreadsheet. The data collected included title, author, source of publication, setting of the work, theoretical orientation of therapist, type of dementia of the client, gender, age of client, and any reported outcomes and who they were reported by (Medcalf & Skewes McFerran, 2016).
3. **Translating the studies into one another.** Identifying and categorising outcomes which are described by the authors, using a grid to facilitate this process (Flemming, 2010).
4. **Synthesising the translations.** The translations were compared with each other to see whether the phenomena they describe could encompass those

described by other accounts. This is based on Reciprocal Transactional Analysis (Noblit & Hare, 1988).

5. **Descriptive statistical analysis.** Results were presented as tables and charts in order to display trends in response categories (Medcalf & Skewes McFerran, 2016).
6. **Expressing the synthesis.** The synthesised translations and the descriptive statistical data were merged to form a synthesising argument (Dixon-Woods et al., 2006).
7. **Comparison with meta-narrative review.** The synthesising argument was compared with the findings from the meta-narrative review. Similarities and differences were identified.

3.5 Procedure

Case studies were located in journal articles and books, using the results of the previously conducted search for the meta-narrative review as well as by searching online databases and using resources such as WorldCat to examine the contents of books. Due to the relatively small number of case studies that were found, strict criteria for inclusion were not applied, and some articles and chapters which were not strictly speaking case studies were included in the review, as long as they were written by music therapists and reported their work with people with dementia in sufficient detail that enough relevant data could be extracted. For convenience, however, all these papers are referred to as case studies in this review.

Once papers and chapters had been screened for inclusion, categorical data was extracted from them and entered into a spreadsheet. The texts were read through and data relating to any outcomes of music therapy was copied into a document, then entered into NVivo 12. NVivo 12 was used as a tool for assigning codes representing outcomes of music therapy, and then for refining and combining

codes when the meaning was felt to be sufficiently close that they were equivalent (translating the studies into one another), and grouping them together into higher level categories. This process was based on Reciprocal Translational Analysis (Noblit & Hare, 1988). Any references to outcomes of music therapy which were described in the texts were coded, although if there was more than one reference to the same outcome in a case study it was only counted once. While developing the categories during the analysis, the five domains which emerged from outcome measures in the previously conducted meta-narrative review were used as a framework for analysis: neuropsychiatric symptoms, quality of life and wellbeing, physiological changes, music-related outcomes and cognitive function. These categories were used in order that the results from the two reviews could be compared and synthesised later, and to see whether the domains were a good fit for the outcomes which were reported in the case studies. Any outcomes which did not fit within the domains were categorised as "Other".

3.6 Results

3.6.1 Characteristics of the data

In total 14 texts were obtained and 12 of these were included in the synthesis. One text was excluded because it transpired on closer reading that the subject did not have dementia, and another was excluded because the case was not reported in sufficient detail.

Information about the case studies and reports included in the review are presented in Table 3:1. Publication dates range from 1991 to 2017, and relate to music therapy work which took place in Europe and North America. No case studies taking place outside these two continents were located. Five of the studies were published in music therapy books, four in music therapy journals and three in other journals. The chapter by Pavlicevic and Nockolds contained one case

which was included (Jim) as well as a brief description of an additional case (Olive), but this additional case was not included in the analysis because there was not enough detailed information. For ease of reference throughout the text of this section, each case study has been assigned a reference number which will be reported in square brackets every time that study is mentioned in the text.

Table 3:1: Articles and chapters included in the review

ID	Reference	Source of publication	Therapist approach	Country
1	Pavlicevic and Nockolds, in Pavlicevic, 1999	Music therapy: intimate notes	not stated	UK
2	Odell-Miller in Bunt & Hoskyns, 2002	The Handbook of Music Therapy	Improvisational music therapy	UK
3	van Bruggen-Rufi & Vink, 2011	Developments in Music Therapy Practice: Case Study Perspectives	Culture centred MT	Netherlands
4	Mercadal-Brotons, 2011	Developments in Music Therapy Practice: Case Study Perspectives	Behavioural MT/CBT	Spain
5	Ahessy, 2017	Arts in Psychotherapy	Person-centred MT	Ireland
6	Ridder & Aldridge, 2005	Nordic Journal of Music Therapy	Tailored approach for people with FTD	Denmark
7	Kydd, 2001	American journal of Alzheimer's disease and other dementias	not stated	Canada
8	Ridder & Gummesen, 2015	Australian Journal of Music Therapy	Improvisation/extemporisation based	Denmark
9	Aldridge, 1995	Clinical Gerontologist	Improvisation based	Europe
10	Radoje, 2014	British Journal of Music Therapy	Kitwood/person centred MT	UK
11	Lipe, 1991	Music Therapy Perspectives	not stated	USA
12	Clair in Bruscia, 1991	Case Studies in Music Therapy	not stated	USA

Table 3:2 gives information about the music therapy clients who are described in the case studies (the I.D. number cross-refer to Table 3:1). The twelve clients, five men and seven women, ranged in age from 50 to 94 at the start of therapy with a

mean age of 72.5, and most of them received music therapy while residing in long term care facilities. Most of them had a diagnosis of Alzheimer's disease or probable Alzheimer's disease, although less common forms of dementia such as fronto-temporal dementia and simultagnosia (an inability to perceive more than one object at a time) are also represented. Two clients had a diagnosis of dementia but the case studies did not specify the type, possibly because it was unknown.

Table 3:2: Demographic and clinical details of music therapy clients

I.D.	Client	Age	Gender	Diagnosis	Setting of work	Referred by	Reasons for referral	Group or individual
1	Jim	82	M	Dementia, brain tumour	LTC facility	Not stated	Aggression and disruptive behaviour, feelings of uselessness,	Individual
2	M	50	M	Simultagnosia	Community	Psychiatrist	To work through some of the emotional implications of his diagnosis	Individual
3	Vonnie	83	F	Probable Alzheimer's disease	LTC facility	Not stated	Depression, isolation, confusion, hoarding behaviour, delusional paranoia	Individual
4	Anne	68	F	Probable Alzheimer's disease	Day centre	Neuro-psychologist	Low mood, difficulty with activities of daily living, enjoys music	Group
5	Margaret	94	F	Alzheimer's disease	LTC facility	Not stated	Chance for self-expression, raise mood & cognitive function, strengthen identity	Group, then individual
6	Mrs F	early 70s	F	Fronto-temporal dementia	LTC facility	Not stated	Aggression and agitation, music seems to make her calmer	Individual
7	Phil	87	M	Probable Alzheimer's disease	LTC facility	Care home staff	Depression, difficulty adapting to care placement, enjoys music	Group, then individual
8	Knud	64	M	dementia, type not specified	LTC facility	Multidisciplinary team	Social isolation and agitated behaviour	Individual
9	No name	55	F	Probable Alzheimer's disease	General hospital	Not stated	Depression, difficulty with daily life	Individual
10	Elsa	89	F	Alzheimer's disease	LTC facility	multidisciplinary team	Challenging outbursts	Individual
11	Ellen	69	F	Alzheimer's disease	LTC facility	not stated	To reduce agitation and aggression, to improve quality of life	Individual
12	Mr O	57	M	Probable Alzheimer's disease	LTC facility	not stated	Unable to take part in other activities	Group

3.6.2 Changes reported in case studies

The domains which had been developed from the meta-narrative review appeared to be a good fit for the changes reported in the case studies. Figure 3:1 shows how many case studies reported a change from each of the five domains. All 12 studies reported at least one change which related to quality of life or wellbeing, and 11 of them reported a music-related change. At the other end of the spectrum, only four studies reported changes relating to the reduction of neuropsychiatric symptoms of dementia, and two reported physiological change. Nine studies had some results which did not fit easily into any of the five domains; these were classified as "other" and flagged for closer examination.

Figure 3:2 shows the total number of references to each outcome domain in the included case studies. Here quality of life or wellbeing clearly emerges in the lead; altogether the 12 included studies contained over 100 references to changes related to this domain. By comparison, the next most commonly reported domain, music-related changes, only had 29 references. The next section examines the changes reported in each of the domains in more detail.

Figure 3:1: Outcomes reported in music therapy case studies

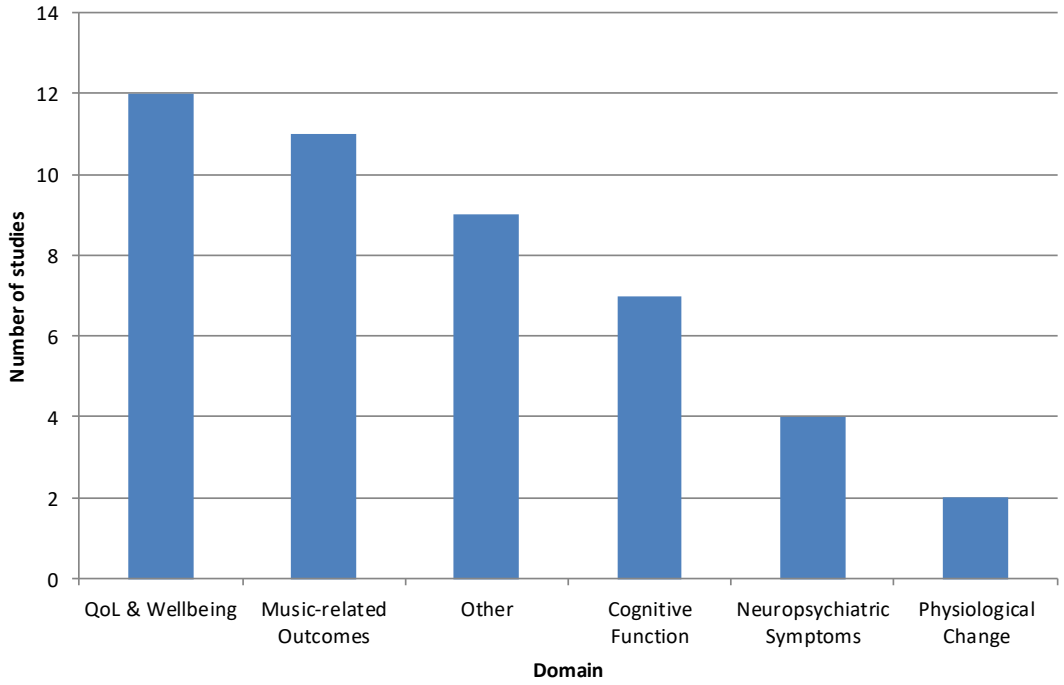
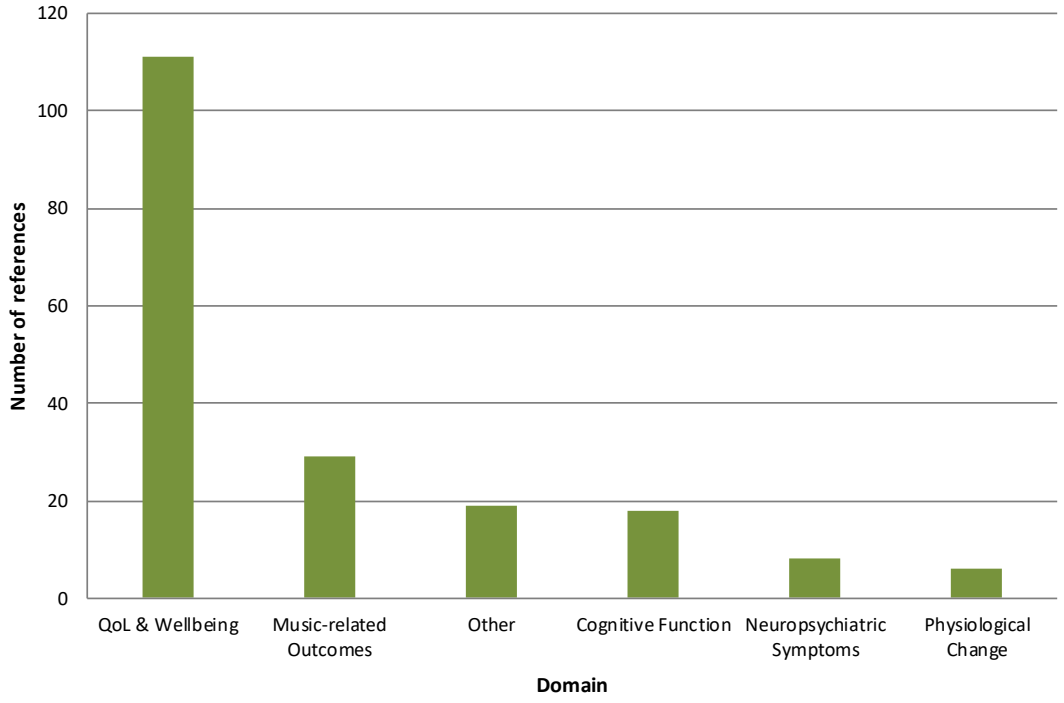


Figure 3:2: Number of references to outcomes in music therapy case studies



The domains and sub-domains which are discussed in the next section of the review are summarised in Table 3:3. Some of the domains were referred to infrequently; in these cases, they were not further divided into sub-domains.

Table 3:3: Domains identified in case studies

Domain	Sub-domain
Quality of Life/Wellbeing	Relationships Positive responses Meeting emotional and psychological needs
Neuropsychiatric symptoms	-
Cognitive function	-
Music-related outcomes	Musical communication Musical creativity Musical response Musical connection Musical success
Physiological outcomes	-
Other outcomes	Carry over to other areas Adapting to change In their own words

Quality of life and wellbeing

The outcomes which were reported in the domain "Quality of life or wellbeing" were further subdivided into three sub-domains: "Relationships", "Positive responses" and "Meeting emotional and psychological needs". It is worth mentioning that the concepts of "quality of life" and "wellbeing" are both somewhat slippery and difficult to define. In a review of concept analysis research comparing quality of life, wellbeing and comfort, it is reported that some studies use the terms quality of life and wellbeing synonymously, while in others wellbeing is considered more related to psychological and spiritual dimensions and QoL reflects the individual's overall satisfaction with their life (Pinto, Martins, Fumincelli, Mazzo, & Caldeira, 2016). For the purposes of this review, quality of life is considered to be a more static concept, while adopting the definition of

wellbeing proposed by Dodge et al. (2012): "stable wellbeing is when individuals have the psychological, social and physical resources they need to meet a particular psychological, social and/or physical challenge" (p.230).

The first category, "Relationships" refers to examples of music therapy supporting the development or maintenance of social interaction. In eight cases, music therapy was felt to have increased the client's interaction with other people, included peers and care staff. Several clients were felt to be having more frequent and successful social interactions with other residents in their care settings [3, 4, 5, 7, 10, 12] while other clients whose dementia was more advanced showed increased social awareness of others in a non-verbal way [6, 8]. Two people with advanced dementia showed orientation to the music therapist, indicating awareness of their presence and a relationship between client and therapist [6, 11]. In one case music therapy was felt to have had a beneficial effect on the client's relationship with his wife, as it was something they could share together [1].

The second category "Positive responses" referred to responses which could be seen as supportive to quality of life and wellbeing. Music therapy was reported to be a means for clients to express themselves; their feeling, thoughts and preferences. Self-expression could be verbal, as in the case of Elsa talking about her trauma as survivor of the Holocaust [10], or musical, as it was for Jim, who found emotional discharge in playing loudly on the drums [1]. There were a number of instances where music therapy was reported to have increased participation, engagement and initiation. Clients were motivated to participate in music therapy sessions, and sometimes the motivation carried over and they were seen as more inclined to take part in other activities too, as in the case of Anne [4]. Some clients were increasingly able to initiate activities in the session, such as suggesting songs or instigating musical dialogue with the therapist and taking the lead. Several clients are described as having a more positive affect after

commencing music therapy; both Ellen and M are described as "brighter" following therapy [2, 11], while Phil is "more pleasant and social" [7]. Music therapy could also support clients' self-esteem by providing an opportunity to contribute something meaningful which they could see the value of themselves, like Margaret's song [5] and Phil's chance to be the "drummer in a band" [7]. Music and memorable songs encouraged some clients to reflect on their lives in a way which brought back happy memories and may have supported their sense of self. For clients whose dementia was more advanced, awareness – either of themselves or their surroundings – was reported during music therapy sessions; for example, Ellen talked about losing her memory in a way which indicated she was aware of her situation [11], while Mr O was noted to watch other members of the group, exhibiting "an awareness of his environment which, according to other observations, he did not demonstrate outside the music therapy sessions" [12].

Many of the outcomes in the third category "Meeting emotional and psychological needs" can be directly linked to Kitwood's (1997) description of the needs of people with dementia: comfort, identity, attachment, occupation, love and inclusion. The most frequently reported need met by music therapy was "identity". With support from the therapist, Jim discovered a way to express his identity as a big, strong man through improvised music [1]. Elsa and Vonnie, both resident in care settings far from their cultures of origin, found confirmation of their identity in traditional familiar music sensitively introduced by the therapist [3, 10]. For Margaret, co-creating a song based on her autobiographical memories supported her identity and promoted continuity of sessions from week to week; although she didn't initially remember writing the song, she was able to recognise herself in its lyrics [5].

Two of the case studies refer to attachment between the client and therapist as a positive outcome of therapy. Elsa's therapist notes that Elsa formed an attachment

to her first of all, but that this carried over to other staff in the facility and she was able to trust them enough to form more attachments [10]. For Jim, the attachment relationship built through shared music-making was strong enough to withstand the loss of Jim's physical capabilities and to guide them into a new phase of working together using his voice [1]. For Elsa, the attachment relationship also contributed to fulfilling another need: comfort [10]. In the cases of Anne and Vonnie, the space created by the music therapy session seemed to be an atmosphere in which they felt comfortable and safe, enabling them to relax and take part in the session [3, 4].

The final two psychosocial needs of people with dementia described by Kitwood (1997) are inclusion and occupation. After attending music therapy, Vonnie is reported to have no longer excluded herself from socialising with other residents on the unit [3], while for Elsa, her sense of inclusion is linked with her relationship with the therapist; she feels included in their music making [10]. The link between music therapy and occupation is only made in one case, again that of Elsa; feeling more comfortable in her care setting enabled her to take part in more activities [3].

Three of the emotional and psychological needs reported in the music therapy case studies do not fall explicitly under Kitwood's categories: containment, feeling understood, and processing trauma. Relationships can be drawn between each of these three needs. Containment is the concept in psychodynamic therapy which refers to the client's use of external objects, like the therapist or the music they create, to cope with and process their own emotions (Bion, 1967). These emotions may be highly confused, painful and fragmented, and are directed towards the therapist, whose role is to mentally process and remove the unbearable qualities from the client's feelings, so that they may begin to cope with them. Containment is particularly relevant for traumatised clients, and through containment clients,

feeling that the therapist has understood them, may begin to process their own unbearable feelings and understand themselves. The process through which music is used to express and process painful emotions may also be characterised as catharsis.

Jim's therapist writes that through music she could validate him and convey that she understood him [1]. Similarly, Vonnie was "recognising her own feelings in the sound and lyrics" and feeling understood because of it [3]. Elsa's therapist writes: "As the mirror of Elsa's memory became more clouded, confused and fragmented, she needed help to see herself, and to hear her feelings reflected and contained musically" [p,34, 10]. Here, the need for containment is explicitly linked to the process of dementia; a person with cognitive impairment may need more help and support from another person's mind when it becomes difficult to articulate their own feelings. In Margaret's case, a joint improvisation on the piano was named "Remembering" by Margaret, who then talked about her family and her feelings about facing death [5]. The therapist writes that the improvisation had acted as a container for her emotions and enabled her to verbalise some of them.

The final category, "Processing Trauma", was relevant in two of the case studies. Elsa and Vonnie had both experienced extremely traumatic events in their much earlier lives [3, 10]. Although it is not made explicit, there is a suggestion in both cases that these experiences had returned to the forefront of their minds with old age and the onset of dementia (Radoje, 2014, p. 32; van Bruggen-Rufi & Vink, 2011, p. 582). Through a combination of musical and verbal reflection, both women were able to share these experiences, possibly for the first time. Although the need to deal with trauma is not applicable to all work with people with dementia, for these two people music therapy seems to have been instrumental in helping them come to terms with what had happened to them.

Neuropsychiatric Symptoms

The group of symptoms commonly called "neuropsychiatric symptoms of dementia" includes agitation, aggression, anxiety, depression, delusions and apathy (Kales, Gitlin, & Lyketsos, 2014). Four case studies had references to decreases in neuropsychiatric symptoms. Music therapy was felt to have decreased agitation and anxiety for Ellen, as it distracted her from auditory hallucinations and reoriented her to the session [11]. Music therapy also appeared to decrease Mrs F's verbal agitation, as there was a marked reduction in her repetition of a single word [6]. Improvements in mood were noted for another two clients, Phil and Margaret, indicating fewer symptoms of depression [5, 7]. Phil in particular is described as happier and looking forward to things; the improvement in mood is carried over to his daily life.

Cognitive Function

Four case studies mention improvements which relate to clients' cognitive capabilities, including their communication, concentration and memory. Several of the studies mention positive changes in clients' verbal abilities; Vonnie becomes better at improvising lyrics [3], Margaret's verbal communication is stimulated by improvising [5], Ellen can fill in the missing lyrics to songs [11], and Anne becomes more willing to speak during music therapy group sessions [4]. There are also improvements in attention to activities both within and outside music therapy sessions for Ellen, Margaret, and an unnamed female client [5, 11, 9]. In two cases, effects of music therapy on memory were reported. Ellen, whose dementia was fairly advanced, was able to remember the therapist's name and location of previous sessions when the therapist arrived for a session on a new unit [11]. She also recalled a particular memory on two occasions a year apart when played certain music, using the same words to describe the memory on both occasions. Phil remembered the names of his fellow music therapy group members from

week to week, and also remembered the name of a song the therapist had written for him [7].

Two case studies refer to clients learning and retaining knowledge within music therapy sessions, which challenges the commonly held perception that learning new material is not possible for people with dementia. Margaret gradually learns the lyrics to the song she and the therapist wrote together and can sing some of them from memory [5]. The unnamed client also learned new melodies and could recall them from session to session [9]. Finally, there are two examples of music therapy lessening confusion and improving orientation to time and place. Phil is described as less confused, with the therapist suggesting that this may be because he is not depressed anymore, as depression can contribute to dementia symptoms [7]. Mr O, whose dementia is advanced, is shown to be oriented to what is happening in the session, as when the therapist says goodbye to him, he responds by standing up and moving towards the door [12].

Music-related outcomes

All except one of the case studies reported at least one outcome which related to how the client used, responded to, or related to music both within the sessions and outside them. The most commonly reported outcome in this category was "Musical communication", when clients were able to use music as a medium for meaningful dialogue or expression. For example, Mr O was able to imitate and respond to rhythmic patterns played by the therapist [12]. M's therapist suggests that his ability to communicate musically outlasted his capacity for verbal expression: "Long after he could hold a meaningful conversation, he could improvise what seemed to be a meaningful improvisation" [2, p.153].

Musical outcomes could involve clients creating their own music and responding to the music of the therapist. In the category "Musical creativity", Margaret

develops in her ability to become immersed in the music [5], and her improvisations became longer and more explorative, while Vonnie gets better at improvising lyrics to songs [3]. The category "Musical response" could represent a broad range of outcomes; what constitutes a significant response is unique to each client and may change depending on the progress of their dementia. For instance, at the beginning of his music therapy Mr O's response to hearing familiar songs is to join in with singing the whole song. As his dementia progresses, this becomes just singing phrases from the choruses. Even when he loses the capacity to sing, he responds by turning his head to the source of a sound and making eye contact with the therapist [12].

In four cases, music is described as a medium through which client and therapist can feel connected. This is similar in some ways to musical communication, but perhaps speaks to a relationship in music which is felt as well as heard. Knud and his therapist are described as "in synchrony with the music" and it is suggested that the familiar music "created a space for him to connect" [8]. Similarly, M is said to have developed a musical rapport with his therapist [2]. And Mrs F responds to hearing a well-known song by reaching out to the therapist and touching her chin; the authors interpret the encounter in this way: "We see this gesture - in this specific situation - as a way of being in dialogue with the therapist. It is an intimate gesture, as Mrs F enters the therapist's personal sphere by gently touching her face" [6]. Context is everything; knowledge of the client and their established relationship allows the therapist to offer an interpretation of a gesture, which, for a different person and situation, could have a very different meaning.

Music therapy may also provide an opportunity for people with dementia to succeed, with potential associated benefits to mood and self-esteem. An important part of Jim's music therapy was the feeling that he was good at playing the drums

and that his contribution was valuable to the music which was created in the sessions [1]. In Anne's case, adapting the activities to meet her capacities ensured that she was successful in them, which is reported to have helped her feel relaxed and secure in the session [4]. In the case of two clients who had been accomplished instrumental players, music therapy helped them rediscover musical skills which they had not recently used. M, a professional musician, had stopped playing the piano with the onset of his dementia because he feared losing his skills [2]. However, after starting music therapy he began to improvise on his own in between sessions. Similarly, Phil was encouraged by the music therapist and his son to begin playing the banjo again, and after he was persuaded to give it a go, his playing improved rapidly [7].

Physiological outcomes

Outcomes which could be linked to physiological change were reported in only two cases. Two clients with more severe dementia, Mrs F and Mr O, who both had a tendency to constantly walk around, were observed to remain seated for long periods during their sessions [6, 12]. Data were collected about Mrs F's heart rate in the week before she started music therapy and after four weeks of music therapy, and statistical tests showed a significant decrease in her heart rate after four weeks of music therapy [6]. It is also noted that Mrs F's dosage of anti-psychotic medication was decreased shortly after the course of music therapy, and was stopped completely a couple of months later.

Other outcomes

There are several outcomes which are reported in the case studies which do not fit easily into other categories. Firstly, in six cases music therapy is explicitly reported to have had an impact upon other areas of the client's life. These impacts may have been mentioned in other categories, but it is interesting to compare the different ways music therapy benefits are generalised; changes in behaviour or ways of

thinking which started within sessions are transferred out to other areas of the client's life. For several people, these benefits were related to social bonding and feeling able to form new relationships, perhaps suggesting that the experience of forming a relationship with the music therapist provided a model for others. Another client was reported to have regained skills which she had lost, such as the ability to cook for herself and find her belongings, as well as having more interest in what was going on around her. For Vonnie, her worry that people were stealing her possessions had lessened; staff reported that this was not an issue anymore [3].

Music therapy provided a way of helping clients adapt to significant changes in their lives, whether this was the transition to living in long-term care or coming to terms with dying. For Jim, music therapy continued right until the end of his life, moving gradually from active to receptive therapy [1]. By expressing her feelings through improvisation first, Margaret found a way to talk about dying and not knowing what to expect next [5]. Staff in Phil's care home observed that music therapy sessions had helped him adjust to his new living situation [7]. Finally, Vonnie had the chance to experience a planned ending when her music therapy finished and the therapist left [3]. The positive and carefully thought about nature of this ending may have helped her to heal from the pain of sudden and unexpected endings and departures in her earlier life.

Finally, a separate category was created for the instances in which people with dementia expressed their responses to music therapy in their own words (Figure 3:3). These are reported here because they reflect the growing interest in the subjective experience of individuals with dementia in research enquiries.

Figure 3:3: In their own words

"This is better than the doctor." – Ellen [11]

"I don't know if something inside deadens the feelings or they deaden of their own accord … but you and I both know you can't live with the dead." – Elsa [10]

"Yes: music can bring peace." – Elsa [10]

"I feel this is so good for me – it's just there, music is here – you touch it and you get it." – M [2]

"It's funny how when the music stops, it just keeps going, it's still there." – Margaret [5]

The words used by these clients convey something of the esoteric and unknowable nature of the musical experience which can make it hard for any of us to describe. It is interesting to note the similarity in the words used by M and Margaret. When M says "music is here – you touch it and you get it", he seems to be describing an experience that is paradoxically impossible to put into words, yet instinctively understood by the participants. Margaret's feeling that the music is "still there" even when it has stopped suggests a musical presence which can be felt even in silence. Elsa speaks eloquently of her suppressed feelings and recognises that she needs to acknowledge them, as well as confirming the role of music in helping with this process. And in more straightforward terms, Ellen conveys her feeling that music therapy has benefits for her that go beyond what is offered by medical care.

3.7 Discussion

The following section discusses the similarities and differences across the different outcomes and forms synthesising arguments.

3.7.1 Intra- and extra-session outcomes

Most of the case studies report outcomes which take place within the session, as well as outcomes which are observed outside sessions. Since the case studies are

written from the perspective of the music therapist who carried out the work, a detailed analysis of what happens in the sessions is to be expected. Furthermore, some outcomes may be observed both during and outside sessions. For example, Phil starts having music therapy because he is felt to be depressed and angry, and is in danger of becoming socially isolated. He is able to participate in the individual sessions, and seems to enjoy them [7]. Song writing in sessions provides a positive way to reinforce his identity, and he is successfully encouraged to start playing his banjo again. In group music therapy, he is more socially interactive, and makes jokes and conversations with other residents. Meanwhile, the staff at the home note that Phil's mood is improved, he participates more generally and seems more inclined to seek out social contact. They report that music therapy has helped him settle into the new setting.

In Phil's case there are outcomes of music therapy which are observed in the session, outside the session and both. In the session, Phil is motivated to participate in activities that he enjoys, and has the self-esteem boost of rediscovering old skills and hearing himself represented in song. The increased participation seems to carry over to group music therapy and outside the session to other activities within the home. Improved mood and adaptation to his circumstances are longer-term outcomes which take place outside the session. Causal links between outcomes and the underlying mechanisms will be discussed later, but it is interesting to consider whether these outcomes are ascribed equal value, or whether the outcomes which "last" outside the session are considered to be more worthwhile than those which take place in the session.

3.7.2 "In the moment"

Related to the previous topic is the idea that some of the outcomes or benefits of music therapy take place "in the moment". This phrase refers to reactions to music which happen briefly and perhaps are fleeting, but nevertheless are valuable and

worthwhile to the people who experience them. The significance of "in the moment" outcomes is in contrast to the notion that outcomes must be clinically significant and sustained in order to be worth measuring. However, due to their ephemeral nature, defining and describing "in the moment" outcomes of music therapy can be difficult.

Many of the music-related outcomes reported in this review might be described as "in the moment". For instance, briefly imitating a rhythmic pattern played by the therapist [12] or connection with the therapist through improvisation [5]. Or there might be a fleeting moment of eye contact or physical contact [6]. Such responses may be difficult to record and interpret because they occur sporadically or unpredictably, because they are small gestures, easily missed, and perhaps also because they require a level of understanding, interpretation and rapport from the therapist, who knows what is a significant gesture from a particular client. These moments may not be obvious to an external observer.

3.7.3 Increasing the positive vs. reducing the negative

Among the outcomes reported in the case studies, those that refer to the reduction of a negative behaviour or symptom are greatly outnumbered by those which refer to a positive change. This may be because the case studies primarily describe the sessions themselves from the perspective of the music therapist, and spontaneous positive responses to music are readily observed during the session (it is also possible that reporting bias on the part of the music therapist plays a role). However, the music-related outcomes, as well as those in the quality of life/wellbeing category and most of the cognitive outcomes can be seen as describing increases in a positive behaviour, response or attitude. Outcomes which relate to symptom reduction may be seen as reducing the undesirable (although the reduction of a negative symptom can be described inversely e.g. reduction of depressive symptoms = improved mood). This raises questions about the

relationship between positive and negative outcomes. Does the absence of negative symptoms necessarily indicate the presence of a high level of wellbeing? And how does the apparent focus on positive responses observed in music therapy case studies reflect the way in which music therapists think about their work?

3.7.4 Causal connections

The case studies described here report outcomes which are based on the observations of music therapists, carers, other professionals and people with dementia. Even assuming that we take the descriptions at face value, it can be difficult, perhaps impossible, to determine from these cases the extent to which the music therapy has caused the outcomes described. This point is raised by the authors of the case study of Mrs F. Referring to the reduction in her antipsychotic medication and heart rate, they write "We saw these changes, but are aware that the single case does not "prove" a connection between the music therapy course and these changes" (Ridder & Aldridge, 2005). Perhaps this is another reason for the focus on "in the moment" and musical responses; it is convincing to attribute changes and response which occur right there in the session to the music therapy itself. Changes which are observed outside the session and are more long-term are more difficult to ascribe to music therapy, even when they appear to correlate with what is happening in the sessions.

We may also consider the extent to which causality can be ascribed between outcomes. For example, Elsa, who forms a strong attachment to the music therapist, is also seen to be more willing and able to form relationships outside the session [10]. Here it is not difficult to describe a possible causal link; the attachment-forming which took place successfully during the session is internalised by the client and transferred to other situations. More difficult to untangle are cases like that of Mrs F [6]; can we ever know whether the decrease in her antipsychotic medication was related to music therapy?

There is an inherent difficulty in ascribing causal links within individual cases, which are sometimes thought of as anecdotal evidence. However, the method of synthesis which is used here could provide an answer to the problem of asserting causality on the basis of isolated cases, since the synthesis and comparison between studies can highlight trends and patterns between as well as within cases, and allow case studies to be used as a body of evidence rather than stand-alone examples.

3.7.5 The unknown and unknowable in music therapy

"Not knowing" is an experience which is familiar to therapists; Gold writes that the therapist "must be able to tolerate a feeling of uncertainty, underpinned by hope", within which the possibility of meaning must be considered in the smallest gesture (K. Gold, 2014, p. 260). However, she goes on to point out that "not knowing" is not particularly compatible with the expectations of funding bodies and healthcare providers generally. There is an undeniable tension between the tolerance of "not knowing" which is essential to the therapeutic space, and the expectation that if a therapy is effective it will be possible to gather rigorous evidence in its favour.

Certain outcomes reported in the case studies, however, highlight the impossibility of empirically measuring all aspects of therapy; for instance, the words of clients in describing their experiences seem to demonstrate that the musical experience is highly significant to them but that it may by its very nature defy description. There are also outcomes which are possible but perhaps not meaningful to measure in isolation. For instance, it would be feasible to count the number of times during a session that a client makes eye contact with the therapist. However, without the therapist's interpretation of the quality and

significance of the eye contact, which is based on their relationship with the client, such a metric lacks important context.

3.8 Synthesis with meta-narrative review

The following section takes the results from the present review and synthesises them with the findings of the meta-narrative review, which examined the indicators that have been used in research to evaluate the impact of music upon people with dementia. Five meta-narratives were developed from the findings of that review, and the case study material will be synthesised with four of them which are felt to be pertinent. The aim of this synthesis is to look for points of divergence and convergence between the two reviews and to ask what conclusions we can draw from these two sources combined. It should be noted that while the critical interpretive synthesis dealt only with music therapy case studies, the meta-narrative review included all kinds of studies which involved music interventions for people with dementia. Therefore, care will be taken to make it clear that some of what is discussed in the following section may apply only to music therapy research.

The fifth meta-narrative presented in Chapter 2 dealt with indicators used to assess responses to group singing for people with dementia. Although group singing is of key importance to this doctoral study, most of the work described in the case studies analysed here related to individual music therapy, and consequently group singing was rarely mentioned. Additionally, despite singing being a regular component of music therapy sessions for almost all the clients described in the case studies, the specific effects of singing or the benefits which singing was felt to convey were not discussed by the case study authors. Therefore, the findings from the present review were not synthesised with the meta-

narrative about singing as there was insufficient relevant data to make this worthwhile.

3.8.1 Developments within music therapy practice and research in dementia

One of the meta-narratives deals with how music therapy research and practice have evolved concurrently. Music therapy research has been dominated by quantitative study designs, a fact which can be linked to the preoccupation of the medical research community with evidence-based practice (Aigen, 2015). Randomised controlled trials may be the gold standard as far as producing generalisable evidence is concerned, but in terms of actually finding out what is going on in music therapy sessions, they could be seen as lacking; DeNora highlights the importance of the musical and emotional relationship between client and therapist and writes that "these interactive features are precisely those that are often excluded and/or derided by proponents of the RCT" (2006, p. 87). Case studies, on the other hand, lack generalisability but offer an insight into what music therapists do and how they think about their work. Where large quantitative studies have the task of demonstrating that music therapy is or is not effective on a macro level, the music therapists in these case studies are responsible for deciding on a micro level whether or not what they are doing is worthwhile for each client. A certain level of reductionism is inherent and perhaps unavoidable for the large-scale studies; music therapy is administered in a controlled and consistent way, like the dose of a drug, and the same responses measured for all participants. However, the insight which the case studies give about how music therapists actually think about the outcomes of their work with people with dementia suggests something more nuanced. As shown here, outcomes of therapy may take place both during the session and outside it. They may be very brief and "in the moment" or longer lasting. Their documentation may be based on both the therapist's observations and those of others. They may be difficult to quantify into an outcome which would be "measurable" and yet still

seen as representing positive change, such as the client making use of the session to express their emotions. Finally, the therapist judges outcomes based on their own feelings, responses and intuition; although the precision of "gut feeling" as a clinical instrument is difficult to determine, its importance should not be underestimated.

The intention of the above is not to laud one type of evidence over another, but to highlight the differences between them and to suggest that, if there is a disconnect between how music therapists think about their work with people with dementia and how it is approached by quantitative research, it may be difficult to reconcile their respective findings. The meta-narrative review also showed that the amount of qualitative and mixed methods research in this area has grown since the mid-2010s, although it is still very much in a minority, which may indicate an increased interest in answering Aldridge's call for research that shows how music therapy works and the processes involved (1999).

3.8.2 The conceptualisation and management of agitation in dementia

The meta-narrative review considered how understanding of agitation in dementia has developed, from assuming it to be purely a symptom of the disease process, to seeing it instead as an attempt to communicate distress and unmet needs. Where agitation was seen as an unavoidable consequence of dementia, drug treatments were applied to suppress the symptoms; the understanding that those symptoms might have a cause that was psychosocial may have led to a move towards identifying treatments that addressed the causes as well as the symptoms. The meta-narrative review showed that reduction of agitation has been extensively prioritised as an outcome measure for music and dementia generally, possibly because it is relatively easy to measure, places a huge burden on caregivers, and because early studies produced encouraging results. Music therapy studies have also targeted agitation, though perhaps less extensively than other

psychosocial interventions. The meta-narrative review highlighted the fact that a number of these studies lack theoretical frameworks suggesting how music therapy may reduce agitation for people with dementia, and justify their choice of outcome measures by citing other studies which have had positive results.

Reduction of agitation is only mentioned as an outcome in two of the case studies in this review [6, 11]. In both of these studies, the change in agitation is observed by the therapist in the session, and we do not learn whether it was maintained outside the session or noticed by other staff members. It is interesting that reduction of agitation, and indeed reduction of neuropsychiatric symptoms generally, is not a commonly reported outcome among these case studies, when in music therapy and dementia studies of other designs it is widely used. This could reflect an actual difference between research and clinical practice; perhaps the former is more likely to look for a reduction in symptoms while the latter tends to focus on increasing so-called positive responses (for instance, Rolvsjord et al. (2005) have written of the challenges of aligning music therapy's strength-focused approach with the priorities of evidence-based practice). If agitation is seen, as in the biomedical model, as a symptom of brain disease, then music therapy can only hope to alleviate the symptom in the same way as a drug. If, however, it is an attempt to communicate need or distress, then music therapy could be seen as providing a way to express these feelings in a more productive way. In this model of agitation, perhaps increase in self-expression and communication could be seen as the "positive behaviour" which is associated with reduction of agitation.

3.8.3 Changing attitudes to dementia in medicine and society

One of the meta-narratives developed in the previous review described how earlier concepts of dementia were that it was "a death which leaves the body behind" and that it was an inevitable part of ageing. The idea that there was nothing to be done for a person with dementia except to look after their physical

needs was challenged by the work of Tom Kitwood and a growing understanding that there were psychosocial forces at play in the dynamics of dementia, not purely biological ones. The meta-narrative review discussed how this changing understanding of dementia is reflected in the development and increasing use of measures of quality of life in music and dementia studies. This is a point of some convergence with the case studies, where outcomes related to quality of life and wellbeing are the most frequently reported. The fact that both case studies and research focus on quality of life and wellbeing is significant in that it demonstrates a belief that maintaining quality of life and wellbeing is possible for people with dementia.

The meta-narrative review has discussed the influence of Tom Kitwood's work, and these ideas are also relevant to the case studies. Kitwood is referred to in four of the case studies (Ahessy, 2017; Radoje, 2014; Ridder & Aldridge, 2005; Ridder & Gummesen, 2015). Ahessy (2017) includes a detailed table outlining how music therapy may meet the psychological needs of people with dementia and discusses the concept of person-centred music therapy, derived from person-centred care and focusing on developing relationships and expressing emotions through music. Radoje (2014) also links many aspects of her work with Elsa to Kitwood's psychological needs, with a particular focus on attachment and identity. These examples show that Kitwood's work has become an important resource for music therapists to define and describe their clinical work with people with dementia. Sherratt et al. (2004b) advocate for the use of Kitwood's theory of personhood as a model for music therapy research, writing that it has far more in common with music therapy philosophy than models such as PLST (Smith, Gerdner, Hall, & Buckwalter, 2004) because it focuses on interpersonal processes rather than symptom reduction. Their assertion, in 2004, that "the view of dementia in music therapy philosophy is currently based on a traditional medical model" suggests

that the theory of personhood represented a paradigm shift for dementia work in music therapy as well as the world of dementia care more generally (2004, p.10).

3.8.4 The subjective experience of dementia

Section 2.10.3 in the preceding chapter highlighted the importance of the work of Kitwood, Bredin and others in leading research away from the assumption that people with dementia were not able to communicate their experiences, to an understanding that it is both possible and necessary to access the subjective impressions of people with dementia through research methods which may have to be adapted. This change demonstrates a rejection of the idea that dementia progressively strips people of their personality, and instead promotes the view that they have an active inner life despite cognitive impairment. It could be argued that music therapy with people with dementia at any stage of the condition cannot take place without a belief that forming a relationship and communicating on some level is possible. However, the case studies vary in the way they describe their subjects, some showing more openness to the possibility of accessing subjective experience than others. For example, in the case of Mr O (published in 1991), it is described how, when offered a maraca, he puts it in his mouth like a baby's rattle and resists attempts to remove it, showing distress. The scene is related factually, and no interpretation is offered of what Mr O may be conveying through this behaviour, what he is experiencing at the time, or what the therapist is thinking or feeling. By comparison, in Mrs F's case, a session is described in which the therapist is singing a song, and Mrs F walks over to the therapist and gently touches her chin (case study published 2005). The authors interpret this action: "Mrs F enters the therapist's personal sphere by gently touching her face" (Ridder & Aldridge, 2005). They go on to say that, although the video recordings of this moment might convey the dialogue between Mrs F and therapist in musical terms, "the essence of being in dialogue with another person is a subjective experience" (p.101). This description conveys something of the difficulty of

measuring subjective experience, especially in severe dementia; the only way to gain access to Mrs F's inner world is through the therapist's own subjectivity. This example highlights again the challenge of balancing the importance of therapists' clinical judgement and experience, based on their own subjective experiences and intuition, with the need for rigour in research methods.

Although music therapists work in a variety of different ways depending on their training and personal style, many draw on concepts from psychotherapy and psychodynamic theory to interpret and understand their work. This style of working often relies on the therapist's intuitive response to the client's emotional state and ways of relating, meaning that a dual subjectivity is introduced: the therapist brings a subjective interpretation of the client's subjective experience. For instance, the psychoanalytic concept of containment (referred to in 3.6.2) relates to the therapist's ability to hold and process difficult and distressing feelings on behalf of the client. With its theoretical roots in mother-infant interactions, containment potentially has high relevance for understanding therapeutic work with people with dementia, since the difficulty of processing the grief and loss which a diagnosis of dementia may bring could be compounded by the cognitive impairment itself. In this situation, the client may make use of the therapist and the music to hold, process and express feelings they are struggling with. Unbearable feelings, once articulated, can be made bearable. The therapist's impressions of what the client is experiencing may therefore add much to the understanding of the subjective experience of people with dementia, in therapy and more broadly. However, such interpretations are fraught with uncertainty and may be difficult to reconcile with standards of evidence requiring proof or measurement.

3.9 Limitations

There are several limitations to the case study synthesis undertaken in this review. Firstly, despite thorough searches, a relatively small number of case studies were located. It is possible that some case studies were missed, particularly if they were printed in older books. The number of case studies is small in comparison with the number of articles included in the meta-narrative review, and by their nature the case studies only represent single examples of practice so care has been taken not to over-generalise from them. The included case studies only represent a very narrow snapshot of music therapy work which is taking place with people with dementia. Secondly, case studies are inherently subjective and written from the point of view of a music therapist who is describing their own work. This may lead to an unconscious or conscious bias, for example, portraying their work in a more favourable light. Thirdly, the motivation to write a case study may have been greater if the case is considered by the author to be particularly interesting or unusual. Included case studies may therefore not be representative of typical examples of music therapy work. However, the authors are all experienced music therapists and therefore it is reasonable to assume that if they believed these cases were exceptional they would highlight this fact, which they do not.

There are also methodological limitations with the CIS method, which are shared with those described by Medcalf and Skewes-McFerran (2016) in the first paper to use this method. The research method is based upon subjective impressions about the papers, and there is no external verification of the selection of studies or the categorisation of their themes. The author's position as a music therapist who has worked with people with dementia is both an advantage and a disadvantage. This experience gives the author an intuitive understanding and perspective on this kind of work, but also unavoidable biases about the effects of music therapy.

3.10 Conclusion

Chapter 3 explored the use of Critical Interpretive Synthesis as a means of integrating data from music therapy case studies. The synthesis aimed to elucidate what outcomes of music therapy were described by people with dementia, their carers, and the music therapists. Analysing data from the case studies indicated that reduction of neuropsychiatric symptoms was not frequently reported in the case studies, despite its prevalence as a targeted outcome in quantitative studies. Instead, many of the outcomes were related to quality of life and wellbeing, and took place within the session, with therapists describing brief momentary transformations of their clients. This raised questions about how long a response to music therapy must last in order to be meaningful and worth measuring. The outcomes described in the case studies also generally focused on increasing positive responses rather than reducing undesirable symptoms, which may reflect a conceptual difference in this approach. Synthesis of case study data with the meta-narratives from the first chapter revealed points of convergence and divergence. Perspectives differ on what outcomes to look for, and choices in this area may be based on pragmatic decisions about what is feasible to measure or ideological ones about what changes are desirable. The move towards person-centred dementia care is evident in both reviews, while the importance of the therapist's intuition and gut feeling, widely used in practice, is a potentially underexploited resource for understanding the outcomes of therapy in research.

Chapter 4: Methodology

4.1 Introduction

Preceding chapters have interrogated music and dementia literature to develop an understanding of whether research reflects the realities of practice in this field, and what benefits music might have. We have seen that there are some discrepancies between the outcomes that are prioritised in research, and those which are the focus of therapy practice. There are many challenges inherent in quantifying the impact of music upon people with dementia, but a growing movement emphasises the importance of prioritising the voices of people with dementia in research as much as possible, rather than relying on proxy report or observation. This chapter introduces the study which was conducted as part of this doctoral project, with the tri-fold aim of evaluating the CHORD manual, understanding the singing group experience, and assessing the feasibility of the chosen research methods. The methodology outlined in this chapter is supported by the findings of the preceding literature reviews in several ways: firstly, in the formulation of its research questions, which seek to understand the experience of the participants as well as measuring benefits; secondly, in its rationale for mixed methodology to elucidate the underlying processes involved in the singing groups; and thirdly, in its choice of outcome measures.

The chapter presents the research questions, followed by discussion of the epistemological and methodological considerations which have played a role in the design of the study. The various research paradigms which have influenced the resulting mixed methods feasibility study design are also discussed. In light of these factors, the operationalisation of the research questions as variables is discussed and rationales for these choices are presented. Finally, some reflections on my position as researcher and participant within the study and singing group are considered.

4.2 Research questions

The study conducted as part of this doctoral research involved inviting a novice facilitator to run a singing group, and recruiting people with dementia and memory problems, and their supporters, to attend the weekly singing sessions over the course of 10 weeks. The study design was based around answering the following research questions:

1. Is the CHORD manual a useful resource for those wishing to run singing groups for people with dementia?
2. How feasible would it be to conduct a full-scale RCT in a similar setting?
3. What is the experience of the CHORD group members? What benefits, if any, do they experience from attending the group?
4. How can the results of this study be used to inform the theory, practice and research methodology of music in dementia care?

The first research question is intended to evaluate the CHORD manual's usefulness as the primary method of communicating ways to run a community singing group within this population; it reflects the process evaluation aims of the study. The second research question relates to the practicalities and issues involved in conducting a full-scale randomised controlled trial in a similar setting. It includes questions about recruitment and retention of participants, suitability of outcome measures, possible control conditions, and the resources required, as well as the appropriateness of the CHORD manual as a standardised intervention (its suitability in this regard is considered distinct to its usefulness as a resource for community singing groups). The third research question also furthers the evaluation of the CHORD manual by investigating the way the group is perceived by the participants and invites exploration of ways in which any benefits might be empirically measured. The final research question explores how the results of this

study, and the accompanying literature reviews, may contribute to practical application and academic research in the field.

4.3 Epistemology

In designing this study, I have considered my epistemological position and the factors which have played a part in forming it. Edwards (2012) makes the point that an epistemological position is always present in research, whether it is explicitly stated or not, and that engaging with it can enhance the quality and validity of the findings and provide an additional source of data. My experiences as a music therapist drew me towards PhD research in the first place, and one of my motivations was to try and reconcile my own first-hand experience of music's potential to improve quality of life for people with dementia, with the recognition that producing results which stand up to the scrutiny of an evidence-based medicine approach is fraught with difficulties. My thinking in this area has been influenced by Onwuegbuzie and Leech (2005) who advocate for researchers to adopt a pragmatic position. This standpoint rejects the idea that qualitative and quantitative methods represent irreconcilably different epistemological and ontological positions, and instead works on the assumption that "there are overwhelmingly more similarities between quantitative and qualitative perspectives than there are differences" (2005, p. 379). This position suggests that quantitative and qualitative data on the value of group singing to people with dementia are equally valuable, and that data collection methods should be driven by the need to answer research questions rather than by epistemological purity.

I am also aware that a certain perspective on dementia is implicit in my approach to evaluating the CHORD manual, which is related to my training and experiences in music therapy. As a music therapist, when working with people with dementia I have tended to focus on improving wellbeing rather than reducing

neuropsychiatric symptoms, and interpreting "problematic" behaviour as essentially communicative rather than a result of disease and cognitive impairment. In taking this approach I am aligning myself with a salutogenic position rather than a pathogenic focus on disease (Antonovsky, 1987). This is reflected in the choice of outcome measures, which evaluate mood and quality of life.

4.4 Methodology

My epistemological position, and alignment with the pragmatic approach discussed above, points to a mixed methods research design. Mixed methods research is an approach which integrates qualitative and quantitative research questions, methods, analysis and results (Pluye & Hong, 2014). The design for this study is similar to the "convergent mixed methods design" outlined by Creswell & Plano Clark (2010). The research questions indicate the use of methods which explore whether the singing group experience is "measurable" and whether such measurements converge with participants' perceptions of what it is like to be in the group. Bradt et al. (2013) advocate for a mixed methods approach on the basis that "music therapists need research that integrates multiple ways of knowing and forms of evidence" and point out that gold-standard evidence gleaned from RCTs may be limited in its applicability to clinical settings (2013, p. 124). The design of this study aims to collect multiple forms of evidence and synthesise them to answer each of the research questions more comprehensively than could be achieved by either qualitative or quantitative research alone. Additionally, a number of research paradigms and methodologies have influenced this study design. These are outlined below, and the impact they have had on the study design is described.

4.4.1 Feasibility studies

There is some inconsistency around the definitions of feasibility and pilot studies; for the sake of clarity the use of the word "feasibility" in the title of this study is based on the characteristics of feasibility studies offered by Haxby Abbott (2014): a feasibility study aims to assess the interaction of different components in a clinical study and to determine whether it would be possible to conduct a larger-scale trial with similar parameters. This includes issues such as the practicalities of accessing and recruiting participants, the viability of the chosen setting, the acceptability and utility of the outcome measures, and the treatment fidelity.

An additional meaning of "feasibility" within the context of evaluating the CHORD manual refers to the use of the manual within a real-world setting. The study aimed to find out whether it is possible for an novice facilitator using the manual to set up and run a singing group, and what the strengths and weaknesses of this approach are. It also considered what kind of information about running singing groups it is possible to communicate through this written form, and whether other forms of training or dissemination are required.

4.4.2 Complex interventions

Guidelines published by the Medical Research Council suggest that the complexity of an intervention is determined by the number of interacting components it contains (Craig et al., 2012). Singing groups for people with dementia may be considered complex interventions for a variety of reasons. Firstly, the delivery of the intervention is determined by the facilitator's interpretation of the manual, their personal experience, and the way the group responds to the sessions. The impact of the singing group upon the attendees is influenced by their own personal situation, life history, their motivations for attending the group and their reactions to the content of the sessions. From these two aspects taken together, it is clear that the outcomes (i.e. the experiences of the participants that can be

measured) may be highly personal, and that tracing causal links between intervention and outcome may be difficult, since there are so many interacting components that controlling for confounding factors is a challenge.

In the MRC guidelines, two questions for evaluation of complex interventions are proposed. The first relates to the intervention's "practical effectiveness": how it works in everyday real-world contexts. The second relates to *how* the intervention works: "what are the active ingredients within the intervention and how are they exerting their effect?" (Craig et al., 2012, p. 7). The present study aimed to evaluate the practical implementation of singing groups informed by the CHORD manual, and to use the synthesis of qualitative and quantitative data to investigate the mechanisms through which the intervention's effects take place. Evaluation of the effectiveness of the intervention is a question for further research. Although the MRC guidelines were taken into consideration when designing the study, it is important to note that the research design does not strictly adhere to them.

4.4.3 Process evaluation

The present study may also be characterised as a process evaluation of the implementation of the CHORD manual. Where feasibility studies aim primarily to establish *whether* the interacting components of a trial can function together, process evaluation focuses on *how* the components of an intervention work together, and may provide data on treatment implementation and fidelity, causal mechanisms, and factors which may influence variation in outcomes (Moore et al., 2015). According to Moore et al., "an understanding of the causal assumptions underpinning the intervention and use of evaluation to understand how interventions work in practice are vital in building an evidence base that informs policy and practice" (2015, p. 1). In other words, it is not enough to know that a complex intervention produces a desirable result when the number of variables at

play in its delivery is so large that the same intervention conducted in a slightly different context might have completely different outcomes. Moore et al. offer a framework for process evaluation in which the intervention and its outcomes are mediated by context, implementation and causal mechanisms. Components of this framework have been included in the design for this study, as outlined in the following pages.

4.5 Operationalisation of research questions

The following section discusses how each of the research questions has been operationalised and the underlying rationale for these methodological decisions. Note that some methods of data collection address only one research question, whereas others may address two or more. The way in which the research questions are operationalised is visually represented in Figure 4:1. In this diagram, the coloured arrows connect each of the first three research questions with the forms of data used to answer them, while the fourth research question encompasses all the data collected during the study.

4.5.1 RQ1: Is the CHORD manual a useful resource for those wishing to run singing groups for people with dementia?

The first research question relates to the utility of the CHORD manual as a tool for running singing groups. It asks whether guidance it contains can be interpreted and put into practice by the facilitator in a way which enhances the experience of the people who attend the group. It also evaluates the practical aspects of implementing the advice in the manual, and evaluates the strengths and weaknesses of the manual. To address this research question, data were collected from analysis of the interview with the facilitator and her session plans and notes, in order to assess her opinion of the manual, how she used it and how this changed over time. Analysis of my notes from watching video recordings of the

sessions provided further data about how the facilitator interpreted and used the manual and how the group responded to the sessions. Finally, interviews and focus groups with the participants were analysed for themes related to their perception of the group and how they felt about the way the facilitator led them.

4.5.2 RQ2: How feasible would it be to conduct a full-scale RCT in a similar setting?

The second research question investigates the issues and challenges involved in carrying out an RCT involving singing groups for people with dementia in a community setting. This research question was addressed with data about the recruitment of facilitator and participants, practical issues about the setting of the study, how to decide on inclusion and exclusion criteria for the study, and whether the measures chosen could be used to detect any change which occurred as a result of the intervention in this context. Data relating to the facilitator's adherence to the manual was also collected, because in the event of a larger scale study it would be important to assess whether the facilitator(s) were delivering a standardised intervention (one which was broadly the same across all groups). Additionally, data were collected about how acceptable the methods used in the study were to the participants, through interview questions and assessing the participants' response to quantitative measures, including any problems encountered in this process and the completion rates.

4.5.3 RQ3: What is the experience of the CHORD group members? What benefits, if any, do they experience from attending the group?

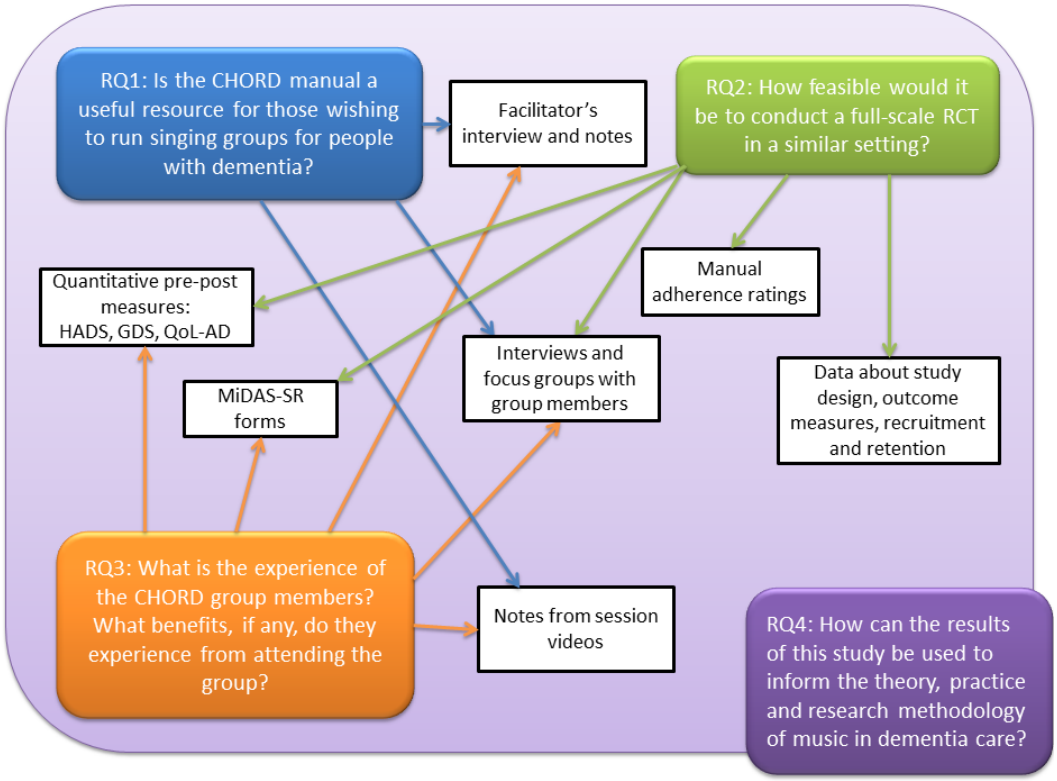
The third research question focuses on the singing group members, their experiences as part of the group and the study, and whether they noticed any changes or outcomes as a result of coming to the group. The word "benefits" is subject to broad interpretation in this question, and refers both to outcomes which may have been detectable by the chosen measures, and to positive effects which

they themselves identified as resulting from it. Data were collected using quantitative outcome measures to detect change over the course of the group (Quality of Life in Alzheimer's Disease Scale and Geriatric Depression Scale for people with dementia and memory problems, Hospital Anxiety and Depression Scale for carers/supporters, MiDAS-SR scales after sessions for musical engagement). Further information on the methodological decisions underlying choice of quantitative outcome measure is provided in a subsequent section. Furthermore, focus group and interview data collected after attending the group for ten weeks was analysed for themes related to benefits of the group. These data were compared with data from baseline interviews, to investigate whether participants' previous experiences of music and their motivations for attending the group had a bearing on the way they responded to it.

4.5.4 RQ4: How can the results of this study be used to inform the theory, practice and research methodology of music in dementia care?

The fourth research question considers how the findings of the study, taken together, may have practical and theoretical implications for the field. On the practical side, the evaluation of the CHORD manual provides data about the implementation of this manual in particular, which may also be applicable to the manualisation of other interventions in an arts and health context. It also informs the practice of setting up and running a singing group for people with dementia in a community setting. On the theory side, the results of the process evaluation component of the study may inform the development of the mechanisms of action through which attendees of the group experience benefit. Finally, the evidence generated about the feasibility of conducting a small-scale study in this context will lead to recommendations about methodological choices for future studies in this field.

Figure 4:1: Operationalisation of Research Questions



4.6 Choice of quantitative outcome measures

The process of choosing quantitative outcome measure was guided by the Joint Programme - Neurodegenerative Disease (JPND) report "Dementia Outcome Measures: Charting New Territory" (Joint Programme - Neurodegenerative Disease, 2015) and the related 2008 paper (Moniz-Cook et al., 2008). The report recommends outcome measures based on their reliability and sensitivity, and the ease with which they can be applied in practice. The Quality of Life in Alzheimer's Disease scale was selected for this study, as it is recommended by the JPND and can be completed either by the person with dementia or a proxy. The JPND recommendations point out that "measurement of the static concept of health related quality of life has overlooked the growing acknowledgement of the importance of social health", and the questions in the QoL-AD scale encompass not only the person's physical and mental health, but their satisfaction with their

living situation, their relationships and their ability to get on with daily activities. It is also fairly brief, containing only 13 questions, so does not place too much of a burden on the respondent.

Since positive changes in mood are reported in several community singing studies, a depression screening scale was used to detect possible changes over time. Using a scale specifically designed for older populations seemed appropriate, since some of the somatic symptoms of dementia reported by younger people (such as difficulty sleeping) are commonly experienced by non-depressed older people (Sutcliffe et al., 2000). The Geriatric Depression Scale (GDS) is one of three measures recommended by the JPND report, although the Cornell Scale for Depression in Dementia is the measure of choice. However, the Cornell Scale is relatively time consuming to administer (approximately 30 minutes) and is intended for use with people with moderate to severe dementia, since it relies mainly on interviewing the person's main caregiver and only includes a brief interview with the person themselves. On the other hand, the GDS-15 may be suitable for people "with awareness of their disabilities" (Moniz-Cook et al., 2008, p. 19). Moniz-Cook et al (2008) also suggest using a shortened twelve item version of the GDS "for studies requiring a short self-report non-diagnostic measure to monitor change". This version (GDS-12R) removes questions which were confusing or irrelevant to people living in residential care, and in doing so improves the validity of the scale (Sutcliffe et al., 2000). However, since it was anticipated that most people participating in this study would have mild to moderate dementia, and would not live in residential care, the GDS-15 was selected.

