

How do arts practitioners engage the  
person with dementia living in a care home  
setting?

Amy Veale BSc. MRes.

A thesis submitted in partial fulfilment of the  
University's requirements for the Degree of  
Doctor of Philosophy

2020

University of Worcester

# Abstract

## Background

The arts are recognised as a form of meaningful activity that can support people with dementia to live well. While the potential benefits of arts engagement are well reported in the dementia research literature, less attention has been paid to the social processes underpinning arts activity engagement. The need to elucidate the theoretical basis of arts activities to understand how and why the arts can enable change in dementia has been noted. This study contributes to the existing evidence base by creating a theoretical framework to explain how arts practitioners engage the person with dementia in a care home setting. This theory is of potential interest to researchers, arts practitioners, and others who wish to understand and articulate how the arts can positively impact the lives of care home residents living with dementia.

## Method

A Straussian grounded theory approach was used to develop a theoretical framework of arts activity engagement. The first phase of the study focused on the development of the theory from a series of in-depth interviews. The second phase of the study involved the testing and further development of the theory based on observations and interviews related to dance therapy and poetry activities at one care home. This two-phased approach to data collection involved arts practitioners, arts mentors/trainers, artistic directors, residents living with dementia, and care staff.

## Results

The metaphor 'scaffolding', borrowed from the field of education, encapsulates the process by which practitioners use the arts to encourage, support, and enhance capacities for meaningful engagement and change in dementia. This metaphor constitutes the core category of the theory comprised of three subprocesses: 'Inviting and inspiring engagement'; 'cultivating meaningful connections'; and 'nurturing

change'. The theoretical framework further consists of a range of conditions that impact upon the process of arts engagement, as well as a range of consequences that can result from it.

## Conclusion

The theory and core category of 'scaffolding' highlight how arts practitioners encourage and support residents to realise their potential for engagement and change. The theory further explains how arts activities can act as a scaffold for positive and affirming relationships in dementia, through which the autonomy, uniqueness, and value of residents can be recognised, and their personhood upheld. As an emergent theory, the framework developed in this study has limitations and would benefit from further testing.

## Acknowledgements

This PhD would not have been possible without support. Firstly, I would like to extend my gratitude to the Alzheimer's Society for funding the research. To my supervisors, Professor Dawn Brooker, Dr Simon Evans, and Professor Amanda Griffiths, thank you for supporting me through this process. Your encouragement, positivity, insights, and patience were much needed and appreciated. To my fellow TAnDem students- the PhD journey would not have been the same without you. Thank you for your friendship, insights, and support.

A huge thank you to all the arts practitioners and other research participants who so generously gave their time to support this PhD. A special thanks to the care home, residents and care staff who participated in the study, and to the arts practitioners who kindly let me observe their practice. My time with you all was truly the highlight of the PhD.

And finally, to Billy, Trevor, Graham, Mum and Dad. I couldn't have done it without you.

# Table of contents

Abstract .....	p.2
Acknowledgements .....	p.4
Table of contents.....	p.5
List of tables .....	p.10
List of textboxes .....	p.10
List of figures .....	p.11

## **1. Chapter 1: Introduction**

1.1. Context for the study .....	p.12
1.2. Arts and dementia research .....	p.14
1.3. Motivations for the PhD study .....	p.15
1.4. My role as the researcher .....	p.16
1.5. Aims, research question, and scope of the study .....	p.18
1.6. Thesis structure .....	p.20
1.7. Conclusion .....	p.21

## **2. Chapter 2: Literature Review**

2.1. Introduction .....	p.22
2.2. Reviewing the literature in grounded theory .....	p.22
2.3. The purpose of the literature review .....	p.23
2.4. Methods of the literature review .....	p.24
2.5. Findings 1: How has arts activity engagement been studied in the literature? .....	p.32
2.5.1. Studies measuring engagement outcomes .....	p.32
2.5.2. Studies examining the impact of different conditions on engagement outcomes .....	p.35
2.5.3. Studies exploring perspectives about the value of arts engagement .....	p.38

2.5.4. Studies that examined arts engagement as a social process.....	p.39
2.6. Findings 2: What is understood about arts engagement	
from the literature? .....	p.40
2.6.1. The social process of arts engagement .....	p.41
2.6.2. The value of arts engagement.....	p.43
2.6.3. Conditions and contextual factors that	
can influence arts engagement .....	p.44
2.7. Discussion of the literature .....	p.46
2.8. Conclusion .....	p.49
<b>3. Chapter 3: Methodology</b>	
3.1. Introduction.....	p.50
3.2. The research paradigm .....	p.50
3.3. Choosing grounded theory as a methodology .....	p.51
3.4. Choosing between grounded theory approaches .....	p.52
3.5. Positionality and reflexivity .....	p.55
3.6. Research design and methods of data collection .....	p.56
3.6.1. The interview .....	p.56
3.6.2. Observations .....	p.58
3.7. Conclusion .....	p.59
<b>4. Chapter 4: Methods, Phase 1</b>	
4.1. Introduction .....	p.60
4.2. Theoretical sampling .....	p.60
4.2.1. Examples of theoretical sampling .....	p.61
4.3. Interview participants .....	p. 63
4.3.1. Inclusion criteria .....	p.63
4.3.2. The recruitment process .....	p.65
4.4. The interviews .....	p.65
4.4.1. The interview approach .....	p.66
4.4.2. Reflections on interviews .....	p.68
4.4.3. Reflections on telephone and face-to-face interviews .....	p.70
4.5. Ethical issues .....	p.71
4.6. Analysis .....	p.72
4.6.1. Data preparation .....	p.72

4.6.2.	Open coding .....	p.73
4.6.3.	Using memos to develop and organize categories .....	p.77
4.6.4.	Axial coding .....	p.78
4.6.5.	Selective coding.....	p.81
4.7.	Conclusion .....	p.85
<b>5.</b>	<b>Chapter 5: Methods, phase 2</b>	
5.1.	Introduction.....	p.88
5.2.	Design and sampling decisions.....	p.88
5.3.	Introducing the care home, the arts practitioners, and the residents.....	p.89
5.3.1.	The care home.....	p.89
5.3.2.	The arts practitioners.....	p.90
5.3.3.	The residents.....	p.91
5.4.	Ethical approval.....	p.94
5.5.	Recruitment.....	p.95
5.5.1.	Recruitment of the care home.....	p.95
5.5.2.	Recruitment of the arts practitioners.....	p.96
5.5.3.	Resident recruitment.....	p.97
5.6.	Data collection.....	p.100
5.6.1.	Observations.....	p.100
5.6.2.	Protocol and procedure for the observations.....	p.102
5.6.3.	Post-observation interviews.....	p.103
5.7.	Analysis .....	p.104
5.8.	Reflections on phase 2 data collection.....	p.106
5.8.1.	Reflections on observations and DCM.....	p.106
5.8.2.	Reflections on my influence.....	p.107
5.9.	Conclusion.....	p.108
<b>6.</b>	<b>Chapter 6: Findings 1: The core category of scaffolding and its subprocesses</b>	
6.1.	Introduction.....	p.110
6.2.	Introduction to the core category.....	p.110
6.2.1.	Perceptions of loss in dementia.....	p.112
6.2.2.	The metaphor of scaffolding.....	p.113
6.2.3.	Cultural, material, and social resources as scaffolds.....	p.114
6.3.	Scaffolding as the core category in the current research.....	p.118

How arts practitioners enhanced capacities for engagement and change.....	p.119
6.3.1. How arts practitioners encouraged capacities for engagement and change.....	p.123
6.3.2. How arts practitioners supported capacities for engagement and change.....	p.126
6.3.3. How arts practitioners scaffolded relationships in dementia .....	p.128
6.4. The subprocesses of scaffolding .....	p.131
6.4.1. Inviting and inspiring engagement .....	p.132
6.4.2. Cultivating meaningful connections .....	p.139
6.4.3. Nurturing change .....	p.147
6.5. Intervening conditions .....	p.151
6.5.1. Practitioner differences .....	p.151
6.5.2. Resident differences .....	p.153
6.5.3. Group size and composition .....	p.154
6.6. Context .....	p.156
6.6.1. Time .....	p.156
6.6.2. The activity space .....	p.158
6.6.3. The care home .....	p.159
6.7. Conclusion .....	p.161
<b>7. Chapter 7: Findings 2: Causal conditions and consequences of scaffolding</b>	
7.1. Introduction .....	p.165
7.2. The causal conditions of scaffolding .....	p.165
7.2.1. A safe and supportive space .....	p.165
7.2.2. Meaningful engagement opportunities .....	p.171
7.2.3. A thoughtful and responsive approach .....	p.175
7.2.4. Authentic and nurturing relationships .....	p.181
7.3. The consequences of scaffolding .....	p.183
7.4. Conclusion .....	p.185
<b>8. Chapter 8: Discussion</b>	
8.1. Introduction.....	p.186
8.2. Engagement.....	p.186



8.2.1. Engagement as a process.....	p.186
8.2.2. Engagement as an outcome.....	p.188
8.2.3. Influence of the care home culture on engagement .....	p.189
8.2.4. The ethics of engagement.....	p.190
8.3. Scaffolding.....	p.193
8.3.1. The usefulness of scaffolding as a metaphor.....	p.193
8.3.2. Practitioner differences and scaffolding.....	p.195
8.4. Person-centredness.....	p.198
8.4.1. The relevance of person-centred philosophy.....	p.198
8.4.2. Person-centred frameworks and arts engagement.....	p.200
8.5. Strengths of the grounded theory .....	p.205
8.6. Limitations of the study.....	p.209
8.7. Conclusion.....	p.211
<b>9. Chapter 9: Conclusion</b>	
9.1. Introduction.....	p. 212
9.2. How this study has contributed to the evidence base.....	p. 212
9.3. Reflections on how I impacted the research.....	p. 213
9.4. How this study has changed me.....	p. 216
9.5. Conclusion.....	p.219
References .....	p.220
Appendices .....	p.231
Appendix 1: Participant information sheet arts practitioners, phase 1.....	p.231
Appendix 2: Participant information sheet care staff, phase 1.....	p.238
Appendix 3: Consent form for arts practitioners, phase 1.....	p.245
Appendix 4: Consent form for care staff, phase 1.....	p.248
Appendix 5: Excerpt from interview transcript.....	p.250
Appendix 6: Participant information sheet arts practitioners, phase 2.....	p.252
Appendix 7: Consent form for arts practitioners, phase 2.....	p. 259

Appendix 8: Consultee information sheet.....	p.261
Appendix 9: Consultee declaration form.....	p.269

## List of tables

Table: 2.1: Search terms used in the literature review.....	p.25
Table 2.2: Characteristics of studies included in the literature review.....	p.27
Table 4.1: Characteristics of phase-1 interviews.....	p.64

## List of textboxes

Textbox 6.1: The Romance. Narrative description of a poetry session.....	p.120
Textbox 6.2: The Horse Bridle, part 1. Narrative description of a poetry session.....	p.125
Textbox 6.3: The Band. Narrative description of a dance therapy session.....	p.127
Textbox 6.4: The Balloon. Narrative description of a dance therapy session.....	p.130
Textbox 6.5: Making Moves. Narrative description of a dance therapy session.....	p.140
Textbox 6.6: The Horse Bridle, part 2. Narrative description of a poetry session.....	p.143
Textbox 6.7: The Cemetery. Narrative description of a poetry session.....	p.149
Textbox 6.8: The Leaf in my Hand. Narrative description of a poetry session.....	p.157
Textbox 7.1: Making Choices. Narrative description of a dance therapy session.....	p.167
Textbox 7.2: The Jam. Narrative description of a poetry session.....	p.173
Textbox 7.3: The Solo. Narrative description of a dance therapy session.....	p.179

## List of figures

Figure 4.1: A tentative grounded theory of arts activity engagement in care homes.....	p.87
Figure 6.1: A grounded theory of arts activity engagement in care homes.....	p.111

# Chapter 1: Introduction

## 1.1. Context for the study

It is estimated that there are almost 885,000 older people living with dementia in the UK (Wittenberg et al., 2019). Dementia refers to a set of clinical symptoms that can include difficulties with language, memory loss, problem-solving, concentration, and planning, as well as visuo-perceptual difficulties. The symptoms experienced by someone living with dementia will vary depending on the underlying cause and the areas of the brain that are impacted. While the underlying causes of dementia are numerous, Alzheimer's disease is the most common type of dementia, accounting for more than 60% of all cases, followed by vascular dementia (Prince et al., 2014). Dementia is not an inevitable consequence of ageing, yet it does disproportionately impact older people. The prevalence amongst those aged 65 and over is currently estimated at 7.1%, while projections show that the number of older adults living with dementia could reach one million by 2024 (Wittenberg et al., 2019). With no cure for dementia, and an ageing demographic, some have called it the biggest health concern of our time.

The launch of the national dementia strategy made dementia a policy priority in England (Department of Health, 2009). The government's commitment to dementia was restated in the Prime Minister's Challenge on Dementia 2020, which aims to make England the best country in the world to live with dementia and to receive care and support (Department of Health, 2016). With a substantial proportion of those affected by dementia residing in care homes (39% of those over the age of 65), and the prevalence of dementia in these settings estimated at 69.0% (Prince et al., 2014), the question of how care home residents can receive the best care and support to live well is fundamental to achieving the government's vision.

The question of how best to care and support people with dementia underwent a paradigm shift in the 1990's. This shift was heavily influenced by the work of Tom Kitwood who criticised the prevailing biomedical approach to dementia care focused on brain pathology. Kitwood believed that dementia care should become person-centred by recognising the personhood of those living with dementia, something he defined as: *'a standing or status...bestowed upon one human being, by others, in the context of relationship and social being.'* (Kitwood, 1997a,

p.8). Person-centred care therefore considers social and psychological aspects of wellbeing in dementia. More recently Droes et al. (2017), have identified three requirements for good dementia care: (1) the capacity to fulfil one's potential; (2) the ability to manage life with some degree of independence; and (3) participation in social activities.

Participation in meaningful activity is of crucial importance for wellbeing in dementia (Nyman & Szymczynska, 2016). For those residing in care homes, cognitive limitations mean that residents are reliant upon the care home to meet activity needs (Mansbach et al. 2017). As such, the National Institute for Health and Care Excellence has published guidance for local authorities, commissioning services, and care providers to ensure that activities are available to promote wellbeing (NICE, 2013; 2019). Yet, while the importance of meaningful activity in dementia is well established, and reflected in NICE guidelines, questions about what constitutes meaningful activity in dementia, and how meaningful activity can positively impact wellbeing, are less well considered. Mansbach et al. (2017) have speculated that content and delivery could impact meaningfulness. Nyman and Szymczynska (2016) have called for the application of psychological theory to examine how activities can bring about change, reasoning that this could help to inform and shape practice in the field.

In recent years there has been a growing interest in the potential of the arts to improve health and wellbeing outcomes, both in dementia and more generally. In 2014, the All-Party Parliamentary Group on Arts, Health and Wellbeing (APPG) was created to raise awareness of the benefits of the arts. Their inquiry (2017) concluded that the arts were a *'resource that should be embraced in health and social care systems'* given the health and wellbeing benefits (p.10). Engagement with the arts is recognised by NICE as a form of meaningful activity in dementia (NICE, 2019) and in care homes (NICE, 2013). The Baring Foundation have also made a compelling argument for the use of arts activities in care homes, outlining how they can help meet definitions of excellence as identified by the Social Care Institute for Excellence (SCIE, 2010), including choice and control, relationships, and purposeful and enjoyable activity (Cutler, Kelly and Silver, 2011).

The strength of conviction about the value of the arts in care homes is evidenced in a growing arts and dementia field. A rapid expansion in the sector has been observed in recent years as a growing number of arts practitioners establish their practice in care homes (Allen, 2018). While this *'wonderfully diverse, rich array of practice,'* is cited as cause for celebration, Allen concludes that the time is now ripe for learning and reflection about what constitutes good

practice in care homes (p.4). Allen further reflects that the need for advocacy or justification for arts in care homes has been replaced somewhat by the need to understand and support best practice. This is something she attributes to the efforts of those who have worked tirelessly to establish effective arts practices in care homes over many years.

## 1.2. Arts and dementia research

Academic studies can demonstrate impact and lend further credibility to the use of the arts in dementia. Yet the utility of quantitative, experimental studies that attempt to measure the impact of the arts, has been called into question. Experimental studies have been criticised on the grounds of small sample sizes, the absence of control groups, lack of consistent measurement, lack of longitudinal data, and for a failure to consider theoretical frameworks (Young, Camic and Tischler, 2016). In the arts therapies, the dominance of clinical outcome measures that focus on the measurement of the Behavioural and Psychological Symptoms of Dementia (BPSD) have been criticised for emphasising the needs of carers over the 'personal enrichment' of the person with dementia (Beard, 2011). The suitability of experimental research designs and the use of standardised measures have also been called into question where attempts to quantify outcomes and generalise findings can overlook the richness and diversity of individual arts experiences (de Madieros & Basting, 2014). Some have advised that qualitative data might be a more appropriate way of capturing the impact of the arts in dementia (de Madieros & Basting, 2014; Davidson & Fedele, 2011).

The ability to demonstrate impact has therefore been complicated by measurement issues, disagreements over what should be measured, and how impact can be demonstrated. Yet, a preoccupation with outcomes has meant that questions about what constitutes an effective arts practice, and how and why arts activities bring about change in dementia, are less well explored. Various aspects of an arts intervention could have an important impact on outcomes, yet interventions tend to be poorly documented and described (Kent & Rose, 2013). The need to better understand the theoretical underpinnings of arts interventions has been noted (Young, Camic and Tischler, 2016). It has been argued that theoretical frameworks would not only contribute to the evidence base but could also have real-world impact by informing the development, delivery, and evaluation of arts interventions (Windle, 2018).

Theoretical frameworks for the arts in dementia have in fact started to emerge in recent years. Notable contributions to date have included a theory of gallery-based interventions (Camic, Baker and Tischler, 2016), a theory of visual arts programmes (Windle et al, 2018), and a theory of music-making in late-stage dementia (Clare et al, 2020). These studies have started to illuminate how the arts can bring about change in dementia. Camic, Baker and Tischler (2016), found that social interaction, intellectual stimulation, and the museum setting, all brought about positive change for both people with dementia and their carers. Clare et al. (2020), found that the ‘multisensory communicative environment’ that was created in live music sessions was fundamental to enhancing communication, social interaction, and agency in dementia. Windle et al. (2018), found that a ‘provocative and stimulating aesthetic experience’, and a ‘dynamic and responsive artistic practice’ underpinned effective visual arts programmes, and that theories relating to person centred care, cognitive stimulation, and resilience all helped to explain how and why visual arts programmes had a positive impact. The studies mentioned above have all provided valuable insights about how and why arts activities can enable change. Yet theory development is still in its infancy. Indeed, Windle et al. (2018) stressed that their theory was not definitive but was intended as ‘*a starting point at identifying theories of change.*’ (p.703). Any number of theories could potentially help to advance our understanding of the arts and dementia. It should also be noted that the theories mentioned above have focused on a particular art form or a specific arts intervention. De Madieros & Basting, (2014) called for a move away from a focus on one art form when effective approaches could cut across different activities. Theory based on a variety of arts activities could advance our understanding of how the arts can bring about change more generally.

### 1.3. Motivations for the PhD study

The TAnDem (The Arts and Dementia) Doctoral Training Centre was established in 2015. TAnDem is funded by the Alzheimer’s Society and is a partnership between the Association for Dementia Studies at the University of Worcester, and the Centre for Dementia at the University of Nottingham. The aim of TAnDem is to contribute to the evidence base for the arts

and dementia. This PhD project is one of six that have contributed/ will contribute to the existing evidence base.

The decision to focus this PhD on theory development and on the topic of arts engagement in care homes was made for several reasons. Firstly, by creating a theory, the PhD would contribute to theoretical knowledge in a relatively under-theorised area. A narrative review of the literature, (the focus of the next chapter), revealed that for the most part, arts engagement had been studied as an outcome and not as a process. The process by which arts practitioners engaged residents during an arts session had received relatively little attention. Secondly, the decision to develop a theory of engagement was driven by a desire to produce something that might hold practical value for arts practitioners. The report of the All-Party Parliamentary Group for Arts, Health and Wellbeing, recommended that stakeholders should work together to '*support the advance of good practice*' (2017, p.154). Given the extent of practical experience in the field, and the need to share learning (Allen, 2018), I reasoned that the theory could serve as a reflective tool for both new and established arts practitioners. I also reasoned that the framework might also be of interest to care homes and commissioners wishing to understand and procure arts activities.

Finally, my background and experience influenced my decision to undertake this PhD and to focus the research as I did. The next section will provide an account of who I am as a person, and what led me to this research.

#### 1.4. My role as the researcher

Because I am part of the social world I am studying, and not separate from it, who I am as a person will have inevitably influenced this research. With this in mind, I engaged in reflexivity throughout the study to consider how my background, interests, beliefs, and assumptions entered into the research. The goal of reflexivity was not to eliminate my impact, but to become more self-aware and transparent about my influence, and to guard against overt bias. Chapter nine will provide a more detailed account of my influence, yet at this point I will share some pertinent background information about who I am and what led me to this PhD.



My first experience of being in a care home was in 1998 when I was required to volunteer as part of the Duke of Edinburgh's Award scheme. The experience was such an upsetting one that I did not return to the home. I had been tasked with helping with dinner. As I brought food from the kitchen, I noticed how some of the residents were being fed, yet staff did not speak to them. One member of staff who did converse with the residents used 'baby talk'. Many of the residents seemed depressed and withdrawn, yet some called for my attention as I walked to and from the kitchen. I was instructed to ignore them. The experience left me with a very negative impression of care homes.

My next encounter with care homes was in a professional capacity. Between 2007 and 2015, I worked for the older people's charity Age NI. During that time, I became involved in several projects in care homes, including a piece of work commissioned by the Department for Health and Social Services in Northern Ireland as part of a review of minimum standards. The main issues identified through talking with residents were a lack of meaningful interaction and occupation/activity in the homes. Residents complained that staff delivered care yet there was no time for conversation. They complained there was nothing to do in the home. Many spent their days confined to their bedrooms, alone. I saw how entitlements to participation in social and cultural life and opportunities for self-fulfilment were often denied to older persons in these settings, and I was concerned by the lack of quality activity provision that I witnessed in some care homes. I became interested in ways to remedy this. My decision to focus this research in care homes was therefore partly driven by my prior experiences. I had developed a concern for the wellbeing of residents. I wanted to make some small contribution to the development of activities in these settings.

In 2015, I undertook a six-week fellowship to North America with the Winston Churchill Memorial Trust to explore arts activities as a form of meaningful activity engagement in dementia. Upon witnessing the potential of the arts, this experience spurred me to undertake the PhD. It seems important to mention that unlike some of my fellow PhD students in TAnDem, I was not an arts practitioner, and I did not come to the PhD from an arts background. Despite my Churchill Fellowship, the topic of arts engagement was still something I knew relatively little about. This also influenced my decision to focus the research as I did. The development of a pragmatic theory allowed me to indulge my curiosity about how the arts engaged persons with dementia, and I relished the opportunity to learn from established practitioners. Yet, whilst I knew I had much to learn, I had inevitably started to form my own

assumptions about engagement during the Churchill Fellowship. Chapter nine provides an account of these assumptions and how they impacted the study. The chapter also explains how my position changed over the course of the research and through interactions with my participants.

## 1.5. Aims, research question, and scope of the study

The aim of this PhD was to contribute to knowledge by producing a theory of arts activity engagement in care homes. The question guiding the study was:

*'How do arts practitioners engage the person with dementia living in a care home setting?'*

Grounded theory was chosen as the methodology best suited to the purpose of theory development. Grounded theory was developed in response to the perceived '*overemphasis on the verification of theory, and the resultant de-emphasis on the prior step of discovering what concepts and hypotheses are relevant*' for a substantive area of inquiry (Glaser and Strauss, 1967). In the seminal text, *the Discovery of Grounded Theory*, Glaser and Strauss (1967) argued that a fixation with testing theory had constrained our understanding of social phenomena. The rationale underpinning grounded theory is a belief that the best theories are those developed inductively from empirical data. Rather than starting analysis with a pre-existing theory, theory that is developed from and 'grounded' in the empirical data, should provide a better explanation of the data, and a more nuanced understanding of a substantive area. While existing concepts and theories may turn out to be highly relevant for the area under investigation, these are to be considered later in the research process so as not to inhibit new insights (Glaser and Strauss, 1967).

A further aim of this study was to produce a pragmatic theory that could explicate the social process of arts engagement. Where several versions of grounded theory exist, it was considered that Straussian grounded theory aligned best with this goal. Straussian grounded theory places action and interaction at the heart of theory development, so that theory can '*guide practice.*' (Corbin and Strauss, 2015, p.27). Straussian grounded theory would therefore

help me develop a pragmatic theory of arts engagement and this could potentially help to inform practice in the field. An in-depth discussion of my decision to use Straussian grounded theory will be reserved for chapter three.

At this point, some clarity about definitions and the scope of the study might prove helpful. This research focused specifically on structured arts activities, led by arts practitioners, in care home settings. The 'arts' in this study refer to the visual, performing, and literary arts. Arts 'activities' refer to activities that involve the active participation of residents (e.g. painting), as well as more receptive activities focused on the appreciation of the arts (e.g. watching a performance). 'Structured' activities refer to those activities organised as part of a scheduled activities programme in a care home. 'Arts practitioners' refer to the professional artists, performers, and arts therapists who deliver arts sessions in care homes. The use of the term 'theory' in this study follows the definition given by Corbin and Strauss (2015) who state that theory '*denotes a set of well-developed categories*' that are '*interrelated through statements of relationship to form a theoretical framework*' (p.62). Theories can be substantive, middle range, or formal in nature (Glaser and Strauss, 1967). The theoretical framework developed in this study is substantive in nature because it applies to the context of arts engagement in care homes. While the theory could potentially have broader applicability, any use of the theory beyond the substantive area from which it emerged (according to the definitions detailed above), would require further research.

It is recognised that this study could have focused differently. The definition of the arts can extend to complementary art forms like gardening and baking (Cousins et al. 2020). Arts activities can be led by volunteers, care staff, and family members. Engagement with the arts can happen in spontaneous ways, and not just as part of a scheduled activities programme (Basting, 2018). The arts can be used to 'manage' the behavioural and psychological symptoms of dementia (BPSD), or to encourage cooperative behaviours such as those related to personal care (Ray & Fitzsimmons, 2014). Yet it was not possible within the scope of this project to explore all the ways in which the arts are used in care homes and some parameters were needed to focus the project. A focus on arts as activities also reflected my interest in personal enrichment and meaningful activity, rather than the arts as an intervention to 'manage behaviours'. A focus on structured activities reflected my own experience. I had attended and participated in many arts activities in care homes – and they had always been provided as part

of a structured activities programme. A focus on professional arts practitioners reflected my interest in the growing number of arts therapists, performers, and professional artists working in care home settings.

## 1.6. Thesis structure

This thesis is comprised of nine chapters in total. In this first chapter I have introduced and explained the rationale for the study. I have highlighted the potential contribution of the study to research knowledge and arts practice.

Chapter two provides an account of findings from a narrative review of the literature focused on the topic of arts engagement for dementia in care homes. The review aimed to situate the current study in the context of the existing literature, and to identify concepts and ideas in the literature that might have proven relevant for my own theory.

Chapter three provides an account of the methodology used in the study. The chapter begins with an account of my ontological and epistemological assumptions. The chapter explains the rationale for using grounded theory as a methodology. The suitability of the different grounded theory approaches is considered and reasons for choosing Straussian grounded theory are made clear. The strengths and weaknesses of grounded theory as a methodology and the Straussian version of the method are discussed. An outline of the research design and methods is provided. The strengths and weaknesses of interviews and observations as methods of data collection are considered.

Chapter four reports on phase one data collection involving a series of in-depth interviews. The aim of this first phase of data collection was to build a tentative theory of arts engagement from the empirical data. The chapter provides an account of recruitment procedures and the use of theoretical sampling. My approach to interviewing is described in detail and reflections about the interviewing process are provided. Ethical issues are also considered. A detailed account of analysis and theory building from interview data using Straussian techniques and coding procedures is presented. The chapter ends with a tentative theory of arts activity engagement.

Chapter five reports on phase two data collection involving a series of observations and reflective interviews in one care home. The aim of this second phase of data collection was to validate the tentative theory developed from phase one data, and to further develop and refine the theory. The chapter provides a detailed account of recruitment and data collection procedures. Ethical considerations are discussed. My approach to the analysis of phase two data is described and additions to the tentative theory are shared.

Chapters six and seven synthesise the findings from the first and second phases of data collection to present a final version of the grounded theory. Interview and observational data are used to illustrate the categories and concepts of the theory. Given the density and complexity of the theory, findings are split across two chapters. Chapter six focuses on the core category and subprocesses of the theory, as well as the contextual and intervening conditions of the theory. Chapter seven focuses on the causal conditions and consequences of the theory.

Chapter eight discusses the grounded theory across three major areas of importance: (1) scaffolding, (2) engagement, and (3) person-centredness. Findings are considered alongside the relevant research literature. Strengths and weaknesses of the grounded theory and the study are considered. The chapter also considers the possible implications of research findings for future research.

Chapter nine clarifies how this study has made an original contribution to research knowledge. The chapter also shares my reflections about how I impacted the research study, and how the research study changed me.

## 1.7. Conclusion

In the absence of a cure for dementia, this chapter revealed how dementia care and support has become a national policy priority in England. The need to support persons with dementia to live well is acknowledged, and there has been a growing interest in the arts as a form of meaningful engagement in dementia. Yet despite a rapidly growing arts and dementia sector, the theoretical underpinnings of arts activities are not well understood. Little is known about how and why arts activities bring about change in dementia. This chapter showed how the study would address this gap in research knowledge by developing a grounded theory to explain arts engagement for people with dementia in care homes.

## Chapter 2: Literature Review

### 2.1. Introduction

Chapter one highlighted limitations in the current evidence base for the arts and dementia. It was proposed that a theoretical framework of arts engagement in care homes would contribute to research knowledge and could potentially inform arts practice in care homes. Before data collection and theory-building commenced, a review of the academic literature was undertaken to gain a deeper understanding of the phenomenon of arts engagement. This chapter presents findings from that review.

### 2.2. Reviewing the literature in grounded theory

Grounded theory proposes that the most useful theories are those developed inductively from empirical data. To discover new insights and to develop a more nuanced understanding of a substantive area, grounded theory researchers are called to approach their data as freely and openly as possible (Birks and Mills, 2015). Extensive engagement with the research literature in the initial stages of a study can impede this process when researchers can become overwhelmed and constrained by pre-existing ideas and concepts so that new insights do not emerge (Glaser and Strauss, 1967). Considerable engagement with the literature in the early stages of a study can also prove unproductive where it is not possible to know what concepts will prove relevant for the theory (Corbin and Strauss, 2015). In grounded theory, researchers are therefore advised that the most pertinent literature should be consulted further into a research project, when relevant concepts or theories can be detected in the empirical data, and then 'interwoven' into an emerging theory (Hallberg, 2010).

In the original grounded theory text, *The Discovery of Grounded Theory*, researchers were advised to initially avoid literature from the substantive area to avoid conceptual 'contamination' of the theory (Glaser and Strauss, 1967). Yet the complete avoidance of the literature at this early stage can be problematic. Firstly, some form of literature review is often

necessary due to academic and ethical requirements (Hallberg, 2010; Birks and Mills, 2015). Secondly, this approach assumes that important concepts will be easily detected by the researcher in the empirical data. Yet conceptualisation is a skill that requires a high level of competence (Hallberg, 2010).