Choosing an outcome measure for the support members of the group posed a challenge since these members are likely to be a diverse group. Partners and children of people with dementia were the most likely to accompany people with dementia to the singing group, but this role might also have been filled by

professional caregivers, friends or other family members. Therefore a fairly broad measure was required to capture change across various domains. The support members' relationship to and role within the life of the people with dementia will also affect the possible mechanisms by which the group benefits them. For example, a spouse in the role of main carer may find the group singing experience strengthens their relationship with their partner (Unadkat et al., 2016), which may in turn lead to improvements in their quality of life or mood. However, this kind of benefit is less likely for a professional carer who does not necessarily have such a close relationship with the person with dementia. Caregiver burden scales were potentially inappropriate, since it is likely that some of the people in the study would be either pre-diagnosis or only recently diagnosed with dementia, so support members may not see themselves as carers and people with dementia may not see themselves as being cared for. In cases like this the implication that the person with dementia is a burden could well be seen as offensive or disempowering. The measure which was selected for this study was the Hospital Anxiety and Depression Scale, which is recommended by the JPND as one of the measures of choice for carer mood.

The three quantitative measures previously discussed were selected to detect change which occurred over the course of the study. A fourth measure, Music in Dementia Assessment Scales – Self-rating version (MiDAS-SR) was used to monitor participants' responses to the sessions immediately after they had happened. The measure is based on the psychometrically validated, observer-rated MiDAS scale (McDermott et al., 2015) and uses five visual analogue scales upon which the respondent rates various aspects of the musical experience they have just had. Although the observer-rated version has been widely used, this study was the first time the self-rated version has been implemented. One reason for its use was to test the feasibility of a self-rated measure of musical response. Another was to gather data about participants' immediate response to the singing group, which

could be compared with the other quantitative and qualitative data. This data could potentially be used to suggest mechanisms of action for the benefits of group singing. Additionally, given that the group would be attended by people with memory problems, it seemed important to gather data about their responses to the group straight after the sessions, since it might have been harder for them to remember later during interviews or focus groups.

4.7 Reflections on my position within the study

I was present for and involved with all the singing group sessions. I saw my role within the group as having three distinct facets which are outlined below:

- **Assisting with practical aspects of the group.** This involved tasks such as setting out the seating for the group, and helping to provide refreshments, as well as taking care of the requirements of the study, such as setting up video cameras and administering MiDAS-SR rating scales at the end of the sessions. It was made clear to JB (the facilitator) that she could ask for musical support from me as she deemed appropriate, and she asked me to fill the role of accompanist for the group.
- **As observing music therapist.** As a qualified music therapist with experience of running singing-based groups for people with dementia, I was well-placed to make observations about the way the group dynamic developed, group members' musical responses and the techniques which were used by the facilitator.
- **As participant member of the group.** Rather than sitting apart from the group and observing from a distance, I planned to take part in the sessions. The rationale for this was that the presence of an observer could make group members uncomfortable and alter their behaviour, and furthermore I believed that taking part would give me some insight into the experience

of being part of the group. In fact, fulfilling the role of accompanist within the group allowed me both to participate in the sessions and to sit slightly apart and observe the group, due to the positioning of the piano.

I was aware that there were some risks associated with my presence in the sessions which had to be considered. Firstly, since I have experience both as a music therapist and in working with this client group in similar circumstances, there was a risk that if I had too much input into the planning and running of the sessions we would not be able to reliably conclude that the group was conducted through JB's interpretation of the manual alone. However, given that JB and I were working closely together to set up the group, it was unfeasible to expect discussion not to take place. To minimise this risk, it was important that both JB and I were aware of the possibility and were able to take it into account when planning and reflecting upon the study. Secondly, my role as participant within the group may be considered less objective and neutral than that of an observer. However, this decision was made because I felt that gaining insight into the experience of being in the group was worth the trade-off of losing some neutrality. Furthermore, the video recordings of sessions provided an opportunity to gather data which may have been missed during the sessions themselves.

4.8 Conclusion

In Chapter 4, the methodological considerations impacting upon the mixed methods feasibility study design were discussed. The adoption of a pragmatic approach reflected the complexity of the intervention and the need to understand how a trial of group singing would function in the real world. The four research questions were outlined with an explanation of how each of them would be operationalised as forms of data collection: the first question focused on evaluation of the manual, the second on the feasibility of a full-scale RCT using similar

methods, the third on the experiences of the CHORD group members and whether the group had benefits for them, and the fourth and final question on how the results of this study would inform theory, practice and research. The impact of my presence as researcher and accompanist upon the group was considered, in light of Chapter 3's conclusions about the potential value of therapist experience as a data source. The following chapter describes in detail the study design and methods of data collection.

Chapter 5: Methods

5.1 Introduction

The study design outlined in the following chapter is conceived as a feasibility study for a randomised controlled trial and may also be characterised as a process evaluation. It employs a mixed methods design. People with memory problems and dementia were recruited to be part of a singing group, which met every week for ten weeks. A person with no prior experience leading singing groups was recruited to be the facilitator, and she used the CHORD manual to guide the planning and execution of the sessions. Data were collected from the participants through interviews, focus groups, mood and quality of life rating scales, video observation and musical engagement questionnaires. Data were collected from the singing group leader through interview and reflective notes. Her adherence to the manual was also measured.

Note: Throughout this and the following chapters, the abbreviation "BD" refers to the author and "JB" to the singing group facilitator.

5.2 Study Design

5.2.1 Setting

The venue used for the study was a sheltered housing establishment comprising approximately 60 flats for people aged 55 or over, mostly living independently, with some requiring extra support. It is located in a suburb of a large city in the Midlands, UK. The room available for the singing group sessions was a large communal space which is normally used for dining, coffee mornings, and social activities of various kinds. Some of the study participants were resident in the sheltered housing complex; others came from elsewhere.

5.2.2 Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
People with dementia: People aged 18 or over who self-identify as having memory problems, and/or who have been diagnosed with dementia. People who expect to be able to attend at least half of the sessions. People who are comfortable with being filmed.	*People with dementia:* People who have such severe neuropsychiatric symptoms of dementia that their safety within the sessions and that of others could be compromised. People whose behaviour would be likely to cause unmanageable disruption to the sessions and/or distress to other group members. People who lack capacity to consent to take part in the study and do not have someone who can commit to accompanying them to the sessions.
Support members: People aged 18 or over providing support or care on a regular basis to the person with dementia or memory problems who is participating in the study. People who expect to be able to attend at least half of the sessions. People who are comfortable with being filmed.	*Support members:* People unwilling or unable to commit to accompanying people with dementia or memory problems to the sessions.

It was decided that people who self-identify as having memory problems would be eligible for inclusion in the study, rather than only those with a formal dementia diagnosis. The reason for this was that not all people with early-stage dementia have sought a formal diagnosis, and singing groups may provide support for those in the early stages of dementia help them to acknowledge the need to seek a diagnosis. It was not necessary for people with dementia/memory problems to

attend the group accompanied by a support member, and several people attended on their own.

Note on terminology: Throughout the chapters discussing the methods and results of this study, the phrase "people with dementia" refers to all participants in the study who had dementia or memory problems. When these two groups need to be differentiated, they are referred to as "people diagnosed with dementia" and "people with memory problems".

5.2.3 Sample

The study used an opportunistic and self-selecting sample. A power calculation to determine sample size was not performed, since this was a feasibility study. Recruitment took place in July to September 2017, and focused on the geographical area where the study was to take place.

5.2.4 Ethics

Ethical approval for the study was obtained in May 2017 through application to the Research Ethics Committee at the School of Sociology, University of Nottingham (reference number 125-16-17-PGR). The letter confirming ethical approval for the study is provided in Appendix 3. This process requires the applicant to submit a form with an outline of the study design, and to complete a checklist where "yes" or "no" answers are given to various questions, in order to identify those areas of ethical concern which demand further exploration. This process highlighted eight concerns for this study, which are detailed in Table 5:1 along with the rationale for this approach and the mitigations in place to minimise risk.

Table 5:1: Ethical issues identified as relevant to this study

Ethical Issue	Rationale/Mitigation of Risk
People with dementia are the intended participants in this study, some of whom may lack capacity to provide informed consent. **Some people may need extra support in order to understand the consent process.**	If someone without capacity to consent is invited to take part in this study, a person who knows them well will be consulted and asked to advise whether their participation is in their best interests. Capacity will be assessed through discussion with each potential participant and with those who know them well, in accordance with guidelines in the Mental Capacity Act 2005. A person with dementia who lacks capacity will be required to have a partner/friend/carer present at all times in order to attend this group. Accessible and simplified materials containing information about the study will be created.
The study may include people who live in residential care.	People who live in residential care will be asked to arrange their own transport, or this will be arranged in consultation with their residence.
The research may involve people with mental health conditions	People with dementia and their carers will be asked to let the researchers know if they have any mental health conditions which may adversely affect their participation in the group, and carers will be asked to accompany the person with dementia to the group if they may need extra support.

Ethical Issue	Rationale/Mitigation of Risk
	If there is cause for concern about a participant's mental or physical wellbeing, they will be consulted and an appropriate medical professional may be contacted. In the case of a potential participant's symptoms being so severe that it is not possible to enable their safe participation in the group (e.g. psychotic symptoms, severe wandering) they may have to be excluded from the study.
The research may involve people with physical or sensory impairments.	When people are approached to be part of the study, any adaptations which need to be made to enable them to take part will be discussed (e.g. large print song sheets, reminders for those who may forget to come to sessions) and this will also be discussed with the singing group leader so she can incorporate it into her planning. The venue is accessible and has suitable disabled toilet and parking facilities.
Declining to take part in the research project will mean that potential participants will not be able to be in the singing group – a possible negative consequence for anyone who is	It will be clearly explained to potential participants that they are consenting to be in the research project as well as the singing group before they decide whether to take part. It will also be made clear that they can withdraw from the study at any time without penalty, and that they can decline to take part in individual outcome measures.

Ethical Issue	Rationale/Mitigation of Risk
particularly keen to do singing but does not want to be part of the research.	If there are potential participants who are very keen to be in the singing group but do not consent to being part of the study, every effort will be made to direct them towards alternative existing community choirs or singing groups which may be able to accommodate them.
Taking part in a singing group is reported by group members to be enjoyable and beneficial (e.g. Davidson & Fedele, 2011; Osman, Tischler & Schneider, 2014), therefore it would be untruthful to tell participants that they are unlikely to experience direct personal benefit.	It will be made clear to participants through the information sheet that some people find the experience of being in a singing group enjoyable and beneficial. It will also be made clear that this is not a universal experience and they may not find the singing group enjoyable or beneficial even if other group members do. The fact that music and singing can be an emotional experience for some people will also be mentioned in the information sheet, as some people may view this as a drawback or risk, and others as a benefit.
The study design involves video recording. If participants decide to withdraw from the study, they will not be able to withdraw video material which has already been recorded.	With the resources available, it would not be possible to edit out a particular person from the video material, and deleting all the footage would mean deleting data which has been collected about participants who are continuing in the study. If a participant does want to withdraw from the study, they will be able to withdraw all data collected about them if they wish to, apart from the video recording. This will be made clear in the information sheet. They will also be reassured that

Ethical Issue	Rationale/Mitigation of Risk
	direct quotes from them will not be used in any publications which follow from the study.
The study design involves making initial visits and follow-up visits to potential participants, to explain the study to them and to collect baseline data. These visits may take place in the potential participants' homes or care settings.	The researcher is a music therapist with extensive experience of making home visits to people with dementia, and therefore knows how to behave sensitively and appropriately within these settings. The researcher will ensure their personal safety by letting someone know where they are going, and will let them know when the visit has been completed.

5.2.5 Recruitment of singing group leader

The procedure for recruiting the singing group leader began in late 2016. An advert was circulated to the mailing list of a network of people who were interested in music and dementia, and recipients were encouraged to forward it to anyone who might be interested. Payment of £50 per session was offered.

The advert stipulated that the ideal person

- was not a trained music therapist or psychologist;
- had some music skills (but did not need to be a trained/professional musician);
- had no prior experience of running this kind of group; and
- was interested in working with people with dementia, and may have had some experience of doing so

The rationale for choosing this set of characteristics was that they most closely matched target users of the CHORD manual: people who are motivated to provide singing activities for people with dementia, but who do not have prior experience of doing so. The study required someone who was not trained in music therapy or psychology in order to test the skill-sharing aspect of the manual, as it would be difficult to tell what the person had learned from the manual if previous related training had been undertaken. The intention of these criteria was to identify a facilitator without extensive clinical or therapeutic experience of work with people with dementia. Some basic musical skills (such as being comfortable singing in front of people) were required, but since the manual is aimed at anyone who feels they could lead singing, more advanced skills were not necessary. Someone with no prior experience of running a similar kind of singing group was desirable, so that the outcomes could be attributed as much as possible to their interpretation of the manual, rather than to previous experience.

Following the circulation of the advert for a singing group leader to the local "Music and Dementia" network, we received expressions of interest from five people, and went on to interview four of them (one decided not to proceed with the application). At the interviews, the applicants had the opportunity to ask us questions, and we asked them questions which were slightly tailored according to their background and experience (see Appendix 4). As a result of the interviews, we asked one of the applicants (JB) to take on the role, and she agreed. JB is an amateur singer with experience of working with people with dementia and an interest in doing so, but she had never led a singing group before. She is a qualified counsellor and has experience in group facilitation. She was comfortable with the intended research methods and with being filmed and audio recorded.

5.2.6 Recruitment of study participants

The process of recruiting the participants for the study began in July 2017. This was a creative and iterative procedure, as new approaches were devised based on the feedback and response rate to earlier attempts. Since the study was recruiting from the local community (rather than through a gatekeeping organisation) it was important to try many different avenues to increase the chances of reaching as many potential participants as possible. A full description of the recruitment process is given in the procedure section (see 5.4).

Since the study offered the chance to join a singing group, there was an obviously unavoidable risk that the sample would be biased towards those with an interest in singing; indeed, it was hardly likely that those with no interest at all in singing would respond to such an invitation. However, in order to minimise the chance that the sample would only include those who already considered themselves experienced singers or musicians, care was taken over the wording of the poster. The term "singing group" was chosen in preference to "choir" as the former was thought to have connotations of formality and the need for experience or skill. In the description of the group on the poster (see Appendix 5), it was emphasised that the group was intended to be fun and informal, and that participants did not need to have any singing experience to take part. The poster was also designed to be dementia friendly, with clear contrast between the colours, sans-serif fonts for ease of reading, and images relevant to music.

5.2.7 Data collection

Data collection methods were selected based on the results of the systematic review, and their suitability and appropriateness for the study in question. Table 5:2 summarises the outcome measures which were administered and the qualitative data collection methods which were used in the study.

Table 5:2: Details of data collection methods used in the study

Data collection method	Respondent	Time to administer	Frequency
GDS-15 (Yesavage et al., 1982)	People with dementia	5-7 minutes	Baseline and 10-12 weeks post-baseline
QoL-AD (Logsdon et al., 1999)	People with dementia	10 minutes	Baseline and 10-12 weeks post-baseline
MiDAS-SR (based on McDermott et al., 2014)	People with dementia	3 minutes	After every session
HADS (Mykletun et al., 2001)	Support members	5 minutes	Baseline and 10-12 weeks post-baseline
Manual adherence	JB & BD	10 minutes	After every session
Interviews	People with dementia, support members, JB	15-30 minutes, 60+ minutes (JB only)	Baseline and 10-12 weeks post-baseline
Focus Group	People with dementia, support members	45-60 minutes	10 weeks post-baseline
Reflective notes	JB & BD	15-30 minutes	After every session/own discretion

Quantitative Outcome Measures

A rationale and explanation for the use of each quantitative outcome measure is given below:

Geriatric Depression Scale (GDS-15) (Yesavage et al., 1982) The 15-item measure is recommended by the EU Joint Programme on Neurodegenerative Disease (JPND) report on appropriate outcome measures for people with dementia as suitable for use in pre-clinical and early dementia (Joint Programme - Neurodegenerative Disease, 2015). The measure yields a total score out of 15, where a higher score indicates more symptoms of depression.

Quality of Life – Alzheimer's Disease Scale (QoL-AD) (Logsdon et al., 1999) This measure is recommended by the JPND report as an appropriate outcome measure for psychosocial interventions in dementia (Joint Programme - Neurodegenerative Disease, 2015). It is widely used with people with all types of dementia and can be administered either as a self-rated scale or by a proxy. It was expected that most of the people who took part in the study would be able to provide their own responses, but if this was not possible, someone who knew the person with dementia well could provide proxy ratings. It is fairly short, comprising 13 questions, and therefore does not place too much of a burden on the respondent. The QoL-AD yields a total score out of 52, with a higher score indicating a higher reported quality of life.

Music in Dementia Assessment Scale – Self Rating Version (MiDAS-SR) The MiDAS-SR has been developed as a self-rated version of the original MiDAS form, which was designed to be completed by carers and music therapists. Although it has not been used in a study before, the original version has been shown to have good psychometric properties (McDermott, Orgeta, et al., 2014). The MiDAS-SR presents the respondent with five questions about the musical experience they have just had, and asks them to rate these from "least" to "most" by making a mark on a Visual Analogue Scale (VAS). A numerical value is then produced by measuring where on the scale the mark lies. Since the form only asks five questions this was not anticipated to be too time-consuming and burdensome for the respondent.

Support members

Hospital Anxiety and Depression Scale (HADS) (Mykletun, Stordal, & Dahl, 2001) The Hospital Anxiety and Depression Scale is recommended by the JPND report as one of the measures of choice for carer mood. It generates a total score for depression and anxiety, each out of 21. These can be combined to give an overall score for emotional distress out of 42.

Manual adherence form

The manual adherence form was developed specifically for this study, and was completed by JB after every session. These ratings were compared with ratings produced independently by BD using the same form after watching the video recordings of sessions, and without looking at the ratings produced by JB. Further details about the development and use of the manual adherence form (MAF) are given in section 5.2.8.

Descriptive data about people with dementia and their supporters was also collected from the group members, and their attendance at the sessions was recorded.

Qualitative Data Collection

Interviews with singing group members were conducted before the start of the sessions and after the 10 sessions had taken place. Both people with dementia and support members were interviewed, normally together. These interviews were semi-structured, and at baseline focused on the participants' musical experiences and preferences, and their expectations for the group. The follow-up interviews were also semi-structured and focused on participants' experiences of being in the group, whether it met their expectations and their feelings about taking part in research. The interview guides used are provided in Appendix 6.

Two focus groups were also conducted with the members of the singing group after sessions 8 and 9. These provided a chance for them to reflect on the experience as a collective, in a context which replicated to a certain extent the dynamic which had developed in the group. The group was divided into two focus groups, since it was too large for one group. An interview with the singing group leader, JB, was conducted following the end of the sessions. This focused on her experience of using the manual to set up and run the group, and her feelings about leading the group in the context of the study, including the process of rating her

adherence to the manual. The guide used for this interview is provided in Appendix 7. All the interviews were audio recorded and the focus groups were video recorded.

Reflective notes were kept by BD and JB. JB's notes were written directly after running the sessions. BD's notes were written after attending each session and reviewing the video recording of it. The notes included comments and observations about setting up the group and running it, feelings about the process, and the successes and challenges of the sessions. Additionally, any relevant comments about the group from the members were recorded anonymously.

5.2.8 Development of Manual Adherence Form

The manual adherence procedure was developed to test whether it was possible to observe and measure how closely the facilitator followed the manual while she was delivering the sessions. Information about manual adherence relates to research questions 1 and 2. Firstly, it allows us to see whether the facilitator was using and referring to the manual and therefore to ascertain whether she found it helpful. Secondly, this approach examines whether it is possible to develop a treatment fidelity measure for a manual such as CHORD which does not define a set of behaviours or actions expected of the facilitator. Establishing the consistency of the intervention delivery would be an important aspect of a randomised controlled trial, especially one where the singing groups were led by multiple facilitators. Although assessing treatment fidelity and use of manualised interventions is an established practice within trials of music therapy, generally the manuals are created specifically for the trial to reflect an already established way of working (for example, the approach proposed by Rolvsjord et al. (2005)). No examples of therapeutic music trials where the manual was also the means of communicating the intervention to the facilitator were found in the literature. In the absence of examples from other studies to follow, the manual adherence form

and procedure which was used was developed specifically for this study, and should be considered exploratory.

To develop the manual adherence form, the CHORD manual was thematically analysed. The original plan was to use the "directed content analysis" approach outlined by Hsieh & Shannon (2005) to produce the categories for the manual adherence form. In this approach, the researcher uses existing research to identify variables for the analysis. The intention was to use three papers which are closely related to this study (McDermott, Orrell, et al., 2014; Osman et al., 2014; Unadkat et al., 2016) as the main source of categories, and to code my analysis of the manual according to these categories. When attempting to apply this technique, it became apparent that it was not suitable, since the manual adherence form needed to contain items which one might reasonably expect to be able to observe in the facilitator's behaviour, while most of the categories found in the papers mentioned above relate to the experience of the participants, and facilitator behaviour is not described in any great detail. Therefore, the approach was adapted as outlined below:

1. The CHORD manual was reviewed, and all text which referred to what the facilitator might do, or how she might do it, was extracted and entered into an Excel spreadsheet.
2. The salient points of these fragments were briefly summarised in the next column of the spreadsheet.
3. A code was assigned to each summary.
4. The codes were entered into a new spreadsheet and the number of times that each was used was recorded.
5. The codes were grouped into overarching categories. These categories were used as items for the manual adherence form.

The analysis of the CHORD manual identified 90 segments of text which related to advice about things that the facilitator might do during the sessions, or how she might do them. Each of these chunks was one or occasionally two sentences long. The 90 segments of text were copied into a spreadsheet, and each was summarised briefly. These summaries were reviewed, and each of them was assigned a code describing the kind of facilitator skill or behaviour which it referred to. This resulted in the generation of 24 unique codes. These codes were further reviewed, and categories were devised to group together similar codes. The 11 resulting categories formed the basis for the questions in the manual adherence form. Table 5:3 gives examples from the CHORD manual analysis process, while Table 5:4 shows the codes and categories which were generated from the manual analysis and their frequency. The resulting manual adherence form is provided in full in Appendix 8.

Table 5:3: Examples from CHORD manual analysis

Text from CHORD	Summary	Code	Category
It often helps to use the same song to start the group for a few weeks. This enables people with dementia to connect with the activity through sameness and familiarity	Same starting song each week may help familiarity	Dementia-sensitive musical choices	Dementia related
It is really important facilitators communicate that there is no right or wrong way to make music.	No right or wrong in music-making	Failure-free creativity	Music - responding
Observational skills are the key. As you look around the group, notice body language and energy levels. Be aware of the singing pace of the group.	Observe body language, energy and pace	Reading mood	Emotional sensitivity

Table 5:4: Frequency of codes and categories from analysis of CHORD manual

Category	Code	Frequency
Dementia related	Dementia-sensitive communication	4
	Dementia-sensitive musical choices	5
	Empowering people with dementia	2
Emotional sensitivity	Making space for emotions	5
	Reading mood	6
	Sensitive encouragement	2
Extra-musical	Extra-musical choices	4
Knowing the group	Knowing your group	4
	Responding to preferences	2
Music - initiating	Musical challenges	3
	Musical choices	12
	Personal musical skills	2
Music - responding	Musical responsiveness	3
	Failure-free creativity	4
Pacing	Pacing - energy	2
	Pacing - speed	7
Planning	Flexible planning	2
	Musical structure	1
Reflective practice	Self-care and reflection	6
Troubleshooting	Coping with problems	3
Working with group	Acknowledging the group	3
	Empowering group members	4
	Group cohesion	1
Working with individuals	Acknowledging individuals	3

5.2.9 Data security

The data collected during the study were stored in accordance with university regulations and the plan established in the ethics application:

- Data were anonymised – names were removed from outcome measure responses and were stored with a number instead. The file linking names and numbers was password protected and was stored separately to all other information relating to the study, on a secure university research drive.

- The paper copies of completed outcome measures were stored in a locked filing cabinet in the university.
- Audio and video material were copied to a secure university research drive and then deleted from the device's storage.
- Data analysis was conducted on a password-protected university computer.

5.3 Data Analysis

5.3.1 Quantitative data

Research question 3 asks "What is the experience of the CHORD group members? What benefits, if any, do they experience from attending the group?" This question of benefits was addressed by statistical testing for change over 10 weeks across the following measures. SPSS was used to carry out the statistical testing and Microsoft Excel was used for the graphical analysis. Table 5:5 summarises the analyses which were carried out. Due to the small sample size, lack of power calculation and absence of control group, it is not possible to draw firm conclusions from the analysis of these quantitative measures. They were considered exploratory, and were conducted primarily to examine trends and consider their potential and feasibility for use in a larger-scale study.

Table 5:5: Analysis of outcome measure data

Measure	Method of analysis
GDS-12R	Graphical analysis in relation to depression threshold, and reported change over the 10-week period. Comparison between time points using related-sample Wilcoxon signed-ranks test. Independent samples t-tests to compare scores of people with and without a diagnosis of dementia.
QoL-AD	Graphical analysis and paired t-tests to compare change in total score over the 10-week period. Graphical analysis in relation to clinically significant change reported by individual participants. Mann-Whitney test to compare scores of people with and without a diagnosis of dementia.
MiDAS-SR	Exploratory graphical analysis to detect change in individual scores across the 10-week period, and overall trends.
HADS	Graphical analysis of anxiety and depression scores, and change over 10-week period.
Manual adherence ratings	Graphical analysis to show change over time. Kappa score used to compare results between the self-rated and researcher-rated results.

Additionally, the scores from the GDS-12R and the QoL-AD were correlated, using Spearman's Rho to see whether changes in mood are associated with changes in quality of life.

5.3.2 Qualitative data

The focus group and interview data collected during the study were analysed using a general inductive approach, described as "a systematic procedure for analysing qualitative data in which the analysis is likely to be guided by specific evaluation objectives" (Thomas, 2006, p. 238). Inductive analysis in this case means that the process is based on deriving concepts and themes through detailed readings of the raw data, as opposed to deductive analysis, which tests whether data are consistent with prior theories or hypotheses. In the general inductive approach, although the findings are influenced by the evaluation objectives and

research questions, they are derived directly from the data. The evaluation objectives provide what Thomas calls "a focus or domain of relevance for conducting the analysis, not a set of expectations about specific findings" (2006, p. 239). The baseline interviews were analysed separately from the post-group interviews and focus groups, but some codes and categories were shared between them. The process for data analysis was as follows:

1. Recordings of interviews and focus groups were transcribed by BD using word processing software, and were then loaded into NViVo 12.
2. The transcripts of interviews and focus groups were closely read by BD, to develop an initial understanding of the themes they described.
3. Using the study research questions as a framework to guide the analysis, the initial first-order coding was carried out by BD. This process involved further close reading of the text and using NViVo to define first-order codes, grouping short chunks of text with similar meanings together.
4. The first-order codes were then reviewed by BD and supervisors, in order to agree upon and group the first-order codes into higher-order categories. At this point, some of the first-order codes were also revised, and those with similar meanings were merged.
5. The resulting categories were used to develop a working model for participants' experiences in the group.

The reflective notes written by BD were already in electronic form, and JB's handwritten notes were typed up and loaded into NVivo by BD. The general inductive approach outlined above was used to analyse these notes too, but the reporting of this analysis takes a more narrative approach, since the notes describe two perspectives on how the group developed over time. The analysis was carried out to ensure that the findings were reported systematically and in order to frame the analysis in terms of the evaluation objectives.

The video recordings taken of each session were reviewed in order to provide a detailed description of the session content, and to complete the manual adherence forms. Since the primary purpose of the video recording was to obtain a record of the session and especially the way the facilitator led the group, the video material was not used for the purposes of musical analysis.

5.3.3 Data integration and synthesis

The mixed methods design requires the collection and synthesis of qualitative and quantitative data (Pluye & Hong, 2014). The data integration was shaped by the development of the group, and guided by the question, "will what participants experience as outcomes in an intervention actually resonate with their experiences with the process?" which is presented by Bradt et al. (2013, p. 132) as a possible question for mixed methods music therapy research. The synthesis process was structured around each of the research questions, and was based upon two techniques outlined by O' Cathain et al. (2010): triangulation and the mixed-methods matrix. The triangulation approach is a "process of studying a problem using different methods to gain a more complete picture" (2010, p.1147) and involves comparing qualitative and quantitative data which have already been analysed in order to find points of convergence, complementarity and dissonance between them. The mixed methods matrix is in itself a form of analysis in which the qualitative and quantitative results from individual cases (in this study, singing group members) are tabulated so that they can be compared side by side. It should also be noted that since the study collected a range of types of data, some of the syntheses conducted to answer the research questions involve the synthesis of different types of qualitative data rather than qualitative and quantitative data.

5.4 Procedure

5.4.1 Setting

The room used for the singing group sessions was a large communal space which is normally used for dining, coffee mornings, and social activities of various kinds. The furniture in the room could be rearranged into different configurations, and an electric piano was available for use. The room was available at several different times each week, and was offered for use without a fee, with the understanding that people who lived within the sheltered housing community and who met the inclusion criteria would be eligible to take part. The chairs were arranged into a semicircle for the group sessions, and after the sessions the group had tea and coffee seated at tables in another part of the room.

5.4.2 Recruitment of Participants

The recruitment of study participants began in July 2017 and ended in September 2017. Participants were recruited directly from the local community, and from the sheltered housing setting where the group was to take place. Techniques used in recruitment included displaying posters, approaching gatekeeping organisations, attending relevant community events, and advertising the study in local media, and via social media. Due to the conditions of the ethical approval for the study, participants could not be recruited through the NHS or council-run social care facilities. The following approaches were used to advertise the singing group study in the local area.

1. Personal connections in the area
2. Displaying posters in public spaces
3. Distribution through Music in Dementia Network
4. Targeting relevant organisations
5. Directly approaching residents at study venue
6. Giving out posters while busking

7. Local media
8. Taster session

Personal connections in the area

JB and I used our personal connections through individuals and community groups, including choirs. Posters were distributed and people were encouraged to display them or show them to those who might be interested.

Displaying posters in public spaces

I approached various shops and local spaces and asked if they would display a poster. Venues which displayed posters included supermarkets, independent businesses, public libraries, pubs, restaurants, and spaces within the university.

Distribution through music in dementia network

A local network operated through the university seeks to promote music for people with dementia, and the meetings are attended by health and care professionals, musicians, music therapists and researchers. The study was introduced to the network at a meeting and attendees were asked to promote it anywhere they felt might be relevant. Digital and paper copies of the poster were provided.

Targeting relevant organisations

The poster was sent to various organisations which have contact with people with dementia and/or their carers. A covering introduction and brief explanation of the study was also included. Organisations which were contacted included the Alzheimer's Society, private day care providers, and community groups (e.g. churches) which provide services. Care was taken to ensure that the study was not seen to be encroaching on other organisations' territory. I visited a meeting of the local memory café to talk to people about the study.

Directly approaching residents at study venue

The manager at the venue where the study was the take place identified residents who met the inclusion criteria and might be interested in taking part. The manager accompanied me and JB on an initial visit, to introduce ourselves and explain the study to potentially interested parties. Word of mouth at the sheltered housing venue led to several people contacting me independently.

Busking

JB and I were joined by a few friends to busk outside a local supermarket on a weekday morning. We sang well known songs accompanied by a ukulele while a volunteer gave out flyers and talked to passers-by about the study and the group. A portable notice board also helped to advertise the study.

Local media

The local newspaper and two free magazines agreed to feature the singing group. The newspaper featured the singing group in their online edition, and the article was also shared on their social media accounts. The free magazines ran short adverts for the singing group. These magazines are distributed to every household in the area, so there was scope to reach a large number of people. The local BBC radio station heard about the study through local media, and this led to JB and I being interviewed about the group on the breakfast show, which also presented a recruitment opportunity.

Taster Session

Since recruiting participants for the study was taking longer than originally planned, the decision was made to hold a taster session for the singing group. The intention behind this was to maintain the interest and involvement of those who had already decided to take part, whilst also giving those who had not yet

committed to taking part the opportunity to try out a session and see what they thought of it. The taster session was not part of the study and no data were collected from it. It was also a useful opportunity for JB and me to practise running and co-ordinating a session. The taster session took place in August 2017 and was attended by 15 people, of whom all but one went on to enrol in the study.

5.4.3 Consent Process

Since the singing group study took place in a community setting, it was expected that many of the people with dementia who took part would have capacity to provide direct informed consent for the study. The possibility that people who could not provide direct consent would participate was also taken into account. The following process was observed:

- Potential participants who got in touch about the study were provided with written information. Four versions of the information sheet were produced: for people with memory problems, for supporters attending the group, for consultees for a person with dementia, and a simplified version with relevant images for those who would find it hard to read and digest a large quantity of text.
- The potential study participants received a home visit during which the researcher would review the information sheet with them and answer their questions.
- If the researcher was confident that the participant had capacity to provide direct consent for the study, they were asked to read and sign a consent form.
- If the researcher felt that a participant did not have the capacity to provide direct consent, a consultee who knew the person well was asked to consider the advantages and disadvantages of this person taking part, and to think about what they would want. If they believed that participation was

in the person's best interests, they were asked to sign a declaration to this effect.

5.4.4 Baseline data collection

Baseline data collection commenced once participants had signed the consent forms and been enrolled into the study. The aim was to collect baseline data in the three weeks prior to the first singing group session. In fact, some participants entered the study after the first session, in which case their data were collected either shortly before or shortly after they attended their first session.

Data were collected during the initial home visits following university guidelines for lone working. Participants with dementia or memory problems were asked to complete the GDS and the QoL-AD. Carers were asked to complete the HADS. Baseline interviews were audio-recorded at this time.

5.4.5 Planning the group

JB received the CHORD manual in May 2017. JB and the researcher met several times before the start of the group to plan the practicalities of the group, and to discuss questions which JB felt were not covered in the manual.

5.4.6 Volunteers

The CHORD manual encourages facilitators to seek volunteers to attend the singing group to promote the smooth running of the group sessions. Three volunteers were recruited for the study through JB and BD's personal connections. These volunteers helped with aspects of the singing group such as welcoming participants, ensuring they were comfortable, handing out song books and instruments, and assisting with the refreshments. Their focus was on helping with the sessions themselves, not the research activities.

5.4.7 Content and structure of sessions

The ten singing group sessions began in September 2017. They took place on Tuesday mornings, beginning at 10.30am. There was normally between 60 and 75 minutes of singing and musical activities, followed by refreshments. JB outlined the basic structure of each session each week, and shared her plan with the researcher. A detailed description of the implementation of the manual and the content of sessions is given in the results section.

5.4.8 Data collection during sessions

All 10 sessions were video recorded from the front of the room. The video camera was mounted on a tripod and was small and unobtrusive. Due to the layout of the room and the size of the group, it was not possible to position the video camera so that all the group members were in the frame, but normally more than half of the group members were captured. After each session, group members were asked to fill in the MiDAS-SR form.

5.4.9 Focus Groups

The focus groups took place after sessions 8 and 9. Two groups were held because the number of participants was too large to accommodate them all in one group. The focus groups were video recorded.

5.4.10 Post-group data collection

In the three weeks following the final session, participants were again visited at their home to complete the GDS, QoL-AD and HADS. Follow-up interviews were audio recorded.

5.5 Conclusion

This chapter has described in detail the study design and methods which were employed. The process for recruiting singing group leader and study participants

was outlined, as well as the forms of data collection which were used. Quantitative data on mood and quality of life was collected pre- and post-intervention, and participants completed weekly post-session MiDAS-SR forms as a measure of musical response and engagement. These data were subjected to exploratory statistical analysis. Interviews and focus groups conducted with the group members and the facilitator were thematically analysed to identify themes related to their experiences in the group, and especially to the benefits they experienced. Data about the implementation of the CHORD manual was collected from facilitator and researcher notes, observations of video material, the manual adherence process and interview with the facilitator. The procedure for synthesising the qualitative and quantitative data was also outlined.

Chapter 6: Results

6.1 Introduction

This chapter contains the results from the study, divided into four sections. The chapter is structured so that the quantitative data from outcome measures and the analysis of qualitative data from interviews and focus groups are presented first. These are followed by sections containing data from different sources which requires more integration: the feasibility of the study, and the evaluation of the CHORD manual. In the first section (6.2), the findings from the quantitative data analysis are presented. The second section (6.3) presents the results from the analysis of qualitative data. The third section (6.4) brings together the data relating to the feasibility of the study. The final section (6.5) describes how the CHORD manual was implemented in practice, and synthesises various forms of data about the facilitator's use of the manual. For the sake of clarity, each of these sections also includes some discussion about the findings it contains. In Chapter 7, these findings are integrated and synthesised.

6.2 Quantitative data analysis

6.2.1 Notes on terminology and abbreviations

Throughout this chapter, the suffix "M" after a participant I.D. number indicates that this person is someone with memory problems or dementia. The suffix "S" indicates that this person is a support member/carer. The participant numbers are paired e.g. 3S is 3M's carer.

Time 0 refers to data collection which took place in the three weeks preceding the start of the sessions.

Time 1 refers to data collection which took place in the three weeks after the end of the sessions.

6.2.2 Demographic information

Table 6:1 gives demographic information for the people with memory problems and dementia who attended the singing group. The majority of the group were female, and the mean age was 78.8.

Table 6:1: Demographic information about participants with dementia and memory problems

I.D.	Gender	Age	Diagnosis
1M	Female	66	Has been to GP about memory problems, no diagnosis
2M	Female	91	Dementia
3M	Female	87	Dementia
4M	Female	76	Lewy body dementia
5M	Female	76	Vascular dementia
6M	Female	74	Dementia
7M	Female	72	No diagnosis
8M	Female	84	No diagnosis
9M	Female	95	No diagnosis
10M	Male	89	Dementia
11M	Female	69	Stroke
12M	Male	64	Alzheimer's Disease
13M	Female	81	No diagnosis
14M	Female	88	Alzheimer's Disease
15M	Male	82	Alzheimer's Disease
16M	Female	67	Frontotemporal Dementia

Table 6:2 gives demographic information for the support members who attended the group, as well as their relationship to the person they attended with.

Table 6:2: Demographic information about support members

I.D.	Gender	Age	Notes
1S	Male		Partner of 1M
3S	Male	80	Husband of 3M
4S	Female	76	Friend of 4M
10S	Female	82	Wife of 10M
11S	Female		Daughter of 11M
12S	Female	61	Wife of 12M
15S	Female	79	Wife of 15M
16S	Female	34	Daughter of 16M

Outcome measures were not completed by 9M (declined to complete) 15M, 1S, 15S, 16S (not available during the period where outcome measure data were being collected).

6.2.3 Description of data

QoL-AD

Time 0 and time 1 scores for 14 people with dementia and memory problems, self-rated across 13 domains, yielding a total score out of 52 and scores for each domain out of four. One person with dementia dropped out and did not complete the time 1 assessment.

GDS

Time 0 and time 1 scores for 14 people with dementia, self-rated, giving a total score out of 15. One person with dementia dropped out and did not complete the time 1 assessment.

HADS

Time 0 and time 1 scores for five carers of people with dementia, self-rated across 14 domains, giving a total score for anxiety out of 21 and a total score for depression out of 21. One carer dropped out and did not complete the time 1 assessment.

MiDAS-SR

Five visual analogue scales which ask participants with dementia and their carers to rate their levels of interest, response, initiation, involvement and enjoyment on a

scale from 1 to 100. Participants were asked to complete this scale after every session. Over the 10 weeks of session, 115 MiDAS-SR forms were fully or partially completed.

6.2.4 Treatment of missing data

Table 6:3 shows the pattern of missing data across the three pre/post outcome measures.

Table 6:3: Missing data for outcome measures

Measure	Time point	Number of participants attempting measure	Number of missing items per participant				
			0	1	2	3	4
QoL-AD	Time 0	14	9	3	1	1	0
	Time 1	13	6	4	1	1	1
GDS	Time 0	14	10	3	0	1	0
	Time 1	13	10	1	2	0	0
HADS	Time 0	5	5	0	0	0	0
	Time 1	4	4	0	0	0	0

Where data was missing from the outcome measures, imputation was used to generate the absent values. The methods chosen for imputation were selected because they had been used in previous studies and are described below:

GDS

Ipsative mean imputation was used to generate the total score for cases which have missing values. This method has been shown to be appropriate with the GDS-15 as long as cases are not missing more than 20% of scores (i.e. 3 questions on the GDS-15) (Imai et al., 2014).

QoL-AD

Missing data were imputed through "last observation carried forward" or "next observation carried back" as appropriate (Davidson & Fedele, 2011; Kahle-Wrobleski et al., 2017). Three cases had an item missing at both time points; scores for these items were calculated by taking the mean value for each case at time 0 and at time 1.

MiDAS-SR

Since the MiDAS-SR scale was a novel measure, and because the results from it were only expected to be analysed graphically, no procedure for imputing missing data was used. Only fully completed forms were used in the graphical analysis. A full description of MiDAS-SR completion rates and the pattern of missing data is given in the feasibility results section (6.4.5).

Missing data due to participant drop-out

Participant 9M only attended one session, and since she did not wish to complete any outcome measures, there was no data to analyse.

Participants 4M and 4S dropped out after attending four sessions. No further data was collected from them. They are included on the initial graphs showing scores before and after the session, but excluded from all analyses comparing scores at these time points.

6.2.5 Findings from Geriatric Depression Scale Analysis

Graphical analysis of the data

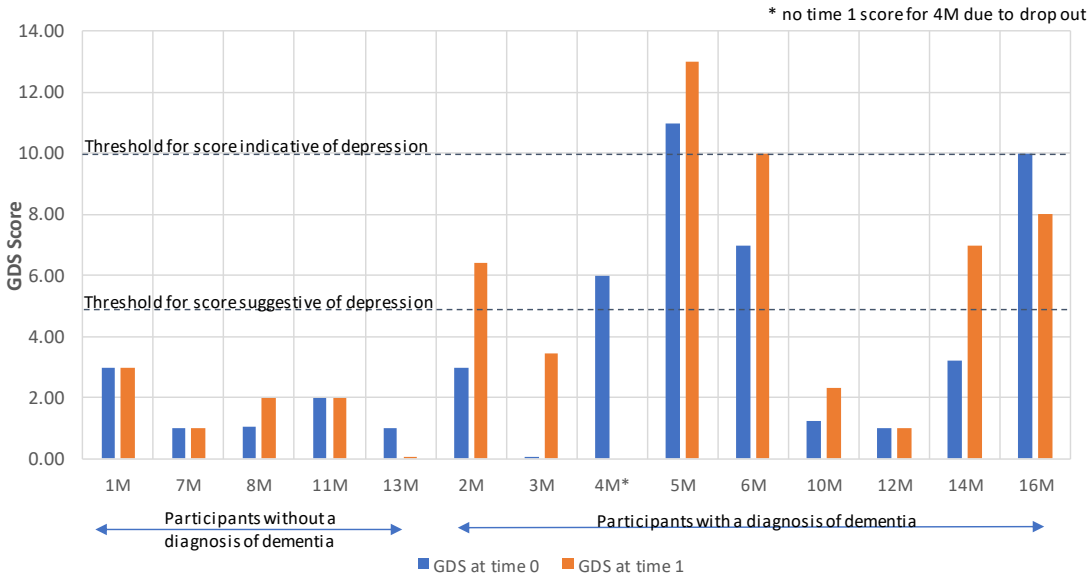


Figure 6:1: GDS scores at time 0 and time 1

Figure 6:1 shows the time 0 and time 1 GDS scores for study participants with memory problems and dementia. The diagnostic status is indicated by labelling on the x-axis. The maximum possible score is 15, with a higher score indicating more symptoms of depression.

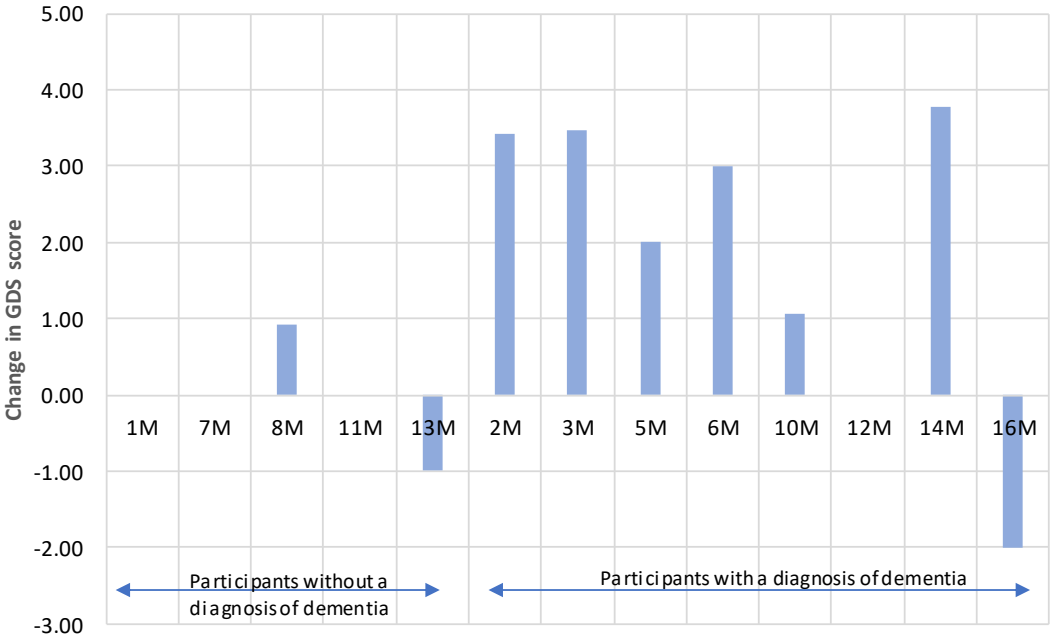


Figure 6:2: Change in GDS scores between time 0 and time 1

Figure 6:2 shows the change in total GDS score between the two time-points for people with memory problems and dementia. A negative value indicates a decrease in total score (fewer symptoms of depression), while a positive value indicates an increase (more symptoms of depression). Note that 4M dropped out of the study and so was excluded from this graph and from further analyses.

Comparison of GDS scores at time 0 and time 1

The time 0 (median=2) and time 1 (median=3) scores for the whole group were compared using the related-samples Wilcoxon signed-ranks test, since the time 0 data violated assumptions of normality (Shapiro-Wilk test, p=0.004). The following hypotheses were set:

Null hypothesis: There is no difference between GDS scores at time 0 and GDS scores at time 1.

Alternative hypothesis: There is a difference between GDS scores at time 0 and GDS scores at time 1.

Although the time 0 (median=2) scores were lower on average than the time 1 scores (median=3), this difference was found not to be significant at the 5% level, although there appears to be a trend towards higher scores (T=6.5, p=0.058). This indicates that overall the group members were slightly more depressed at time 1 than at time 0.

Comparison of GDS scores between people with and without a diagnosis

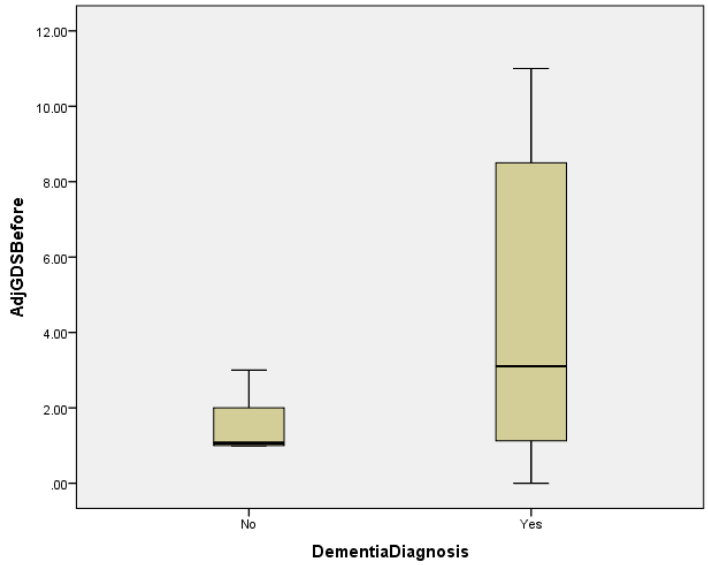


Figure 6:3: Spread of GDS scores at time 0 subdivided by diagnosis

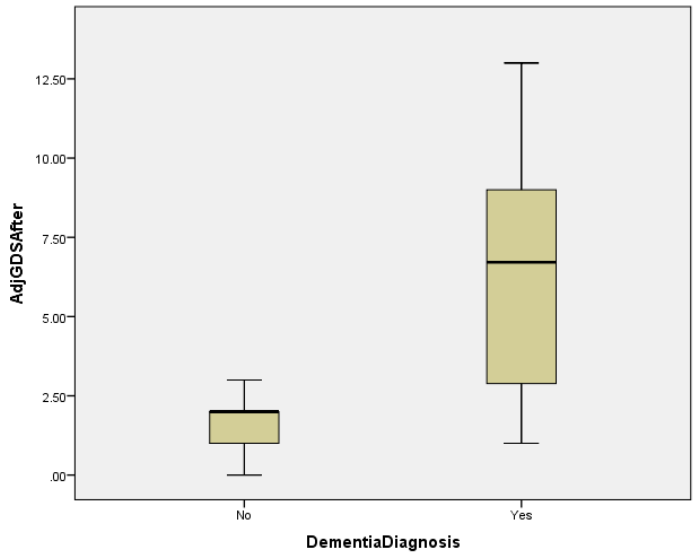


Figure 6:4 Spread of GDS scores at time 1 subdivided by diagnosis

Figure 6:3 and Figure 6:4 are box-and-whisker plots which show the spread of GDS scores when the group is subdivided by dementia diagnosis. Visual inspection of the data suggests that there might be a difference: at both time points, the profile of scores for people with a diagnosis of dementia appears to be more spread out and higher than the scores of people without a diagnosis, which are more clustered together around a lower median. When normality tests were conducted

on the time 0 and time 1 GDS scores grouped by diagnosis, non-significant results were returned, indicating that the data met assumptions of normality.

Null hypothesis: there is no difference in GDS score between people with a dementia diagnosis and people without a dementia diagnosis at time 0.
Alternative hypothesis: there is a difference in GDS score between people with dementia diagnosis and people without dementia diagnosis at time 0.

People with a diagnosis of dementia had a higher GDS score at time 0 on average (M=4.56, SE=1.50) than those without (M=1.61, SE=0.39). This difference (-2.94, 95% C.I. [-6.52, 0.63]) was not significant t(7.94)=-1.90, p=0.094.

Null hypothesis: there is no difference in GDS score between people with a dementia diagnosis and people without a dementia diagnosis, at time 1.
Alternative hypothesis: there is a difference in GDS score between people with dementia diagnosis and people without dementia diagnosis, at time 1.

People with a diagnosis of dementia had a higher GDS score at time 1 on average (M=6.4, SE=1.43) than those without a diagnosis (M=1.6, SE=0.51). This difference (-4.8, 95% C.I. [-8.93, -0.67]) was significant t(11)=-256, p=0.027. The effect size was 1.62.

In other words, when the group was subdivided by dementia diagnosis, comparison between the GDS scores of people with and without dementia suggested that people with dementia were more depressed. This difference was more pronounced at time 1 than at time 0.

6.2.6 Findings from Quality of Life in Alzheimer's disease analysis

Graphical analysis of the data

Figure 6:5 shows the total QoL-AD score at time 0 and time 1, for participants with and without a diagnosis of dementia. The maximum possible score is 52 (i.e. a rating of "excellent" across all 13 domains); the lowest possible score is 13 (i.e. a rating of "poor" across all 13 domains). Diagnostic status is indicated by labelling on the x-axis.

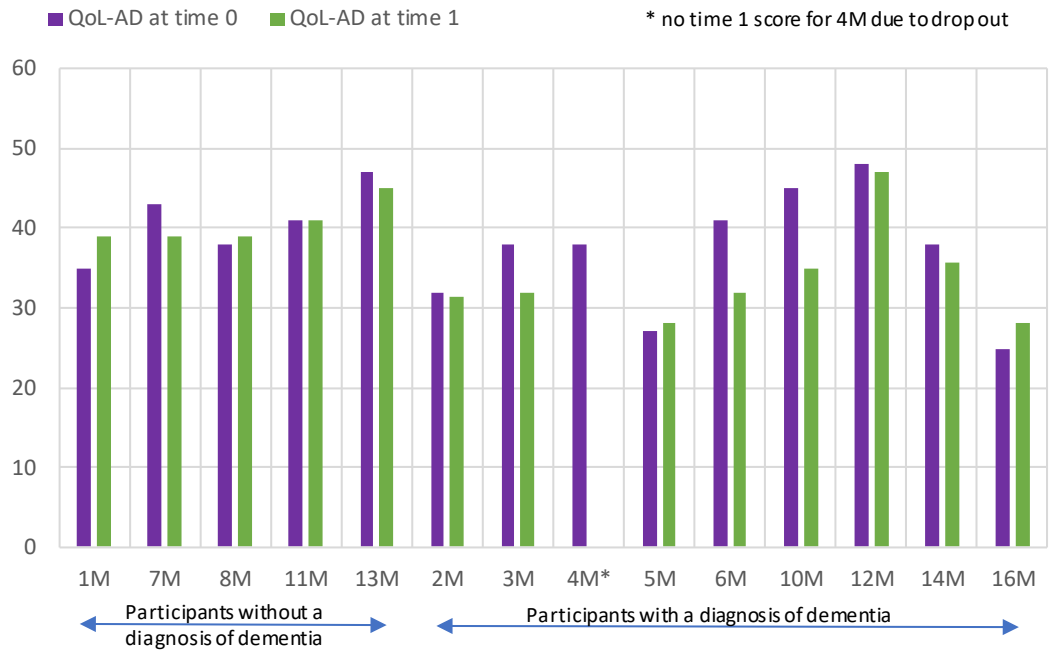


Figure 6:5: QoL-AD scores at time 0 and time 1

Figure 6:6 show the overall change in QoL-AD score between time 0 and time 1 (a negative value indicates a decrease in total score, while a positive value indicates an increase). Note that 4M dropped out of the study so was excluded from this graph and from further analyses.

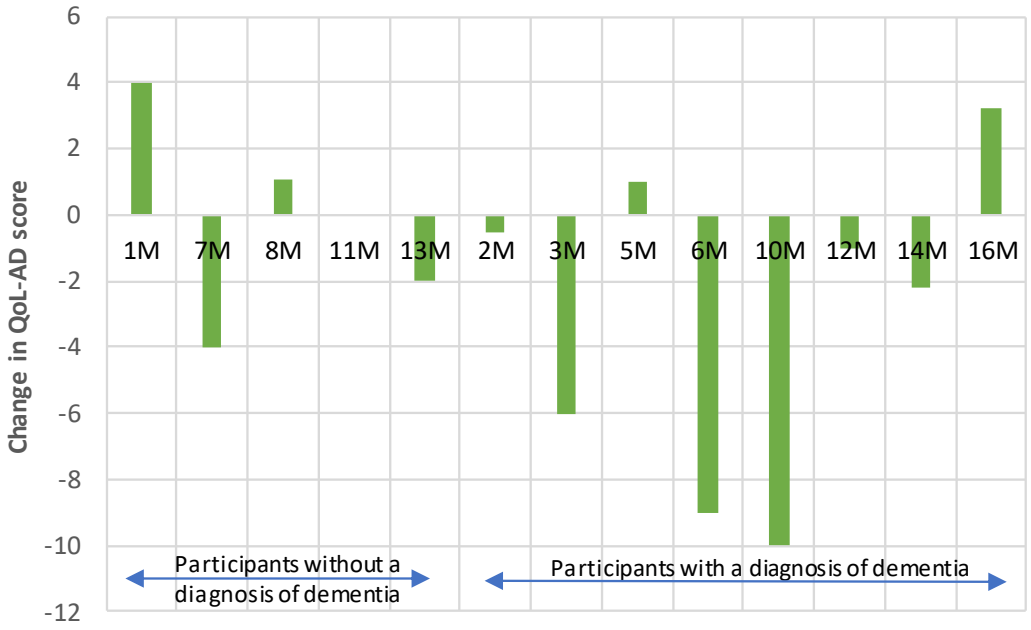


Figure 6:6: Change in QoL-AD score between time 0 and time 1

Comparison of QoL-AD Scores between time 0 and time 1

The time 0 and time 1 QoL-AD scores were compared for the whole group using a paired-samples t-test, since the data met assumptions of normality. The following hypotheses were set:

Null hypothesis: There is no difference between QoL-AD scores at time 0 and time 1.

Alternative hypothesis: There is a difference between QoL-AD scores at time 0 and time 1.

On average, participants had a higher QoL-AD score at time 0 (M=38.3, SE=1.98) than at time 1 (M=36.3, SE=1.66). This difference, 1.95, 95% C.I. [-0.65, 4.55] was not significant t(12)=1.633, p=0.128. However, despite the non-significant result there is a trend towards lower scores at time 1. In other words, participants tended to report a lower quality of life score at time 1 than at time 0.

Clinically significant change in QoL-AD score

Hoe *et al.* (2009) interpret a change in overall QoL-AD score of three or more points as being clinically significant. Using this metric, six participants experienced a clinically significant change in their QoL-AD score: 1M and 16M reported a positive change, while 7M, 3M, 6M and 10M reported a negative change. The scores of these participants were explored graphically using radar plots.

Figure 6:7 and Figure 6:8 are radar charts which show the profile of QoL-AD scores for participants 1M and 16M, at time 0 and time 1. These are the two participants who reported a clinically significant positive change overall. The positioning of the domains around the edge of the chart is arbitrary, but is the same in every radar chart. The time 0 scores are represented in red and the time 1 scores in blue, with any overlap between them shown as purple. Domains in which both reported a positive change are family, having fun, and mood. Both participants reported a negative change in living situation.

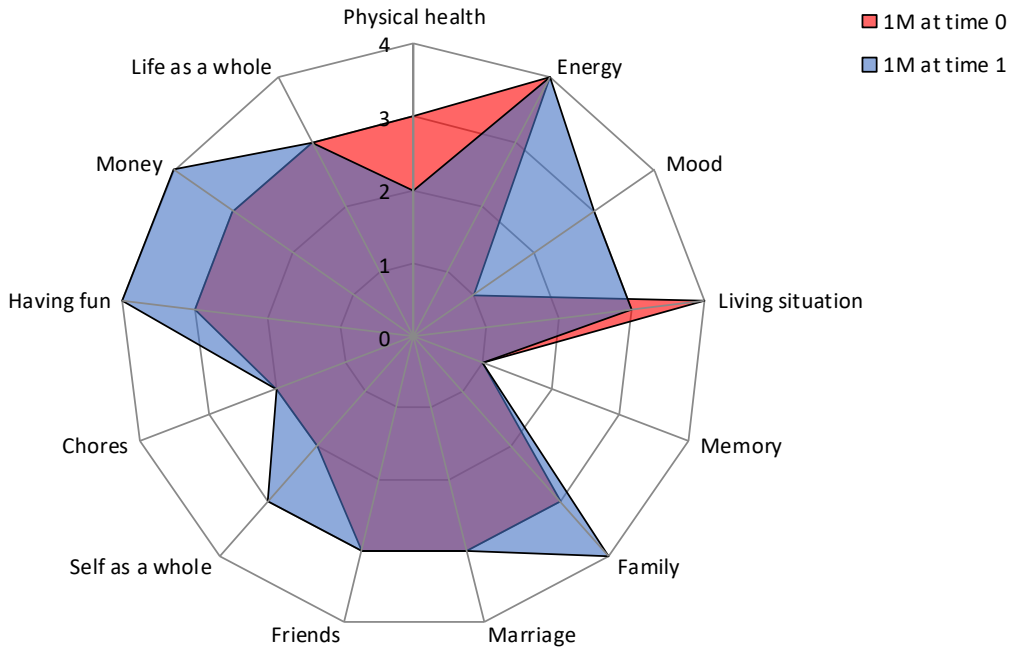


Figure 6:7: QoL-AD score for 1M at time 0 and time 1

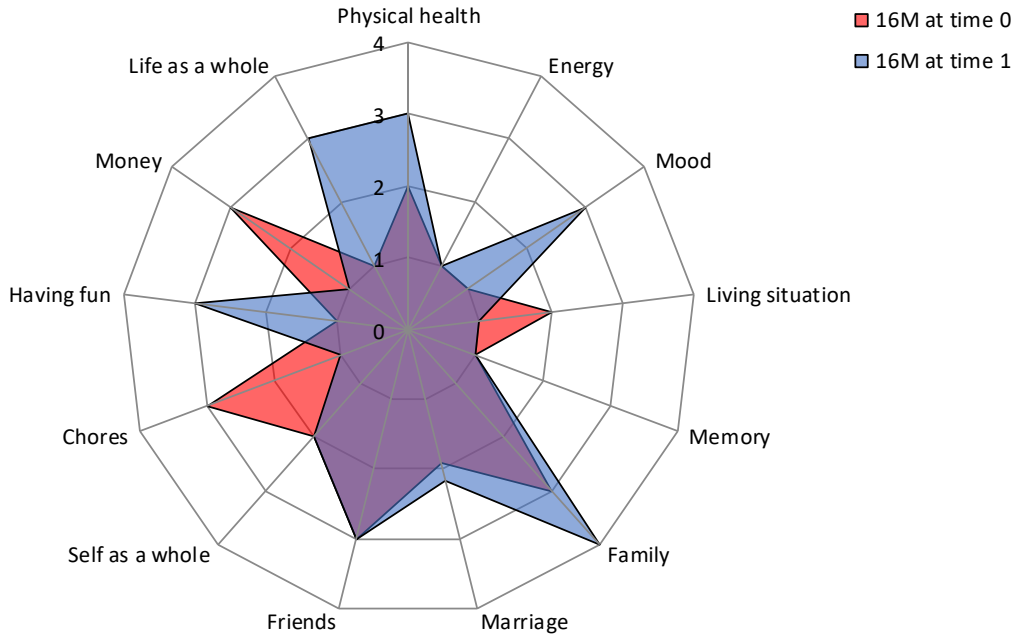


Figure 6:8: QoL-AD score for 16M at time 0 and time 1

Figure 6:9 to Figure 6:12 show the profile of scores for participants 3M, 6M, 7M and 10M. These are the four participants who reported a clinically significant negative change overall. The domains in which change was reported are varied, with most participants reporting a small change in several domains rather than a

large change in a few. The implications of these changes and a more detailed exploration of individual cases will be discussed later.

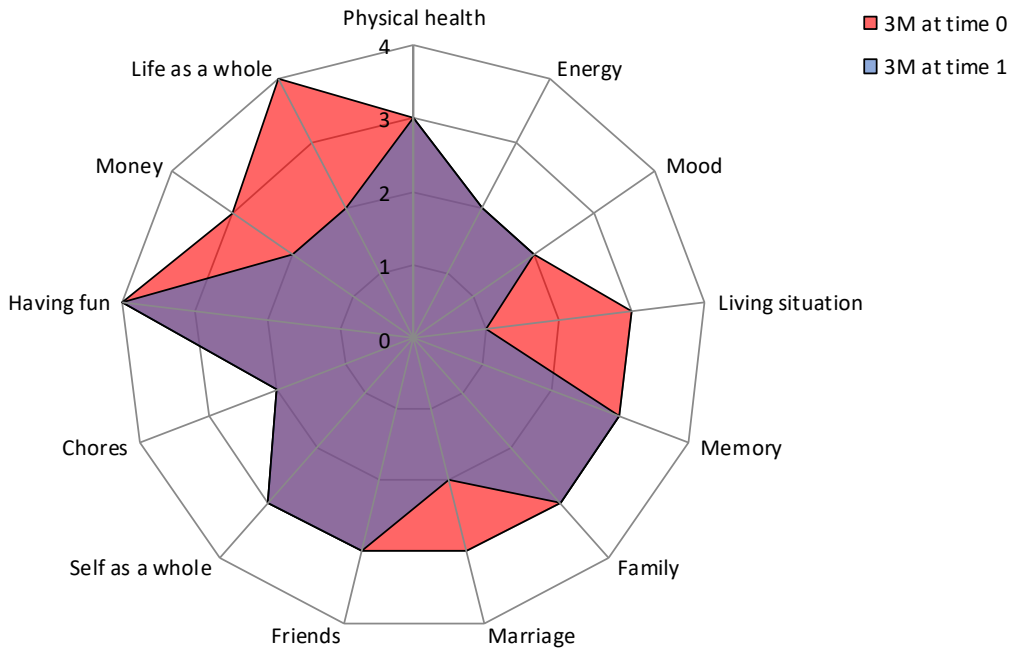


Figure 6:9: QoL-AD scores for 3M at time 0 and time 1

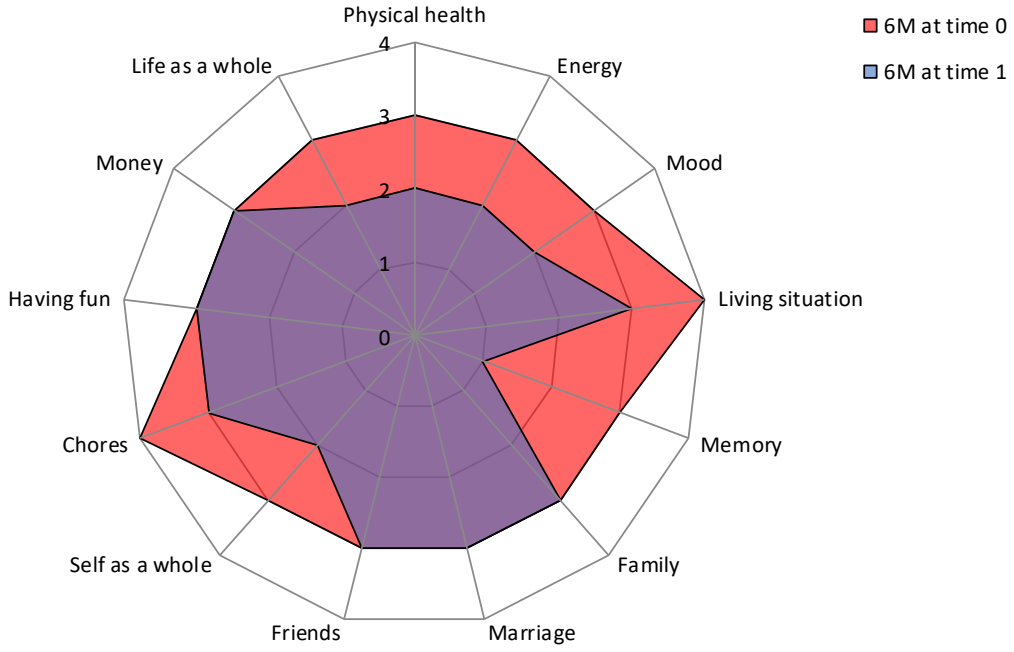


Figure 6:10: QoL-AD scores for 6M at time 0 and time 1

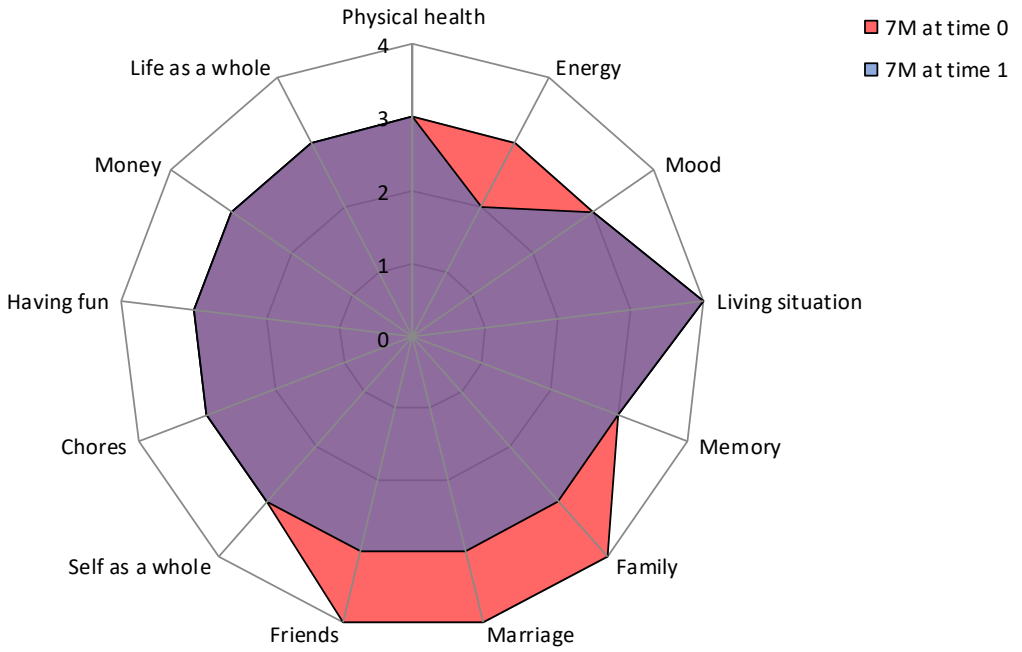


Figure 6:11: QoL-AD scores for 7M at time 0 and time 1

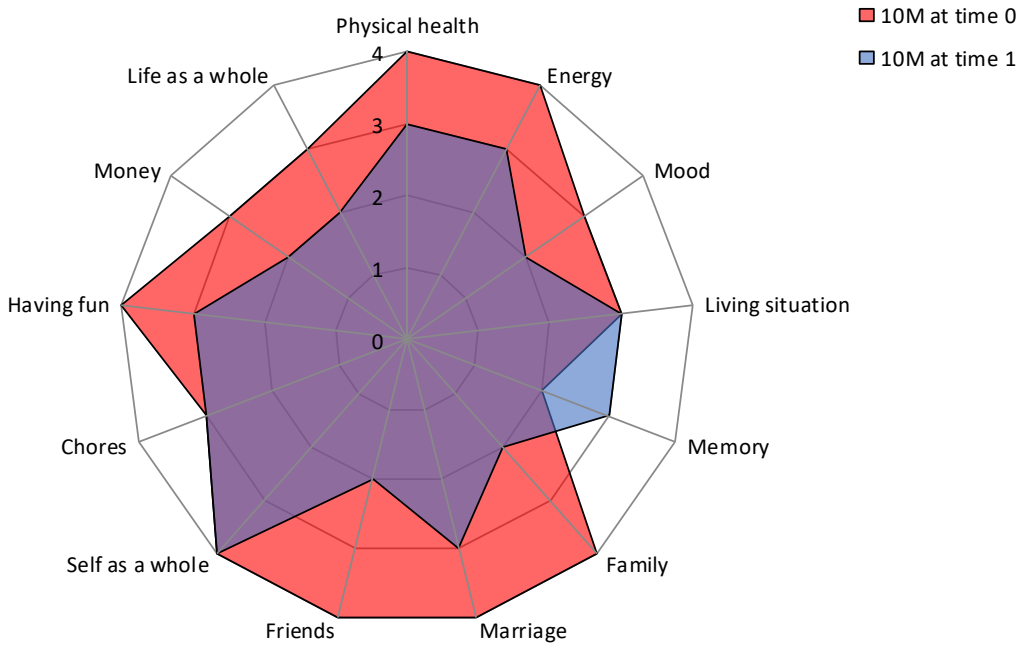


Figure 6:12: QoL-AD scores for 10M at time 0 and time 1

In order to compare the change within and between the groups which experienced positive and negative clinically significant change, the mean change was calculated for each domain and each group. This allows us to compare the change experienced in each domain by members of the group; the further a score is from zero, the more agreement is apparent between individuals. Figure 6:13 shows the mean change in each domain for the "positive" and "negative" groups. The individual radar plots give the original scores.

The group who experienced a positive change overall showed positive agreement in the following domains: mood, family, self as whole, marriage, having fun and life as a whole. They showed negative agreement in the domains of energy, living situation, chores and money. The group who experienced a negative change overall showed negative agreement in the following domains: energy, living situation, family, marriage, friends, money and life as a whole. None of the domains had a mean positive change for this group.

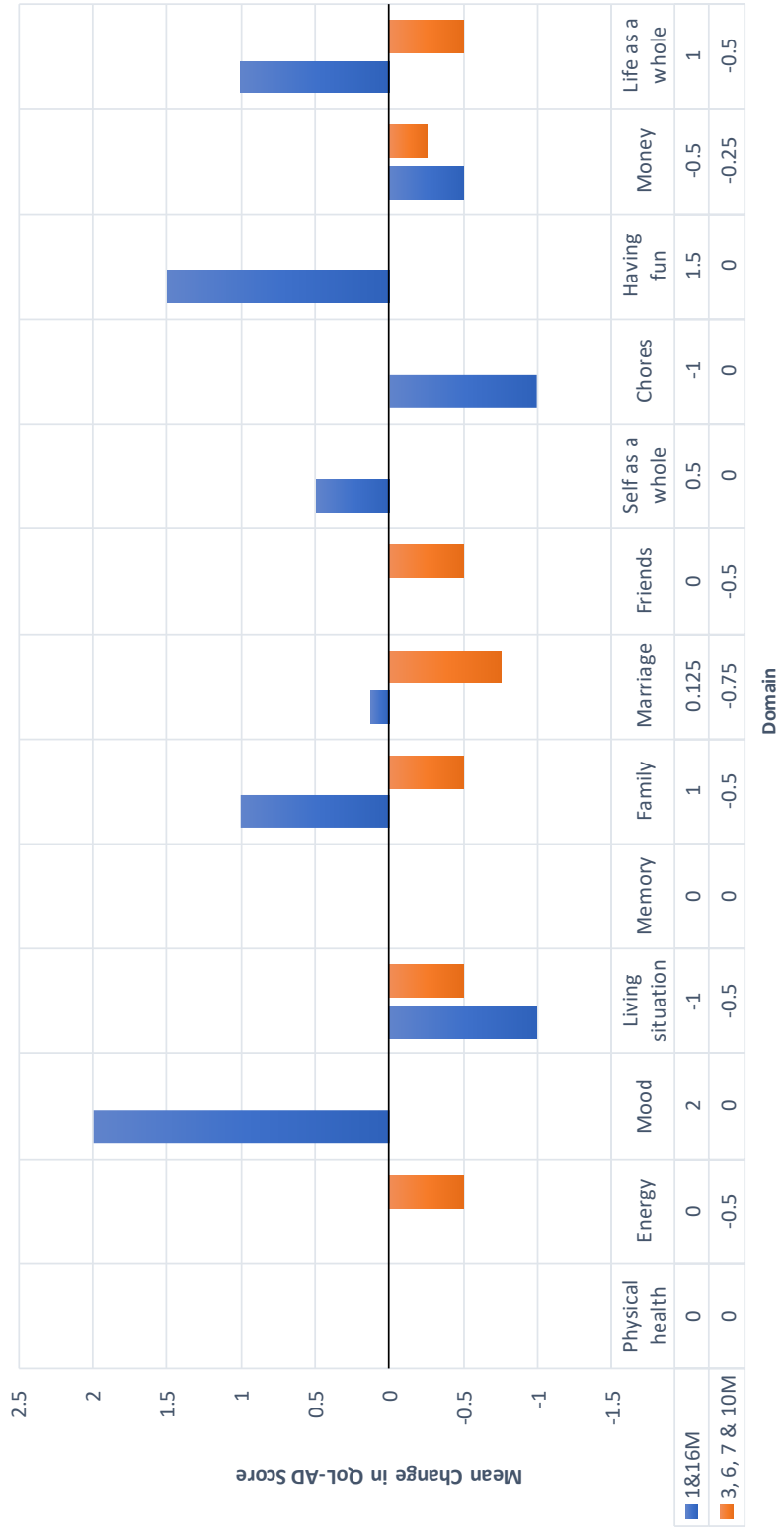


Figure 6:13: Mean change in QoL-AD score by domain for participants reporting clinically significant change

Comparison of QoL-AD scores between people with and without a diagnosis of dementia

Based on visual inspection of the QoL-AD graphs and the characteristics of the GDS data, the possibility that there were differences in quality of life between the people with and without a diagnosis of dementia was explored.

Figure 6:14 and Figure 6:15 show the central tendency and spread of the data for people with and without a diagnosis of dementia. The scores of people with a diagnosis of dementia are more spread out than those without. This is quite similar to the profile of the GDS scores, where people without a diagnosis had a narrower range of scores and the scores of people with dementia were more widely distributed. The time 1 scores shown in Figure 6:15 seem potentially indicative of a difference between the two groups; the scores of people with dementia appear lower than those without a diagnosis.

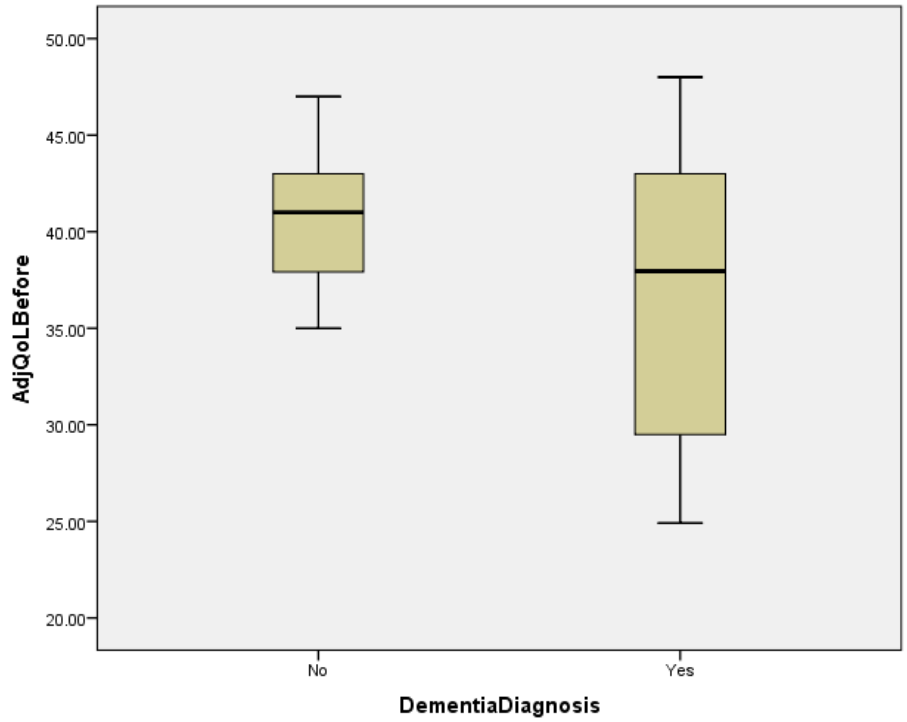


Figure 6:14: Spread of QoL-AD scores at time 0 subdivided by diagnosis

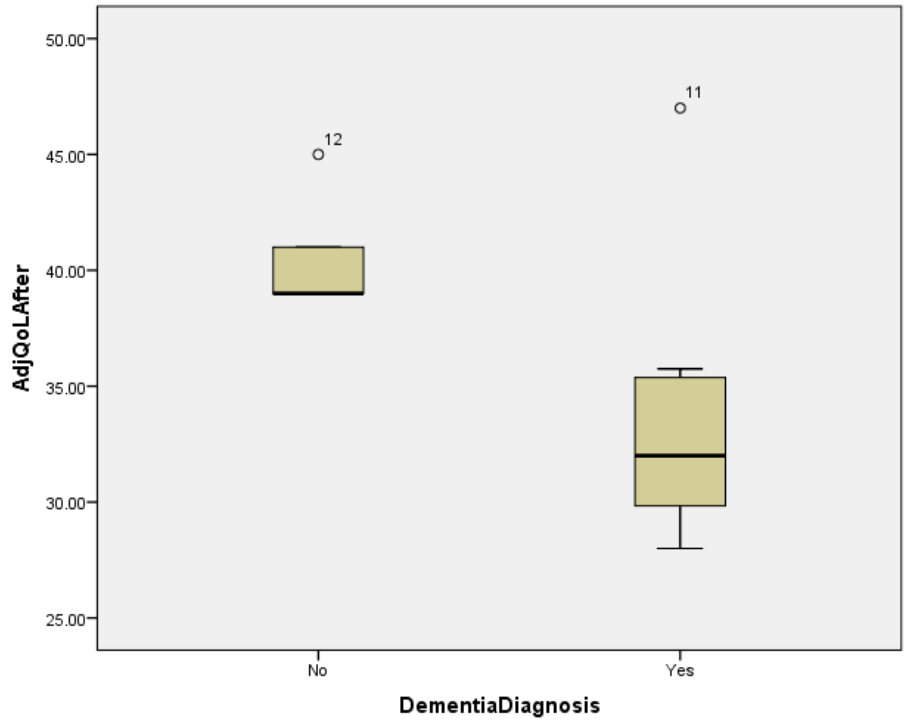


Figure 6:15: Spread of QoL-AD scores at time 1 subdivided by diagnosis

Tests were performed to investigate the differences between the two groups further. The time 1 data for people with and without a diagnosis violated

assumptions of normality, so the Mann-Whitney test was used to compare the two groups at the two different time points.

Null hypothesis: there is no difference in QoL-AD score between people with a dementia diagnosis and people without a dementia diagnosis at time 0.
Alternative hypothesis: there is a difference in QoL-AD score between people with dementia diagnosis and people without dementia diagnosis at time 0.

QoL-AD scores of people with a dementia diagnosis (Mdn=37.96) were lower than QoL-AD scores of people without a diagnosis (Mdn=41) at time 0. However, this difference was not significant, U=17, z=-0.74, p=0.518.

Null hypothesis: there is no difference in QoL-AD score between people with a dementia diagnosis and people without a dementia diagnosis, at time 1.
Alternative hypothesis: there is a difference in QoL-AD score between people with dementia diagnosis and people without dementia diagnosis, at time 1.

QoL-AD scores of people with a dementia diagnosis (Mdn=32.00) were lower than QoL-AD scores of people without a diagnosis (Mdn=39.00) at time 1. This difference was found to be significant, U=5, z=-2.21, p=0.03.

Change in QoL-AD score of people with a diagnosis of dementia

Based on the results of preceding tests, it seems that a change in QoL-AD score over time may be apparent when participants are grouped by diagnosis. Specifically, it appears that the QoL-AD scores of the people with a diagnosis of dementia have decreased, but that this result is diluted when people with and without a diagnosis of dementia are grouped together since the scores of those without a diagnosis remained more stable. In order to investigate this effect, tests were performed to compare the QoL-AD scores at time 0 and time 1, grouped by

diagnosis. Since the data violated assumptions of normality, the Wilcoxon signed-rank test was used.

Null hypothesis: there is no difference in QoL-AD score between time 0 and time 1 for people with a diagnosis of dementia.
Alternative hypothesis: QoL-AD scores for people with dementia were lower at time 1 than they were at time 0.

The QoL-AD scores for people with a diagnosis of dementia were higher at time 0 (Mdn=37.96) than at time 1 (Mdn=32). However, this difference was not significant, T=7.5, p=0.141.

6.2.7 Findings from Hospital Anxiety and Depression Scale Analysis

Graphical analysis of the data

The Hospital Anxiety and Depression Scale (HADS) asks respondents to rate symptoms of depression and anxiety across 14 domains, giving a total score out of 21 for depression and for anxiety. These scores can be combined to give a total score for emotional distress out of 42. The thresholds for each subscale are as follows: normal 0-7, mild 8-10, moderate 11-14, and severe 15-21.

Figure 6:16 shows the depression scores for each participant carer at time 0 and time 1. Note that 4S dropped out of the study and so the data for time 1 is missing. All five carers fall within the "normal" range, according to the standard interpretation of the scale.

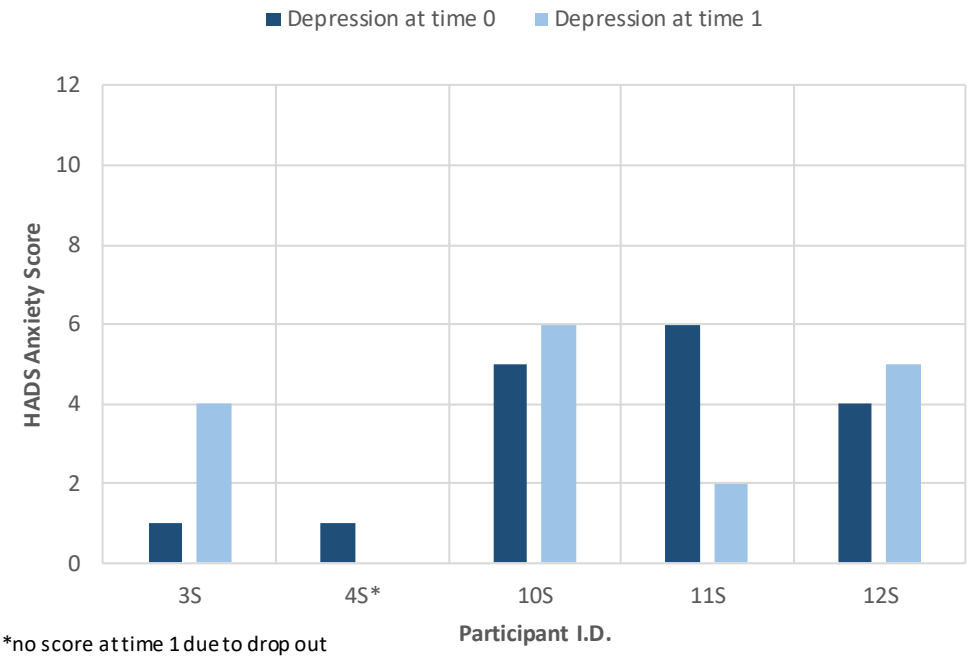


Figure 6:16: HADS depression scores for support members at time 0 and time 1

Figure 6:17 shows the anxiety scores for each carer at time 0 and time 1. The anxiety scores are generally higher, with two carers meeting the threshold for mild anxiety at one time point, and one carer in the threshold for moderate anxiety at time 0.

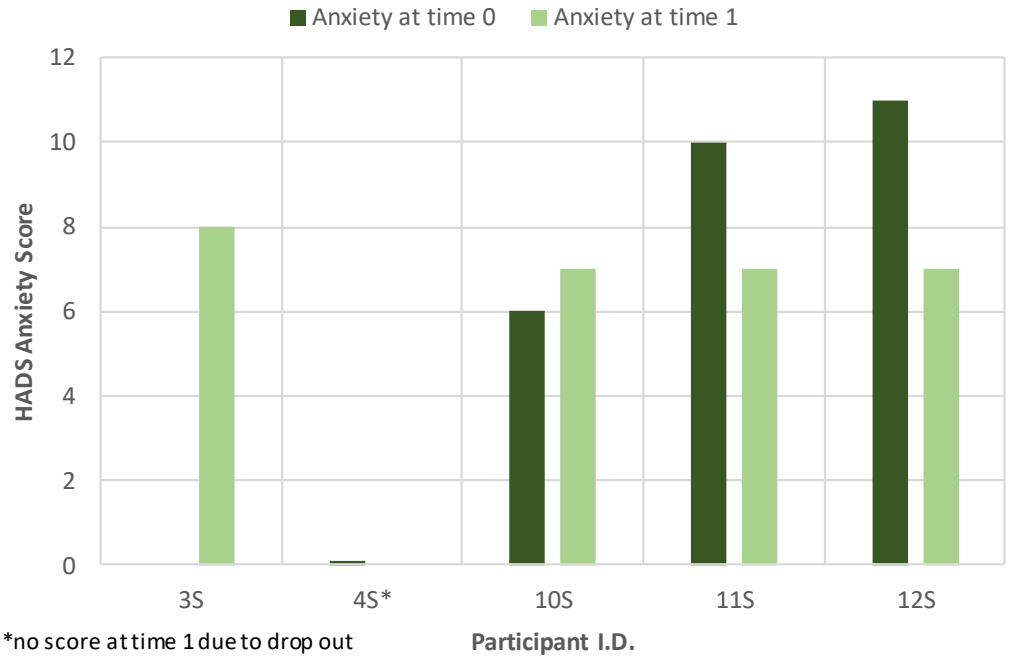


Figure 6:17: HADS anxiety scores for support members at time 0 and time 1

Figure 6:18 shows the change in HADS anxiety and depression score between time 0 and time 1. One participant's scores increased considerably across both domains, one remained fairly stable, one participant experienced a fall in depression score and two participants reported a fall in anxiety score.

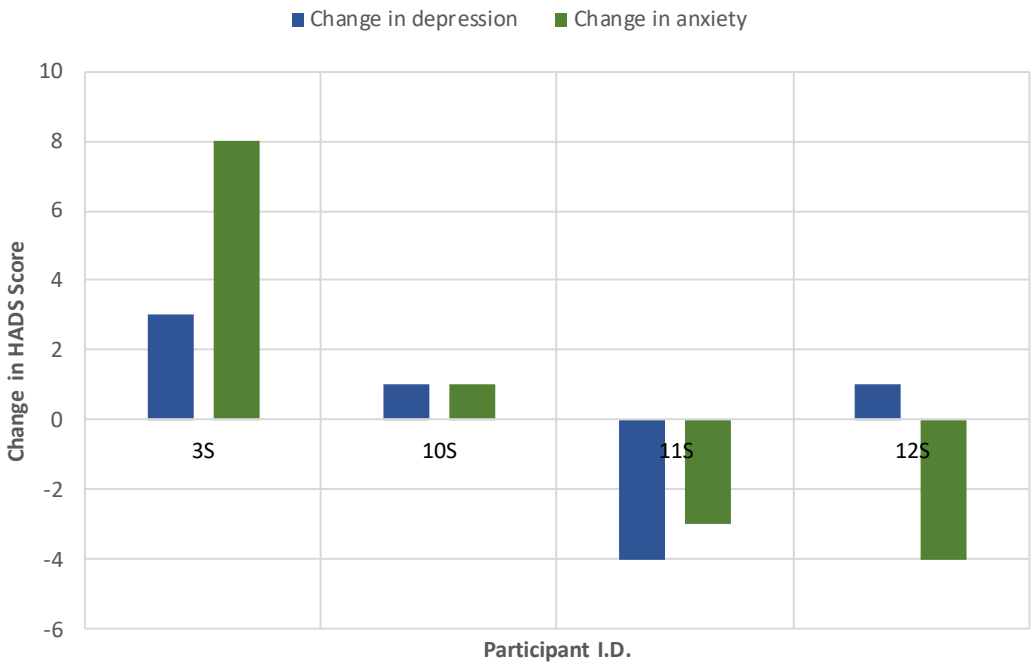


Figure 6:18: Change in HADS scores between time 0 and time 1 for support members

With a sample size of four, it may not be appropriate to conduct statistical tests using this data. The HADS anxiety scores at time 1 do not meet assumptions of normality so a paired sample t-test cannot be used, and its non-parametric alternative, the Wilcoxon signed-ranks test cannot return a significant result at the 5% level for a sample size smaller than five. The HADS scores were instead explored as individual cases and in relation to the corresponding GDS and QoL-AD scores of the other member of each dyad.

6.2.8 Correlations between GDS and QoL-AD scores

Figure 6:19 shows the correlation between GDS scores and QoL-AD at time 0. The scatter plot suggests a negative correlation: people with higher QoL-AD scores tended to have lower GDS scores. Figure 6:20 shows the scatter plot of GDS scores and QoL-AD scores at time 1, which exhibits a similar trend. Spearman's rho was calculated for both pairs of variables, since some of the data violated assumptions of normality. A strong negative correlation was found for both time points, with a correlation coefficient of -0.699 for time 0 and -0.882 for time 1. The correlation was significant at time 0 ($p=0.008$) and time 1 ($p<0.001$). R^2 was calculated as 0.49 at time 0 and 0.78 at time 1, indicating that variability in QoL-AD score shared 49% of the variability in GDS score at time 0, and 78% of variability at time 1.

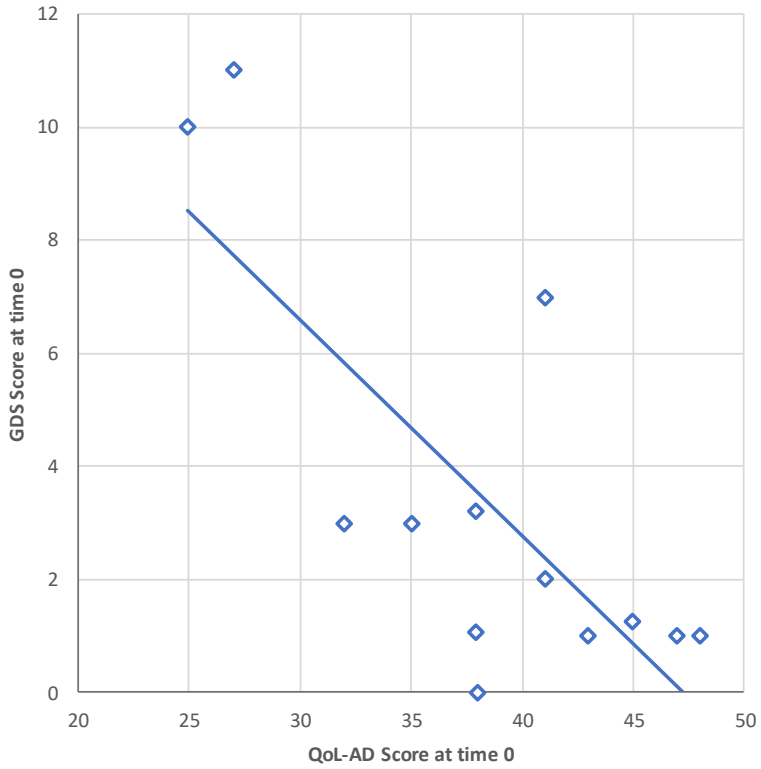


Figure 6:19: Scatter plot of GDS scores against QoL-AD scores at time 0

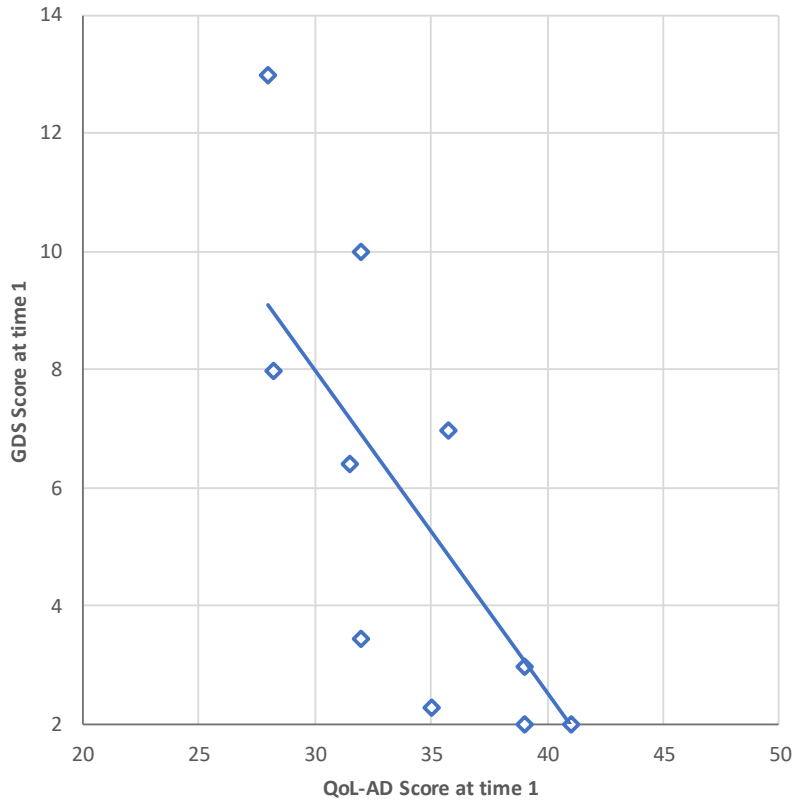


Figure 6:20: Scatter plot of GDS scores against QoL-AD scores at time 1

Due to the strong correlation between GDS and QoL-AD at both time points, it was considered relevant to investigate the relationship between the change in both these variables. Figure 6:21 shows a scatter plot of change in GDS score against change in QoL-AD score. Pearson's correlation coefficient was calculated, since the data met assumptions of normality, and a moderate negative correlation was found (r=-0.43) which was not significant (p=0.14).

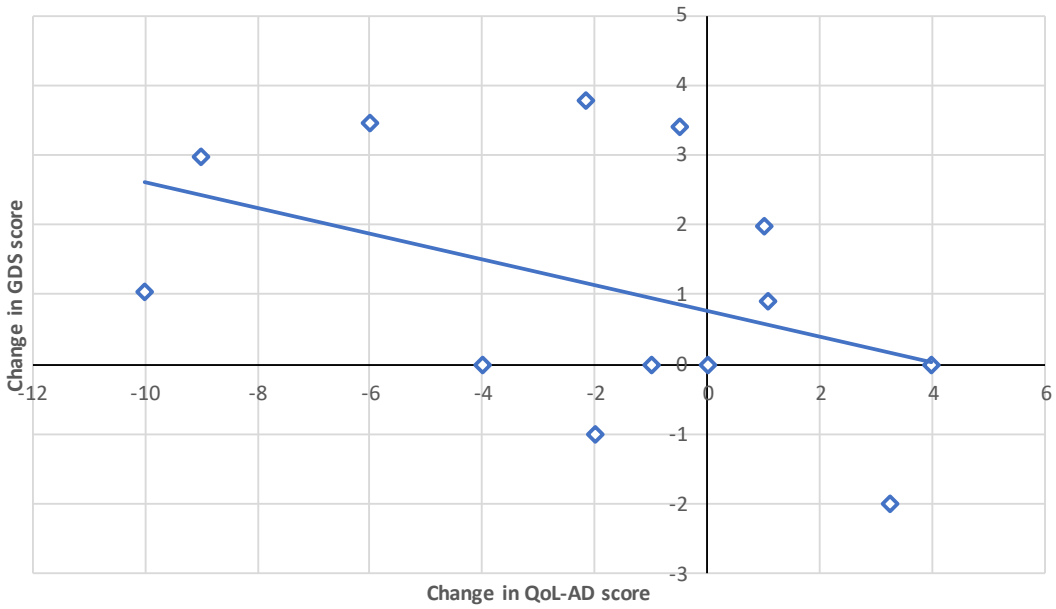


Figure 6:21: Scatter plot of change in GDS score against change in QoL-AD score between time 0 and time 1

6.2.9 Findings from MiDAS-SR Scale

MiDAS-SR data were converted to numerical scores by measuring the position of the mark made on each of the visual analogue scales. Each VAS (Interest, Response, Initiation, Involvement, Enjoyment) was meant to be 100mm long on paper, meaning that the measurement in millimetres would automatically yield a score out of 100. However, since the forms had not printed to scale but were slightly short, it was necessary to convert the MiDAS-SR scores. Since MiDAS-SR was a new measure and because the data set was fairly incomplete, it was not appropriate to use statistical tests. Instead, the data were explored graphically for evidence of trends over time across sessions and participants. The aim of the graphical analysis was to show how the scores of the group as a whole changed from session to session, and whether individuals' scores changed over time.

Profile of MiDAS-SR scores across sessions

The first set of graphs give a general overview of the range of MiDAS-SR scores across a sample of sessions. Figure 6:22 to Figure 6:26 show the profile of MiDAS-SR scores from sessions 1, 3, 5, 7 and 9 for participants who successfully completed a MiDAS-SR form for each session. Note that these are not necessarily the same participants each week, although some participants did consistently complete their form each week. The aim of these graphs is to show the profile of the groups scores and any trends over time. The scores from sessions 2, 4, 6, 8 and 10 are not shown because five graphs displaying every other session were considered sufficient to demonstrate the characteristics of the group's scores, and because the completion rates for sessions 2, 4 and 10 were comparatively low.

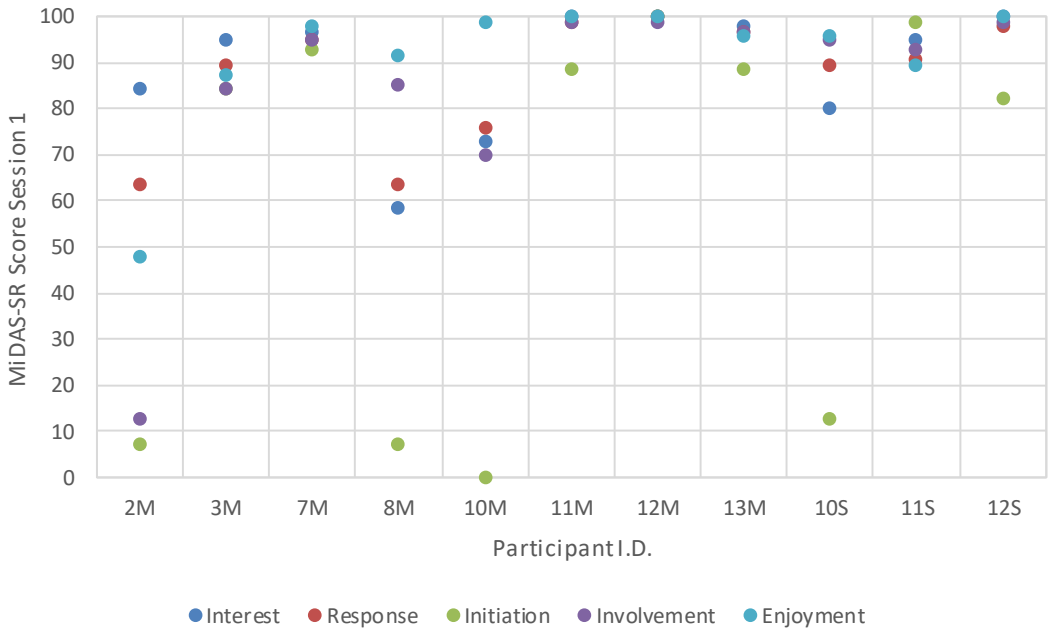


Figure 6:22: MiDAS-SR scores for session 1

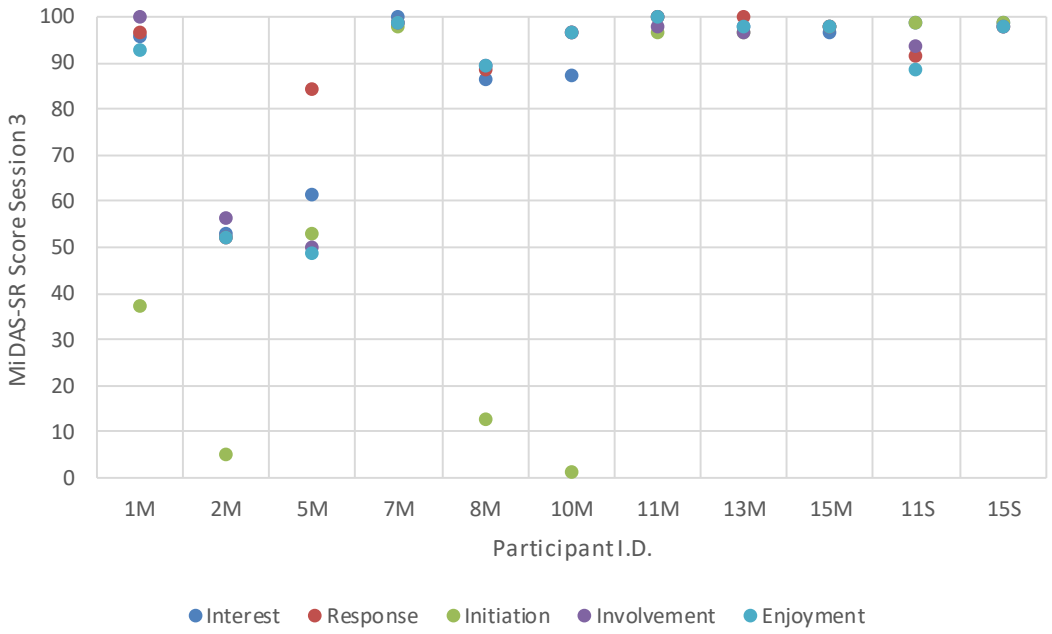


Figure 6:23: MiDAS-SR scores for session 3

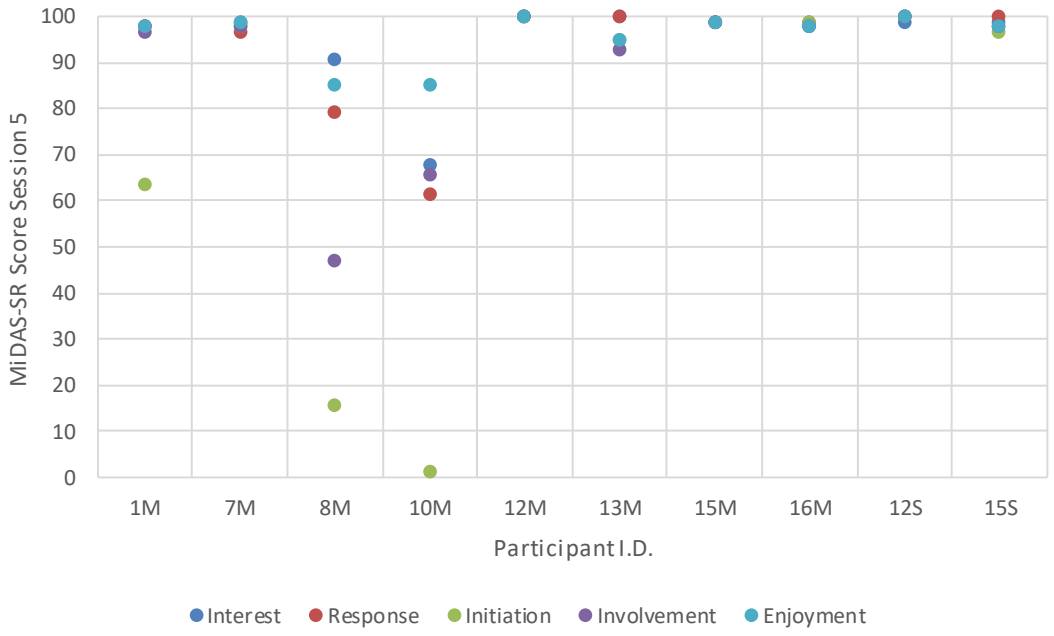


Figure 6:24: MiDAS-SR scores for session 5

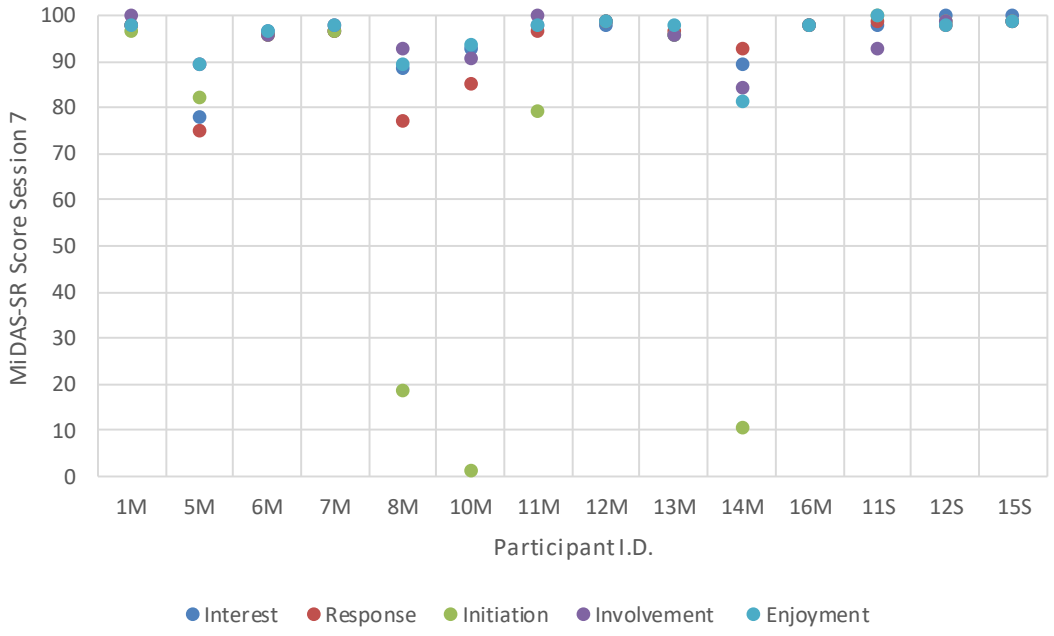


Figure 6:25: MiDAS-SR scores for session 7

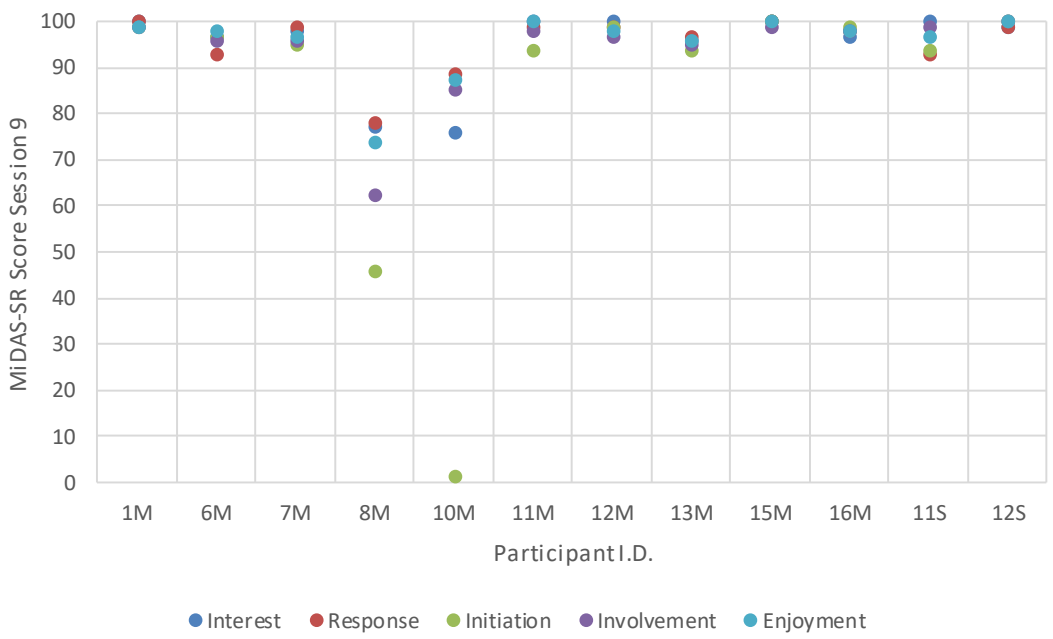


Figure 6:26: MiDAS-SR scores for session 9

The profile of scores across the five sessions represented here shows that participants tended to rate their responses to the session very highly. In each of the sessions above except for session 1, more than half of the respondents placed all of their VAS ratings in the 90s. There is evidence of a "ceiling effect", especially in the later three sessions; in session 1 and 3, even when respondents rated each VAS highly, there was more separation between each individual's scores. However, in later sessions, a number of respondent's scores seem very clustered together as though they are responding almost identically to each VAS. It is also noticeable that of the five domains, "initiation" is the only one which is regularly given a low rating by respondents, even when their scores for other domains are high.

Individual MiDAS-SR scores over time

Figure 6:27 to Figure 6:32 present the MiDAS-SR scores for individual participants, showing how their scores varied over the course of the sessions. The six participants whose scores are represented here were selected because they had the most complete set of MiDAS-SR ratings.

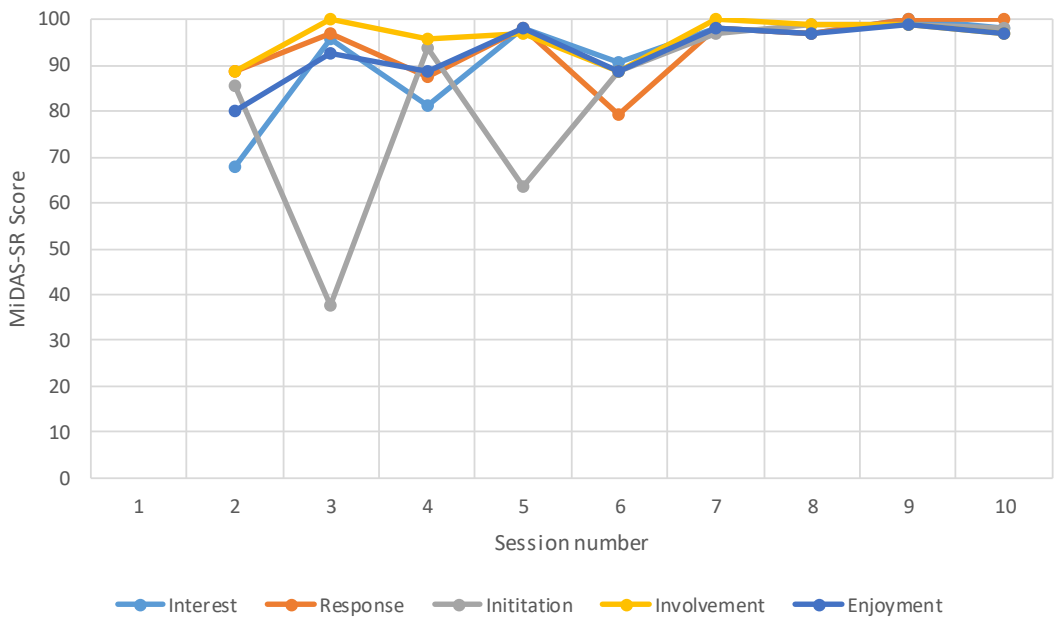


Figure 6:27: MiDAS-SR Scores for 1M

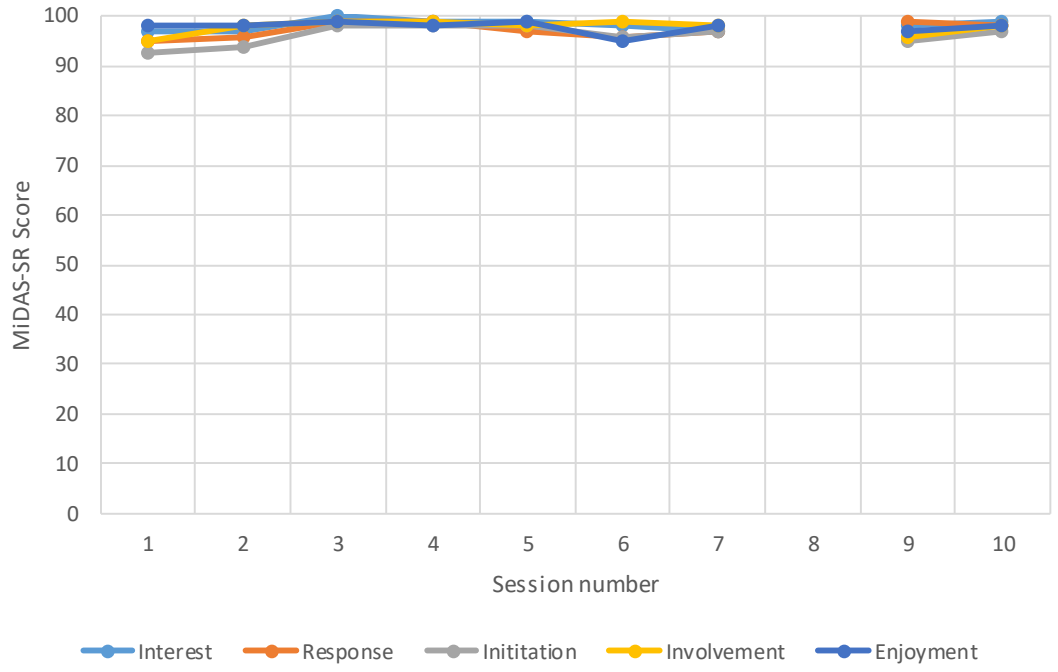


Figure 6:28: MiDAS-SR Scores for 7M

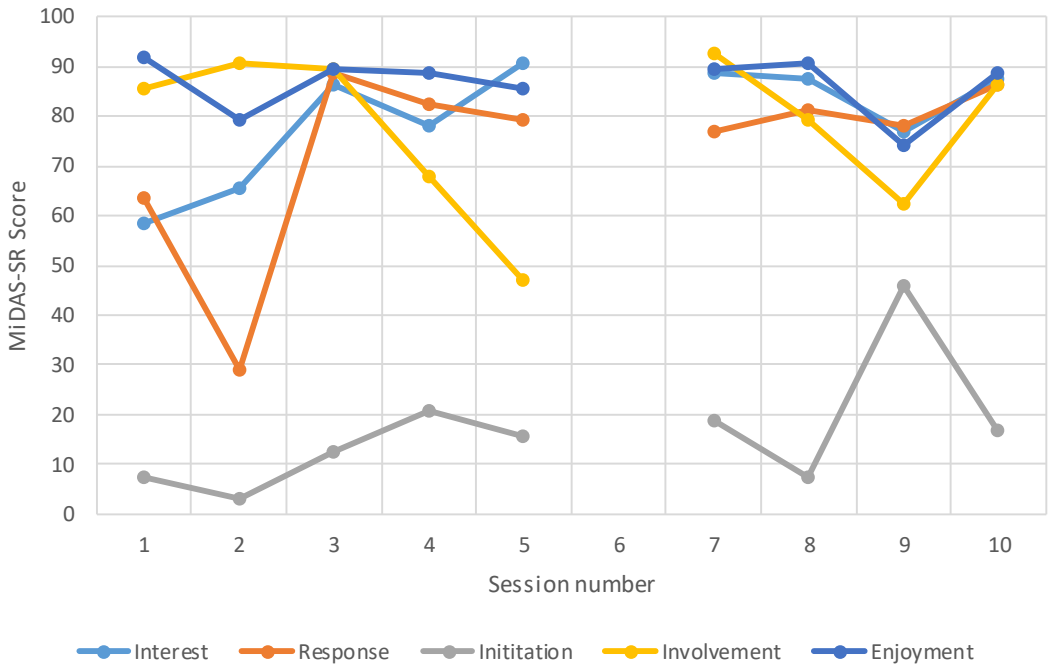


Figure 6:29: MiDAS-SR Scores for 8M

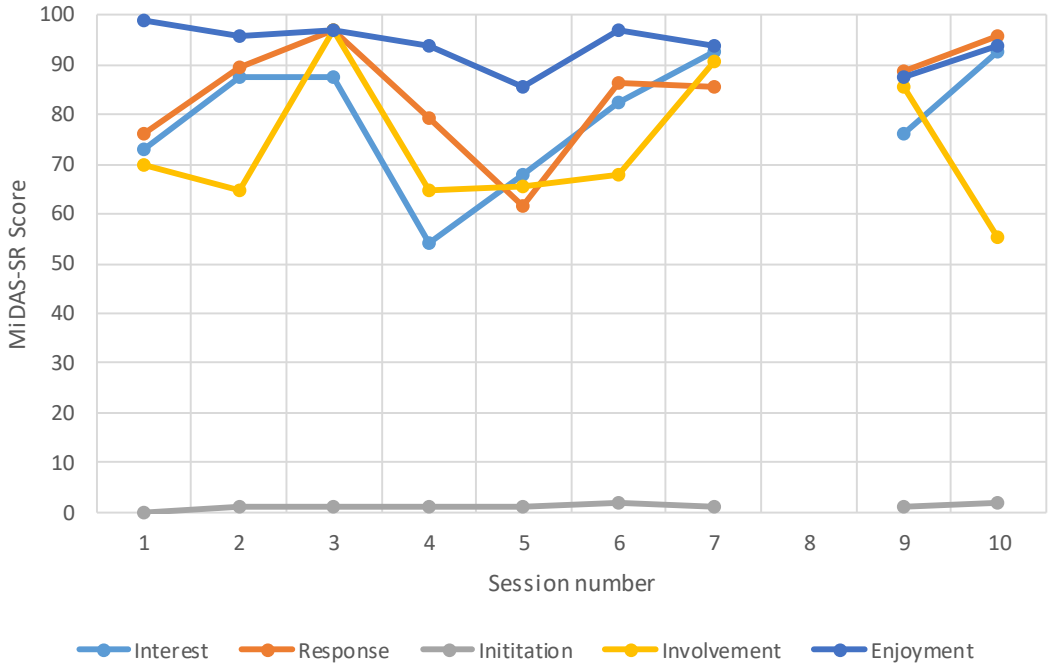


Figure 6:30: MiDAS-SR Scores for 10M

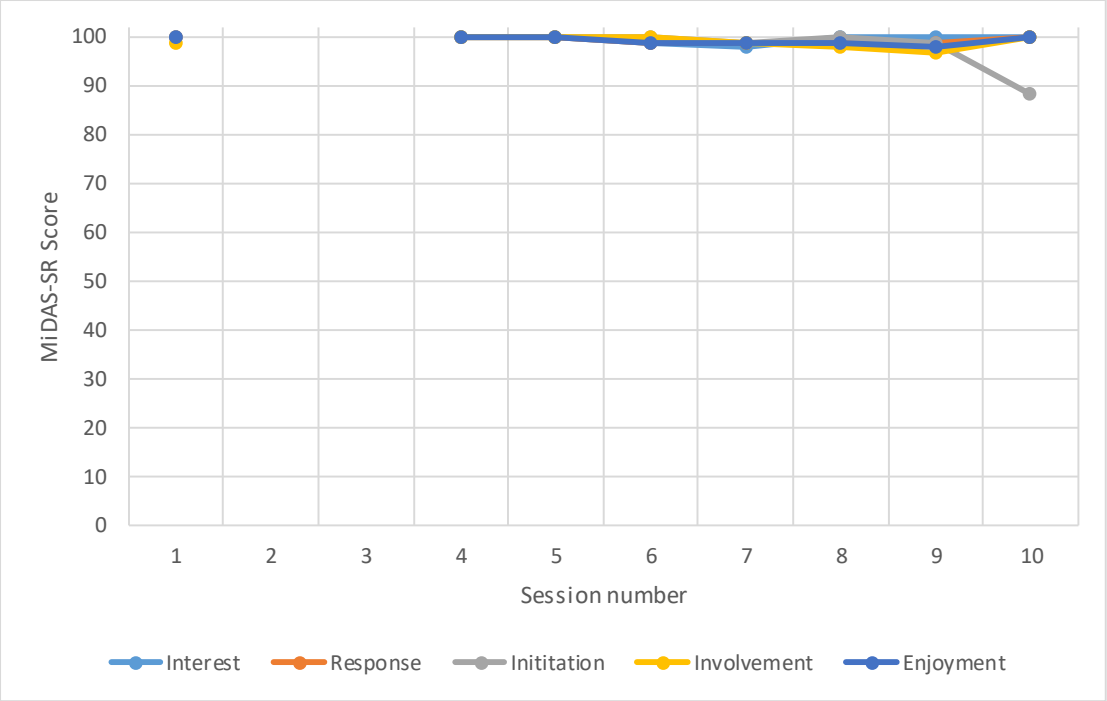


Figure 6:31: MiDAS-SR Scores for 12M

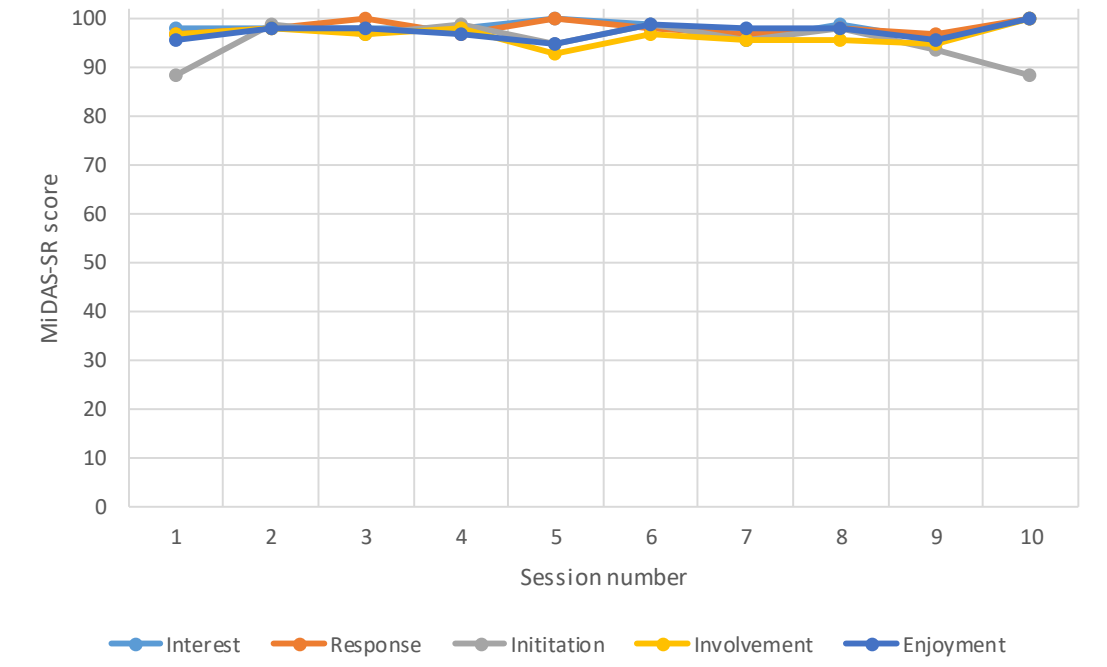


Figure 6:32: MiDAS-SR Scores for 13M

The MiDAS-SR scores for these six individuals vary in the trends they display over time. Three of them (7M, 12M and 13M) have consistently high ratings across all the domains and in all the sessions. 1M has consistently high scores towards the end of the sessions, but at the beginning there is more variation between the domains, and the scores are lower overall. For 8M and 10M, the scores are much more spread out in general, and they do not display a noticeable trend over time. Both 8M and 10M, as well as 1M in earlier sessions have a tendency to rate the domain "initiation" much lower than all the others.