Subsequent versions of grounded theory have taken a more relaxed approach to the literature. Corbin and Strauss (2015) maintain that a considered early review of the literature does not violate the method. While they caution against an exhaustive early review of the literature, when it can '*stand between the researcher and the data*', they consider that some level of engagement with the literature can support theory development by enhancing sensitivity to important ideas and concepts in the data (p.55). Corbin and Strauss therefore advocate a middle ground between an exhaustive and in-depth review of the literature and the complete avoidance of it. While they stress that researchers should not enter the field forearmed with '*an entire list of concepts*', familiarity with key findings and concepts can alert researchers to important ideas and concepts in their own data (p.50). Where concepts recur repeatedly in the literature and in the empirical data, this can confirm their significance. Corbin and Strauss do however stress that when reusing concepts, researchers must ensure these concepts adequately capture the meaning of their data – and are not imposed or forced upon it.

### 2.3. The purpose of the literature review

My approach to the literature was guided by the advice of Corbin and Strauss (2015). The purpose of this early review of the literature was two-fold. Firstly, I wanted to situate my own research within the context of the existing literature. Secondly, I wanted to familiarise myself with key findings and concepts that related to the phenomenon of arts engagement, thereby aiding the analytical process and the process of conceptualisation should these ideas and concepts recur in my own data.

My approach to reviewing the literature needed to reflect these aims. I selected the narrative review as the most appropriate form of literature review in this study. Narrative reviews involve the chronological, conceptual, or thematic analysis of the literature for summation, and are undertaken when researchers wish to gain a broad understanding of what is known about a research topic (Grant & Booth, 2009). I considered that a narrative review would help

me to situate my research in the context of the existing literature and would sensitise me to ideas and concepts that might prove relevant for my own study. Other types of literature review were deemed less suited to these goals. For example, I was not attempting to appraise and synthesise evidence about a research question (as would be the case for a systematic review), to synthesise a model or develop a hypothesis from the literature (as would be the case for a critical review), or to map out evidence to commission further research (as would be the case for a mapping review).

It is noted that narrative reviews have been criticised for lacking rigor (Byrne, 2016). The lack of comprehensive searching that is permissible in narrative reviews can result in an incomplete evidence base from which to draw conclusions (Green, Johnson and Adams, 2001).

Unsystematic approaches can bias the selection of studies and information that will support a researcher's world view (Grant & Booth, 2009). Lack of quality appraisal can give prominence to poor quality research (Byrne, 2016). Yet comprehensiveness, objectivity and in-depth quality appraisal were not major concerns where the purpose of this review was not to conduct an exhaustive evaluation of the evidence base. Indeed, a rigorous, exhaustive, and in-depth quality appraisal would have been inconsistent with grounded theory approach, where researchers are warned not to become too steeped in the literature (Corbin and Strauss, 2015). The question directing the narrative review was as follows:

*How has arts activity engagement for dementia been studied and understood in the academic literature?*

## 2.4. Methods of the literature review

Between February and March 2017, the following databases were searched for articles pertinent to the review question: Medline, CINAHL complete, PsycInfo, Web of Science, and Scopus. The terms used to search these databases are listed in table 2.1. The term 'participation' was also used as a search term as a synonym for engagement. My research topic was focused on care homes, however the term 'long-term care' was included in my search, to include long-term residential facilities for dementia, such as continuing care communities.



Given the relative infancy of the field, only articles published from the year 2000 onward were considered for inclusion. A total of 461 articles were identified through this process. The breakdown of papers that were returned for each database were as follows: Medline (61), CINAHL complete (70), PsycInfo (62), Web of Science (74), and Scopus (194).

**Table: 2.1: Search terms used in the literature review**

1.	Dementia OR Alzheimer*	AND
2.	Activit* OR therapy	AND
3.	Art* OR music OR dance OR drama OR poetry OR painting OR singing OR creativity	AND
4.	Engagement OR participation	AND
5.	Care homes OR residential care OR nursing homes OR long-term care	

The 461 journal papers were screened for relevance according to a set of inclusion and exclusion criteria. To be included in the review, studies needed to:

- Examine the impact of arts activities on engagement levels OR
- Examine the process of arts engagement or the strategies used to engage residents during arts activities OR
- Examine perspectives about the value of arts engagement OR
- Examine factors that might facilitate or impede resident engagement in arts activities.

Studies were to be excluded from the review if they:

- Were not published in the English language.
- Did not include people with dementia who resided in a care home or other dementia care facility.

- Were focused on leisure activities that would not be considered 'arts-based', e.g. quizzes.
- Were focused on engagement in relation to activities of daily living, e.g. personal care, mealtime, exercise.
- Were focused principally on the 'treatment' of people living with dementia i.e., physical rehabilitation, cognitive stimulation therapy, or the management of the behavioural and psychological symptoms associated with dementia.

The screening process happened in two stages. During the first stage, titles and abstracts were read and screened for relevance according to the criteria above. Papers that were deemed to be potentially relevant were noted. A total of 80 papers were identified for possible inclusion at this stage, so that 381 were excluded. The removal of duplicates (n=48) further reduced this number to 32. In the second stage, the 32 remaining papers were retrieved and read in full and assessed again according to the inclusion and exclusion criteria.

Decisions about the suitability of some papers were not always clear-cut at this stage, as some studies appeared to meet both the inclusion and the exclusion criteria. By way of example, one study examined the impact of choral singing, and conducted interviews with participants to determine what they valued about their participation. Yet the same study placed a significant emphasis on therapeutic goals and the measurement of changes in pain, mood, and energy levels. Because this review did not need to be exhaustive, the decision was made to exclude studies if there were any grounds for ambiguity. After this process, a total of 16 articles remained. An overview of the 16 articles is provided in table 2.2.

Findings from a review of these studies are presented in two parts: Findings 1 relates to the question of how arts engagement has been studied in the academic literature. Findings 2 explains what is known about arts engagement as a phenomenon.

**Table 2.2: Characteristics of studies included in the literature review**

<b>Study</b>	<b>Location</b>	<b>Activity</b>	<b>Study participants</b>	<b>Measures</b>
Campbell et al (2017)	One care home in Northwest England.	'Music in Mind': A 10-week improvisational music activity.	11 participants including 4 musicians, one music therapist, organisational staff, care home activity workers, and the care home manager.	Semi structured interviews, reflective diaries, and de-brief sessions.
Cevasco (2010)	5 different facilities including dementia units of retirement centres.	Music therapy	38 individuals in the early-middle stages of Alzheimer's disease and other dementias.	Observation of participation level and affect.
Cohen-Mansfield (2010)	7 Nursing homes in Maryland, USA.	Engagement with a mixture of arts-based and non-arts-based stimuli	193 nursing home residents with dementia.	The Observational Measurement of Engagement (OME)

Cohen- Mansfield (2011)	7 Nursing homes in Maryland, USA.	Engagement with a mixture of arts-based and non-arts-based stimuli.	193 nursing home residents with dementia.	The Observational Measurement of Engagement (OME)
Davidson and Fedele (2011)	One singing group in a residential care unit. One singing group for clients in the community. Perth, Australia	A 6-week group singing programme.	The care home group included 18 residents with dementia alongside professional carers.  All residents had mild to moderate dementia.	An observational checklist.  QOL- AD scores, (pre and post programme).  Hierarchic Dementia Scale, (pre and post programme).
George & Houser (2014)	Dementia special care units at a continuing care retirement community. Pennsylvania.	Timeslips, a group-based storytelling programme.	10 residents with dementia and staff.	Semi-structured interviews with resident participants and members of staff

Kontos et al. (2017)	A dementia unit in a long-term care facility. Ontario, Canada.	Elder-clown visits, using a mixture of arts modalities.	23 residents with moderate to severe dementia (73.9% Alzheimer's disease; 13% mixed Alzheimer's disease and vascular dementia; 8.7% Lewy body dementia; 4.4% vascular dementia).	Qualitative interviews, ethnographic observations.
Lancioni et al. (2015)	One residential social medical centre. Italy.	Individualised music displayed on a computer screen.	11 residents with Alzheimer's Disease residing at the social medical centre (7 severe Alzheimer's, 4 moderate Alzheimer's disease)	Indices of positive participation (singing, rhythmic movements, verbal comments, or smiles). Computer verbal reminders.
Luyten et al. (2017)	A nursing home in the Netherlands.	An interactive art installation.	Ten residents with dementia.	A framework of codes of human-human and human-artwork responses, each categorised by physical, verbal, and emotional responses.

MacPherson et al. (2009)	The National Gallery of Australia (NGA).	Sensory engagement and discussion of artworks.	8 people with dementia from a residential care facility (alongside fifteen people with dementia from the community).	Behavioural observations of engagement. Focus groups.
McDermott, Orrell and Ridder (2014)	Two NHS care homes in the UK.	Music therapy.	12 residents with dementia. 15 family carers. 14 care home staff. 8 music therapists.	Focus groups and interviews
Pavlicevic et al. (2015)	N/A	Music therapy.	6 Nordoff-Robins music therapists.	Focus groups.
Rentz (2002)	One dementia-specific nursing home, one assisted living site, and four day centres.	Memories in the Making art programme.	41 participants in total.	Observations of engagement, pleasure, self-esteem, and emotions.

Sauer et al. (2016)	Three long-term care facilities in Ohio.	Opening Minds through Art (OMA), a visual arts programme.	38 residents, all with moderate to advanced dementia	Measurement of well-being (social interest, engagement, and pleasure) using an adaption of the Greater Cincinnati Chapter Well-Being Observational Tool.
Sixsmith and Gibson (2007)	N/A	Music.	Sample of 26 people with dementia and their carers, 8 of whom resided in residential care.	Semi-structured interviews with people with dementia and their carers.
Van der Vleuten, Visser and Meeuwesen (2012).	Six nursing homes in the Netherlands.	A live music performance from the Dutch foundation 'Diva Dichtbij' (Diva in Proximity).	Sample included 45 residents, 29 with dementia, and 16 with severe dementia.	Observation rating scales developed specifically for the study.

## 2.5. Findings 1: How has arts activity engagement been studied in the literature?

The first aim of this review was to examine how arts engagement had been studied in the academic literature to situate my own research in the context of the literature. This section provides an account of how arts engagement has been examined and is organised into four sections:

- Studies that primarily focused on the measurement of engagement as an outcome.
- Studies that examined the impact of different conditions on engagement outcomes.
- Studies primarily focused on perspectives about the value of arts engagement.
- Studies primarily focused on understanding engagement as a process.

### 2.5.1. Studies measuring engagement outcomes

Six studies in this review examined engagement outcomes to determine the effectiveness of an arts programme for dementia (Macpherson et al. 2009; Luyten et al. 2017; Davidson and Fedele, 2011; Sauer et al. 2016; Rentz, 2002; and Van der Vleuten, Visser and Meeuwesen, 2012). Macpherson et al. (2009) tried to determine if people with dementia would 'significantly engage' in a gallery-based arts activity in the National Gallery of Australia (NGA). The arts programme was developed in line with Artists for Alzheimer's (ARTZ) in the USA. Video footage of eight care home residents was coded using time sampling methods, (where two independent raters had 5 seconds 'on' to observe residents, and 5 seconds off to code behaviour), for weeks one and five of the programme. Engagement behaviours were categorised as negative (e.g. withdrawn), neutral (e.g. talking to self), engaged (e.g. showing interest, looking at artwork), and highly engaged (e.g. laughing, nodding while listening). Analysis showed that engagement was high during the sessions, with tentative evidence to suggest that care home residents became more engaged as sessions progressed.

Davidson and Fedele (2011) explored the engagement behaviours of 18 care home residents with dementia to determine the effectiveness of a 6- week group singing programme. All residents had mild to moderate dementia. Alongside a battery of other measures, video



footage of singing sessions was used to document engagement behaviours according to an observational checklist. Behaviours were recorded as active (e.g. usually singing), passive (e.g. usually listening), independent (usually participated independently), assisted (usually participated with assistance), spontaneous (e.g. usually engaged in spontaneous singing), and social (usually interacted with others). Observations about mood, concentration, and levels of arousal were also made. Analysis of video data showed that a high percentage of residents (83%) were usually actively engaged in singing, dancing, or movement, and that 89% usually interacted with others. A high proportion of participants usually appeared focused (67%) and demonstrated a positive mood during sessions (83%).

Luyten et al. (2017) tried to determine whether and how nursing home residents engaged with the interactive art installation VENSTER. The art installation showed pre-recorded calming, active, or interactive content, and each type of content contained several different scenes. Ten residents participated in the study. More than 8 hours of video footage was accrued across eight VENSTER sessions. All responses were recorded according to human-human, and human-artwork engagement, (each divided into verbal, physical, and emotional responses). Overall, VENSTER was deemed effective in eliciting responses, with 1417 resident responses recorded. While responses ranged from verbal reactions to active physical engagement (e.g. waving to a person in a scene), VENSTER was found to be most effective in promoting human-human verbal interactions between residents and staff. The subcategory *recognising/naming/remembering scene*, accounted for the largest proportion of responses (26.8%) when staff or residents recognised content, so that the installation acted as '*a catalyst for conversation and interaction between the care provider and residents*' (p.93).

Other studies have judged programme effectiveness by considering engagement as a dimension of a broader concept like wellbeing or quality of life. Sauer et al. (2016) for example, studied engagement as one dimension of wellbeing to judge the effectiveness of the Opening Minds through Art (OMA) program. The behaviours of 38 residents (with moderate to advanced dementia) residing at three different long-term care facilities were coded using a modified version of the Greater Cincinnati Chapter Well-being Observational Tool. Behaviours that related to domains of wellbeing (social interest, engagement, and pleasure) and illbeing (disengagement, negative affect, sadness, and confusion) were coded at 5-minute intervals using 25 indicators. The intensity of behaviours was coded using a 3-point scale so that, for

example, *'loud and exuberant laughter'* was coded as high intensity, and *'a quiet smile'* as low intensity (p.900). The authors considered that a successful session would be characterised by high-intensity levels of well-being and low intensity levels of ill-being. Results showed a high percentage of moderate or high intensity wellbeing during OMA sessions with little to no illbeing. A subsample of OMA participants also showed significantly higher levels of high intensity engagement and pleasure when compared to more traditional arts activities.

Rentz (2002), considered the impact of a visual arts programme called Memories in the Making on the wellbeing of 41 participants with dementia. The sample included six sites where the Memories in the Making sessions were run. One of these sites included a dementia- specific nursing home. At each identified site, individuals were observed as they participated in a single Memories in the Making session. An observational tool was used to document participant behaviours as they engaged with the activity. The tool included 12 statements that were intended to indicate wellbeing or illbeing. Statements related to engagement (e.g. socialising, sustained attention), pleasure (e.g. smiles, relaxed body language), emotional expression while painting or drawing (e.g. reminiscence, tears), and enhanced self-esteem (e.g. expressions of pride). The frequency with which the 12 indicators of wellbeing or illbeing occurred for each participant was rated on a 4-point scale. Data was not broken down by site, but overall findings suggested that the programme had the potential to positively impact on wellbeing where 83% of participants showed sustained attention for more than 30 minutes and 80% showed pleasure throughout. Observers also recorded that 80 to 90 percent of the participants *'never displayed nonverbal behaviour of discomfort as evidenced by tears or distorted facial expressions or grimaces'* (p.177). The authors concluded that further research using comparison groups would be required to determine if these impacts could be *'attributed with certainty to the intervention'* (p.175)

Finally, Van der Vleuten, Visser and Meeuwesen (2012), assessed the impact of intimate live music performances given by a Dutch foundation called 'Diva Dichtbij', on quality of life (QOL) outcomes for 45 nursing home residents living with dementia (16 of whom had severe dementia). Unlike the studies mentioned previously, this study documented changes in resident engagement behaviours *after* the performance. Observation checklists were circulated to family and caregivers for completion after the performance, and changes in care relationships, human contact, communication, positive emotions, and negative emotions were

documented along a three-point scale from (1) decreased/worsened, (2) did not change, or (3) increased improved. The study found that the performance led to improvements in relationships between care givers and residents, improved human contact, communication, and more positive emotions, particularly for those residents with mild dementia.

In the studies described in this section, engagement was studied as an outcome to draw conclusions about the effectiveness of an arts program. Beyond author speculation, these studies did not consider which aspects of an arts program had impacted on engagement levels. The exception to this was the study by Luyten et al. (2017), which found that familiar content elicited the largest number of responses for the VENSTER installation. Several studies in this review did examine how different conditions could impact upon engagement levels. These studies are described below.

#### 2.5.2. Studies examining the impact of different conditions on engagement

Cevasco (2010), examined the effects of a music therapist's non-verbal behaviour on levels of participation and affect for seven different groups of clients across five care facilities (including dementia units of retirement centres). Thirty-eight clients with early to middle stage Alzheimer's and other related dementias participated. At each music therapy session, the same activities (related to movement, singing, and rhythm) were presented in the same order. Four treatment conditions were implemented in each session. The first condition consisted of affect and proximity combined, (where the music therapist would make eye contact, smile, and approach the person). The second condition involved the use of affect only, so that the therapist would keep a distance of five to eight feet from all clients. The third condition involved the use of proximity only, so that the therapist would approach clients, but would use no affect. The fourth and final condition involved no proximity or affect, so that the music therapist kept a distance, made little eye contact, and displayed no change in affect. The participation levels of each person were recorded at 15 second intervals according to whether they participated as directed by the music therapist, participated but not as directed by the therapist, did not participate but watched, or did not participate. Analysis showed that the condition involving both proximity and affect elicited the greatest amount of 'accurate' participation where the precise movements of the therapist were imitated.

Lancioni et al. (2015), assessed the effects of an active, response-related music condition versus a passive music condition, on the participation behaviours of eleven individuals with Alzheimer's at one residential social medical centre. Seven participants were diagnosed as having severe Alzheimer's and four moderate Alzheimer's. Positive participation behaviours included singing, rhythmic movements, verbal comments, or smiles. Both music conditions involved the display of music tailored to the preferences of each resident on a personal computer screen. In the active, response-related condition, residents had been instructed in the use of technology to control the presentation of the music. A song was presented in 15 second segments and repeated microswitch responses meant a resident could listen to an entire song. Verbal reminders were also issued in this condition after a period of inactivity. By contrast, the passive condition simply involved the uninterrupted presentation of the same music and did not depend upon any input from the resident. Analysis showed that six of the eleven residents had higher levels of positive participation in the active condition compared to the passive condition. No difference was found for the remaining five residents. The authors speculated that the active condition had a beneficial impact on participation for some by *'promoting alertness and refocusing attention'* (p.172).

In a series of papers by Cohen-Mansfield et al. (2010; 2011), the Comprehensive Process Model of Engagement (Cohen-Mansfield, Dakheel-Ali, and Marx, 2009), was used to predict engagement outcomes for 193 nursing home residents with dementia. The framework predicts that engagement with a stimulus will be influenced by personal attributes, stimulus attributes, environmental attributes, and their interactions. To test the influence of person-stimulus interaction on engagement, the past and present interests of residents in the areas of art, music, babies, pets, reading, television, and office work, were determined with relatives using a self-identity questionnaire. Resident engagement behaviours (attitude, levels of attention, and duration of engagement) were recorded using the Observational Measurement of Engagement (OME) as residents engaged with a range of stimuli over a three-week period. Colouring with markers was intended to correspond with an interest in art, and pre-recorded music with an interest in music. A robotic animal, a plush animal, a real dog, a life like doll, a large print magazine, and various other stimuli, were used to represent other interest areas such as reading, babies, and pets. Two different personalised stimuli were also presented, based on what was most integral to a resident's sense of self-identity. Engagement behaviours were consistent with the Comprehensive Process Model of Engagement in that stimuli that

reflected preferences were found to positively impact upon engagement. Residents who had an interest in music, art, and pets were more engaged with stimuli that reflected these interests than residents without these interests (Cohen-Mansfield et al. 2010).

In a subsequent paper from the same study, a multivariate analysis was used to determine the relative effects of a wide range of additional independent variables on engagement (Cohen-Mansfield et al, 2011). The multivariate model showed that higher cognitive and functional status, and greater clarity of speech, positively impacted on engagement. Significant environmental variables included the long introduction of the stimulus with modelling (compared to a minimal introduction), background noise, and the presence of between 2 and 24 people in the room. For stimulus attributes, the stimulus that had the most potent impact on engagement was the 'live human' category (i.e. interaction with a research assistant), followed by personalised stimuli based on a resident's self-identity. The study illuminated the value of social interaction, so that the opportunity for social interaction and a social setting would impact on engagement.

The studies described so far have all considered engagement as an outcome or have tried to determine the impact of different conditions on engagement outcomes. While these studies reveal the potential of the arts as a medium for engagement in dementia and provide some insights about factors that might influence engagement, insights are limited in several respects. Firstly, the perspectives and experiences of those who deliver arts-based activities, and those who participate in them are not considered (though some insights were generated from focus groups in the study by MacPherson et al. 2009). These studies do not answer the question of why arts engagement is significant in dementia, or what the value of arts engagement is. Secondly, insights about arts engagement as a process, or *how* arts practitioners engage residents during sessions are relatively unaddressed in these studies. Indeed, only a small number of studies in this review set out to investigate these issues in any detail, by drawing upon the perspectives and experiences of those involved in arts-based activities, and by conducting detailed and nuanced observations of arts practice. The remainder of this section will provide an account of the approaches taken in these studies.

### 2.5.3. Studies that explored perspectives about the value of arts engagement

Four studies identified in this review examined the value of arts engagement in dementia. Three focused on music. Sixsmith and Gibson (2007), conducted 26 in-depth interviews with people with dementia (8 of whom lived in residential care), and their carers to consider their perspectives about the meaning and importance of music in their lives. The ecological model of wellbeing in dementia (Torrington et. al 2006), which posits that meaning derived from activities will contribute to wellbeing was used to guide open-ended interviews and provided a template for analysis. Thematic analysis revealed a variety of ways in which music was meaningful in dementia as well as a range of factors that impacted engagement with music. McDermott, Orrell and Ridder (2014), also examined perspectives about the importance of music for people with dementia. A series of focus groups and interviews were conducted with music therapists, care home residents, families, and care home staff. Rather than using an existing model for analysis (like Sixsmith and Gibson), the authors used an inductive approach guided by thematic analysis techniques. Six key themes were identified, relating to the value and purpose of music, leading to the development of the *Psychosocial Model of Music in Dementia*.

Campbell et al. (2017) considered the perspectives of those who had taken part in “Music in Mind”, a ten-week improvisatory music programme facilitated by professional musicians and music therapists. The programme was open to residents, care staff, and families. The study was conducted in one care home. Data from nineteen semi-structured interviews (with musicians, a music therapist, a care home manager, activity workers, and the organisational team) were analysed alongside data from reflective diaries and de-brief sessions. A thematic analysis resulted in three overarching themes; two that described the value of the improvisational musical activity in dementia, and one that described the logistics of organising a session in the care setting.

Finally, in a non-music related study, George and Houser (2014), examined the perspectives of residents and staff who had participated in the group-based creative storytelling programme called Timeslips. The twice-weekly programme took place in a dementia special care unit (in a continuing care retirement community) over the course of six weeks. Semi-structured interviews focusing on subjective experiences of the programme were conducted with 8

residents and 6 staff in the final week of the programme. Again, data were analysed using thematic analysis techniques. Three themes were identified that highlighted the value of engagement for residents, for staff, and for the wider nursing home community.

The studies described here have provided insights about the value of arts engagement in dementia, from the perspectives of arts practitioners, care staff, families, and residents. Findings from these studies are considered in section 2.6.2. Yet, these studies revealed relatively little about engagement as an on-going process or *how* arts practitioners engaged residents during arts activities. Only two studies included in this review examined arts-based practice and the process underpinning activity engagement in any detail. These studies are described below.

#### 2.5.4. Studies that examined arts engagement as a social process

Pavlicevic et al. (2015), attempted to identify and classify music therapy strategies used by Nordoff Robins music therapists in care home settings. This practice-based study was conducted in response to the prevalence of outcomes focused research in the field. The authors considered such studies problematic when they overlooked the complexity of music-therapy, when they ignored practice-based knowledge, and when they focused on outcome measures that did not align with music therapy values. To gain a deeper understanding of practice, the authors worked with six experienced music therapists who provided video and audio-recordings of their sessions with accompanying narrative accounts. These recordings and accounts formed the basis of an initial focus group discussion, which then informed three subsequent focus group discussions and a plenary session. Music therapists also kept research journals to document their reflections. Focus group transcripts and journals were analysed thematically using interpretative phenomenological analysis. The strategies and techniques used by music therapists were documented and detailed at a micro (person-to person musicking), meso (musicking beyond the session) and macro level (within the care home and beyond). This practice-led and iterative approach resulted in thick and rich descriptions of the engagement process and ensured that findings were grounded in the realities and complexities of practice.

In a similar vein, Kontos et al. (2017), documented and examined elder-clown practice to understand the strategies and techniques used by elder-clowns during a 12-week, arts-based programme. Four professionally trained elder clowns took part in the programme and worked in pairs to conduct twice weekly visits to a dementia unit at a long-term care facility. Twenty-three residents were visited on an individual basis. All residents had moderate to severe dementia. Most had a diagnosis of Alzheimer's disease (73.9%). A range of art forms were used during interactions. Four hundred and seventeen visits were videotaped, resulting in 66 hours of recorded material. After completion of the programme, interviews were conducted with the elder clowns, to explore their strategies and techniques. Video-recordings of encounters were transcribed using ethnographic observation techniques, resulting in thick and rich descriptions of the engagement process. Descriptions, video-recorded reflections, and interviews were then analysed using thematic analysis. The overarching practice of 'relational presence', was found to be pivotal to elder-clown practice. The findings from the studies by Pavlicevic et al., and Kontos et. al. are discussed in section 2.6.1.

## 2.6. Findings 2: What is understood about arts engagement?

The second aim of this review was to identify concepts in the literature that might prove pertinent to my own research question; *How do arts practitioners engage the person with dementia living in a care home setting?* Findings that seemed relevant to this question are organised into three sub-sections below. The first subsection reports on findings that related to engagement as a process, and the strategies and techniques that were used by arts practitioners during arts activities. The second subsection reports on findings related to the value of arts engagement. The final subsection reports on findings related to conditions and contextual factors that might influence engagement.

It should be noted that the concepts reported here do not represent an exhaustive account of the concepts that were present in these studies. Consistent with the advice of Corbin and Strauss (2015), I was mindful of the need to approach my own data as freely and openly as possible to uncover new insights. I understood that this task would be less possible if I became overwhelmed with an extensive list of concepts. As such, the goal here was to develop some degree of familiarity with the main ideas and concepts expressed in these studies, to aid



conceptualisation should these concepts recur, without hindering the potential for new interpretations and insights.

### 2.6.1 The social process of arts engagement

While many of the studies included in this review focused on the measurement of engagement outcomes, several studies categorised engagement outcomes in ways that documented engagement strategies. In the study of the Memories in the Making visual arts program for example, Rentz (2002), recorded that 78% of participants needed to be prompted all the time, or some of the time to engage. Davidson and Fedele (2011), observed that 22% of residents would participate during a singing session when they received guidance. Luyten et al (2017), found that verbal instructions and coaching accounted for 9.9% of all human-human interactions during the interactive art installation 'VENSTER'. Care providers also physically guided residents to interact with the installation, for example by pointing or gesturing.

Other outcome studies speculated about strategies that might have positively impacted upon engagement outcomes. For example, Van der Vleuten, Visser and Meeuwesen (2012), considered that 'authentic contact', a strategy that involved the use of eye contact, interaction, and physical closeness, was an important component of the live music performances given by 'Diva Dichtbij'. Sauer et al. (2016), speculated that the person-centred approaches that underpinned the Opening Minds through Art programme (OMA), partly accounted for its success. Volunteers in that study were trained to promote selfhood by building relationships with residents through 'positive person work' (Kitwood, 1997a). Davidson and Fedele (2011), speculated that the highly structured and repetitive nature of singing group sessions, facilitated engagement by creating a recognisable pattern for residents.

Some of the insights and assertions made in outcome studies have received support. For example, Cevasco (2010), found that practitioner proximity and affect positively impacted on engagement outcomes, lending support to the importance of 'authentic contact' as described by Van der Vleuten, Visser and Meeuwesen (2012). Cohen-Mansfield et al. (2011), found that guidance had a significant and positive impact on engagement outcomes, when engagement behaviours were modelled for residents. Lancioni et al. (2015), found that cueing in the form

of a computer issued verbal reminder, led to higher levels of engagement when it prompted residents in their study to re-engage during a computer-based music listening activity.

While the studies above provide some insights about strategies that might promote engagement, they do not provide a comprehensive account of the breadth of strategies employed by arts practitioners, nor do they provide an account of engagement as an on-going process. Pavlicevic et. al. (2015), and Kontos et al. (2017) offered more insights in this regard. The micro-level strategies (person-to person musicking) documented and detailed by Pavlicevic et. al. (2015) explained how practitioners would build musical relationships with residents. They documented and detailed a process where therapists used a strategy of 'moment-to-moment attending' meaning that they were attentive to the movements and vocalisations of a resident. The therapists used 'musical matching' where they matched the tempo, intensity, and pitch of their playing to the resident. From this, therapists tried to assemble a 'shared' and 'predictable musical structure' a using repetition and patterns, to create a musical relationship with the resident. A similar process was described for group sessions, where the therapist would help residents to settle into a musical relationship with one another, before 'dropping out' or stepping back so that relationships could continue. The authors ultimately found that music therapy strategies were directed towards a process of 'reframing', where music enabled the transformation of care homes, individuals, and relationships. Residents and staff were freed from restrictive roles and identities when the music allowed them to act and interact as 'empowered musicians'.

Kontos et al. (2017), documented and described the engagement strategies and processes used by elder clowns during interactions with residents, concluding that fruitful encounters were underpinned by 'relational presence', achieved through the use of three primary strategies: (a) co-constructed imagination; (b) reciprocal playfulness; and (c) affective relationality. For the strategy of 'co-constructed imagination', the authors detailed a process whereby clowns would synchronously co-create stories with residents by building upon their organic and spontaneous offerings, even when these were 'incoherent', 'nonsensical', or 'delusional' (p.60). For the strategy of reciprocal playfulness, the authors described a two-way exchange when 'clown driven' play could lead to playful responses in residents, while clowns were also responsive to resident expressions of playfulness. For the strategy of affective relationality, the authors detailed how clowns took care to accept and respond to the emotions of residents in ways that were '*inclusive of both joy and sadness*' (p.58). The clowns

acknowledged feelings of sadness and grief where these were present. The authors concluded that the core practice of 'relational presence' and its associated strategies, were driven by a desire to reimagine relationships in dementia, and to find ways of relating to residents in ways that acknowledged their realities and their capacities for creativity and playfulness. Strategies of 'co-constructed imagination' and 'reciprocal playfulness' challenged views of incompetence and apathy in dementia when residents were able '*to initiate affective, creative, and playful engagement*' (p.60). The co-construction of stories from the 'incoherent', 'nonsensical', or 'delusional', challenged the notion that people with dementia should be brought back to reality. A strategy of embracing difficult emotions through affective relationality, opposed the view that difficult emotions should be ignored or played down in dementia.

#### 2.6.2. Perspectives about the value of arts engagement

An understanding of the value of arts engagement can provide insights about the motivations that drive arts practitioners. For example, the arts held instrumental value for practitioners in the studies by Kontos et al. (2017) and Pavlicevic et. al. (2015), when they were a tool for reframing dementia, and for reimagining relationships in dementia. The strategies that were documented and detailed in these studies were ultimately directed towards these goals, so that for example, residents were empowered to take the lead and control the direction of an interaction.

Studies that examined the value of arts engagement more closely in this review included those by McDermott, Orrell and Ridder (2014) and Sixsmith and Gibson (2007). Both studies found that music was valued for its ability to support relationships in dementia. Music was considered an important medium for connection and relationships, when individuals could sing and dance together, and when music could stimulate memories and enable meaningful conversations (Sixsmith and Gibson, 2007). The music therapists and family members who participated in focus groups and interviews with McDermott, Orrell and Ridder (2014), also stressed that music enabled a connection with the person and supported therapeutic and familial relationships. Campbell et al. (2017) and George and Houser (2014), also found that arts-based engagement supported relationships, yet participants in these studies also emphasised the feelings of togetherness that emerged during musical and storytelling

activities, where the community effort of *'creating something together'* meant that *'a bond was created'*. George and Houser further noted that this community-based approach was valued by residents when they *'were subjectively aware they were contributing'* something *'as part of a collective group'*. (p.681)

Engagement with the arts was also valued for its ability to preserve self-identity in dementia. In the study by McDermott, Orrell and Ridder, hymns were used with residents who had identified as strongly religious, as a way of preserving their religious identity. Music also held instrumental value for music therapists when it acted as a vehicle for positive person work as described by Tom Kitwood (1997a). The authors explained that therapists could support selfhood when the individuality of a person was revealed during musical interactions and could then be acknowledged. Studies also revealed that the arts could also introduce new modes of being and new possibilities for selfhood, when residents could become *'empowered musicians'* or *'a storyteller'*, (Pavlicevic et al, 2015; George and Houser, 2014).

Finally, the arts were valued for their ability to enhance mood in dementia. In the study by McDermott, Orrell and Ridder (2014), care staff noted that music had an ability to soothe residents, to increase alertness and interest, and to improve mood in *'immediate and observable'* ways (p712.). Sixsmith and Gibson also found that music could lift mood, increase feelings of happiness, and reduce feelings of agitation, while in the study by George and Houser (2014), staff members commented that participation in storytelling sessions created a sense of *'liveliness, laughter and fun'* for residents (p.681).

### 2.6.3. Conditions and contextual factors that can influence arts engagement.

Studies included in this review offered some insights into other factors that could impede or promote engagement. At an individual level, several studies revealed how cognitive functioning could impact engagement. Higher levels of cognitive functioning, (as determined by Mini-Mental State Examination scores), were positively associated with higher engagement levels in the study by Cohen-Mansfield et al. (2011). The authors speculated that cognitive limitations made engagement with stimuli more challenging where cognitive function is related to the ability to focus and pay attention. Van der Vleuten, Visser and Meeuwesen

(2012) found that intimate live performances had a greater impact for those with mild dementia than for those with severe dementia. They speculated that higher levels of cognitive impairment meant that those with severe dementia struggled to focus their attention to be aware of the performance and to derive benefits. In the study by McPherson et al. (2009), care home staff revealed that cognitive limitations could present a barrier to engagement *before* an activity, when residents were reluctant to attend gallery-based arts sessions. This reluctance was attributed to an inability to recall attendance at previous sessions, so that residents required some '*cajoling*' to return to the gallery, yet '*brightened up*' during sessions (p.749). Hearing and visual impairments were also found to present a barrier to engagement (Sixsmith & Gibson, 2007; McPherson et al., 2009).

Several studies found that the content of an activity would influence engagement. Luyten et al. (2017), found that familiar visual content would lead to comments and would stimulate memories for residents who engaged with the art installation 'VENSTER'. The authors concluded that recognition played an important role in terms of engagement with the installation. Children, animals, and familiar places were found to be particularly effective in promoting engagement, while residents would sing, hum, whistle, or tap to familiar music. The authors raised questions about the suitability of more abstract or unfamiliar art.

Cohen-Mansfield et al. (2010) found that content tailored to individual preferences might also impact upon engagement levels. Interestingly, content that aligned with current interests proved more effective than content rooted in past interests. While a prior interest in music was found to be somewhat predictive of responsiveness to music, *current* interests in music and art were found to be more potent predictors of engagement.

The authors speculated that this difference might have been a consequence of cognitive decline or changes in interests that can occur with ageing. Finally, Cohen Mansfield (2010; 2011), found that activity content that was rooted in what had been *most* pivotal to a resident in their life (e.g. their family role, professional role, leisure activity role), was an even more powerful predictor of engagement. While the stimuli rooted in self-identity were not necessarily arts-based in this study, the finding resonates with those of McDermott, Orrell and Ridder (2014), who found that hymns were an effective way of engaging residents whose religious identity was integral to their sense of self.

Finally, Campbell et al. (2017) and MacPherson et al. (2009) found that logistical issues *outside* the activity could impact upon engagement during an arts session, stating that the success of a

session depended upon adequate preparation. These preparations included getting residents to sessions on time, the suitable prior setup of the room, and ensuring that residents had hearing aids and glasses if required.

## 2.7. Discussion of the literature

The first purpose of this review was to situate my own research within the context of the existing literature. Most of the studies included in this review examined engagement as an outcome or examined the impact of different conditions upon engagement outcomes. Few studies focused on perspectives about the value of arts engagement. Even fewer studies examined arts engagement as a process. The need for more research examining arts-based practice is apparent. This study will therefore seek to contribute to knowledge by examining arts practice and explicating the social process underpinning arts activity engagement.

The review also highlighted a lack of diversity in terms of art forms studied (with music being the most common), in addition to an absence of theory to explain how arts practitioners engage residents. The theoretical models that were identified through this review did not address the question of *how* arts activities engage residents. The Psychosocial Model of Music in Dementia developed by McDermott, Orrell and Ridder (2014), for example, focused mainly on the importance of engagement with music in dementia, revealing little about engagement as an on-going social process. The Comprehensive Process Model of Engagement developed by Cohen-Mansfield, Dakheel-Ali and Marx (2009), focused on the factors that could predict resident engagement behaviours with stimuli, rather than how engagement is actively promoted during an activity. This study therefore seeks to contribute to knowledge by developing a grounded theory that can explain arts engagement as a social process. The theory will span different art forms and different arts-based approaches (therapy, participatory arts, and performance).

Finally, a deeper understanding of arts practice could potentially have implications for how efficacy is judged, and how arts programs are evaluated. While the outcome studies reviewed here have revealed the potential of arts activities as a form of engagement in dementia, an examination of these studies reveals a possible tension between evaluation and practice, (something also noted by Pavlicevic et al., 2015). Evaluation studies all measured engagement outcomes in somewhat different ways, the intensity, duration, and frequency of engagement,

alongside the presence of positive affect and absence of negative affect, were typically viewed as markers of success. Yet, studies in this review that have examined arts engagement from a practice perspective, raise the possibility that these measures might not be entirely appropriate if they can overlook the realities of practice and do not align with practitioner intentions.

To illustrate this possible tension, consider the evaluation of the Opening Minds through Art programme (Sauer et al., 2016). The programme was deemed effective due to the prevalence of high intensity engagement behaviours that indicated wellbeing (e.g. 'loud and exuberant laughter') and the absence of behaviours that indicated illbeing (e.g. disengagement and negative affect). Also consider the evaluation of the Memories in the Making arts programme (Rentz, 2002), which was considered effective when 83% of participants showed sustained attention for more than 30 minutes, and 80 to 90 percent of the participants '*never displayed nonverbal behaviour of discomfort as evidenced by tears or distorted facial expressions or grimaces*' (p.177). Yet, expressions of grief and sadness that were found amongst residents in the elder clown study by Kontos et al. (2017), were not considered 'negative' or undesirable, but were thought to reflect the challenges that could accompany life with dementia and older age. Rather than trying to shift these emotions and encourage more 'positive' expressions, the elder clowns wanted to '*bear witness*' to the lived experiences of residents and so they adopted a strategy of 'affective relationality', where they would embrace '*a recognition and acceptance of sadness*' (p.54). Moreover, fleeting engagement could also be a valued outcome. Music therapists in the study by Pavlicevic et. al. (2015), revealed that the fleeting and fragmented vocalisations of residents allowed them to develop musical relationships, and that even the briefest of these relationships was considered worthwhile (p.666). The possible tensions between the measurement of engagement outcomes, and the realities of arts practice is revisited in the discussion chapter, in-light of my own findings.

The second purpose of this review was to develop an awareness of ideas and concepts in the literature that might prove relevant for my own research. The goal was to increase sensitivity to my own data. Yet concepts were treated as tentative, so that to be included in the theory, they needed to occur repeatedly in my own data. In terms of the value of arts engagement, the review showed that the arts were valued for their ability to enhance mood, to empower residents, to preserve self-identity, to create new avenues for identity, to maintain relationships, and to reimagine relationships in dementia. In terms of conditions and

contextual factors that might influence engagement, cognitive functioning, personal interests, identity, health, logistical issues, and care staff support were all identified as potentially significant.

This review also provided some potentially useful insights about strategies that might be used during the engagement process. Person-centred philosophy and ways of supporting personhood through ‘*positive person work*’ e.g. *recognition* and *celebration* (Kitwood, 1997a) were briefly discussed in two studies (McDermott, Orrell and Ridder., 2014; Sauer et al., 2016). While person-centred philosophy was not explicitly mentioned in other studies, ways of relating that were described in these studies were synonymous with ‘positive person work’: Elder-clowns would *empower* residents to take the lead during interactions, and would *validate* their difficult emotions (Kontos et al. 2017). The use of authentic contact or *warmth* was considered integral to engagement in the studies by Van der Vleuten, Visser and Meeuwesen (2012), and Cevasco (2010). Arts practitioners would also *facilitate* engagement in by prompting (Rentz, 2002), guiding (Davidson and Fedele, 2011; Luyten et al., 2017), and modelling behaviours (Cohen-Mansfield et al, 2011). Given the ubiquity of person-centred philosophy in the dementia field, and the presence of practitioner behaviours that aligned with ‘positive person work’, I was alerted to the potential significance of person-centred approaches and the need to explore these approaches, should they recur in my own data.

The only two studies that examined the engagement process in great depth in this review (Kontos et al., 2017, and Pavlicevic et al. 2015), described a highly improvised approach. These studies documented the *co-constructed* and *reciprocal* nature of engagement, where engagement was improvised and manifested between practitioners and residents in unpredictable ways. Kontos et al. (2017) were particularly critical of highly structured and less ‘organic’ and ‘spontaneous’ arts-based approaches, and considered that the imposition of ‘*artificial strictures*’ could ‘*thwart the creative expression*’ of residents and overlook their capacities to initiate engagement (p.60). Yet, the entirely improvised approach advocated here was sharply contrasted by the highly structured and pre-planned singing sessions described by Davidson and Fedele (2011), where singing groups followed the exact same sequence of activities each week. Authors of this study speculated that structure and repetition of this structure, created a sense of recognition amongst participants that facilitated engagement. These findings alerted me to different approaches to arts engagement, where some activities might be more improvised and others more planned. It also alerted me and to the potential



significance of structure, and how and why practitioners might use structure, or seek to avoid it.

## 2.8. Conclusion

This chapter revealed how engagement has mainly been studied as an outcome in the arts and dementia literature. The chapter showed that a preoccupation with engagement outcomes has meant that arts engagement is not well understood as a social process. Few studies have considered how arts practitioners effectively engage persons with dementia in care homes, and there is currently an absence of theory to explain the process of arts engagement in these settings. This chapter showed how the study would address this gap in research knowledge by examining arts engagement as a social process, and by developing a theory to explain this process.

## Chapter 3: Methodology

### 3.1. Introduction

Chapter two reported on findings from a narrative review of arts and dementia research in care homes. The review revealed that arts engagement had been studied mainly as an outcome. Less attention had been paid to understanding arts-based practice. The need for a theory that could explicate the social process of arts engagement in care homes was justified. This chapter provides an account of my decision to use grounded theory, and more specifically Straussian grounded theory, as a methodology for theory development. My decision to use Straussian grounded theory is justified in-light of my philosophical worldview, my research goals, and my circumstances. The chapter also provides an overview of the research design and the rationale for using interviews and observations as methods of data collection.

### 3.2. The research paradigm

Ontology is concerned with the nature of reality (Crotty, 1998). A realist ontology posits that reality exists independently of the mind, while a relativist ontology sees that reality is rooted in our subjective experiences of the world, so that multiple realities exist (Crotty, 1998). Ontologically, I would position myself as a realist. I do so because I believe there is an external reality that exists separate to what we think about it. I include social phenomena in my conception of reality and concur with Cupchik (2001) who states that social phenomena are *real* so that individuals '*might construct interpretations of events*' yet '*the underlying phenomena do not rely on them for existence*'. Yet, while I believe that phenomena exist independent to what anyone thinks, I also believe that knowledge is constructed out of the meanings that persons give to phenomena. I am therefore ontologically realist and epistemologically constructionist, a position that Crotty (1998) states is entirely possible to hold. This is a paradigm that is at odds with both positivism and postmodernism. It posits that knowledge is neither objectively discovered nor subjectively created, but that '*meanings are constructed by human beings as they engage with the world they are interpreting*' (Crotty, p.43). The constructivist view sees that an objective reality exists, yet it posits that the

meaning we give to the world will be subject to interpretations and influenced by individual, social, and cultural factors. In the constructivist view, interpretations are therefore shaped by the phenomena and by social influences (Levers, 2013).

This is a worldview that has implications for this study. I recognise that the theory constructed in this study represents the attempts of both myself and my research participants, to make sense of a complex social phenomenon- arts engagement. The complexity of engagement and the interpretative nature of knowledge generation means that the grounded theory is partial, fallible, and incomplete. It is just one of potentially many theories that could provide insights about engagement. Because interpretation is relative to who we are as persons, and given my dominant role in theory development, I acknowledge that the construction of the theory was inevitably shaped by my worldview. A different researcher would have produced a different theory. I have therefore attempted to provide some account of my influence in chapters 1 and 9. Yet despite this influence, and following from my realist ontological stance, I still believe that there are things to learn about engagement and how to effectively engage persons with dementia. I believe that theory can and should provide a plausible and recognisable account of the engagement phenomenon. This belief meant that I used criteria to judge the credibility of the theory, for instance 'checking' to see if it resonated with participants and others who had direct experience of the phenomenon (see chapter 8). As such, whilst I acknowledge that the theory developed in this study represents one interpretation of engagement that is imperfect and incomplete, I also believe that it offers a useful and recognisable explanation of the phenomenon.

### 3.3. Choosing grounded theory as a methodology

The aim of this research was to develop a theory of arts engagement in dementia. The question guiding the study was: *'How do arts practitioners engage the person with dementia living in a care home setting?'* Grounded theory was selected as the most appropriate research methodology in this study for several reasons. Firstly, grounded theory moves beyond description to explanation and aims to explain *how* a phenomenon occurs (Birks & Mills, 2015). It is well suited to the study of social processes (Corbin and Strauss, 2015). I needed to

understand how arts practitioners engaged residents as a social process, and this process could be explicated using a grounded theory approach. Secondly, theory development is the purpose for which grounded theory was designed and it is a well-respected and well-established approach to theory development. The methodology involves a *'tried-and-true set of procedures for constructing theory from data'* including the use of constant comparisons, theoretical sampling, memo writing, and rigorous coding procedures (Corbin and Strauss, 2015, p.11). When properly applied, these procedures can lead to the development of credible and useful theories (Corbin & Strauss, 2015).

Yet grounded theory is not without its limitations. It is recognised as a difficult and demanding methodology. Bryman (2008), notes that the development of a grounded theory is a time-consuming process, and that researchers can feel overwhelmed by the methodological stipulations of the approach and the vast quantities of data involved. Stiel et al. (2010) advised that grounded theory studies should be guided by someone familiar with the approach given the *'high methodological requirements and rather complex analysis procedures.'* (p.997). Yet, despite these challenges, grounded theory is not beyond the competencies of the student researcher and is considered a suitable approach for PhD dissertations (Patton, 2015). The systematic procedures of grounded theory can also make it more suited to the task of theory development than other qualitative methods (Stiel et al, 2010).

### 3.4. Choosing between grounded theory approaches

Glaser and Strauss created grounded theory methodology, yet since the original text, *The Discovery of Grounded Theory* (Glaser and Strauss, 1967), other versions of grounded theory have emerged. While Glaser has continued to advocate for the 'Classical' approach, Strauss developed his own way of grounded theory, known as 'Straussian' grounded theory. (Corbin and Strauss, 2015). Kathy Charmaz developed a third way of doing grounded theory known as 'Constructivist' grounded theory (Charmaz, 2006). All three versions of grounded theory share the same core procedures (Rieger, 2019). They all start with an inductive approach. They all involve the simultaneous collection of data collection, analysis, and theory development. Constant comparison is used to identify commonalities and differences between data, concepts, and categories, so that increasingly more abstract categories can be formed.

Theoretical sampling is used to guide sampling decisions and to aid the development of theoretical categories. Memo writing aids this process. These are the common features of a grounded theory study, yet important distinctions between Classical, Straussian, and Constructivist grounded theory do exist. Each approach is distinguished by different philosophical assumptions, unique coding procedures, and different ways of engaging with the research literature (Kenny & Fourie, 2015). Views about the validity of each of the approaches have been debated extensively, yet all three approaches have their advantages (Evans, 2013). Researchers are therefore advised to select the version that best fits with their own philosophical worldview, the purpose of their study, and their preferred way of working. (Evans, 2013. Birks & Mills, 2015).

Constructivist grounded theory was developed in response to the perceived '*positivism in both Glaser's, and Strauss and Corbin's versions of the method*'. (Charmaz, 2006, p.9). The constructivist approach is rooted in a relativist ontology and is considered a '*postmodern interpretative rendition of the GT methodology*.' (Kenny & Fourie, 2015, p. 1284). Because Constructivist grounded theory is rooted in a relativist ontology, an understanding of participant interpretations is the major concern. Charmaz advocated for intensive interviewing to understand how persons make sense of their experiences (Charmaz, 2006; Kenny & Fourie, 2015). Constructivist grounded theory typically results in an 'interpretative understanding' of a social phenomenon, often presented as a 'story', rather than an explanatory theory that clarifies causal relationships around a core phenomenon (Rieger, 2019). I considered that the philosophical assumptions underpinning Constructivist grounded theory did not align with my own. Moreover, the purpose of Constructivist grounded theory did not fit well with the needs of this study. I wanted to develop an explanatory theory of arts engagement. I considered that Constructivist grounded theory was less suited to this goal and so it was ruled out as an appropriate methodology.

Both Classical and Straussian approaches to grounded theory are considered compatible with a realist ontology (Kenny and Fourie, 2015; Charmaz, 2006). Both versions lead to an explanatory theory that demonstrates how a core concern is addressed (Rieger, 2019). Yet there are important distinctions between the two approaches. These distinctions caused me to identify Straussian grounded theory as the most suitable version of grounded theory for this study. Firstly, when following the Classical approach, researchers aim to 'discover' a theory from their data. To 'discover' theory from data, researchers are advised to avoid engagement with the

substantive literature, to put aside prior knowledge, and to let the theory emerge through the constant comparison technique (Kenny and Fourie, 2015). Such a view sees that theory exists in the data waiting to be discovered. Yet I believe that researchers create rather than discover theories, and that researchers will make sense of their data in different ways, so that the same data will lead to the development of different theories. This is a view that aligns with a Straussian perspective, that see that theories are *'constructed by researchers out of stories that are constructed by research participants, who are trying to make sense out of their experiences and lives'* (Corbin and Strauss, 2015, p.26). In direct contrast to the Classical approach, researchers are encouraged to draw upon their experiences and prior knowledge where this can aid theory development (Corbin and Strauss, 2015). Corbin states that since it is *'impossible to completely block out'* one's experience, *'why not put that knowledge to good use.'* (Corbin and Strauss, 2015, p.98). The Churchill Fellowship to North America, where I visited with a range of arts and dementia projects, meant that I had experiences I could reflect upon when developing the theory. It seemed unrealistic to think that this knowledge and experience could be completely put to one side – or that it would be desirable to do this. Furthermore, early avoidance of the literature was not practical in this study given the academic requirements of the PhD.

Secondly, I wanted to produce a theory that might have practical value for those delivering arts sessions in care homes. The stated purpose of Straussian grounded theory is *'to develop knowledge that will guide practice'* (Corbin and Strauss, 2015, p.27). Straussian grounded theory is heavily influenced by pragmatism and symbolic interactionism, associated with the works of John Dewey (1859-1952) and George Herbert Mead (1863–1931). Symbolic interactionism posits that humans act towards things based on the meanings they give to them, and that these meanings are subject to modification through ongoing action and interaction. Pragmatism sees knowledge and action as interlinked, so that humans encounter a problem, anticipate a solution, and test an idea through action (Corbin and Strauss, 2015). Straussian grounded theory therefore places a heavy emphasis on understanding how individuals give meaning to a situation, how they act and interact to resolve an important concern, and how these actions and interactions may be subject to modification under different conditions. Straussian grounded theory was therefore deemed compatible with my goal of developing a pragmatic theory of arts engagement.

Finally, Straussian grounded theory was suited to my needs as a researcher. Straussian grounded theory gives plenty of guidance and structure and provides range of techniques and frameworks for analysis and theory building. Given my relative lack of research experience, the development of a theory seemed more accessible and possible with a Straussian approach. However, like all approaches to grounded theory, Straussian grounded theory has drawn criticism. While Straussian techniques and coding frameworks have been deemed overly complicated and excessive by some (Kenny and Fourie, 2015). Glaser has been particularly critical of the use of the 'forcing' of concepts and categories into frameworks (Kenny and Fourie, 2015). Yet Corbin has clearly stated that Straussian techniques and frameworks are intended to aid analysis and theory development, so that these approaches are not a set of directives and can be used flexibly (Corbin and Strauss, 2015). It is up to researchers to decide what approaches work best for their study. My reflections on Straussian analytic techniques and coding procedures are provided in chapter 4.

### 3.5. Positionality and reflexivity

What a researcher brings to their study as a person will influence what they can see in their data (Charmaz, 2006). I did not consider myself to be an objective and passive observer of the phenomenon I was studying. My interests, beliefs, and expectations will have exerted an effect in this study. This will have impacted upon my choice of research question, my interactions with participants, my approach to analysis, and the development of the theory (Birks and Mills, 2015). I do not consider that this influence was undesirable. Indeed, prior knowledge and personal experience can serve to enhance theory development (Corbin and Strauss, 2015). Yet given the likely extent of my impact in this study, I understood the need to reflect upon my influence to at least some degree.

Corbin and Strauss (2015) call for researchers to make an attempt at reflexivity. They advocate the use of a reflective journal for this purpose. I used a reflective diary throughout this study to record my assumptions and expectations at the outset of the study, and to note my reactions to things I had seen and heard. The purpose of this reflection was not to eliminate my influence but to become more aware of how my assumptions and expectations shaped the study, to be transparent about my influence, and to guard against overt bias. I share my reflections in subsequent chapters, and particularly chapter nine.

### 3.6. Research design and methods of data collection

In grounded theory, researchers can draw upon data from a wide variety of sources including interviews, observations, questionnaires, surveys, journals, and policy documents (Charmaz, 2006). Yet the usefulness of different data sources will depend upon the research problem, so that researchers are advised to select the methods that are best suited to their study (Charmaz, 2006). Given the influence of pragmatism and symbolic interactionism, Straussian grounded theory sees that *'actions and interactions that are taken, are directed at managing something based on the meaning the person has given to it'* (Corbin and Strauss, 2015, p.153). The task of the researcher is therefore to understand how individuals manage a core concern through their actions/ interactions, and how these actions and interactions vary under different conditions. Interviews and observations were identified as superior to other methods when trying to explore these factors.

The interview was considered the most obvious way of examining how meanings shaped practitioner behaviours, when individual perspectives and motivations can be accessed using the method (Patton, 2015). The flexibility of the interview meant that participant accounts could be further examined during interviews, while unforeseen lines of enquiry could be followed up. Observations would allow a finer examination of engagement behaviours, and how these behaviours changed under different conditions. The respective strengths of interviews and observations made them complimentary forms of data collection. A two-phased approach to data collection was followed in this study. Phase one focused on in-depth interviews with arts practitioners, arts mentors/trainers, artistic directors, and care staff. Analysis of phase one interview data resulted in the development of a tentative theory of arts activity engagement. Phase two data collection focused on observations of dance therapy and poetry activities in one care home, and post-activity interviews (with arts practitioners and the activity coordinator). Phase two data was used to check and further elaborate the tentative theory.

#### 3.6.1 The interview

The unstructured interview is considered the best method of interviewing in grounded theory. An unstructured approach allows participants to talk freely can lead to a more insightful theory



(Corbin and Strauss, 2015). Yet, it is also accepted that a complete lack of structure can be overwhelming and less suited to the inexperienced interviewer (Corbin and Strauss, 2015). Charmaz (2006) therefore recommends the use of an interview guide, with '*well-planned, open ended questions and ready probes*' to avoid becoming '*distracted by what to ask next and how to ask it*' (p.29). I endeavoured to let interviewees talk as freely as possible, yet given my relative inexperience, I brought a small number of broad core questions with sub-questions to use as prompts if needed in early interviews. As data collection and analysis progressed, more focused questions started to emerge in line with the developing theory. The initial development and subsequent evolution of interview questions are discussed in the next chapter.

The stated advantage of the interview is its ability to access perspectives, assuming that the perspectives of others are '*meaningful, knowable and can be made explicit*' (Patton, 2015, p.426). Yet, this is an assumption that has been contested by Silverman (2017), who considers that the ability of the interview to do this is overstated. Silverman reasons that behaviour is often carried out with little conscious awareness, so that participants can struggle to provide a reliable account of their actions and motivations. To address this concern, I clearly communicated the purpose of the study to all prospective interviewees when inviting them to interview. I also developed a detailed participant information sheet that was shared well in advance of the interview (appendix 1). I hoped that these actions would encourage at least some degree of introspection and contemplation prior to interviews, allowing participants to provide a thoughtful account of their actions and motivations. I also considered that early and clear communication would discourage anyone with a lack of insight or interest in the topic from participating.

I also understood that interviewee accounts would be influenced by my abilities as an interviewer. Good quality data is more likely when a researcher can ask questions carefully, be sensitive to responses, and can clarify meanings (Charmaz, 2006). Quality interviews require clarity, sensitivity, and openness and flexibility on the part of the researcher, as well as the ability to retain information to ask relevant follow-up questions (Kvale, 1996; Patton, 2015). While I had practiced interview skills through my master's degree, I considered that I was relatively inexperienced in the method. To hone my interviewing skills, I attended interview training with the Researcher Development Programme, at the University of Worcester. I also understood that interview skills would likely grow with time and practice, and so I tried to

reflect upon my approach to identify areas for improvement. Some reflections about interviews and my progress as an interviewer, are shared in the next chapter.

### 3.6.2. Observations

Observations would allow me to examine engagement behaviours more directly and to check the appropriateness of the tentative theory developed from phase one interviews since *'it is not unusual for persons to say they are doing one thing, while in reality they are doing something else'* (Corbin and Strauss, 2015, p41). Observations would also allow identify aspects of engagement that might have been overlooked during interviews, since individuals are *'not always aware of, or able to articulate, the subtleties of what goes on during interactions between themselves and others'* (Corbin and Strauss, 2015, p.41). Finally, observations would enable thick and rich descriptions of the engagement process, allowing others to draw conclusions about the phenomenon by vicariously experiencing what was observed. Descriptive examples would also add a richness and depth to the theory. Post-observation interviews with arts practitioners after each activity would then allow me to verify my interpretations about the activity.

A further reason for observations was to ensure people with more advanced dementia were included in data collection. While it is possible to access the perspectives of those living with dementia through interviews these efforts are not always fruitful (Pols, 2005). Observations would therefore ensure that the experiences of care home residents were well considered in the study. Post-activity interviews were to be conducted with residents (where possible), immediately after arts activities. It was reasoned that resident perspectives about the activities might be more accessible when conducted in this way. Yet interview attempts with residents did not prove fruitful. Reasons are discussed in chapter 5.

Non-participant observations were deemed a more suitable approach to observations than participant observation. To answer the research question, I needed to capture the nuances of engagement as fully as possible, and so I considered that my own involvement in arts activities would have distracted from this objective. A somewhat structured approach to observations was also considered more appropriate than a completely unstructured one in this study. Structured observational tools are generally considered less suited to grounded theory studies

where these tools impose a potentially unsuitable framework (Corbin and Strauss, 2015). Yet, good unstructured observations demand a high level of skill (Patton, 2015). I needed to balance the ideals of grounded theory, with what was pragmatic. As a relatively inexperienced researcher, I considered that I would benefit from some level of structure to prevent overwhelm during observations. Dementia Care Mapping (DCM), a structured, non-participant observational tool, ultimately provided a very loose framework for observations (Kitwood & Bredin., 1992). Information about DCM and my reflections of using the tool, are shared in chapter 5.

### 3.7. Conclusion

This chapter explained why Straussian grounded theory was identified as the most suitable methodology for theory development given its focus on pragmatic theory development, and my need to produce a practical theory that could inform arts practice. The chapter also explained how the high levels of structure and guidance given in the Straussian approach were best suited to my needs as a relatively inexperienced researcher. Interviews and observations were identified as suitable and complimentary forms of data collection in the study. The rationale for a two-phased approach to data collection was shared when practitioner engagement behaviours and motivations could be explored through interviews in phase one, and when observations of activities would allow a finer examination of engagement behaviours in the second phase of the study.

## Chapter 4: Methods, phase 1

### 4.1. Introduction

In chapter three, Straussian grounded theory was identified as the most suitable methodology for theory development in this study. Chapter three also outlined the two-phased approach to data collection that would be used to develop the theory. This chapter reports on phase one data collection and analysis involving in-depth interviews with arts practitioners, arts mentors/trainers, artistic directors, and care staff. The question guiding phase one data collection was: *'How do arts practitioners engage the person living with dementia in a care home setting?'*

This chapter explains how interviewees were identified and recruited to the study and how data were collected and analysed. The chapter provides an account of theory building using a Straussian framework called the paradigm. The chapter ends with a tentative theory of arts activity engagement in care homes.

### 4.2. Theoretical sampling

Theoretical sampling is a core feature of grounded theory. It is a concept driven approach to sampling, where each episode of data collection can inform subsequent sampling decisions (Corbin and Strauss, 2015). Theoretical sampling can start after the first episode of data collection. Analysis leads to the generation of concepts - or words that signify the meaning of the data. Analytic thinking about these concepts will generate questions so that researchers can go to the *'places, persons, and situations'* that will provide further insights about concepts (Corbin and Strauss, 2015, p.135). Theoretical sampling therefore facilitates theory development by directing data collection *'to those areas that will best serve the developing theory'* (Corbin and Strauss, 2015, p.134).

Theoretical sampling stands in contrast to more conventional forms of sampling where sample size and sample composition are decided upon in advance. In grounded theory it is the *'representativeness of concepts'* that is the concern (Corbin and Strauss, 2015, p.146). To

ensure that the resulting theory will have broad applicability, researchers should be *'on the lookout for opportunities or situations that will maximise similarities and differences within and between concepts'* (p.141). Sampling can stop when saturation is reached, meaning that no new concepts emerge, and that existing categories (high-level concepts) show depth and variation, and are well-integrated (Corbin and Strauss, 2015). The point at which saturation is reached will vary between grounded theory studies so that researchers cannot know how much data they will need to collect. Corbin and Strauss do however advise that *'it is rare that five or six one-hour interviews will provide sufficient data to lead to saturation'* (Corbin and Strauss, 2015, p.140).

While theoretical sampling is the ideal form of sampling in grounded theory, the ideals of the method can be balanced with the practicalities of a study (Corbin and Strauss, 2015). Corbin and Strauss concede that it is possible to conduct a grounded theory study using convenience or purposive sampling, and that researchers can develop theory using already-collected data. Concept development is still possible under these conditions as *'differences in data emerge naturally because of natural variations in situations'* (Corbin and Strauss, 2015, p144). Yet, theory development can be hindered when a researcher cannot decide where to sample, or when there is no opportunity to collect additional data to further develop a category (Corbin and Strauss, 2015). While some participants were recruited to the study purely based on convenience, I resolved to use theoretical sampling in this study as far as possible. This meant that I approached individuals for interview if I thought they might provide a deeper or contrasting perspectives about one or more concepts.