Figure 6:33 and Figure 6:34 show the maximum and minimum MiDAS-SR scores, by session, for every participant who completed MiDAS-SR forms for more than 50% of sessions. The purpose of these graphs is not to display every score in detail but to give a sense of the range of individual participants' scores, and how these varied within the group and over time. Note that these graphs do not indicate where the other scores within the range fall. Mean or median values were not calculated for these data because average values were not felt to be particularly meaningful for this set of variables. Furthermore, since a number of participants rated four domains highly and one very low, average scores could be potentially misleading.

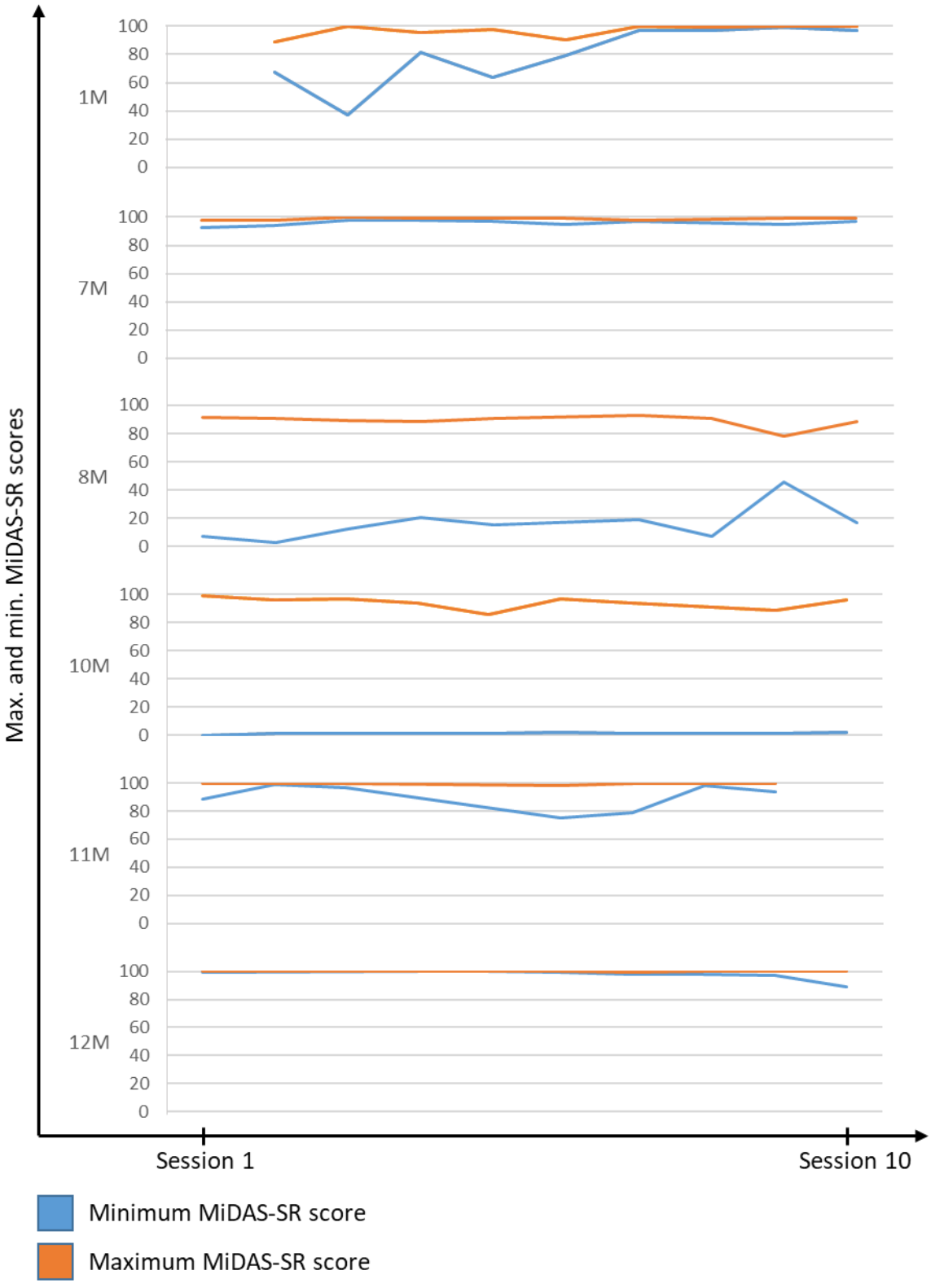


Figure 6:33: Maximum and minimum MiDAS-SR scores by participant

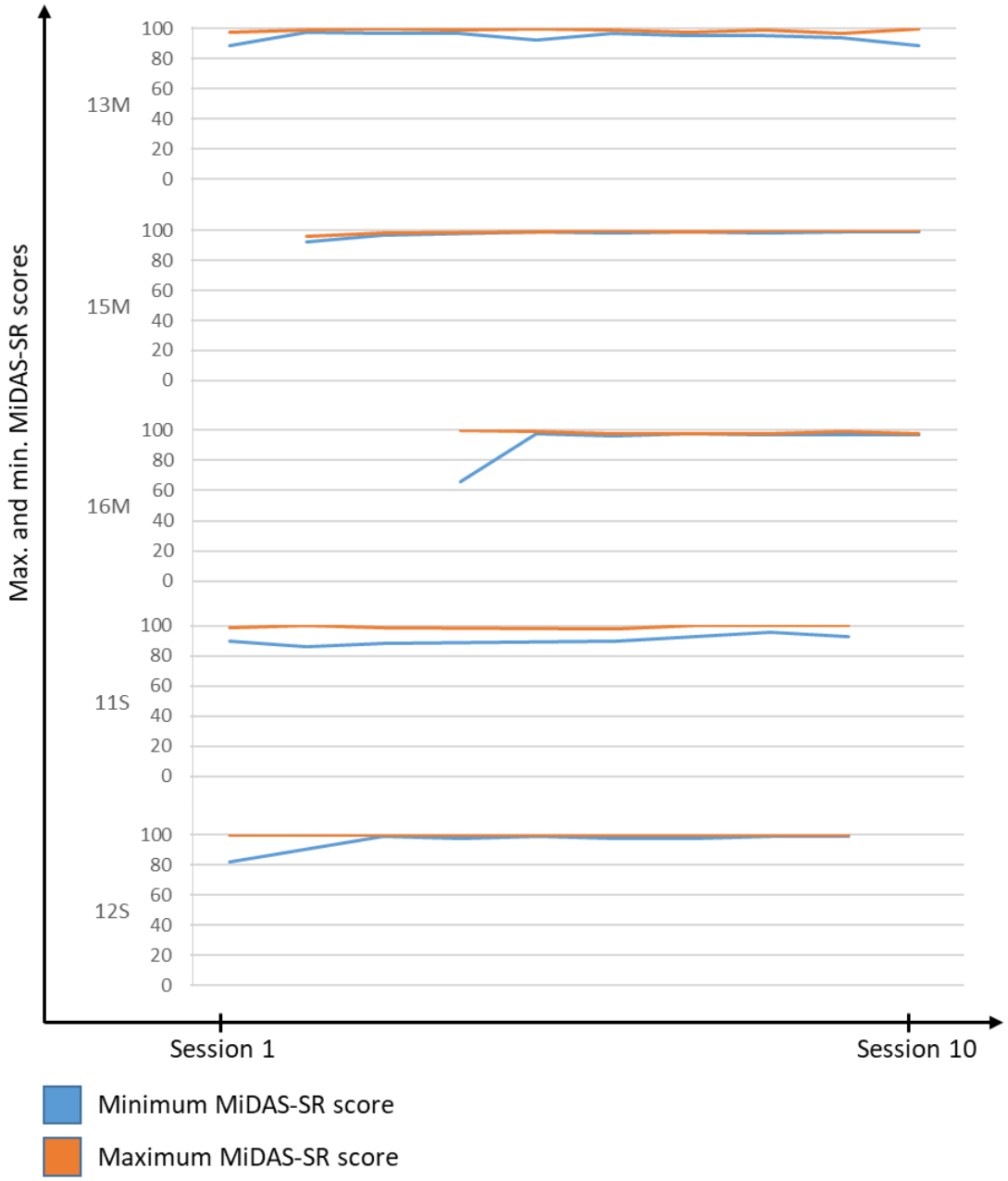


Figure 6:34: Maximum and minimum MiDAS-SR scores by participant (continued)

6.2.10 Discussion

Discussion of analysis of GDS scores

Analysis of the GDS data showed that GDS scores were higher on average at time 1 than at time 0, and higher among people with a diagnosis of dementia than people without. The results from the comparison between time 0 and time 1 did not show a significant change in GDS scores. However, the p value of 0.058 indicates a trend towards significance and six out of the eight participants with a diagnosis of dementia had higher GDS scores at time 1 than they did at time 0. Since the sample size is small, individual results may exert a strong influence on the overall picture. Three participants (1M, 5M and 6M) mentioned that they felt illness and worries relating to specific events in their lives had influenced their responses to the GDS at time 1. Another factor which may have influenced the results is the participants' relationship to the interviewer. All data were collected by the researcher, who was a stranger to them at the beginning of the study. However, by the end participants and researcher had got to know each other through attending the singing group. It is possible that participants felt more comfortable reporting symptoms of depression to a familiar person than to a stranger. Conversely, it is also possible that they felt more comfortable responding truthfully at the start of the study because of the sense of detachment from the researcher. It is also necessary to bear in mind that some of the GDS scores may be less reliable than others, since those participants with more severe dementia may have had more difficulty understanding the question and remembering how they had been feeling recently. Although every person with dementia who took part in the study was involved to some extent in rating their own mood, some of those whose dementia was more severe required help from a carer with answering the GDS.

The possibility that attending the group contributed to the raised depression scores among people with dementia must also be considered. This could have happened if

the attendees found the experience of the group very unpleasant or distressing, or if it confronted them with realities about their situation which they had not previously considered. For example, spending time with other people whose dementia was more advanced might have made participants more aware or more fearful of what would happen to them in the future. Alternatively, taking part in the group might have been challenging in a way which made them more conscious of the cognitive abilities and skills they had lost. The music itself could have played a role, since music may encourage self-reflection and reminiscence which might lead to feelings of loss or sadness in those with dementia, or frustration at not being able to remember events from the past. Finally, it is possible that the questions in the outcome measures caused participants to think about their feelings in hitherto unexplored ways, and that this led to them reporting previously unacknowledged symptoms. In future larger studies, the inclusion of a control group would enable better understanding of which changes were due to the singing group.

In the present study, it is not possible to tell from the scores themselves which, if any, of these speculative factors may have had an influence on symptoms of depression. However, the GDS scores may be compared to the other quantitative data (QoL-AD and MiDAS scores) and interpreted in the light of the qualitative data, to explore the mechanisms and dynamics underlying the group and the reasons for the upward trend in GDS scores. This result can also be compared with the findings of Camic, Williams and Meeten (2011). Over the course of a singing group for people with dementia and their carers lasting ten weeks, they found a significant increase in GDS scores of people with dementia. To account for this, the authors suggest that simply attending a singing group once a week is not enough to counteract other factors which could increase symptoms of depression among people with dementia.

It is interesting to note the difference in range of scores when the group is sub-divided by diagnosis. None of the people with self-reported memory problems but without a diagnosis of dementia scored higher than three on the GDS at any point, and the median score was 1.07 at time 0 and 2.00 at time 1. The scores of the people with a diagnosis of dementia range from 0 to 13, with median scores of 3.11 at time 0, and 6.72 at time 1. Since the prevalence of depression is higher among people with dementia than among elderly people who do not have dementia, this result is perhaps not surprising (Savva et al., 2009). However, it does have implications for any future larger study conducted along similar lines. The decision not to exclude people without an official diagnosis from this feasibility study was made for pragmatic reasons, and because group singing may have potential to support people who are worried about memory changes but have not yet received a diagnosis. However, if change in mood is to be used as an outcome it may be necessary to limit inclusion to people diagnosed with dementia. Including people with subjective memory problems may dilute the results, since they are less likely to show symptoms of depression.

Discussion of analysis of QoL-AD scores

Analysis of the QoL-AD data showed that the group's QoL-AD scores were higher at time 0 than at time 1. People without a diagnosis of dementia tended to have a higher QoL-AD score, and their self-rated quality of life remained more stable over the course of time. This may speak to the effect which dementia and the associated deterioration in condition may have on quality of life. It is necessary to interpret the results of the statistical tests with caution, since a number of missing values had to be imputed. However, the significant difference between people with a diagnosis and people without at time 1 supports the idea that those diagnosed with dementia may be more prone to decreases in quality of life. Since the scores of participants without a diagnosis of dementia showed less variation, it

is also possible that this represents a "ceiling" effect; their quality of life was very high to begin with, so there was little scope for change.

The trend towards lower scores at time 1 must also be considered, especially in light of the results from the GDS scores (since mood is a component of quality of life). Similar reasons to those explored with respect to the GDS scores may be relevant. However, since the QoL-AD is a multivariate outcome measure, there is more data about what specific changes were experienced. Some domains of the QoL-AD may be more likely to detect change which is related to participation in a singing group than others. Research has indicated that singing groups for people with dementia can be fun, enjoyable experiences; that participants report improvements in mood and self-esteem; and that they are an opportunity to make new friends (Camic et al., 2011; Davidson & Almeida, 2014; Davidson & Fedele, 2011). Participants who attend with a partner or family member may also experience benefits in their relationship with this person (Unadkat et al., 2016). Participants may therefore be more likely to experience change in the corresponding domains of the QoL-AD: ability to have fun, mood, self as a whole, relationships with friends, relationship with family and relationship with spouse. Changes in memory might also be reported in either direction, since attending a singing group could affect the way a person felt about their memory. For example, they might be pleased to find they could remember song lyrics, or upset that they had forgotten them. On the other hand, it seems less likely that attending a singing group could effect change in domains like money, ability to do chores, and living situation. Therefore it may be productive to synthesise QoL-AD scores with qualitative data, and to draw on previous research into singing groups, in order to establish whether the change reported by participants (positive and negative) may have been due to the singing group.

Figure 6:13 on page 172 shows the mean change in the 13 domains for those who reported a clinically significant change in QoL-AD score, and may give some insight into whether these changes were caused by the group. If this is the case one might expect to see agreement between participants, and change in the domains most likely to be affected by group singing. Those who reported a positive change overall showed the strongest agreement in the domains of mood (2 points), having fun (1.5) and life as a whole (1.5). Mood and having fun may have both been influenced by attending the singing group, and it is possible that these changes could alter the way a person felt about their life as a whole. Those who reported a negative change overall showed moderate agreement (mean change between -0.5 and -1) in these domains: energy, living situation, family, marriage, friends, money and life as a whole. Family, marriage and life as a whole may have been negatively influenced by the group (depending on whether these participants attended with a partner or family member), but the fact that no domains show high agreement may indicate that these changes in score were caused by different reasons for each participant, and ones not necessarily related to attending the group. Given the small sample size, it is also possible that the overall changes in the group were caused simply by noise, or random variation in the data. These results are explored further in Chapter 7 through individual case studies and synthesis of qualitative and quantitative data.

Discussion of correlation between variables

The strong negative correlation between GDS score and QoL-AD score at both time points indicates that people with a higher QoL-AD score tended to score lower on the GDS, at both time 0 and time 1. In other words, people who scored their overall quality of life higher tended to report fewer symptoms of depression. Mood is one of the components of the QoL-AD, so it makes sense that there is a relationship between them. Additionally, depression may affect QoL-AD score in a more general way: those who have a low mood may feel more negatively

towards aspects of their life which are not directly mood-related, and so rate them lower. This finding is supported by Logsdon *et al.*, (2002) who report significant negative correlation between both self- and caregiver-rated GDS and QoL-AD (r=-0.51 and -0.52 respectively; p<.001) and other studies which have found significant relationships between quality of life and mood for people with dementia using different measures (Thorgrimsen et al., 2003; Trigg et al., 2007).

The moderate negative correlation between change in QoL-AD score and change in GDS score indicates that those who experienced larger changes in one score tended to experience larger changes in the other score, in the opposite direction. For example, if a participant's QoL-AD score increased, then their GDS score tended to decrease by a corresponding amount. This finding provides moderate support for the theory that reported quality of life is related to mood. However, the correlation is not very strong, and it is obvious from the spread of the data that some people reported large changes in one variable but not in the other, so clearly there are other factors at play.

Discussion of analysis of MiDAS-SR scores

The MiDAS-SR scores provide information about how participants responded to the sessions, as well as data about the suitability of a self-rated measure of musical response for this kind of study. The profile of scores by session indicate that many of the participants consistently rated all five domains very highly, in the 80s and 90s. Over time, there seems to be a tendency for ratings to increase, although this may be because participants who gave lower ratings in earlier sessions (such as 2M and 5M) were either absent or did not complete forms in later sessions. "Initiation" stands out as one domain which tended to be rated lower by some participants; if any domain had a low rating, it was likely to be initiation.

When the scores were graphically analysed by participant for those with a high completion rate, there did not seem to be much evidence of a trend over time in most cases. The six participants whose scores were plotted either tended to rate their reactions extremely highly throughout the study, or where there was variation in the five domains, they varied similarly across the sessions.

Part of the intention behind using VAS (rather than a Likert scale, for example) is that there is more scope for detecting small nuances in participant's responses and minor variations in the scores. However, some participant's scores show a "ceiling effect", where ratings are uniformly very high, or occasionally very low. This may suggest that in these cases the MiDAS-SR scale is not capturing these nuances as it is essentially being treated as a bipolar scale. The domain "initiation" is particularly interesting as the one domain which was rated very low by several participants. This may be related to their interpretation of the measure. "Initiation" in this case was possibly felt to refer to fairly major instances of starting an activity, such as instigating a song or encouraging people to dance. In fact, much smaller gestures, such as starting a conversation with an adjacent person, could also be considered "initiation". The tendency for participants to give consistently high ratings from the start of the study means that any potential increase in their scores over the course of the study would be difficult to detect. Since MiDAS-SR is a novel measure, a full exploration of its feasibility is provided in section 6.4.5.

6.2.11 Conclusion

The quantitative analyses presented in this chapter are from a feasibility study which uses a small convenience sample and does not include a control group. Clearly, the results from it are not intended to be generalisable to larger populations. However, some of the findings may be used to inform the choices made in designing larger studies. Firstly, the ambiguous results from the QoL-AD

and GDS call into question the suitability of these measures in a trial of group singing. Secondly, the difference in results between people with subjective memory problems and those with a formal diagnosis suggests that distinguishing these two groups may elucidate the findings. Thirdly, the use of multivariate outcome measures such as QoL-AD may have an advantage over univariate outcome measures because they are able to provide more nuanced data about why change might have occurred, rather than just an overall score. Finally, the need for a larger study to include a control condition is self-evident.

The preceding section has described analyses which looked for change on a group level. However, these results also offer us the opportunity to consider individual change, and to examine the scores on a case-by-case basis. In Chapter 7, the quantitative results will be synthesised with the findings from the analyses of focus groups, interviews and observations in order to build up a richer portrait of the group members and address research question three: "What is the experience of the CHORD group members? What benefits, if any, do they experience from attending the group?" This data synthesis will potentially also inform the question explored by the literature reviews: do quantitative outcome measures capture data which reflect the experiences of people with dementia who attend group singing? Findings relating to the feasibility of these outcome measures and their acceptability to the participants are presented in section 6.4.5.

6.3 Qualitative data analysis

6.3.1 Analysis of baseline interviews

Before data analysis was begun, the recordings of the interviews were transcribed. The transcripts were then loaded into NVivo, which was used for data analysis. The baseline and post-group interviews were analysed separately, with the baseline analysis being undertaken first. The transcripts were read several times until I had become familiar with their content. Then I began to code sections of text in the transcripts, bearing in mind the principle of the general inductive approach, which is to be guided by evaluation objectives/research questions (Thomas, 2006). This seemed hard to follow for the baseline data, as the interviews were not directly related to the evaluation objectives but were concerned with the collection of data which illuminate the characteristics of the group members and their motivations, hopes and concerns which might affect how they experienced the group. However, the principle I followed was to focus the data analysis on themes which might affect participation in the group and the reasons people had chosen to attend.

When I began coding, my first attempts used "In vivo" coding, where direct quotations from the text are used as codes. This method aims to prioritise participants' voices. However, it proved difficult to establish commonalities between cases; although there were shared meanings, the phrases each participant used were unique to them. I then followed instead the guidelines for inductive coding, which is very similar, but advises creating categories from the meanings or actual phrases in the text. The first cycle of coding the transcripts resulted in the generation of approximately 100 codes. These were reviewed and codes which had very similar meanings were combined in order to reduce the total number. The codes were reviewed again, and grouped into categories which summed up the themes that the codes encompassed. The themes were not necessarily reflective of shared opinion, but were instead shaped by the concepts that were discussed,

which broadly related to music within people's lives, their attitudes and feelings about attending the singing group and taking part in research, and their feelings about memory loss and dementia. These six themes are discussed below, and an outline is given detailing how each of them can be related to the evaluation objectives. Some of the themes are linked and these links are discussed. It should be noted that in the general inductive approach, it is acceptable that some data are not coded (as it is not related to evaluation objectives) and that some data are coded more than once. This was the case with the data which was analysed.

6.3.2 Themes from baseline interviews

Two of the themes, "My life in music" and "My self in music" are closely related but subtly different. The former refers to the role that music itself plays in respondents' lives, and also encompasses musical activities which people participate in, from listening to music in the home to taking part in organised singing groups and choirs. The latter theme deals with the way group members conceive of themselves with respect to music, which could also be called their musical identity. This has been separated from their musical life, the role that music plays, because it became apparent that some people had an extremely strong connection to music, but did not think of themselves as musically skilled – perhaps even the opposite. However, the idea of having an emotional connection to music must be closely linked to the significance of music in a person's life, so there is some interplay between the two themes. These are related to the evaluation objectives inasmuch as it is desirable to know the characteristics of the group of participants at the start of the evaluation, and also provides data about the extent to which they are comparable to other similar studies; are they a representative sample?

The next two themes also complement each other, since they can be seen as representing the motivators and barriers which might affect an individual's

participation in and attendance at the group. The first theme "What I want from the group" relates to the reasons and motivations for participants to attend the group, while the second "My worries about the group" relates to any concerns which people had about attending. These two themes can be related to the evaluation objectives because people's expectations and concerns at the outset will have affected the outcomes which they reported at the post-group interviews. People may of course report outcomes which they did not expect, but it is interesting to compare whether their expectations align with their actual reported outcomes, and whether this affects their satisfaction with the group overall.

The next theme "My feelings about dementia" relates to how participants talked about and described their own dementia or memory problems, and also how they felt about dementia and memory generally. Data were collected about diagnosis from each participant, but this was also discussed during some of the interviews if participants seemed happy to talk about it; it was treated with sensitivity and interviewer judgment was exercised to decide if this topic would be acceptable to each participant. Aside from data about diagnosis being an important part of demographic information, it is related to evaluation objectives since changing the way people feel about their own diagnosis or their perception of dementia generally was a potential outcome of the group.

The final theme "My feeling about research" deals with to how participants felt about being part of the study, whether they had any concerns about this or whether it had motivated them or given them any cause for concern. This theme relates to evaluation objectives, since part of the aim of the research is to investigate the feasibility of conducting a larger study using similar methods. The attitude of participants to the kinds of data collection used in the study is an important part of this, and collecting this data at baseline also allows for

comparison with the post-group data about whether their expectations of taking part in research were met in reality.

"My life in music"

This theme relates to the role that music had played in respondents' lives and the significance it had for them. Participants were asked about music in their life and what kind of musical activities they had taken part in. For some respondents, it was clear that actively taking part in music was a big part of their lives: "the house has always been full of music" (2M); "our lives are filled, been filled with music" (4M); "music's really been one of the main things in my life. I wouldn't give it up unless I really had to" (4M). These respondents tended to have been heavily involved in singing or playing instruments throughout their lives. For others, music was seen as a significant part of their lives, but perhaps something they tended to consume passively rather than actively: "you like coming in here and putting your headphones on or just – just listening don't you" (12S); "I love to sit and hear other people sing. More so than myself." Only two participants said that music hadn't really been significant to them, and for one of these people this had been true earlier in her life but had changed in recent years: "music doesn't play much part in my life I must admit" (8M); "I'm a child of the 60s who wasn't mad into music" (1M).

Participants were also asked what kinds of musical activities they were taking part in at the moment and whether these had changed recently. The most commonly reported kind of music activity was listening to music in some shape or form: "We like watching and listening to concerts on the TV, don't we?" (12S); "I don't spend much time listening to music but when it's on in the car I sing along I love music" (1M); "well I have the radio on, but it's sort of background music". For one participant, a certain musical activity which she used to do with her partner had stopped after his death: "I used to go to jazz when my partner was alive but don't

go anymore" (8M). Several participants who lived at the sheltered housing setting where the group took place were already attending a casual singing group which met there once every three weeks. Three participants sang in other local choirs, and another had recently given up singing in a choir "because I've got dementia"; she felt that she wouldn't be able to keep up, despite saying that she had loved being in the choir (16M).

"My self in music"

This theme relates to the way group members thought of themselves in relation to music, with regard to both musical skill and what music meant to them personally. Several participants talked about their musical life or reported taking part in activities in a way which implied they considered themselves to have some musical skill, although it was not common for them to explicitly state that they thought of themselves as skilled: "well, I've always known I could sing" (13M); "Well my father, he encouraged me, he pushed me, and I did, I did quite a few exams. […] I did my intermediate exam and I got quite good marks for that" (3M). At the other end of the spectrum, several participants referred to themselves as unmusical or unable to sing: "I can't sing, but I just enjoy it" (11M); I'm a dreadful singer, so I wouldn't say I'm not musical at all, but erm …" (12M); "No musical talent whatsoever. And I sing very badly." (1M). It's interesting to note that these participants still wished to take part in a singing group despite their beliefs that they were not musical or bad at singing, although one participant also said "I've got a terrible voice so I would never present myself at any sort of a choir" (1M), perhaps implying that the word "choir" carried implications of a pre-requisite level of music skill which "singing group" did not.

Two of the participants who were experienced singers described how they had adapted to age-related changes in their voices. One had been put off singing because of the change ("I stopped singing, uh a few years ago because I felt I'd got

a vibrato. Didn't like it." (13M)) but had got used to the change and said that her voice was "still there". Another acknowledged changes in her voice but was thankful that she could still sing: "touch wood, my voice is as good as ever. It's a bit wobbly, it's a bit – an older voice…" (4S).

Some participants described a deep emotional connection with music which may have been difficult to put into words. Interestingly, two of these participants used the word "heart" to express what they felt about music: "But music, I can feel the music in my heart" (14M); "I just love singing from my heart" (13M). Another participant said that she felt singing had a positive effect on her emotional state: "I think actually if you sing a nice song, it does lift you" (7M). A number of participants related musical memories during the interview, often linked to their childhood or parents and not always positive. One participant described how he had to sing on his own in front of the class when he was at school, but that his teacher's reaction had had a life-long effect on his participation in music: "I got a wallop over the earhole and that was the end of it, and that put me off forever" (12M). Another participant relayed many stories about her experiences travelling the world and singing with choirs, and it seemed that she wished to convey what a significant role music had played in her life (3M).

"What I want from the group"

This theme relates to the expectations and hopes participants had which led to them wanting to join the group (it is worth noting that some participants had already attended a "taster" session, and refer to this in their answers). Many participants said that their main motivation was simply that they found singing enjoyable: "if we didn't like it we wouldn't go again the following week you know but... erm, we went, we enjoyed it" (11S); "I have really no expectations at all, other than I think I would enjoy it." (1M); "we'll just come along and take part in the singing and hopefully enjoy it" (4S). Two participants felt that coming to the

group would be something to fill their day: “Oh, I’ll join anything… For something to do” (2M); “And it’s something to look forward to. Which will probably help me because I won’t be, you know, sitting here.” (6M). Another couple valued the chance to “try something new” (12M&S).

Other participants mentioned general or specific benefits of singing. One referred to having read that singing could be good for you: “we’ve read that - dunno where now - but in the recent past that you know singing – whether you’re alone or especially with a group I think y’know can – can really benefit people of any age whether you can sing or not” (12S). Another felt that any activity which was new would be beneficial to her: “I think anything that you do that you’ve never done before you benefit from” (1M). Singing was felt to have potential positive impacts on cognitive abilities such as memory and concentration: “And I thought the singing group would probably help with concentration as well, and memory” (11S); “I think you keep your brain going, if you’re singing, your brain’s working. […] even if you’ve got words in front of you, you still got to keep your brain going to put the words to the music” (7M). Another participant whose husband had dementia commented that it seemed important for him to carry on singing as he could still remember the words even though he had practically stopped talking (10M&S).

A widely reported motivation for joining the group was the hope that it would facilitate socialising and making new friends: “I’m hoping to um… make friends” (16M); “I just wanted mum to go out a bit more and socialise cos she always used to be a social sort of person” (11S); “Every new thing you do incorporates more friends, more people, more interests – join it” (2M). It was hoped the group would provide “company” (6M) and the opportunity for “getting together with other people” (8M). It was unclear whether participants thought that the activity of singing had a particular capacity for facilitating social bonding, or whether they

simply felt that it was a chance to join a group which would increase their social circle.

Two participants referred to the physical benefits of singing. One mentioned that this was a motivation for joining the group: "I also thought the singing would help mum with her breathing cos she's had a few chest problems" (11S). Another person who was an experienced singer also identified breathing-related benefits: she said that she had suffered from asthma as a child, but that singing had helped her to grow out of it.

"My concerns about the group"

Participants were asked whether there was anything they were worried or concerned about to do with the group, or anything that might put them off or stop them from coming. In general, few concerns were mentioned. Two participants, 4M & 4S, were concerned that their singing experience might make them stand out in the group, and that other group members might be put off by knowing they were experienced singers: "knowing human nature if they know somebody's there from a choir that is a singer um you'd find they'd be frightened to let themselves go because they think we're going to be listening to them and whatever." [4M] One participant mentioned that she thought she might feel a bit anxious but that "everybody is when they go to new places" (6M). Another participant (5M) was concerned about a particular group member, based on her experience at the taster session where she had found this individual annoying because of her perceived tendency to argue and talk over other people: "Well it was just that she sat so close to us and the whole thing was her arguing" (5M). It should be noted that many participants had attended the taster session, so they had some idea of what to expect from the group already.

"My feelings about dementia"

Some participants shared their feelings about their own diagnosis of dementia and memory problems. Several people expressed concern about their memory problems. One participant had sought support from her GP but had not received a diagnosis: "It's given me so much cause for concern that twice I've been to the GP in the 2 years and had those very standard memory tests which I passed with flying colours but it's hardly surprising because they are so basic and haven't really got any faith in the results" (1M). Changes in this person's cognition had been noticed by her family as well, and she seemed frustrated that no diagnosis had been forthcoming: "[The cognitive tests] are so basic they're almost insulting and to be honest there has to be a much broader spectrum of way of examining people's memory for it to be meaningful at all." She also described how her memory problems were having a negative effect on her self-esteem: "You feel you know, a bit less of a person, because you're not able to remember things" (1M).

Two other participants also expressed some concern over their memory problems, but made comparison with others to indicate that they didn't think they had that much to be worried about. One participant, who did have a diagnosis of dementia, suggested that her memory problems were not causing too much difficulty at the moment, but hinted at a concern that this could change: "Well it's intermittent […] I haven't forgotten anything too serious yet […] but I have a worry that I'm going to any time now […] I feel I'm on the brink at the moment" (2M). She also said that "most of my friends here have memory problems" and so "I'm not exceptional". Another participant with no diagnosis of dementia identified memory problems which she felt were not severe, but was fearful of dementia because of her experience caring for her mother: "I do have lapses of memory, but not … not bad, but my mother lost her mind when she couldn't go out, and this is what frightens me" [7M]. However, she also suggested that her memory was more or less the same as friends her age: "Sometimes we have a day when we're as bad as

each other, we can remember what we're saying, but I think that's natural with a lot of people in a way". Both these participants conveyed a sense that they felt a distinction between age-related memory changes and something more sinister, and suggested that they used their peers as a yardstick for what was considered "normal".

"My attitude to research"

Participants were directly asked how they felt about taking part in research, and some also referred to research during other parts of the interview. In general, participants were either unconcerned about taking part in research (it was not a motivation for them, but they weren't worried by it) or were positive about it, usually because they saw it as a way to make a contribution. Some people felt that by taking part in research they were making a contribution to other people who had dementia: "And I think it's like everything, research has got to be done to try and get to the bottom of all these troubles and that" (7M); "If there's a benefit for you and lots of other people who um eventually might join groups like ours, it's an added bonus, isn't it?" (12S); "I like to feel that it may contribute to something however small, in the future and it may benefit some people in the future, so I feel good about that." Others expressed satisfaction that they were helping with this particular researcher's project: "I hope that, you know, you get a lot out of what we're doing" (13M); "And I hope it's going to benefit your research." (8M) One participant expressed the belief that research was necessary if progress was to be made.

Two participants, a man recently diagnosed with Alzheimer's disease and his wife, were positive about taking part in research, and said that this study was acceptable because "you don't have to go through those horrific cognitive tests". They were referring to tests which are commonly part of the diagnostic procedure, but which this participant had found very unpleasant. His wife said that if those tests had

been part of this study "we wouldn't be having this conversation, let's put it that way" and he agreed with this statement.

6.3.3 Analysis of post-group qualitative data

Transcripts of interviews conducted after ten weeks of attending the group were analysed, along with transcripts of focus groups and any comments which had been recorded on the MiDAS-SR forms. JB's interview was included in the analysis, and any references to how individual participants or the group as a whole responded were coded. The post-group coding followed the same principle as the baseline coding: the general inductive approach (Thomas, 2006). This approach stipulates that analysis should be guided by the evaluation objectives, which in the case of the data collected after the singing group meant data relating to how participants felt about the group, what they got out of it, how they felt about the facilitator and their attitude to taking part in research. The initial coding resulted in the generation of 79 first order codes. In order to enhance the transparency of the process and the reliability of the results, these first order codes and the raw data were shared with a second coder. Second-order codes/themes were generated from discussion and agreement between the two coders.

Some of the themes which were identified from the analysis of the post-group qualitative data were shared with the baseline interviews, while others were new. The table below shows the distribution of themes between baseline and post-group qualitative data.

Table 6:4: Distribution of themes from qualitative data analysis

Baseline themes	Shared baseline and post-group themes	Post-group themes
Expectations for group Worries about group My self in music/musical identity	My life in music Attitude to research	Session content Session ethos Facilitator "In the moment" benefits Social benefits Personal benefits

The themes from the post-group analysis could be divided into three broad higher-order categories: participant characteristics, session characteristics and benefits. The first category, participant characteristics, refers to aspects of each individual's attitude to music and research which might have affected the way they took part in the group. The second category, session characteristics, refers to the content and ethos of the sessions and participant's feelings about these, as well as their opinions about the facilitator and the way she ran the group. The third category refers to any benefits which the participants reported as a consequence of coming to the group; these are further subdivided into themes which will be discussed in more detail below.

Category: participant characteristics

Theme: "My life in music"

Where this theme was identified in the post-group data, it normally related to ways in which the group had affected their musical life. A number of participants made it clear that they intended to keep coming to the group and that they hoped that it could continue. One participant indicated that the ending of the group may have been experienced as a real loss for them: "some of us might have been a bit bereft if it hadn't been carrying on, those who don't have maybe very full lives". Other participants indicated that they would be willing to pay if it enabled the group to continue running.

Participants were asked whether their musical lives outside the group had been changed by coming to the group. Where participants reported positive changes, these were coded as benefits and are reported later. However, a number of participants reported no change in their musical life apart from attending the group. They said that they had continued with musical activities in the same way that they did before coming to the group, most of them by casually listening to music on the radio or television. Only one participant mentioned that she thought her previous musical experience affected the way she felt about the group. She had a generally unfavourable opinion of the sessions, though she had difficulty recalling exactly why. In a discussion exploring what it was she did not like about the group, we talked about her previous extensive musical experience, and she said "I'm a bit critical", implying perhaps that the musical activities in the group did not meet her standards or that the content was pitched wrong for someone with her level of experience. However, she was not able to be more specific about what aspects of the group she did not like.

Theme: "Attitude to research"

Participants were asked to describe how they felt about taking part in the study, and whether this had affected the way they participated in any way. Responses to these questions suggested that most participants felt that the demands of taking part in research had not unduly imposed upon them or the sessions. The kind of language used indicated a relaxed and accepting attitude towards the study: "it's alright", "we just do it", "it doesn't bother me", or "I'll have a go". Participants who discussed the content of the questionnaires seemed to feel that these were not too difficult or burdensome. One participant described the process as "painless", contrasting this with the "nightmare" of cognitive tests which her husband had to go through when being diagnosed. Another participant (1M) summed up this attitude when she said: "it didn't impose. You know, it was just a form at the end

of having a blooming good time. Whilst we were having tea and good laugh. It didn't impose, it was a very simple form, it was very easy to fill in and when you'd done it twice you knew what the questions were almost sort of thing." The same participant also said that she didn't feel that taking part in the study had affected the way she took part in the singing group, and that she did not even really think about it during sessions. This viewpoint was shared by the facilitator, who said that she did not think taking part in the research caused people to behave differently within the group. However, she did feel that the study had helped to bring the group together, suggesting that a sense of being part of something a bit special or different helped to gel the relationships within the group and unite the participants through a shared experience.

A number of participants reported having a positive attitude to taking part in research, and gave similar reasons to those which were reported at baseline. Being involved in research was seen as a way of helping and making a contribution to other people with dementia ("you're helping other people as well as yourself" (11M)) and participants also felt a motivation because they knew that their participation would help me with my PhD. Two participants expressed the view that taking part in research was empowering for them. One had experience of taking part in research from a different angle as she was a retired nurse, and she linked her experience in this field with her attitude to research now when she said "I suppose it gives you a feeling of power" (5M). It seemed important for her to convey that, like me, this had been part of her career too. Another person said that taking part in research was "fabulous". Due to her difficulties with expressive language, she struggled to expand on this, but I believe she was trying to say something like "It puts you on a par", conveying a sense that taking part in research meant that she felt her opinion was valued and respected, on a par with others.

Two participants reported that taking part in this study had changed their attitude to research. They were a couple, a man with young onset Alzheimer's (12M) and his wife (12S), and he had received his diagnosis fairly recently. In their baseline interview, they mentioned that if there had been cognitive testing as part of this study it would have discouraged them from taking part, because 12M had found the testing he had to undergo to obtain his diagnosis "horrific" and "gruelling". Immediately after receiving the diagnosis he was invited to take part in some research, but declined: "Well then it was too raw and I thought no, I'm bloody well not" (12M). However, the combination of time passing, feeling more accepting of the diagnosis and having a positive experience of taking part in this study had changed his attitude, resulting in him actively seeking more opportunities to join research.

Few participants reported having experienced worries or having negative feelings about the research, although it is possible that they did not disclose this to me for fear of causing offence. One participant said that she was nervous of being filmed, recorded and asked questions, although it also transpired that she had forgotten the camera was there most of the time. Another participant expressed some doubts in the purpose of the research, although she had enjoyed participating in the group, saying "I mean I can't actually see how … you're going to change things" (5M).

Finally, some of the data which was coded in this theme related to considerations which could potentially affect the findings of the study. Several participants had difficulty remembering details from the sessions. This was sometimes reported directly by the participant or their carer, or else it was clear from the way they responded to the questions about the sessions that they did not recall attending the group. One participant, when asked what she thought of the facilitator, replied "I'm 83 now… and my memory slips me, I can't – I remember a nice lady but

that's about all I remember" (14M). When shown a photo of JB, she recognised her but could not remember details about the session. Another participant had a generally negative impression of the group but could not remember specifics, saying "to be quite honest this is – beyond my memory range, so I think you're wasting your time on this one" (2M). Additionally, one participant implied that they found it difficult to pick out and describe specific benefits from the session, even though they experienced them.

Category: Session Characteristics

Theme: Session content

The theme "Session content" refers to participants' opinions about what actually went on in the sessions: the activities they took part in, what they liked and disliked and how they felt about the sessions as a whole. The overwhelming majority of the participants who completed the post-group measures described the group in favourable terms, with only one person who was interviewed saying that she was not impressed by it. A number of people expressed great enthusiasm when asked about the group and strongly favourable feelings about the sessions, either using the word 'love' or superlative adjectives (e.g. "I think it's marvellous" (16M), "I just love it and I'm so thrilled it's going on" (1M), "Loved it!! Highlight of the week!" (12S)) A similar number of participants expressed positive or favourable impressions of the group without using such strong or enthusiastic language, saying for example that they liked the group or enjoyed it (e.g. "I didn't have any strong feelings about it, I enjoyed it" (5M), "I was quite happy to come to it and it was, you know, most of the songs I knew and liked", "I mean it was just a pleasant experience" (8M)). Only one person expressed that overall she did not have a positive impression of the group, saying in her interview "I'm not terribly impressed by what you're doing, which isn't very complimentary I'm afraid". When asked why she was not impressed, she elaborated "I don't think you've got

enough to build on to head forward" but due to her difficulty recalling the sessions, she was not able to say exactly what it was she did not enjoy about them.

Participants described activities and aspects of the session which they enjoyed, as well as those which they enjoyed less or would have liked to have been different. There was a general agreement that the type and variety of songs which were sung in the group were suitable. Participants appreciated having choice and control over what was sung, and expressed gratitude to JB for creating the songbooks based on their preferences. It was important to participants to have variety in what was sung each week, but also to have an established routine and certain parts of the sessions that were the same every time and felt familiar. Some people mentioned that they thought starting and ending with the same song each week was important: "I like having the opening song that we have and the end song so it's sort of like you know the group's starting and you know when the group's ending with those two and then in between is whatever happens" (11S). In particular, the Shalom song with which we ended each session had become popular with the group, even though most of the members did not know it initially. One person commented "it's beginning to become one of my favourites" (11M).

Generally, variety in song choices was appreciated, but some people liked more variety than others. For instance, one participant commented "we don't stick to the same songs every week, we've started moving on" (11M) suggesting that the level of variety was appropriate for her. However, another person thought that there was still too much repetition, and suggested that she would choose not to repeat songs from week to week, or to sing all the verses of a song: "I'm not a person of habit and routine, so when we sang the same ones regularly I was less excited by those, when we sang different ones, yeah I thought "ooh we haven't done this" cos I always chose one, and I always tried to choose one that we hadn't

done before" (1M). Another aspect of the group which split opinions was playing the percussion instruments. The majority of the group members either commented on this favourably or did not mention it. The group members who attended one focus group discussed how they had particularly appreciated the percussion instruments, and were thinking of getting their own instruments so they could play outside the session. One of the carers thought this would be an accessible activity for her husband, and said that she would use them "to bash out all my frustration" (10S). However, two other group members said that they had not enjoyed the percussion, expressing this feeling with quite similar comments: "I didn't enjoy the rattle things" (5M), "I wasn't too keen on this … rattling things, it seemed a bit juvenile". Interestingly, they both chose the word "rattle" to refer to the percussion, with its connotations of a toy for babies.

A number of people said that they appreciated the opportunities for movement and gentle exercise which were afforded by the group. This included the warm up at the beginning of the session, and the dancing which arose later in the life of the group. Participants felt this added variety and was a valuable part of the session: "I think the dance the movement is very good, it's a good idea. Instead of just sitting staid and just singing" (12S); "the getting [up] and dancing, the movements that we all do – it's good for everybody you know" (13M). One participant said that it helped him to feel less tense: "it releases all the – hustle and bustle away from you […] waggling your feet, and tapping, you know, and getting rid of the tension round here" (3S) Another person said that doing the warm-up exercises and songs with actions was for them like "going back to school" but "in a nice way".

Several people mentioned noticing and appreciating other people's contributions to the group as something they particularly enjoyed. For example, several participants commented that listening to group members perform solos or duets was a highlight for them: "Yes I thought that was memorable that – that duet. So it

was nice to hear other people sing solos as well" (5M). Others simply appreciated the chance to be with other people and see how they responded to the music and singing: "it's being with people and their reactions. I do notice them" (13M); "I thought it was lovely looking around and seeing the happy faces. Faces that have obviously had trouble. And can manage to survive them and they all look as though they're thoroughly enjoying it" (14M).

Theme: Facilitator

Group members were asked about their opinion of the singing group facilitator and how she had led the sessions. Their responses were overwhelmingly positive, with only two group members expressing less favourable opinions. Group members described her as "brilliant", "lovely" and "tremendous". Many of the positive comments focused on JB's personal qualities and indicated that they felt comfortable and put at ease by her. One group member said that JB was "warm" and that "her humanity projects out, so she must love people I think" (10S). Another group member said that she was "motherly" (14M). Others indicated that they appreciated her enthusiasm and encouragement, saying that it was clear she was enjoying herself as well. She was seen as approachable: "she was very easy, you could approach, you could have little – little laugh or a little joke with her" (7M). Some of the group members were surprised to be reminded that JB had not led a singing group before, with one saying, "she's got, she's got the er touch of a – a professional really" (3S). However, another group member expressed a contrasting opinion, saying JB "really didn't make you feel 'ah here's a professional' […] and you've got to rise to her standards" (10S). These seemingly opposing viewpoints may not actually be contradictory if 3S's use of the word professional implies a sense of professional competence, while 10S's comment refers to professional expertise. In other words, JB gave a sense of knowing what she was doing without creating the impression that she expected others to live up to any particular expectations. Of the two group members who had a less positive

impression of JB's leadership, one expressed neutral feelings, saying "I didn't sort of go for her in a big way" but did not know exactly why, simply saying that it had been her first impression and she had not changed her mind. The other group member felt that JB's style had not been appropriate to the group, saying it was "a little bit for children" (2M). This comment came from someone who had been an accomplished amateur musician, which may have been a contributing factor in her generally negative feelings about the group.

Some group members expanded more on the qualities which they felt made JB a good leader for the group. Several people referred to her in terms which indicated that they felt that she was on the same level as the group members, rather than having an elevated status as group leader: "she wasn't like a teacher […] she was – in fact, she was like one of us really". The facilitator was seen as relaxed, especially in her attitude towards her own mistakes, with one group member commenting: "where she's gone wrong, instead of getting worked up about it she's just laughed it off and made us all feel more relaxed, I think" (11S). Occasions in the life of the group when group members initiated or led activities were mentioned by some people in the interviews and focus groups (including the facilitator herself). One group member said that she appreciated the fact JB was happy to let others lead, reflecting that she herself had a tendency to "take over a little bit" and that the facilitator "allowed me to do that, and you know I tried to not overdo that but I appreciated the fact that she allowed me to do that and she allowed people to do solos and duets and things when they wanted to and you know that's a great skill" (1M). Several group members felt that JB was flexible in her approach to leading the group; she was not "rigid" in her format but was able to "listen to people and to let them express themselves" (1M). One participant felt that JB had grown in her confidence throughout the sessions and was "sort of learning and evolving herself as she was going" (11M). There was a sense that the facilitator felt sufficiently relaxed and confident in her role that she did not have to be in charge all the time.

Theme: Session ethos

This theme refers to the ethos of the sessions as perceived by the group members. The term ethos has been chosen to convey the spirit, feeling or atmosphere of the group which is created by and contributed to by all the group members (i.e. it is not just a result of the way the facilitator leads the group). The ethos represents the less concrete aspects of the sessions; not what activities took place, but how the interaction between facilitator, group members and shared musical experience created a particular "feel". There were many references to the group ethos from participants during the interviews and focus groups. A number of people described the group atmosphere as "happy" and "relaxed", with a sense of fun and playfulness. One member said that it was "like coming to a little party every Tuesday, it's really joyful, it's a joyful space and time" (1M). JB felt that the atmosphere of the group was intimate compared to other similar groups, and that people felt safe to give things a try within this context. Others suggested that the reality of the group had been different from their expectations, in a positive way. One group member who had memory problems said that she had expected the atmosphere to be "quite down", based on her perception of dementia, but that this expectation had been completely reverse and she had found the atmosphere uplifting (1M). She related how her partner had similar feelings; at the start of the sessions he had not been interested in coming: "In the beginning he would have thought 'a singing group for people with memory problems, I don't think so' and now he says 'I'm not going to organise work for next week so I can come again'".

Participants were asked whether they felt the group had changed over time, and if so, in what way. The group was somewhat split on this question; although the majority of people felt the group had changed over time, two group members disagreed (2M & 16M). Many of the comments about the way the group had changed referred to the members getting to know each other and becoming more

relaxed and familiar in each other's presence: "well we've all become friends […] they were strange at first but we've all got used to each other" (13M); "as time's gone on everybody's sort of got more integrated and everybody seems to get on very well together" (15S). Two people referred to changes in the group in a way which suggested they felt the group had become a kind of independent, organic entity, with one describing this process: "But it's amazing how it's evolved and it's going on evolving into a different…" (11M) while the other felt the group had taken on "a life of its own".

The growing familiarity between the group members meant that they felt more comfortable to try new things and become fully involved in the sessions, and new activities therefore became possible, such as dancing and doing solos ("And then people became more individual and expressed themselves so it introduced more things into the group like the solos and the percussion" (1M); "it's relaxation and and er having confidence in joining in" (3S). This was also observed by the group facilitator: "I think the group as a whole it feels much more permissive, much safer, that people are more willing to, you know. As you'd expect of a group, the kind of gelling and becoming a more kind of functioning group" (JB). Comments made by the group members suggested that the relationship between the evolving group dynamic and the willingness to take part in more experimental activities was reciprocal. The growing familiarity of group members with each other meant that getting up and dancing felt possible; comments from one group members suggested that if this had been introduced in the first session it would have felt a bit overwhelming:

But I think it's good the way it has slowly evolved as people have gained more confidence you know, I think if you'd gone "let's all get up and dance around" I think people would have gone "no I'm not doing that" and felt uncomfortable to start with, straight away. (11S)

However, another group member commented that she felt dancing had helped to break the ice: "I think it was more just getting up and jiggling about a bit […] rather than just sitting looking at people across the chairs" (7M).

Apart from the sense that the familiarity within the group had changed over time, there were a number of other more specific comments about the group dynamic, with people mentioning features which had affected their participation and perception of the group. A couple who attended noted that they felt it was important that the group had been newly formed for the purposes of the study. They suggested they would have felt very differently about it if they had had to slot in as new additions to an existing group, imagining others' attitudes: "those newcomers they're rubbish, you know, let's get rid of em. They're not performing" (12S). There was a gender imbalance within the group, with only five men among its members, but only one person commented upon this, indicating that his initial worries were not realised: "I thought it'd be weird that I'd be the only bloke, well I'm not far off, but it's worked out very well" (12M). Several people mentioned that the group was a varied collection of people but that they felt this was a positive feature: "it's nice cos we're all so different, backgrounds and experiences – and that's actually the nicest part about being old" (10S); "I think it would be quite boring if we were all … the same" (12S). There were no reports of tension or difficulty within the group. One person who had been worried in her initial interview that another member was going to dominate the group said that although this had been an issue at the beginning, she had calmed down and sung with others. Another participant commented on the specific value of singing as opposed to any other group activity: "I suppose with singing, you're all singing together, if you went to sort of like where you're doing a painting group that's sort of more individual work whereas with singing like a choir it's a group activity isn't it, you're all involved?"(15M). Her comments suggest that it is the communal

experience of singing together which makes this kind of group different from other activities which may be superficially similar.

A feature of the group's ethos which was regularly referred to was the sense that making mistakes and not being perfect was OK. Although the group contained some experienced musicians, the majority of participants would not have described themselves as singers and did not think they were musical. This was an aspect of the group which was promoted by the facilitator and which she herself thought had been an important part of her leadership of the sessions:

"I mean I think the biggest thing for me, and this may be me rationalising, is that I didn't even though I had some shortfalls musically, that hasn't stopped it being a great group, and has probably contributed to it being a great group because of the you know being able to make mistakes and laugh it off" (JB)

Many group members made comments which indicated the group's ethos supported them to have a go at singing and take part in any way they were able: "I don't know about others but I never felt self-conscious about my dreadful singing and it's really been impressed on us that it really didn't matter which is great" (1M); "So I think because it's very relaxed, it's not you've got to sing in tune" (11S); "when it's at a lower level, it's more enjoyable you see, because you haven't got an audience to criticise us" (3S); "you don't have to be a proper singer" (11M); "No audition needed. You know and it's emphasised a number of times it doesn't matter if you feel that you can't sing or you're not a good singer" (12S). Group members seemed to have internalised the message that enjoying the experience of singing together was more important than getting the notes right. Several also mentioned that they felt being able to choose how to take part in the sessions was important. If someone did not want to participate in an activity, they were allowed to make that choice and were not pressured to join in. Two group

members talked about how one of the others did not want to join in the dancing, but was not "bullied into it": "You've got the choice, and you're not made to feel awkward or party pooper or whatever" (12S). JB also commented on this, saying that she thought people were quite tolerant of parts of the sessions which they personally did not want to take part in.

Category: Benefits

Theme: "In the moment" benefits

"In the moment" benefits refer to aspects of the singing sessions which were described as beneficial by the participants, and which occurred during the actual experience of singing itself. These experiences may be closely linked with other benefits, and in some cases it was difficult to determine from the data whether the benefit described was just "in the moment" or whether it had longer-lasting effects.

A number of participants described the experience of singing as enjoyable, and JB reported that she had been "quite bowled over by how much they've enjoyed it, the whole experience". In some ways, enjoyment of singing might have been seen by the participants as too obvious a benefit to report. Several people mention that they found singing uplifting, with one person using this particular word (1M), and others using words and phrases with similar meanings: "it dusted a few feathers off me again, and it brought the spark back" (3S), "you can't be sad if you're singing" (6M); "I felt it's lifted me. Lifted my spirits and that" (7M). The sessions were also felt to be enlivening by several people. Two participants (7M and 13M) described how one of the other group members "comes alive" when he got up to dance, both using this phrase. These same two participants also felt that the group had an enlivening effect for them, describing how "it livens your spirits" (7M) and "it keeps me alive" (13M). At the other side of affect regulation, one participant reported that the warm up aspect of the group had a calming effect on her (10S).

JB also reported that this participant seemed as though she had become calmer. Finally, two participants indicated that they found the singing experience had spiritually nurturing qualities, with one group member talking about the "songs that captivate your soul" (10S) while the other described how singing "feeds your soul somehow" (1M).

Theme: Personal benefits

This fairly diverse range of benefits refers to those experienced by the participants which represented a sustained personal change (longer lasting than "in the moment" benefits). These have been further divided into sub-themes: keeping things going, attitude to music, attitude to dementia, psychological benefits, cognitive benefits, and physical benefits.

"Keeping things going" was a phrase used by one of the participants to describe her feeling that attending the singing group was a motivation for her to keep things going in a literal and metaphorical sense. The fact that she thought the group was enjoyable meant that she was motivated to keep going to it, and she felt that attending the group helped her to keep herself and her brain active. The singing group sessions were seen by many of the group members as something to look forward to. One group member described it as "a real highlight of the week" and described how, in the week during the study where we didn't have a session, she and her husband felt lost for something to do (12S). Another participant said that attending the singing group helped to give a structure to her week; without it, there was a tendency for all the days to seem the same (10S). One participant, who initially said that she did not have strong feelings about the group, went on to say that she had enjoyed it because it was "not me doing nothing" (5M). There overall sense was that the group had provided positive, meaningful occupation for many of its members, and that it had affected their day-to-day lives by being an enjoyable focal point for their week.

For several participants, coming to the group had had an effect on their musical lives; either they found that their attitude to music had changed positively, or they found that music was a bigger part of their life. Two people who had thought of themselves as non-singers felt more confident in their singing ability after attending the group. One of them described herself as having a "terrible voice" but said that she was thinking of joining a local community choir, adding that attending the group had "definitely made me feel different" (1M). She was also planning to start listening to some of her old cassette tapes, feeling that this would make a big difference to her day. Another group member who had always felt that she couldn't sing said that she was now enjoying singing (6M), and two group members said that they were now singing at home together (11M &11S).

Some members whose musical activities had declined in recent years said that the group had helped them to bring music back into their lives. One group member expressed this feeling poetically, saying "the dying strings in my heart it's replucked them again you see" (3S). Another described her musical childhood and then said simply "I found it again" (14M). For one group member in particular, coming to the group restored her confidence in her singing. She had spent much of her life performing solo roles in amateur performances of operas and musicals, but had given this up a few years previously because she had developed a vibrato in her voice which she didn't like. After a few weeks of coming to the group, she felt confident enough to sing a solo to the rest of the group, saying "to be able to have the opportunity to sing, it works wonders for me" (13M). She later said that she now forgot about the vibrato when she was singing.

Three people reported that the group had changed their perception of dementia, with one of them saying that it had helped her to accept her diagnosis. One group member, the wife of a man with dementia, said that she often found it difficult to

tell who had dementia and who did not (10S). This viewpoint was reflected by another group member, who did not have a diagnosis of dementia but was worried about her memory. Her expectations of what the group would be like were not matched by reality: "I thought the mood might be generally quite low as some people with dementia are often quite depressed I imagine […] but really it hasn't been, it's been totally uplifting" (1M). She found that being in an environment where she knew other people had similar problems had helped her feel less frightened about dementia: "It's not so scary because there are people there who've got like me, you know, just increasing memory problems. I don't know what level their memory problems are because we just have so much fun". Another participant who was diagnosed with dementia said that the group had helped her "not with the dementia itself but with accepting the fact that I've got dementia" (5M). There was a sense from all three participants that spending time with other people who they knew had dementia or memory problems, but in an environment where dementia was not the focus, helped them to feel more comfortable and accepting of the condition.

Several participants reported psychological benefits as a result of attending the group. The most frequently reported benefit was an improvement in mood. Participants said that coming to the group made them feel happier: "Can't wait for next week. It makes me feel so happy" (1M); "It – makes me cheerful, it makes me happy" (6M). One carer said that she felt it had made her husband "very happy", whilst acknowledging that she generally found it difficult to determine his mood: "I don't know whether he was in a bad mood before or not. He has to be in a very bad mood before I know" (10M & 10S). Several people said that they had left the sessions feeling a positive change in mood, implying that the change lasted at least until the end of the session and potentially longer: "I came away feeling uplifted" (1M); "I – come out and Tuesday I really feel ooh yes I feel really – really happy about it." (7M). Others found that the group had improved their confidence, either

with respect specifically to singing or in general. In one of the focus group sessions, four participants who had not been regular singers agreed that their confidence about singing had increased (11M, 11S, 12M &12S). Another participant who had previously been a very active singer spoke about how her "confidence has come back", and how hearing her singing voice "makes me feel good about myself", indicating an associated boost for her self-esteem (13M). One of the participants felt that the group had increased her general confidence as well as her confidence in singing, saying that she spoke more (11M). Other group members confirmed that they had noticed this change in her too, with one person (1M) indicating that she felt 11M's self-confidence had improved dramatically. 11M's daughter agreed with her mother that the group had "brought you out of yourself" and felt that "singing's helped you find your voice" (11S). This last comment is especially interesting as it directly links the experience of singing with gains in other areas.

Memory and cognition was another area in which group members reported benefits. The group was seen as a welcome opportunity to use cognitive skills and keep the brain active by some. In one of the focus group there was agreement with the idea that "you need to keep doing things, using the brain" (7M). This was a motivation for attending the group for some participants, and there was also a sense that activities such as this might have a protective quality against developing dementia in the future. One participant described how joining in with the group involved using several difference cognitive skills for her mother (e.g. reading the words, remembering how the song goes) and that she felt this task had helped to improve her concentration (11S). Singing old, familiar songs was felt by participants to "ignite" their memories: "it's the songs from yesterday isn't it, your childhood" (3S); "it does spark memory off, definitely" (12S). The experience of a song sparking a memory was compared by one participant, a carer (3S), to being on a walk you have done before, turning a corner, and suddenly finding that the

memories of who you were talking to come flooding back. Importantly, the memory is "hidden until you turn the corner"; the walk, like the song, has to be re-experienced in order to stimulate the memory. Another participant, a man with dementia, described how being able to remember the songs without needing to look at the words was a positive experience for him: "I can you know remember a lot of it, a lot of what's there, now that we've been doing it, and it seems to it sticks, that's the big thing" (12M). His wife added that being able to spontaneously remember songs and start singing them outside the group was a benefit for him. Another participant described the experience in a similar way: "The words just sort of come into your brain sometimes, don't they, you don't know how they got there" (5M). There is a sense that remembering the songs spontaneously, without really trying, is a positive experience for people with dementia because it makes a change from situations where recalling information feels like a big effort.

Finally, several participants suggested that the group had physical benefits for them. The warm-up and later the dancing provided opportunities to do some simple exercises and move around a bit: "getting us to do exercises without us hardly noticing – very clever" (1M); "even when we get up to have a little jig, you know it's – gets you going" (7M). One carer felt that the exercises and singing had been beneficial for her mother's breathing, as she was prone to chest infections (11S & 11M). She felt that the breathing exercises in the warm up "gets her breathing in the right place".

Theme: Social Benefits

The opportunities afforded by the singing group for social interaction and support were mentioned by the majority of the participants. The group was seen as an opportunity to make new friends, and there was a general feeling that although they had started off as strangers, bonds between the group members had formed quickly: "as time's gone on everybody's sort of got more integrated and everybody

seems to get on very well together" (15M). One group member commented "I do wonder sometimes if half of them go for the biscuits or the singing, you know" (11S) and although she was joking, her comment underlines the possibility that for some group members the social aspect of the group was at least as important as the singing, if not more so. JB noted that it seemed that the group had bonded well and that "people do look out for each other". She speculated that being part of the research and filling in the forms together at the end of the sessions had contributed to a sense of "specialness" among the group members which could have accelerated the forming of friendships.

The feeling of camaraderie and closeness between the group members was demonstrated not just in the way they described their experience, but in the way they interacted with each other and me during the focus groups and interviews. For example, one group member made the others in the focus group laugh by referring to a recent incident when things did not go to plan: "today we were all singing one song, but it was about 8 different tunes" (1M). Far from being a negative experience, moments when things went wrong appeared to have the potential to unite the group through shared humour: "I don't think any of us will forget trying to sing along with Frank Sinatra … in the end we none of us could stop laughing" (11S). One group member talked about how the experience of singing brought the group together and catalysed the social bonding (3S).

Having a shared experience of dementia and memory problems was important to the members of the group. This experience meant that they felt others in the group understood them, and it also enabled them to share support. Dementia was not the focus of the sessions; it was enough that group members knew they were all there for the same reason: "that kind of feeling that you're there with a group of people who are in a similar position" (5M); "nobody's asked me [about my diagnosis] and it obviously doesn't matter to them either which is great. We just all know that we

have a shared problem" (1M). One carer said that the mutual understanding of dementia and memory problems meant she felt she could relax in the group "because you know that everybody's not going to be judgmental to the person you're caring for" (11M).

The group members were also able to offer and receive both emotional and practical support from each other. One carer commented that of all the dementia-related services and activities they had tried, her husband had had "most benefit and support in the most positive way from Blue Skies" (12M); another group member felt that the group had been "really uplifting and really helpful through those difficult times" (1M). Carers found it helpful to meet and spend time with others who had a similar role, and who understood the challenges of being a carer: "It's like your life slows down when you're caring for somebody because you have to go at their pace when – when we come to the group we can just be ourselves, and then sort of be at our pace which is great I think for everybody". From a practical point of view, the group members shared resources and swapped notes about local events and services. Those who were experienced at navigating dementia services were able to offer advice to others with more recent diagnoses. For example, one dyad found out about a physiotherapy group through other group members, and began to regularly attend, and another group member signed up for a computer course. Advice was not necessarily related to dementia; when one group member's toilet broke, it turned out that one of the support members was also a plumber. A group member summarised it thus: "it's a support network, which is a real added bonus" (12S).

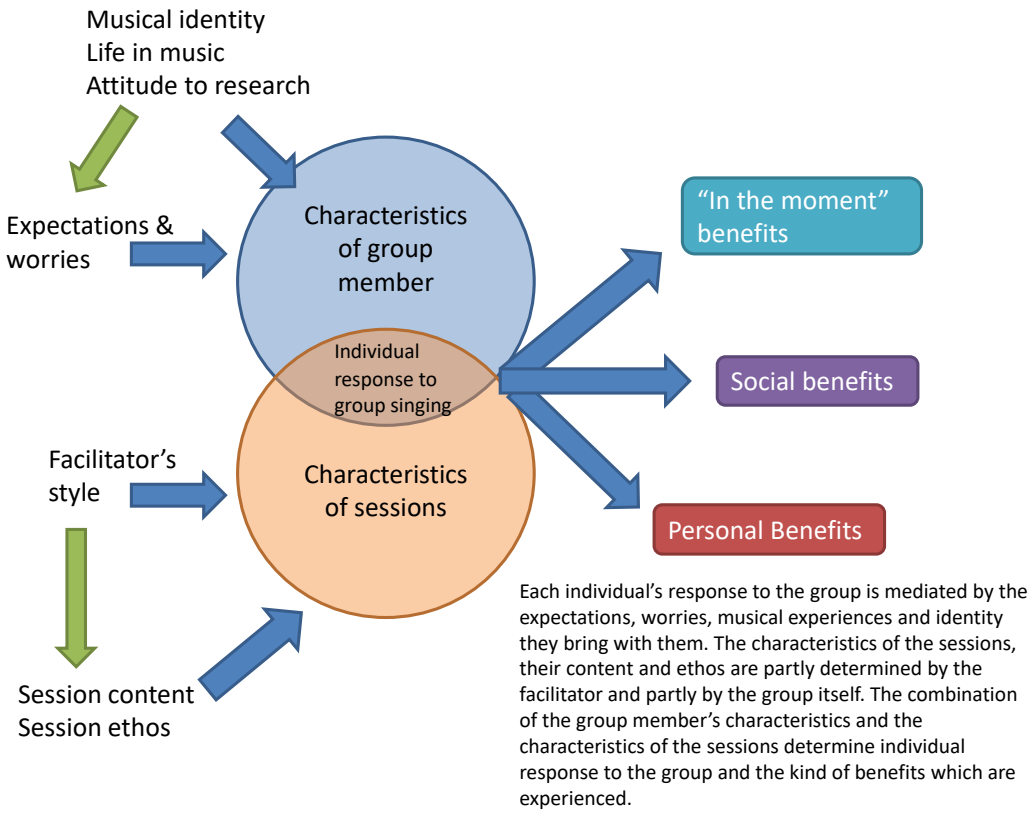
Care partners who attended the group together were asked if this had had any effect on their relationship. Some reported that the sessions had had a positive effect by providing a shared activity: "anything that's shared that you – that you have fun with it – it is a benefit to your relationship absolutely" (1M). Another

group member who attended the group with her daughter said that it had brought them closer together (16M). Other group members felt that it had not had an effect on their relationship with the person they attended with.

6.3.4 A model for group members' experiences

The previous sections have identified some of the participants' reasons and motivations for attending the group, their musical experience and preferences, as well as what they thought about the group and took away from it. In the data synthesis section, consideration will be given to the associations between baseline and post-group qualitative data i.e. how individuals' previous experience and motivation affected their participation in the sessions. The current discussion brings the themes from the qualitative data analyses together and proposes a model for understanding how, in general, an individual's response to group singing might be mediated by various factors (Figure 6:35). In this model, each individual comes to the start of the sessions with an existing musical identity and a lifetime of musical experience, as well as their own feelings about taking part in research. These past experiences shape their expectations and worries about taking part in the group. Session characteristics are determined by the facilitator's style, but also by the attitudes and expectations of the group members themselves. Each individual's response to group singing is therefore a product not only of what the sessions are like, but of their own expectations, experiences and musical identity. Hence the benefits experienced by singing group attendees are specific to each individual, and will differ from person to person depending on the variables described above.

Figure 6:35: Model of interactions between qualitative themes



The model described above focuses on the themes which were identified in the analysis of qualitative data, and is not intended to be comprehensive. Other factors will play a role in determining how each individual responds to group singing which may not have been identified in the analysis of qualitative data. The model was developed by considering all the themes derived from the analysis of qualitative data, and making a visual sketch describing how the themes related to and interplayed with each other. Gradually, the sketch was refined until each of the themes were represented.

6.4 Feasibility of CHORD Study

The following section describes the practicalities of setting up and running the singing group according to the procedure outlined in the "Methods" chapter. It deals with the recruitment of the singing group leader and group members, session attendance, drop-out rates, and feasibility of using the chosen outcome measures. In doing so it addresses research question 2: "How feasible would it be to conduct a full-scale RCT in a similar setting?"

6.4.1 Results of recruitment procedure

In total 25 people were recruited and enrolled into the study. This included 16 people with dementia and memory problems, and nine "support members", who were spouses, family members and friends who attended with a person with dementia. Because the sample included people at a range of different stages of dementia, some of these support members were in a caring role and some of them were not.

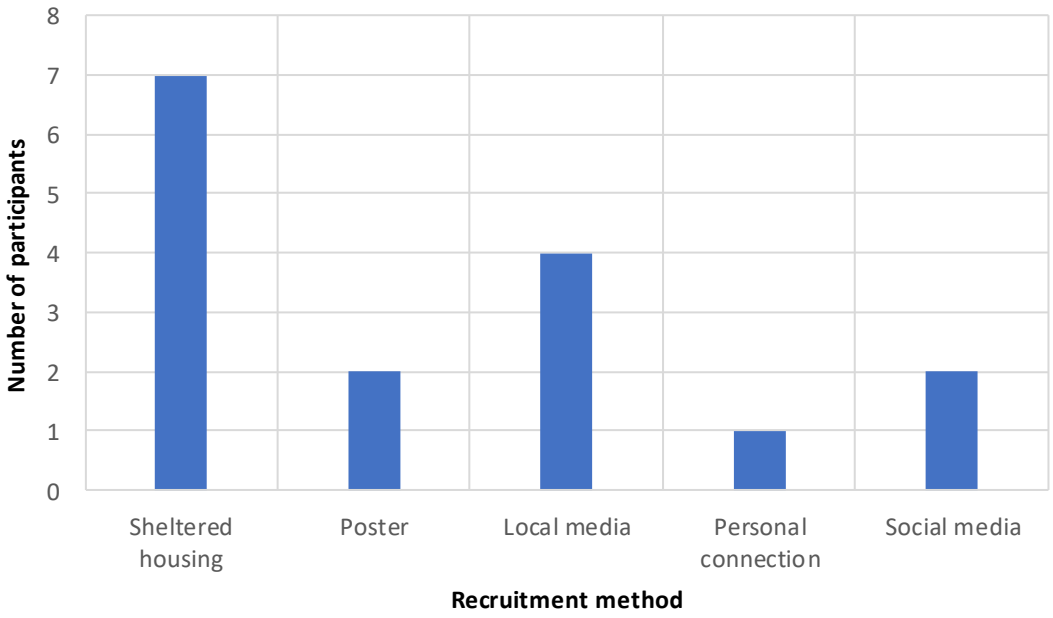


Figure 6:36: Avenues for recruitment of study participants

Figure 6:36 shows the number of people recruited through each different channel, including only the people who were eventually enrolled (note: only participants with dementia are included in this figure. Where people with dementia attended with a support member, it can be assumed that they were recruited by the same means). The category "sheltered housing" indicates that these participants found out about the study because they were resident in the sheltered housing setting where the study took place. Local media, both in print and online, and its social media presence, was an effective way of recruiting participants.

6.4.2 Participants

The people with dementia and memory problems who attended the group ranged in age from 64 to 95 years, with an average age of 78.8 years.

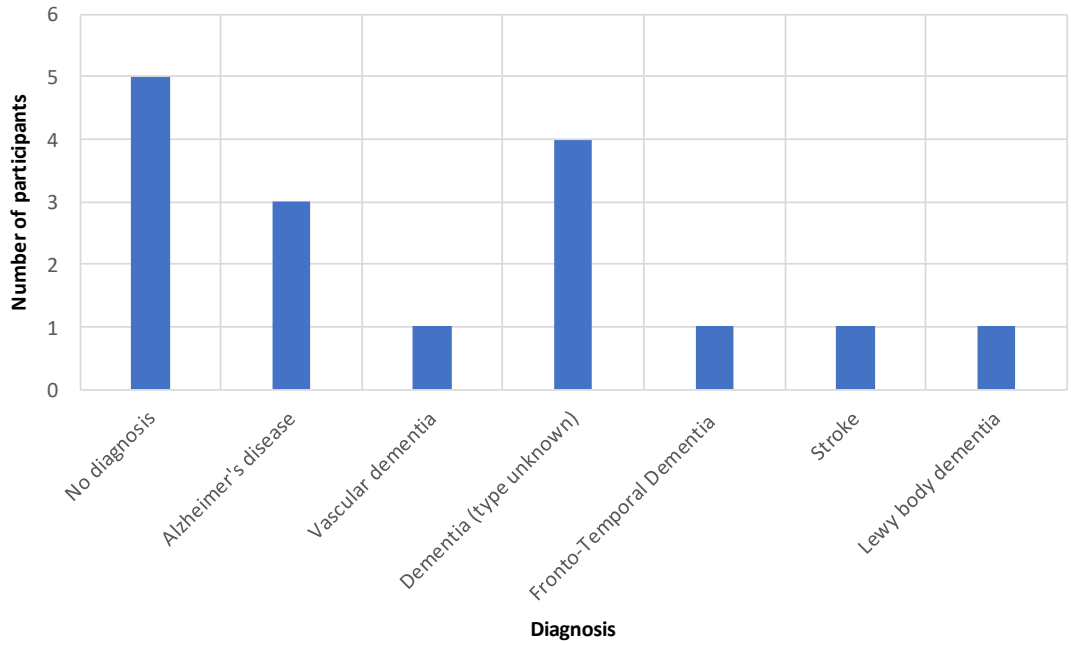


Figure 6:37: Profile of diagnoses of singing group participants

Figure 6:37 shows the profile of diagnoses of the people who attended the singing group. Of the people without a diagnosis, one had memory problems which she felt concerned about, and which had prompted her to visit her GP. However, she did not receive a diagnosis of dementia. Three of the people without a diagnosis reported some memory problems which they felt were not unusual for their age, and they had not consulted their GP. One reported no memory problems but was very to join the group as she had COPD and believed that singing was beneficial for her breathing. Since cognitive screening was not part of the study, we only have self-reported evidence of memory problems from those without a diagnosis. It is possible that some of these people may have exaggerated their difficulties because they wanted to join the group, or because they thought that singing might have preservative effects on cognitive function and stop them developing dementia in the future.

6.4.3 Attendance

The mean number of sessions attended by participants was 7.04. Since six participants enrolled in the study when at least one session had already taken place, the proportion of sessions attended by each person was calculated by dividing the number attended by the total number they could have attended. The average proportion of sessions attended was 74%. Reasons for missing sessions included pre-existing commitments, hospital appointments, illness and not wanting to come. Several people with dementia who lived in the sheltered housing were responsible for making their own way to the group and would often forget to come, so a system was established for reminding them on the day.

The attendance data is somewhat skewed by outliers: the three people who dropped out of the study, one after one session and two after three sessions. When these three individuals are excluded from the attendance calculations, the mean number of sessions attended rises to 7.47 and the average proportion of session attended increases to 81%.

Figure 6:38 shows the attendance at the 10 sessions. The number of people present at each session ranged from 13 to 20. Although the number of people at each session did fluctuate from week to week, there does not appear to be a noticeable trend over time; attendance did not tend to improve or drop off as time went on.

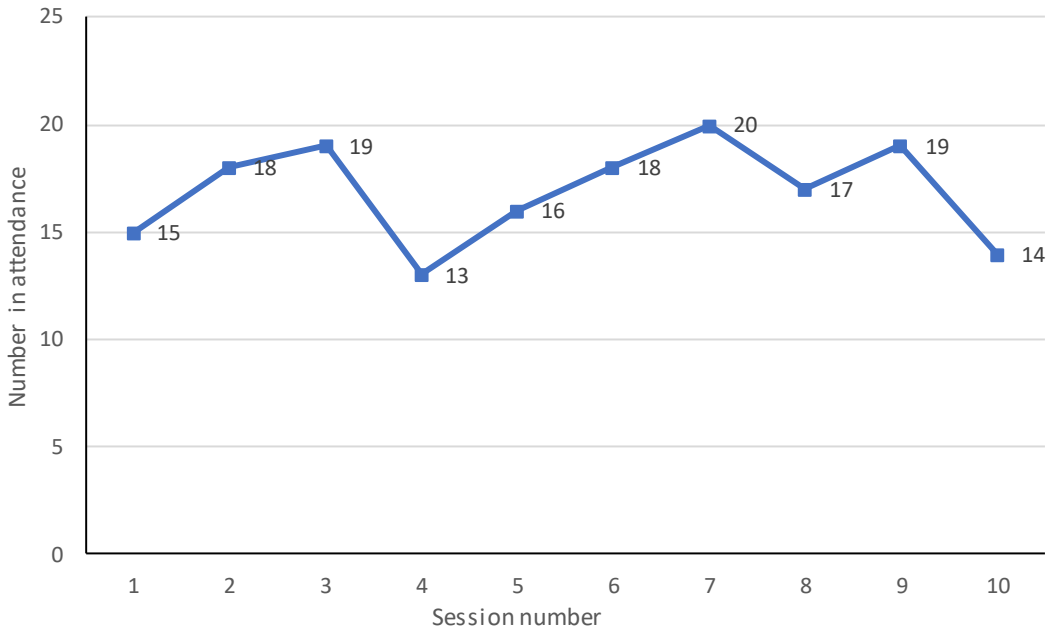


Figure 6:38: Attendance at singing group sessions over time

6.4.4 Retention

Three participants dropped out over the course of the study. One participant dropped out after one week, citing her health as the reason why she wished to stop coming. This participant did not have a diagnosis of dementia and had enrolled in the study but did not wish to complete any outcome measure or be interviewed, therefore no further data were collected from her once she had withdrawn from the study. The other two participants were a person with dementia and accompanying support member who dropped out after attending the first three sessions. They did not wish to be interviewed after leaving the group but provided some feedback about the group and why they had decided to stop coming. The given reason was that they were both accomplished singers with many years' experience performing and singing in choirs, and they felt that the kind of singing which the group was doing was not at a level which suited them. All other participants completed the study and the outcome measures.

6.4.5 Feasibility and acceptability of outcome measures

QoL-AD

Apart from the one participant who declined all outcome measures, all participants agreed to complete the QoL-AD questionnaire. The instructions for administering this measure state that the interviewer should ask the questions according to the script, while the respondent is given the answer sheet and responds by putting a circle round one of the four choices in each of the thirteen categories. Some participants could fill in the answer sheet with no problems. Others found the layout confusing or the print too small. Some read the categories on the answer sheet and began filling in their answers without waiting to hear the questions. When participants were unable to use the answer sheet, it was sometimes helpful to provide the choices "Poor, Fair, Good, Excellent" in large letters on a piece of paper, as it was easier for them to choose from words in front of them than to remember the four words and pick one. It was not uncommon for respondents to give a meaningful answer which was not one of those words (e.g. "It's alright, I suppose"). When this happened, they were encouraged to choose one of the four words, but if they ultimately did not, the item was scored as missing. Some participants whose dementia was more advanced required some input from their carer to answer the questions. One participant commented on their form "Difficult to answer some of the questions as they are so broad".

No participant reported finding any of the questions distressing, and no-one showed any distress while answering them. However, some questions did prove difficult to answer. Figure 6:39 shows the breakdown of missing items by category. The most commonly unanswered question was the one which asks about the participant's relationship with their spouse or partner. If the respondent does not currently have a partner or spouse, they are asked to consider their relationship with the person to whom they are closest instead. Several of the respondents did not answer as they were unable to think of an appropriate person. The question

relating to the "self as a whole" was unanswered three times. The phrasing asks, "When you think of your whole self, and all the different things about you, would you say it's poor, fair, good or excellent?" This is quite an abstract question, and might be considered difficult for anyone to answer, and especially challenging for those with cognitive difficulties. The question about ability to do chores around the home was unanswered three times. The reason for this is unclear; possibly the people who did not answer were unused to doing chores, so the question was not relevant to them. One respondent answered "Don't think much about it" when asked about their ability to do chores. The question relating to "ability to do things for fun" was missing three times, for reasons which are not clear; possibly participants could not think of activities which would fall into that category.

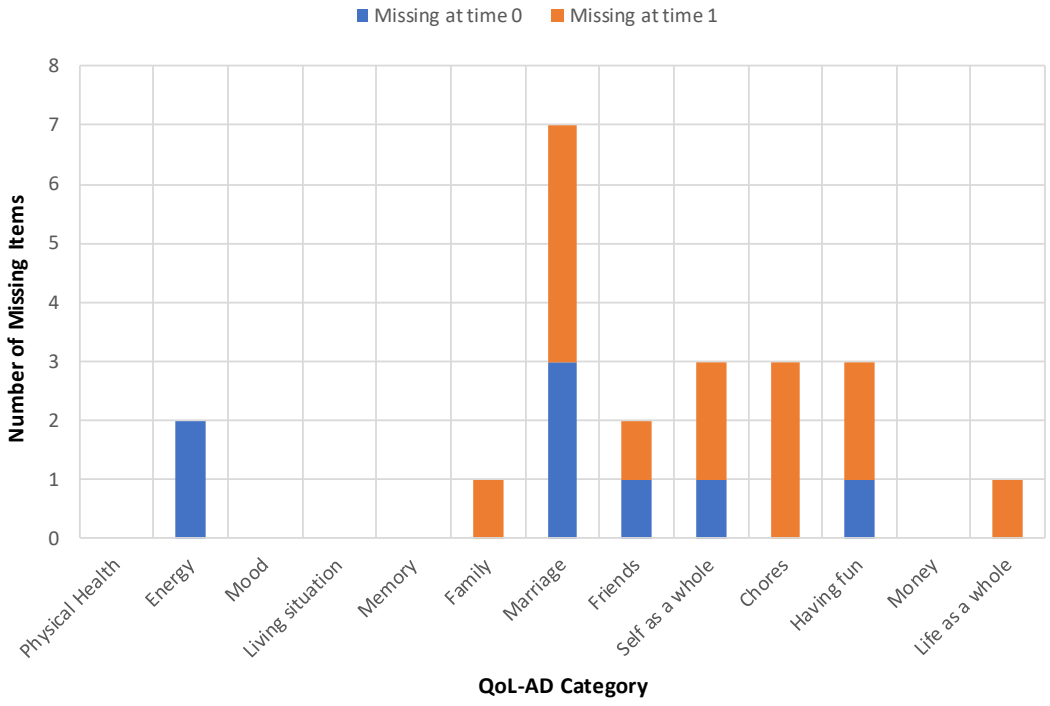


Figure 6:39: Missing QoL-AD items by category

GDS

Apart from the one participant who declined all outcome measures, all participants agreed to complete the GDS questionnaire. The respondent is asked 15 questions and instructed to think of how they have felt in the past week and

answer “yes” or “no”. In general, participants seemed to find the “yes” or “no” questions in the GDS easier to answer than the QoL-AD where there were four options to choose from. However, sometimes respondents found it hard to make the binary choice, saying that the answer was “sometimes” or “it depends”. When this happened, they were encouraged to choose the best answer or the one which was true most of the time. No participant said that they found the questions upsetting and no one showed any signs of distress.

Some questions on the GDS were not answered and were scored as missing. There does not seem to be a trend in which questions were missed; of the fifteen items, six were never missing, seven were missing once and two were missing twice.

HADS

All participant carers who were available at the time of the baseline data collection were asked to complete the HADS questionnaire, and all agreed. Participants were given the questionnaire and filled it in themselves. Apart from one carer who dropped out of the study, all the carers completed the questionnaire at baseline and after the group. There were no missing items. None of the carers reported any distress or difficulty in answering the questions.

MiDAS-SR

The MiDAS-SR questionnaire was presented to all participants after every session. The questionnaire consists of five visual analogue scales (VAS), and the participant is invited to think about the activity they have just done and rate their levels of interest, engagement, initiation, response and enjoyment by drawing a vertical line on each of the VAS. The questionnaire has written instructions and an example VAS for interest with a pre-drawn line. In the first session, the forms were distributed to the participants and it was explained to them how they should complete it. In the first two sessions the forms were given out straight after the

session had finished, while the group members were still sitting in the circle where the singing took place. However, after these first two sessions, it was decided that it would be more pleasant for the participants if they were able to complete the forms while seated at tables and having their post-group refreshments. Participants were encouraged to complete the forms, but it was made clear that they did not have to. Carers and support members were told that they were welcome to complete the forms if they wished to, although we were primarily interested in the responses of people with dementia and memory problems.

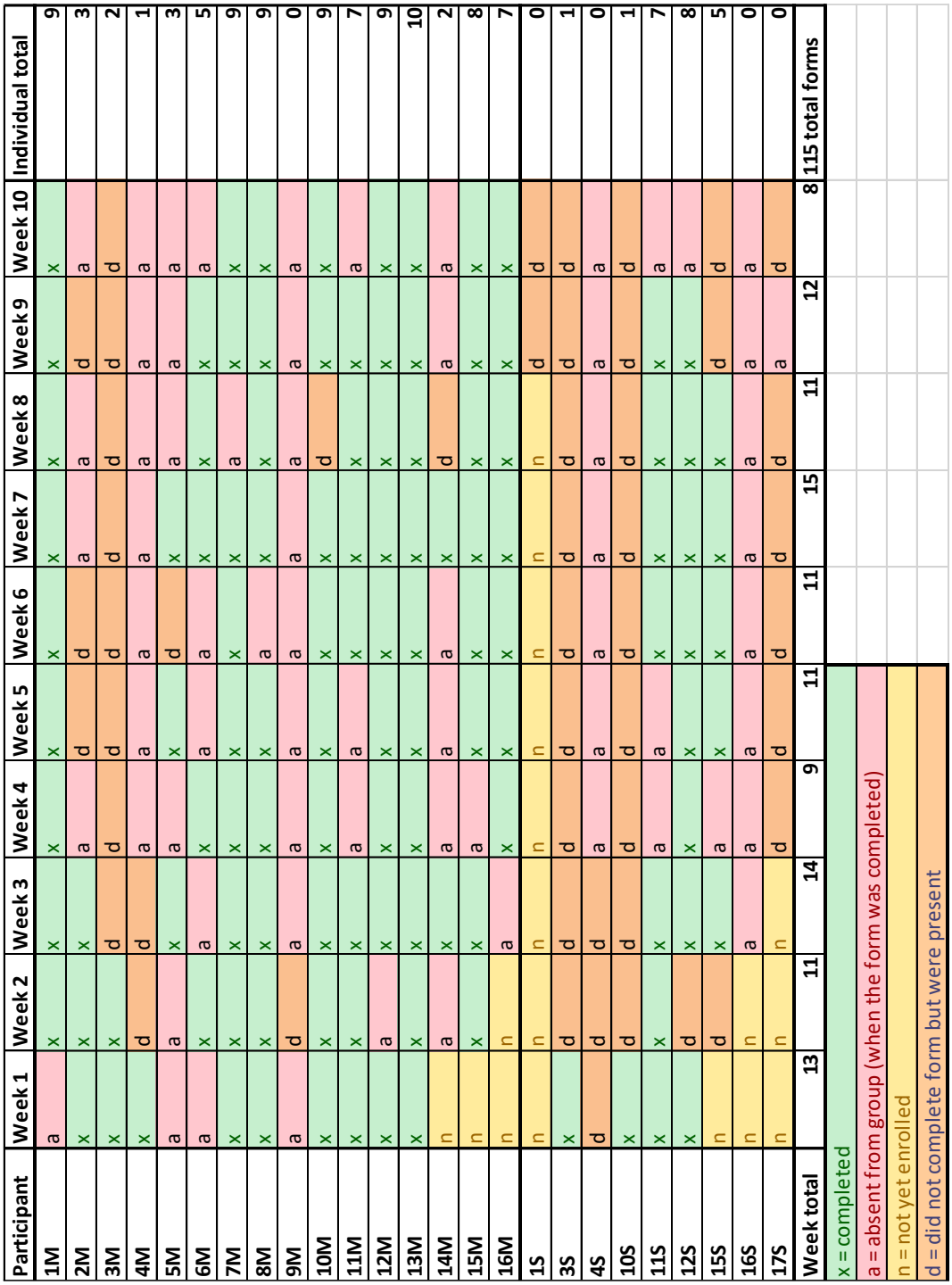
Many participants were able to successfully complete the MiDAS-SR forms; however, some difficulties were experienced:

- Some participants did not realise that the first VAS was an example and marked an answer on it.
- Some missed the last three questions because they did not realise that the form had two sides.
- Some participants wrote verbal answers on the VAS lines rather than making a mark.
- Some participants made a different kind of mark on the VAS (such as a cross or a tick) which could make it hard to determine the exact positioning of the line.
- Some participants wished to express their strength of feeling by marking the line off the upper end of the VAS, or by annotating it with plus signs. Overall, a high proportion of the VAS were marked right at the upper end of the scale, indicating a "ceiling" effect.
- Some participants whose dementia was more severe found it difficult to complete the form. In some cases, the form was completed with help from their carer, or on their behalf by the carer. In other cases, they stopped

completing the form after a couple of sessions because it was taking a lot of time and effort.

The form includes a comment box at the end and many respondents used this to offer feedback on their experience of the group or to explain their responses to the form in more detail. No participant reported experiencing any distress from completing the form, and judging by the completion record, it seems that those who found it particularly difficult to complete the form simply stopped doing it. One participant commented after a session that she felt like she was just recording the same thing, week after week.

Figure 6:40 shows the breakdown of MiDAS-SR completion for individuals over the course of the 10-week study. The "individual total" column shows the number of forms returned by each participant over ten weeks. The "week total" row shows the number of forms which were returned after each session. However, some forms which were returned were incomplete.



Participant	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7	Week 8	Week 9	Week 10	Individual total
1M	a	x	x	x	x	x	x	x	x	x	9
2M	x	x	x	a	d	d	a	a	d	a	3
3M	x	x	d	d	d	d	d	d	d	d	2
4M	x	d	d	a	a	a	a	a	a	a	1
5M	a	a	x	a	x	d	x	a	a	a	3
6M	a	x	a	x	a	a	x	x	x	a	5
7M	x	x	x	x	x	x	x	a	x	x	9
8M	x	x	x	x	x	a	x	x	x	x	9
9M	a	d	a	a	a	a	a	a	a	a	0
10M	x	x	x	x	x	x	x	d	x	x	9
11M	x	x	x	a	a	x	x	x	x	a	7
12M	x	a	x	x	x	x	x	x	x	x	9
13M	x	x	x	x	x	x	x	x	x	x	10
14M	n	a	x	a	a	a	x	d	a	a	2
15M	n	x	x	a	x	x	x	x	x	x	8
16M	n	n	a	x	x	x	x	x	x	x	7
1S	n	n	n	n	n	n	n	n	d	d	0
3S	x	d	d	d	d	d	d	d	d	d	1
4S	d	d	d	a	a	a	a	a	a	a	0
10S	x	d	d	d	d	d	d	d	d	d	1
11S	x	x	x	a	a	x	x	x	x	a	7
12S	x	d	x	x	x	x	x	x	x	a	8
15S	n	d	x	a	x	x	x	x	d	d	5
16S	n	n	a	a	a	a	a	a	a	a	0
17S	n	n	n	d	d	d	d	d	a	d	0
Week total		13	11	14	9	11	15	11	12	8	115 total forms

x = completed

a = absent from group (when the form was completed)

n = not yet enrolled

d = did not complete form but were present

Figure 6:40: MiDAS-SR form completion over the course of the study

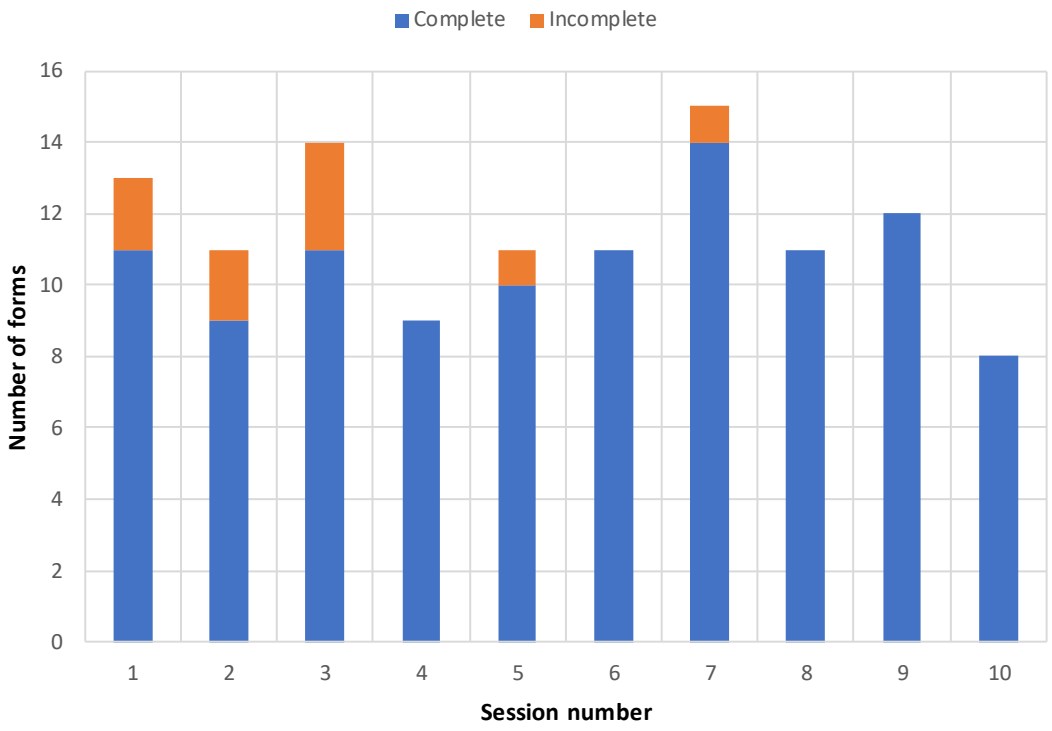


Figure 6:41: Number of complete and incomplete MiDAS-SR forms by session

Figure 6:41 shows the number of successfully completed and incomplete MiDAS-SR forms which were returned each week. A completed form is one where a mark has been made on all five VAS, sufficiently clearly that a numerical value can be obtained for each of them. An incomplete form is one where one or more of the VAS answers are missing, or filled in so unclearly that it is not possible to determine a numerical value. The graph shows that in the first few sessions, two or three forms had incomplete data but that the number of incomplete forms tended to decline as time went on. The total number of attempted forms also tended to decrease as time went on, with the exception of session 7.

Since the number of people in attendance at each session varied, it is also useful to consider the percentage of session attendees who returned a MiDAS-SR form each week, and the proportion of MiDAS-SR forms which were successfully completed. This data is presented in Figure 6:42.

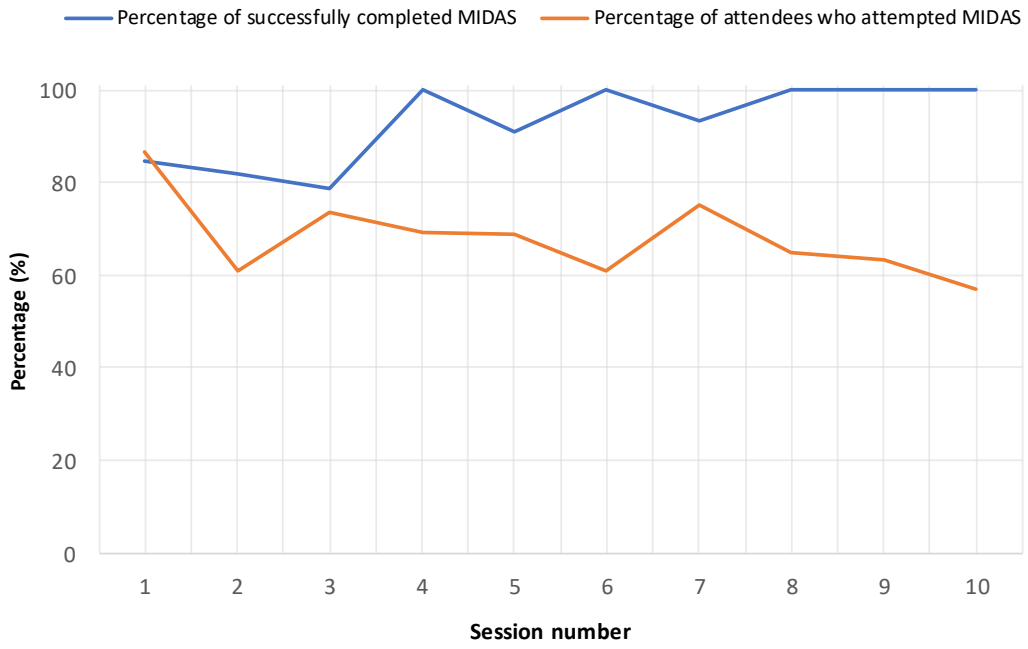


Figure 6:42: Proportion of attempted and completed MiDAS-SR forms

The graph shows that the proportion of successfully completed MiDAS-SR forms tended to increase as time went on. However, the proportion of attendees who actually attempted a MiDAS-SR form tended to decrease. These results seem to imply either that participants grew more familiar with the MiDAS form over time and were therefore more likely to complete it successfully, or that the people who found it particularly difficult to complete stopped attempting it. It is also possible that both these effects played a combined role. The anomalous spike in session 7 is perhaps due to the fact that this session was followed by a longer break than normal (two weeks rather than one) and attendance was high at this session. Participants might have felt more enthusiastic about filling in the forms due to this imminent break.

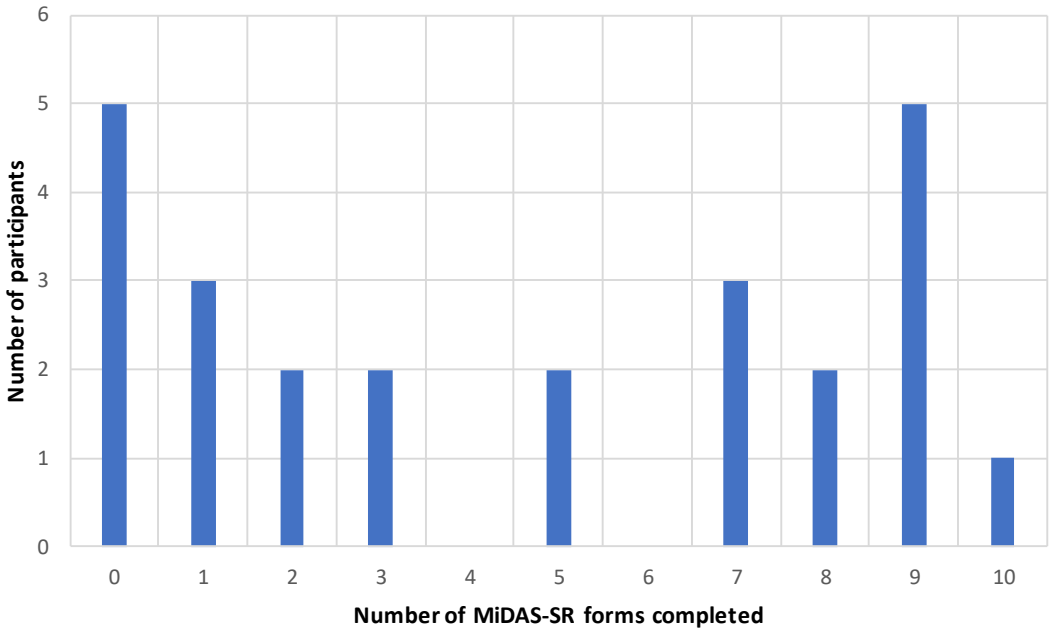


Figure 6:43: Number of MiDAS-SR forms completed by participant

There was a wide range in the number of MiDAS forms completed by each participant. Figure 6:43 shows the total number of MiDAS forms completed and the number of participants with this total (note that this chart includes both successfully completed and attempted MiDAS-SR forms). Most of the participants who completed no forms were support members who were instructed to complete forms for themselves only if they wanted to. Some of these members helped their care partner with their forms. All but one of the people with dementia and memory problems attempted at least one form (the sole exception was a partially sighted person who had declined all outcome measures).

The mean number of completed forms was 4.6 and the median number was 5. Of the 25 people who attended the group, 13 of them (52%) completed MiDAS-SR forms for five or more sessions. Of these, three were support members and the rest were people with dementia or memory problems. Since nearly half the group members completed MiDAS-SR forms for fewer than half of the sessions, analysis of MiDAS-SR data was only undertaken for those individuals who had a relatively

complete data set. The completion rate for each person has implications for the feasibility of MiDAS-SR as an outcome measure in a larger study. In such a study, ensuring a reasonably complete data set would be necessary in order to maximise the validity of findings.

As previously mentioned, some of the participants wrote in the comments box at the end of each form. In total, 75 of the 115 submitted forms (65%) included a comment. These comments tended to fall into one of three categories:

1. Comments about whether or not the participant had enjoyed the session, or specific part they enjoyed:
    - *"I did not think I learned anything."*
    - *"Really enjoyed it, can't wait until next week."*
    - *"Love the dancing and percussion"*
2. Reflections about the participant's engagement with the session, sometimes written on their behalf by a carer:
    - *"Says he enjoyed the singing. He joined in singing each song we sang."*
    - *"Not quite connecting as much after my accident."*
    - *"I feel that since starting at this group [name]'s concentration has really improved i.e. reading a book longer being able to do jigsaws."*
3. Expressions of thanks for running the group or hopes for the group's future:
    - *"I love it and I don't mind paying in future."*
    - *"Thanks again for organising this group!!"*

6.4.6 Implementation and acceptability of qualitative methods

Interviews

Interviews were conducted with people with dementia and memory problems and their support members, before the group started and after 10 weeks of sessions.

Apart from one participant who declined all outcome measures, all participants agreed to be interviewed. One dyad was not interviewed at baseline as they joined the study late and we could not find a time which suited them. Interviews ranged widely in length from 3.5 minutes to 47 minutes. No participant showed any distress during the interviews. Some of the participants whose dementia was more severe had some degree of difficulty remembering the group. For example, one participant had a sense that she had disliked certain aspects of the group, but could not remember exactly what they were. For others, it was unclear whether they remembered attending the session at all. Finally, the interview process may have been more difficult for participants whose dementia particularly affected their expressive language abilities.

Focus Groups

Two focus groups were conducted after sessions 8 and 9. It was felt that one group would have been too large to manage. Several participants were unable to attend the focus groups as they had other commitments after the sessions. The first focus group lasted for 26.5 minutes and the second for 32 minutes.

6.4.7 Feasibility of manual adherence procedure

Completing the forms

The manual adherence forms were completed by JB after each session. JB completed each form based on her own perception of her use of the manual during the session. For each of the 11 questions relating to how much she had followed the manual during each session, she chose one of the five categories: “very much”, “quite a lot”, “somewhat”, “not at all”, or “it wasn’t relevant”.

BD completed the manual adherence forms independently after reviewing the video footage of each session. Initial attempts were made to complete a manual adherence form after reviewing a complete session. However, it was difficult to

answer the questions based on a video lasting an hour or more without some way of recording what had been observed in the viewing of the session. A checklist was therefore used, based on the sub-categories which had been created in the process of developing the manual adherence form. BD watched each session, marking items on the checklist when they occurred, and also noting what had been observed. For example, at the start of session 6, it is observed that "J goes round to talk to individual members". This is recorded on the checklist under the sub-category "Make each member feel appreciated" which falls under the "individuals" category on the checklist. BD also recorded (infrequent) instances where JB appeared to contravene advice in the manual; these occurrences were given a negative score.

Once BD had filled in the checklist for each session, the result was a numerical score for each category. This was converted to a percentage by dividing by the total number of items in each category. Since there was a different of items number in each). These percentages were converted to categorical data in the following way.

Not at all	0
Somewhat	1 to 33
Quite a lot	34 to 66
Very much	67 to 100

It should be noted that BD did not review JB's manual adherence forms until after she had completed her own ratings.

Limitations of this approach

This approach is novel and untested, and its purpose was to test the feasibility of measuring adherence to the CHORD manual rather than to evaluate the manual

itself. Much of the difficulty arises from the fact that the CHORD manual is not a set of steps and procedures which must be followed (or ones which must be avoided), but a collection of hints and tips which may be more or less relevant to different situations. Therefore, it is not possible to produce a manual adherence form which is an inventory of necessary components because that is not how the manual itself is intended to be used. Furthermore, there is an unavoidable discrepancy between the group facilitator's perception of the sessions and that of the independent observer, since it is not possible to observe the underlying thought processes which guide the group facilitator's running of the group. The independent observer can only base their ratings on fairly concrete observations which are made while watching the sessions, whereas the group facilitator will be aware of the subtle changes in the way they run the group which are influenced by the manual. These could include things like tone of voice, body language, or the way that the facilitator thinks about people with dementia and associated changes in attitude. These aspects may be impossible to observe but are still associated with adherence to the manual.

Another limitation of this approach relates to the way manual adherence changes over time. The group facilitator, if she feels the manual offers helpful advice, may internalise this advice. The guidance in the manual will therefore become part of her own personal toolkit. This may mean that over time she feels she is following the manual less and less, as she becomes familiar with and internalises its components; yet she is still following its advice in the sense that she is putting into practice what is written in the manual. The observer is unable to witness this internalisation process. The only thing that they can observe is whether or not the actions are taking place. Therefore, they may record that the facilitator continues to follow the manual, when the facilitator herself feels that she is referring to it less and less. It is also worth noting that the material in the manual may not be new to the facilitator. Some of the guidance which is present may be things that

she would have done anyway, without the manual. There is no way for the observer to distinguish these elements from those which have been newly learned from the manual.

The method used to calculate the observer's manual adherence scores is crude, and the results should be interpreted with caution. In particular, the category boundaries for the percentage scores are arbitrary. It is possible that calculating a kappa score for interrater agreement is not appropriate for this data; it may be more informative and less potentially misleading to compare graphical representation of the data.

Manual adherence analysis

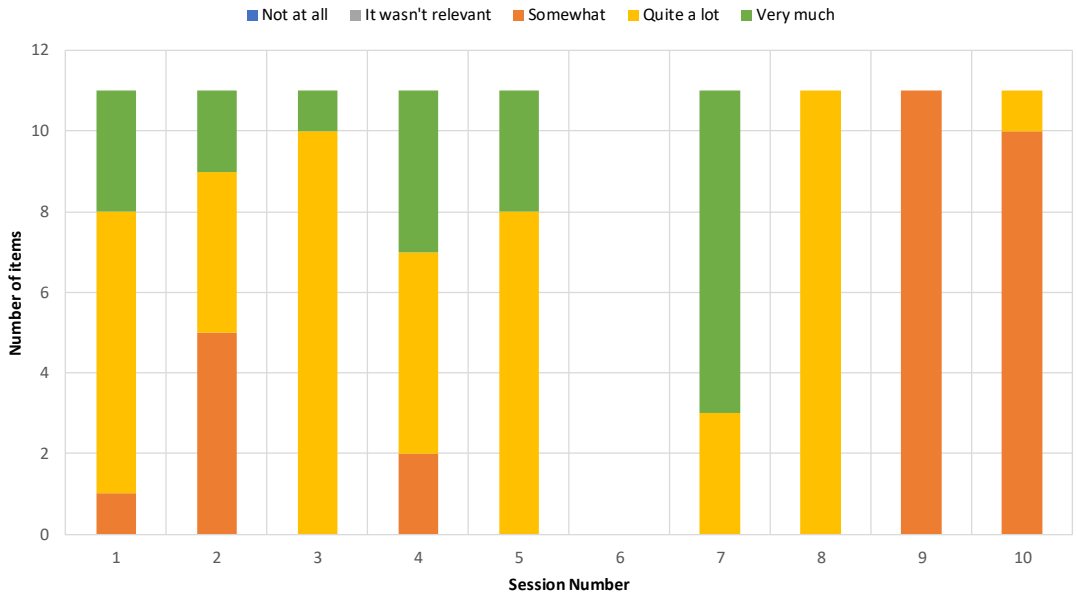


Figure 6:44: Facilitator's manual adherence ratings by session

Figure 6:44 shows the facilitator's ratings of her adherence to the manual, broken down by session, for each of the 11 items on the manual adherence form. The bars show the frequency of each category of rating, shown in different colours. This allows the change between sessions to be compared, although it doesn't show how each question was answered. The manual adherence form for session 6 was not completed. Overall, the group facilitator's ratings vary over the first 7 sessions without a clear pattern emerging; the "very much", "quite a lot" and "somewhat" answers are selected in varying proportions. Then for the last three sessions she indicates that she feels she is following the manual less; there are no "very much" answers, and in the final two sessions, all the answers except one are "somewhat". It should be noted that there was a gap of two weeks between sessions 7 and 8, twice as long as normal and it is possible that this may have had an effect on the extent to which the facilitator followed the manual, or felt that she was following it. Two of the possible answers, "it wasn't relevant" and "not at all", were never

used, indicating that the facilitator was following the manual to some extent at all times.

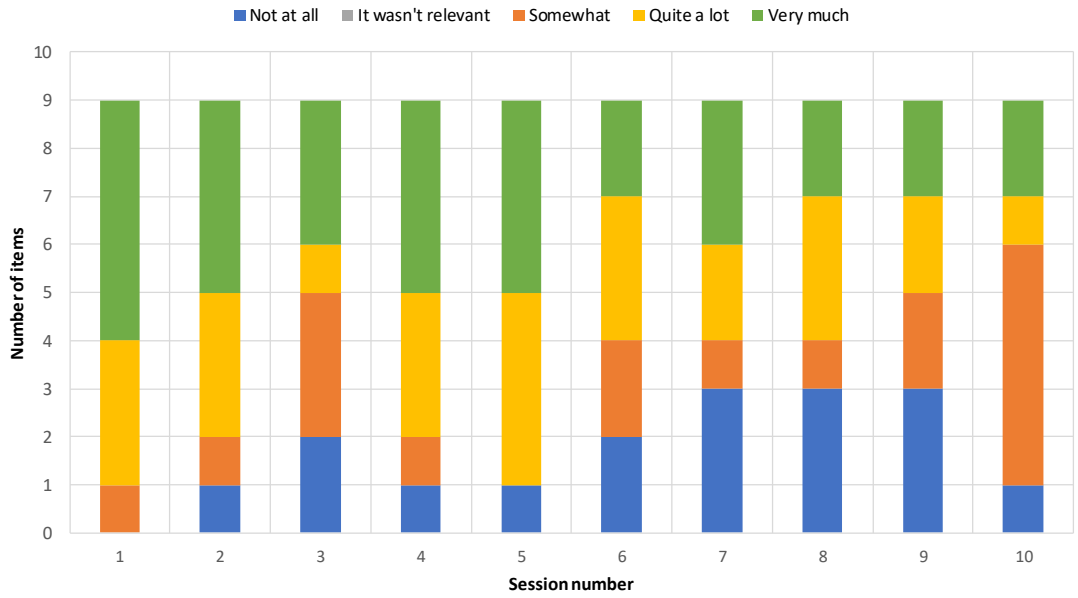


Figure 6:45: Observer's manual adherence ratings by session

Figure 6:45 shows the observer's ratings of adherence to the manual, by session, for the nine categories on the MA form which could be rated by observer. The questions about planning the session and debriefing/self-care were not completed by the observer as it was felt it could not be ascertained through observation of the session whether these had been followed or not. Overall, there seems to be a trend towards the facilitator following the manual less over time, although it is not very strong. The category "it wasn't relevant" was not used at all by the observer, because it was not possible to distinguish occasions where certain pieces of advice weren't relevant from occasions where they simply weren't used – it would be necessary to know the facilitator's underlying thought processes in order to make the distinction. From visual comparison of the two graphs, there does not appear to be a high amount of agreement between the raters.

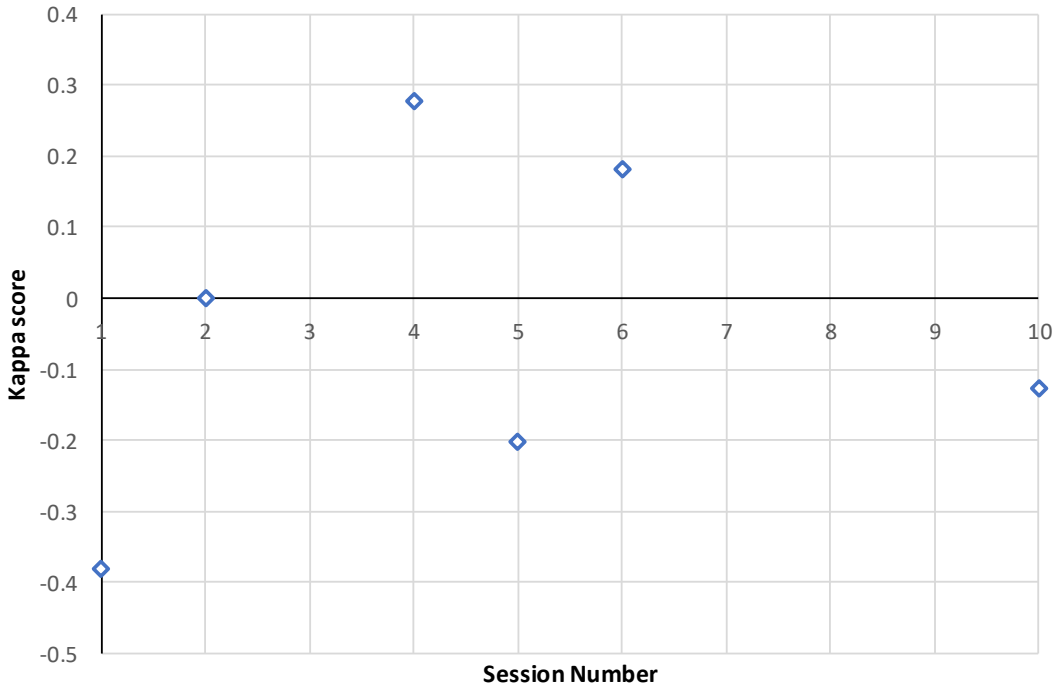


Figure 6:46: Cohen's Kappa score for manual adherence ratings by session

SPSS was used to calculate Cohen's kappa for each session (Figure 6:46). This statistic shows the degree of agreement between two raters and is preferable to percentage agreement because it accounts for the amount of agreement which would be expected through random chance. 0 indicates no agreement, while the closer a score is to 1 the stronger the agreement between raters. Negative kappa scores indicate that the two observers agreed less than would have been expected by chance. Kappa scores could not be calculated for sessions 3, 8 or 9 because the facilitator scored the same for each of the questions, so her scores are interpreted as a constant. The kappa scores for the manual adherence data indicate little agreement between the raters, although this varies between session. None of the scores were significant at the 5% threshold. Overall, the data indicates that there is no consistent agreement between raters.

Feasibility of manual adherence procedure

The manual adherence rating procedure as described here does not seem to be an effective way of measuring adherence to the manual in a reliable way, such as

might be required for an RCT. If measuring CHORD manual adherence was required for this purpose, a different method should be sought. However, this does not mean that the manual adherence form is without value; for example, it could be adapted to provide a way for singing group facilitators to record and reflect on the process of setting up and leading the group.

6.5 Evaluation of the CHORD manual

The follow section evaluates the CHORD manual by describing the way the manual was interpreted by the facilitator, and how she planned and implemented the sessions. This section also considers the facilitator's feelings about the CHORD manual, and how her use of the manual is reflected in others' opinions about the way she ran the group. Firstly, a detailed description of the sessions is provided. Secondly, a narrative description of the interview conducted with the facilitator after the ten sessions is provided. Thirdly, analysis of session notes written by me and the facilitator is discussed with respect to the content of the manual. Finally, points from the interviews and focus groups with the participants which are related to the facilitator's style and the way she used the manual are discussed. These forms of data are then drawn together in the discussion section.

6.5.1 Description and content of sessions

The following section describes the singing group sessions, including the preparation and aftermath of the sessions, in some detail. This description is based on a typical session, rather than any one session in particular. A high level of detail is provided in order to show how the CHORD manual was interpreted and implemented by the facilitator, JB. Some of my own reflections as member and observer of the group are also included.

Planning the sessions

Before each session JB wrote a plan which she emailed to me, outlining the structure of the session, song choices and a theme for the session, if there was one. The outline which JB used for the session plan was based on the suggested session structure which is included on p.35 of the CHORD manual. The sessions were divided into sections, relating to the type of song they contained or the general mood, and the section were arranged so that there were contrasts between them

and natural breaks for the singers' voices. As an example, the plan for session three is presented below in Table 6:5.

Table 6:5: JB's plan for Session Three

Greetings and introductions	About me – love to sing and helping Becky with her project About volunteers – Chris, Eloise, Stew, Chris About the group –10 weeks from mid-September Ground rules – self, each other, place – have fun, be comfortable and ask for help
Warm-up	Physical Movement Humming and arpeggios 'I am on top of the world' Blue Danube or Brahms Lullaby Bella signora Sing, a song or She'll be coming round the mountain, Drunken sailor
Hello songs	Morning has broken Oh what a beautiful morning Good morning Hello Dolly
Theme - Summer	You are my sunshine When you're smiling Sunshine on my shoulders
Rounds/Action	London's burning My bonnie lies over the ocean If you're happy and you know it Percussion to Ricky Martin or Buena Vista?
Rousing	I've got rhythm Happy Talk Yellow submarine Que sera sera
Mellow	Drink to me only Feeling groovy Danny boy Mull of Kintyre Moon River
Farewell	Side by side Show me the way to go home Bye Bye Blackbird Shalom
Refreshments	Depart

JB felt that it was important to have a plan in place each week. However, that did not mean that she necessarily intended to follow the plan; an element of freedom and flexibility was important to the ethos of the group, and we both understood this. In most sessions, the plan provided a basic outline to guide the session, but did not need to be rigidly adhered to.

Before starting the sessions, JB prepared songbooks for the group. The song choices were based on the information in the CHORD manual, suggestions made by people who came to the taster session, and JB's own ideas. The songs were printed in clear, large font on A4 paper and each was illustrated with a picture, to make it easier to find them. They were inserted into the pockets of display books, which also included an index at the front. Throughout the weeks group members suggested more songs and these were added to the song books. Eventually, a second song book was created to accommodate the songs.

Preparation for the sessions

The sessions took place in the communal space of a local sheltered housing setting and began at 10.30am. Before each session at around 9.45am, JB and I would arrive early in order to set up the room with the help of the volunteers. We would set out a semicircle of chairs for the participants in the far end of the room near the windows, with a table and chair for the facilitator in the centre (Figure 6:47). The piano was moved so that it was facing the semi-circle and the facilitator. The camera was discreetly positioned to capture as much of the group as possible (due to the angle, it was impossible to film the entire group at the same time). Preparations were made so the refreshments would be ready at the end of the sessions.

Before the beginning of each session, a volunteer was stationed on the front door to welcome group members and to let them in. I visited group members who lived in the sheltered housing setting if they had requested a reminder about coming to the group.

Figure 6:47: Chairs arranged ready for a session

Session content and structure

Arrival and warming up

Group members began arriving for the session at about 10.15am. After being welcomed into the room by JB and me, they were invited to make a name badge. The session began at 10.30am, with JB welcoming the whole group and inviting them to sit and begin the session. Each week, the session began with a physical and vocal warm-up. This involved gentle physical movements such as marching on the spot, rolling the shoulders and wriggling fingers. Next, vocal warm ups were introduced. These included humming, singing arpeggios to "la" or to simple phrases, and then usually humming or singing along to a well-known melody without the words. In some sessions, we also sang a well-known song without song books but with the words, such as "She'll be coming round the mountain when she comes".

Singing activities

After the warm up, the volunteers would distribute the song books. The group would always begin with the same song from the books, "Sing" by the Carpenters. This song was chosen by JB because she felt that the lyrics captured the ethos which she wanted the group to have: "Don't worry that it's not good enough for anyone else to hear/Just sing". She felt that this conveyed the sense that the main purpose of the group was to provide people with an experience of singing that they themselves found worthwhile and enjoyable, not to produce an aesthetically beautiful sound. After singing this song, JB would generally suggest several other songs which the group would sing. Sometimes songs would be repeated if the group particularly enjoyed them or felt that one sing-through was too short. JB would invite song suggestions from the group, and people would choose songs from the books or would mention songs that had popped into their head. If a song was mentioned but we didn't have the words for it, JB would make a note and then try to provide the words for the next session. During the sessions, I accompanied the singing on the electric piano, using sheet music or chord charts if I had them for each song, or otherwise improvising the accompaniments. In some cases, the songs were accompanied by recorded music played through speakers.

Other activities

The sessions often included a section where group members were invited to play percussion instruments. These included maracas, tambourines, bells and small drums, and would be distributed throughout the group by the volunteers. They would then play along to one or two songs chosen because they had strong rhythms and a clear pulse. In the fourth session, two of the group members stood up and started dancing while everyone was playing the percussion. Other group members joined them in the dancing as well, and this became a regular part of subsequent sessions. Most group members would join in with the dancing, but those who did not want to or felt unable to would remain seated. This became a

part of the group where people would move around and mingle with each other, before returning to their seats for the remainder of the session.

Sessions also sometimes included solos from group members. This was introduced by a group member in session four, when she brought the sheet music for a song she used to perform. The performance was warmly received by the group, and after that there were occasional solos during the sessions, both planned and spontaneous.

Pacing the sessions

After the percussion, dancing and solos, which normally took place as a kind of interlude towards the middle of the session, the singing would resume with suggestions from JB and from group members. Other singing based activities included rounds (e.g. London's Burning) and action songs (e.g. Heads, Shoulders, Knees and Toes). JB aimed to introduce contrast and variety to the sessions through the chosen songs. It was common for a fast and lively song to be followed by something more mellow. She also took into account that people's voices might be getting tired, and allowed time for water breaks and activities which didn't involve singing as appropriate.

Ending sessions and socialising

The sessions usually lasted between 60 and 75 minutes. JB would let the group members know that the end of the session was approaching, and would suggest one or two songs with a theme of ending as a way of marking this, such as "Show me the way to go home" or "We'll meet again". The sessions always ended with the same song, "Shalom", the words of the song offering peace "until we meet again". This song was new to most of the group members at the beginning of the sessions, but they learnt it quickly.

At the end of the sessions, hot drinks and biscuits were provided and the group members would usually sit round the tables at the other end of the room and have a chat. Initially, I asked group members to complete their MiDAS forms straight after the end of the session while seated in the semi-circle, but it soon proved easier to set the forms out on the tables so that the group members could complete them while having their refreshments. The members would usually stay for 30-45 minutes after the end of the session.

6.5.2 Interview with JB

JB was interviewed approximately one month after the 10 singing group sessions. The interview questions aimed to investigate what she thought of the manual and how she used it in practice, but it was also relevant to enquire about her background, previous experience and expectations for leading the singing group, as this would affect how she used and interpreted the manual. She was also asked her thoughts on the responses of the group members to her as a facilitator.

Experience, background and motivation

In response to the question about her expectations for the singing group, JB described approaching it with a strong motivation to take part in the project, but with a lack of knowledge of what the details might involve:

> *"I think because it was something I really wanted to do and felt that I could do but hadn't got any experience of doing so I was sort of quite excited about it and um and quite confident that I could do it but probably not really realising almost like the complexity of what's involved."*

Her initial anxieties about running the group were about supporting people with dementia, and being able to accommodate their needs; she remembered feeling worried that someone would "act out" or need something she was unable to

provide. Although she did not consider herself a musical expert, she did not really worry about this before the start of the group, and it was only when the sessions started that she identified some musical skills which she thought she would like to develop:

> *"I think what I do is quite instinctive and it's quite kind of it's not highly trained. But I don't think I really worried about that because I think what I was thinking was that we're just going to go and have a sing song and again I think some of those things like how to bring people in and how to set the pace and stuff that I see you do I kind of think I wasn't even thinking about things like that at the time, but they're the kind of things that I've become aware of as we've gone on, like "oh it would be really helpful if I could do that"*

JB said that there were some areas she felt comfortable with prior to the group, from her professional experience as a counsellor and facilitator and her personal experiences too. She felt experienced at creating environments in which people felt safe and secure, and felt she was able to let go of being in control of the group as necessary. Her personal experience of dementia had taught her "to let go of any expectations of what I think might be normal", and to try to meet people with dementia in their reality, rather than trying to bring them back to her own. She also felt personally convinced of the benefits of singing groups for people with dementia, from having attended some Singing for the Brain sessions.

Reactions to the manual

JB reported that her initial reaction to the manual was one of relief that it was a slim volume rather than the "A4 binder full of stuff" she had imagined. She appreciated the brevity and layout of the manual, and found that it was very useful for what she called "getting a group off the ground", taking on board the

advice about having volunteers and a co-facilitator and the hints and "watch-outs" included in the manual. She was appreciative of the fact that the manual encouraged reflection and seeking supervision if needed. She turned to other resources when it came to ideas for new material when the group was up and running, but overall found the manual accessible, practical and easy to take in.