#### 4.2.1 Examples of theoretical sampling

Four examples of theoretical sampling are given below to illustrate how sampling decisions were driven by emerging concepts in this study:

The first example relates to sampling decisions made following the analysis of the first interview. The concepts of *'self-reflection'*, *'getting acquainted'*, and *'forming an understanding'* emerged as tentative and related concepts in this early interview. The interviewee, a dance movement psychotherapist, spoke about the importance of understanding residents by getting acquainted with them as individuals. The interviewee also used self-reflection to understand those she worked with. The interviewee explained that self-

reflection was a strategy she had learned through her training as a therapist, so that by reflecting on her own emotional responses, she could pick up on the emotions of others and understand their experiences. To learn more about the concepts '*self-reflection*', '*getting acquainted*', and '*forming an understanding*' I maximised differences by approaching a non-therapist (a singing facilitator) for the second interview. I wondered if a non-therapist would try to form an understanding of residents, and if they used similar or different strategies to the first interviewee to do this. I wondered if self-reflection was a strategy used exclusively by therapists. From this second interview, the concepts '*forming an understanding*' and '*self-reflection*', were developed further.

The second example relates to the concept '*consulting with care staff*'. The first two interviewees explained that they consulted with care staff about basic health and safety information. They did not seek out other information about residents in advance of their sessions. Yet I was aware of two arts practitioners who did liaise more extensively with care staff/plans in their work (interviewees 3 and 4). These practitioners were approached for interview to offer a contrasting perspective. Contrasting views on this matter did not negate previous findings, but instead helped me to form a more nuanced understanding about why arts practitioners might (or might not) want to consult with care staff in their work.

The third example relates to the concept '*being intentional*'. During early interviews, it was clear that practitioners were using the arts in very intentional ways to bring about desired change. Practitioners described how they used the arts to help residents feel in control, to realise their creative potential, to express themselves, to connect with other residents etc. Yet early interviewees all ran participatory arts sessions. I wondered if performers were also intentional in their approach. I wondered if they shared any of the intentions described by participatory artists – or if performance-based activities were simply a form of entertainment. Those who were involved in performance-based activities were approached for interview to examine the intentions that underpinned their practice (interviewees 14 and 16).

The fourth example relates to the concepts of '*practitioner skills*' and '*practitioner disposition*.' Rather than providing a contrasting perspective, sometimes interviewees were approached if they could provide deeper insights about emerging concepts. Findings from early interviews suggested that certain skills and dispositions were advantageous for working with residents. I thought that arts mentors and trainers who had experience of coaching arts practitioners

would be well placed to offer insights about the skills and dispositions that were needed to work in the field. Interviewees 8, 9 and 10 were recruited to the study on this basis.

The examples above highlight how theoretical sampling was used to gain deeper and contrasting perspectives about emerging concepts. These examples are not exhaustive and other examples are given later in this chapter.

### 4.3. Interview participants

Interviews were ultimately conducted with 17 individuals in phase 1. Brinkman (2013), advises that 15 in-depth interviews should offer ample insights and a manageable volume of data for analysis, reasoning that *'fewer interviews more thoroughly analysed are preferable to many interviews that are superficially explored'* (Brinkman, 2013, p.59). Interviewing stopped when no new insights seemed to be emerging and when categories appeared well developed. Table 4.1 provides an overview of the interviews that were conducted in this first phase of the study.

#### 4.3.1 Inclusion criteria

While theoretical sampling involved an open and flexible approach to sampling, quality criteria provided some parameters for participant recruitment. I was keen to build the theory from people who had sustained experience of using the arts in care homes settings. To be included in the study participants needed to have:

- a. had at least 1 years-experience in delivering or directing/managing arts-based activities, or mentoring/training arts practitioners in a care home setting.
- b. undertaken their work in a paid capacity. This is not to suggest that those who are not paid do not produce quality work, but that market forces suggest that those who are paid are likely to be highly valued.

Care home staff were also interviewed in this study. To be included, care staff needed to have:

- a. regularly observed or participated in arts activities delivered by arts practitioners.
- b. had at least 1 years-experience of working with people with dementia in a care home.

**Table 4.1: Characteristics of phase-1 interviews.**

<b>Participant number.</b>	<b>Participant Role</b>	<b>Name</b>	<b>Date of interview</b>	<b>Location of interview</b>
01	Dance movement psychotherapist	Kelly	15 June 2017	University of Worcester
02	Singing facilitator	Ruth	27 June 2017	University of Worcester
03	Music therapist	Rachael	14 July 2017	Participant's home
04	Visual artist	Julie	19 July 2017	Coffee shop
05	Performer; Cellist	Claudia	7 September 2017	Coffee shop
06	Visual artist	Gavin	5 October 2017	Coffee shop
07	Artistic director theatre company	Rhonda	6 October 2017	Telephone
08	Mentor and Dance facilitator	Elizabeth	18 October 2017	Coffee shop
09	Mentor and Poet	Kenneth	26 October 2017	Telephone
10	Trainer and Visual art activity kit developer	Michelle	26 June 2018	University of Worcester
11	Activity coordinator	Rita	3 July 2018	Care home



12	Activity coordinator	Susan	3 July 2018	Care home
13	Drummer	Louisa	5 July 2018	Coffee shop
14	Opera singer	Lisa	9 July 2018	Telephone
15	Dance music psychotherapist	Simon	10 July 2018	Telephone
16	Director opera company	Clarissa	11 July 2018	Telephone
17	Musician	James	6 August 2018	Telephone

#### 4.3.2 The recruitment process

In line with a theoretical sampling approach, recruitment to the study was staggered and was directed by the emerging theory. Prospective interviewees who met the inclusion criteria above were identified through on-going care home visits, through attendance at conferences and seminars, and through conversations with students and supervisors at the TAnDem Doctoral Training Centre. All prospective interviewees were invited to participate by e-mail, and inclusion criteria were confirmed where needed. The purpose of the interview was explained in the e-mail request, and a detailed participant information sheet and consent form was attached for information (see appendices 1, 2, 3 and 4). The recruitment process was relatively straightforward, and only one individual who was approached for interview declined the opportunity to take part.

#### 4.4. The interviews

Interviews took place between June 2017 and August 2018. Participant convenience was the key concern so that individuals were interviewed at a time and place that was most convenient for them. Face-to-face interviewing was the main mode of interviewing in this study, yet due to geographical dispersion, logistical challenges, and the stated preference of one participant, telephone interviews were deemed necessary to allow for wider participation in the study. Six interviews in phase one were conducted by telephone. The shortest interview was 45 minutes in duration (a telephone interview). The longest interview was over 90 minutes long (a face-to-face interview).

#### 4.4.1. The interview approach.

Information sheets and consent forms were sent to participants in advance of the interview. Before obtaining consent and beginning the interview, time was taken to ensure that participants understood the content of the information sheet and that they were happy to proceed. Interviewees had been advised that they should allow around one hour for the interview itself, as well as time to complete the consent form.

The unstructured interview is considered the most effective form of interviewing in grounded theory, yet given my relative inexperience as an interviewer, I decided to use a small number of broad, core questions as prompts in early interviews. Questions included the following: *'Can you tell me about your work in care homes?; How do you engage residents during your sessions?; 'Do you ever need to adapt or tailor your approach?; 'Do you need to know anything about residents to engage them?; 'Can you tell me about a time you struggled to engage someone?'* I tried to follow the interviewees lead as much as possible and work my questions into the natural flow of the interview.

As data-collection, analysis and theory building progressed, new questions emerged and these became more focused. I needed to check the relevance of the emerging concepts and categories. I also needed to develop the categories of the theory. Emerging questions included the following: *'Some people take steps to help residents feel comfortable and relaxed in their sessions – do you need to do this?; 'Some people have said that they need to be highly adaptable and responsive when working with residents, is that your experience?; 'What are your intentions*

*when you run a session?'; 'Some people like to use a plan or follow a structure in their sessions—do you do this?'; 'Are there any qualities or competencies a practitioner needs to do this work well?'; 'Do you challenge residents in your sessions?'; 'Do you have any preference in terms of group size?'; 'Do you ever try to encourage interaction in the group?'; 'Some people seem to prefer working with the same residents over time- has that been your experience?'; 'Does the care setting influence how residents engage during your sessions?'; 'If a resident is disruptive in a session, how do you respond?'; 'Do you think you need resilience to deliver sessions in care homes?'; 'Do you ever find out information about the residents you work with?'; 'One practitioner said it is helpful to know about a resident's dementia diagnosis – do you seek this sort of information?'*

As interviews progressed, more questions emerged. Of course, it was not possible to address all my questions during interviews. Questions were therefore prioritised if I believed an individual might offer a deeper or contrasting perspective on something, or if a question would help me to expand an underdeveloped category. Following the advice of Corbin and Strauss (2015), I tried to follow the interviewees lead and work questions into the natural flow of the interview as far as possible. Corbin and Strauss (2015) advise that incidents relating to relevant concepts will often emerge naturally during the course of an interview so that researchers should to *'allow the participant proceed at his or her own pace while keeping the concept in mind'* (P140). If an important question had not been addressed, I made sure to ask this towards the end of the interview.

A variety of questioning strategies were also used during interviews to check my understanding and to stimulate more detailed responses. Probing questions were frequently used so that interviewees would elaborate on a response, for example: *'So you said you like getting to know individuals in a session. Can you say a bit more about why that is?'* (participant 01). Interviewees were sometimes asked to elaborate on their use of a particular word or phrase as advised by Kvale (1996), for example: *'You say that you need to create a 'safe space' for residents – what does that mean?'* (participant 01). My interpretations of interviewee accounts were also checked using interpreting questions such as: *'So the person might not be as cognitively aware of what is going on is what you're saying?'* (participant 02). These sorts of questions kept the interview flowing, where small prompts often meant that participants would continue to share their experiences, leading to more detailed responses.

#### 4.4.2. Reflections on interviews

As stated in the previous chapter, I considered that my beliefs and expectations would impact upon my interactions with participants. Additionally, my relative inexperience as an interviewer could have had implications for the quality of data generated in interviews. As such, I tried to reflect upon my influence and approach in interviews to identify areas for improvement. A reflective diary was kept for this purpose. Immediately after the first interview, I made the following reflections in my diary:

*'For a first interview, I think it went ok, but it could have gone much better. The interviewee's responses brought up many different avenues to explore. It was hard to keep track of emerging threads while also making sure that my core questions were addressed. I felt a little overwhelmed at times – and worried that I was not doing a very good job. The room was too hot – but it was too noisy outside to have the windows open. This was a little distracting for both me and the participant'.*

My initial afterthoughts therefore related to anxiety about my abilities as an interviewer, a loss of control over the interview, and environmental distractions. These concerns mirrored some of those reported by other doctoral students who have described feeling 'rattled' by environmental distractions, 'worried about their performance' and distracted by 'self-talk' (Roulston, deMarrais & Lewis, 2003, p.649, p.661). The process of transcribing and relistening to the first interview also helped me to reflect upon my approach. Despite my initial concerns, the core questions had been addressed. I had followed upon on important threads reasonably well, and responses were rich and insightful. I realised that my fear of losing control over the interview was inconsistent with a grounded theory approach. I also realised that this urge had caused me to interrupt the interviewee mid-flow on quite a few occasions. Important insights might have been missed as a result. I was reminded of the advice given by Kvale (1996), to be gentle in interviews, and to pause and allow participants time to finish and share their thoughts. I resolved to relax more in future interviews. The process of transcribing the interview also caused me to reflect upon my use of follow-up questions. These tended to be poorly constructed. I was reassured to find that difficulties formulating questions in interviews can be

a common frustration for doctoral students (Roulston, deMarrais & Lewis, 2003). Again, I was reminded of the need to pause before asking questions and to keep the wording of my questions as clear and simple as possible.

Learning of course was not confined to the first interview. With the best intentions, issues identified from the first interview were not completely resolved in later interviews. I did continue to interrupt at times, and follow-up questions were sometimes framed in an awkward and clumsy manner. New issues also emerged. For example, when reflecting after the second interview I realised that I had been frustrated by the interviewee's response to a question. Both the first and second interviewees explained that they did not seek to know information about a resident beyond basic health and safety information. I had assumed that arts practitioners would want to liaise with care staff about residents' interests to tailor their sessions accordingly. My own view was that this would lead to a more engaging arts session. Rather than accepting the interviewee's answer, I kept asking the question – in the hope that this would lead to a different response. I realised I was trying to impose my own biases onto the data.

Despite the challenges highlighted here, I do not believe that my inexperience or my biases had a detrimental effect on the research data. Awkwardly worded questions became less common, and my urge to interrupt was better managed. Where my own biases started to influence my line of questioning, participants were unswayed. By checking my emotional responses, I became more aware of my biases learned to keep these in check. I learned to listen more carefully and respectfully – and to better understand why someone took a particular view. Environmental distractions were difficult to anticipate, yet by arriving extra early to interviews, I tried to ensure that the interview space was suitable. For example, the coffee shop where I had arranged to meet interviewee 08 was particularly busy. By arriving early, I was able to find a much quieter coffee shop in a nearby hotel.

I believe that the quality of interview data obtained in phase-one data collection was of a good standard. The criteria for judging interview quality, as developed by Kvale (1996), were particularly useful when considering quality. Kvale proposed that the indicators of a quality interview were spontaneous, detailed, and lengthy answers, where meanings were clarified. I believe that phase-one interviews were a success according to these markers. Participants raised issues in an unprompted manner, indicating that they felt comfortable and willing to

share their insights. Accounts were lengthy and rich and insightful. There were occasions where I had missed the significance of what was being said and should have asked a follow up question. Yet I had been attentive and sensitive for the most part, clarifying and prompting where needed.

I had also gained consent from participants to clarify responses after the interview if this was needed. As discussed in chapter 3, Silverman (2017) stated that interviewees could lack the insight required to provide a reliable account of their actions and motivations. Yet this was not my experience at all. Indeed, participants provided a thoughtful and detailed account of their actions and motivations. Perhaps this was because they were passionate about the interview topic.

#### 4.4.3 Reflections on telephone and face-to-face interviews

While most interviews in this study were conducted in person, six were conducted by telephone. Ward (2015) asserts that telephone interviewing is a valid form of data collection in grounded theory, challenging the '*tacit assumption that face-to-face is the best option for the qualitative interview*'. Vogl (2013) found that the quality of the data gathered through telephone interviews was comparable to that generated from face-to-face interviewing. The inclusion of both forms of interviewing in this study allowed me to reflect upon the value of each approach.

My own experience was that both methods of interviewing had their advantages. Face-to-face interviews were generally longer than telephone interviews, and participants tended to give more detailed answers, resulting in a richer source of data for analysis. I suspect this was because face-to-face interviews allowed me to establish a greater level rapport with participants, which typically resulted in a more relaxed interview. The earliest interviews (1-6) were all conducted face-to-face, and the depth and breadth of insights gathered at this early stage set a good conceptual foundation for the study. Telephone interviews seemed to work well in the later stages of the study when I wanted to focus more directly on important concepts. Interviewees seemed less inclined to digress on the telephone which made for a more focused interview. Telephone interviewing also facilitated the inclusion of individuals where face-to-face interviewing was less possible.

One drawback of telephone interviews was the loss of visual cues. The strength of a participant's feelings was often reinforced during face-to-face interviews where visual cues were present. Interview 7 for example sent an email immediately after our telephone interview to apologise for sounding irritated. This was not something I had identified during the interview, and so the email came as a surprise. When I listened back to the interview recording however, the individual did seem slightly annoyed when I posed a question about self-reflection, indicated by a sigh. Learning from this experience, I took extra care to inform interviewees that some questions might be less relevant in their practice, so that they should feel free to disagree with any of my questions if they made little sense.

#### 4.5. Ethical issues

Ethical approval for phase 1 data collection was gained from the Health and Science Research Ethics Committee (HSREC) at the University of Worcester. I understood that even with ethical approval I needed to continually consider the ethical implications of my actions throughout the study (de Laine, 2000).

The insights of Diener and Crandall (1978) provided a useful framework for considering ethics in this study. They suggested that researchers should think about the ethical implications of their study in four areas: deception, informed consent, harm to participants, and invasion of privacy. To avoid deception and to ensure that consent was informed, participant information sheets and consent forms were provided well in advance of interviews to allow participants time to consider their involvement and to raise questions. Time was also allocated at the start of each interview to go through the information sheet and the consent form. Clear information was provided about the reason for the study, what participation would involve, and how findings would be disseminated. The potential risks and benefits of involvement were highlighted. Individuals were informed of their right to refuse to take part or to withdraw from the study. In terms of privacy, all digital files were stored on a password-protected folder of the University of Worcester network and data held in manual files were stored in a locked filing cabinet at the University of Worcester. Identifiable features of the data were removed. Steps were also taken to reduce the risk of participants being identified in this thesis and other

research outputs by changing names and limiting other information that could cause someone or a care home to be identified.

When considering potential harm to participants, given the interview topic, I believed that the risk of harm was low. Yet, the potential for any interview to cause distress was recognised and so a protocol was agreed with the Health and Science Research Ethics Committee. This protocol was to be acted upon in the event of participant distress. To my surprise, one participant did become emotional during an interview when discussing a care home resident who had recently died. The incident reminded me of de Laine's assertion that the '*impersonal, objective and rational*' approach of ethics committees, does not prepare researchers for the '*personal and interactive*' ethics that are often needed. I stopped the interview recording immediately and communicated my sympathies to the participant.

## 4.6. Analysis

### 4.6.1 Data preparation

Transcription was considered the first stage of analysis in this study. While the transcription of interviews has been identified as one of the more demanding tasks of qualitative research (Bryman, 2008), the process of transcribing interviews can stimulate analytic thinking (Brinkmann, 2013). Transcription was an opportunity to get familiar with my data, and so all interviews were transcribed without the assistance of a transcription service. Researchers need to decide what level of transcription is most appropriate given the aims of their study (Baily, 2008). Brinkmann (2013) advises researchers to consider the purpose of their study, as well as what is practical and possible. Some studies permit a loose transcription, while others require a more thorough and detailed account. In this study, I made the decision to transcribe interviews mostly in full. In grounded theory, researchers are expected to allow interviewees to digress to at least some degree. While certain segments of interview data did not seem particularly relevant or illuminating to the research question, I understood that these incidents might prove pertinent as the research progressed. For example, when an interviewee explained how they had sessions with a counsellor to discuss the emotional impact of their work, I initially thought this was unessential information. Yet as interviews progressed, I



realised it was important. A meticulous level of transcription however that captured pauses, speed, tone of voice etc., was deemed unnecessary and impractical in this study.

#### 4.6.2 Open coding

Ideally, each episode of data collection in grounded theory should be followed by analysis so that emerging concepts can inform subsequent sampling decisions (Corbin and Strauss, 2015). Analysis therefore started immediately after the first interview in this study.

Straussian coding procedures follow 3 successive stages: open coding, axial coding, and selective coding. While there is a progressive nature to these coding procedures, analysis involves a process of going back and forth between open, axial, and selective coding (Corbin and Strauss, 2015). Open coding is the earliest stage of coding and is primarily concerned with concept identification and elaboration. When engaged in open-coding, grounded theorists break their data up into sections, often paragraphs, and then think of words or 'concepts' that represent the meaning of the data (Corbin and Strauss, 2015). Take the following example from the first interview:

*'I might invite people to do something and they can say no and that's absolutely fine ...I always encourage people to do something, but if someone is saying really very clearly that they don't want to, I think it's just as helpful to say it sounds like that's the sort of thing that you really don't want to do'.*

The following tentative concepts were created to signify the meaning of the data in the excerpt above: *'Being tentative'*; *'Inviting engagement'*, *'Encouraging engagement'*; *'Acknowledging feelings'*; *'Refusal to engage'*; and *'Respecting choice'*. Table 4.2 contains a list of the tentative concepts that were created from the initial coding of the first interview.

**Table 4.2: Tentative concepts created after initial open coding of the first interview**

Interview	Concepts
001	<p><i>'Making connections'; 'Re-enacting'; 'Reminiscing'; 'Getting engagement'; 'Noticing responses'; 'Gravitating'; 'Asserting oneself'; 'Self-reflection'; 'Needs'; 'Abilities'; 'Experience'; 'Beliefs/Perceptions'; 'Tailoring opportunities to the person'; 'Using reverse psychology'; 'Stepping back'; 'Getting acquainted'; 'Forming an understanding'; 'Validating'; 'Creating a safe space'; 'Comforting'; 'A loss of self'; 'Reinforcing a sense of self'; 'Being playful'; 'Complexity and diversity of needs'; 'Experimenting'; 'Enhancing self-worth'; 'Feeling comfortable'; 'Consulting'; 'Empowering residents'; 'Inviting engagement'; 'Encouraging engagement'; 'Acknowledging feelings'; 'Respecting choice'; 'Expressing challenging emotions'; 'Keeping an open-mind'; 'Having a plan'; 'Using rituals and repetition'; 'Discovering the person through the art'; 'Celebrating'; 'Using a recognisable structure'; 'Transitioning/Easing in'; 'Being tentative'; 'Being flexible'; 'Staying present- working in the moment'; 'Enabling relationships'; 'Having a safe zone'; 'Group dynamics'; 'Refusal to engage'; 'Embracing diversity of expression'; 'Care home cooperation'; 'Disposition'; 'Feeling valued'; 'The care setting'; 'Group size and composition'; 'Severity of dementia'; and 'Recognising and reflecting individuality'.</i></p>

The open coding of early interviews was not easy. Meanings felt elusive at times. Some segments of data were left un-coded, and important incidents in the data were initially overlooked. Corbin and Strauss (2015) advise that sensitivity to the significance of data will grow with incoming data. This was my experience. By way of example, I did not notice the use of persuasion strategies in the data until later in the study – yet these strategies were present in early interviews. By continually revisiting interviews, I was able to spot things in the data I had initially overlooked. As such, I engaged in open coding right up until the end of this study.

While concept identification felt hard at times, the process was aided somewhat by my prior knowledge and by my prior engagement with the literature. Incidents pertaining to person-centred theory and positive-person work like *'validation'*, *'recognising'*, and *'celebration'* were prevalent in the data (Kitwood, 1997a). Other ideas and action and interaction strategies that

had emerged in the literature review were also present in the data (e.g. prompting, modelling, matching). As advised by Corbin and Strauss (2015), I took care to ensure that any pre-existing concepts adequately captured the meaning of my data and were not forced upon it. The suitability of concepts was supported by the fact that interviewees often used these words themselves. Concept identification was also aided by the creation of 'in vivo' codes. In grounded theory, in vivo codes are concepts that use the actual words of participants. These codes are used when participants conceptualise something so well that a researcher would struggle to find a better term. Two examples of in vivo codes used in this study were: '*creating a safe space*', and '*getting the fit right*'.

Open coding is not only concerned with concept identification, but also concept elaboration. Researchers should try to elaborate their concepts by learning more about them. The constant comparison technique aids this process. When using constant comparison, researchers look for conceptually similar incidents in their data and ask what else they can learn about a concept. By way of example, '*self-reflection*' was used by several interviewees – yet in slightly different ways. Some practitioners reflected on their strengths and weaknesses to improve their practice. Some reflected on their motivations and desires during a session- to understand if they were acting out of their own interests at the expense of what residents wanted and needed to do. Some reflected on their emotional responses in a situation – to better understand how residents might be feeling. In this way the concept of self-reflection developed some nuance.

Corbin and Strauss also offer a range of additional strategies to help researchers think more deeply about their concepts. One strategy that was extremely helpful in this study was to look for words that indicated time such as: *when, then, after, before, and if*. In the interview excerpt above, the arts practitioner explained that she would always encourage residents to engage, yet **if** someone strongly expressed that they did not want to do something, she would accept their decision. This suggested that encouragement was contextualised according to participant readiness. Incoming data confirmed this idea and '*encouraging engagement*' was located on a continuum from refusal to eagerness. Strong refusals to engage were respected. Yet practitioners would intensify encouragement to those who were somewhat reticent or reluctant. Those residents who were eager or enthusiastic could be encouraged to expand upon their efforts or challenged to engage in more significant ways. Words that indicated time were also helpful for contextualising the concept '*supporting engagement*'. Again, the data

showed that resident abilities varied along a continuum from those who were less able to those who were more able. Interview data showed that practitioners intensified support when a less able resident was unable to engage or was struggling to engage. Take the following examples:

*'If somebody is sitting there unable to do anything, **then** you sit next to them and you start trying to guide them...'*

Julie (Visual artist)

*'Sometimes she will say 'I'm ready' and then just for a few moments she might hold this maraca and you might **then** have to prompt her and say shake the maraca and she might shake it'.*

Rachael (Music Therapist)

Another useful analytic strategy was 'waving the red flag'. Corbin and Strauss explain that researchers and research participants can become so fixated on their ideas about how things are or the right way to do things – that they can fail to acknowledge exceptions. By 'waving the red flag', researchers stay alert to both their own assumptions and those of their participants. Corbin and Strauss advise that the use of the terms *always* or *never* should cause researchers to wave a red flag. By way of example, for the concept '*Inviting engagement*', invitations tended to be open-ended so that residents could interpret and act upon opportunities in their own ways. When writing up the theory I wrote that offers to engage should **always** be open-ended. This caused me to wave a red flag. I revisited my interviews and found exceptions linked to ability and perceptions of readiness. For example, one practitioner (a poet) believed that residents could be nervous at the start of his sessions, and so he began sessions by directing engagement, asking residents to repeat his words as he read from poems. The poet claimed that this was an easy task that helped residents relax. Open-ended questions were asked after this point when residents were more relaxed. This gave more variation to the concept '*Inviting engagement*'.

Finally, Corbin and Strauss advise that researchers can learn more about concepts by paying attention to emotional responses. The concept '*Consulting with care staff*' continued to be developed through theoretical sampling and constant comparison. It transpired that practitioners would consult with care staff about different things, at different times. One practitioner (a visual artist) explained that she liked to find out information about a resident's dementia and symptomology where possible, including any behavioural issues. When I put this strategy to a subsequent practitioner, it provoked an angry response. This angry response made me realise that I needed to understand why this practitioner felt so strongly about the matter. By paying attention to emotions, the concept '*Consulting with care staff*' was further developed and contextualised.

#### 4.6.3 Using memos to develop and organise categories

Memo-writing is an integral part of theory development in grounded theory (Corbin and Strauss, 2015). Through open coding, concepts start to become increasingly numerous. The constant comparison technique means that concepts related to the same phenomena can start to be grouped together under higher-level concepts called categories. Several tentative categories were created after the first interview. The concepts of '*self-reflection*'; '*getting acquainted*', and '*consulting with care staff*', were all directed towards the purpose of understanding residents and so these concepts were grouped together under the tentative category '*forming an understanding*'. As data collection proceeded, concepts that were relevant to the idea of forming an understanding continued to be identified through constant comparison. These concepts were incorporated into the category. Concepts included: '*drawing upon relevant theories*'; and '*training and development*'.

Categories start to become increasingly dense over time, and so researchers need a space where they can document the details of a developing category. Memos are used for this purpose. Memos provide a space to for researchers to speculate, document insights, raise questions, and consider where they might find answers to these questions (Corbin and Strauss, 2015). The act of memo-writing can therefore '*stimulate and document analytic thought processes and provide direction for theoretical sampling*' (Corbin and Strauss, 2015, p.127). Another early tentative category was '*creating a safe space*'. Through a process of constant

comparison, the concepts *'transitioning/easing in'*; *'having a safe zone'*; and *'using a recognisable structure'* were all actions taken by the first interviewee to help residents to relax and feel safe in her sessions. In the memo for the tentative category *'Creating a safe space'*, I pondered if the notion of 'a safe space' would hold relevance beyond therapy-based arts sessions. Would other arts practitioners want to create a safe space? Would the idea of a safe space hold relevance for non-participatory arts activities? Did performers create a 'safe space' - or was this less applicable to their work? The concept of a 'safe space' proved highly relevant and the category continued to grow. It became clear that arts practitioners also needed to feel safe in their sessions. The category was therefore developed further to include the actions arts practitioners took to feel safe themselves.

As categories become increasingly dense, researchers can start to develop subcategories to organise the category (Kenny and Fourie, 2015). Memos can provide a space to organise categories in this way. I realised that the concepts that related to the idea of creating a safe space for example were focused slightly differently. Some concepts were about *'instilling control'* (e.g. *'reminding of choice'*), others were about *'reducing uncertainty'* (e.g. *'introducing oneself and the session'*). The higher-level concept or category *'Creating a safe space'* therefore started to be organised into subcategories.

#### 4.6.4 Axial coding

Lower-level concepts provide the detail of a theory. Higher level concepts/categories provide the structure of a theory, and a way of integrating the theory (Corbin and Strauss, 2015). To develop a theory, I needed to have a small number of well-developed categories that could be *'woven or linked back together'* to tell the story of the research in conceptual terms (Corbin and Strauss, 2015, p.157). Open coding had resulted in a long list of standalone concepts and categories – and I was unsure of how these concepts and categories were related. Axial coding helped me to start thinking about the relationships between emerging categories and concepts. This allowed me to incorporate concepts and categories under even more abstract categories, which would in turn make integration more possible (Corbin and Strauss, 2015; Kenny and Fourie, 2015).

Axial coding is a stage of coding that is unique to Straussian grounded theory. Axial coding involves the use of a tool called the paradigm. The original paradigm related concepts and

categories to a more abstract category by defining them as: a) causal conditions, b) contextual conditions, c) intervening conditions, d) action/interaction strategies, or e) consequences (Strauss & Corbin, 1990). Axial coding and the use of the paradigm has been subject to criticism and some consider that Straussian procedures are unduly onerous and complicated (Kenny and Fourie, 2015). Perhaps in response to these criticisms, a simplified version of the paradigm can now be used. Corbin has also warned against the blind application of the paradigm, stressing that it is *'a tool'* to aid theory development *'not a set of directives'* (Corbin and Strauss, 2015, p.157). I understood the need to reflect carefully upon the suitability of the paradigm for this study.

The updated and simplified version of the paradigm relates emerging concepts and categories to a more abstract category by defining them as: a) conditions, b) action/interaction strategies, or c) consequences (Corbin and Strauss, 2015). Corbin explains that the paradigm is influenced by pragmatism and symbolic interactionism. When engaged in axial coding, researchers are simply asking how individuals take steps to address or manage a concern, and what they hope to achieve through their actions. The paradigm provides a framework to *'sort out and arrange concepts'* by considering what actions/interactions are taken (action/interaction strategies), in response to what circumstances – either real or perceived (conditions), and with what anticipated outcomes (consequences) (Corbin and Strauss, 2015, p.157). The paradigm can therefore help researchers develop a pragmatic theory by keeping action and interaction at the heart of their analysis *'while sorting out the relationship between it and other concepts'* some of which will represent conditions, and others consequences (Corbin and Strauss, 2015, p.166).

While the paradigm will not be suitable for every grounded theory study, it worked well in this study. The use of the paradigm felt intuitive and not forced. The framework helped me to think through the concerns of arts practitioners, the actions they took to address these concerns, and what they hoped to achieve. I started to see relationships between my emerging concepts and categories. Axial coding helped me to start to create some sense of order out of what felt like chaos. A smaller number of abstract categories were created through this process, making final integration of the theory more possible. By considering why arts practitioners acted as they did, axial coding also helped me to move from description to explanation.

To demonstrate the use of axial coding in this study, consider the application of the paradigm to the category *'creating a safe space'*. I had already identified a range of actions/interactions

that pertained to the idea of helping residents feel safe, and I had started to organise these into subcategories. By using the paradigm, I realised that practitioners took action to help residents feel safe because they believed that activities had the potential to be anxiety provoking due to fear of the unknown and nervousness about ability and what would be expected. Perceptions about *'fear of the unknown'* and *'fear of expectations'* were the conditions that caused practitioners to act and interact in ways that would help residents *'feel at ease'* and to be *'open to possibilities'* for engagement (consequences). I also realised that practitioners were not creating a safe environment so that residents would participate in a predetermined way. Rather they were aiming to create a safe **and supportive** environment, so that residents would feel free to engage in ways that were meaningful for them. Some practitioners considered that care homes could be quite *'imposing spaces'* where residents could feel pressured to conform (condition). Practitioners did not want to impose on residents but wanted residents to *'feel in control'* and to *'feel accepted'* for their choices and their contributions – whatever these looked like. The tentative category *'creating a safe space'* was renamed *'creating a safe and supportive space'*. The category *'being inclusive'* with its associated action and interaction strategies (e.g. *'welcoming and valuing diversity of expression'*) were subsumed into the newly formed category.

The paradigm was also applied to the tentative category *'forming an understanding'*. Arts practitioners talked about *'complexity'* and *'diversity'* of resident needs and desires, and the *'unpredictability'* of resident responses (conditions). Arts practitioners explained that to effectively engage residents in their sessions, they needed to *'be responsive'* to residents (consequence). Practitioners did this by *'forming an understanding'* of residents. Yet I realised that practitioners took additional steps to manage the complex and unpredictable nature of their work, and to stay responsive to residents. Practitioners explained that they needed to be flexible and adaptable. The category *'staying flexible and adaptable'* (and its associated concepts), were incorporated under the newly created higher-level category *'A responsive approach'*. A further category was also added. To cope with the complex nature of their work, and to stay responsive, practitioners explained that they needed a degree of resilience. The category *'developing resilience'* along with its associated concepts were also incorporated into the category.



#### 4.6.5. Selective coding

Selective coding refers to the act of integrating the categories around a core category (Kenny and Fourie, 2015). The first stage in this process is the selection or creation of one central core category. The core category must be *'abstract and broad enough to be representative of all participants in the study,'* and to integrate all other categories (Corbin and Strauss, 2015, p.188). When integrated, the grounded theory needs to tell a coherent story of the research findings in conceptual terms (Corbin and Strauss, 2015). I needed one single category that would not only capture the main idea of the research, but that could be linked to the other categories in a coherent way. Indeed, Strauss and Corbin described the core category as being *'like the sun, standing in relationship to its planets'* (1990, p. 124.) Yet the selection (or creation) of a core category is recognised as one of the most difficult tasks of a grounded theory study (Corbin and Strauss, 2015). This task proved much more difficult than I had anticipated, and I did not arrive at the final core category until after I had completed my interviews.

To arrive at a suitable core category, I needed to have a clear sense of what the major concern of my interviewees was and how they tried to address it. Corbin and Strauss (2015) advise that researchers take a broad, birds-eye view of their data to get a sense of what the major concern of participants might be and how they resolve it. As such, I read and re-read transcripts in their entirety. I also began free-writing memos. Glaser (2013) advocates free writing as a *'device to unlock the connections between the conscious, unconscious, and preconscious mind'*. The act of free writing was invaluable in generating insights and identifying possible contenders for the core category. Ultimately there were three main contenders in my search for a suitable core category.

While researchers usually identify a suitable core category in the later stages of their research, open, axial, and selective coding do not have to proceed in a linear way. I understood that identification of the core category would help with open and axial coding by providing a lens for analysis. As such, a significant amount of time was invested in trying to arrive at a core category from early in the analysis. The first potential core category was identified after the fourth interview. When reading early interview transcripts, the idea of using the arts to support selfhood in dementia came through. The first interviewee talked about reflecting things about a resident to enhance the resident's sense of self. Other interviewees talked

about using the arts to help residents connect with their emotions (the *'emotional self'*), explore their creativity (*'the creative self'*) etc. I wondered if *'supporting a sense of self'* could be the major theme of the research and a suitable core category. I made a note of the possible core category and resolved to proceed with an open mind, understanding that other ideas would likely emerge over time (Corbin and Strauss, 2015).

The second contender for the core category emerged later in the analysis. One indication that a concept can serve as a core category is the frequency with which a concept appears in the data (Corbin and Strauss, 2015). I noticed that the word 'connections' recurred repeatedly throughout the interview transcripts. Practitioners explained that they were enabling residents to re-connect with other people, with cultural opportunities and the world around them, with their creativity, with their thoughts and feelings, with their body etc. I considered that *'cultivating connections'* might be a suitable core category.

For a while I was convinced that *'cultivating connections'* was the most suitable core category. It represented a key idea running through the research. Yet with on-going reflection, I felt that the concept (along with supporting a sense of self) did not do justice to the story of the research. I went back to the interview transcripts, re-reading them again and again. Eventually, I was struck by two ideas in the data. Firstly, I was struck by the idea of loss. The potential loss that can be experienced by those living with dementia in a care home was a theme that ran through all of the interviews. It represented a major concern that practitioners wished to address through their practice (e.g. a loss of confidence; a loss of control; a loss of recognition and respect etc). Secondly, when considering how arts practitioners resolved this concern, I was struck by the idea of scaffolding.

The concept of *'scaffolding'* already existed as a category in the theory. In Straussian grounded theory, researchers can reflect upon their own experience to assist with concept development. When attending an arts session in an informal capacity, I was struck by how the practitioner seemed to continually adapt levels of support and guidance for each resident. The practitioner modelled behaviours, gave prompts, and made suggestions where needed, but encouraged residents to engage as independently as possible. After this session, I read some literature on modelling behaviours and was led to educational research and to the concept of *'scaffolding'*. A fuller account of scaffolding will be provided in chapter 6. In brief, scaffolding is a metaphor used in education to convey the ways in which teachers will 'scaffold' or encourage and

support a learner to engage at a higher level, to reach their potential. They do this by challenging students to engage just beyond their comfort zone, and by offering *just* enough support to enable the student to complete a task. Guidance and support are intensified where needed and withdrawn where possible, so that the student can engage as independently as possible and can acquire knowledge and skills. I realised that the practitioner I had observed had been scaffolding engagement.

In grounded theory pre-existing concepts and theories '*may work brilliantly on some data*' and can be borrowed, yet these concepts and theories must be scrutinised against the data and grounded in it (Corbin and Strauss, 2015, p.381). When revisiting my interview data and concepts, I realised that the idea of scaffolding was present. By encouraging and supporting engagement, practitioners enabled residents to engage at a higher level than would have otherwise been possible. Practitioners were also using scaffolding strategies. They were: '*challenging*'; '*demonstrating/modelling behaviours*'; '*giving prompts*'; '*intensifying support*' where needed, and '*withdrawing/tapering support*' where possible. I created the tentative category '*scaffolding*' and checked the relevance of the idea with subsequent interviewees (see appendix 5). Yet at this stage, I did not consider that scaffolding could be the core category. I was interviewing performers, and they did not engage in '*scaffolding*' behaviours. The core category needed to represent the experiences of all research participants. My search for a core category continued. When I was confronted by the idea of loss however, I was struck by the notion of scaffolding again.

I came to realise that arts activities also acted as a scaffold for relationships in dementia. When communication and collaboration were encouraged and supported, activities aided the building of new relationships in dementia, and the maintenance of existing ones. I also reasoned that affective capabilities (or the ability to feel and express emotions), were enhanced through performance-based art. Papers on scaffolding by Maise (2016) and Colombetti and Krueger (2015), and a re-reading of my interview data, confirmed and cemented this idea. I came to realise that practitioners used material and cultural resources in arts sessions as scaffolds to enhance resident capacities to think, feel, act, and interact. My interview data made sense through a scaffolding lens. I tentatively considered that scaffolding was a useful and practical metaphor to explain how arts practitioners engaged residents. The tentative core category of the theory was as follows:

*Scaffolding: Encouraging, supporting, and enhancing capacities for meaningful engagement and change through the arts.*

At this stage, I needed to make sure that the other categories of the theory could be integrated around this proposed core category without 'forcing'. To assist this process, I used the original paradigm as a framework for integration (Strauss & Corbin, 1990). As stated, the original paradigm classified concepts and categories according to 5 types: a) causal conditions, b) context, c) intervening conditions, d) action/interactional strategies and e) consequences. I also consulted more extensively with the scaffolding literature. Integration of the theory was relatively straightforward after the core category had been identified, and the process of integration was aided by the literature. A diagram of the tentative grounded theory developed from phase-1 data is shown in figure 4.1.

As stated, open, axial, and selective coding do not need to proceed in a linear way. When looking at my data through a scaffolding lens, I was able to identify additional concepts in the data. I also amended, developed and renamed existing categories. For example, the category 'authentic relationships' was developed and renamed 'authentic and nurturing relationships.' Scaffolding is about giving encouragement and support in a way that enables the individual to reach their potential. A reading of the scaffolding literature showed that a belief in the capabilities and potential of the individual is an important prerequisite for scaffolding. From re-reading interviews, it was evident that arts practitioners believed in the potential of residents, and that this belief underpinned their practice. The relationships described by practitioners were not only authentic, they were nurturing. Practitioners believed that with encouragement and support, residents could flourish. Again, this was something I had initially overlooked in the interview data. The category '*a responsive approach*' was also revised, prompted by the reading of a paper by Shin and Partyka (2017). To effectively encourage and support engagement, arts practitioners needed to be responsive to the wants and needs of residents. Yet interviews revealed that practitioners were also intentional in their approach – practitioners put forethought, and sometimes planning and preparation into their sessions. The category was revised to '*a thoughtful and responsive approach.*'

In terms of integration of the theory, causal conditions are things that lead to the development of the core category (figure 4.1, box a). To encourage engagement, it was clear that practitioners needed to generate meaningful engagement opportunities that would be

accessible for residents and that would hold appeal. It was clear that a safe and supportive space was important if residents were to feel comfortable and open to engagement opportunities. Authentic and nurturing relationships, and a thoughtful and responsive approach were also foundational to an effective arts practice. Subprocesses (figure 4.1, box c) captured the phases of the scaffolding process. The first phase 'inviting and inspiring engagement' was concerned with getting engagement. The second phase 'cultivating meaningful connections' was concerned with growing engagement in ways that were meaningful to the person. It was also concerned with cultivating relationships. The third phase 'nurturing change' was concerned with the transformation that was enabled through positive and affirming relationships. The action and interactions associated with these subprocesses were shaped, facilitated, and constrained by a range of intervening conditions (box e) and contextual factors (box d). Consequences (box f) provide an account of the outcomes that practitioners tried to bring about through scaffolding. A full account of the theory supported by the research data will be reserved for chapters six and seven.

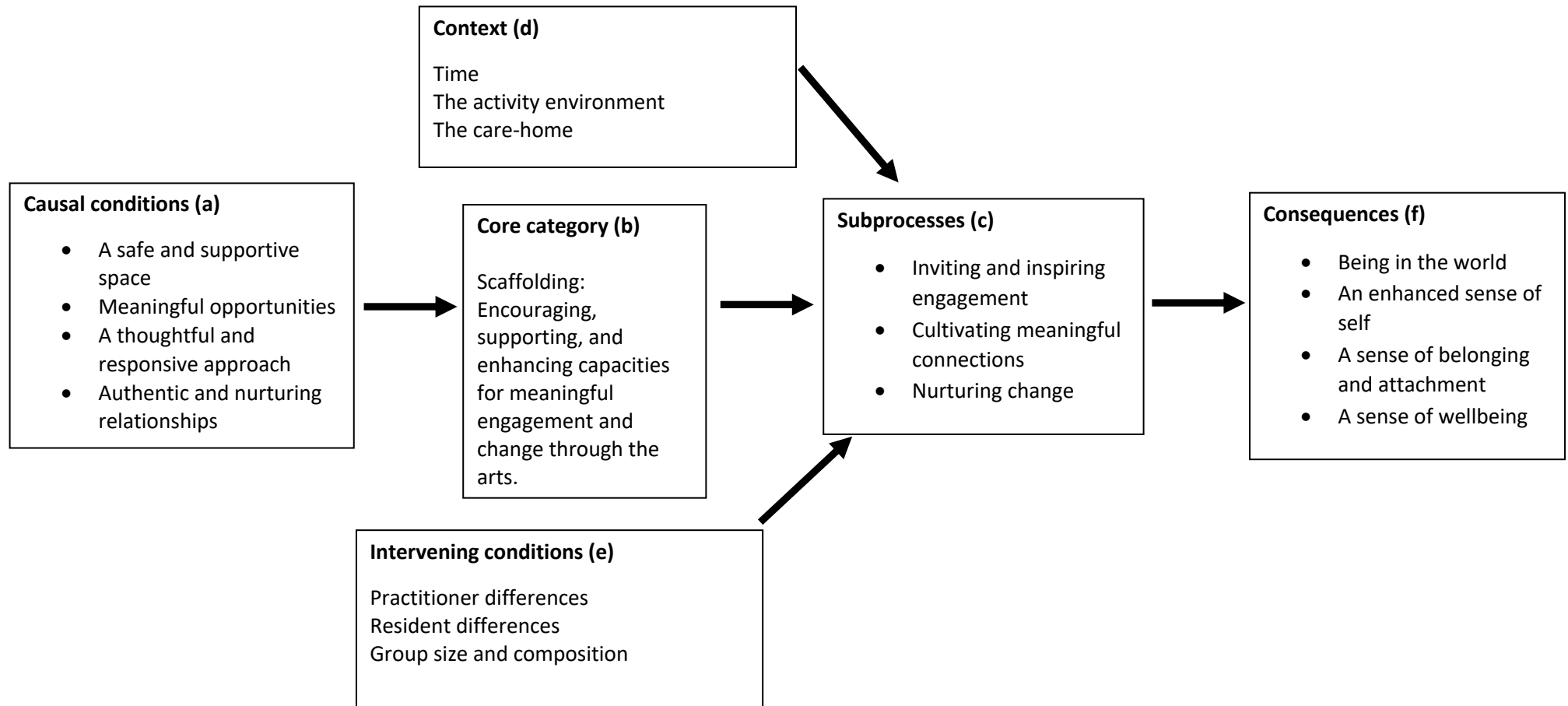
At this stage, the theoretical framework represented in figure 4.1 was still treated as tentative. While categories were well developed and integrated, a Straussian grounded theory is not finalised until it is validated against the data. I had checked the theory against my interview data. Yet observations would provide an additional source of data to check validity, to modify the theory if necessary, and to further develop categories.

## 4.7. Conclusion

This chapter reported on phase one data collection involving a series of in-depth interviews with arts practitioners, arts mentors/trainers, artistic directors, and care staff. Interviews explored the question of how arts practitioners engaged care home residents living with dementia. Data collection and analysis proceeded concurrently from the very first interview. The chapter demonstrated how open coding and axial coding led to the development and organisation of tentative categories, and how these categories continued to be developed through memo writing, questioning, and theoretical sampling. The chapter described the process of selective coding, how this eventually led to the identification of a tentative core category: scaffolding. The chapter ended by showing how the paradigm was used to integrate

the other categories of the theory around this proposed core category, resulting in a tentative theory of arts engagement.

**Figure 4.1: A tentative grounded theory of arts activity engagement in care homes**



## Chapter 5: Methods, phase 2

### 5.1. Introduction

Chapter four reported on phase one data collection and analysis of interviews (with arts practitioners, arts mentors/trainers, artistic directors, and care staff). The chapter ended with a tentative grounded theory of arts engagement (figure 4.1). The core category of the theory was identified as follows: *Scaffolding: Encouraging, supporting, and enhancing capacities for meaningful engagement and change through the arts.*

This chapter reports on phase two data collection and analysis that involved a series of observations of arts activities and post-activity reflective interviews. The main aim of phase two data collection was to check the validity of the tentative theory and the usefulness of scaffolding as a concept to explain arts engagement. As such, the questions guiding phase 2 data collection were: *'Is scaffolding a useful concept to explain the process of arts activity engagement?'*; and *'How do arts practitioners scaffold the engagement of residents during an arts activity?'*

A secondary aim of phase-two data collection was to identify anything of significance that might have been overlooked in phase one interviews, with a particular focus on the further development of the core category of scaffolding and its subprocesses.

### 5.2. Design and sampling decisions

Phase 2 data collection focused on poetry and dance therapy activities at one care home. Each activity was observed on three separate occasions, over the course of three consecutive weeks in October 2018 (poetry) and December 2018 (dance therapy). The design and sample were consistent with a theoretical sampling approach. Practitioners had explained that that engagement could often be more effectively encouraged and supported with time. By repeating activities, I hoped to explore this phenomenon further. The decision to focus on a



therapy-based and non-therapy-based activity, was driven by a desire to maximise differences between activities, in line with a theoretical sampling approach. The decision was also driven by the dominance of studies focused on music and visual art forms (Schneider, 2018).

A total of six care home residents living with dementia were recruited to the study. All six residents were observed taking part in poetry and dance therapy sessions. Each activity session lasted one hour in total. In line with a theoretical sampling approach, I worked with the care home to identify residents who differed in terms of ability, needs, and dispositions, as these factors were deemed important in phase one interviews. Following each observation, reflective interviews were also conducted with the care home activity coordinator and with the arts practitioner. Attempts were also made to interview some of the residents immediately after the activity sessions, yet these attempts did not prove fruitful.

### 5.3. Introducing the care home, the arts practitioners, and the residents.

To provide context for the observations, this section includes some information about the care home, the arts practitioners and their activities, and the residents who participated in them. This information is based on my own observations, and conversations with the practitioners and the activity coordinator at the care home. All names have been changed here to protect the identity of the care home and the individuals who took part.

#### 5.3.1 The care home

In the early stages of the PhD I had contacted several care homes in the West Midlands to tell them about the research project. Management at Hawthorne House, a privately owned residential care home, expressed a strong interest in the study and requested a meeting with me.

Hawthorne House was impressive and well maintained and was situated in an idyllic rural location. Residents at the home seemed to be well cared and catered for, and this was reflected in a CQC rating of outstanding. The home offered an abundance of activities for

residents including: history talks; gardening; crafts; quizzes; armchair yoga; tai-chi; meals out; visits to concerts, museums and sporting events; and visits from local schools and clubs. The home was also committed to arts-based engagement and a wide range of arts activities were offered. Activities included: singing; performances; dancing; drumming; painting; drama; and poetry. In addition to activities, there were plenty of spaces for residents to relax and meet with other residents, care staff, and family members. A key feature of the home was a charming little coffee shop situated near the entrance, that was always well stocked with cakes and buns. In the nicer weather, residents were encouraged to make use of the well-maintained outdoor spaces and gardens.

My main point of contact at the home throughout this project was Susan, the activity coordinator. Susan had worked for the owners of Hawthorne House for several years. She had a warm and bubbly personality and her enthusiasm for her job was evident. Susan always spoke highly of the residents and she had a natural rapport with them. Over time I learned that Susan had an interest in the arts herself and was a gifted singer. She had also previously worked as a music and movement practitioner, and so she especially enjoyed leading and participating in music-based sessions in the home.

### 5.3.2 The arts practitioners

I met Jane, the poet, during one of my many visits to Hawthorne House. Susan had been particularly impressed by the sessions Jane was running at the home and so she suggested that I should attend a session, with Jane's permission. Jane was an experienced poet and writer, having published her work and performed at various events and festivals over the years. Jane also worked with a range of community groups including children and young people, and older adults living in care homes. Jane had worked with people with dementia in care homes for 5 years and had been visiting Hawthorne House for around a year. Upon first seeing one of Jane's sessions at the home, I observed that she was a kind and gentle person. I also noted that she had a charming and captivating presence. Jane had the ability to capture and hold the attention of the entire room. Yet Jane's abilities extended beyond performance, and she had a wonderful rapport with the residents and was able to encourage and support participation well.

Jane's sessions at Hawthorne House were participatory in nature and she would use a range of stimuli to facilitate poetry-making with residents. For this study, Jane brought along a horse bridle in the first week, a basket of flowers and fruit the second week, and printed copies of a painting for the final session. While these stimuli served as inspiration for residents, no set topic was imposed in the sessions. Jane would encourage residents to explore objects and images and would gather whatever comments or thoughts emerged, recording them in her notebook. Jane would read comments back to the group, before composing a poem that would be shared with residents the following week.

The second arts practitioner, Zara, was a qualified dance movement psychotherapist. Zara had formerly worked as a carer for people living with dementia and she now worked as a dance psychotherapist in both nursing and residential care homes, in NHS dementia assessment wards and in sheltered housing. At the time of the observations, Zara had delivered dance therapy in care homes for three years. A colleague had suggested that I should see Zara's work, and my first encounter with her was in a nursing home. Upon meeting Zara, I was struck by her caring nature. She exuded kindness and warmth, and her genuine affection for the residents was obvious. I was also impressed by her ability to include and involve residents who had very advanced dementia. Like Jane, Zara's sessions were participatory in nature. She would invite residents to move, to sing, or to just listen to a range of familiar songs such as *Que Sera, Sera*, and *Raindrops Keep Fallin' on My Head*. At times, Zara would sit at the front of the room. At other times she would make her way around the room, inviting each resident to dance with her in turn. Zara made use a range of props in her sessions including a large elasticated band, balloons, scarves, and bubbles. Residents were also invited to make suggestions throughout the sessions and there was always time for residents to share their thoughts and feelings.

### 5.3.3 The residents

#### Dorothy

Dorothy was one of the first residents I met. I was instantly struck by how lively and fun she was and how she loved to talk. Dorothy was by far the most confident and eager member of the group and was instantly willing to engage in the sessions. Susan informed me that Dorothy

was an eager participant in all activities and that she would engage freely with anyone, unlike some of the other residents who tended to be more reserved. Dorothy's lack of inhibition injected a sense of liveliness into the sessions, yet in her enthusiasm she would sometimes interrupt the other residents, most notably during the poetry sessions.

While Dorothy's dementia was apparent, she was highly articulate. Susan claimed that apart from Rachael, Dorothy was the most cognitively able member of the group. Susan also informed me that Dorothy had previously worked as an English teacher, and this influence was also apparent in observations. Dorothy had an insatiable curiosity about people and the world around her and was always asking questions. Dorothy would also give instructions to the other residents and would frequently share her knowledge with the group.

### Rachael

When I first met Rachael, I was struck by her gentle nature. While Rachael was friendly and smiley, she was more reserved than Dorothy. Rachael appeared to enjoy her participation in activities for the most part and would make active contributions to the group. Yet she needed more encouragement than Dorothy, at least initially. Susan informed me that Rachael was the most cognitively able member of the group. Like Dorothy, Rachael was very articulate. With prompting, she seemed to vaguely remember having attended previous poetry sessions. Susan told me Rachael was known as a very caring person in the home. I noticed how she looked out for the other residents in the activity sessions. For example, in one of the poetry sessions, she made sure that Helen (who was seated next to her), had a biscuit, and even offered her own. Susan informed me that Rachael had lived all her life on a farm, and Rachael was particularly delighted by the horse bridle Jane brought to the first poetry session.

### Helen

Music played a big role in Helen's life and she loved to sing. In her earlier life she had worked in a cathedral and was a member of the cathedral choir. I was informed by Susan that music was the best way to 'reach' Helen and that after attending music-based sessions, she would sit in her room and sing for hours. Helen had a close relationship with Susan, perhaps in part because of their shared love of singing. They would often sing together before and during

activity sessions. I was told that Helen was fascinated by bumble bees, and that she loved bubble baths. While she was known for her cheery disposition, baths were known to put her in a particularly good mood.

Helen was visibly the frailest member of the group, and she needed to be carefully supported to stand and walk. Helen's dementia also appeared to be the most advanced and this was confirmed by Susan and observed by both practitioners. Helen would often struggle to focus her attention during a session and seemed to drift off into her own world at times. Yet she could also engage very well at times. Even when Helen wasn't engaged with what was going on around her, she seemed happy and content for the most part, and would often sing, talk, or laugh to herself. Susan informed me that Helen was unlikely to engage much in the poetry sessions, but would engage much more during dance therapy sessions, given her love of music.

#### **Pam**

Like Dorothy, Pam had been an English teacher earlier in life, and she also enjoyed poetry. Pam was known in the home for being very shy and more of a people watcher than an active participator. I noted that Pam's speech was very limited, and that while she did occasionally use other words, she most often responded with a yes or no. Susan told me that while dementia had considerably affected Pam's speech, her quietness was also a result of her reserved nature. While Pam was quiet during activities, I observed that her concentration was excellent. Pam seemed to particularly enjoy one-to-one interactions, and she responded well to gentleness, affection, and expressions of gratitude. Susan claimed that Pam responded less well to people who had loud and dominant personalities, and that she seemed to find such people overbearing.

#### **Bessie**

Bessie had four daughters and had been a homemaker all her life. Susan explained that family was extremely important to Bessie. Next to Helen, Susan claimed that Bessie had the most advanced dementia of the group. Bessie would sometimes present as very confused, asking who people were and what was happening, usually after she had woken from a snooze. Bessie also seemed to have issues concentrating during activity sessions, yet when her attention was

directed, she could focus well and would show interest. I observed that Bessie seemed to tire quite easily during the sessions and would often fall asleep. I also noticed that she had a great sense of humour and playfulness, and these qualities came to the fore on several occasions.

### Annie

I observed Annie as a gentle and sweet-natured person. Like Helen, Annie was one of the frailer members of the group, and she also needed a lot of support to stand and to walk. Annie focused well when she was awake in sessions, yet she seemed to tire very easily, and would appear to sleep or rest her eyes during activities quiet frequently. Like Pam, Annie's dementia had affected her speech. Annie would tend to speak fluently and would then start to struggle so that her speech would become incoherent. Susan told me that Annie could often be angry in her interactions with care staff which surprised me greatly, given her nature during arts sessions.

## 5.4. Ethical approval

It was deemed likely that at least some of the residents in this study would lack the mental capacity to give fully informed consent for their involvement. Before beginning recruitment for phase 2 data collection, I therefore needed to gain ethical approval from the Social Research Ethics Committee (SCREC).

The process of gaining ethical approval for this study was not straightforward, and my first application to the SCREC resulted in an unfavourable decision. While the Committee considered that the decision to include those who lacked capacity in the study was justified, they deemed that my plans for data collection could impose a disproportionate burden on residents and the home. I had originally planned to observe residents before, during, and after each arts activity, to understand how they engaged outside a session. I also planned to video-record arts sessions to supplement my observational notes. The Committee ruled that video recording could be experienced as intrusive and inappropriate where a non-consenting resident could be inadvertently captured on film. It was felt that prolonged observations would be disruptive to residents and to the care home. I realised that the Committee's decision was

fair. Ethically, intrusive actions need to be warranted. I realised that my research question did not necessitate prolonged observations outside the arts session, and I understood that video recording was not essential and could have been experienced as an unnecessary additional intrusion.

I respected the Committee's decision, yet the review process was frustrating. A lengthy application process and two submissions for approval meant that the review process took a considerable amount of time. Confronted with the task of undergoing the application and review process for a second time, I briefly considered that I should not undertake observations. Yet I felt that observations would provide a richness and depth to the grounded theory. I also wanted to consider the experiences of people with dementia in this study. West et al. (2017) note that the practicalities of including people in dementia research can pose significant challenges for researchers due to concerns about vulnerability and risk. Yet these authors state that the *'failure to include'* people with dementia *'could contribute to further harm by hampering evidence-based practice'* (p.685). I wanted to include people with dementia in research about services that affected them.

In the second application I therefore took care to address the concerns raised by the SCREC. I explained how I would minimise intrusion and disruption for both residents and the care home. I explained that my presence in the home would be minimised, and that observations would be limited to the arts activities. I stated that observations would take place in a designated activity room, so that non-participating residents were less likely to be disturbed by my presence. I also stated that video recording would not take place. The Committee were satisfied by these changes and the second application for ethical approval received a favourable decision in December 2017. While the Committee were satisfied with the new proposal, I understood the need to continually reflect upon ethical implications throughout the study.

## 5.5. Recruitment

### 5.5.1 Recruitment of the care home

After ethical approval had been granted by the SCREC, I formally approached Hawthorne

House to invite their participation. While management at Hawthorne House had expressed a strong interest in the study, it was important that they could commit to the research and that they were fully aware of the implications of their involvement. I met with the home in a formal capacity to discuss requirements, the benefits and drawbacks of participation, and the finer details of the study. I explained that the home would need to commit to the following actions:

- Assistance in the identification of suitable residents for the study.
- Assistance with consent processes.
- Assurance that the activity coordinator, Susan, would be available to attend all six observations and to participate in six post-activity interviews.
- Provision of a designated area in the care home to observe arts sessions.
- Provision of a quiet space in the home for interviews.

I assured management that I would minimise disruption to the home by scheduling data collection at convenient times. I explained that activities would be fully funded by the University of Worcester. Ethically, it was imperative that the home did not incur the cost of activities that were being organised for the purpose of the PhD and in addition to their regular activity schedule, and where sessions would be restricted to the six participating residents. Management at Hawthorne House were given two weeks to consider their involvement. Formal approval for the study was given by the home in July 2018. Despite this approval, I understood the need for on-going reflection about how my study was impacting upon the routines of those living and working in the care home.

### 5.5.2 Recruitment of the arts practitioners

Once formal approval was given by management at the care home, I needed to formally recruit arts practitioners to the study. For the research to be fruitful, I wanted to work with practitioners who delivered high quality arts activities. Inclusion criteria used in phase 1 of the study were applied again in this second phase (see chapter 4, section 4.3.1). Jane, the poet, was approached on the recommendation of Susan, who was able to confirm that she met the inclusion criteria. Zara, the dance movement psychotherapist, was approached on the



recommendation of a colleague at the Association for Dementia Studies who was also able to confirm her suitability.

After attending Jane and Zara's activity sessions, I met with each practitioner to describe the study and to explain what participation would involve. Again, it was important that practitioners could commit to the research and that they understood what would be expected of them. After an initial expression of interest, an information sheet and consent form were e-mailed for further consideration (see appendices 6 and 7). I received quick confirmation from both practitioners.

### 5.5.3 Resident recruitment

After Jane and Zara confirmed their involvement, I asked Hawthorne House to identify six residents who met the inclusion criteria, and who they believed would be willing to participate in the study (either by their own consent, or with the approval of a consultee). To be included in the research, residents needed to have a diagnosis of dementia and a history of participation in poetry and dance activities in the home. Residents were to be excluded from the study if they had shown no previous involvement in these activities. On observation days, residents were also to be excluded if they presented with any acute physical or mental health problems. In the event of a resident becoming annoyed or distressed by my presence, I would cease my observation and leave the room. The resident would not be included in future observations.

In terms of the recruitment process, the following protocol was agreed with Hawthorne House:

- The care home manager would act as a gatekeeper for the study by advising on capacity (as advised by the SCREC).
- After suitable residents had been identified for the study, care home management would consider each resident's capacity to consent to their involvement. In accordance with the Mental Capacity Act it was agreed that all reasonable steps would be taken to gain informed consent from residents themselves where this was possible.
- Where a resident had the capacity to consent, the care manager would approach the individual in the first instance to gauge interest in the study.

- Where the resident expressed an interest in taking part, I would meet with the resident to discuss the project. I would assess the capacity of the resident to understand the information presented and to retain information long enough to make an informed decision about their inclusion.
- Where the care manager advised that a resident lacked the capacity to consent, next-of-kin would need to be appointed to advise about their participation.
- The care home manager would speak with next-of-kin in the first instance to tell them about the study and to ask if they would consider acting as a personal consultee. Where they expressed an interest in acting as a personal consultee, they would be given an information sheet and approval form to consider (appendices 8 and 9).
- I would then follow up by telephone to discuss the study in greater detail. I would confirm that the person understood the role of a personal consultee and that they were willing to act as personal consultee. I would then ask the individual to consider if their relative's participation would be in their best interest, and what their wishes would likely be based on previously held views and advance directives.
- Personal consultees would then be asked to sign the approval form. My contact details would be shared in case of any questions. Personal consultees would also be reminded that they could withdraw their relative from the study at any time without giving a reason.