JB suggested that her wish to find new material and activities for the group might reflect a personal desire to "keep things alive" and developing throughout the group's life, and also to keep her engaged in the process. She made an effort to keep aspects of the group the same each week (like the starting and finishing songs), but also to introduce new material and activities. She emphasised that her intention was not to help the group improve: "it wasn't about wanting it to develop or that people had to get better or perform better but just kind of keeping it fresh". Activities which JB looked for in other resources included rounds, action songs and warming up exercises. In particularly, she sought reassurance that it was appropriate to use certain activities, like action songs, from other resources that were specifically about working with people with dementia. She read quite a lot of additional material about how to warm up the group; although warming up was mentioned in the manual, it did not contain ideas about the kinds of activities to use.

Using the manual

JB was asked to outline how she would plan for a session and what elements of the manual she would use for this. She said that early in the process she sketched out a structure which she used as an outline in most of the sessions, with different components (e.g. "checking in", "in the middle", "winding down", and "checking out"). This was based on the example session structure given in the manual. She would then choose songs for each of these different sections, and sometimes consider having a theme for the session based on seasonal events, for example. She

maintained this method of planning the sessions throughout the duration of the study. However, she did not necessarily stick to the plan that she had made, citing her motto "Plan tight, hang loose":

> *"So I kind of have this schedule, and then invariably we don't do most of it, but because I've thought about it I can fall back on it at any time, so it's been quite interesting that sort of how much you stick to what you planned and how much you go with what people want to do."*

JB thought that although her opinion of the manual did not change over time, her use of it did. She found herself referring to it less as leading the group became more familiar and natural to her; in her words "you kind of wean yourself off it". However, she still referred back to the manual throughout the study, to check details about what to do in certain situations and for reassurance. Overall, she felt that the manual was comprehensive and provided "really good advice".

Suggestions for improvement

There were a few items which JB felt could have been included in the manual which were not present, although because one of the things that she valued about the manual was its conciseness, she was not necessarily suggesting that they should be added. One item which JB felt might have been helpful was advice on how to bring people in at the start of songs. This was something which she found difficult in the first few sessions, but which she had not prepared for because it was not something she had anticipated. In discussion with her, we talked about the difficulty of communicating musical advice in a written form. We theorised that it might have been sufficient for musical issues like this to be highlighted in the manual so that the facilitator was made aware of them, rather than providing instructions (e.g. "Think about how you're going to bring people in"). The issue of how to keep the group going once it had started however was something which

she returned to several times. She suggested that a section called "Now you've got going" should be included, focusing on the middle phase of the group and how to maintain interest and involvement. JB also suggested the possibility of having an audio-visual resource included as part of the CHORD manual, such as a video recording of an example session.

Reflections on leading the group

During reflection about her role as facilitator, JB suggested that her personal outlook on the priorities of singing group facilitation were reflected in the manual:

> *"…how do you convey that for me what's important is working with the group and where the group is, rather than this is how you do it and you have to do it this way. So there's a bit of a balance isn't there, there's some things that you have to do this way because that's what's needed and some of it is like well, let's you know, and it's in here, it's what's the mood of the room, where are people, how are they feeling. And I think that is conveyed in the book actually."*

JB's reflections about the importance of working with the mood of the group and understanding its members is similar to the idea in the CHORD manual that how you lead the group can be just as important as what you do. JB's perspective seems aligned with that of the manual in emphasising the importance of the atmosphere which is co-created in the room by the facilitator and the group members.

JB believed that her own skill set (having professional therapeutic but not musical experience) made running the group easier than if she had been someone with the opposite skills (an expert musician with no therapeutic training). She felt that it was easier to learn musical skills from the manual or "on the job" than it would have been to pick up therapeutic and interpersonal skills, which she felt came

naturally to her in this role because of her training. She also thought that not being an expert musician may have actually had some advantages:

> *"…even though I had some shortfalls musically, that hasn't stopped it being a great group, and has probably contributed to it being a great group because of the you know being able to make mistakes and laugh it off so – and I'm thinking if you were teaching people how to do this, that would be one of the things I'd really want to get over, is the atmosphere you create and how you do that and maybe for someone who's very highly musically trained that might be harder to let go of."*

Here, JB suggested that because she did not see herself as a musical expert, it may have been easier for her to relax, embrace mistakes and to focus on the atmosphere of the group rather than on getting the songs right or making a nice sound. She identified a few mistakes she thought had made herself, such as putting people on the spot or drawing attention to them without meaning to. She attributed these incidents to nerves and lack of experience.

When asked how JB felt the group had responded to her as leader, she said that she felt being open with them about not having done this before was important as it created a shared experience, suggesting that the newness of the singing group situation was something everybody had in common. JB said she had been surprised by their eagerness and enthusiasm, finding how ready they were to take part and to take ownership of the group. JB thought that embracing her own mistakes had been a way of showing that the group was an accepting and permissive environment, but that this had to be done authentically.

6.5.3 JB's post-session notes

The notes kept by JB were written on the manual adherence forms after the session had taken place. They provide a record of her observations about the session, any significant moments, reminders to herself about aspects of her facilitation to work on and thoughts about the manual and about completing the adherence forms. JB divides several of the post-session notes into the subheadings WWW ("What Went Well") and WNW ("What Needs Work").

Some of JB's notes mention her musical skills and how these develop over the span of the group. After the second session she identifies starting off songs, pitching and setting the pace as aspects she could work on. She mentions that this went better in session three's notes, and after later sessions writes that she has been discussing starting off and pitching with me prior to the beginning of songs and that this has worked better. JB's notes from session two mention a lack of musical advice in the CHORD manual. In the notes from sessions two and three she writes that she would like more guidance about how to maintain variety in the sessions, and in session three she notes that she has been looking to other resources to meet this need. After session nine she is thinking about planning for the final session and mentions that there is not much in the manual about making a good ending. She also reflects on her development as facilitator, writing in the notes from session nine that she feels "much more instinctive" about running sessions and that although she is still planning the structure of the sessions in advance, she is "only using about 1/3 of it". She says that she is referring to the manual less as time goes on, unless there is a specific thing to check.

JB's session notes also contain some observations about the group atmosphere and ethos and how it developed, relating both to her own facilitation and what she notices about others. In the notes from session 2, she writes about how she introduced "Head Shoulders Knees and Toes", an action song with the added

challenge of sequentially missing out a word on each repetition. She says that this was "great fun" and went "surprisingly well", adding that it felt risky to do it but that it represented a challenge for the group "which they met fully". Setting the group this challenge in an early session seems to suggest that JB trusted that the group would cope with something which would not be easy. It also shows a willingness to relinquish control by allowing some unpredictability into the sessions. In the notes from session 3, JB writes that she needs to slow down between songs to allow space and time for stories to be told and to get to know the group better. This suggests that she is keen to create a group atmosphere where people feel willing and comfortable to share their thoughts and feelings.

Other notes relate to the idea that the group can take ownership of itself and is not just passively led by JB. In the notes from session 5, JB identifies a need for more consultation with the members so that they feel it is *their* group. Then in later sessions this intention seems to be coming to fruition; in session 9 JB writes that she is "Noticing people looking at each other more & helping each other with song books and encouraging each other", while after the final session she says that the group members are keen to contribute to keeping the group going, with offers to help with the song sheets and the refreshments. These observations suggest that the group has begun to run itself to some extent. The idea of a permissive group atmosphere where mistakes are embraced is also mentioned in the notes. In session 2, JB writes that the group attempted to sing a song which was not very well suited to group singing, and that although it went wrong, the attempt was enjoyable and made people laugh. After some enthusiastic dancing in session 7, JB writes that the group members "seem very willing to have a go and risk looking silly", and she records feedback from one of them that because JB makes mistakes and laughs about them, it "gives others freedom". There is a sense in this comment that the facilitator's behaviour provides a model which the rest of the group have internalised.

6.5.4 BD's post-session notes

My post-session notes were written while viewing the video recordings of each session. They were primarily intended to provide a written record of what happened during each session, what the facilitator did during the session, and how the group members responded and took part. They also include some of my subjective reflections on what happened in the sessions, including how I remember feeling at the time. The video camera was not able to capture all of the group members all the time due to the filming angle, but it was always positioned so that the facilitator was visible throughout the recording. In the following description I focus on how the facilitator led the group and how her leadership changed and developed over time.

The session notes regularly refer to features of the facilitator's leadership which contributed to the creation of a particular group ethos. The characteristics of this group ethos were that singing in this context was primarily about enjoyment rather than making a beautiful sound: it was okay to make mistakes, there was time and space for everyone to participate in their own way, and everyone could contribute to the group. Aspects of this group ethos were explicitly stated by JB on several occasions, often at the start of sessions. For instance, at the beginning of session three JB said to the group: "This is singing for fun, this is all about having a good time, not about singing perfectly, and just taking care of yourself and enjoying singing, helping each other out." She also often emphasised the group's ethos when introducing the usual opening song, saying on one occasion "I didn't mean for this to become a theme song, but I think it captures what we're doing so well, singing for fun, singing out loud, not worrying about getting it right all the time".

Other aspects of JB's facilitation which supported this group ethos included acknowledging, embracing mistakes, humour and sensitivity. JB made a point of acknowledging contributions which group members made, as well as significant events in the life of the group. For instance, she would remember who had initially suggested a particular song and would refer to this in later sessions. She would also make sure that the group was aware when the sessions were going to end by regularly signposting this. JB modelled through her behaviour that mistakes could be embraced and were nothing to be embarrassed about. For example, when singing a song called "Getting to know you" JB shouted at the end of the first verse "I've lost the tune, keep going!" The group continued to sing but there was a lot of laughter, and one of the group members shouted, "Make it up!" Humour was frequently a part of JB's facilitation and was a way to make group members feel comfortable and relaxed. Humorous moments were unplanned and occurred spontaneously, often as a result of making a mistake or saying something wrong. There were also frequent examples of JB's sensitivity to the feelings and moods of the group and individuals within it. For example, when JB sensed that energy in the room was flagging or that people's voices were becoming tired, she would suggest a gentler, quieter song or remind the group to have a drink of water. She was also sensitive to the differences within the group and the need to accommodate a range of different paces. For instance, when one of the group members who had dementia was being enthusiastically encouraged by her husband to take part in the warm up, JB reassured her that she could take part at her own pace.

A number of the observations in my post-session notes relate to JB's musical skills. The notes highlight the musical aspects of group facilitation which JB found difficult, but also indicate that her skills developed over time. For instance, in the first session she found it hard to start songs and did not provide a starting note before the singing commenced, making it hard for people to come in. However,

her intuitive musicianship was already observable, as she used hand gestures to map out the contour of an unfamiliar melody. There are a few occasions in the earlier sessions where I offered some musical guidance, although I was conscious of not wanting to "take over" or to offer unwanted help. For instance, in the third session, JB suggested singing the song "London's Burning" as a round, where the group divides into sections and starts singing the same song at different times. She was about to launch straight into singing the song in parts when I intervened to suggest singing it through all together first.

As the sessions progress there is evidence that JB was feeling more musically secure. In session 4 my notes contain the observation: "JB is getting more confident with beginning songs and is either counting in or requesting an intro. When she does count in, often she counts an appropriate beat and people are coming in with more confidence." This is evidenced in the way JB led the group; for example, in session 7 she clearly signposted which section was coming up next in a complicated song; in session 8 she used body movements and conducting to indicate changes in tempo, and communicated to the group that they were going to repeat a song by simply continuing to sing confidently. She also demonstrated that she felt comfortable sharing her challenges with the group and inviting group members to take the lead. In session 8, she told the group that she did not know the middle section of "Cruising down the river" very well, and when it became apparent that some of the group members were familiar with it, she invited them to sing it on their own. Although some musical aspects of the group continued to be a challenge, the session notes indicate that she quickly took on board musical skills which helped the group to run more smoothly, and was not afraid to ask me and the other group members for help when required.

6.5.5 Discussion

The interview and session notes provide evidence of how JB interpreted and used the manual, in combination with her pre-existing skills, to set up and lead the singing group. Overall, there seems to be a high level of agreement between the way JB talked about her leadership of the group in her interview, how she described it in her notes, and how I observed it in the video recordings of the sessions. JB's counselling training and experience in facilitating other types of groups meant that creating a relaxed and permissive group ethos came naturally to her, as did forming a bond with the group members and treating them with sensitivity. JB reflected on this aspect of facilitation during the interview, and I also wrote about it in my notes. JB knew before starting the group that she was less secure in her musical knowledge and skills, but in her interview she reported that the musical aspects she struggled with most were those which she had not thought of in advance (such as how to initiate songs). JB's notes and mine both indicate the musical aspects which she found challenging, as well as providing evidence that JB was better able to meet these challenges as time went on. JB's session notes support what she said in her interview about planning for sessions but not necessarily following the plan, and about feeling more instinctive in leading the group and relying on the manual less and less as time went on.

Various aspects of the CHORD manual content are reflected in the way JB led the group. As she noted in her interview, she took on board many of the practical suggestions in the manual about setting up the group, such as having a co-facilitator and having volunteers to help with the sessions. However, less concrete elements of the advice in the manual were also in evidence in JB's facilitation style. The manual advises the reader "When you run a singing group, what you do is extremely important. However, it is often how you do it and how you are with group members that makes a big difference to people living with dementia". This second aspect, knowing how to be with the group members, is difficult to observe

and describe, but it seemed to be present in JB's facilitation, although it is hard to know whether this is due to the manual's guidance or her pre-existing skills and experience. Examples of this include JB's regular acknowledgements of time spent together, her reaffirmations of the purpose and ethos of the group, her sensitivity to group members' emotions, her ability to adapt the session according to mood and energy levels, and her willingness to embrace her own mistakes. Many of these behaviours are guided by intuition or instinct, and although they can be described in general terms, it may be difficult to communicate through a written form specifically what the facilitator should do.

Developing musical skills was a component of group facilitation which was noted by both JB and me. I have found it interesting to consider my own responses to the aspects of group facilitation which JB found musically challenging. From reading my notes and from my memory of being part of the session, I think that I found times when things went wrong musically a challenging and anxiety-provoking experience. This was partly because I was unsure about whether to step in and help, but mainly because I identified with the experience of making mistakes in similar situations. As an experienced musician and music therapist, musical competence is tied up with my sense of self, and part of me felt vulnerable and exposed when mistakes happened in a session which I was helping to run. At the same time, I did not feel at any point that musical mistakes detracted from participants' positive experience of the sessions; on the contrary, mistakes were a valuable way through which participants could observe the permissive and welcoming atmosphere of the group. In a sense, JB trusted the group to cope with her mistakes, and in doing so showed them that she could cope with theirs. The value of embracing mistakes is encapsulated by the previously mentioned feedback from a group member who said that it "gave others freedom", and is also mentioned by several participants in their interviews.

Overall, it seems that the manual provided JB with a resource that she found valuable and worthwhile in running the group. Although not totally comprehensive, the manual contained relevant and useful information, especially about how to get the group started. As time went on JB found that she needed the manual less and less, having taken on board and internalised its advice and also probably feeling more comfortable relying on her own experience and instinct. JB appeared to have a natural capacity for sensitivity and reflection which enabled her to effectively interpret and use advice in the manual relating to more esoteric concepts. JB was able to use the advice in the manual, harness her personal strengths, and embrace her challenges to provide an authentic and compassionate style of leadership which group members could relate to and identify with.

6.6 Conclusion

Chapter 6 presented the findings of the study in four separate sections. Firstly, the analysis of quantitative data from the outcome measures showed that there was no significant difference between scores before and after the interventions, although there were significant differences between people with and without a diagnosis of dementia. Secondly, the qualitative data from the group members was analysed and themes were identified. At baseline the themes related to their motivations and expectations for the group, their musical histories and their feelings about taking part in research. After the group, themes related to the participants' feelings about the sessions and the facilitator, and the benefits they felt they derived from attending. Three main categories of benefits were described: "in the moment", personal, and social benefits. A working model of group members' experiences was developed from the qualitative data, suggesting that a combination of personal and social factors contribute to the way any individual engages with the singing group sessions. Thirdly, the data about the feasibility of the study showed that recruitment into the study was successful and retention was good, with the outcome measures and research methods in general acceptable to the participants.

The procedure for monitoring the manual adherence was not found to be feasible, due to a lack of agreement between facilitator and researcher ratings. Finally, the evaluation of the CHORD manual found that the manual could be used successfully to plan and implement a singing group, and that the facilitator thought that it was a valuable resource. Suggestions for its improvement included more musical advice and ideas for keeping sessions fresh once the group was established. The facilitator felt more instinctive in her work and relied on the manual less as time went on. In the following chapter, synthesis of different forms of data is used to address each of the research questions in turn, and the implications of the findings of this study are considered in the broader context of research in this area.

Chapter 7: Synthesis and Discussion

7.1 Introduction

The following chapter presents a synthesis and discussion of the qualitative and quantitative data collected and analysed as part of the study. The synthesis process is one of the key elements of conducting mixed methods research (Tashakkori & Teddlie, 1998). The synthesis is structured around the research questions, and adopts two approaches outlined by O'Cathain et al. (2010): triangulation and the mixed-methods matrix. Throughout the synthesis and discussion, connections and points of comparison are drawn between the findings of this study and previous research in this area. Later in the chapter, the original contribution made by this thesis is outlined in the context of current research, and future directions for work in this field are suggested.

7.2 RQ1. Is the CHORD manual a useful resource for those wishing to run singing groups for people with dementia?

Data relating to the utility of the CHORD manual was collected from four different sources. The facilitator's interview and notes give insight into her opinion of the manual and how she described her own use of it. The notes made from reviewing session videos offer an observer's perspective on how the facilitator actually ran the group, and how the manual's information was translated into observable behaviour. The qualitative data collected from interviews and focus groups with the singing group participants indicate their views and experiences about the facilitator's interpretation of the manual. Finally, the manual adherence forms give some quantifiable insight into how the facilitator actually used the manual, and whether this changed over time, while also comparing the level of agreement between the facilitator's and observer's

assessment of manual adherence. The following section synthesises these four sources of data.

JB's overall impression of the manual was positive, and she found it accessible, particularly appreciating its brevity. She found that it provided comprehensive practical advice about how to get a group started. In her interview, she described how she found herself referring to the manual less and less as time went on, as she got used to leading the group. This gradual decrease in her use of the manual is reflected to some extent in the pattern of the manual adherence forms completed by JB and BD. However, there is quite a lot of variation in JB's assessment of her own adherence to the manual, and there is no consistent visible trend. It is not until the final two weeks of sessions that JB appears to be following the manual a lot less. It is also possible that two slightly different concepts are at work here. The manual adherence forms ask the facilitator how much she followed various types of advice in the manual, while JB's own reflection on the process indicate that she was referring to the manual less as time went on. However, it is reasonable to assume that she would to some extent remember and internalise the advice in the manual, so it may be that although she was referring to the manual less, she was still following the advice that it contained.

Any facilitator leading a singing group using the CHORD manual would inevitably bring their own areas of expertise and areas where they felt less secure. This was true of JB; she had counselling training, a lot of experience of working with groups, experience of people with dementia, but did not feel secure in her musical skills. This was an area of the CHORD manual which she felt could have been developed more. JB's assessment of her musical expertise was supported by my session notes written after observation of the videos, which mention some aspects of leading the group musically which JB found difficult, such as how to initiate songs. However, JB had other musical skills which were observed even in early

sessions, but which she may not have been aware of as they were instinctive. An example of this was the way JB would use her hand to conduct the group, with her hand position mirroring the contours of the music. Instinctive musical gestures such as this may be difficult to notice, describe and include in manuals like CHORD. JB felt that a facilitator who had been a musical expert but had no therapeutic experience or knowledge of dementia would have found it harder to lead the group using the manual. An interpretation of this is that she considered skills like compassionate and sensitive interaction with people with dementia to be more difficult to communicate through a written medium than musical skills. Her experience also suggests that lack of musical skills is not necessarily a huge drawback for a facilitator – but a lack of compassion or sensitivity almost certainly would be.

From observer's notes on JB's sessions, many aspects of her facilitation seem to have contributed to the creation of a session ethos that was safe and welcoming for participants. She regularly reminded the group that they were there to have fun and enjoy singing rather than to sing perfectly, and she modelled this in her own behaviour. JB recognised this aspect of the way that she led the sessions: "Even though I had some shortfalls musically, that hasn't stopped it being a great group, and has probably contributed to it being a great group because of […] being able to make mistakes and laugh it off". JB's assessment of her own leadership can be compared with the group members' perspectives, the majority of whom had a favourable impression of the way she led the group. They especially valued the way that she promoted a group atmosphere where people did not feel afraid to make mistakes, and several people reported that they felt she was "one of them".

To summarise, the singing group leader in this study found that the CHORD manual was a valuable resource. Although it did not contain absolutely all the information she required, she felt that the brevity of the resource was one of its

advantages, making it accessible and easy to use. Evidence from the participants and from research notes support JB's assessment that the group was successful. Discussion with JB about the manual and observation of the way she led the group highlighted the difficulty of communicating some types of skills through a written modality, especially therapeutic and musical skills. Comparison of evidence from the manual adherence forms and JB's own assessment suggested that JB was relying on the manual less as time went on, though this may have been because she had internalised the information it contained rather than because the information became less relevant. Overall, the manual was useful and relevant to JB and helped her to build on her particular set of skills. An issue in the evaluation of the manual is that we do not know how JB would have led the group without it. Consideration of what kind of facilitator may benefit most from using the manual is an issue for further evaluation of CHORD.

The present study provides data about only one facilitator's experience of using the manual in a particular context, so it is important not to over-conclude from her experience. However, the study findings raise questions about skill-sharing in the context of music therapy and dementia, the kinds of skills which can be shared, and the facilitator qualities which contribute to the success of the group. Skill-sharing in music therapy is not a new concept; music therapists have often been called upon to share insights and ways of working as part of their clinical roles; however, these activities have not been the subject of much discussion or academic enquiry until relatively recently. McDermott et al. (2018) use the term "indirect music therapy" to give examples of ways in which a music therapist might work through other professionals to share insight and skills in order to "optimize the benefits of music therapy" (p.259). Although the CHORD manual is mentioned in this article, it is unique among the other examples of skill sharing because it is the only one which does not involve face to face contact with the music therapist. There are questions about whether the manual is an appropriate

way to transmit this information, since there is no accompanying training which is intended to be delivered with the CHORD manual (such as a workshop or audio-visual material). Certain kinds of information or skills may lend themselves more easily to being communicated through written form. For example, JB felt that a facilitator who was musically skilled but did not have therapeutic experience would have found it more challenging to lead the group using the manual. Although the CHORD manual does not aim to teach therapeutic skills, its focus on sensitive and compassionate working with people with dementia is common to the basic principles of therapy training.

The concept of music therapy skill sharing carries an implication that the therapist has musical and therapeutic expertise which can be communicated to others to the benefit of people with dementia. However, JB's experience with leading the group suggests that her lack of musical expertise was an advantage in leading the group, since it was combined with an openness to sharing her challenges and a sense of security in her position as group leader. In this particular context, it is not clear that the group would have been more successful if JB had been an expert musician, as the majority of the group felt that they were on a level with her and felt comfortable making their own mistakes. There was a sense of equality between the facilitator and the group as they discovered the pleasures and challenges of singing together, which can be contrasted with the power dynamics which may threaten the successfulness of the music therapeutic relationship, if the music therapist's perceived musical expertise is seen as a source of difference and inequality between the therapist and client. Of course, any therapeutic relationship may be subject to unequal power dynamics, but this could be even more apparent when the focus of the relationship is playing music, an activity which is often perceived to be a domain restricted to those with the necessary skill, training and talent.

Power relations within music therapy has been a topic of discussion among the profession. Rolvsjord (2006) identifies a tendency in music therapy scholarship to focus on how the therapist's intervention affects the client, implying that the power in the relationship – the potential to cause change – lies within the therapist or their music, rather than with the client and their own resourcefulness. She goes on to suggest that we may "have failed to see that it is the client her/himself that uses music as a health resource" (p.8). The reason for raising this discussion is that it may be tempting for music therapists to see potential users of the CHORD manual as lacking the therapeutic skills and musical expertise necessary to deliver a successful singing group. In fact, a facilitator who feels secure enough to have a go at running a singing group despite lacking musical expertise may discover that they are able to provide an empowering experience of mutual discovery which an experienced facilitator could not. We could also speculate that there is a resonance between the experience of the novice facilitator and that of the person with dementia, who may both contend with the feeling of being unskilled and facing a daunting new landscape.

7.3 RQ2: How feasible would it be to conduct a full-scale RCT in a similar setting?

Data relating to the feasibility of the CHORD study were collected from four different sources. Information about recruitment, retention, attendance and the acceptability of the study design provide evidence about whether the strategies used in the study worked in the real world. Analysis of qualitative data from the participants and the singing group leader demonstrates whether they found the research methods acceptable. The actual outcomes from the quantitative measures used (HADS, QoL-AD, MiDAS and GDS) indicate whether these measures would be an appropriate choice for a full-scale RCT. Finally, the manual adherence assessment procedure tested a possible way of establishing treatment fidelity if the

CHORD manual were to be used to standardise the intervention. These four sources of data were synthesised to answer questions about the feasibility of various features of a potential RCT study design.

7.3.1 Recruitment and retention

The recruitment strategies used included approaches to local press, social media, contact with relevant charities and organisations, and posters in the local area. These strategies were successful, and the retention of participants in the study was generally good. The two participants who dropped out did so because the kind of singing the group was doing was not to their taste; they were accustomed to a more formal kind of choir, with a focus on quality of singing. Their withdrawal from the study demonstrates the difficulty of structuring and implementing an activity so that it is acceptable and enjoyable for everyone who might attend.

The decision to include participants who did not have a diagnosis of dementia in the study was made partly for pragmatic reasons, in order to boost numbers and due to the difficulty of confirming diagnosis, but also because it was felt to be important to include people who might not yet have a diagnosis of dementia but who were concerned about their memory. Examination of the quantitative results revealed unsurprisingly that people with a diagnosis were quite different to people without one, in terms of the central tendency and spread of their QoL-AD and GDS scores. In a future RCT, in order to maximise the chance of detecting an effect due to group singing, it would be important to ensure that the sample was as homogenous as possible, potentially meaning that inclusion criteria should be narrowed to only recruit people with a diagnosis of dementia, perhaps at a mild or moderate stage of the disease. However, it is ethically important to consider that attending a singing group may be helpful and supportive for people without a diagnosis but coping with the reality of mild cognitive impairment. Furthermore,

singing groups in the real world frequently do not exclude people without a diagnosis of dementia from their membership.

7.3.2 Choice of instruments

The outcome measures were feasible in the sense that most people were able to complete them, although some people with more advanced dementia had difficulty with some of the questions, especially the more abstract ones in the QoL scale. One person with dementia had deteriorated quite a lot over the course of the study, which meant that their carer responded to more of the questions on their behalf at time 1 than time 0. This may have affected results, since there is evidence that carers tend to rate the person with dementia's quality of life lower than their own self-rating (Hoe, Katona, Orrell, & Livingston, 2007). In a future study, it would be preferable to collect both carer and self-ratings for quality of life at both time points. This allows the ratings to be combined and compared. The outcome measures appear to have been acceptable to participants; no-one showed any distress while completing them, and no-one indicated during their interview that the measures had been unpleasant or too burdensome. In order to achieve a higher completion rate with the MiDAS-SR forms, it would probably be necessary to have more researchers available to assist participants as some of them seemed to find the MiDAS-SR form conceptually difficult to grasp. Overall, participants tended to have a positive or neutral attitude towards research, with most saying either that they didn't mind taking part in the study, or that they appreciated it because they felt as though they were helping other in a similar situation.

Although the study was not powered to detect significant change, we can look at the tendencies within the results to make suggestions about the suitability of these measures for future studies which are sufficiently powered. Despite the evidence from the qualitative data that people experienced benefits from attending the group, the analysis of the quantitative data for the group did not show any

tendencies towards improved mood or quality of life which would reflect these changes. It is possible that the outcome measures which were used were not sensitive enough to detect the kind of changes which people experienced from attending the group. Based on analysis of the qualitative data, it seems likely that this is because the changes, such as improvements in mood and memory, did not last long enough to have an impact on mood and quality of life as measured by GDS and QoL-AD. Additionally, as discussed in Chapter 6, items such as "life as a whole" proved difficult to answer, while others seemed less potentially relevant to the singing group experience (money, living situation, ability to do chores). Any future RCT would need to consider whether and how standardised, clinically acceptable outcome measures could be used to detect these kinds of changes.

7.3.3 Possible control conditions

A suitable control condition would be an integral part of any future RCT of group singing. Evidence from the present study may offer insight into potentially suitable conditions. Many different components determine the parameters of the group singing experience (social, psychological, musical etc.) and we do not know how the potential effects of attending a singing group are weighted between each component. For example, does the musical experience of singing together convey more of the benefit than the opportunity for social interaction? This is important from an economic point of view because there would be no value in paying a singing group facilitator to lead a group when the same benefits could be conveyed by an unstructured social gathering, requiring no facilitation.

There are several possibilities for a control condition:

1) Group singing could be compared with no intervention, or "treatment as usual". The disadvantage of this approach is that if any difference emerged between the two groups, it would not be possible to tell whether this was

due to a real difference or a so-called "Hawthorne effect", or to isolate the particular effect of singing as opposed to other activities.

2) Group singing could be compared an active control intended to provide the opportunity for social stimulation. This could either be a structured activity (e.g. a book group) or an unstructured one (e.g. a coffee morning). This would to some extent isolate the effects of singing from those produced by social interaction, although the similarities and differences between the types of social opportunity afforded by the activities would have to be carefully considered. Davidson and Almeida (2014) used a quiz as the control activity in their study of group singing and dementia, with the rationale that it included many of the same elements of questions, informal chat and entertainment that singing would also entail.
3) Group singing could be compared with another music activity, such as music listening or music therapy. This approach could allow comparison of the effectiveness of different music interventions for different populations and needs, and help to identify how the available resources may be used most efficiently to the benefit of the greatest number of people. For example, Werner et al. (2017) compared the effects of music therapy with recreational group singing for depressed nursing home residents and found that music therapy decreased symptoms of depression more effectively than singing. A similar approach in a study of community singing could help to identify which people with dementia may find singing meets their needs and which would benefit more from other interventions such as music therapy.
4) A further possibility would be to have more than one control condition. For example, group singing could be compared to an active social control as well as treatment as usual. This approach allows for comparison between the three groups, and could provide data about singing-specific effects as well as social interaction. However, in practice an adequately powered

three-armed trial would difficult to implement due to the large sample size required.

The findings from the present study suggest that it would be productive to compare group singing with an active social control condition. Evidence from the qualitative data gathered during this study showed that the social side of the group was very important to many of the participants, who derived support and companionship from the group. It could be speculated that any social activity could provide the same level of social support more cheaply and efficiently than a singing group. Singing may convey other benefits in addition to the social aspects (e.g. mood, cognition), but it is also possible the activity of singing itself played a role in forming the social connections within the group. One participant suggested that the shared activity of singing and working together to create something had a special quality that could facilitate social bonding. This theory is supported by previous research, which has shown that group singing can form social connections faster than other non-musical group activities (Pearce, Launay, & Dunbar, 2015) and that behavioural and hormonal markers for social bonding were higher in a group of adult singers after singing than after chatting (Kreutz, 2014). However, research has not yet explored the implications of these findings for people with dementia and their carers. Pearce et al. (2015) suggest that although non-singing groups eventually reach equal levels of social bonding, the process is accelerated by singing. This finding has particular relevance for people with dementia as the acceleration in social bonding may compensate for any delay in forming bonds caused by memory loss and cognitive impairment.

In a future randomised controlled study, a control condition could be a social activity with no singing, such as a coffee morning or a book group. Any differences observed between the groups could then be attributed specifically to singing, rather than just to attending a group activity. If this approach was chosen,

it would be important to include a measure of interpersonal interconnectedness such as the "Inclusion of Other in the Self" Scale (Aron, Aron, & Smollan, 1992), but it is likely that any such measure would require adaptation for use with people with dementia (and thus would need to be psychometrically validated for use with this population). It may also be important to consider the role that a facilitator plays in forming social connections; non-musical activities with a facilitator or leader may therefore be more comparable with group singing.

7.3.4 Treatment fidelity

To enhance the rigour of any future RCT, it would be important to ensure that the content and structure of sessions was known and recorded, and that there was some way of assessing "treatment fidelity"; that is to say, ensuring that the singing group activity is delivered consistently and that, if there is more than one facilitator, they are doing more or less the same thing. Establishing replicability of all parts of the trial is a key part of RCT research design. The CHORD manual is a potential tool for standardising the intervention and ensuring it is replicable, while the manual adherence form developed for this study was shown not to be an effective way of establishing whether the facilitator followed the manual. This does not mean that the CHORD manual is unsuitable for standardising the singing intervention within the context of an RCT, but a different way of assessing adherence would be necessary. It is inherently difficult to measure adherence to a manual which describes an intervention that is flexible and adaptive.

The challenge of manual adherence has been explored by Rolvsjord, Gold, & Stige (2005) who discuss the benefits and drawbacks of a manualised approach to resource-oriented music therapy for the purpose of conducting an RCT. Their manual is based on a number of principles for the music therapy approach, divided into four categories: 1) essential and unique (to this approach) 2) essential but not unique 3) acceptable but not necessary and 4) proscribed principles. The manual is

therefore similar to the CHORD manual in that it can be applied flexibly, but differs in that it has been created specifically for an RCT to reflect an approach which is already established, rather than representing a guide for practitioners. Their proposed approach for establishing treatment fidelity involves a Likert scale on which the therapist is asked to rate their adherence and competence concerning each principle. Although this approach is not dissimilar to that developed in the CHORD manual adherence form, the clarity of the principles provides a stronger framework against which the facilitator/therapist can assess their own performance. It may be possible to combine the data collected during the present study with this approach to develop a more effective manual adherence formal. Analysis of the CHORD manual has provided data about the activities, facilitator behaviours and attitudes which can lead to successful singing group sessions, and analysis of interviews has provided complementary data about what leader qualities participants appreciate; these could be termed "principles" for group singing in dementia. It would be possible to develop a more straightforward, inventory-based checklist from this data, focusing only on observable characteristics of the session, which would leave less room for interpretation and could be completed by an observer more easily. An approach like this would be suitable for ensuring that the singing groups were delivered consistently, while still allowing facilitators freedom and flexibility to run the groups according to their personal style, and would also be more straightforward for the facilitator to use.

7.4 RQ3: What is the experience of the CHORD group members? What benefits, if any, do they experience from attending the group?

Answering this third research question through the synthesis of qualitative and quantitative data is complex, since the results are divergent. Through the

qualitative data, participants' experiences of attending the group and insight into what the group meant to them is represented. From these results, it is apparent that nearly everyone who attended the group felt that it was beneficial for them in some way. The video footage and notes from the sessions demonstrate the camaraderie and bonding between the participants, and the MiDAS-SR forms generally show very high ratings for their response to and engagement with the sessions. In general, participants' positive experiences of attending the group are not reflected in the overall trends in the GDS, HADS and QoL-AD scores. However, change on an individual basis may be observed by comparing qualitative and quantitative results for each participant.

In order to address the complexity and divergence in the data relating to this research question, the data has been analysed using a mixed-methods matrix (O'Cathain et al., 2010). This approach allows for comparison between cases by showing qualitative and quantitative results in a table. In the matrix (Table 7:1) data from people with dementia and their supporters are presented in pairs to allow for comparison between their results. Only findings from participants who completed both pre- and post-group outcome measures and interviews are included (n=17). For the people with dementia, change in GDS and QoL-AD between the two time points is given. A negative change in GDS score represents fewer reported symptoms of depression after the group, while a positive change in QoL-AD score represents a higher reported overall quality of life after the group. For supporters of people with dementia, change in HADS score is given, with a negative score representing fewer overall symptoms of anxiety and depression. Codes referring to benefits reported by participants are also provided.

Table 7:1: Mixed methods matrix

ID	Age	Gender	Status	Musical experience	Change in quant scores			Qualitative benefits reported		
					GDS	QoL-AD	HADS	In the moment	Personal	Social
1M	66	F	Has been to GP about memory problems, no diagnosis	Enjoys listening, describes self as unmusical	0	4 [0]		Uplifting, feeds your soul	Look forward, changed perspective on dementia, changed attitude to music, improved mood	Shared problem, sharing resources, cameraderie, relationship benefits
2M	91	F	Diagnosed with dementia	Has played piano all her life	3.43	-0.5 [0]		Enjoyment of singing	None reported	None reported
3M	87	F	Diagnosed with dementia	Experienced instrumentalist and choral singer	3.46	-6 [0]			More talkative	
3S	80	M	Husband and carer of 3M	Experienced choral singer			11	Uplifting.	Change in attitude to music, ignites memory	Cameraderie, encouraging each other, social bonding.
5M	76	F	Diagnosed with vascular dementia	Learned instruments at school, sung in choirs throughout life	2	1 [0]		None reported	Changed perception of dementia, helped accept diagnosis, ignites memory, meaningful occupation	Shared problem
6M	74	F	Diagnosed with dementia	Regular singing in community choirs	3	-9 [0]		Uplifting	Changed attitude to music, looked forward to it, improved mood	
7M	72	F	No diagnosis of dementia, memory affected by other health issues	Piano lessons as child, some singing in recent years	0	-4 [-1]		Uplifting, enlivening	Changed attitude to music, improved mood, keeping things going, looked forward to it	Social bonding
8M	84	F	No diagnosis of dementia	Used to listen to music and go to concerts, less often recently	0.93	1.08 [0]				Social bonding
10M	89	M	Diagnosed with dementia	Regular singing in choirs until a few years ago	1.06	-10 [-2]		Enjoyment of singing	More music outside the group, improved mood	Social bonding
10S	82	F	Wife and carer of 10M	Used to sing at school, used to play the piano but has not done for a long time			2		Improved mood, changed perspective on dementia	Sharing resources
11M	69	F	Cognitive problems after stroke	Enjoys listening, says she can't sing	0	0 [0]			More confident, physical benefits, using cognitive skills, ignites memory, changes in attitude to music, more music outside the group	Cameraderie, relationship benefits, sharing resources, social bonding
11S	48	F	Daughter and carer of 11M	Enjoys listening to music			-7		Changes in attitude to music, more music outside the group	Support for carers, sharing resources, shared problem, camerarderie, relationship benefits
12M	64	M	Diagnosed with Alzheimer's disease	Enjoys listening, describes self as unmusical	0	-1 [0]		Enjoyment of singing	More music outside the group, ignites memory	Support, social bonding
12S	61	F	Wife and carer of 12M	Enjoys listening and casual singing			-3	Enjoyment of singing		Sharing resources, support for carers, social bonding
13M	81	F	No diagnosis	Experienced choral and solo singer	-1	-2 [-1]		Enlivening, enjoyment of singing	Look forward to it, more confidence, found music again, self-esteem boost	Social bonding, encouraging each other, camaraderie
14M	88	F	Diagnosed with Alzheimer's disease	Enjoys listening, experience of singing and playing the piano	3.79	-2.17			Found music again	Social bonding
16M	67	F	Diagnosed with frontotemporal dementia	Used to sing in community choir; gave up after diagnosis	-2	3.25 [0]				Social bonding, relationship benefits

7.4.1 Changes in mood

Several findings of interest emerge from the comparisons in the matrix. Four people with dementia or memory problems and one supporter had improved mood as one of their reported qualitative outcomes. However, this was not reflected in the GDS scores of the participants; in two cases the scores remained the same and in two others cases more symptoms of depression were reported after the group. Similarly, the supporter who qualitatively reported improvements in her mood had a higher HADS depression score after the group than before it. Conversely, none of the participants who had fewer symptoms of depression after the group (as measured by GDS or HADS) reported improved mood in the qualitative data.

There are several possible reasons for this discrepancy between qualitative and quantitative data about participant mood. It is possible that when participants talk about improvements in their mood, this is conceptually different to the variable which is measured by GDS. When participants said that they felt happier or uplifted after the sessions, they may have been referring to a short- or medium-term improvement in their mood, lasting perhaps a few hours after the session, or until the next day. The GDS, on the other hand, asks respondents to consider how they have been feeling over the past two weeks. It seems possible that short and medium-term improvements in mood caused by the singing group would not have an effect on overall symptoms of depression if they are relatively short-lived compared to the timeframe considered by the GDS.

Relatedly, another possible explanation is that the participants who reported fewer symptoms of depression may not have consciously noticed this change if the improvement was subtle and took place across several weeks. Furthermore, even if they did notice that their mood was better, there is no reason that they would necessarily associate the improvement with their attendance at the singing group.

In the interviews and focus groups, participants were asked whether coming to the groups had any benefits for them, which may have prompted them to focus mainly on the time during and immediately after the sessions. Feeling better or happier straight after the session would be a more apparent benefit than a general improvement in mood. It should also be noted that the study took place over only a few months; it could be argued that dramatic and noticeable improvements in mood would not be expected within this timeframe.

7.4.2 Social benefits

An additional point of interest is that most participants reported social benefits from attending the group, such as the feeling of camaraderie and bonding and the opportunity to share resources and support each other. If the group did have an impact on the social lives of the people who attended, this might be reflected in the QoL-AD question which asks about the respondent's relationship with their friends. For this reason, the overall change in individual scores from the social domain of the QoL-AD is included in the table (the value in square brackets following the overall QoL-AD change). In fact, the majority of the participants gave the same answer to the question about their relationship with friends before and after the group. This was an area which was generally rated highly, with all participants saying their relationship with friends was good or excellent at time 0. At time 1, two participants who had previously answered "excellent" changed this answer to "good" and one participant went from "excellent" to "fair". In fact, despite most participants reporting social benefits from the group, these benefits were not reflected in the QoL-AD item most likely to detect them. Similarly to the GDS, this lack of change may be because the instrument is designed to measure quality of life in a broad, overall sense, and small changes which occur over a relatively short space of time do not have enough of an impact to affect the way that participants felt about their social relationships in their life in general.

The same discrepancy between qualitative and standardised quantitative results is reflected in the results of other research into group singing and dementia, raising questions about what characteristics of this particular activity make it difficult to capture the benefits quantitatively. Researchers present various explanations for this phenomenon. Camic, Williams and Meeten (2011) suggest that lack of change in standardised quantitative measures might indicate that the singing group helped people with dementia to maintain their stress, anxiety and quality of life at stable levels, when in fact their condition would make deterioration likely. Davidson and Fedele (2011) consider that group singing's impact may have immediate rather than long-term benefits, or that the outcome measures they chose were "too general and not sufficiently specific to the benefits associated with the singing experience" (p.419). However, research using study-specific measures focusing on shorter-term changes may show more promise, such as the rating scales for variables such as mood, lucidity, and agitation used by Davidson and Almeida (2014), although the lack of standardisation means the results are not generalisable. A further limitation is that in all these studies, including the present one, sample sizes are small and the work is described as exploratory. Identifying (or developing) a way of capturing the benefits of group singing would make a major contribution to the ultimate goal of proving its effectiveness.

The importance of the social aspect of the singing sessions which was reported by a number of participants in the present study is mirrored in the findings of other studies. For instance, the carers in the study by Camic et al. (2011) appreciated the opportunity to meet other carers who were in a similar situation within a setting where the focus was not on medical care or illness; in the present study, the value of knowing that everyone had a "shared problem" was reported. Unadkat, Camic and Vella-Burrows (2016) explored the impact of singing on the relationship between couples where one has a dementia diagnosis, and found that the opportunity to take part equally in a shared activity had a strengthening effect for

their relationship as a couple and also between people who were part of the singing group. For attendees at "Singing in the Brain" in the study by Osman, Tischler and Schneider (2014) the groups had a positive impact on the relationship between care partners, on the social inclusion of people with dementia, and on the support network formed between carers. These findings suggest that singing groups potentially have multiple interrelated social benefits for people with dementia and their carers. Furthermore, since group singing is often described as a shared activity which encourages equal participation in the face of cognitive impairment, there is a suggestion that singing has inherent characteristics which facilitate social bonding, which is supported by the previously-cited research of Pearce et al. (2015). No study of group singing and dementia has yet used a standardised measure of social inclusion or connectedness; this may be a direction which is worth exploring.

7.4.3 Case vignettes

In order to explore the experience of group members in more detail, the following section presents three case vignettes. These are based on the quantitative data, the interview and focus group data and on the observed responses of the person in question. The group members included in these case vignettes have been selected because they provided particularly full and rich data sets and because their responses to the group are interesting and varied. Although they are not intended to be representative of the whole group, the participants described in the vignettes provide examples of the range of people who took part, since they include people dwelling in the community and in sheltered housing both with and without a diagnosis. The vignettes provide a means of illustrating these group members' experiences, and their inclusion is intended to provide a more realistic and comprehensible picture of what it was like to be in this group for these particular individuals. Names have been changed and other identifying details have been changed or removed.

Vignette 1: Steve and Joanne

Steve is in his early 60s and lives with his wife, Joanne. He was diagnosed with young-onset Alzheimer's disease about six months before he started attending the singing group. Although he enjoys listening to music and has done all his life, he thinks of himself as unmusical and bad at singing because of comments made by a teacher when he was at school. Joanne enjoys singing but has never been in a choir.

When they saw the advert for the study, Steve and Joanne were motivated to take part because they thought it was something they would enjoy, and they would like to have a go at something new. Since Steve's diagnosis, they had received lots of information about services and activities which were aimed at people with dementia, but in reality they had found that these were either difficult to access or not really suitable. They had also heard in the media that singing was beneficial for people with dementia. They were motivated to take part in research as they saw it as an opportunity to make things better for other people with dementia. However, they emphasised that Steve would not have wanted to take part if cognitive testing had been part of the study, since he had found this process while he was being diagnosed very unpleasant. He also said that although he had been invited to take part in some studies shortly after diagnosis, he had needed time to process the diagnosis before he felt ready to participate.

Before attending the singing group, Steve's baseline score on the Geriatric Depression Scale was 1 and his Quality of Life in Alzheimer's Disease Score was 48, indicating no depression and high quality of life (the maximum score is 52). Joanne's score on the anxiety component of the HADS was 11 and on the depression component it was 4, indicating moderate anxiety and no depression.

Steve and Joanne were regular attendees at the group. They suggested songs that the group might like to sing, and quickly formed friendships with the other group members, with whom they sat and chatted during the refreshments after the sessions. They both completed MiDAS-SR scales most weeks, and their ratings were consistently very high, scoring above 90 in almost every domain, indicating that they were both very engaged in the sessions and enjoying them a lot.

In the focus group and interview, Joanne and Steve were enthusiastic about the group and its benefits. They recounted moments of the group that had been particularly memorable for them, especially amusing moments. Steve said that he found it very satisfying that he could remember the melodies and words to lots of the songs without difficulty, and it seemed to have stimulated a renewed interest in listening to music outside the sessions for him. Joanne felt that the social side of the group was extremely important, especially for carers, who were able to informally share resources as well as friendship and support. She also described the group as the best and most supportive thing that she and Steve had found since his diagnosis. After attending the group for ten weeks, Steve's GDS score was unchanged and his QoL-AD score had decreased by a single point. Joanne's HADS depression score had increased by one point to 5, but her anxiety score had decreased by four points, to 7. They both intended to keep coming to the group if it was to continue.

Vignette 2: Karen

Karen is in her late 60s. Although she doesn't have a formal diagnosis of dementia, she has noticed problems with her memory over the past few years, which have also been picked up by her friends and family. Karen has told her GP about her concerns, but on screening tests she scores well above the threshold for a dementia diagnosis. She finds this frustrating as she feels very strongly that something is not right. Karen wanted to join the singing group when she saw a poster for the study

as she has always wanted to be in a choir despite describing herself as having a terrible voice and being unable to sing. Before attending the singing group, Karen's baseline score on the Geriatric Depression Scale was 3 and her Quality of Life in Alzheimer's Disease Score was 35, indicating no depression and moderately high quality of life.

In the sessions, Karen was a lively presence who made many suggestions and contributions to the life of the group. She threw herself into singing enthusiastically, and encouraged other people to join in too. She preferred singing new and different songs to repeating the same ones each week. Karen's husband, Geoff, did not intend to join her in coming to the sessions. However, half way through the study he decided to try the group out, and enjoyed it so much that he came to almost all of the rest of the sessions. Karen completed MiDAS-SR scales for all but one of the sessions, and her ratings of each domain appeared to increase over time, indicating that she was finding herself more engaged and responsive to the session as time went on.

After attending the sessions for 10 weeks, Karen said that she found the experience of singing "uplifting" and said that it "feeds your soul". She said that coming to the group had changed the way she felt about dementia; she had expected that the overall mood in the group would be quite down, but that it had completely defied her expectations. Spending time in the company of people with dementia had made her feel differently about the prospect of a dementia diagnosis and she said that it seemed less scary. For similar reasons, she also appreciated the social support provided by a group of people who had a shared problem. She felt that the group had given her support at a difficult time in her life. She also thought that once Geoff started coming to the group, this shared activity had benefits for their relationship. Although Karen still said that she was a bad singer with a terrible voice, her confidence about singing did seem to have improved

because she said that she was thinking about joining another community choir. She was also grateful to the group facilitator for having a relaxed attitude to the control of the group; Karen felt that a tendency to take over a bit was part of her own personality, and JB had been comfortable enough to allow this to happen and relinquish her own control. After the study, Karen's GDS score was unchanged but her QoL-AD score had increased by four points to 39.

Vignette 3: Emily

Emily is in her 80s and lives in a flat in the sheltered housing setting where the singing group takes place, with support from carers. She has a diagnosis of dementia as well as other health problems which affect her mobility. Emily has had a musical life, having had instrumental lessons at school and sung in choirs throughout her life, although she doesn't think of herself as musical. Her enjoyment of singing songs she knows was her main motivation for joining the group. She was also particularly interested in taking part in the study, as she had been involved in a lot of research during her career as a healthcare professional. Her only concern for the sessions was that there would be difficulties in the group dynamic, such as one person dominating the sessions. Before the sessions started, Emily's score on the GDS was 11 and her QoL-AD score was 27, indicating symptoms of depression and moderate quality of life.

Emily was a regular attendee at the group, although at first she did need to be reminded about the session earlier the same morning. During the sessions she normally sat with her fellow residents, although she did reconnect with one of the other group members whom she used to know but had lost touch with. She said at the end of the study that she had enjoyed the group and the fact that it gave her something to do but that she didn't have any strong feelings about it. An aspect of the sessions which she enjoyed less was playing the percussion instruments because she found it childish. Her fears about some personalities taking over were

not realised. Additionally, she found that spending time in a group with other people with dementia had helped her accept her own diagnosis. Previously, her feelings about the condition had been based on her professional experience and medical knowledge, so being part of this group seemed to have been helpful. She was positive about taking part in research and said that it had given her a feeling of power. After attending the sessions, Emily's GDS score had increased by 2 points to 13, and her QoL-AD score had increased by 1 point, from 27 to 28. She did not complete many MiDAS-SR scales, but the ones she did complete showed moderate and occasionally high ratings across the five domains.

Discussion of Vignettes

The three vignettes presented here give three contrasting accounts of being in the group. There are various points of comparison between them. Steve, Joanne and Karen were all extremely enthusiastic about the sessions, while Emily was fairly positive but not to the same extent as the others. The three group members in these vignettes who lived outside the sheltered housing setting seemed to derive more social benefits from being in the group than Emily, perhaps because they felt there was more opportunity to meet new people. For Emily, group singing was something she had done all her life, whereas for the others it was a new experience and so perhaps more likely to make an impression on them. It is interesting that although Karen did not have a diagnosis of dementia, and Emily did, they both came to the sessions with a preconceived notion of what people with dementia were like which was challenged by their actual experience in the group. In both cases, this experience seemed to help them accept their different situations. The group seemed to reduce the stigma of dementia for these two individuals.

Before the sessions began, Steve reported very high quality of life scores and virtually no symptoms of depression. It is not surprising that although the group

seemed to have many benefits for him, these scores did not change. His wife, Joanne, did show an overall improvement in her HADS score; although her depression score remained fairly stable, her anxiety score decreased by four points. Karen rated her quality of life more highly after attending the group. However, Emily's high depression score increased over the course of the group while her fairly low quality of life score increased by one point. It is not possible to comment on whether these individual changes were related to attending the group or not. However, the examples of these individuals highlight the fact that even within this fairly small group there was a wide variation in baseline quality of life, depression and anxiety scores as measured by the chosen scales. The potential of these scales to detect any changes which occurred over the course of the sessions is also limited by the starting point. For example, Steve rated most areas of his life as "excellent" at baseline so his results show a ceiling effect. In a similar study which took place over a longer period of time, maintaining quality of life with a dementia diagnosis could represent a worthwhile outcome for those who begin with a high QoL score in the first place. The extent to which these participants valued and enjoyed the group seems to be reflected in their MiDAS-SR scores too; very high scores in the cases of Steve, Joanne and Karen, who were all very enthusiastic about the sessions, and moderate scores in the case of Emily, who was more measured in her response to the group.

The diversity of responses to group singing among this small sample of group attendees brings into focus the difficulty of making general claims about the benefits of this activity. De Medeiros and Basting highlight this point, writing of cultural arts interventions "that because individuals vary in their tastes, interests, levels of engagement, and other deeply personal characteristics, people are likely to be affected in very different ways, even when participating in the same intervention" (2014, p. 345). The different group members had different expectations of the sessions and different responses to them, and that these were

driven by their previous experiences and expectations. It would be possible to design a study with narrow inclusion criteria and focus on a particular problem; for example, a singing group for people with mild dementia and depression. However, it seems as though the strengths of a group such as this lie in social integration between different people and focus on a shared activity rather than on a diagnosis or specific symptom of dementia. A study which was driven by demonstrating effectiveness of group singing by strictly limiting inclusion based on symptoms might not be representative of real-world singing groups.

7.5 RQ4: How can the results of this study be used to inform the theory, practice and research methodology of music in dementia care?

To consider the implications of the present study, this discussion moves away from synthesis of qualitative and quantitative data and towards consideration of the overall impact. It takes into account the findings from the two literature reviews as well as those from the study, and places these in the context of recent research in this area as well as research which is currently taking place.

Firstly, the findings of the study provide data about the experiences of people with dementia who attend singing groups. The analysis of qualitative data was used to develop a working model of the participants' experiences (see 6.3.4), which contributes to our theoretical understanding of how people benefits from singing groups. These findings can be compared with other models which have been developed and used in this area; for example, the "group singing model in dementia for couple dyads" (Unadkat et al., 2016) and the "Senses Framework" (Camic et al., 2011; Nolan, Ryan, Enderby, & Reid, 2002). Understanding how the different components of group singing work together and their underlying mechanisms will help to develop relevant and effective interventions. The

findings from the two literature reviews contribute to more general theory about the benefits of music for people with dementia, and whether the choices made by researchers are an accurate reflection of the way music is used in practice. Specifically, they question the dominance of measures of symptom reduction in research, as there are many other potentially relevant facets of music in dementia care.

The broader relevance of these findings speaks to questions about the meaningfulness of measuring arts-based experiences. Perhaps the difficulty of measuring the impact of music upon people with dementia should not just make us redouble our efforts to find the most appropriate tool, but should also provoke questions about the appropriateness of this quest. Have we been blinded by the medical model into focusing on this approach to the exclusion of all others? Is expecting the effect of music, with all its cultural, social, psychological and neurological dimensions, to be distilled into a single measure not only unrealistic but reductionist? De Medeiros and Basting (2014) emphasise the limitations of a "one size fits all" approach to dementia research, advocating that the quality of a study should not be judged on whether it adheres to the strictures of a randomised controlled design, but on the appropriateness of what is measured. They argue that expecting arts-based interventions to be quantifiable in the same way as a medical treatment for dementia is unfeasible, because the mechanism of action through which arts interventions convey benefit is completely different, and because medical treatments do not carry the same potential for a "transformative experience".

Secondly, the evaluation of the CHORD manual carried out in this study has implications for practice. It demonstrates that the manual can be used to inform the delivery of group singing for people with dementia, and that the information contained in it is relevant and useful. Given the growing popularity of singing

groups, access to a manual which has been evaluated in a real-world context will be beneficial to people who wish to attend singing groups, and will enable potential facilitators to undertake their role with more confidence. Increasing the pool of resources available to facilitators may ultimately lead to increased provision of groups for people with dementia to attend.

The evaluation of the CHORD manual in combination with the facilitator's experience of leading the sessions and the participants' response to them suggests that lack of facilitator experience is not necessarily a drawback, because it fosters a sense of equality and comradeship between the facilitator and the people in the group. From a pragmatic point of view, the goal of making appropriate musical interventions more easily accessible to people with dementia is aided by the suggestion (supported by the findings of this research) that facilitators of certain groups need not be experts in order to provide meaningful and relevant musical support for people with dementia. The widens the pool of people from which potential facilitators may be drawn. However, there is an imperative to match the level of training, skill and experience according to need. Novice facilitators trained through the CHORD manual may provide "good enough" singing group sessions for people with dementia and their carers. This has important implications for practice through capacity building; a singing group run by an amateur musician using the CHORD manual potentially frees up a music therapist who might otherwise have run the group, leaving them to work with those who need their skills and training the most. There is an argument that skill-sharing practices like these could take work away from music therapists, but with current provision of music therapy in the UK equivalent to 30 seconds per week for each person with dementia, it is clear that there is no shortage of clientele (Schneider, 2018). However, we must be mindful that a manual is not a substitute for face-to-face training, and although it may be useful for areas such as group singing, there are

other aspects of skill-sharing which are not suitable for communicating in written form.

Thirdly, the feasibility element of the study, in combination with the literature reviews, contributes to our understanding of research methodology. The successful recruitment procedure, high retention rate and the acceptability of the outcome measures suggest that similar methods could be employed in future studies. The evaluation of the manual showed that it is an appropriate tool for a group facilitator to use, but the manual adherence procedure which was used in this study proved unsuitable, and an alternative would need to be developed if the manual was to be used in an RCT to standardise the intervention. The discrepancy between the qualitative and quantitative findings are similar to the results from previous studies and provide further evidence of the challenges of successfully capturing the benefits of group singing (Camic et al., 2011; Davidson & Fedele, 2011). More broadly, the discussion of the challenges of measurement in this specific study along with those highlighted by the literature reviews form part of a body of critical scholarship relating to the evaluation of the arts in health. Gray, Evans, Griffiths, & Schneider (2018) identify the dominance of narratives about evidence-based practice and methodological rigour within this field, and point out that although alternatives to quantitative methods have been employed in this area, these are usually with the aim of understanding experiences or mechanisms at play, rather than evaluation of the outcomes or effects of arts and dementia activities.

The work described in this thesis has taken place at a time of rapid development in research into musical interventions for people with dementia, with new findings published regularly and several exciting studies on the horizon. The prevalence and focus of these studies demonstrates that the findings of the present doctoral research are relevant to current work in the wider field. One recent study, the

Remini-Sing project (Tamplin, Clark, Lee, & Baker, 2018), has several clear parallels and points of comparison with the CHORD study: it was also a feasibility study of a group singing intervention for home-dwelling people with dementia and their carers, and like the CHORD study, the researchers found no statistically significant change on the selected outcome measures, despite a very positive response to the group being reported using qualitative methods. The primary outcome measure was the Quality of Patient-Carer Relationship Scale (QCPR) but the researchers suggest that in a future, larger-scale study they would select different outcome measures and would include a measure of social connectedness as they recognise the potential of the singing group to contribute to social bonds not just between care partners but within the members of the group as a whole. These conclusions are similar to those of the present study, and highlight the perceived social impact of group singing, as well as the challenges of successfully measuring these impacts amongst a diverse group of community-dwelling people with dementia. A feature of the Remini-sing project was that it sought to extend the impact of the singing sessions by creating three personalised playlists for reminiscence, relaxation and reduction of anxiety for each participant. Since one of the potential problems of evaluating weekly group singing is that it does not have enough of an impact on a participant's day-to-day life to effect a change in terms of measureable outcome, the playlist approach offers a relatively straightforward way to maximise the benefits of attending group singing and enable these benefits to carry on at home.

The CHORD study raised questions about how musical interventions of various types differ in their effects. The Music Interventions for Dementia and Depression in ELderly care (MIDDEL) study has recently published its protocol and is currently being implemented (C. Gold et al., 2019). This is a multinational project with a cluster RCT design which aims to compare the effects of group music therapy (GMT), recreational choral singing (RCS), both interventions, and neither,

on depressive symptoms among people with dementia resident in care homes. In the study protocol, the researchers hypothesise that GMT and RCS differ in their underlying psychological, social and biological mechanisms, and hence their specific effects may be different. For example, emotional processing may be a more important component of GMT, and therefore reduction of agitation and neuro-psychiatric symptoms is a more likely outcome. On the other hand, the physical effects of singing and movement may be important in both GMT and RCS, but more pronounced in RCS. The authors predict that both GMT and RCS will lead to reduced symptoms of depression through a combination of emotional, biological, social and cognitive mechanisms, and that for participants who receive both interventions, synergistic effects may occur. The findings from the MIDDEL project will therefore offer insight into the different pattern of benefits offered by RCS and GMT, and potentially an increased understanding of the mechanisms underlying these interventions. These results may provide evidence that will support referrals to different music interventions in a targeted way, according to the specific needs of individuals with dementia. Another feature of this study is that the participants will all have symptoms of at least mild depression, and the primary outcome measure is the Montgomery-Åsberg Depression Rating Scale (MADRS). This potentially means that the sample will be more homogenous than that of the CHORD study, and consequently if the intervention has its intended effect, the depression scale will detect a measurable change over the course of the study.

The CHORD study has also raised questions about what might be suitable control conditions for music-based interventions. Although it does not include group singing, the forthcoming findings from the HOMESIDE study will offer valuable insight into the specific effects of music as a medium for interaction (Baker et al., 2019). HOMESIDE is a multinational study which will compare the effects of a home-based musical intervention for people with dementia with an active control

condition and treatment as usual. In the three-armed RCT, the musical intervention consists of family caregiver-delivered interactive music sessions at home, informed by Kitwood's model of person-centred care, whilst the active control intervention involves shared reading or reciting combined with discussion and reflection. In both cases the caregivers will be trained to deliver the intervention using a manual. In the case of the music intervention the training will be provided by a music therapist and it therefore seems reasonable to infer that it will involve elements of skill-sharing even if this is not explicitly stated in the protocol. It will be interesting to compare the implementation of this face-to-face training with family caregivers, with the kind of skill-sharing offered by CHORD. The choice of a shared reading intervention as control condition is an interesting one, as it has similarities with music as a creative social activity which stimulates reminiscence. The researchers' hypothesis is that reading will be superior to treatment as usual, but that music will be superior to both as it is less reliant on verbal skills and has more potential to facilitate social connection. This thesis has discussed possible alternative control conditions for a larger study of the CHORD manual in section 7.3.3; the forthcoming work on HOMESIDE will provide valuable data which will inform the selection of control conditions, because it isolates the unique properties of music by comparing it with an intervention which preserves a similar dyadic social interaction. The value of adding any structured group activity to the routine of people with dementia is demonstrated by a recent study in which singing-focused group music therapy was provided to residents in a care home, alongside a music listening group and a television group as the control conditions (Cho, 2018). Only the music therapy group had a significant increase in QoL-AD scores from pre- to post-intervention, but the other two groups' scores also increased noticeably. The author suggests that although the residents in the control groups would regularly experience music listening and watching TV in their daily life, in this case the activities were implemented "in a group format in the presence of activity staff, who was

instructed to validate and process the participants' responses" (Cho, 2018, p. 9). The findings of this study highlight how important it is to control for the positive effects of any structured group activity in this kind of research, but also underline the importance of social activity, engagement and validation in general for this population.

Overall, the recent developments in this field offer positive evidence that research is moving towards larger studies, with a focus on understanding the specific properties of music interventions and how these can be harnessed to support people with dementia's diverse needs, according to their personal circumstances and the stage of their illness. The findings of the present study contribute to the field by furthering our understanding of participants' experiences in singing groups, highlighting the specific qualities in a facilitator which contribute to successful groups, and elucidating some of the challenges faced by researchers in evaluating the impact of music-based interventions on people with dementia.

7.6 Implications of this thesis

7.6.1 Original contribution to knowledge

Several aspects of this thesis represent original contributions to knowledge in the field. Firstly, the meta-narrative review technique has not been used before with music and dementia studies, and no other review has covered a comparably broad range of types of intervention and timeframe. This review provides an overview of the state of play as well as the historical trends which have led there and can be used by researchers to inform their choice of outcome measures and methods for data collection. The meta-narratives may encourage researchers to think more critically about the choices they make in their work and to question the underlying values and assumptions of their field. The review goes some way towards answering the call by Gray et al. (2018) for research in the arts and dementia to explore "how and why methodological choices are made, what

pragmatic, political or personal factors determine these choices […] and how the cross-disciplinary nature of the arts and dementia field is reflected in the process" (p.781). The first part of this meta-narrative review has been published in the journal Maturitas (Dowson et al., 2019).

Secondly, the critical interpretive synthesis of case studies in this thesis is a contribution to music therapy research and practice. To date, this is only the second instance of CIS being used with music therapy case studies, the other dealing with the unrelated area of boundary crossings in music therapy (Medcalf & Skewes McFerran, 2016). The review provides a technique for synthesising case study data to investigate the effects of music therapy, and explores the strengths and limitations of this approach. It highlights the potential for case studies to contribute to the evidence base, rather than just being considered stand-alone examples of anecdotal evidence. The synthesis of the CIS with meta-narrative review suggests a disconnect between research and music therapy practice in the sense that outcomes are prioritised or conceptualised differently. This finding contributes to a body of music therapy scholarship which has reflected critically on the tensions between music therapy and evidence-based practice. The CIS approach used here represents a potential way of reconciling those differences, by combining real examples from practice with a system for analysing them and understanding the mechanisms at work.

Thirdly, the study represents the first evaluation of a manual of this kind, created specifically for facilitators of singing groups and intended to share music therapy skills. The results of the study demonstrate that the knowledge necessary to run the singing group could be communicated successfully through the medium. The study also identified some aspects of singing group facilitation which were more difficult to convey through the manual, which is relevant for anyone who is planning to use CHORD or to design a similar manual. The study also highlighted

some characteristics of singing group facilitation which may lead to a successful group; specifically, that lack of expertise is not necessarily a drawback if the facilitator is able to channel this experience into a sense of kinship and equality with their singing group. This is an original finding, and suggests that a less experienced facilitator could potentially have some advantages over an expert, such a professional community musician or music therapist.

Finally, the feasibility aspect of the study contributes to the body of knowledge about how best to implement randomised controlled trials of music interventions, and the challenges involved in conducting them. The results support earlier research in showing that the chosen outcome measures, the length of study or the overall impact of the group upon the participants may be insufficient to cause detectable benefits, although we also know that participants feel that the group is valuable to them. The findings of the study also contribute to understanding of possible control conditions which could be used in future RCTs, suggesting that comparing group singing with other social activities could be a way to explore whether singing has unique benefits. The analysis of the qualitative data illustrates the experiences of the group members, and in particular the findings about the role of a non-expert facilitator in making the group feel safe and comfortable challenge assumptions about the qualities a facilitator should have. This study also contributes to knowledge about the potential of manualised interventions as a way of standardising treatment within an RCT context. Its findings highlight some of the challenges of this approach when the intervention in question is delivered in a flexible and not prescriptive way.

7.6.2 Limitations of this thesis

There are several limitations to the work carried out for this thesis. The most obvious is that the study which was conducted to evaluate the CHORD manual was very small and no power calculation was conducted. There was no control

group to provide a point of comparison for the data gathered before and after the study. The participants in the study were a self-selected convenience sample, so they cannot be considered representative of the wider population of people with dementia and their carers. This means that even if the exploratory analyses which were carried out with the quantitative data had yielded significant results, it would have been impossible to draw any conclusions from them or to make any generalisations. Additionally, although elements of the qualitative data analysis were conducted by more than one person (e.g. the grouping of codes into categories was undertaken collaboratively), the coding of the raw data was only done by one person, meaning that the data analysis may be seen as lacking equipoise.

A further limitation is that people with subjective memory problems were included in the sample for this study alongside people with a diagnosis of dementia. There were two main reasons for including these people; firstly, the group singing experience was felt to be potentially helpful for those with memory concerns because it could help to remove some of the stigma and fear about a potential future diagnosis of dementia. Secondly, including people without a formal diagnosis was considered to be a more accurate reflection of the way community-based singing groups operate in the real world. However, people with memory concerns are not the same as people with dementia, and this study did not attempt to classify them beyond describing their concerns in their own words. Some of them may have had diagnosable mild cognitive impairment, and some may go on to develop dementia in the future, but not all will (Jessen et al., 2014). Furthermore, the quantitative results indicate a difference between participants with a diagnosis of dementia and those with subjective memory problems. The inclusion of people with self-defined memory problems limits the generalisability of the findings on a group level.

The evaluation of the CHORD manual which was carried out as part of this research provided data about one person's experience of using the manual. Although the exploration of the issues involved in the manual's implementation was thorough, the experience of the facilitator in this study is not necessarily representative of how other potential users would find it. Indeed, JB may not be typical of a potential CHORD user due to her background in counselling. The findings of the present study suggest that the CHORD manual can be successfully used by a novice singing facilitator. However, more research would be required to ascertain which potential users this tool is best suited to.

Another limitation of this research relates to my role as researcher and participant member of the group. Although I believe that taking part in the sessions as accompanist and getting to know the group members had advantages in that it gave me insight into the experience of being in the group, it may have affected the responses which participants gave to questions. For example, participants might have felt uncomfortable mentioning aspects of the group which they did not enjoy when they were interviewed by me, because they felt that I was part of the group and did not want to cause any offence.

7.6.3 Future directions for research

The findings of this PhD study suggest that although singing has benefits for people with dementia, it is difficult to establish the effectiveness of the intervention through quantitative measures, a conclusion it shares with other work in the field. This challenge highlights the need for further research, firstly to establish what approaches may detect change and secondly to evaluate group singing in a randomised controlled study. Since there are still many unknowns about study design in this area, more feasibility studies would help to define crucial factors such as possible control activities and the necessary frequency and duration of any singing intervention. If feasibility studies such as these are

successful, a pragmatic randomised controlled trial could then demonstrate the effectiveness of group singing in a community setting.

In parallel with future quantitative research, there is a need for more qualitative research to further understand the meaning of music to people with dementia and their carers. Such research would help to identify the unique properties of singing, and would explore the factors which determine what sort of music intervention is appropriate for any given individual. This in turn would allow resources to be directed more efficiently, and would help people with dementia to access music-based interventions which are relevant to them. Qualitative research will also inform the design of randomised controlled trials by helping to explain the underlying mechanisms of the complex interactions between participants, facilitator, and music. Additionally, it would guide researchers in their choice of outcome measures, and enable them to base their choices on direct evidence from the people who take part in singing groups about what is relevant to them. Mixed-methods research designs also offer the opportunity to simultaneously explore the measurable outcomes of group singing and the mechanisms which bring these about, and could be invaluable for developing an evidence base which is well-supported by understanding of participants' experience. Furthermore, although musical analysis of video material was not used in this doctoral research, this technique offers further opportunities to understand the musical processes at play in the singing group experience. A method which analyses the musical dynamics of the sessions on a group rather than an individual level would be particularly helpful for understanding the musical properties of singing groups which make them successful.

This PhD study has highlighted the fact that the field of arts and health is subject to interdisciplinary tensions, particularly where evaluation and measurement is concerned. As well as research which seeks pragmatic solutions to these

challenges, there is also a need for methodological enquiry which critically engages with how we assess the value and meaning of music in a health and wellbeing context. This thesis has already discussed the difficulty of designing research into music-based interventions so that it complies with the standards of evidence-based practice, leading to criticisms of methodological weakness. Such claims may have as much to do with the inherent qualities of music as with the research designs themselves. Therefore there is a need to investigate how research methods can evolve to meet the challenge of demonstrating the value of music in a way which reflects the complexities and nuances of the musical experience, whilst still providing evidence which is considered rigorous enough; as De Medeiros and Basting (De Medeiros & Basting, 2014) write, "it is through careful rethinking of what constitutes rigorous and effective research that the potential of cultural arts interventions may eventually be understood" (p.352).

A novel aspect of this study is that it evaluates a manual designed to share music therapy skills. Although skill-sharing in music therapy is not new, recent discussion in the field has developed understanding of how skill-sharing works in practice and shed light on the kind of skill-sharing which is already taking place (McDermott et al., 2018). The present study has raised questions about what kind of skills can be shared, with whom and in what formats. We know that music therapists working in dementia care are already sharing their skills with other healthcare professionals, care staff and relatives, but more research could illuminate the most efficient and effective ways to do this. The recent report by the Commission on Dementia and Music suggests that innovative practice in skill-sharing is one way to address the funding challenges which often plague the sector (Bowell & Bamford, 2018). The unique potential of a manual is that, if effective, it allows music therapy skills to be shared without requiring extra time on the part of the music therapist; essentially removing some of the burden which may come with indirect music therapy practice. The CHORD manual is also potentially a

cost-effective way of resourcing facilitators to provide helpful interventions, and any future trial of CHORD should also include an economic analysis to explore this possibility further.

7.7 Conclusion

In Chapter 7, the qualitative and quantitative data were drawn together and synthesised to address each of the four research questions. Based on the data from participants, facilitator and researcher, the CHORD manual was felt to be a useful resource which aided the creation of a successful group which was viewed positively by the majority of attendees. One especially interesting finding was that the facilitator's relative lack of musical experience was seen as a positive by many group members, as it made them feel comfortable and safe to make their own mistakes. The recruitment and retention data showed that the trial was feasible, with outcome measures that were acceptable to participants; however, the outcome measures were not feasible in the sense that they did not detect any change over the course of the study. Given the importance of the social side of the group for many of its members, the idea of a group social activity as a control condition in an RCT was considered. A control condition such as this would allow the unique properties of singing to be explored. To synthesise data about the benefits of coming to the group, change in outcome measure scores was tabulated and compared with qualitative benefits for each member of the group who completed all outcome measures and qualitative data. Points of divergence were identified; for instance, some participants who qualitatively report improvements in mood did not show an improvement on their GDS score and vice-versa. Case vignettes were used to give more detailed examples of what experiences and motivations individuals brought to the group and how their quantitative scores variously agreed or disagreed with the outcomes they reported qualitatively.

In light of the findings from the data synthesis and the literature reviews, the original contributions to knowledge made by this thesis were discussed. The value of the contextual and historical overview of research and practice in music and dementia which is provided by the literature reviews was highlighted. The evaluation of the CHORD manual has implications for practice, while the feasibility aspects of the study offer some suggestions for researching this methodologically complex area. Finally, suggestions for future research were provided, with a focus on how researchers may evaluate the effectiveness of music interventions without compromising their inherent creativity and flexibility. The final concluding chapter summarises the thesis and its findings and sets them in the context of current policy and practice.

Chapter 8: Conclusion

Dementia is an increasingly pressing challenge for our ageing society and in the absence of a cure, there is a need for social interventions which help people with dementia to live well with the condition and take pressure off their family carers. Singing groups can fill this need: they provide an opportunity for self-expression, meaningful activity, social contact and a self-esteem boost for people with dementia, with the added opportunity for their carers to access peer support. The relationship between care partners may benefit as a result. Singing groups are fairly cheap and straightforward to implement, but demand for them exceeds supply.

Music therapists have a skill set which can easily lend itself to running singing groups, but there is not enough capacity within the profession. Skill-sharing offers a way of increasing singing opportunities by transferring necessary skills to willing individuals. We wanted to know how these skills can be transferred most effectively and efficiently, and which skills are amenable to being shared in various contexts. We also wished to understand how research can meaningfully capture and understand the group singing experience, in order to provide evidence of its benefits. The topic of this thesis was an exploration of ways to expand access to singing groups for people with dementia by testing an approach to skill-sharing (the CHORD manual), understanding the perspective of group attendees, and by evaluating commonly-used ways of measuring the benefits of singing.

The main findings of this thesis are 1) that the CHORD manual has the potential to provide an accessible way of expanding access to singing interventions, but that care must be taken to ensure that the skills which are shared are suitable for dissemination in this way; 2) that response to group singing is complex and individual, and measuring its benefits is a challenge for research, and 3) that there

is a need to develop methodological solutions which provide reliable evidence for the value of the arts at a meaningful level without undermining the flexible and intuitive essence of the intervention which they are designed to evaluate. This concluding chapter will outline the salient points from these three findings and situate them in the wider context of research and policy.

This thesis has demonstrated that a novice singing group facilitator can set up and lead a successful group using skills shared through the CHORD manual. Despite the resource only being provided in written form, the medium was sufficient to communicate information which JB needed to run the group. JB found that although the manual was not completely comprehensive, its brevity was an advantage and made it accessible to refer to and use. JB's experience of leading the group was that not being a musical expert was not a disadvantage; instead, this quality gave her something in common with the members of the singing group, most of whom had never done any organised singing before.

Skill-sharing initiatives such as this manual could be interpreted as a challenge to the music therapy profession, representing a way to provide something a bit like music therapy for a lot less money (McDermott et al., 2018). An alternative, pragmatic view is that access to music therapy for people with dementia is primarily restricted by the number of music therapists available, and that skill-sharing initiatives such as the CHORD manual can expand access to a cheap and effective intervention (Schneider, 2018). This is the starting point for the present research into CHORD. In sharing music therapy skills relevant to singing groups, the intention is not to train people to be music therapists. Clearly, a manual cannot be a substitute for a master's degree-level qualification which trains people to work therapeutically in a wide range of contexts. However, for a singing group, the risks are minimal, and skills may be shared which enable the facilitator to lead a group which is "good enough". The potential of a manual is that it provides a

way of disseminating relevant information cheaply, can be made widely available relatively easily, and offers a singing group intervention which is replicable.

The thesis has also shown that the way in which individuals respond to the group singing experience is complex and is mediated by both personal and group factors. Personal musical history, expectations for the group, the characteristics of the sessions and the style of the facilitator all play a role in determining how participants experience and react to the sessions. The individuality of the responses to singing represents a challenge for research and practice. In the same way that it is difficult to run a singing group which will satisfy everyone all the time, it is difficult to find standardised outcome measures which are sensitive enough to detect change and broad enough to encompass the responses of the diverse range of people who attend the group.

The spectrum of benefits which are reported qualitatively in this study suggest that group singing has much to offer people with dementia. Analysis of the qualitative data shows how important the social aspects of attending the singing group were for its members. The sessions provided opportunity for social contact as well as peer support and resource sharing for people with dementia and their carers at the same time. Group members appreciated the chance to spend time with others who had a shared problem, but without the need for dementia to be the focus of the session. It may be that this kind of unspoken solidarity between members, combined with the shared activity of singing, contributed to the rapid formation of strong social bonds between the group members, which is evidenced in the way they describe the sessions.

Finally, this thesis explored some of the challenges of designing and conducting research into singing and dementia using quantitative methods. These challenges fall into three main categories: selecting outcome measures which are suitable,

ensuring the replicability of what goes on in the sessions, and finding a way to balance the demands of research rigour with the flexibility and nuance of group singing. Surrounding all these issues is an overarching question about the value of applying medically oriented research methods to interventions which are predominantly psycho-social in nature.

This standpoint of this thesis is pragmatic: although there are clear points of dissonance between medical and social research methods, we find ourselves in a landscape where RCT evidence is the gold standard, and providing this kind of evidence for an intervention attracts funding for it. It is possible to design research which meets these standards as far as it can, whilst also critically engaging with its limitations. However, there is a need to explore methodological solutions which provide sufficiently rigorous evidence without being reductionist, and without compromising or undermining the essential qualities of the intervention which they are designed to evaluate.

The research carried out for this thesis has implications for practice, as well as research methods and methodology. The thesis has demonstrated that in principle an approach to skill-sharing such as the CHORD manual can work. Further investigation could usefully investigate the kinds of skills and contexts where sharing is most appropriate and necessary, explore how the dissemination of such a manual would function on a larger scale. This carries its own set of challenges, because if the manual is freely available it is difficult to monitor who is using it and what its impact is. The experience of the singing group members has shown that group singing can convey a range of benefits, not all of them directly related to singing itself, and that response is highly personal and shaped by past experiences and preferences. The measurement of social benefit as an outcome of group singing for people with dementia is an avenue which future research could explore. Understanding the unique properties of singing and how they interact

with the social context of a group setting would enable the benefits of group singing to be maximised, while investigating the factors which shape individual response to singing would allow interventions to be designed and signposted to meet specific needs. Although previous research has explored the effects of singing as a social catalyst in a general population, similar research with a dementia focus would help to understand the potential of this intervention to support those with a condition which puts them uniquely at risk of social isolation.

From a methodological perspective, this thesis has highlighted some of the challenges involved in capturing the benefits of singing for people with dementia. Balancing the creative essence of arts interventions with the demand for rigorous, gold-standard evidence, researchers may feel a paradoxical pressure to evaluate "rigidly defined areas of doubt and uncertainty" (Adams, 1979). There is no easy solution to this dichotomy, but, as Gray et al. (2018) suggest, some answers may be found through exploring why and how methodological choices are made. This suggestion is supported by the meta-narrative review in Chapter 2; decisions about what to evaluate and the methods used involve an inherent value judgment about what is worth measuring. This finding calls for more transparency and reflectiveness among researchers in this field about the assumptions underlying their methodological decisions. It is also vital that researchers include people with dementia and their carers, not just as participants, but fully involved in all aspects of research design. Their expertise by experience must be the starting point for all our enquiries.

The work described in this thesis has taken place at a time where the value of the arts in contributing to health and wellbeing is becoming more widely recognised. The UK government has made social prescribing a priority, with link workers supporting primary care to create personalised plans for patients. In 2019 the Utley Foundation launched its "Music for Dementia 2020" campaign, with the

stated goal of making music available for everyone living with dementia by 2020. Meanwhile, a WHO-commissioned scoping review of the arts in health highlighted music, and singing in particular, as holding much potential to improve the lives of people with dementia (Fancourt & Finn, 2019). Amid these developments, there is an undeniable need to increase provision of music-based activities for people with dementia, but also to ensure that the activities provided are relevant to their intended users, that they are helpful and not harmful, and that we can demonstrate their benefits. Although music therapy is gaining acknowledgment as a powerful medium for supporting people with dementia, lack of capacity within the profession means that access to music therapy is very limited. The potential for group singing to contribute to the wellbeing of society at large is huge, and in this context it is worth discovering how we can understand and describe these benefits, however complex and challenging this process may be. The experience of failure-free singing in a supportive environment shows great promise to meet the needs of people with dementia. Further research and dissemination of findings will help to spread the ethos of singing for wellbeing, inclusion and enjoyment. These benefits continue to be felt by the members of Blue Skies singing group, which, at its members' request, continued after the end of the study and goes from strength to strength. Their motto is taken from a line by The Carpenters, which captures the ethos of singing for wellbeing: "Don't worry if it's not good enough for anyone else to hear, just sing".

References

Abbott, J. H. (2014). The Distinction Between Randomized Clinical Trials (RCTs) and Preliminary Feasibility and Pilot Studies: What They Are and Are Not. *The Journal of Orthopaedic and Sports Physical Therapy*, *44*(8), 555–558. https://doi.org/10.2519/jospt.2014.0110

Ahessy, B. (2017). Song writing with clients who have dementia: A case study. *Arts in Psychotherapy*, *55*, 23–31. https://doi.org/http://dx.doi.org/10.1016/j.aip.2017.03.002

Aigen, K. (2015). A critique of evidence-based practice in music therapy. *Music Therapy Perspectives*, *33*(1), 12–24. https://doi.org/10.1093/mtp/miv013

Aldridge, D. (1993). Music therapy research: II. Research methods suitable for music therapy. *The Arts in Psychotherapy*, pp. 117–131. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc3&NEWS=N&AN=1993-46589-001

Aldridge, D. (1994). An overview of music therapy research. *Complementary Therapies in Medicine*, Vol. 2, pp. 204–216. https://doi.org/10.1016/0965-2299(94)90021-3

Aldridge, D. (1995). Music therapy and the treatment of Alzheimer's disease. *Clinical Gerontologist*, Vol. 16, pp. 41–57. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed6&NEWS=N&AN=26001515

Aldridge, D. (1999). Personal opinion: Developing a community of inquiry. *Nordisk Tidsskrift for Musikkterapi*, *8*(1), 25–35. https://doi.org/10.1080/08098139909477951

Alexander, D. A. (1972). Senile Dementia: A Changing Perspective. *British Journal of Psychiatry*, 207–214.

Algase, D. L., Beck, C., Kolanowski, A., Whall, A., Berent, S., Richards, K., & Beattie, E. (1996). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer's Disease and Other Dementias*, *11*(6), 10–19. https://doi.org/10.1177/153331759601100603

All Party Parliamentary Group on Arts Health and Wellbeing. (2017). *Creative health: The arts for health and wellbeing*. Retrieved from https://www.artshealthandwellbeing.org.uk/appg-inquiry/Publications/Creative_Health_Inquiry_Report_2017_-_Second_Edition.pdf

Annandale, E., Harvey, J., Cavers, D., & Dixon-Woods, M. (2007). Gender and access to healthcare in the UK: A critical interpretive synthesis of the literature. *Evidence and Policy*, *3*(4), 463–486. https://doi.org/10.1332/174426407782516538

Ansdell, G. (2002). Community Music Therapy & The Winds of Change. *Voices: A*

World Forum for Music Therapy, *2*(2), 1–46. https://doi.org/http://dx.doi.org/10.15845/voices.v2i2.83

Antonovsky, A. (1987). *Unraveling the Mystery of Health: How People Manage Stress and Stay Well*. https://doi.org/10.1097/00005053-198907000-00014

Aron, A., Aron, E. N., & Smollan, D. (1992). Inclusion of Other in the Self Scale and the Structure of Interpersonal Closeness. *Journal of Personality and Social Psychology*, *63*(4), 596–612. https://doi.org/10.1016/j.jesp.2011.07.015

Baker, F. A., Bloska, J., Braat, S., Bukowska, A., Clark, I., Hsu, M. H., … Odell-Miller, H. (2019). HOMESIDE: Home-based family caregiver-delivered music and reading interventions for people living with dementia: Protocol of a randomised controlled trial. *BMJ Open*. https://doi.org/10.1136/bmjopen-2019-031332

Baker, F. A., Grocke, D., & Pachana, N. A. (2012). Connecting through music: A study of a spousal caregiver-directed music intervention designed to prolong fulfilling relationships in couples where one person has dementia. *Australian Journal of Music Therapy*, *23*, 4–19. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc9&NEWS=N&AN=2012-27692-001

Banerjee, S. (2010). Living well with dementia - Development of the national dementia strategy for England. *International Journal of Geriatric Psychiatry*, *25*(9), 917–922. https://doi.org/10.1002/gps.2598

Bannan, N., & Montgomery-Smith, C. (2008). `Singing for the Brain': reflections on the human capacity for music arising from a pilot study of group singing with Alzheimer's patients. *The Journal of the Royal Society for the Promotion of Health*, *128*(2), 73–78. https://doi.org/10.1177/1466424007087807

Barrington, A. (2008). Challenging the profession. *British Journal of Music Therapy*, *22*(2), 65–72.

Barrington, A. (2015). Music therapy in Europe: Paths of professional development Perspectives on the Development of the Music Therapy Profession in the UK. *Approaches: Music Therapy & Special Music Education | Special Issue*, *7*(1).

Basaglia-Pappas, S., Laterza, M., Borg, C., Richard-Mornas, A., Favre, E., & Thomas-Anterion, C. (2013). Exploration of verbal and non-verbal semantic knowledge and autobiographical memories starting from popular songs in Alzheimer's disease. *International Psychogeriatrics*, *25*(5), 785–795. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=23388499

Belgrave, M. (2009). The effect of expressive and instrumental touch on the behavior states of older adults with late-stage dementia of the Alzheimer's type and on music therapist's perceived rapport. *Journal of Music Therapy*, *46*(2), 132–146. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med6&NEWS=N&AN=19463031

Bion, W. R. (1967). *Second thoughts: selected papers on psycho-analysis*. New York: Aronson.

Bond, J., & Corner, L. (2001). Researching dementia: Are there unique methodological challenges for health services research? *Ageing and Society*, *21*(1), 95–116. https://doi.org/10.1017/S0144686X01008091

Bowell, S., & Bamford, S. M. (2018). *"What would life be - without a song or a dance, what are we?": A report from the commission on dementia and music*. Retrieved from http://www.ilcuk.org.uk/index.php/publications/publication_details/what_would_life_be_without_a_song_or_dance_what_are_we

Bradt, J., Creswell, J. W., & Burns, D. S. (2013). Mixed methods research in music therapy research. *Journal of Music Therapy*, *50*(2), 123–148.

British Association for Music Therapy. (2017). What is music therapy? Retrieved from https://www.bamt.org/music-therapy/what-is-music-therapy.html

Brooker, D. (2003). What is Person-Centred Care in Dementia? *Reviews in Clinical Gerontology*, *13*(3), 215–222. https://doi.org/10.1017/S095925980400108X

Brotons, M., & Pickett-Cooper, P. K. (1996). The effects of music therapy intervention on agitation behaviors of Alzheimer's disease patients. *Journal of Music Therapy*, Vol. 33, pp. 2–18. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc3&NEWS=N&AN=1996-03116-001

Bruer, R. A., Spitznagel, E., & Cloninger, C. R. (2007). The temporal limits of cognitive change from music therapy in elderly persons with dementia or dementia-like cognitive impairment: a randomized controlled trial. *Journal of Music Therapy*, *44*(4), 308–328. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med5&NEWS=N&AN=17997623

Bruscia, K. E. (1991). *Case studies in music therapy*. The University of Michigan: Barcelona Publishers.

Bunt, L. [Ed], & Hoskyns, S. [Ed]. (2002). The handbook of music therapy. (A. Aigen Aigen, Alajouanine, Alan, Aldridge, Aldridge, Aldridge, Alvin, Alvin, Amir, Andrews, Ansdell, Ansdell, Ansdell, Ansdell, Ansdell, Assagioli, Axline, Bailey, Bailey, Barham, Baron-Cohen, Bartram, Bartram, Basso, Beatty, Bent, Berliner, Bernstein, Bi, Ed.). *The Handbook of Music Therapy.* Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc4&NEWS=N&AN=2003-02193-000

Camic, P. M., Williams, C. M., & Meeten, F. (2011). Does a "Singing Together Group" improve the quality of life of people with a dementia and their carers? A pilot evaluation study. *Dementia*, *12*(2), 157–176. https://doi.org/10.1177/1471301211422761

Caspi, E. (2013). Time for Change: Persons With Dementia and "Behavioral Expressions," Not "Behavior Symptoms." *Journal of the American Medical*

Directors Association, *14*(10), 768–769. https://doi.org/10.1016/j.jamda.2013.05.019

Ceccato, E., Vigato, G., Bonetto, C., Bevilacqua, A., Pizziolo, P., Crociani, S., … Barchi, E. (2012). STAM protocol in dementia: a multicenter, single-blind, randomized, and controlled trial. *American Journal of Alzheimer's Disease and Other Dementias*, *27*(5), 301–310. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med7&NEWS=N&AN=22815078

Cevasco, A. M. (2010). Effects of the therapist's nonverbal behavior on participation and affect of individuals with Alzheimer's disease during group music therapy sessions. *Journal of Music Therapy*, *47*(3), 282–299. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed12&NEWS=N&AN=359917047

Cheong, C. Y., Tan, J. A. Q., Foong, Y.-L., Koh, H. M., Chen, D. Z. Y., Tan, J. J. C., … Yap, P. (2016). Creative Music Therapy in an Acute Care Setting for Older Patients with Delirium and Dementia. *DEMENTIA AND GERIATRIC COGNITIVE DISORDERS EXTRA*, *6*(2), 268–275. https://doi.org/10.1159/000445883

Cho, H. K. (2018). The effects of music therapy-singing group on quality of life and affect of persons with dementia: A randomized controlled trial. *Frontiers in Medicine*, *5*(OCT), 1–13. https://doi.org/10.3389/fmed.2018.00279

Clair, A. A., & Bernstein, B. (1990). A preliminary study of music therapy programming for severely regressed persons with Alzheimer's-type dementia. *Journal of Applied Gerontology*, Vol. 9, pp. 299–311. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc3&NEWS=N&AN=1991-07777-001

Clair, A. A., & O'Konski, M. (2006). The effect of rhythmic auditory stimulation (RAS) on gait characteristics of cadence, velocity, and stride length in persons with late stage dementia. *Journal of Music Therapy*, *43*(2), 154–163. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med5&NEWS=N&AN=16897907

Clare, M. (2014). Soothing sounds: reducing agitation with music therapy. *Nursing & Residential Care*, *16*(4), 190–195. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=103930186&site=ehost-live

Clements-Cortes, A. (2013). Buddy's Glee Club: Singing for life. *Activities, Adaptation & Aging*, *37*(4), 273–290. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc10&NEWS=N&AN=2013-43783-002

Clements-Cortes, A. (2015). Singing for health, connection and care. *Music and Medicine*, *7*(4), 13–23. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc12&NE

WS=N&AN=2016-07315-003

Cohen-Mansfield, J. (2000). Nonpharmacological Management of Behavioural Problems in Persons with Dementia: The TREA model. *Alzheimer's Care Quarterly*, Vol. 1, pp. 22–34.

Cohen-Mansfield, J., & Billig, N. (1986). Agitated Behaviors in the Elderly: I. A Conceptual Review. *Journal of the American Geriatrics Society*, *34*(10), 711–721. https://doi.org/10.1111/j.1532-5415.1986.tb04302.x

Cohen-Mansfield, J., Marx, M. S., Thein, K., & Dakheel-Ali, M. (2011). The impact of stimuli on affect in persons with dementia. *The Journal of Clinical Psychiatry*, *72*(4), 480–486. Retrieved from http://www.psychiatrist.com/privatepdf/2011/v72n04/v72n0407.Pdf

Cotrell, V., & Schulz, R. (1993). The Perspective of the Patient with Alzheimer ' s Disease : A Neglected Dimension of Dementia Research 1. *The Gerontologist*, *33*(2), 205–211.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2012). *Developing and evaluating complex interventions*. Retrieved from www.mrc.ac.uk/complexinterventionsguidance

Creswell, J. W., & Plano Clark, V. L. (2010). Designing and conducting mixed methods research. In *Sage Publications*. Thousand Oaks, CA: Sage.

Dassa, A., & Amir, D. (2014). The role of singing familiar songs in encouraging conversation among people with middle to late stage Alzheimer's disease. *Journal of Music Therapy*, *51*(2), 131–153. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=25013944

Davidson, J. W., & Almeida, R. (2014). An exploratory study of the impact of group singing activities on lucidity, energy, focus, mood and relaxation for persons with dementia and their caregivers. *Psychology of Well-Being*, *4*(1), 24. https://doi.org/10.1186/s13612-014-0024-5

Davidson, J. W., & Fedele, J. (2011). Investigating group singing activity with people with dementia and their caregivers: Problems and positive prospects. *Musicae Scientiae*, *15*(3), 402–422. https://doi.org/10.1177/1029864911410954

De Medeiros, K., & Basting, A. (2014). Shall I compare thee to a dose of donepezil? Cultural arts interventions in dementia care research. *Gerontologist*, *54*(3), 344–353. https://doi.org/10.1093/geront/gnt055

Defra. (2010). *Measuring progress: Sustainable development indicators 2010*.

DeNora, T. (2006). Evidence and Effectiveness in Music Therapy: Problems, Power, Possibilities and Performances in Health Contexts (A Discussion Paper). *British Journal of Music Therapy*, *20*(2), 81–99. https://doi.org/10.1177/135945750602000203

Department of Health. (2010). *Our Health and Wellbeing Today*. https://doi.org/10.1371/j

Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., … Sutton, A. J. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical*

Research Methodology, *6*(35). https://doi.org/10.1186/1471-2288-6-35

Dowson, B., McDermott, O., & Schneider, J. (2019). What indicators have been used to evaluate the impact of music on the health and wellbeing of people with dementia? A review using meta-narrative methods. *Maturitas*, *127*(June), 26–34. https://doi.org/10.1016/j.maturitas.2019.06.001

Edwards, J. (2002). Using the Evidence Based Medicine Framework to Support Music Therapy Posts in Healthcare Settings. *British Journal of Music Therapy*, *16*(1), 29–34.

Edwards, J. (2012). We need to talk about epistemology: orientations, meaning, and interpretation within music therapy research. *Journal of Music Therapy*, *49*(4), 372–394. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/23705343

El Haj, M., Antoine, P., Nandrino, J. L., Gely-Nargeot, M.-C., & Raffard, S. (2015). Self-defining memories during exposure to music in Alzheimer's disease. *International Psychogeriatrics*, *27*(10), 1719–1730. Retrieved from http://journals.cambridge.org/action/displayJournal?jid=IPG

El Haj, M., Clement, S., Fasotti, L., & Allain, P. (2013). Effects of music on autobiographical verbal narration in Alzheimer's disease. *Journal of Neurolinguistics*, *26*(6), 691–700. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed15&NEWS=N&AN=369358108

El Haj, M., Postal, V., & Philippe, A. (2012). Music enhances autobiographical memory in mild Alzheimer's disease. *Educational Gerontology*, Vol. 38, pp. 30–41. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc9&NEWS=N&AN=2011-27113-004

Engstrom, G., Hammar, L. M., Williams, C., & Gotell, E. (2011). The impact of singing in caring for a person with dementia: Single case analysis of video recorded sessions. *Music and Medicine*, *3*(2), 95–101. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc8&NEWS=N&AN=2011-13187-005

Fancourt, D., & Finn, S. (2019). *WHO Health Evidence Synthesis Report - Cultural Contexts of Health: The role of the arts in improving health and well-being in the WHO European Region*. Retrieved from http://www.euro.who.int/en/publications/abstracts/what-is-the-evidence-on-the-role-of-the-arts-in-improving-health-and-well-being-a-scoping-review-2019

Flemming, K. (2010). Synthesis of quantitative and qualitative research: An example using Critical Interpretive Synthesis. *Journal of Advanced Nursing*, *66*(1), 201–217. https://doi.org/10.1111/j.1365-2648.2009.05173.x

Flicker, L. (1999). Dementia Reconsidered: The Person Comes First. *Bmj*, *318*(7187), 880. https://doi.org/10.1136/bmj.318.7187.880a

Forbes, D. A. (1998). Strategies for managing behavioural symptomatology associated with dementia of the Alzheimer type: a systematic overview. *The*

Canadian Journal of Nursing Research = Revue Canadienne de Recherche En Sciences Infirmieres, *30*(2), 67–86. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed7&NEWS=N&AN=128327191

Fukui, H., Arai, A., & Toyoshima, K. (2012). Efficacy of music therapy in treatment for the patients with Alzheimer's disease. *International Journal of Alzheimer's Disease*, 1–6. https://doi.org/2012/531646

George, D. R. (2010). Overcoming the social death of dementia through language. *The Lancet*, *376*(9741), 586–587. https://doi.org/10.1016/S0140-6736(10)61286-X

Gerdner, L. A. (1997). An individualized music intervention for agitation. *Journal of the American Psychiatric Nurses Association*, *3*(6), 177–184. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=107246247&site=ehost-live

Gerdner, L. A. (2000). Effects of individualized versus classical "relaxation" music on the frequency of agitation in elderly persons with Alzheimer's disease and related disorders. *International Psychogeriatrics*, *12*(1), 49–65. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed8&NEWS=N&AN=30180714

Gerdner, L. A., & Swanson, E. A. (1993). Effects of individualized music on confused and agitated elderly patients. *Archives of Psychiatric Nursing*, *7*(5), 284–291. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed6&NEWS=N&AN=24848407

Gill, L. M., & Englert, N. C. (2013). A Music Intervention's Effect on Falls in a Dementia Unit. *Journal for Nurse Practitioners*, *9*(9), 562–567. https://doi.org/10.1016/j.nurpra.2013.05.005

Gilliard, J., Means, R., Beattie, A., & Daker-White, G. (2005). Dementia care in England and the social model of disability: Lessons and issues. *Dementia*, *4*(4), 571–586. https://doi.org/10.1177/1471301205058312

Goddaer, J., & Abraham, I. L. (1994). Effects of relaxing music on agitation during meals among nursing home residents with severe cognitive impairment. *Archives of Psychiatric Nursing*, *8*(3), 150–158. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med3&NEWS=N&AN=8080303

Gold, C., Eickholt, J., Assmus, J., Stige, B., Wake, J. D., Baker, F. A., … Geretsegger, M. (2019). Music Interventions for Dementia and Depression in ELderly care (MIDDEL): Protocol and statistical analysis plan for a multinational cluster-randomised trial. *BMJ Open*, *9*(3), 1–14. https://doi.org/10.1136/bmjopen-2018-023436

Gold, K. (2014). But does it do any good? Measuring the impact of music therapy on people with advanced dementia (Innovative practice). *Dementia*, *13*(2), 258–264. Retrieved from

http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=24339096

Götell, E., Brown, S., & Ekman, S.-L. (2002). Caregiver singing and background music in dementia care. *Western Journal of Nursing Research*, *24*(2), 195–216. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed8&NEWS=N&AN=35482323

Götell, E., Brown, S., & Ekman, S.-L. (2003). Influence of caregiver singing and background music on posture, movement, and sensory awareness in dementia care. *International Psychogeriatrics*, *15*(4), 411–430. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med4&NEWS=N&AN=15000420

Götell, E., Brown, S., & Ekman, S.-L. (2009). The influence of caregiver singing and background music on vocally expressed emotions and moods in dementia care: a qualitative analysis. *International Journal of Nursing Studies*, *46*(4), 422–430. https://doi.org/10.1016/j.ijnurstu.2007.11.001

Gray, K., Evans, S. C., Griffiths, A., & Schneider, J. (2018). Critical reflections on methodological challenge in arts and dementia evaluation and research. *Dementia*, *17*(6), 775–784. https://doi.org/10.1177/1471301217734478

Greenhalgh, T., Robert, G., MacFarlane, F., Bate, P., Kyriakidou, O., & Peacock, R. (2005). Storylines of research in diffusion of innovation: A meta-narrative approach to systematic review. *Social Science and Medicine*, Vol. 61, pp. 417–430. https://doi.org/10.1016/j.socscimed.2004.12.001

Greenhalgh, T., & Wong, G. (2013). Training materials for meta-narrative reviews. *Center for Primary Care and Public Health - Blizard Institute*, (July 2013), 1–24.

Hall, G. R., & Buckwalter, K. C. (1987). Progressively lowered stress threshold: a conceptual model for care of adults with Alzheimer's disease. *Archives of Psychiatric Nursing*, *1*(6), 399–406. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/3426250

Hammar, L. M., Emami, A., Engström, G., & Götell, E. (2010). Reactions of Persons with Dementia to Caregivers Singing in Morning Care Situations. *Open Nursing Journal*, *4*, 34–41. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=104510382&site=ehost-live

Hammar, L. M., Emami, A., Engström, G., & Götell, E. (2011a). Communicating through caregiver singing during morning care situations in dementia care. *Scandinavian Journal of Caring Sciences*, *25*(1), 160–168. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed13&NEWS=N&AN=361259360

Hammar, L. M., Emami, A., Engström, G., & Götell, E. (2011b). Finding the key to communion-Caregivers' experience of "music therapeutic caregiving" in dementia care: A qualitative analysis. *Dementia: The International Journal of Social Research and Practice*, *10*(1), 98–111. Retrieved from

http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc8&NEWS=N&AN=2014-10994-007

Harris, P. B., & Caporella, C. A. (2014). An intergenerational choir formed to lessen Alzheimer's disease stigma in college students and decrease the social isolation of people with Alzheimer's disease and their family members: a pilot study. *American Journal of Alzheimer's Disease and Other Dementias*, *29*(3), 270–281. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=24413542

Hartley, N. (2008). The Arts in Health and Social Care -- Is Music Therapy Fit for Purpose? *British Journal of Music Therapy*, *22*(2), 88–96. https://doi.org/10.1177/135945750802200208

Hillecke, T., Nickel, A., & Bolay, H. V. (2005). Scientific perspectives on music therapy. *Annals of the New York Academy of Sciences*, *1060*, 271–282. https://doi.org/10.1196/annals.1360.020

Ho, S.-Y., Lai, H.-L., Jeng, S.-Y., Tang, C.-W., Sung, H.-C., & Chen, P.-W. (2011). The Effects of Researcher-Composed Music at Mealtime on Agitation in Nursing Home Residents With Dementia. *Archives of Psychiatric Nursing*, *25*(6), e49–e55. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed13&NEWS=N&AN=362988510

Hoe, J., Hancock, G., Livingstone, G., Woos, B., Challis, D., & Orrell, M. (2009). Changes in the quality of life of people with dementia living in care homes. *Alzheimer Disease and Associate Disorders*, *23*(3), 67–73. https://doi.org/10.1097/WAD.0b013e318194fc1e.CHANGES

Hoe, J., Katona, C., Orrell, M., & Livingston, G. (2007). Quality of life in dementia: care recipient and caregiver perceptions of quality of life in dementia: the LASER-AD study. *International Journal of Geriatric Psychiatry*, *22*, 1031–1036. https://doi.org/10.1002/gps

Holmes, C., Knights, A., Dean, C., Hodkinson, S., & Hopkins, V. (2006). Keep music live: Music and the alleviation of apathy in dementia subjects. *International Psychogeriatrics*, *18*(4), 623–630. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med5&NEWS=N&AN=16805928

Hong, I. S., & Choi, M. J. (2011). Songwriting oriented activities improve the cognitive functions of the aged with dementia. *The Arts in Psychotherapy*, *38*(4), 221–228. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed13&NEWS=N&AN=51580388

Hsieh, H. F., & Shannon, S. E. (2005). Three Approaches to Qualitative Content Analysis. *Qualitative Health Research*, *15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

Hsu, M. H., Flowerdew, R., Parker, M., Fachner, J. J., & Odell-Miller, H. (2015). Individual music therapy for managing neuropsychiatric symptoms for people

with dementia and their carers: a cluster randomised controlled feasibility study. *BMC Geriatrics*, *15*, 84. https://doi.org/10.1186/s12877-015-0082-4

Hubbard, G., Downs, M. G., & Tester, S. (2003). Including older people with dementia in research: Challenges and strategies. *Aging & Mental Health*, *7*(5), 351–362. https://doi.org/10.1080/1360786031000150685

Imai, H., Furukawa, T. A., Kasahara, Y., Ishimoto, Y., Kimura, Y., Fukutomi, E., … Matsubayashi, K. (2014). Ipsative imputation for a 15-item Geriatric Depression Scale in community-dwelling elderly people. *Psychogeriatrics*, *14*(3), 182–187. https://doi.org/10.1111/psyg.12060

Jellinger, K. A., Caplan, L. R., & Esiri, M. (1997). The basis for behavioural disturbances in dementia (multiple notes). *Journal of Neurology Neurosurgery and Psychiatry*, Vol. 62, pp. 303–304. https://doi.org/10.1136/jnnp.62.3.303-a

Jennings, B., & Vance, D. (2002). The short-term effects of music therapy on different types of agitation in adults with Alzheimer's. *Activities, Adaptation & Aging*, Vol. 26, pp. 27–33. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc4&NEWS=N&AN=2003-04252-003

Jessen, F., Wolfsgruber, S., Wiese, B., Bickel, H., Mösch, E., Kaduszkiewicz, H., … Wagner, M. (2014). AD dementia risk in late MCI, in early MCI, and in subjective memory impairment. *Alzheimer's & Dementia*, *10*(1), 76–83. https://doi.org/10.1016/J.JALZ.2012.09.017

Johnston, E., Rasmusson, X., Foyil, B., & Shopland, P. (2017). Witnesses to transformation: Family member experiences providing individualized music to their relatives with dementia. *COGENT EDUCATION*, *4*. https://doi.org/10.1080/2331186X.2017.1362888

Joint Programme - Neurodegenerative Disease. (2015). *Dementia Outcome Measures: Charting New Territory*. Retrieved from http://www.neurodegenerationresearch.eu/wp-content/uploads/2015/10/JPND-Report-Fountain.pdf

Kahle-Wrobleski, K., Ye, W., Henley, D., Hake, A. M., Siemers, E., Chen, Y. F., & Liu-Seifert, H. (2017). Assessing quality of life in Alzheimer's disease: Implications for clinical trials. *Alzheimer's and Dementia: Diagnosis, Assessment and Disease Monitoring*, *6*, 82–90. https://doi.org/10.1016/j.dadm.2016.11.004

Kales, H. C., Gitlin, L. N., & Lyketsos, C. G. (2014). Management of Neuropsychiatric Symptoms of Dementia in Clinical Settings: Recommendations from a Multidisciplinary Expert Panel. *Journal of the American Geriatrics Society*, *62*(4), 762–769. https://doi.org/10.1111/jgs.12730.Management

Keough, L. A., King, B., & Lemmerman, T. (2017). Assessment-Based Small-Group Music Therapy Programming for Individuals with Dementia and Alzheimer's Disease: A Multi-Year Clinical Project. *Music Therapy Perspectives*, *35*(2), 181–189. https://doi.org/10.1093/mtp/miw021

Kitwood, T. (1988). The technical, the personal, and the framing of dementia. *Social Behaviour*, *3*, 161–179.

Kitwood, T. (1990). The dialectics of dementia: with particular reference to Alzheimer's disease. *Ageing and Society*, *10*(May 2018), 177–196.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Maidenhead, UK: Open University Press.

Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing and Society*, *12*(3), 269–287. https://doi.org/10.1017/S0144686X0000502X

Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A. Wittenberg, R., Adelaja, B., … Salimkumar, D. (2014). Dementia UK: Update. In *Alzheimer's Society*. https://doi.org/10.1007/s13398-014-0173-7.2

Kreutz, G. (2014). Does singing facilitate social bonding? *Music and Medicine*, *6*(2), 51–60.

Kuhn, D., Ortigara, A., & Kasayka, R. (2000). Dementia Care Mapping: An innovative tool to Measure Person-Centered Care. *Alzheimer's Care Today*, *1*(3), 7.

Kuhn, T. S. (1962). The Structure of Scientific Revolutions. In *Structure* (Vol. 2). https://doi.org/10.1046/j.1440-1614.2002.t01-5-01102a.x

Kydd, P. (2001). Using music therapy to help a client with Alzheimer's disease adapt to long-term care. *American Journal of Alzheimer's Disease and Other Dementias*, *16*(2), 103–108. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med4&NEWS=N&AN=11302070

Lancioni, G. E., O'Reilly, M. F., Singh, N. N., Sigafoos, J., Rigante, V., De Franciscis, L., … Lang, R. (2013). A further evaluation of the impact of self-regulated music stimulation on positive participation of patients with Alzheimer's disease. *Journal of Developmental and Physical Disabilities*, pp. 273–283. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc10&NEWS=N&AN=2013-16626-001

Lancioni, G. E., Singh, N. N., O'Reilly, M. F., Sigafoos, J., Renna, C., Pinto, K., … Caffo, A. O. (2014). Persons with moderate Alzheimer's disease use simple technology aids to manage daily activities and leisure occupation. *Research in Developmental Disabilities*, *35*(9), 2117–2128. Retrieved from http://www.elsevier.com/locate/redevdis

Ledger, A. J., & Baker, F. A. (2007). An investigation of long-term effects of group music therapy on agitation levels of people with Alzheimer's disease. *Aging & Mental Health*, *11*(3), 330–338. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=105917638&site=ehost-live

Lipe, A. W. (1991). Using music therapy to enhance the quality of life in a client with Alzheimer's dementia: A case study. *Music Therapy Perspectives*, Vol. 9, pp. 102–105. Retrieved from

http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc3&NEWS=N&AN=1993-18854-001

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental Health and Aging*, Vol. 5, pp. 21–32.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine*, *64*(3), 510–519. https://doi.org/10.1097/00006842-200205000-00016

Lyman, K. . (1989). Bringing the Social Back In: A Critique of the bio-medicialisation of Dementia. *Gerontologist*, *29*(5), 597–604.

McCabe, L., Greasley-Adams, C., & Goodson, K. (2015). "What I want to do is get half a dozen of them and go and see Simon Cowell": Reflecting on participation and outcomes for people with dementia taking part in a creative musical project. *Dementia (London, England)*, *14*(6), 734–750. https://doi.org/10.1177/1471301213508128

McDermott, O. (2018). *Music Therapy Charity Large Research Grant Report: Development and evaluation of the CHORD (CHOrus Research in Dementia) manual*. Retrieved from https://www.musictherapy.org.uk/admin/kcfinder/upload/files/CHORD report November 2018.pdf

McDermott, O., Crellin, N., Ridder, H. M., & Orrell, M. (2013). Music therapy in dementia: A narrative synthesis systematic review. *International Journal of Geriatric Psychiatry*, *28*(8), 781–794. https://doi.org/10.1002/gps.3895

McDermott, O., Orgeta, V., Ridder, H. M., & Orrell, M. (2014). A preliminary psychometric evaluation of Music in Dementia Assessment Scales (MiDAS). *International Psychogeriatrics*, *26*(6), 1011–1019. https://doi.org/10.1017/S1041610214000180

McDermott, O., Orrell, M., & Ridder, H. M. (2014). The importance of music for people with dementia: the perspectives of people with dementia, family carers, staff and music therapists. *Aging & Mental Health*, *18*(6), 706–716. https://doi.org/10.1080/13607863.2013.875124

McDermott, O., Orrell, M., & Ridder, H. M. (2015). The development of Music in Dementia Assessment Scales (MiDAS). *Nordic Journal of Music Therapy*, *24*(3), 232–251. https://doi.org/10.1080/08098131.2014.907333

McDermott, O., Ridder, H. M., Baker, F. A., Wosch, T., Ray, K., & Stige, B. (2018). Indirect music therapy practice and skill-sharing in dementia care. *Journal of Music Therapy*, *55*(3), 255–279. https://doi.org/10.1093/jmt/thy012

McFerran, K. S., Hense, C., Medcalf, L., Murphy, M., & Fairchild, R. (2017). Integrating Emotions into the Critical Interpretive Synthesis. *Qualitative Health Research*, *27*(1), 13–23. https://doi.org/10.1177/1049732316639284

McHugh, L., Gardstrom, S., Hiller, J., Brewer, M., & Diestelkamp, W. S. (2012). The effect of pre-meal, vocal re-creative music therapy on nutritional intake of residents with Alzheimer's disease and related dementias: A pilot study. *Music Therapy Perspectives*, *30*(1), 32–42. Retrieved from

http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc9&NEWS=N&AN=2012-25301-006

Medcalf, L., & Skewes McFerran, K. (2016). A critical interpretive synthesis of music therapy case studies: Examining therapeutic boundary themes in the context of contemporary practice. *British Journal of Music Therapy*, *30*(1), 22–35. https://doi.org/10.1177/1359457516639556

Meilan Garcia, J. J., Iodice, R., Carro, J., Sanchez, J. A., Palmero, & Mateos, A. M. (2012). Improvement of autobiographic memory recovery by means of sad music in Alzheimer's disease type dementia. *Aging Clinical and Experimental Research*, Vol. 24, pp. 227–232. Retrieved from http://www.kurtis.it/download/index.cfm?id=7874&t=hres

Melhuish, R. (2013). Group Music Therapy on a Dementia Assessment Ward: An Approach to Evaluation. *British Journal of Music Therapy*, *27*(1), 16–31. https://doi.org/10.1177/135945751302700103

Melhuish, R., Beuzeboc, C., & Guzmán, A. (2017). Developing relationships between care staff and people with dementia through Music Therapy and Dance Movement Therapy: A preliminary phenomenological study. *Dementia (14713012)*, *16*(3), 282–296. https://doi.org/10.1177/1471301215588030

Mercadal-Brotons, M. (2011). Music therapy and dementia: a cognitive-behavioural approach. In A. Meadows (Ed.), *Developments in Music Therapy Practice : Case Study Perspectives* (pp. 543–555).

Moniz-Cook, E., Vernooij-Dassen, M., Woods, R., Verhey, F., Chattat, R., De Vugt, M., … Interdem, M. O. (2008). A European consensus on outcome measures for psychosocial intervention research in dementia care. *Aging & Mental Health*, *12*(1), 14–29. https://doi.org/10.1080/13607860801919850

Moore, G. F., Audrey, S., Barker, M., Bond, L., Bonell, C., Hardeman, W., … Baird, J. (2015). Process evaluation of complex interventions: Medical Research Council guidance. *BMJ (Online)*, *350*, 1–7. https://doi.org/10.1136/bmj.h1258

Moussard, A., Bigand, E., Belleville, S., & Peretz, I. (2012). Music as an aid to learn new verbal information in Alzheimer's disease. *Music Perception*, *29*(5), 521–531. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc9&NEWS=N&AN=2012-15378-007

Moussard, A., Bigand, E., Belleville, S., & Peretz, I. (2014). Learning sung lyrics aids retention in normal ageing and Alzheimer's disease. *Neuropsychological Rehabilitation*, *24*(6), 894–917. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=24881953

Moyle, W., Gracia, N., Murfield, J. E., Griffiths, S. G., Venturato, L., BehSc, B., … Assistant, R. (2011). Assessing quality of life of older people with dementia in long-term care: a comparison of two self-report measures. *Journal of Clinical Nursing*, *21*, 1632–1640. https://doi.org/10.1111/j.1365-2702.2011.03688.x

Mykletun, A., Stordal, E., & Dahl, A. A. (2001). Hospital Anxiety and Depression (HAD) scale: Factor structure, item analyses and internal consistency in a large population. *British Journal of Psychiatry*, *179*(DEC.), 540–544. https://doi.org/10.1192/bjp.179.6.540

Myskja, A., & Nord, P. G. (2008). "The day the music died": A pilot study on music and depression in a nursing home. *Nordic Journal of Music Therapy*, pp. 30–40. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc6&NEWS=N&AN=2008-03738-004

Nasman, B., Bucht, G., Eriksson, S., & Sandman, P. O. (1993). Behavioural symptoms in the institutionalized elderly- relationship to dementia. *International Journal of Geriatric Psychiatry*, Vol. 8, pp. 843–849. https://doi.org/10.1002/gps.930081007

NICE. (2019). *Dementia Quality Standard (QS184)*.

Noblit, G., & Hare, R. (1988). Meta-Ethnography. In *Qualitative research methods series Newbury Park* (Vol. 11). https://doi.org/10.4135/9781412985000

Nolan, M., Ryan, T., Enderby, P., & Reid, D. (2002). Towards a more inclusive vision of dementia care practice and research. *Dementia*. https://doi.org/10.1177/147130120200100206

Nygård, L. (2006). How can we get access to the experiences of people with dementia? *Scandinavian Journal of Occupational Therapy*, *13*(2), 101–112. https://doi.org/10.1080/11038120600723190

O'Cathain, A., Murphy, E., & Nicholl, J. (2010). Three techniques for integrating data in mixed methods studies. *British Medical Journal*, *341*, 1147–1150.

Onwuegbuzie, A. J., & Leech, N. L. (2005). On Becoming a Pragmatic Researcher: The Importance of Combining Quantitative and Qualitative Research Methodologies. *International Journal of Social Research Methodology*, *8*(5), 375–387. https://doi.org/10.1080/13645570500402447

Osman, S. E., Tischler, V., & Schneider, J. (2014). Singing for the Brain: A qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers. *Dementia*, *15*(6), 1326–1339. https://doi.org/10.1177/1471301214556291

Park, H., & Pringle Specht, J. K. (2009). Effect of individualized music on agitation in individuals with dementia who live at home. *Journal of Gerontological Nursing*, *35*(8), 47–55. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed12&NEWS=N&AN=355388284

Patton, M. (1990). Qualitative Evaluation and Research Methods. *Qualitative Evaluation and Research Methods*, 169–186. https://doi.org/10.1002/nur.4770140111

Pavlicevic, M. (1999). Music therapy: Intimate notes. *Music Therapy: Intimate Notes.* Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc3&NEWS=N&AN=1999-02822-000

Pearce, E., Launay, J., & Dunbar, R. I. M. (2015). The ice-breaker effect: Singing mediates fast social bonding. *Royal Society Open Science*, *2*(10). https://doi.org/10.1098/rsos.150221

Peeters, M. M. M., Harbers, M., & Neerincx, M. A. (2016). Designing a personal music assistant that enhances the social, cognitive, and affective experiences of people with dementia. *COMPUTERS IN HUMAN BEHAVIOR*, *63*, 727–737. https://doi.org/10.1016/j.chb.2016.06.003

Pluye, P., & Hong, Q. N. (2014). Combining the Power of Stories and the Power of Numbers: Mixed Methods Research and Mixed Studies Reviews. *Annual Review of Public Health*, *35*(1), 29–45. https://doi.org/10.1146/annurev-publhealth-032013-182440

Pollack, N. J., & Namazi, K. H. (1992). The effect of music participation on the social behavior of Alzheimer's disease patients. *Journal of Music Therapy*, Vol. 29, pp. 54–67. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc3&NEWS=N&AN=1992-44199-001

Radoje, M. (2014). Where Were You Born? A Music Therapy Case Study. *British Journal of Music Therapy*, *28*(2), 25–35. https://doi.org/10.1177/135945751402800206

Raglio, A., Bellandi, D., Baiardi, P., Gianotti, M., Ubezio, M. C., Zanacchi, E., … Stramba-Badiale, M. (2015). Effect of Active Music Therapy and Individualized Listening to Music on Dementia: A Multicenter Randomized Controlled Trial. *Journal of the American Geriatrics Society*, *63*(8), 1534–1539. Retrieved from http://www.blackwellpublishing.com/journal.asp?ref=0002-8614&site=1

Ragneskog, H., Kihlgren, M., Karlsson, I., & Norberg, A. (1996). Dinner music for demented patients: analysis of video-recorded observations. *Clinical Nursing Research*, *5*(3), 262–282. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med4&NEWS=N&AN=8850771

Ray, K. D., & Mittelman, M. S. (2017). Music therapy: A nonpharmacological approach to the care of agitation and depressive symptoms for nursing home residents with dementia. *Dementia (14713012)*, *16*(6), 689–710. https://doi.org/10.1177/1471301215613779

Ridder, H. M., & Aldridge, D. (2005). Individual Music Therapy with Persons with Frontotemporal Dementia: Singing Dialogue. *Nordic Journal of Music Therapy*, *14*(2), 91–106. https://doi.org/10.1080/08098130509478132

Ridder, H. M., & Gummesen, E. (2015). The use of extemporizing in music therapy to facilitate communication in a person with dementia: An explorative case study. *Australian Journal of Music Therapy*, *26*, 6–29. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=110306376&site=ehost-live

Ridder, H. M., Stige, B., Qvale, L. G., & Gold, C. (2013). Individual music therapy for agitation in dementia: an exploratory randomized controlled trial. *Aging*

& Mental Health, *17*(6), 667–678. https://doi.org/10.1080/13607863.2013.790926

Riley, P., Alm, N., & Newell, A. (2009). An interactive tool to promote musical creativity in people with dementia. *Computers in Human Behavior*, *25*(3), 599–608. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc6&NEWS=N&AN=2009-06406-003

Rogers, C. R. (1957). The necessary and sufficient conditions of therapeutic personality change. *Journal of Consulting Psychology*. https://doi.org/10.1037/h0045357

Rolvsjord, R. (2006). Whose Power of Music?: A Discussion on Music and Power-Relations in Music Therapy. *British Journal of Music Therapy*, *20*(1), 5–12. https://doi.org/10.1177/135945750602000103

Rolvsjord, R., Gold, C., & Stige, B. (2005). Research Rigour and Therapeutic Flexibility: Rationale for a Therapy Manual Developed for a Randomised Controlled Trial. *Nordic Journal of Music Therapy*, *14*(1), 15–32. https://doi.org/10.1080/08098130509478122

Ropper, A. H. (1979). A rational approach to dementia. *Canadian Medical Association Journal*, *121*(9), 1175–1190. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1704685/pdf/canmedaj01457-0019.pdf

Sabat, S. R. (2003). Some Potential Benefits of Creating Research Partnerships with People with Alzheimer's Disease. *Research Policy and Planning*, *21*(2), 5–12.