On the advice of management at Hawthorne House, a total of 8 weeks was allowed for this process. This would give the care home ample time to approach relatives in the first instance. Of the six residents that were eventually identified as potential participants, management advised that none had the capacity to give fully informed consent and that a personal consultee would need to be appointed for all six residents. The inclusion of all residents in this study was therefore approved by a personal consultee.

There are arguably limitations to the consent/approval protocol outlined above. Where a care home acts as a gatekeeper, it is possible that residents who have the capacity to consent for themselves will be erroneously deemed unable to do so. Yet the care manager was conversant in the intricacies of the Mental Capacity Act and was experienced in applying its principles, and so I trusted that judgements about capacity would be sound. Yet I understood that even with the approval of personal consultees I still needed to consult with residents (Slaughter, 2007).

Even when persons do not have the capacity to give fully informed consent, they can often still express their wishes (Slaughter, 2007). These wishes must be respected regardless of consultee approval, and in line with guidelines from the Medical Research Council (2007). I wanted to avoid a situation where residents were not given the opportunity to assent in some way. I liaised with care home management to consider how to gain assent from residents without overwhelming them. I was advised that the preferred approach was for Susan, the activity coordinator, to lead in this process. It was reasoned that Susan had a strong relationship with residents and knew how to best tailor communications to each person.

On the morning of the observations I arrived at Hawthorne House well in advance of each of the activity sessions. Susan and I discussed how the research would be explained and the level of information that was appropriate for each person. I accompanied Susan as she introduced/reintroduced me to each resident in turn, inviting them to participate, and explaining the research in a way that was deemed appropriate. I confirmed that the resident was happy for me to attend the session and to make notes. All residents seemed to understand that I would be joining them and observing the session, and everyone seemed happy for me to do this. Susan advised that I could talk about the study in some more detail with Dorothy and Rachael, two of the more cognitively able residents. While both residents said that they were happy for me to observe and take notes, neither seemed to retain information about the project. Dorothy remarked that classroom inspectors did an important job and that she was glad to help!

Consent was treated as an on-going process throughout phase 2 observations. I continued to arrive early for each observation, meeting with each of the residents before the activity. Susan would re-introduce me, and I would seek assent as outlined above. Immediately before the session, Susan or the arts practitioner would again remind residents that I was observing the session and taking notes. Verbal and non-verbal signs of annoyance at my presence were continually monitored before sessions and throughout the observations.

## 5.6. Data collection

### 5.6.1. Observations

During observations I needed to document thick and rich descriptions of how arts practitioners and residents acted and interacted during arts sessions. This would allow me to check the validity of the tentative theory. As the core category of a grounded theory is the most important category, I needed to closely consider the usefulness of scaffolding as a concept to explain the engagement process. Thick and rich descriptions would allow me to consider the usefulness of the concept, and further develop the category if possible.

Dementia Care Mapping (DCM) acted as a very loose framework for observations. DCM is a structured, non-participant approach to observations in dementia (Kitwood & Bredin., 1992). The tool was developed as a '*serious attempt to take the standpoint of the person with dementia*' (Kitwood, 1997a, p.4). While DCM was originally intended as a tool for service improvement, it has shown promise as a research tool (Brooker, 2005). A recent review concluded that DCM was a comprehensive and useful framework for the observation of arts activities (Algar, Woods and Windle, 2016). DCM provides a rigorous framework for observations and I had undergone a 4-day intensive training programme and passed an assessment of competence to use the tool. As a relatively inexperienced researcher, I reasoned that DCM would provide some level of structure for observations and would stop me from feeling overwhelmed.

When using DCM, a researcher observes and documents engagement behaviours for up to 8 people with dementia at five-minute intervals. Behaviours are documented as Behavioural Category Codes (BCCs), with 26 possible behaviours to choose from. Levels of engagement and mood are also documented for each resident at each 5-minute timeframe, along with any care-giver behaviours that have the potential to undermine (Personal Detractors: PD) or enhance (Personal Enhancers: PE) mood and engagement. Researchers are further encouraged to make qualitative notes about the caregiver behaviours as they interact with residents. Residents are normally mapped at five-minute intervals over the course of at least four hours, after which individual and group wellbeing scores are calculated (by adding mood and engagement values and dividing by the total number of recorded time frames).

DCM ultimately provided a very loose observational framework in this study. I was concerned with process and not outcomes. I did not need to draw conclusions about resident well-being, and so I did not need to produce a full map of BCCs, PDs, PEs, along with engagement and mood values for each resident at each five-minute time interval. Indeed, doing this would have distracted from the task of documenting the engagement process in detail. Yet, I felt that the flexible use of DCM would support observations in this study, and would provide a useful and relevant framework for the following reasons:

- DCM would provide a reliable way of determining levels of engagement for residents, and would alert me to significant shifts in engagement, and would prompt me to consider why these shifts had occurred.
- The Personal Enhancers (PES) of DCM include ‘recognition’, ‘acknowledging’, ‘warmth’, ‘celebration’, ‘holding’, ‘facilitation’, ‘empowerment’, and ‘validation’. These were all highly relevant to this study, corresponding with practitioner behaviours that were described during interviews, and sensitising me to the occurrence of these behaviours.
- The Behavioural Category Codes (BCCs) of DCM also seemed to correspond well with the engagement behaviours that were described during phase one data collection. By way of example, the code G for ‘going back’ aligned with the concept of reminiscing; I for ‘intellectual’ captured how residents would use their thinking capacities; E for ‘expressive’ captured how residents would express themselves during activities; T for ‘timalation’ captured engagement of the senses. These codes provided a short-hand way of documenting engagement behaviours.
- By structuring observations according to individual residents at five-minute intervals, I would be reminded of the need to document the behaviours of each of the residents. This would ensure that the experiences of residents were well considered in the study and that quieter residents were not overlooked.

While DCM provided a framework for observations, the tool does not include any mention of scaffolding as a concept (though ‘facilitation’ and ‘empowerment’ are aligned with the idea). In

addition to documenting engagement behaviours and PEs, I also needed to make detailed qualitative notes to capture if and how arts practitioners scaffolded during their arts sessions.

#### 5.6.2. Protocol and procedure for the observations

One of the lounges in the home was used as a designated space for the activities. All residents were typically seated in the lounge and ready to commence the activity ten or fifteen minutes before the session started. I took time this as an opportunity to talk with residents and to make sure they were comfortable in my presence. As such, I did not begin formal observations during this time-period. I also used this time to find a suitable seating position. I needed to have a clear view of the residents, while being as unobtrusive as possible.

Observations began as soon as the activity started, and DCM provided a template for data collection. A total of 12 data sheets were created for each one-hour arts activity. Each data sheet corresponded with a 5-minute time interval, and each of the 12 data sheets were divided into 6 sections for each resident. Sections were marked with the residents' initials. As soon as activities commenced, I scanned the room coding resident engagement behaviours and mood and engagement values. Where a resident appeared to be considerably engaged in what was happening, or when I noted a shift in engagement, I focused my attention on documenting the episode as fully possible, making detailed qualitative notes about what was happening, how the resident was engaging and being encouraged and supported to engage, and what the consequences were. I also documented the interactions that occurred between arts practitioners and residents. Once an incident was documented to my satisfaction, I continued scanning the room, until another incident was identified.

While I did not take part in the activities or seek to interact with any of the residents during activities, it was ethically important that I responded to any resident who spoke to me.

Dorothy tried to get my attention in the second poetry activity. Despite having given assent twice before the session had started, Dorothy was curious to know who I was and why I was making notes. I put down my pen and paper and spoke with Dorothy about the study. Dorothy started to tell me about her job as a teacher, and I took time to hear what she had to say. This incident reminded me of the importance of seeing consent as an on-going process and not a

one-time event, as well as the importance of relating to residents as persons and not research subjects.

### 5.6.3. Post observation interviews

Post-observation reflective interviews were conducted with arts practitioners, and Susan the activity coordinator immediately after or in the days following each activity. These interviews focused on how practitioners engaged residents. Significant episodes of engagement were discussed. This allowed me to verify my interpretations about how residents had engaged, and why arts practitioners had acted and interacted in the ways they had. The suitability of the scaffolding metaphor to describe the engagement process was also checked with the practitioners.

I also wanted to access the perspectives of residents after activities. Post-activity interviews were to be conducted with residents (where possible). To prompt recall, I planned to conduct interviews immediately after each activity, and in the room where the activity had taken place. Questions were single faceted in line with the recommendations of Cridland et al. (2016). I also planned to keep interactions as informal and relaxed as possible so that residents would not feel intimidated or overwhelmed. Susan, the activity coordinator was to act as gatekeeper, advising who I could approach for interview on observation days. Only Dorothy and Rachael were identified as suitable interviewees. Again, there were arguably limitations to Susan acting as a gatekeeper for interviews. It is possible that some of the other residents would have been willing and able to share their perspectives. Yet Pam and Annie struggled with language, while Helen struggled to concentrate. I accepted Susan's judgement that these residents would likely have found interviews stressful and that interviews were unlikely to have been particularly fruitful.

Unfortunately interviews with Dorothy and Rachael did not prove possible. The first reason for this was the timing of activity sessions. All activities took place a time that was most convenient for the home – and this was late morning and immediately before lunch time. When activities ended, care staff descended upon the room to escort residents to their lunch. It was clear that keeping Dorothy and Rachael back from their lunch would have been disruptive to both them and the routines of the care home. On one occasion, I did get to talk

very briefly with Dorothy after a poetry activity. While Dorothy agreed to answer questions, she quickly changed the topic. My experience mirrored that of Pols (2005), who found that residents in her study used the interview as an opportunity to talk more generally. I also had the opportunity to talk with Rachael after one of the sessions. Yet when I asked Rachael if she would answer questions for my study, she seemed shy and redirected my attention. Rachael did not give her assent and so I could not interview her. While post-observation interviews with residents were not possible, residents did provide valuable insights in a spontaneous and unprompted manner during the activities. This was particularly true for Dorothy, who could say some very profound things. I tried to capture her insights during observations.

## 5.7. Analysis

Observational notes made during activities were written up as soon as I returned from the care home and while the observation was still fresh in my mind. Interviews were transcribed in full. The constant comparison technique was then employed to examine incidents in the data and to compare these incidents against the categories and concepts of the tentative theory. Observations and practitioner accounts confirmed the validity of the theory and the usefulness of 'scaffolding' as a metaphor to explain the engagement process. Examples will be shared in chapters 6 and 7.

A secondary aim of phase two data collection was to identify anything of significance that might have been overlooked during phase one interviews, with a particular focus on the core category and its subprocesses. Through the process of constant comparison, it was evident that nearly all incidents in the data corresponded to existing concepts and categories. Yet some new insights were gained. Firstly, residents seemed to become more confident and competent over the course of repeated interactions with the arts practitioner, engaging more freely and needing less encouragement and support as a session progressed. This insight was confirmed by both practitioners. Examples are provided in chapter 6. Further insights were also gained about the influence of the activity space. Resident position and proximity in relation to the arts practitioner seemed to impact on engagement, especially for those with more advanced dementia. During poetry activities, residents with more advanced dementia



engaged more when seated next to the poet or facing the poet. The importance of resident comfort also became apparent. These influences will be discussed in chapter 6.

Several additional concepts were also created from phase-2 data. During observations it was clear that in addition to giving praise, showing appreciation/saying thank you was an incredibly effective strategy to promote engagement. This had not been mentioned in interviews, yet I repeatedly saw how responsive residents were when they were thanked for a contribution. The concept '*showing appreciation*' was created and was subsumed under the existing category '*communicating value*'. A new category '*being a clear and compelling communicator*' and several associated lower-level concepts were also created. This new category was subsumed under the existing category '*meaningful opportunities*.' I noticed how both Zara and Jane made opportunities more meaningful (i.e. more accessible and appealing) by communicating in clear and compelling ways. Both practitioners were expressive in their communications and used their speech, body-language, facial expressions, and gestures to convey meaning and to generate enthusiasm. The importance of clear communication was not something that had come up during interviews. Another concept identified in phase-2 observations was 'dropping out' (a concept identified from the literature review). This was a strategy that had been used by music therapists in the study by Pavlicevic et al., (2015). Zara used this strategy frequently in her sessions, when she would stand back from the group when residents were interacting well, enabling residents to focus more on one another.

Phase two data supported the validity of the theory, and practitioners confirmed the suitability of scaffolding as a core category. To finalise the theory, I needed to complete two tasks. Firstly, I needed to check the theory against phase 1 and phase 2 data to ensure that most of the data was accounted for. Secondly, I needed to trim the theory. Concepts need to occur repeatedly to be included in a grounded theory (Corbin and Strauss, 2015). In this study, concepts needed to occur at least three times to make it into the final theory. Some concepts were removed through this process. By way of example, the concept '*buddying*' was discarded as the idea only occurred once in the data. The concept reflected a strategy described by one interviewee where a nervous resident would be paired with a more confident resident/ staff member. The concept '*incentivising*' was also discarded. This concept reflected a persuasion strategy used by one practitioner who enticed residents with the promise of tea and biscuits. The removal of these concepts was a little frustrating, as they seemed like useful and common-sense sorts of

strategies. Yet because these ideas were not repeated in the data, I did not include them in the final theory. The final version of the grounded theory is presented in chapters 6 and 7.

## 5.8. Reflections on phase 2 data collection

### 5.8.1. Reflections on observations and DCM

As a relatively inexperienced researcher I understood the importance of developing my research skills. My observation skills had grown somewhat during a four-day training course on DCM run by the University of Bradford. Yet I also understood the importance of reflecting upon my approach to observations after each session, with a view to further improve my approach. I used my reflective diary to make notes about my experiences after each observation.

Like interviews, I found that observations were challenging and overwhelming at first. It was difficult to pay close attention to what was happening, while also making detailed notes. There was also a lot happening simultaneously in the space and I was frustrated by my inability to pay attention to everything significant that was happening. I knew that video recording would have addressed these challenges to a large extent, and I did briefly consider submitting an amendment to the SCREC. Yet, interestingly, the dance movement psychotherapist was opposed to videoing, contending that it was both unnecessary and intrusive. Despite my initial disappointment, observations did become easier. Several factors played a role here. Firstly, I learned to relax. I realised that it was not possible to capture every incident or to every nuance of an interaction. I resolved to concentrate on documenting individual episodes as thoroughly as I could, and to stop being distracted by what else I might be missing in the space. Secondly, I realised the importance of mental and physical preparation. I had not anticipated that observations would be so exhausting, and so I made sure that I was mentally prepared and well rested for subsequent observations. Finally, observations became easier over time as I got to know the residents. I became familiar with their different dispositions and limitations, and thus became increasingly aware of what to look for during observations.

When reflecting on observations, I also needed to reflect upon the suitability of DCM as a framework, and whether it helped or hindered the observations. While I did not need to use

DCM, I believe I would have been completely overwhelmed had I not. This was mainly an issue of confidence. By providing structure, DCM gave me some sense of control during observations. DCM was also helpful in other ways. It provided a short-hand way of coding practitioner and resident behaviours (e.g. I coded N for sleep). By structuring observations for individual residents at 5-minute intervals, I kept my attention on residents and how they were interacting and responding. I was also alerted to a tendency to overlook certain residents. After the first observation for example, I noticed that many 5-minute time frames were completed for Dorothy – yet hardly any were completed for Annie. Dorothy nearly always engaged with vigour, and so she drew my attention repeatedly. While I was busy making notes about Dorothy however, I was overlooking Annie. I took care to pay more attention to Annie, and quieter members of the group in subsequent observations.

#### 5.8.2. Reflections on my influence

In chapter three I explained that my experiences will have impacted how I interacted with research participants, how I made sense of my data, and how I assembled the theory. As such, I needed to be as aware and transparent as possible about my influence.

The resulting theory in this study places a strong emphasis on person-centred approaches and positive person work as espoused by Tom Kitwood (1997a). I came to the study with some prior knowledge of person-centred theory. I also developed an awareness of positive person work through my early reading of the literature. Having observed and participated in many arts activities as part of my Churchill Fellowship, I was able to reflect upon how arts practitioners had used ‘person-centred’ strategies in their sessions. I fully expected that there would be evidence of positive person work in my own data. Yet I needed to be vigilant to any tendency to impose my assumptions onto the data. To avoid bias, I took time to care to ensure that person-centred ideas were grounded in the data, and not forced upon it.

A further and unexpected influence in this study was my undergraduate degree in psychology. I had studied social psychology as part of my degree, and so I came to recognise persuasion strategies in my data. I firstly recognised the use of ‘foot-in-the-door’ technique, where a practitioner would make a tiny request of a more reticent resident, in the hope that the person

would eventually engage in a more substantial way. This helped me to recognise other persuasion strategies in my data and this aided conceptualisation.

In chapter four, I explained how I had used a reflective diary to note my emotional responses to the data. This had alerted me to overt bias on occasion – when participant accounts did not align with my assumptions. I continued to use a reflective diary during phase two data collection. In my diary I had noted my increasing frustration at being unable to identify a suitable core category. The process of arriving at scaffolding had been a long and difficult one. By the time of observations, I was heavily invested in the idea, and recognised the danger of overlooking disconfirming evidence and becoming biased in my interpretations.

To guard against this, I documented episodes of engagement as fully as possible so that others could appraise incidents for evidence for scaffolding. I tried to find disconfirming evidence in my observational notes and my interview transcripts to challenge the appropriateness of the concept. I also checked the relevance of the concept with both arts practitioners. Finally, I checked in on my emotions. My emotions had alerted me to my own bias in the past. When I had identified the concepts '*supporting a sense of self*' and '*cultivating meaningful connections*' as possible core categories, I had initially felt a sense of relief, yet over time I started to develop a nagging feeling that these concepts did not fully capture the essence of the research. I tried to remain alert to a similar sense of uneasiness during the observations and during my analysis. This feeling never manifested. Ultimately, I believe that while scaffolding is not the only core category that could have done justice to the research – the concept proved to be a satisfactory one. The next chapter will provide an account of the final grounded theory that was developed using interview and observational data.

## 5.9. Conclusion

This chapter provided an account of phase-two data collection involving observations of 6 persons with dementia participating in poetry and dance therapy activities in one care home. Each activity was observed over three separate occasions. Data collection also involved post-activity interviews with both arts practitioners and the activity coordinator at the care home. The constant comparison technique was used to compare incidents in the data against the tentative theory that had been developed from phase-one interviews. The validity of the

theory and the usefulness of scaffolding as a concept to explain the engagement process were confirmed at this stage. Some new insights were also gained during observations. Of particular significance was the observation that residents seemed to grow in competence over the course of repeated interactions with arts practitioners.

# Chapter 6: Findings 1: The core category of Scaffolding and its subprocesses

## 6.1. Introduction

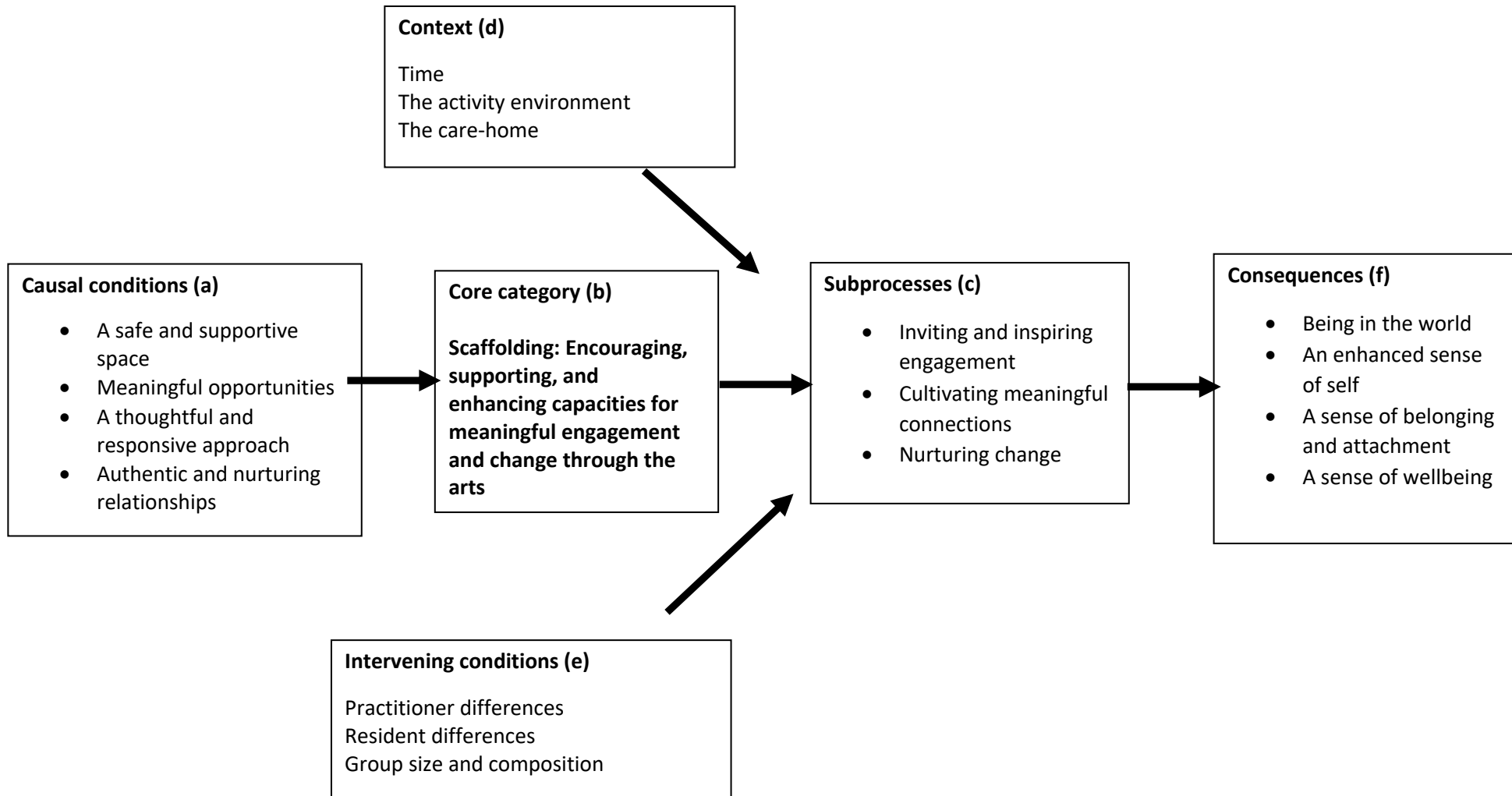
The findings of this study are split across two chapters. A diagrammatic representation of the final grounded theory is shown in figure 6.1. As the most important component of a grounded theory, this chapter will focus on the core category of scaffolding (box b), and its subprocesses (box c). The first half of the chapter will introduce the concept and will explain why scaffolding is a useful metaphor to explain arts engagement. The second half of the chapter will describe the subprocesses of scaffolding, or how arts practitioners scaffolded during an arts session. It will also explain how different contexts (box d) and intervening conditions (box e) influenced the scaffolding process. Chapter 7 will then focus on the causal conditions (box a) and consequences (box f) of scaffolding.

## 6.2. Introduction to the core category

The core category of a grounded theory should represent the major concern of research participants and should be '*abstract and broad enough to be representative of all participants in the study*' (Corbin and Strauss, 2015, p.188). Based on interview and observational data, I believe the fundamental concern for all arts practitioners in this study was a perception of loss in dementia. Arts practitioners used their activities to address loss, and to enable meaningful engagement and change in dementia. I propose that *scaffolding* is a useful metaphor to explain how they did this. The core category of this study is as follows:

*Scaffolding: Encouraging, supporting, and enhancing capacities for meaningful engagement and change in dementia through the arts.*

Figure 6.1: A grounded theory of arts activity engagement in care homes.



### 6.2.1. Perceptions of loss in dementia

Arts practitioners in this study all expressed a concern about loss in dementia. Practitioner accounts of loss are shared in table 6.1. Practitioners explained that the capacity to understand and to be understood could start to diminish in dementia, meaning that residents could start to become disconnected from others and the world around them. They reported that pre-existing avenues for purpose, value, and fulfilment (such as prior interests and roles) could become less accessible in a care home. They explained that a resident's sense of self-identity could start to fragment, and that the competence and control needed to direct one's life could start to erode. Some described how residents could experience a sense of sadness or frustration related to loss. They could experience a loss of confidence. Practitioners believed that residents also experienced a loss of recognition and respect from others. Societal attitudes about dementia and older age meant that residents could be underestimated and undervalued. Practitioners explained that feelings of powerlessness or incompetence could be exacerbated where asymmetric care-based interactions became the norm. Feelings of invisibility and insignificance could result when the person was no longer seen as a unique and valuable person. Residents could experience a lack of understanding and acceptance when they were treated as difficult or a burden.

Arts practitioners believed that their practice could counter loss in dementia a multitude of ways. By focusing on the remaining capacities of the person, activities could open-up new opportunities for growth and fulfilment. Activities could restore a sense of possibility and potential in dementia. Residents could regain a sense of competence and control. Where a sense of self could start to erode, practitioners believed that the arts could help residents connect with who they were, and with their capacities to think, and feel, and act. Many explained that activities also had the potential to positively impact relationships in dementia. Practitioners explained that the arts could counter barriers to communication enabling residents and others to come together. The arts could provide avenues for self-expression, so that residents could be seen and heard and understood. Individuality could be recognised. Practitioners also explained how activities could challenge perceptions about what was possible in dementia. The capabilities of residents could be acknowledged. Moreover, where residents could make contributions to other people and their environments, more balanced and appreciative relationships could result. The diversity of arts practitioners involved in this study (including professional artists, performers, and arts therapists) meant that practitioners



had somewhat different priorities, and different ways of approaching their work (for a fuller explanation, see section: 6.5.1). Yet common to all was a concern about loss in dementia, and a common belief that residents still had immense value and potential as individuals, even if this was unrecognised by many. This thesis proposes that the metaphor of scaffolding is a useful concept to understand how arts practitioners encouraged and supported residents to realise their capacities and achieve their potential. The metaphor also explains how practitioners used the arts to build relationships and to enable more positive and affirming relationships in dementia.

### 6.2.2 The Metaphor of Scaffolding

The metaphor of a scaffold was originally proposed in the seminal paper by Wood, Bruner, and Ross, (1976). The metaphor was applied to the field of education and was used to illustrate the support given by a tutor that enabled a learner to accomplish a task beyond their immediate grasp. To scaffold effectively, the tutor would give just enough support by controlling task elements that were beyond the learner's capabilities, giving assistance only where needed. By not intervening unnecessarily the learner was able to use their capacities and grow in competence. Crucially, the goal of scaffolding is not the completion of a task, but the acquirement of knowledge and skills. The role of the tutor is to encourage the learner and to give just enough support so that they can engage as independently as possible. Much like a physical scaffold, scaffolding is contingent, temporal, and adjustable, meaning that challenge is set at an appropriate level, and that support is increased as needed and *'subsequently withdrawn according to the learner's ongoing progress and the situation at hand.'* (Van de Pol, Volman, and Beishuizen, 2010, p.272). Over time and through interaction, the learner can come to acquire the knowledge and skills needed to perform the task independently. Wood, Bruner, and Ross, (1976) identified numerous tutor behaviours as integral to this process, including: the recruitment of interest; the demonstration or modelling of behaviours; the management of frustration; the marking of critical task features, and the reduction in degrees of freedom (i.e. simplification of the task).

The concept of scaffolding is often related to the work of the psychologist Lev Vygotsky (Van de Pol, Volman, and Beishuizen, 2010). Vygotsky believed that social interaction played an

important role in cognitive development, and created the term, the 'Zone of Proximal Development' (ZPD) to convey the difference between what a learner could do alone and what they could achieve when working with someone who was more knowledgeable. To enhance learning, Vygotsky claimed that teachers needed to set a task within a child's Zone of Proximal Development, by encouraging child to engage just beyond their existing capacities, while providing just enough support.

Drawing upon the work of Wood, Bruner and Ross, and Vygotsky, the usefulness of the scaffolding metaphor has been studied extensively in the field of education and in the study of caregiver-child interactions. Studies have shown how teachers and caregivers encourage and support more complex and competent engagement in children. Mothers have been found to scaffold the attention of their children, by maintaining and re-directing attention to toy objects (Findji, 1998). Bigelow, MacLean and Proctor (2004) found that mothers scaffolded more sophisticated play in their infant children through verbal encouragement, positioning objects, and modelling. Jung and Recchia (2013), found that teachers scaffolded more competent play by making verbal suggestions, expanding on a child's play, modelling, and by being 'a supportive presence'. They also found differences in scaffolding practices, where a teacher could take a more direct approach by actively challenging the child, or a more passive approach, when a teacher would adapt the space in ways that were encouraging and supportive of the child's self-directed play. Regardless of the exact approach, Jung and Recchia suggested that scaffolding was more effective when it was responsive to the interests and motivations of the child.

### 6.2.3 Cultural, material, and social resources as scaffolds

Scaffolding has more recently been applied beyond a learning and development context. Much like a learner or a child can benefit from the encouragement, knowledge, and skills of a more competent adult or peer, it has been reasoned that the cultural, material, and social aspects of our environments can scaffold cognition and affect. Using this broader conceptualisation, a 'scaffold' can be any resource, (cultural, material, or social), that succeeds in encouraging, supporting, and enhancing the cognitive and/or affective capabilities of the person. Colombetti and Krueger (2015) for example, explain that we frequently use music to help us feel

energised, to *'unwind and relax'*, to *'vent'*, or to *'give voice to emotions'* (p.1162), while we frequent cinemas and art galleries to keep ourselves stimulated. They note how certain items of clothing are worn to elicit particular feelings, like comfort or security, and how keepsakes and photos are often used to recall memories and to *'elicit special feelings'* (p.1163). They assert that we seek out interactions with other people and engage in shared activities because our experiences are *'qualitatively enriched by the presence of others'* (p.1166). In her examination of the scaffolding capabilities of the expressive arts, Maiese (2016) demonstrated how dance therapy could scaffold both cognition and affect. Movement to music could scaffold cognition when it bypassed the intellect and need for verbal communication. Gestures and mirroring for example acted as a shorthand way of inviting others into a relationship. Maiese asserted that the dance therapy context could also scaffold affect, when coordinated movements with others promoted feelings of togetherness and enabled *'the achievement of affective states'* that would otherwise be *'inaccessible to the isolated subject'* (p.7).

**Table 6.1: Perceptions of loss in dementia as reported by arts practitioners**

Loss of personhood	<i>'I've had so many carers saying so and so has gone away when the person is very real and there to me'</i> (Kenneth, poet)
Loss of recognition	<i>I think it is easy for people to feel a bit like they're just all the same. That's the problem with being institutionalised isn't it, is that you are just any old person who is sat in your chair and not being treated as an individual'</i> (Kelly, Dance Movement Psychotherapist)
Loss of respect	<i>'I'm not going to say Mary stop being so daft. Come on Mary, come and sit down, where are your teeth?'</i> (Rhonda, Artistic Director, Theatre Company)
Loss of possibility and potential	<i>'We do have this sort of attitude of closing down, closing down, closing down, dead. Rather than saying, ok, new opportunity, new possibility.'</i> (Gavin, Visual artist)
Loss of significance	<i>'There is that sense of people being diminished, and that they don't have a space in the world, and they don't have a purpose in the world'</i> (Kelly, Dance Movement Psychotherapist)
Loss of self-determination/control	<i>'The contexts I work in people haven't got control over what time they get up, what they have for breakfast...'</i> (Elizabeth, Dance practitioner)

Loss of confidence	<i>'They can feel useless, they are being looked after, their food is being cooked, beds are being made...'</i> (Gavin, visual artist)
Loss of connection and belonging	<i>'In these care homes people seem isolated... some stay in their own rooms. Some go into social rooms... but they don't talk to each other.'</i> (Kenneth, poet)
Lack of stimulation	<i>'They are sitting in four walls... meeting new people and learning new things and having different experiences... it's not like us, they can't get up and go see a film ... it's just not so easy for them to do anything.'</i> (Claudia, Cellist)
Feelings of loss	<i>'He would talk about sad feelings, about the past, about how he was aware that he was becoming less and less able to sort of think things through and was more confused'</i> (Rachael, Music therapist)
Loss of self-identity	<i>'People can start to lose a sense of identity... the things that we might identify with... your role in your family, or your job ... the hobbies that you do. If you are in a care home and you have dementia, then those things are less and less.'</i> (Kelly, Dance Movement Psychotherapist)
Loss of understanding and acceptance	<i>'We all feel angry, and we can shout and snap and throw things... If you are living in a care home, any time you lose your temper, you get told off, you're labelled, you're disapproved of'.</i> (Kelly, Dance Movement Psychotherapist)

### 6.3 Scaffolding as the core category in the current research

This thesis contends that the metaphor of scaffolding can explain how arts practitioners engaged people with dementia in care homes. Consistent with the scaffolding literature, the metaphor describes how capacities for engagement and change in dementia were encouraged, supported, and enhanced in an arts session. Sterile and uninspiring care environments could be filled with social and cultural engagement opportunities. Residents could access and draw upon material resources (objects), cultural resources (music, art, poetry), and social resources (the knowledge and skills of arts practitioners and others) to feel more intensively and to engage more extensively than might otherwise have been possible.

The responsive nature of scaffolding was also evident in the research data. Practitioners described the importance of connecting with residents 'where they were' and adapting their approach and the arts space to accommodate for the moods, needs, abilities, and desires of residents. Participatory arts practitioners described the need for appropriate challenge, so that residents were encouraged to engage just beyond their immediate comfort zones, while receiving adequate levels of support to prevent overwhelm. They explained how they intensified guidance and support where needed, and how they used a range of support strategies that were consistent with the scaffolding literature (e.g. suggesting, prompting, modelling). Yet, consistent with scaffolding, practitioners explained that autonomy was promoted where possible. Guidance and support were given only when needed, and only to the extent needed. This allowed residents to engage as freely as possible and to use their own capacities to the fullest.

Finally, this thesis contends that the metaphor of a scaffold explains how arts activities enabled meaningful engagement and change in relationships. Arts activities were a temporary support structure that encouraged and supported residents and others to come together and interact. More than this, arts activities could transform relationships in dementia. Asymmetric care-based relationships were challenged when residents could contribute to others. More appreciative relationships could flourish when care staff and families were encouraged people to see the value and potential of the person. When residents were encouraged and supported to make contributions, these could be recognised and celebrated. When residents could express themselves in an arts session, individuality could be recognised, and understanding and acceptance conveyed.

In the sections that follow, research data will be shared to demonstrate why scaffolding is a relevant and useful concept to explain how practitioners engaged residents using the arts. The second half of this chapter (beginning at section 6.3) will provide a more detailed explanation of how scaffolding happened in practice, and how a practitioner's approach to scaffolding was shaped, facilitated, and constrained by different contexts and different conditions.

### 6.3.1 How arts practitioners enhanced capacities for engagement and change

Colombetti and Krueger (2015), asserted that we think and feel more fully by connecting to the people and the world around us. Arts practitioners in this study enhanced or amplified the cognitive and affective capabilities of residents by bringing cultural resources, and material resources (natural and man-made) into care homes. Objects, flowers, fabrics, costumes, music, poetry, images, props etc. functioned as scaffolds in dementia when they enabled residents to think, feel and act more intensively and more extensively than might otherwise have been possible. From a cognitive perspective, the properties, and the qualities of the material and cultural could enhance cognitive capacities for engagement. Moreover, where engagement was rooted in the visual, the auditory, the tactile, the olfactory, the kinesthetic, and even the gustatory, ways knowing and acting could be rooted in the sensorimotor impulses and capacities of the person. The rhythmic pulse of music, the smell of a flower, the grasp of a paintbrush, the taste of a sweet, or the beat of a drum, could stimulate the body and the senses and enable even those with more advanced dementia to engage in an arts session:

*'It's beautiful to see how people with very limited speech can participate without a cognitive stretch to have to think, they just have to feel a desire to move, in however small a way'.*

Simon (Dance movement psychotherapist)

Practitioners explained that attentional and perceptual capacities could be enhanced by the vividness and vibrancy of an arts space or the use of props, that could help residents to focus. Many explained how capacities to remember could be enhanced by using familiar songs, objects, images, and smells. Capacities to communicate and comprehend were enhanced

when the need for language was circumvented so that meaning could be conveyed through images, movements, and emotion. It was also believed that capacities for imagination and creativity could be stimulated through the senses:

*'You could sort of ask people to eat sweets and ask people to describe them and those descriptions become a poem, a poem about sweets'*

Julie (Visual artist)

The assertion that cognition was enhanced during arts sessions was supported by the observational data. During observations I saw how sensory stimuli like the band seemed to help Helen focus her attention at times (textbox 6.3, the band). I saw how imaginative thinking was stimulated by the image of the girl in the bath, and how comprehension was improved when Jane was able to point to the images of the Myna Bird and the tin bath (textbox 6.1, the romance). I saw how Jane used her body, objects, an image, and emotion in her speech to convey meaning and aid comprehension about jam-making (textbox 7.2, the jam). I saw how the horse bridle enhanced capacities to remember when the object evoked memories for Rachael and Dorothy, stimulating insights for the group poem (textbox 6.2, the horse bridle, part 1).

## The Romance

Jane produces copies of a picture 'The Singer' and gives a copy to each resident. The picture is quirky and unusual. It depicts a man singing on a balcony, while a lady bathes in a tin bath on the roof above in the moonlight. Jane invites the group to share their thoughts about the picture. There is silence for a while – but everyone is studying the picture intently, except for Helen who is looking at her skirt and mumbling to herself. Jane eventually prompts the group by asking what they think is going on in the picture. Rachael states that the girl is having a bath. The room is quiet again. After a while Dorothy declares, *'you're not sure if he's singing to keep her happy, or if she's thinking he's not finished, I daren't get out yet...it gets the imagination going!'* Jane tells Dorothy that her insights are wonderful, and she writes them down. After some silence Dorothy seems to have a further realisation; *'You are not quite sure if*



*she's doing it to attract him or if he's down there, trying to attract her. Who is wooing who?*

Jane compliments Dorothy saying that this is a lovely comment before writing it down.

Dorothy looks pleased with herself.

About half-way through the session, Helen has yet to participate. Helen's attention seems to be focused elsewhere. Jane approaches Helen with the picture and directs her attention to the girl in the bath. Jane tells Helen that she thinks it is a hip bath, the sort that was used in front of the fire. Helen laughs, *'very complicated things they used to do...'*, before matter-of-factly stating, *'that's all I've got'*, seeming to understand that Jane is seeking contributions.

The group is quiet again for a while. Rachael asks a question about the birds in the picture unprompted. Jane asks if everyone can see the birds and points them out to the others. A brief conversation about the Myna bird ensues between Dorothy, Rachael, and Jane. Helen unexpectedly joins in, *'I really wish I had one of those. It's really amazing what these things can do'*. Jane is visibly impressed by Helen, and concurs, describing how the bird copies human speech. Helen continues; *'Yes, I have been seeing them recently and they have been doing that'*. Jane excitedly declares that she must write this down and Helen appears delighted with herself. Jane then directs Helen's attention to the man in the picture and asks what she thinks. Helen declares *'he is very handsome'*. Laughter erupts in the group. Jane suggests that girl is perhaps on the roof because of the handsome man. At this point Annie leans forward in her chair and gives a playful and dramatic 'YES!' with a wink and a nod. Laughter erupts again. Jane laughs and encourages her to continue, *'is that right Annie?'*. Annie continues to tease, giving another wink. The playful mood continues when Dorothy says that he must know the woman is having a bath and he is singing in the hope that she will get out. There is more laughter.

**Text box 6.1: Narrative description of an observation of a poetry session at Hawthorne House on 25/10/2018**

Consistent with the assertions of Colombetti and Krueger (2015), and Maiese (2016), practitioner accounts suggested that the affective capabilities of residents were also enhanced during arts sessions. Practitioners used cultural and material resources in intentional ways to help residents achieve certain arousal states. The intensity and vibrancy of an arts space, infused with costumes, props, or upbeat tempos could enhance resident capacities to feel energised, uplifted, and invigorated. By contrast quieter environments, flowing images, gentle

music, soothing sounds, and the rhythmic nature of repetitive movements could be used to promote a sense of calmness and relaxation:

*She enjoyed the rolling this paintbrush over the surface... I think she enjoyed the activity of the repetition.... that sort of momentum of movement that there was a sort of a calming thing going on.*

Julie (Visual artist)

Practitioners explained that material and cultural resources could also be used to arouse and amplify a wide range of emotions for residents. Costumes and props could enhance feelings of frivolity and fun. Patriotic music could be used to help residents connect with feelings of pride. Sad music could be used to help a resident release their emotions or happy music could be used to cheer someone up. Some practitioners also explained that resources could be harnessed in ways that helped give voice to difficult emotions, for example when residents could bang a drum with aggression or punch a balloon.

Zara used music to evoke or amplify certain arousal states in dance therapy. Upbeat and high tempo songs like Glen Miller's *'In the Mood'*, seemed to invigorate residents, while slower songs like Vera Lynn's *'There'll be Bluebirds'*, seemed to engender a sense of stillness and calm. During poetry sessions, the tone, tempo, and pitch used by Jane in her poetry readings appeared to have a calming and soothing effect at times, and a more invigorating one at others. In dance therapy props seemed to energise or further enliven residents when they passed the balloon or danced with a band. Yet residents also used props to relax. For example, Annie appeared to enjoy the sensation of repeatedly pulling the scarf through her hand, while Dorothy was soothed by the soft fabric of the band when she rubbed it against her face (declaring that she would like one to help her sleep at night). In terms of emotional responses, bubbles, balloons and scarfs seemed to amplify a sense of fun and playfulness during dance therapy, while the horse bridle resonated in a very joyful way for Rachael and Dorothy, evoking fond memories and feelings of nostalgia and delight, (textbox 6.2, the horse bridle, part 1).

Finally, and consistent with the assertions of Colombetti and Krueger (2015), and Maiese (2016), the presence of other people also seemed to enhance the affective capabilities of individual residents. Practitioners explained that joy and enthusiasm could be amplified in a group context. One practitioner also explained that where a resident expressed difficult or challenging emotions in a session, they could give voice to those who shared similar experiences but were less able to express these feelings. Dorothy made the following comment during a dance therapy session:

*'You know psychologically being in a group rather than on your own... You laugh together and you're serious together ... you wouldn't get all the places if you just did it on your own would you?'*

Dorothy, Resident, Dance therapy observation at Hawthorne House.

### 6.3.2. How arts practitioners encouraged capacities for engagement and change

Engagement capacities were encouraged in a variety of ways during arts activities. Practitioners would encourage residents to use their imagination; explore their environment; move their bodies; engage their senses; be creative; be critical; use their judgement; express their feelings; take the lead; engage in contemplative thought etc. Diverse forms of engagement were present in poetry and dance therapy observations. Residents were encouraged to: smell lavender; stroke teasel; admire artwork; learn about quinces, jam-making, and Myna birds; move to music; reminisce; and share their feelings. Practitioners explained that diverse forms of engagement were more possible because of the expansive and unrestricted nature of arts activities. The interpretative and experimental nature of the arts meant that engagement was unbounded by the confines of memory, right or wrong, or true or false. In the final poetry session, residents worked together to create a poem about a painting (textbox 6.1, the romance). The somewhat ambiguous nature of the painting meant that there was no right or wrong answer. Jane explained that residents were free to make their own associations. Likewise, in dance therapy sessions residents were free to experiment with their

movements, meaning that Bessie and Annie were able to engage with creativity and playfulness (textbox 6.4, the balloon).

*'It is about feeling very freed of the things that are difficult, the things where you need to be precise or you need to be rational or you need to be able to remember'*

Jane (Poet).

Consistent with scaffolding, participatory arts practitioners would also encourage residents when they challenged residents to use their capacities to the fullest and to engage just beyond their comfort zones at times. In poetry and dance therapy sessions residents were challenged to; come up with new dance moves and songs; to share their stories; to lead the group; and to offer insights. A willingness to challenge was evident when practitioners would let residents struggle to some extent:

*'I don't want to leave everyone in their kind of complete comfort zones, and I will sort of encourage but not push ... people should be sort of nudged just a little bit gently into doing something'*

Gavin (Visual artist)

Finally, the social nature of activities also encouraged residents to engage. Practitioners explained that by running activities in a group, residents would often encourage each other (both intentionally and unintentionally). When the bridle was produced at beginning of the first poetry session, Dorothy and Rachel both squealed with delight and their enthusiasm seemed to capture the interest of the others (textbox 6.2, the horse bridle, part 1). Dorothy was always an eager participant, yet her enthusiasm was also infectious. Many practitioners described a kind of contagion in group work where enthusiasm was infectious and would spread amongst residents. I witnessed and experienced this phenomenon repeatedly during observations. In the first dance therapy session during the balloon exercise, residents were swept along in a wave of enthusiasm so infectious that I wanted to join in myself (textbox 6.4, the balloon).

## The Horse Bridle, part 1.

Jane excitedly informs residents that she has brought in something special to show them. This seems to spark the interest of most. Jane asks the group if they can remember horses and carts, before briefly sharing her own childhood memories. Dorothy and Rachael seem particularly captivated, with Rachael exclaiming *'how interesting!'*. After a while, Jane excitedly reveals a horse bridle which had been hidden from view behind a chair. Dorothy and Rachael squeal with delight in unison, *'a horse bridle!'*. Most of the others are watching intently. Jane explains that a neighbouring farmer had given her the bridle as a gift when she was a child, yet the barn was demolished, so that this was a very special bridle, *'a survivor from times long-ago'*. Jane makes her way round the room with the bridle, letting each resident examine it in turn. Jane points out different features of the bridle for each resident to inspect.

Jane is at the opposite end of the room when Dorothy loudly and spontaneously declares that *'a lot of it developed when petrol was rationed, and you hadn't to take a car out.'* Jane runs to grab her notebook and pen, and encourages Dorothy to continue, leaning forward in her chair, saying *'tell me more'*. Dorothy continues to talk about feeding the horses after school for quite some time, and Jane captures her stories. After a while, the room goes quiet. Susan asks Rachael if she had horses on her farm. Rachael says yes and smiles, but she is less forthcoming than Dorothy and seems a little shy. Jane prompts her with some questions and before long Rachael starts to fondly reminisce about the times she sat on top of a horse with two of her sisters as a child, and how she could *'see the whole world from up there!'*

Jane produces a painting of horses working in a field. This seems to spark Dorothy's memories about the horses in Yorkshire and Lancashire. Jane encourages her to share; *'tell me all about it'*. Dorothy proceeds by giving directions to three different farms, recalling that her mother preferred the one with the creamiest milk. When Jane informs Dorothy that her mum also liked creamy milk, Dorothy asks where she lived. Much to Dorothy's delight, it transpires that they both attended the same school, so that Jane and Dorothy exchange stories for a while. They find much in common. Jane re-reads the information that Dorothy has given, prompting further insights about 3 lads who worked the farm and life during the war. Dorothy is eager to reminisce and share her stories about the war. Jane continues to encourage her contributions, very occasionally needing to prompt Dorothy by repeating something she had said.

**Text box 6.2: Narrative description of an observation of a poetry session at Hawthorne House on 11/10/2018**

### 6.3.3. How arts practitioners supported capacities for engagement and change

Practitioners also supported engagement and change in a variety of ways. Support could be cognitive, or physical, or emotional. Cognitive support was prevalent in arts sessions. Akin to Vygotsky's '*more knowledgeable other*', residents were able to engage at a higher level by drawing upon the knowledge and skills of the arts practitioners. Practitioners made suggestions, modelled behaviours, gave prompts, simplified tasks, and generally controlled elements of an activity that were beyond the abilities of residents.

*'How do you use the skills and knowledge that you have... whereby those skills are, where that knowledge is supporting the participation and the creativity and the contribution of everybody within the group.'*

James (Musician)

Again, when working in groups, the social context could play an important role. Practitioners explained that by running sessions in groups, residents would sometimes draw upon the skills and knowledge of their peers (and others). In poetry and dance therapy observations, I noticed how residents would sometimes look to each other, and to Susan for guidance. As the most able members of the group, Dorothy and Rachael guided and supported the others at times. As Helen's attention wandered in the third and final poetry session for example, I watched Rachael gently redirect her attention back to the image of the girl in the bath. In the third dance therapy session, Rachael supported Bessie's engagement with some coloured scarves by modelling a throwing action for her to copy. Helen was able to join in with a group dance by imitating Dorothy's movements from across the room (textbox 6.3, the band).

## The Band

A giant, multicoloured fabric band is produced at the start of the second dance therapy session. The band had been a source of great fascination for Dorothy, Rachael, and Annie in the previous session. They had all examined and manipulated the band for quite some time. The band stimulates Dorothy's curiosity again this week. Dorothy repeatedly makes comments about how lovely it feels, rubbing the fabric against her face, and asking questions about how it was made. Zara always takes the time to respond to Dorothy's questions.

Zara makes her way round the circle, handing each resident a portion of the band in turn. Upon reaching Helen, Zara spends a considerable amount of time trying to draw her attention. Helen has been singing to herself and seems unaware of what is going on. Zara kneels in front of her and rubs the fabric of the band against her hand to get her attention, before holding the band at eye level and demonstrating a pulling motion. Zara explains what is about to happen. This goes on for some time. Zara places the band in Helen's hand. She holds it on her lap, closes her eyes and continues to sing.

Zara returns to the front the room and models a series of possible movements with the band, yet she also encourages residents to explore their own movements. At first, Dorothy watches Zara very closely, copying her actions, yet over the course of the song, *One Love*, she starts to rely less on Zara and moves more freely. Pam is also watching, with apparent interest, yet she is not making use of the band. Zara approaches her from across the room and models a pulling motion which Pam then copies. Zara moves round the room, and Pam continues to watch her, copying her movements for a while.

Bessie appears to be sleeping throughout the song, holding the band on her lap. Susan, who is seated beside her, pulls on the band and causes it to slip from Bessie's hand. Bessie immediately opens her eyes, sits up straight and attempts to recover it. Upon successfully retrieving the band, Bessie once again drops her head and appears to sleep.

Helen is still holding the band on her lap and her eyes remain closed. About halfway through the song, Helen opens her eyes and looks down at the band in her hands. She studies it. After a few moments, Helen looks across the room to Dorothy who is pulling the band apart between her hands. Helen slowly looks back at the band and then back to Dorothy, before leaning in to copy Dorothy. While Helen's range of motion is much smaller than Dorothy's, she is engaging

with just as much effort and intensity. At the end of the song, Helen immediately sits back in her chair, drops the band to her lap and closes her eyes.

**Text box 6.3: Narrative description of an observation of a dance movement psychotherapy session at Hawthorne House on 08/12/2018**

#### 6.3.4 How arts practitioners scaffolded relationships in dementia

The metaphor of a scaffold also explains how arts activities scaffolded relationships in dementia. Practitioners explained how arts activities could encourage and support residents and others to come together and act together with a shared sense of purpose and understanding. The arts could support communication and open-up avenues for communication that did not rely upon memory or logic. Additionally, because participatory arts sessions could be interdependent in nature, cooperation and collaboration was encouraged and supported. Practitioners explained that residents were often required to work together in a shared activity. When arts practitioners created this common activity, residents did not need to do this. Residents, practitioners, care staff, and family were encouraged and supported to relate to one another in new and meaningful ways. Existing relationships could be sustained, and new relationships could flourish.

*'Her family were really struggling to communicate with her because a lot of the time she won't talk, but they have started coming in on days when we have singing so that they can sit and sing with her'*

Susan (Activity Coordinator)

In the third poetry session, I saw how the image of the girl in the bath served as a scaffold when it encouraged and supported residents to interact with shared understanding (textbox 6.1, the romance). In dance therapy sessions I saw how the balloon activity created a shared sense of purpose when residents were invited to pass the balloon to one another (textbox 6.4, the balloon). The interdependent nature of this activity meant that residents were encouraged



to interact, while communication and collaboration were supported when residents could communicate their intentions with ease as they passed the balloon. Spontaneous interactions also occurred quite frequently in dance therapy sessions. By way of example, Pam, who rarely spoke, wiggled the band to draw Bessie's attention, and waved her scarf at various points to engage with Zara. Rachael and Dorothy would sing to each other. Residents would coordinate their movements in time to the music. These incidents mirrored the accounts of other practitioners. Rachael, the music therapist, Ruth the singing facilitator, and Louisa the drummer, had all explained how residents would communicate and collaborate spontaneously in their sessions, by using instruments like cymbals and drums as communicative devices. Images, props, instruments, and songs were scaffolds when they encouraged and supported residents to interact in these ways.

Arts activities could also encourage and support more positive and affirming interactions. Practitioner accounts showed that positive person work was supported during arts sessions. When residents could make contributions during an activity, practitioners explained that these contributions could be recognised and celebrated. When residents could freely express themselves during arts sessions, responses could provide valuable insights about who a resident was, how they were feeling, and what was meaningful to them. Feelings could be acknowledged. Understanding and acceptance could be conveyed. Individuality could be recognised:

*'It's quite a quick way of getting to know people... with the music and the movement ... people's personalities come out quite quick.'*

(Kelly, Dance Movement Psychotherapist).

The relationships and bonds that could develop during arts activities could also be transformational. When arts practitioners could serenade a resident with a song, hold their hand as they painted, or embrace them in a dance, warmth and care could be conveyed. Some practitioners explained that the deep relationships they developed with residents through arts activities could help a resident feel safe to open-up and share their troubles. Some practitioners believed that arts activities could also encourage and support more equal and balanced relationships in care homes. When residents could make contributions to the home,

share their knowledge and skills, and even assist those who would normally care for them, care relationships could be turned on their heads. Practitioners explained that their activities could challenge assumptions about dementia, and promote more affirming and appreciative relationships when staff (and family) could see what residents were capable of doing and experiencing:

*'I think it can be a way of encouraging care staff to recognise the person as an individual, rather than pathologizing and relating to people as their illness. I think it has the potential to positively affect relationships between carers and residents'*

James, (Musician)

## The Balloon

Zara produces a large, red balloon and stands at the front of the room. Zara demonstrates a range of movements that residents might want to try including tapping, throwing, bouncing, kicking, and heading movements. Zara says that these are just suggestions and that residents can do whatever they like. Bessie has just woken up from a short sleep and seems very confused, asking who Zara is and what is happening. Zara re-introduces herself, explains what is happening and invites Bessie to join if she wishes. Zara gives Bessie a full demonstration of all the ways she might want to use the balloon but informs Bessie that she can do whatever she pleases.

Bessie holds the balloon between her hands and looks round each person with a cheeky expression, taking her time. She fixes her gaze towards Dorothy and Rachael. Rachael warns, *'watch out, she's coming, get ready!'* Rachael and Dorothy brace themselves to receive the balloon when Bessie suddenly turns the other way, and dramatically heads the balloon towards Susan. Most of the residents (except for Helen and a sleeping Annie), clap and cheer and there are squeals of laughter. Susan shouts *'I wasn't expecting that- well done Bessie'*. Bessie sits back in her chair and chuckles. This is the first time I've seen Bessie's playfulness and wicked sense of humour. Later the balloon is passed back to Bessie who, once again, heads the balloon to Susan. There are more cheers and laughter. Dorothy shouts approvingly;

*'now that's what you call a header!'* Bessie seems pleased with herself. Zara congratulates residents as they catch and pass the balloon. Most of the residents (except Helen and Annie) are watching and waiting for the balloon and there is a real sense of anticipation and lots of laughter.

I notice that Zara steps back once the momentum builds in this activity, stepping in only if the balloon goes astray or if someone needs help to catch it. Zara does step in at one point to invite Annie's participation. Annie has recently woken up, but no one seems to be passing the balloon to her. Zara takes the balloon to Annie, and again clarifies what is happening before demonstrating a variety of ways she might want to use the balloon. Annie taps the balloon quickly between her fingers, (one of the possible options that has been demonstrated by Zara), yet she continues to hold possession of the balloon for quite some time. Zara invites Annie to pass the balloon if she wants. Like Bessie, Annie decides to tease the group, responding with a *'oh no'* with a mischievous glint in her eye. There are more squeals of laughter.

**Text box 6.4: Narrative description of an observation of a dance movement psychotherapy session at Hawthorne House on 01/12/20.**

## 6.4 The subprocesses of scaffolding

The first half of this chapter introduced the concept of scaffolding and explained why it was a useful metaphor to explain arts engagement. The remainder of the chapter will focus on the subprocesses of scaffolding to explain how arts practitioners scaffolded during an arts activity. In grounded theory a major process needs to be broken down into subprocesses. Subprocesses are sequential in nature and should demonstrate a series of successive steps that make up the overarching process. Scaffolding represented the major process of the theory. Three subprocesses (along with their associated action and interaction strategies) were identified in this study as: *Inviting and inspiring engagement*; *Cultivating meaningful connections*; and *Nurturing change* (diagram 6.1, box c). The overarching process of scaffolding and its three subprocesses were prevalent in the research data. Yet there were variations in how a practitioner scaffolded, and scaffolding subprocesses were shaped, facilitated, and constrained

by different contexts and conditions. The arrows feeding from boxes d and e in diagram 6.1, show the contexts and conditions that impacted upon scaffolding subprocesses.

The remainder of this chapter will provide an account of the three scaffolding subprocesses in turn and the action and interaction strategies associated with these. Table 6.2 provides a summary of the subprocesses and their action and interaction strategies. The chapter will end with an examination of how these subprocesses and their associated action and interaction strategies were influenced by different contexts and different conditions.

#### 6.4.1 Inviting and inspiring engagement

Findings show that in the first phase of scaffolding, arts practitioners talked about trying to 'get engagement' or get a response from residents. Arts practitioners considered the sorts of engagement opportunities that might hold appeal for residents and that might entice engagement and stimulate a response. Invitations refer to the offers of engagement extended by the practitioner at the start of a session and throughout a session. Inspiration refers to the sources of inspiration used in an activity (e.g. objects, poems, smells, props, music).

The initial recruitment of interest is a key consideration for scaffolding (Wood, Bruner, and Ross, 1976). Practitioners explained that cultural and material resources could generate interest and stimulate capacities for engagement. Some practitioners invested in high-quality materials or gave a high-quality performance so that opportunities would hold a strong aesthetic appeal. Many practitioners used resources that were likely to be familiar to residents in some way, (e.g. culturally familiar objects or personally significant music) and that could evoke feelings of nostalgia and memories. Some explained how they used novelty (e.g. unusual objects, new smells) to generate interest, arouse curiosity and stimulate the senses and the imagination. The novelty of the large elasticated band introduced at the beginning of the first dance therapy session generated interest when it piqued the curiosity of Rachael, Annie and Dorothy. The use of the balloon and the bubbles grabbed the attention of most by creating a sense of anticipation about where a bubble would land or who would receive the balloon next (textbox 6.3, the band; textbox 6.4, the balloon).

*'I think that art, well at least the art in the kit, is that art has some beauty to it... there is something quite alluring.'*

Michelle (Trainer and Visual art activity kit developer)

Arts practitioners explained how they would encourage engagement by generating interest and enthusiasm themselves. Some did this by communicating the value of opportunities. Some would generate interest by arousing curiosity, or by building a sense of anticipation about their sessions. In poetry sessions, Jane was highly effective at generating interest and enthusiasm. At the beginning of the first session, Jane communicated value by declaring that she had brought something very special to show the residents (textbox 6.2, the bridle, part 1). Jane aroused a sense of curiosity when she did not immediately reveal what this was, keeping the bridle hidden from view. Jane then built a sense of anticipation through her storytelling, before dramatically revealing the bridle from behind a chair. Jane further communicated the value of the bridle by telling the group it was 'a survivor' from long ago. Jane's own enthusiasm also seemed to capture the attention of residents. Jane adopted a similar approach in the second poetry session. I watched as a gorgeous and abundant basket of fruit and flowers was revealed from behind a chair to gasps of delight. While the basket was aesthetically pleasing, it also seemed to arouse a sense of curiosity when residents were told they could 'dig inside' to see what it contained.

To encourage engagement, opportunities had to be attractive, accessible, and actionable. Yet practitioners recognised the diverse and changing interests, needs and desires of those they worked with. One practitioner spoke about the need to 'get the fit right' between what she offered and what might entice a resident to engage. Practitioners used a range of strategies to 'get the fit right'. When practitioners did not know residents well, or when they were unsure of what would hold appeal, some would experiment with different approaches to see how residents responded: *'If I got nothing out of (name)...I'd put Match of the Day music on and watch, .... or maybe do some kicking and saving the goal'* (Elizabeth, Dance Practitioner). Claudia the cellist explained how she experimented with different genres of music to see how residents reacted in her sessions. Over time, as practitioners became more familiar with and more attuned to residents, they were better able to anticipate what was likely to encourage engagement, and could tailor opportunities accordingly:

*'You get to know members of the group so you could select material that you know will appeal to this group and possibly not another group'*

Kenneth (Poet)

Some practitioners got the fit right by including an abundance of diverse and multi-faceted engagement opportunities that could accommodate for a range of interests and abilities. This approach seemed to be an especially useful strategy in the context of a one-off session or when practitioners did not know residents well. Julie the visual artist explained that when she did not know residents well, she would plan her sessions in ways that included lots of different components, understanding that some things would appeal to residents more than others. Ruth, the singing facilitator took a similar approach, including lots of different elements in her sessions (including more physical elements and more challenging cognitive elements). Again, Ruth stated that some parts of the session would be more relevant and would hold more appeal for some than others. Both practitioners explained that when they were able to work with residents over time, they could start to tailor their sessions more. The inclusion of diverse and multi-faceted opportunities was also useful in the context of a one-off performance/production:

*'We make lots of different offers... some people will engage with some props and not others... different music styles... and then the art and the storyline... it's all those different offers'*

Rhonda (Artistic Director; Theatre Company)

During poetry observations I noticed how an abundance of diverse and multi-faceted engagement opportunities accommodated for different abilities and interests in the group. Sessions had cognitive, physical, emotional and sensory components. In the second poetry session for example, Racheal and Dorothy were eager to learn about the jam-making process (textbox 7.2, the Jam). While it was not clear that the others connected in this way, Pam, Bessie, Annie and Helen all seemed to be entertained by Jane's dramatic expressions and

sounds as she told her stories, and most appeared to be delighted by the vibrant colour and smell of the quinces or amused by the weight of the fruit in their hands.

The inclusion of an abundance of multisensory and motor-based opportunities was also deemed important way of 'getting the fit right'. Rhythm, movements, scents, sounds, touch, colours, textures, images etc provided sensory and motor-based pathways for engagement that could be more accessible for those with advanced dementia, could provide alternative engagement pathways for those with impairments (e.g. sight loss). Practitioners often considered how different sensorimotor based elements could be incorporated into their sessions to accommodate for different needs and abilities. Michelle, a trainer and visual arts kit developer, explained how images in her kit could be explored through 'movements and stroking on the picture' and through 'looking at colours' and 'singing songs'. Julie the visual artist explained how she incorporated touch or scent in sessions to provide pathways for engagement for those who were visually impaired.

*'It's hearing music...it's got to be about visuals, it's got to be about touch, smelling if possible...it's about presenting an option, opening a door'*

(Gavin, Visual artist)

Practitioners explained that sensorimotor based options could also stimulate a response and provide the foundation for other forms of engagement (e.g. reminiscence or creative self-expression). Kenneth the poet explained how he used images, scents, sounds and music to stimulate responses in his sessions. Julie the visual artist explained how movements with a paintbrush could be encouraged by singing to residents. In poetry sessions, I noticed how Jane would stimulate a response by encouraging sensory exploration, when residents were invited to hold and smell the fruit and flowers, and to touch and explore the bridle. Residents seemed to derive pleasure from this sensory-based mode of engagement, yet it would often evoke a response when a resident would offer an insight for the poem.

*'I've got pictures... someone starts telling a story...and then you're off because ...that's something you can work with'.*

(Louisa, Drummer).

Practitioners also 'got the fit right' by creating open-ended opportunities. Some practitioners worked in more open-ended ways and would give residents a high degree of choice and control in a session (or for part of a session). These practitioners would let residents initiate engagement and would follow the resident's lead. Julie the visual artist for example explained that she would sometimes place an assortment of materials on a table and wait to see what a resident engaged with. A similar approach was described by Michelle, the activity kit developer, when she explained how she would lay out three or four images in front of a resident to '*see if physically they drift towards one of them, and then just looking at that one image*'. James the musician explained how he took a highly improvised approach and would create space in his sessions for residents to initiate with their instruments. In one-to-one sessions, Kenneth the poet explained how he would invite a resident to talk about whatever they wanted, so that there was no theme or stimulus.

In dance therapy sessions, Zara gave residents a significant amount of choice and control at times. Zara invited choice frequently throughout her sessions, typically asking residents what they would like to do and what songs they would like to hear. Residents did not find it easy to make choices, and each time Zara invited choice a period of silence would always follow. Yet over time, and with repeated opportunities Dorothy and Rachael were able to make choices about songs, and this had a significant impact on engagement (textbox 7.1, making choices). Others struggled to make choices, and so Zara supported choice by narrowing options, for example asking a resident if they wanted to hear a fast song or a slow song. Zara also took inspiration from residents. Helen would sometimes seem unaware or possibly uninterested in what was going on around her, so that she would sing to herself instead. Rather than trying to re-direct Helen's attention to what the group was doing, Zara would often take inspiration from Helen and would follow her lead. Other residents would often join-in. This proved to be a highly effective approach with Helen (textbox 7.3, the solo). By the third session, Helen seemed to use her singing very deliberately to influence the actions of the group.

While practitioners could invite choice and follow a resident's lead, practitioners would often take the lead and would make choices or present more defined tasks for residents (e.g. inviting residents to comment on an image or object, or to make something). Yet practitioners explained that these opportunities were open-ended. Opportunities had room for individual interpretation or experimentation. Julie the visual artist explained how she made masks with



residents, yet each person put whatever they wanted on their mask and used a different set of processes. When opportunities were open-ended, residents could follow their own inclinations and engage in the ways that were meaningful to them:

*'(We) were looking at a picture and eventually the conversation was about their fears during their first pregnancy, which wouldn't have been a topic that I would have.... that never would have crossed my mind .... but it was evoked, somebody brought up pregnancies'*

Michelle (Activity kit developer and trainer)

In poetry the bridle was a source of inspiration for the group poem, yet residents made their own interpretations. Jane would ask open-ended questions and invite residents to share their thoughts about the bridle, or *'anything at all'*. Jane explained afterwards that objects and images in her sessions were simply intended to act as a stimulus for engagement, so that residents were free to make their own associations and share whatever they wanted. This approach meant that Dorothy reminisced about the horses in Yorkshire and Lancashire, the war, and the boys who worked on the farm. Rachael shared stories about sitting on top of a horse with her sisters as a child. In dance therapy Zara modelled possible movements, yet she encouraged residents to experiment with their own, and to engage in any way they pleased. Sometimes this meant that a resident would simply watch or close their eyes and relax. Bessie for example would often appear to be sleeping – yet she was still engaged (textbox 6.3, the band; textbox 7.1, making choices).

While practitioners in this study were not dogmatic about how a resident should engage, participatory practitioners did challenge residents by inviting them to try things. Appropriate challenge was itself seen as a motivator for engagement. Reminiscent of Vygotsky's Zone of Proximal Development, practitioners challenged residents to engage *just* beyond their comfort zones. To 'get the fit right' practitioners explained that they needed to set challenges that were appropriate, as too much challenge could be overwhelming, while too little challenge could cause more capable residents to lose interest. Louisa, the drummer, for example explained how levels of challenge could be adjusted in her drumming session. A call and response activity meant that residents could copy a simple beat or series of beats, yet more

capable residents could be more creative in their responses or could be invited to improvise with a solo. While both Zara and Jane were accepting of what residents wanted to do, they would both challenge residents at times. Jane and Zara would give more direct encouragement by approaching the less forthcoming members of the group (textbox 6.2, the horse bridle, part 2; textbox 6.1, the Romance). Other practitioners also described how they would carefully challenge a resident by giving a gentle nudge or prompt to engage:

*'Some people seem to need a little encouragement...I test through eye contact, body language, physical position, gently, probably more than once, unless I get a very negative reaction'*

(Ruth, Singing facilitator).

Finally, when extending offers or invitations to engage, many practitioners encouraged engagement by using persuasion. A variety of persuasion strategies were present in this study. A persuasion technique called foot-in-the-door fits well with an approach described by several practitioners where they would make a very small request of a more reluctant resident in the hope that this would break an engagement barrier (e.g. by inviting someone to sit at the back of the room and watch, or asking someone to try something for a very short time). Some practitioners persuaded residents to join in by using humour. Some appealed to need by asking for help or by asking a resident to engage as a favour. Some used flattery by complimenting past efforts (in poetry sessions, Jane started the activity by complimenting residents for their efforts the previous week). Several practitioners persuaded residents to engage by communicating the benefits of a session (e.g. health and wellness, a contribution to the care home, enjoyment).

*'With a lot of people I work with there is that element of why are we doing this...that kind of stuff does come up... I'll talk about well we are going to create this to show to other people....it's about them having value and a reason to do the project.'*

(Gavin, Visual artist)

#### 6.4.2 Cultivating meaningful connections

The first phase of scaffolding was about getting engagement. The second phase of scaffolding was about encouraging and supporting residents to connect to themselves and to others.

By experimenting with different approaches, and by creating open-ended, diverse, and abundant opportunities, residents could engage in ways that were meaningful to them. They could connect with their emotions, their memories, their thoughts, their creativity, their bodies etc. Cultivating connections was about encouraging and supporting residents to grow in their engagement, so that they could engage more deeply and express themselves more fully. It was also about noticing when a resident was really struggling to engage, so that greater assistance could be given.

One way in which practitioners cultivated connections was by creating a facilitating environment, meaning an environment that catered to the needs and desires of residents. This meant practitioners would expand or extend the sorts of opportunities that residents were seeming to find value in. Elizabeth, the dance practitioner, explained that she would prolong or extend segments of her sessions that residents seemed to be particularly enjoying. Lisa, the opera singer, for example explained that she would introduce more humour when residents seemed to appreciate this aspect of her performance. Julie, the visual artist described how she would re-arrange the physical space according to what a resident wanted to do:

*'I will put distinctive trays on the table of objects ... if they start looking at something then I'll move it closer to them because they are enjoying that'.*

Julie (Visual artist).

Arts practitioners also created a facilitating environment by harnessing and matching resources and their behaviours, in ways that were conducive to how residents wanted and needed to feel and act. Claudia the cellist, explained that she would play sad songs if a resident was feeling sad and needed to cry. Louisa the drummer explained that when a resident would bang a drum in frustration, she would get everyone to join in to help lift this feeling of frustration. Kelly, a dance movement psychotherapist, explained how she engaged in a tug of

war with a resident to help relieve their frustration. Ruth, a singing facilitator, explained how she encouraged and supported a very energetic resident to express herself more fully by joining her in a dance, and matching her demonstrative actions (also see textbox 6.5, making moves). Sometimes a facilitating environment simply meant holding space in a session and allowing a resident to continue if they engaged in an unanticipated way:

*'There is always time to share your stories. Otherwise, it becomes about the music and not about the group'.*

Louisa (Drummer).

In the first dance therapy session, Zara created a facilitating environment with upbeat tempos, a fast pace, and an abundance of colourful props, matching and amplifying the already energetic and playful mood of residents. In the second dance therapy session some of the residents were visibly fatigued. There were fewer props than there had been in the previous week. The pace of the session was slower and there were breaks between the dancing for residents to sing and reminisce. Zara explained that she constantly observed how residents were responding in her sessions and was reflecting on what they wanted and needed to do next:

*'We didn't use as many props today .... we were in a place of sharing about the war and singing, to then go and get the balloons wouldn't have felt right, so I stuck with what was going on'.*

Zara (Dance Movement Psychotherapist)

## Making moves

Zara plays Land of Hope and Glory and asks Dorothy if she would like to stand and dance. Dorothy eagerly accepts. Most of the group are watching intently, as they dance together in the centre of the room. While Dorothy initially copies Zara's movements, she starts to get creative with the lyric 'make me mighty', taking a wide stance, and making a series of dramatic poses to the rhythm of the song, pumping her fist, flexing her biceps and stamping her foot.

Zara joins her, doing variations of these movements, matching Dorothy's energy, and her power.

Zara invites Dorothy to stand and dance to the theme of the Pink Panther. Again, Dorothy initially copies Zara, yet before long she starts to tease the group by putting her hands on her hips and giving a dramatic and playful wiggle. This has been entirely unprompted by Zara. Zara laughs and matches Dorothy's movements. This seems to encourage Dorothy's playfulness even further so that she continues for a while before giving Zara a playful slap on the side of her hip and sitting down. Susan is roaring with laughter, and Pam and Rachael are also clearly enjoying the performance. Dorothy looks pleased with herself and has clearly relished entertaining everyone. Helen hasn't been watching the dance, yet she picks up on the laughter in the room and joins in, continuing to laugh heartedly for some time, exclaiming '*we are having a good time here aren't we!*'

**Text box 6.5: Narrative description of an observation of a dance movement psychotherapy session at Hawthorne House on 01/12/2018**

Participatory arts practitioners also cultivated a growth in engagement through encouraging and supportive interactions; '*Whatever people are doing I am encouraging and supporting and hoping that we might see a little bit more of it*' (Simon, Dance Movement Psychotherapist). When a resident was engaging, practitioners would often encourage the resident to expand upon their thoughts, feelings, or movements. In poetry observations, I saw how Jane encouraged residents to continue sharing their words and stories through active listening. When a resident spoke, Jane would give them her full attention, with her pen poised (textbox 6.2, the horse bridle part 1). Zara would often encourage residents to expand upon their efforts by inviting a resident to stand to dance or to expand their range of motion. When residents were limited in their range of motion, or not using parts of their body, Zara would use her body to encourage movement or would use props like the balloon or bubbles, so that residents would reach forward or upwards.

*'It extends into me using my body as a vehicle to encourage them to use new parts of their body that they might not be using...so it's also about encouraging new areas of movement'*

Zara (Dance Movement Psychotherapist)

Some residents could require encouragement if they lacked confidence and were a little inhibited in their engagement, or if they got frustrated. Ruth the singing facilitator explained that she would affirm the actions of residents who seemed a little uncertain of what they were doing, by smiling or nodding. In poetry sessions Jane would show residents that what they were saying was right by affirming their verbal contributions (smiling and nodding, or by making approving noises). Rachael the music therapist explained how one of her residents would sometimes get frustrated at her inability to sing as well as she would have liked, so that Rachael would reassure her. In the first poetry session Annie became frustrated at her inability to remember words. Yet Jane kindly reassured Annie that the words would come back. Annie visibly relaxed and was able to offer words at a later point. While Jane was warm and kind with everyone, she had a reassuring presence that was even more pronounced when she interacted with quieter members of the group.

Practitioners would also need to give cognitive and/or physical support at times (e.g. guiding, making suggestions, giving prompts). Yet crucially, participatory practitioners in this study wanted residents to engage as independently as possible. This meant that practitioners would intensify support where only needed, yet they would also withdraw support where possible. Louisa the drummer for example explained that residents could feel daunted in her drumming activity so that she would intensify guidance and support by simplifying the task and modelling behaviour. Yet Louisa would gradually withdraw her support so that the person could come to engage independently. Julie the visual artist explained how she intensified encouragement and support for residents who struggled to engage; *'holding somebody's hand and then in the hand, you can maybe put a paintbrush... and then you encourage them to put the paintbrush into the paint and then before you know it, they're actually into something'*. Crucially, practitioners in this study knew when to intervene and to what extent, and when to withhold. The research data showed that practitioners did not intervene to give assistance immediately, so that some degree of struggle (but not overwhelm) was acceptable.

*'It might be that you are withholding at times ... or it might be that you are having to use those skills to support somebody'*

(James, Musician).

During observations I noticed how Jane would intensify guidance and support only where needed. In doing so, Jane explained that residents were free to talk about what was meaningful to them and to use their capacities for creative and associative thinking. As residents shared what was meaningful to them, Jane saw that her task was to further *'encourage things in that direction.'* When Dorothy shared her stories about the horses, the war, and the boys on the farm, Jane encouraged her to continue (textbox 6.2, the horse bridle, part 1). Jane needed to intensify support quite significantly so that Pam could comment on the horse bridle (simplifying the task by asking yes or no questions). Yet Jane also tapered support and challenged Pam by opening-up the conversation again. Pam was able to offer the word 'feet' - a significant achievement for Pam (textbox 6.6, the horse bridle, part 2). In the third poetry session, Jane only intensified support after periods of silence by asking an easier question (simplifying the task), by directing attention, and by making suggestions. By allowing for periods of silence, and not intervening immediately, Dorothy was able offer some profound insights about the girl in the bath (textbox 6.1, the romance). Annie was also able to contribute her own words in the second poetry session (textbox 6.7, the cemetery).

During dance therapy, I also observed how Zara did not intervene immediately when residents struggled to think of a song or a dance move. This allowed Dorothy and Rachael to make quite significant choices and contributions (textbox, 7.1. making choices). I also observed how Zara continually adjusted levels of guidance and support. Zara encouraged residents to explore their own movements, yet she would also model a range of possible movements so that residents could copy her if they needed (textbox 6.3, the band; textbox 6.4, the balloon). When a resident was not moving, Zara would intensify guidance and support by demonstrating a single movement or by guiding the resident in a seated dance. When Zara withdrew her support, I noticed how a resident would often continue to move independently for a while after she had moved on. Zara also 'dropped out' of the group at times when residents were interacting well with one another, only stepping back in when needed to give assistance (textbox 6.4, the balloon).

### The Horse Bridle, part 2.

Pam has been watching intermittently throughout the session, but she has been very quiet and has not contributed to the group poem. Jane goes to Pam and kneels in front of her, smiling. Jane asks Pam if she would like to share anything about the bridle or anything at all.

Pam is extremely responsive to Jane's attention and they hold eye contact, smiling warmly, their body language and expressions mirroring one another. Yet Pam doesn't reply. Jane simplifies the task by asking Pam a series of questions instead. Do you remember seeing horses when you were a girl? Pam gives a very loud and enthusiastic YES. Jane says YES back and smiles warmly. Did horses go by on the lane? YES. Did you ever touch one? YES. Jane then gives Pam another opportunity to share asking her; *'do you want to tell me about it?'* Pam says a solitary word- *'feet'* and Jane agrees *'yes, big horses, and big feet... they have such big hooves don't they?'* Pam responds emphatically 'YES!' Jane proceeds to tell Pam a story about a horse she used to know as a child. The intimacy and genuine affection conveyed between Jane and Pam is a lovely thing to watch. When Jane moves on, Pam's mood and engagement has shifted notably, and she continues to follow Jane closely, craning forward in her chair to watch. Pam had not been doing this earlier in the session. This is by far the most engaged Pam has been.

**Text box 6.6: Narrative description of an observation of a poetry session at Hawthorne House on 11/12/2018**

Cultivating meaningful connections also refers to the interpersonal connections that were made during activities. Many practitioners wanted to grow relationships in the group. In group sessions, residents would sometimes communicate and collaborate in spontaneous ways, yet practitioners employed a range of strategies to further encourage and support interaction. Some did this by directing the attention of the group to what a resident was doing. Some would highlight common ground between residents. Some encouraged interaction by using turn-taking activities, so that residents were encouraged to notice each other as they would pass a sound, a ball, or a balloon. In dance therapy observations Zara explained that she would introduce props like the balloon and the band as a way of encouraging and supporting more interaction in the group, if she felt that residents were not interacting much. Zara also encouraged interaction by modelling interactions with Susan, skipping together with the band, or throwing scarves to one another. Some residents picked up on these behaviours and initiated similar interactions with their neighbours. When the group were interacting well with each other, Zara would sometimes 'drop out' of the space, by physically standing or sitting back from the group. This seemed to encourage residents to focus on each other even more, rather than on her (textbox 6.4, the balloon; textbox 7.1, making choices).



*'I'll roll the ball and they'll roll the ball back to me, and then if the room allows it, they'll roll the ball to each other.... these connections are being made together'*

Elizabeth (Dance practitioner).

Practitioners in this study also wanted to cultivate their own personal connections with residents, to build relationships, and to ensure that residents felt noticed as individuals. Practitioners cultivated connections through making eye contact and using proximity, and by giving a resident personal time and attention.

Practitioners also cultivated connections by noticing things about residents as individuals. When residents had the freedom to express themselves during arts sessions, some practitioners explained that they could reveal things about themselves. They could show their feelings and could reveal their personalities. By noticing and reflecting these things, practitioners could build relationships and ensure that a resident felt seen and heard as an individual. Some practitioners also explained that this could help residents connect more with who they were as a person.

*'Whether it's your sense of humour or taste in music, or things that you like to do or don't like to do... I try quite hard to reflect those things so that people feel seen'*

Kelly (Dance Movement Psychotherapist).

During poetry and dance therapy sessions, resident personalities came to the fore. Bessie, Annie, and Dorothy all had a great sense of humour and could be very playful. This was noticed by Jane and Zara (and others) and reflected during sessions. For example, Jane noticed Annie's playfulness in the final poetry session, and reflected this by joking and laughing with Annie and encouraging her further (textbox 6.1, the romance). Bessie's wicked sense of humour was noticed and reflected by Zara and others in the balloon activity (textbox 6.4, the balloon). Dorothy's curiosity about the world and learning, and her desire to teach others was evident during observations. Dorothy would teach the group about the history of various songs or life

in the war (textbox 7.2, the jam). Jane and Zara both noticed and reflected this aspect of Dorothy's identity by listening to Dorothy with interest as she imparted her knowledge.

Some practitioners explained that residents would make sense of activities by drawing on prior experience and re-enacting things from their past. These practitioners took care to notice and respond to residents in ways that were consistent with the resident's beliefs. Claudia, the cellist explained how one resident who was 'in another world' had been in a band previously. Claudia would engage with him by joining-in as he played his keyboard in a 'jamming session'. Kelly, the dance movement psychotherapist, explained how a resident who had been a dressmaker would use the scarves in her dance sessions to dress her and others in the group. Kelly made sure she always brought scarves to these sessions so the lady could continue to do this. Rachael the music therapist, explained a similar approach when she would join-in with a gentleman who had been a boiler engineer:

*'We had an instrument and the first thing he did was dismantle it ... when I approached it as though I was working on a job with him... we actually ended up having a really good relationship.'*

Practitioners would also cultivate personal connections by noticing and responding to the movements, or mannerisms, or words of residents. Zara for example explained that during dance therapy, even the smallest of actions like the tapping of a hand, could provide a way to connect when she could join-in with what a resident was doing. Some practitioners explained that they would use mirroring to establish a connection and build rapport. Rhonda (artistic director for a theatre company) explained how she connected with a resident by placing her hand next to the resident's hand, and 'mirroring the tiny movements of the little finger'. Mirroring was evident in poetry and dance therapy sessions. Zara and Jane both seemed to build rapport by mirroring the resident they were interacting with. By way of example, when interacting with a placid and softly spoken Annie, Zara and Jane would often crouch down, speak softly, and use gentle movements. Yet Zara and Jane would adopt a more energetic and playful manner when interacting with Dorothy. In dance therapy, I noticed how Helen would often hold her clenched fist in front of her and wrap her other hand around it. Zara frequently mirrored this action, holding her clenched fist directly in front of Helen's. This would provoke a

positive response from Helen. Jane mirrored the words of residents. Even if a resident uttered a single word, Jane tended to repeat the word, explaining that she wanted the resident to know that they had been heard.

Turn-taking was also apparent during observations. In the third dance therapy session, when Bessie loudly and spontaneously declared 'in the mood' as Glen Miller played, Zara noticed and immediately responded with 'in the mood'. This prompted Bessie to repeat the words, and this went back and forth a few times. This happened at several points during dance therapy sessions. Turn-taking was also evident in a conversational sense. Just as residents were invited to share, Zara and Jane were also willing to share things about themselves with residents. Jane for example conversed with Dorothy and Rachael about growing up in the countryside and Shire horses and they were able to find common ground (textbox 6.2, the horse bridle, part 1).

#### 6.4.3 Nurturing change

Residents were changing when they could connect with their capacities to think, and feel, and act, and when they could interact with others. The third phase of scaffolding was about nurturing this change through relationships, by communicating value, by communicating understanding and acceptance, and by communicating deep admiration and care.

Practitioners explained that they made the effort to show residents how valuable their contributions were. Some stressed the importance of valuing very subtle contributions (like the tapping of a foot) just as much as more overt displays of engagement. Practitioners communicated value by recognising contributions. Contributions could be recognised when a resident's words were included in a group poem for example. Contributions were recognised when a practitioner emulated what a resident was doing, sometimes inviting others to do the same; *'they get a sense of achievement ... it's actually something that's worth copying'* (Elizabeth, Dance Practitioner). Practitioners also communicated value by celebrating achievements. In poetry for example, Jane would praise a resident by telling them that their insight was wonderful. In dance therapy Zara (and others) would clap and cheer when a resident would head the balloon, dance for the group, or sing. Residents always seemed proud when their contributions were valued in these ways. Some practitioners would celebrate

achievements by displaying creative work in the care home and holding an event for family and friends.

In observations, residents also seemed to gain immense satisfaction from helping others and from being appreciated. Practitioners communicated value by showing appreciation verbally and non-verbally. This seemed to be a hugely effective strategy in observations. For example, Pam did not seem to be overly enthused by the dancing in the first dance therapy session, yet she would beam with delight each time Zara would thank her after a 1-1 dance. The gratitude expressed by Zara seemed to bring Pam great satisfaction even when the dancing did not. The importance of showing appreciation was also commented upon by Jane in post-observation interviews. Jane made the following statement about Annie:

*'When I got something from her I repeated it back to her with appreciation ...that seemed to please her very much... it gave her pleasure because at the end of it all she felt that she had provided me with words'*

Jane (Poet)

Finally, when residents could express themselves in sessions, practitioners (and others) could communicate things of value about a person, by giving compliments in ways that affirmed a resident's sense of self. During dance therapy observations for example, when Dorothy would regularly share her knowledge with the group, Susan complimented this aspect of her identity (e.g. saying that Dorothy was a 'font of knowledge'), much to Dorothy's delight.

*'We talked about him being a boxer ... when we would use the balloon he was giving it a good left hook... he really beamed he would look really proud, like yeah, that's me that's who I am'.*

Kelly (Dance Movement Psychotherapist)

Arts practitioners also communicated their understanding and acceptance of residents. When arts were a vehicle for self-expression, practitioners explained that residents could sometimes

be boisterous, disruptive, or critical, and that they could express sadness, frustration, anger, or disgust. Practitioners in this study did not admonish, ignore, or deny these sorts of expressions, but instead respected a resident's right and need to express themselves. Practitioners nurtured change when they acknowledged a resident's feelings, and some would also validate these feelings:

*'She was telling me very clearly that it was stupid... my approach is in that situation to acknowledge the stupidity and not to say it's not stupid because actually it is a bit silly ...it's patronising to say to somebody, well it's not, or to deny what someone is telling you'*

Kelly (Dance Movement Psychotherapist).

Practitioners also showed understanding and acceptance when they chose not to correct residents, discount their contributions, or ridicule them. During observations, Dorothy would frequently share information that was clearly inaccurate or impossible, for example telling the group that Emily Dickinson was her mother or that she used to be Helen's childminder (also see the Jam, textbox 7.2). Yet Dorothy was never corrected or teased for her errors. Similarly, when Helen declared that she had seen Myna birds recently, Jane accepted Helen's words and wrote them into the poem (textbox 6.1, the romance). Annie and Pam would struggle to offer words for the group poem. Yet Jane would validate the words they did contribute by writing them in her notebook and including them in the group poem, even when these words were scarce or made little sense (textbox 6.7, the cemetery; textbox 6.6, the horse bridle, part 2). I wondered if others perhaps avoided talking with Annie or Pam out of a sense of awkwardness.

### The Cemetery

Jane approaches Annie and crouches in front of her smiling. She explains that she has brought some flowers and holds out some fuchsias. Annie responds with a big smile *'they're lovely'*. Jane then takes some lavender and squashes it between her fingers, asking Annie if she would like to smell it. Jane asks if it reminds her of anything. Annie tries to communicate her thoughts *'it's the...cem...cem...cem...cem....'*. Annie is looking into her lap and is clearly trying hard to form

a word. Jane is kneeling on the floor patiently looking up at Annie with her notebook opened and pen poised. After quite some time, Jane prompts Annie with a suggestion; *'is it a place?'* Annie responds with a yes. *'Is it the cemetery?'* Annie responds with a very enthusiastic yes, nodding. Jane asks if Annie is talking about people leaving flowers at a cemetery. Annie again responds with a YES! Jane says that she wants to write this down in her notebook for the poem. Annie watches her do this and seems pleased. Annie then continues unprompted, *'let me tell you, there was him and there was me....'* Annie's speech trails off and becomes incoherent, yet she clearly states the words *'funny one'*, and so Jane mirrors her; *'it was a funny one?'* Annie responds with a yes, yes! Jane writes the words in her notebook and Annie watches closely with a satisfied expression. Jane thanks Annie and moves on.

**Text box 6.7: Narrative description of an observation of a poetry session at Hawthorne House on 18/12/2018**

Finally, practitioners nurtured change through the bonds they formed. Practitioners wanted residents to understand that they were precious and wanted, and they did this by communicating their genuine admiration and care for residents. Clarissa, an opera company director, explained how her singers were able to make residents feel special during their performances. Many practitioners explained how they communicated their care by showing affection in more tactile ways, using touch or embrace as they engaged with a resident. Several practitioners explained that they would convey their care for a resident by giving comfort and reassurance if a resident revealed that they were sad or troubled in some way.

In observations I noticed how Zara and Jane would communicate their deep care and affection residents during 1-1 interactions, and how they seemed to develop emotional bonds with residents. While I did not witness this with every one-to-one interaction, there were many such tender moments. They often involved sustained eye contact, physical closeness, and sometimes touch. In the first poetry session for example, the bond that developed between Pam and Jane seemed to be of far greater significance than the act of making the poem, (although the relationship was facilitated by the act of doing something together, see textbox 6.6, the horse bridle, part 2). Pam's mood and behaviours changed markedly after the interaction and she continued to follow Jane around the room for some time. I saw this phenomenon repeatedly in observations of both poetry and dance therapy. I believe that

residents were responding to a feeling of being genuinely wanted and needed by another person. Residents also tended to become more engaged in a session after these episodes.

*'I don't think I've had anyone who's not enjoyed that sort of comfort or intimacy or reassurance or friendship'*

Julie (Visual artist)

## 6.5. Intervening conditions

In this study, the arts practitioner's approach to scaffolding and their actions and interactions were shaped, facilitated, and constrained by different intervening conditions. Three intervening conditions were identified: practitioner differences, resident differences, and group size and composition. Each of these influences will now be considered in turn.

### 6.5.1. Practitioner differences

The core process of scaffolding was applicable to all cases in this study. Yet arts practitioners had different values and beliefs, and so this would influence their approach to scaffolding. Some practitioners would invite and encourage emotional self-expression, while others placed a greater emphasis on creative self-expression. Some practitioners stressed the importance of agency and empowerment so that they would give residents a high degree choice and control and would follow a resident's lead. Practitioners who wanted to reinforce a resident's sense of self would take care to notice and reflect what was unique about a resident. Some practitioners wanted to encourage and support a sense of group. These practitioners would invite residents to work together on something or would cultivate connections between residents by using strategies like turn-taking. Some practitioners in this study (mainly though not exclusively therapists) valued emotional expression and would encourage and support residents to express themselves if they were experiencing more challenging emotions.

Zara explained that her major goal was to build therapeutic relationships with residents. Zara wanted residents to trust her deeply, to feel safe enough to open-up and share their feelings. This goal was reflected in Zara's invitations to share feelings through movement and through talking. It was reflected in the considerable amount of time Zara invested in 1-1 interactions to cultivate close personal connections with residents. Jane's major goals were to encourage and support residents to connect with their capacities for associative and imaginative thinking and to communicate their words. Jane wanted residents to know that their insights and words were of value. These major goals were reflected in Jane's invitations to share thoughts. They were reflected in Jane's act of valuing and recognising words by capturing them in a poem.

Interviewees also stressed the importance of experience, and the skills and knowledge they had developed as a practitioner. Artistic skills could help practitioners to inspire residents. Jane for example explained that she was able to draw upon her performative skills to capture the interest of the group, and she did this beautifully (textbox 6.2, the horse bridle, part 1). Julie the visual artist explained that her extensive artistic knowledge gave her plenty of options to draw upon to accommodate for different needs and preferences. The ability to stay in the present moment and the agility to be responsive to what residents wanted and needed, were also considered important skills. Some practitioners claimed that they had initially struggled with this, yet they had come to hone these skills over time through their practice.

*'When you work with people with dementia you have to be really flexible....I think it's just practice, and I think that some people find it easier to be like in the moment'*

Kelly (Dance Movement Psychotherapist)

Finally, many interviewees stressed that practitioner disposition was of fundamental importance. It was reasoned that practitioners who had large egos or who lacked warmth were deemed less willing and able to notice and connect with residents on a more personal level. Practitioner disposition could also shape how a practitioner showed their care towards residents. While many practitioners in this study were very demonstrative and tactile with residents, one interviewee explained that he was less inclined to show his care in this way.



### 6.5.2. Resident differences

Practitioners in this study were constantly making adjustments to be responsive to the residents they worked with. Practitioners made ongoing judgements about the diverse and changing moods, abilities, needs, levels of readiness, beliefs, and values of residents, and adjusted their approach accordingly.

The research data showed that resident differences in cognitive and physical impairment, meant that some residents required more intensive levels of cognitive or physical support to engage in a session than others. Residents with high levels of cognitive impairment could struggle to be aware of what was happening around them and could require more direct stimulation to even be aware of engagement opportunities. This was most obvious with Helen in dance therapy and poetry sessions. Zara and Jane often needed use more intense and prolonged sensory stimulation with Helen to get a response (text box 6.3, the band; text box 6.8, the leaf in my hand). Levels of cognitive and physical ability also seemed to vary considerably between residents in observations. Dorothy and Rachael, who were considered the most cognitively able of the group, required less cognitive support to engage than either Helen, Annie, Bessie, or Pam. Physical limitations also meant some residents had to be more carefully supported to stand and dance in dance therapy sessions.

Practitioners explained that differences in levels of resident readiness were also a consideration in their sessions. Some explained that some residents did not enjoy personal attention for example, so that they needed to be sensitive to this. Simon, the dance movement psychotherapist, reported that he would sometimes start his sessions using humour to break the ice if he sensed that residents were a bit resistant. Yet