Sambandham, M., & Schirm, V. (1995). Music as a nursing intervention for residents with Alzheimer's disease in long-term care. *Geriatric Nursing (New York, N.Y.)*, *16*(2), 79–83. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med3&NEWS=N&AN=7774824

Sanchez, A., Maseda, A., Marante-Moar, M. P., de Labra, C., & Lorenzo-Lopez, L. (2016). Comparing the Effects of Multisensory Stimulation and Individualized Music Sessions on Elderly People with Severe Dementia: A Randomized Controlled Trial. *Journal of Alzheimer's Disease*, *52*(1), 303–315. https://doi.org/10.3233/JAD-151150

Särkämö, T., Tervaniemi, M., Laitinen, S., Numminen, A., Kurki, M., Johnson, J. K., & Rantanen, P. (2014). Cognitive, Emotional, and Social Benefits of Regular Musical Activities in Early Dementia: Randomized Controlled Study. *The Gerontologist*, *54*(4), 634–650. https://doi.org/geront/gnt100

Savva, G. M., Zaccai, J., Matthews, F. E., Davidson, J. E., McKeith, I., & Brayne, C. (2009). Prevalence, correlates and course of behavioural and psychological symptoms of dementia in the population. *British Journal of Psychiatry*, *194*(3), 212–219. https://doi.org/10.1192/bjp.bp.108.049619

Schäfer, T., & Sedlmeier, P. (2009). From the functions of music to music preference. *Psychology of Music*, *37*(3), 279–300. https://doi.org/10.1177/0305735608097247

Schneider, J. (2018). Music therapy and dementia care practice in the United Kingdom: A British Association for Music Therapy membership survey. *British Journal of Music Therapy*, *32*(2), 58–69. https://doi.org/10.1177/1359457518799854

Sherratt, K., Thornton, A., & Hatton, C. (2004a). Emotional and behavioural responses to music in people with dementia: An observational study. *Aging & Mental Health*, *8*(3), 233–241. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed9&NEWS=N&AN=38639438

Sherratt, K., Thornton, A., & Hatton, C. (2004b). Music interventions for people with dementia: A review of the literature. *Aging & Mental Health*, *8*(1), 3–12. https://doi.org/10.1080/13607860310001613275

Shibazaki, K., & Marshall, N. A. (2017). Exploring the impact of music concerts in promoting well-being in dementia care. *Aging & Mental Health*, *21*(5), 468–476. https://doi.org/10.1080/13607863.2015.1114589

Simmons-Stern, N. R., Budson, A. E., & Ally, B. A. (2010). Music as a memory enhancer in patients with Alzheimer's disease. *Neuropsychologia*, *48*(10), 3164–3167. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med6&NEWS=N&AN=20452365

Simmons-Stern, N. R., Deason, R. G., Brandler, B. J., Frustace, B. S., O'Connor, M. K., Ally, B. A., & Budson, A. E. (2012). Music-based memory enhancement in Alzheimer's disease: promise and limitations. *Neuropsychologia*, *50*(14), 3295–3303. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med7&NEWS=N&AN=23000133

Sixsmith, A., & Gibson, G. (2007). Music and the wellbeing of people with dementia. *Ageing & Society*, Vol. 27, pp. 127–145. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc5&NEWS=N&AN=2007-03276-007

Smith, M., Gerdner, L. A., Hall, G. R., & Buckwalter, K. C. (2004). History, development, and future of the progressively lowered stress threshold: A conceptual model for dementia care. *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY*, *52*(10), 1755–1760. https://doi.org/10.1111/j.1532-5415.2004.52473.x

Spector, A., & Orrell, M. (2010). Using a biopsychosocial model of dementia as a tool to guide clinical practice. *International Psychogeriatrics*, *22*(6), 957–965. https://doi.org/10.1017/S1041610210000840

Sung, H., Lee, W., Li, T., & Watson, R. (2012). A group music intervention using percussion instruments with familiar music to reduce anxiety and agitation of institutionalized older adults with dementia. *International Journal of Geriatric Psychiatry*, *27*(6), 621–627. https://doi.org/10.1002/gps.2761

Sutcliffe, C., Cordingley, L., Burns, A., Mozley, C. G., Bagley, H., Huxley, P., & Challis, D. (2000). A new version of the geriatric depression scale for nursing

and residential home populations: the geriatric depression scale (residential) (GDS-12R). *International Psychogeriatrics / IPA*, *12*(2), 173–181. https://doi.org/10.1017/S104161020000630X

Sweeting, H., & Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health & Illness*, *19*(1), 93–117. https://doi.org/10.1111/j.1467-9566.1997.tb00017.x

Tabloski, P., Mc Kinnon-Howe, L., & Remington, R. (1995). Effects of calming music on the level of agitation in cognitively impaired nursing home residents. *The American Journal of Alzheimer's Care and Related Disorders and Research*, *10*(1), 10–15. https://doi.org/10.1177/153331759501000105

Tamplin, J., Clark, I. N., Lee, Y. E. C., & Baker, F. A. (2018). Remini-sing: A feasibility study of therapeutic group singing to support relationship quality and wellbeing for community-dwelling people living with dementia and their family caregivers. *Frontiers in Medicine*, *5*(AUG), 1–10. https://doi.org/10.3389/fmed.2018.00245

Tanaka, Y., & Nogawa, H. (2015). Evaluating the Effects of Singing Songs in Ethnic Music Therapy for Dementia Patients with a Novel Near-infrared Spectroscopy (Data Analysis Method). *INTERNATIONAL JOURNAL OF GERONTOLOGY*, *9*(1), 7–14. https://doi.org/10.1016/j.ijge.2014.01.006

Tanaka, Y., Nogawa, H., & Tanaka, H. (2012). Music Therapy with Ethnic Music for Dementia Patients. *INTERNATIONAL JOURNAL OF GERONTOLOGY*, *6*(4), 247–257. https://doi.org/10.1016/j.ijge.2012.01.026

Tashakkori, A., & Teddlie, C. (1998). Mixed Methodology. Combining Qualitative and Quantitative Approaches. In *Applied Social Research Methods Series* (Vol. 46, p. 183). https://doi.org/10.2307/2655606

Thomas, D. R. (2006). A General Inductive Approach for Analyzing Qualitative Evaluation Data. *American Journal of Evaluation*, *27*(2), 237–246. https://doi.org/10.1177/1098214005283748

Thomas, D. W., Heitman, R. J., & Alexander, T. (1997). The effects of music on bathing cooperation for residents with dementia. *Journal of Music Therapy*, Vol. 34, pp. 246–259. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc3&NEWS=N&AN=1997-38507-002

Thomas, D. W., & Smith, M. (2009). The effect of music on caloric consumption among nursing home residents with dementia of the Alzheimer's type. *Activities, Adaptation & Aging*, *33*(1), 1–16. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc6&NEWS=N&AN=2009-04046-001

Thorgrimsen, L., Selwood, A., Spector, A., Royan, L., de Madariaga Lopez, M., Woods, R. T., & Orrell, M. (2003). Whose Quality of Life Is It Anyway? *Alzheimer Disease & Associated Disorders*, *17*(4), 201–208. https://doi.org/10.1097/00002093-200310000-00002

Topo, P., Maki, O., Saarikalle, K., Clarke, N., Begley, E., Cahill, S., … Gilliard, J. (2004). Assessment of a music-based multimedia program for people with

dementia. *Dementia: The International Journal of Social Research and Practice*, Vol. 3, pp. 331–350. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc4&NEWS=N&AN=2004-20807-006

Trigg, R., Skevington, S. M., & Jones, R. W. (2007). How can we best asses the quality of life of people with dementia? The Bath Assessment of Subjective Quality of Life in Dementia (BASQID). *Gerontologist*, *47*(6), 789–797.

Unadkat, S., Camic, P. M., & Vella-Burrows, T. (2016). Understanding the Experience of Group Singing for Couples Where One Partner Has a Diagnosis of Dementia. *The Gerontologist*, *00*(00), 1–11. https://doi.org/10.1093/geront/gnv698

van Bruggen-Rufi, M., & Vink, A. (2011). Home is where the heart is. In A. Meadows (Ed.), *Developments in Music Therapy Practice : Case Study Perspectives* (pp. 569–581).

van der Geer, E. R., Vink, A. C., Schols, J. M. G. A., & Slaets, J. P. J. (2009). Music in the nursing home: Hitting the right note! the provision of music to dementia patients with verbal and vocal agitation in Dutch nursing homes. *International Psychogeriatrics*, *21*(1), 86–93. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med6&NEWS=N&AN=18947457

van Der Steen, J. T., Smaling, H. J. A., Van Der Wouden, J. C., Bruinsma, M. S., Scholten, R. J. P. M., & Vink, A. C. (2018). Music-based therapeutic interventions for people with dementia (Review). *Cochrane Database of Systematic Reviews*, (7), 1–86. https://doi.org/10.1002/14651858.CD003477.pub3.

van der Vleuten, M., Visser, A., & Meeuwesen, L. (2012). The contribution of intimate live music performances to the quality of life for persons with dementia. *Patient Education & Counseling*, *89*(3), 484–488. https://doi.org/10.1016/j.pec.2012.05.012

Vink, A. C., & Birks, J. S. (2013). Music therapy for people with dementia. *Cochrane Database of …*, (3). https://doi.org/10.1002/14651858.CD003477

Vink, A. C., Zuidersma, M., Boersma, F., De Jonge, P., Zuidema, S. U., & Slaets, J. P. J. (2013). The effect of music therapy compared with general recreational activities in reducing agitation in people with dementia: A randomised controlled trial. *International Journal of Geriatric Psychiatry*, *28*(10), 1031–1038. https://doi.org/10.1002/gps.3924

Watson, B., Tatangelo, G., & McCabe, M. (2018). Depression and Anxiety Among Partner and Offspring Carers of People With Dementia: A Systematic Review. *The Gerontologist*, *xx*(xx), 1–14. https://doi.org/10.1093/geront/gny049

Werner, J., Wosch, T., & Gold, C. (2017). Effectiveness of group music therapy versus recreational group singing for depressive symptoms of elderly nursing home residents. *Nordic Journal of Music Therapy*, *25*(2), 147–155. https://doi.org/10.1080/13607863.2015.1093599

Wetherick, D. (2009). A response to Nigel Hartley's article "The arts in heath and social care - is music therapy fit for purpose?" *British Journal of Music Therapy*, *23*(1).

Whitehouse, P. J., & Rabins, P. V. (1992). Quality of life and dementia. *Alzheimer Disease and Associated Disorders*, *6*(3), 135–137. https://doi.org/10.1097/00002093-199206030-00001

Wigram, T. (2002). Indications in Music Therapy : evidence from assessment that can identify the expectations of music therapy as a treatment for Autistic Spectrum Disorder (ASD); meeting the challenge of Evidence Based Practice. *British Journal of Music Therapy*, *16*(1), 11–28.

Wittwer, J. E., Webster, K. E., & Hill, K. (2013). Effect of rhythmic auditory cueing on gait in people with Alzheimer disease. *Archives of Physical Medicine and Rehabilitation*, *94*(4), 718–724. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed15&NEWS=N&AN=52387338

Wong, A., Burford, S., Wyles, C. L., Mundy, H., & Sainsbury, R. (2008). Evaluation of strategies to improve nutrition in people with dementia in an assessment unit. *The Journal of Nutrition, Health & Aging*, *12*(5), 309–312. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med6&NEWS=N&AN=18443712

Yesavage, J. A., Brink, T. L., Rose, T. L., Lum, O., Huang, V., Adey, M., & Leirer, V. O. (1982). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research*, *17*(1), 37–49. https://doi.org/10.1016/0022-3956(82)90033-4

Appendix 1: Sample pages from CHORD manual

Table of contents

Acknowledgement	1
Contributors	2
Table of contents	4
Introduction	6
Starting a Singing Group	7
What can you offer?	8
Making contact	9
Membership	9
Venue	14
Setting-up the group	16
Skills and Techniques	17
Session structure	18
'Finding a way in'	19
Some aspects to consider when choosing songs for your group	20
Key elements to remember	22
Being in the moment of a shared musical experience	24
More on musical techniques	26
After the group	32
Troubleshooting	33
A possible session outline	35
List of songs to start you off	36
About Dementia	39
Living with dementia	
Singing with people with dementia - Research	42
The importance of music for people with dementia	43
Feedback from the CHORD group members	44
Further information	46
Selected studies on group singing with people with dementia	47

7

Starting a singing group

Where do you start? There are several key stages for setting up a singing group. Use our flowchart to check each step.

Every facilitator has a different style and it is important to feel comfortable with the structure of your group. However, if you need a bit of framework to start off with, see 'Possible session outline' p.35.

'Finding a way in': How do you start a session?

The beginning of the session is the time to acknowledge each other. Some facilitators choose to use a well-known song, or the same song to start each session to develop familiarity. Other facilitators may prefer to start a session with a greeting that includes the participants' names. Have a think about what may be most suitable for your group and what you feel comfortable with so that group members can relax and feel welcomed.

Two therapists share their experiences on 'finding a way in':

"It often helps to use the same song to start the group for a few weeks. This enables people with dementia to connect with the activity through sameness and familiarity. It also gives the facilitator a chance to gauge the energy levels in the room – who is singing straight away who is not, what pace of singing is being established. This first song is often called the 'gathering' song." (JC)

"Starting with a structured exercise, whether a verbal 'check in', breathing or vocal exercises or a greeting song may make for a more cohesive start to the session. Your choice of how to 'check in' depends on your sense of what the most effective way to put your particular group at ease is." (RB)

22

Key elements to remember when facilitating a singing group

Attuning to the mood of the group

"Observational skills are the key. As you sing look around, notice body language and energy levels. Be aware of the singing pace of the group." (JC)

"We encourage volunteers (facilitators) not to expect that because something worked last time, it will again. It's okay to have a plan but be prepared to move away from it. Always read the mood of the room and if everyone is subdued don't try and "jolly the group" up - let them be reflective." (JR)

"If you notice that people are overwhelmingly restless, lethargic or possibly irritable, then adapt the session. Perhaps change the pace, the types of the songs you use, how much or little you talk. These changes can be an effective way of acknowledging the feelings in the group." (RB)

Starting a song

"The worst that can happen is that you sing a verse of something too high or too low. Don't worry about it. Just know that you can begin again at a more appropriate pitch - my experience would suggest that, generally, gauging the pitch comes with practice - with greater confidence starting on the 'wrong' note becomes less of a problem." (JR)

"In my experience, people will join in pretty quickly as soon as you've started, so I don't feel the need to count in. Listen, in case someone else in the group starts a song (listen carefully as voices may be frail) as this does happen, and can be a very validating experience for the group member when everyone joins in with the song they started!" (MG)

Musical pacing

Contrasting musical elements (e.g. fast vs. slow, loud vs. quiet, minor key vs. major key) gets people's attention. Quick changes in musical gestures creates excitement, but the overall pace should be slower than you are probably used to. Make sure people are not left behind because the speed of the group is too fast for them. More 'breathing spaces' between songs/activities and careful observation of participants' responses should help you to find the right pace for the group.

Sharing their musical experience

Some people may want to talk about the emotional reactions evoked by the songs, or talk about the past events that the songs reminded them of. Other people may prefer to have reflective moments for themselves. Acknowledge the mood of the group, acknowledge the differences in people's reactions if/when appropriate. Sometimes music can suddenly remind them of personal events that they might not have thought of for some time. Sometimes music becomes a reminder how they 'used to be' (before dementia started affecting their lives). This can have a big emotional impact on the person. Acknowledge their responses and perhaps offer extra space if they wish to share their stories.

Emotional reactions to music

Music often evokes strong emotional reactions in all of us. Some people might become upset or start crying. It is important that the person feels safe in the group when they are vulnerable. Offer reassurance that it is okay to show their emotions and support whatever they wish to share. Some facilitators might feel uncomfortable when someone becomes upset and might feel the mood of the group needs to be uplifted. However, remember that your group members need space to be able to be themselves. It is important to remember that trying to make everyone 'have a good time' all the time is not necessarily helpful. On the other hand, if someone (person with dementia or family member/friend) in the group becomes upset every week, you need to inform appropriate health professionals (e.g. Memory Service Team, GP or a family member) as they may need extra help and support.

Being aware of your own feelings

Being in the moment with your group members and empathising with their reactions can also have a strong emotional impact on a facilitator. Be kind to yourself if such emotional reactions come as a surprise. Talk with your colleague or your supervisor. For you to be able to keep supporting your group members, you also need to feel supported by others.

Space to be together

Facilitators, particularly those who have had formal musical training, may sometimes need to check with themselves whether they are too caught up in trying to achieve higher musical standards. As a trained musician, it may be a natural instinct to push for improvement. However, we need to remind

33

Troubleshooting

If you are feeling that things are not quite going to plan **during** the session…

Be patient and follow through with an activity or idea - don't swap and change. Try to stay with something until people have had a chance to explore it thoroughly and then decide whether or not it is working.

mindsong
music for dementia

After the session, you may want to consider:

- Were our expectations too high?
- Were the pace of the session and songs too fast?
- Did we use appropriate songs? (e.g. were the words of the songs too complicated?)
- Was the pitch too high / low?
- Did we use too much spoken language and at too fast a pace?
- Were there too many questions?
- Is it the wrong time of day to run this group?
- Did we have too many interruptions?
- Are we being supported enough with staff / volunteers / carers?

35

Possible Session Outline
Ideas that may help structure a session

Appendix 2: Papers included in meta-narrative review (Chapter 2)

Ashida, S. (2000). The effect of reminiscence music therapy sessions on changes in depressive symptoms in elderly persons with dementia. *Journal of Music Therapy*, *37*(3), 170–182. A

Baker, F. A., Grocke, D., & Pachana, N. A. (2012). Connecting through music: A study of a spousal caregiver-directed music intervention designed to prolong fulfilling relationships in couples where one person has dementia. *Australian Journal of Music Therapy*. Australia: Australian Music Therapy Assn, Inc. A, C

Ballard, C., Brown, R., Fossey, J., Douglas, S., Bradley, P., Hancock, J., … Howard, R. (2009). Brief psychosocial therapy for the treatment of agitation in Alzheimer disease (The CALM-AD trial). *American Journal of Geriatric Psychiatry*, *17*(9), 726–733. A

Bannan, N., & Montgomery-Smith, C. (2008). "Singing for the Brain": Reflections on the human capacity for music arising from a pilot study of group singing with Alzheimer's patients. *The Journal of the Royal Society for the Promotion of Health*, *128*(2), 73–78.

Basaglia-Pappas, S., Laterza, M., Borg, C., Richard-Mornas, A., Favre, E., & Thomas-Anterion, C. (2013). Exploration of verbal and non-verbal semantic knowledge and autobiographical memories starting from popular songs in Alzheimer's disease. *International Psychogeriatrics*, *25*(5), 785–795. D

Belgrave, M. (2009). The effect of expressive and instrumental touch on the behavior states of older adults with late-stage dementia of the Alzheimer's type and on music therapist's perceived rapport. *Journal of Music Therapy*, *46*(2), 132–146. A, F

Boulay, M., Benveniste, S., Boespflug, S., Jouvelot, P., & Rigaud, A.-S. (2011). A pilot usability study of MINWii, a music therapy game for demented patients. *Technology and Health Care : Official Journal of the European Society for Engineering and Medicine*, *19*(4), 233–246.

Brotons, M., & Marti, P. (2003). Music therapy with Alzheimer's patients and their family caregivers: a pilot project. *Journal of Music Therapy*, *40*(2), 138–150. A, C

Brotons, M., & Pickett-Cooper, P. K. (1996). The effects of music therapy intervention on agitation behaviors of Alzheimer's disease patients. *Journal of Music Therapy*. US: American Music Therapy Assn. A

Brotons, M., & Pickett-Cooper, P. (1994). Preferences of Alzheimer's disease patients for music activities: Singing, instruments, dance/movement, games, and composition/improvisation. *Journal of Music Therapy*. US: American Music Therapy Assn.

Bruer, R. A., Spitznagel, E., & Cloninger, C. R. (2007). The temporal limits of cognitive change from music therapy in elderly persons with dementia or dementia-like cognitive impairment: a randomized controlled trial. *Journal of Music Therapy*, *44*(4), 308–328. D

Camic, P. M., Williams, C. M., & Meeten, F. (2011). Does a "Singing Together Group" improve the quality of life of people with a dementia and their carers? A pilot evaluation study. *Dementia*, *12*(2), 157–176. A, C

Ceccato, E., Vigato, G., Bonetto, C., Bevilacqua, A., Pizziolo, P., Crociani, S., … Barchi, E. (2012). STAM protocol in dementia: a multicenter, single-blind, randomized, and controlled trial. *American Journal of Alzheimer's Disease and Other Dementias*, *27*(5), 301–310. A, F

Cevasco, A. M. (2010). Effects of the therapist's nonverbal behavior on participation and affect of individuals with Alzheimer's disease during group music therapy sessions. *Journal of Music Therapy*, *47*(3), 282–299. B

Cheong, C. Y., Tan, J. A. Q., Foong, Y.-L., Koh, H. M., Chen, D. Z. Y., Tan, J. J. C., … Yap, P. (2016). Creative Music Therapy in an Acute Care Setting for Older Patients with Delirium and Dementia. *DEMENTIA AND GERIATRIC COGNITIVE DISORDERS EXTRA*, *6*(2), 268–275. B

Choi, A.-N., Lee, M. S., Cheong, K.-J., & Lee, J.-S. (2009). Effects of group music intervention on behavioral and psychological symptoms in patients with dementia: a pilot-controlled trial. *International Journal of Neuroscience*, *119*(4), 471–481. A, C

Christie, M. E. (1992). Music therapy applications in a skilled and intermediate care nursing home facility: A clinical study. *Activities, Adaptation & Aging*. US: Haworth Press. B

Chu, H., Yang, C.-Y., Lin, Y., Ou, K.-L., Lee, T.-Y., O'Brien, A. P., & Chou, K.-R. (2014). The Impact of Group Music Therapy on Depression and Cognition in Elderly Persons With Dementia: A Randomized Controlled Study. *Biological Research for Nursing*, *16*(2), 209–217. A

Clair, A. A., Mathews, R. M., & Kosloski, K. (2005). Assessment of active music participation as an indication of subsequent music making engagement for persons with midstage dementia. *American Journal of Alzheimer's Disease & Other Dementias*, *20*(1), 37–40. B

Clair, A. A., & Bernstein, B. (1990). A preliminary study of music therapy programming for severely regressed persons with Alzheimer's-type dementia. *Journal of Applied Gerontology*. 9(3), 299-311. B

Clair, A. A. (1996). The effect of singing on alert responses in persons with late stage dementia. *Journal of Music Therapy*, *33*(4), 234–247. B

Clair, A. A. (2002). The effects of music therapy on engagement in family caregiver and care receiver couples with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, *17*(5), 286–290. B

Clair, A. A., & Bernstein, B. (1994). The effect of no music, stimulative background music and sedative background music on agitated behaviors in persons with severe dementia. *Activities, Adaptation & Aging*, *19*(1), 61–70. A

Clair, A. A., & Ebberts, A. (1997). The effects of music therapy on interactions between family caregivers and their care receivers with late stage dementia. *Journal of Music Therapy*. US: American Music Therapy Assn. A,C

Clair, A. A., & O'Konski, M. (2006). The effect of Rhythmic Auditory Stimulation (RAS) on gait characteristics of cadence, velocity, and stride length in persons with late stage dementia. *Journal of Music Therapy*, *43*(2), 154–163. E

Clare, M. (2014). Soothing sounds: reducing agitation with music therapy. *Nursing & Residential Care*, *16*(4), 190–195. B

Clarkson, K. A., Cassidy, K.-L., & Eskes, G. A. (2007). Singing soothes: Music concerts for the management of agitation in older adults with dementia. *Canadian Journal of Geriatrics*. 10(3), 80-87. A

Clement, S., Tonini, A., Khatir, F., Schiaratura, L., & Samsony, S. (2012). Short and longer term effects of musical intervention in severe Alzheimer's disease. *Music Perception*, 29(5), 533–541. A

Clements-Cortes, A. (2015). Singing for health, connection and care. *Music and Medicine*. 7(4), 13-23. B

Cohen-Mansfield, J., Marx, M. S., Freedman, L. ., Murad, H., Regier, N. G., & Thein, K. (2011). The comprehensive process model of engagement. *American Journal of Geriatric Psychiatry*, *19*(10), 859–870. B

Cohen-Mansfield, J., Marx, M. S., Freedman, L. ., Murad, H., & Thein, K. (2012). What affects pleasure in persons with advanced stage dementia? *Journal of Psychiatric Research*, *46*(3), 402–406. B

Cohen-Mansfield, J., & Werner, P. (1997). Management of verbally disruptive behaviors in nursing home residents. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, *52*(6), M369–M377. A

Cohen-Mansfield, J., Marx, M. S., Dakheel-Ali, M., Regier, N. G., Thein, K., & Freedman, L. (2010). Can agitated behavior of nursing home residents with dementia be prevented with the use of standardized stimuli? *Journal of the American Geriatrics Society*, *58*(8), 1459–1464. A

Cohen-Mansfield, J., Marx, M. S., Dakheel-Ali, M., & Thein, K. (2015). The use and utility of specific nonpharmacological interventions for behavioral symptoms in dementia: An exploratory study. *American Journal of Geriatric Psychiatry*, *23*(2), 160–170. A, C

Cohen-Mansfield, J., Marx, M. S., Thein, K., & Dakheel-Ali, M. (2010). The impact of past and present preferences on stimulus engagement in nursing home residents with dementia. *Aging & Mental Health*, *14*(1), 67–73. A, C

Cohen-Mansfield, J., Marx, M. S., Thein, K., & Dakheel-Ali, M. (2011). The impact of stimuli on affect in persons with dementia. *The Journal of Clinical Psychiatry*, *72*(4), 480–486. B

Cooke, M. L., Moyle, W., Shum, D. H. K., Harrison, S. D., & Murfield, J. E. (2010). A randomized controlled trial exploring the effect of music on agitated behaviours and anxiety in older people with dementia. *Aging & Mental Health*, *14*(8), 905–916. A

Cox, E., Nowak, M., & Buettner, P. (2011). Managing agitated behaviour in people with Alzheimer's disease: The role of live music. *The British Journal of Occupational Therapy*. 74(11), 517-524. A

Cox, E., Nowak, M., & Buettner, P. (2014). Live music promotes positive behaviours in people with Alzheimer's disease. *The British Journal of Occupational Therapy*. British Association of Occupational Therapists. A

Crispi, E. L., & Heitner, G. (2002). An activity-based intervention for caregivers and residents with dementia in nursing homes. (C. Bass Guberman,

Guerriero-Austrom, Knoth, Pearlman, Rabinovich, Shanas, York, Ed.), *Activities, Adaptation & Aging*. US: Haworth Press.

Cuddy, L. L., Sikka, R., Silveira, K., Bai, S., & Vanstone, A. (2017). Music-evoked autobiographical memories (MEAMs) in Alzheimer disease: Evidence for a positivity effect. *Cogent Psychology*, 4(1). D

Dassa, A., & Amir, D. (2014). The role of singing familiar songs in encouraging conversation among people with middle to late stage Alzheimer's disease. *Journal of Music Therapy*, *51*(2), 131–153.

Davidson, J., & Almeida, R. (2014). An exploratory study of the impact of group singing activities on lucidity, energy, focus, mood and relaxation for persons with dementia and their caregivers. *Psychology of Well-Being, 4(1),* 24. C

Davidson, J. W., & Fedele, J. (2011). Investigating group singing activity with people with dementia and their caregivers: Problems and positive prospects. *Musicae Scientiae*, *15*(3), 402–422. C

El Haj, M., Antoine, P., Nandrino, J. L., Gely-Nargeot, M.-C., & Raffard, S. (2015). Self-defining memories during exposure to music in Alzheimer's disease. *International Psychogeriatrics*, *27*(10), 1719–1730. D

El Haj, M., Clement, S., Fasotti, L., & Allain, P. (2013). Effects of music on autobiographical verbal narration in Alzheimer's disease. *Journal of Neurolinguistics*. *26(6),* 691-700. D

El Haj, M., Postal, V., & Philippe, A. (2012). Music enhances autobiographical memory in mild Alzheimer's disease. *Educational Gerontology*. *38(1),* 30-41. D

Engstrom, G., Hammar, L. M., Williams, C., & Gotell, E. (2011). The impact of singing in caring for a person with dementia: Single case analysis of video recorded sessions. *Music and Medicine*. 3(2), 95-101. B

Foster, N. A., & Valentine, E. R. (2001). The effect of auditory stimulation on autobiographical recall in dementia. *Experimental Aging Research*, *27*(3), 215–228. D

Fukui, H., Arai, A., & Toyoshima, K. (2012). Efficacy of music therapy in treatment for the patients with Alzheimer's disease. *International Journal of Alzheimer's Disease*, 1–6. E

Gardiner, J. C., Furois, M., Tansley, D. P., & Morgan, B. (2000). Music therapy and reading as intervention strategies for disruptive behavior in dementia. *Clinical Gerontologist*, *22*(1), 31–46. A

Gerdner, L. (1997). An individualized music intervention for agitation. *Journal of the American Psychiatric Nurses Association*, *3*(6), 177–184. A

Gerdner, L. A. (2000). Effects of individualized versus classical "relaxation" music on the frequency of agitation in elderly persons with Alzheimer's disease and related disorders. *International Psychogeriatrics*, *12*(1), 49–65. A

Gerdner, L. A. (2005). Use of individualized music by trained staff and family: translating research into practice. *Journal of Gerontological Nursing*, *31*(6), 22–26. A

Gerdner, L. A., & Swanson, E. A. (1993). Effects of individualized music on confused and agitated elderly patients. *Archives of Psychiatric Nursing*, *7*(5), 284–291. A

Gill, L. M., & Englert, N. C. (2013). A Music Intervention's Effect on Falls in a Dementia Unit. *Journal for Nurse Practitioners*, *9*(9), 562–567. E

Giovagnoli, A., Manfredi, V., Parente, A., Schifano, L., Oliveri, S., Avanzini, G., & Giovagnoli, A. R. (2017). Cognitive training in Alzheimer's disease: a controlled randomized study. Neurological Sciences, 38(8), 1485–1493. D

Goddaer, J., & Abraham, I. L. (1994). Effects of relaxing music on agitation during meals among nursing home residents with severe cognitive impairment. *Archives of Psychiatric Nursing*, *8*(3), 150–158. A

Gold, K. (2014). But does it do any good? Measuring the impact of music therapy on people with advanced dementia: (Innovative practice). *Dementia (London, England)*, *13*(2), 258–264. A, C

Götell, E., Brown, S., & Ekman, S. (2009). The influence of caregiver singing and background music on vocally expressed emotions and moods in dementia care: a qualitative analysis. *International Journal of Nursing Studies*, *46*(4), 422–430.

Götell, E., Brown, S., & Ekman, S.-L. (2003). Influence of caregiver singing and background music on posture, movement, and sensory awareness in dementia care. *International Psychogeriatrics*, *15*(4), 411–430.

Götell, E., Brown, S., & Ekman, S.-L. (2002). Caregiver singing and background music in dementia care. *Western Journal of Nursing Research*, *24*(2), 195–216.

Groene, R. (2001). The effect of presentation and accompaniment styles on attentional and responsive behaviors of participants with dementia diagnoses. *Journal of Music Therapy*, *38*(1), 36–50. B

Groene, R., Zapchenk, S., Marble, G., & Kantar, S. (1998). The effect of therapist and activity characteristics on the purposeful responses of probable Alzheimer's disease participants. *Journal of Music Therapy*. US: American Music Therapy Assn. *35(2),* 119-136. B

Guetin, S., Portet, F., Picot, M.-C., Pommie, C., Messaoudi, M., Djabelkir, L., … Touchon, J. (2009). Effect of music therapy on anxiety and depression in patients with Alzheimer's type dementia: Randomised, controlled study. *Dementia and Geriatric Cognitive Disorders*. 28(1), 36-46. A

Hammar, L. M., Emami, A., Engström, G., & Götell, E. (2010). Reactions of Persons with Dementia to Caregivers Singing in Morning Care Situations. *Open Nursing Journal*, *4*, 34–41.

Hammar, L. M., Emami, A., Engström, G., & Götell, E. (2011). Finding the key to communion-Caregivers' experience of "music therapeutic caregiving" in dementia care: A qualitative analysis. *Dementia: The International Journal of Social Research and Practice*, *10*(1), 98–111.

Hammar, L. M., Emami, A., Engström, G., & Götell, E. (2011). Communicating through caregiver singing during morning care situations in dementia care. *Scandinavian Journal of Caring Sciences*, *25*(1), 160–168.

Hammar, L. M., Emami, A., Götell, E., & Engström, G. (2011). The impact of caregivers' singing on expressions of emotion and resistance during morning care situations in persons with dementia: An intervention in dementia care. *Journal of Clinical Nursing*, *20*(7–8), 969–978. A, C

Hanson, N., Gfeller, K., Woodworth, G., Swanson, E. A., & Garand, L. (1996). A comparison of the effectiveness of differing types and difficulty of music activities in programming for older adults with Alzheimer's disease and related disorders. *Journal of Music Therapy*. 33(2), 93-123. B

Harris, P. B., & Caporella, C. A. (2014). An intergenerational choir formed to lessen Alzheimer's disease stigma in college students and decrease the social isolation of people with Alzheimer's disease and their family members: a pilot

study. *American Journal of Alzheimer's Disease and Other Dementias*, *29*(3), 270–281.

Helmes, E., & Wiancko, D. C. (2006). Effects of Music in Reducing Disruptive Behavior in a General Hospital. *Journal of the American Psychiatric Nurses Association*. 12(1), 37-44. A

Hicks-Moore, S. L., & Robinson, B. A. (2008). Favorite music and hand massage: Two interventions to decrease agitation in residents with dementia. *Dementia (14713012)*, *7*(1), 95–108. A

Hicks-Moore, S. L. (2005). Relaxing music at mealtime in nursing homes: effects on agitated patients with dementia. *Journal of Gerontological Nursing*, *31*(12), 26–32. A

Ho, S.-Y., Lai, H.-L., Jeng, S.-Y., Tang, C.-W., Sung, H.-C., & Chen, P.-W. (2011). The Effects of Researcher-Composed Music at Mealtime on Agitation in Nursing Home Residents With Dementia. *Archives of Psychiatric Nursing*, *25*(6), e49–e55. A

Holmes, C., Knights, A., Dean, C., Hodkinson, S., & Hopkins, V. (2006). Keep music live: Music and the alleviation of apathy in dementia subjects. *International Psychogeriatrics*, *18*(4), 623–630. B

Hong, I. S., & Choi, M. J. (2011). Songwriting oriented activities improve the cognitive functions of the aged with dementia. *The Arts in Psychotherapy*, *38*(4), 221–228. D

Hsu, M. H., Flowerdew, R., Parker, M., Fachner, J. J., & Odell-Miller, H. (2015). Individual music therapy for managing neuropsychiatric symptoms for people with dementia and their carers: a cluster randomised controlled feasibility study. *BMC Geriatrics*, *15*, 84. A, C

Irish, M., Cunningham, C. J., Walsh, J. B., Coakley, D., Lawlor, B. A., Robertson, I. H., & Coen, R. F. (2006). Investigating the Enhancing Effect of Music on Autobiographical Memory in Mild Alzheimer's Disease. Dementia and Geriatric Cognitive Disorders, 22(1), 108–120. A

Jennings, B., & Vance, D. (2002). The short-term effects of music therapy on different types of agitation in adults with Alzheimer's. *Activities, Adaptation & Aging*. 26(4), 27-33. A

Johnson, J. K., Cotman, C. W., Tasaki, C. S., & Shaw, G. L. (1998). Enhancement of spatial-temporal reasoning after a Mozart listening condition in Alzheimer's disease: a case study. *Neurological Research*, *20*(8), 666–672. D

Johnson, J. K., Shaw, G. L., Vuong, M., Vuong, S., & Cotman, C. W. (2002). Short-term improvement on a visual-spatial task after music listening in Alzheimer's disease: A group study. *Activities, Adaptation & Aging*. 26(3), 37-50. D

Johnston, E., Rasmusson, X., Foyil, B., & Shopland, P. (2017). Witnesses to transformation: Family member experiences providing individualized music to their relatives with dementia. COGENT EDUCATION, 4(), 1-12.

Keough, L. A., King, B., & Lemmerman, T. (2017). Assessment-Based Small-Group Music Therapy Programming for Individuals with Dementia and Alzheimer's Disease: A Multi-Year Clinical Project. Music Therapy Perspectives, 35(2), 181–189. F

Korb, C. (1997). The influence of music therapy on patients with a diagnosed dementia. *Canadian Journal of Music Therapy*. 5(1), 26-54. B

Kumar, A. M., Tims, F., Cruess, D. G., Mintzer, M. J., Ironson, G., Loewenstein, D., … C., E. (1999). Music therapy increases serum melatonin levels in patients with Alzheimer's disease. *Alternative Therapies in Health and Medicine*, *5*(6), 49–57. E

Lancioni, G. E., Bosco, A., De Caro, M. F., Singh, N. N., O'Reilly, M. F., Green, V. A., … Zonno, N. (2015). Effects of response-related music stimulation versus general music stimulation on positive participation of patients with Alzheimer's disease. *Developmental Neurorehabilitation*, *18*(3), 169–176.

Lancioni, G. E., O'Reilly, M. F., Singh, N. N., Sigafoos, J., Rigante, V., De Franciscis, L., … Lang, R. (2013). A further evaluation of the impact of self-regulated music stimulation on positive participation of patients with Alzheimer's disease. *Journal of Developmental and Physical Disabilities*. 25(3), 273-283. B

Lancioni, G. E., Singh, N. N., O'Reilly, M. F., Green, V. A., Ferlisi, G., Ferrarese, G., … Zonno, N. (2013). Self-regulated music stimulation for persons with Alzheimer's disease: impact assessment and social validation. *Developmental Neurorehabilitation*, *16*(1), 17–26. B

Lancioni, G. E., Singh, N. N., O'Reilly, M. F., Sigafoos, J., Renna, C., Pinto, K., … Caffo, A. O. (2014). Persons with moderate Alzheimer's disease use simple technology aids to manage daily activities and leisure occupation. *Research in Developmental Disabilities*, *35*(9), 2117–2128. B

Ledger, A. J., & Baker, F. A. (2007). An investigation of long-term effects of group music therapy on agitation levels of people with Alzheimer's disease. *Aging & Mental Health*, *11*(3), 330–338. A

Lesta, B., & Petocz, P. (2006). Familiar Group Singing: Addressing Mood and Social Behaviour of Residents with Dementia Displaying Sundowning. *Australian Journal of Music Therapy*. 11(3), 330-338. A, C

Li, C.-H., Liu, C.-K., Yang, Y.-H., Chou, M.-C., Chen, C.-H., & Lai, C.-L. (2015). Adjunct effect of music therapy on cognition in alzheimer's disease in Taiwan: A pilot study. Neuropsychiatric Disease and Treatment. 11, 291-296. A

Lin, Y., Chu, H., Yang, C. Y., Chen, C. H., Chen, S. G., Chang, H. J., … Chou, K. R. (2011). Effectiveness of group music intervention against agitated behavior in elderly persons with dementia. *International Journal of Geriatric Psychiatry*, *26*(7), 670–678. A

Locke, J. M., & Mudford, O. C. (2010). Using music to decrease disruptive vocalizations in a man with dementia. *Behavioral Interventions*. 25(3), 253-260. A

Martin, L. S., McDowell, S., O'Leary, J., Hagens, C., Bonas, B., Waxman, S., … Rozon, L. (2004). An Observational Study of the Impact of Vibrotactile Rhythm Playing on Seniors in Long Term Care. *Activities, Adaptation & Aging*. 28(2), 57-71

Mathews, R. M., Clair, A. A., & Kosloski, K. (2001). Brief in-service training in music therapy for activity aides: Increasing engagement of persons with dementia in rhythm activities. *Activities, Adaptation & Aging*. 24(4), 41-49. B

McDermott, O., Orgeta, V., Ridder, H. M., & Orrell, M. (2014). A preliminary psychometric evaluation of Music in Dementia Assessment Scales (MiDAS). *International Psychogeriatrics*, *26*(6), 1011–1019. C, F

McDermott, O., Orrell, M., & Ridder, H. M. (2015). The development of Music in Dementia Assessment Scales (MiDAS). *Nordic Journal of Music Therapy*, *24*(3), 232–251. F

McDermott, O., Orrell, M., Ridder, H. M., O., M., & M., O. (2014). The importance of music for people with dementia: the perspectives of people with dementia, family carers, staff and music therapists. *Aging & Mental Health*, *18*(6), 706–716.

McHugh, L., Gardstrom, S., Hiller, J., Brewer, M., & Diestelkamp, W. S. (2012). The effect of pre-meal, vocal re-creative music therapy on nutritional intake of residents with Alzheimer's disease and related dementias: A pilot study. *Music Therapy Perspectives*, *30*(1), 32–42. E

Meilan Garcia, J. J., Iodice, R., Carro, J., Sanchez, J. A., Palmero, & Mateos, A. M. (2012). Improvement of autobiographic memory recovery by means of sad music in Alzheimer's disease type dementia. *Aging Clinical and Experimental Research*. 24(3), 227-232. D

Melhuish, R. (2013). Group Music Therapy on a Dementia Assessment Ward: An Approach to Evaluation. *British Journal of Music Therapy*, *27*(1), 16–31. B

Melhuish, R., & Beuzeboc, C. (2017). Developing relationships between care staff and people with dementia through Music Therapy and Dance Movement Therapy: A preliminary phenomenological study. *Dementia*. 16(3), 282–296.

Moussard, A., Bigand, E., & Belleville, S. (2014). Music as a mnemonic to learn gesture sequences in normal aging and Alzheimer's disease. *Frontiers in Human Neuroscience*. 8(), 1-9. D

Moussard, A., Bigand, E., Belleville, S., & Peretz, I. (2014). Learning sung lyrics aids retention in normal ageing and Alzheimer's disease. *Neuropsychological Rehabilitation*, *24*(6), 894–917. D

Myskja, A., & Nord, P. G. (2008). "The day the music died": A pilot study on music and depression in a nursing home. *Nordic Journal of Music Therapy*. 17(1), 30-40. A, C

Nair, B. K., Heim, C., Krishnan, C., D'Este, C., Marley, J., & Attia, J. (2011). The effect of Baroque music on behavioural disturbances in patients with dementia. *Australasian Journal on Ageing*, *30*(1), 11–15. A

Narme, P., Clement, S., Ehrle, N., Schiaratura, L., Vachez, S., Courtaigne, B., … Samson, S. (2014). Efficacy of musical interventions in dementia: Evidence from a randomized controlled trial. *Journal of Alzheimer's Disease*, *38*(2), 359–369. A

Norberg, A., Melin, E., & Asplund, K. (1986). Reactions to music, touch and object presentation in the final stage of dementia. An exploratory study. *International Journal of Nursing Studies*, *23*(4), 315–323. (note: this paper was republished in the same journal in 2003). C

Olderog Millard, K. A., & Smith, J. M. (1989). The influence of group singing therapy on the behavior of Alzheimer's disease patients. *Journal of Music Therapy*, *26*(2), 58–70.

Osman, S. ., Tischler, V., & Schneider, J. (2014). Singing for the Brain: A qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers. *Dementia*, *15*(6), 1326–1339.

Park, H., & Pringle Specht, J. K. (2009). Effect of individualized music on agitation in individuals with dementia who live at home. *Journal of Gerontological Nursing*, *35*(8), 47–55. A

Peeters, M. M. M., Harbers, M., & Neerincx, M. A. (2016). Designing a personal music assistant that enhances the social, cognitive, and affective experiences of people with dementia. *COMPUTERS IN HUMAN BEHAVIOR*, *63*, 727–737.

Pollack, N. J., & Namazi, K. H. (1992). The effect of music participation on the social behavior of Alzheimer's disease patients. *Journal of Music Therapy*. 29(1), 54-67. B

Raglio, A., Bellelli, G., Traficante, D., Gianotti, M., Ubezio, M. C., Gentile, S., … Trabucchi, M. (2010). Efficacy of music therapy treatment based on cycles of sessions: a randomised controlled trial...[corrected] [published erratum appears in AGING MENT HEALTH 2012; 16(2):265-7]. *Aging & Mental Health*, *14*(8), 900–904. A

Raglio, A., Bellandi, D., Baiardi, P., Gianotti, M., Ubezio, M. C., Zanacchi, E., … Stramba-Badiale, M. (2015). Effect of Active Music Therapy and Individualized Listening to Music on Dementia: A Multicenter Randomized Controlled Trial. *Journal of the American Geriatrics Society*, *63*(8), 1534–1539. A, C, F

Raglio, A., Bellelli, G., Traficante, D., Gianotti, M., Ubezio, M. C., Villani, D., & Trabucchi, M. (2008). Efficacy of music therapy in the treatment of behavioral and psychiatric symptoms of dementia. *Alzheimer Disease and Associated Disorders*, *22*(2), 158–162. A, C

Ragneskog, H., Asplund, K., & Kihlgren, M. (2001). Individualized music played for agitated patients with dementia: analysis of video-recorded sessions. *International Journal of Nursing Practice*. 7(3), 146-155. B

Ragneskog, H., Kihlgren, M., Karlsson, I., & Norberg, A. (1996). Dinner music for demented patients: analysis of video-recorded observations. *Clinical Nursing Research*, *5*(3), 262–282. E

Ray, K. D., & Mittelman, M. S. (2017). Music therapy: A nonpharmacological approach to the care of agitation and depressive symptoms for nursing home residents with dementia. Dementia (14713012), 16(6), 689–710. A

Remington, R. (2002). Calming music and hand massage with agitated elderly. *Nursing Research*, *51*(5), 317–323. A

Ridder, H. M. O., Stige, B., Qvale, L. G., & Gold, C. (2013). Individual music therapy for agitation in dementia: an exploratory randomized controlled trial. *Aging & Mental Health*, *17*(6), 667–678. A

Ridder, H. M., & Aldridge, D. (2005). Individual Music Therapy with Persons with Frontotemporal Dementia: Singing Dialogue. *Nordic Journal of Music Therapy*, *14*(2), 91–106. A

Ridder, H. M., Wigram, T., & Ottesen, A. M. (2009). A pilot study on the effects of music therapy on frontotemporal dementia -- developing a research protocol. *Nordic Journal of Music Therapy*, *18*(2), 103–132. A, C

Riley, P., Alm, N., & Newell, A. (2009). An interactive tool to promote musical creativity in people with dementia. *Computers in Human Behavior*, *25*(3), 599–608.

Runci, S., Doyle, C., & Redman, J. (1999). An empirical test of language-relevant interventions for dementia. *International Psychogeriatrics*. 11(3), 301-311. A

Sakamoto, M., Ando, H., & Tsutou, A. (2013). Comparing the effects of different individualized music interventions for elderly individuals with severe dementia. *International Psychogeriatrics*, *25*(5), 775–784. A

Sambandham, M., & Schirm, V. (1995). Music as a nursing intervention for residents with Alzheimer's disease in long-term care. *Geriatric Nursing (New York, N.Y.)*, *16*(2), 79–83. F

Sanchez, A., Maseda, A., Marante-Moar, M. P., de Labra, C., & Lorenzo-Lopez, L. (2016). Comparing the Effects of Multisensory Stimulation and Individualized Music Sessions on Elderly People with Severe Dementia: A Randomized Controlled Trial. *Journal of Alzheimer's Disease*, *52*(1), 303–315. A

Särkämö, T., Tervaniemi, M., Laitinen, S., Numminen, A., Kurki, M., Johnson, J. K., & Rantanen, P. (2014). Cognitive, Emotional, and Social Benefits of Regular Musical Activities in Early Dementia: Randomized Controlled Study. *The Gerontologist*, *54*(4), 634–650. C

Satoh, M., Yuba, T., Tabei, K., Okubo, Y., Kida, H., Sakuma, H., & Tomimoto, H. (2015). Music Therapy Using Singing Training Improves Psychomotor Speed in Patients with Alzheimer's Disease: A Neuropsychological and fMRI Study. *DEMENTIA AND GERIATRIC COGNITIVE DISORDERS EXTRA*, *5*(3), 296–308. A, C

Sherratt, K., Thornton, A., & Hatton, C. (2004). Emotional and behavioural responses to music in people with dementia: an observational study. *Aging & Mental Health*, *8*(3), 233–241. B

Silber, F. (1999). The influence of background music on the performance of the Mini Mental State Examination with patients diagnosed with Alzheimer's disease. 36(3), 196-206. D

Simmons-Stern, N. R., Budson, A. E., & Ally, B. A. (2010). Music as a memory enhancer in patients with Alzheimer's disease. *Neuropsychologia*, *48*(10), 3164–3167. D

Simmons-Stern, N. R., Deason, R. G., Brandler, B. J., Frustace, B. S., O'Connor, M. K., Ally, B. A., & Budson, A. E. (2012). Music-based memory enhancement in Alzheimer's disease: promise and limitations. *Neuropsychologia*, *50*(14), 3295–3303. D

Sixsmith, A., & Gibson, G. (2007). Music and the wellbeing of people with dementia. *Ageing & Society*. 27(1), 127-145

Shibazaki, K., & Marshall, N. A. (2017). Exploring the impact of music concerts in promoting well-being in dementia care. Aging & Mental Health, 21(5), 468–476.

Shiltz, D. L., Lineweaver, T. T., Brimmer, T., Cairns, A. C., Halcomb, D. S., Juett, J., … Plewes, J. (2018). "Music first": An alternative or adjunct to psychotropic medications for the behavioral and psychological symptoms of dementia. GeroPsych: The Journal of Gerontopsychology and Geriatric Psychiatry, 31(1), 17–30. A

Smith-Marchese, K. (1994). The effects of participatory music on the reality orientation and sociability of Alzheimer's residents in a long-term-care setting. *Activities, Adaptation & Aging*. 18(2), 41-55. C

Sung, H.-C., Chang, A. M., & Lee, W. (2010). A preferred music listening intervention to reduce anxiety in older adults with dementia in nursing homes. *Journal of Clinical Nursing*, *19*(7–8), 1056–1064. A

Sung, H., Lee, W., Li, T., & Watson, R. (2012). A group music intervention using percussion instruments with familiar music to reduce anxiety and agitation of institutionalized older adults with dementia. *International Journal of Geriatric Psychiatry*, *27*(6), 621–627. A

Suzuki, M., Kanamori, M., Watanabe, M., Nagasawa, S., Kojima, E., & Ooshiro, H. (2004). Behavioral and endocrinological evaluation of music therapy for elderly patients with dementia. *Nursing and Health Sciences*, *6*(1), 11–18. A, C

Suzuki, M., Kanamori, M., Nagasawa, S., Tokiko, I., & Takayuki, S. (2007). Music therapy-induced changes in behavioral evaluations, and saliva chromogranin A and immunoglobulin A concentrations in elderly patients with senile dementia. *Geriatrics & Gerontology International*. 7(1), 61-71. A

Svansdottir, H. B., & Snaedal, J. (2006). Music therapy in moderate and severe dementia of Alzheimer's type: a case-control study. *International Psychogeriatrics*, *18*(4), 613–621. A

Tabloski, P., Mc Kinnon-Howe, L., & Remington, R. (1995). Effects of calming music on the level of agitation in cognitively impaired nursing home residents. *The American Journal of Alzheimer's Care and Related Disorders and Research*, *10*(1), 10–15. A

Takahashi, T., & Matsushita, H. (2006). Long-term effects of music therapy on elderly with moderate/severe dementia. *Journal of Music Therapy*, *43*(4), 317–333.

Tanaka, Y., & Nogawa, H. (2015). Evaluating the Effects of Singing Songs in Ethnic Music Therapy for Dementia Patients with a Novel Near-infrared Spectroscopy (Data Analysis Method). *INTERNATIONAL JOURNAL OF GERONTOLOGY*, *9*(1), 7–14. E

Tanaka, Y., Nogawa, H., & Tanaka, H. (2012). Music Therapy with Ethnic Music for Dementia Patients. *INTERNATIONAL JOURNAL OF GERONTOLOGY*, *6*(4), 247–257. E

Thomas, D. W., Heitman, R. J., & Alexander, T. (1997). The effects of music on bathing cooperation for residents with dementia. *Journal of Music Therapy*. 34(4), 246-259. A

Thomas, D. W., & Smith, M. (2009). The effect of music on caloric consumption among nursing home residents with dementia of the Alzheimer's type. *Activities, Adaptation & Aging*. 33(1), 1-16. E

Thompson, R. G., Moulin, C. J. A., Hayre, S., & Jones, R. W. (2005). Music enhances category fluency in healthy older adults and Alzheimer's disease patients. *Experimental Aging Research*. 31(1), 91-99. D

Topo, P., Maki, O., Saarikalle, K., Clarke, N., Begley, E., Cahill, S., … Gilliard, J. (2004). Assessment of a music-based multimedia program for people with dementia. *Dementia: The International Journal of Social Research and Practice*. 3(3), 331-350.

Unadkat, S., Camic, P. M., & Vella-Burrows, T. (2016). Understanding the Experience of Group Singing for Couples Where One Partner Has a Diagnosis of Dementia. The Gerontologist, 0(0), 1–11.

Valdiglesias, V., Maseda, A., Lorenzo-Lopez, L., Pasaro, E., & Millan-Calenti, J. C. (2017). Is Salivary Chromogranin A a Valid Psychological Stress Biomarker During Sensory Stimulation in People with Advanced Dementia? *Journal of Alzheimer's Disease*, *55*(4), 1509–1517. A

van der Geer, E. R., Vink, A. C., Schols, J. M. G. A., & Slaets, J. P. J. (2009). Music in the nursing home: Hitting the right note! the provision of music to dementia patients with verbal and vocal agitation in Dutch nursing homes. *International Psychogeriatrics*, *21*(1), 86–93. A, F

van der Vleuten, M., Visser, A., & Meeuwesen, L. (2012). The contribution of intimate live music performances to the quality of life for persons with dementia. *Patient Education & Counseling*, *89*(3), 484–488. B

Vink, A. C., Zuidersma, M., Boersma, F., De Jonge, P., Zuidema, S. U., & Slaets, J. P. J. (2013). The effect of music therapy compared with general recreational activities in reducing agitation in people with dementia: A randomised controlled trial. *International Journal of Geriatric Psychiatry*, *28*(10), 1031–1038. A

Werner, J., Wosch, T., & Gold, C. (2017). Effectiveness of group music therapy versus recreational group singing for depressive symptoms of elderly nursing home residents. *Nordic Journal of Music Therapy*, *25*(2), 147–155. A

Wittwer, J. E., Webster, K. E., & Hill, K. (2013). Effect of rhythmic auditory cueing on gait in people with Alzheimer disease. *Archives of Physical Medicine and Rehabilitation*, *94*(4), 718–724. E

Wong, A., Burford, S., Wyles, C. L., Mundy, H., & Sainsbury, R. (2008). Evaluation of strategies to improve nutrition in people with dementia in an assessment unit. *The Journal of Nutrition, Health & Aging*, *12*(5), 309–312. E

Ziv, N., Granot, A., Hai, S., Dassa, A., & Haimov, I. (2007). The effect of background stimulative music on behavior in Alzheimer's patients. *Journal of Music Therapy*, *44*(4), 329–343. A

Appendix 3: Confirmation of ethical approval

University of Nottingham
UK | CHINA | MALAYSIA

Faculty of Social Sciences
School of Sociology & Social Policy
University of Nottingham
University Park
Nottingham
NG7 2RD

24/05/2017

Reference: 125-16-17-PGR

Dear Becky

Your application for ethical approval from the School of Sociology and Social Policy

On behalf of the Research Ethics Sub-Committee, I am pleased to confirm that your project "*Evaluation of the CHORD manual: Feasibility study for a randomised control trial*" has been reviewed and approved and you are now welcome to begin your data collection.

If you propose to make any amendments to the approved project or supporting documentation, you must first send details of the amendment along with any supporting documents to the Research Ethics generic email address, LQ-ResearchethicSSP@exmail.nottingham.ac.uk for approval. Please do not use any unapproved or amended documents or procedures before these have been reviewed and approved by the Ethics Sub-Committee.

If you have any queries during your project, please contact either the Research Ethics administration team or your academic supervisor(s).

Good luck with your project!

Kind regards

pp. Dr Alison Mohr
Research Ethics Sub-Committee Officer

Appendix 4: Singing group facilitator recruitment questions

1. What made you apply for this post?
2. What has provoked your interest in working with people with dementia?
3. What challenges have you encountered in working with people with dementia (or care homes/memory cafes) and how do you think you might address them?
4. How do you think music/singing might be beneficial for people with dementia?
5. As part of the study, you would be asked to provide reflections on your work and be observed (potentially filmed/recorded) while running the sessions. How do you feel about this prospect?
6. What do you hope to gain from taking part in this project?

Appendix 5: Poster used to advertise the singing group

Do you have memory problems or dementia?
Would you like to join a singing group?

Researchers at the University of Nottingham are investigating group singing for people with memory problems, and their friends, family and carers. We're recruiting people to join a singing group.

The group will take place in West Bridgford and is expected to begin in August. It will last for ten weeks.

You don't need to have any previous experience of singing to take part!

Interested? Get in touch to find out more!

Phone or Text: 07928618644

Email: lqxerdo@nottingham.ac.uk

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This study has been granted ethical approval by the Research Ethics Sub-Committee at the School of Sociology and Social Policy, University of Nottingham.

Project Reference: 125-16-17-PGR

Appendix 6: Interview topic guides for participants

Interviews conducted with participants before the sessions	
Topic: Music and the role it plays in your life.	• What has music meant to you in life? • What does it mean now? • What sort of musical activities (singing, listening to the radio etc.) do you do now? • Has the way music is present in your life changed? • Do you think of yourself as musical? Or perhaps the opposite?
Topic: Expectations and hopes for the singing group	• Why are you interested in joining the singing group? • What do you expect from it? • Do you have hopes or fears? • Do you think it might benefit you in any way? • Do you think it might benefit anyone who comes with you, or the relationship between you?
Topic: Being part of research	• How do you feel about being part of research? • Have you been involved in research before?

Interviews conducted with participants after the sessions	
Topic: Musical and social experience of being in the group	• What was it like being in the group? • What did you enjoy about it, and what did you not like so much? What would you have changed? • What did you think of the group leader? • How did the group change over time, and how did the relationships between people in the group develop?
Topic: Benefits of the group	• Did you find that the group had any benefits for you? • Has the group changed anything about the way you use music in your day to day life? • If someone came to the group with you, did it affect your relationship with them?
Topic: Being part of research	• What was it like being in the study? e.g. being filmed, doing the outcome measures. • Do you think it affected the way you took part in the group? • Would you do it again?

Appendix 7: Interview topic guide for facilitator

Topic: Using the CHORD manual.

1. What were your expectations for running the group?
2. Was there anything which you felt particularly concerned about? (either skill-related or generally)
3. Were there any areas you felt pretty comfortable with already?
4. What were your expectations of the manual? What were your initial reactions to it? Do you think it is user-friendly (format/layout etc)?
5. Can you describe how you would plan for a session at the start of running the group, and how you would use the manual to do that?
6. Did you use any other resources as well as the manual and why? (i.e. what was missing from the manual?)
7. Having started leading the group, did your opinion of the manual change?
8. Did your use of the manual change during the run of the group?
9. What did you like about the CHORD manual, if anything?
10. What would you change about the manual, if anything?
11. Was there anything in the manual that you thought was irrelevant?
12. Having led the group for a couple of months, is there anything that you wish you had known at the start?
13. If you hadn't had the CHORD manual, what, if anything, do you think you would have done differently?
14. Who do you think the CHORD manual is for?

Topic: Experiences of singing group members

1. How did you feel the group responded to singing?
2. What other aspects of the sessions were important?
3. Did you notice any changes in the group during the course of the sessions?
4. Did you notice any changes in individual group members?
5. Do you think people's responses differed according to the severity of their dementia?
6. Do you think group members experienced any benefits from attending the group?
7. How did you feel the group responded to you and the way you lead the sessions?

Topic: Feasibility of research methods

1. How did you feel about taking part in research?
2. How did you find the manual adherence forms?
3. Did you feel that being part of research affected the dynamic of the group and what happened during the sessions?
4. Thinking about future research, there's the possibility of an RCT based on the CHORD manual. Do you think it would be a possible to use the CHORD manual to ensure a standardised intervention?

Appendix 8: CHORD manual adherence form

Chord Manual Adherence Form

This form is not about testing you! It's about seeing whether it's possible to describe the extent to which the advice in the manual is followed. Please read the form and circle the most appropriate response for each question. Try and fill it in soon after the session if you can, so it's fresh in your mind. Think about just today's session, and the preparation you did for it, when you answer. If you find a question difficult to answer, or you aren't sure, just give your best guess.

When you think about the questions, if there was no opportunity to use a certain piece of advice during the session, select "It wasn't relevant". If there was the opportunity to use a piece of advice and you did not use it, select "Not at all".

There's a space at the end where you can record any thoughts you have about filling in the form. If you find any questions particularly difficult to answer, please make a note of them here.

Before today's group…

1) To what extent did you use advice from the CHORD manual about **planning and structuring** to prepare for today's session?

1. It wasn't relevant	2. Not at all	3. Somewhat	4. Quite a lot	5. Very much

2) To what extent did you follow advice about **debriefing and looking after yourself** in the week before this session?

1. It wasn't relevant	2. Not at all	3. Somewhat	4. Quite a lot	5. Very much

During the group today…

3) To what extent did you follow advice from the CHORD manual about **initiating music** in the session? (e.g. choosing what songs to sing and how to sing them)

1. It wasn't relevant	2. Not at all	3. Somewhat	4. Quite a lot	5. Very much

4) To what extent did you follow advice about **how to respond to music or ideas initiated by group members?** (e.g. picking up the key a person starts singing in, responding to remarks with an appropriate song)

1. It wasn't relevant	2. Not at all	3. Somewhat	4. Quite a lot	5. Very much

5) To what extent did you follow advice about **how to pace the session?** (e.g. going at an appropriate speed, leaving breathing space between songs, making choices based on the energy levels in the room)

1. It wasn't relevant	2. Not at all	3. Somewhat	4. Quite a lot	5. Very much

6) To what extent did you follow advice about **basing your choices on knowledge about the group?** (e.g. choosing music with an appropriate level of challenge and familiarity)

1. It wasn't relevant	2. Not at all	3. Somewhat	4. Quite a lot	5. Very much

7) To what extent did you use advice about **how to work sensitively with people with dementia** (e.g. being patient in communication, using "la-la-ing" instead of words)?

1. It wasn't relevant	2. Not at all	3. Somewhat	4. Quite a lot	5. Very much

8) To what extent did you use guidance about **how to encourage group cohesion and feeling** (e.g. acknowledging the group's time together, empowering the group to make choices)?

1. It wasn't relevant	2. Not at all	3. Somewhat	4. Quite a lot	5. Very much

9) To what extent did you follow advice about **acknowledging individuals within the group** (e.g. basing suggestions on an individual's preferences, using your knowledge of them to decide to offer a solo)?

1. It wasn't relevant	2. Not at all	3. Somewhat	4. Quite a lot	5. Very much

10) To what extent did you use advice about **coping with problems** (e.g. what to do when a song doesn't go so well, sharing your challenges with the group)

1. It wasn't relevant	2. Not at all	3. Somewhat	4. Quite a lot	5. Very much

11) To what extent did you follow advice about **being emotionally sensitive and receptive** to group members (e.g. reading the mood in the room, allowing people time and space for strong emotional reactions)

1. It wasn't relevant	2. Not at all	3. Somewhat	4. Quite a lot	5. Very much

Please write any other thoughts or comments (about filling in this form or using the manual generally) below: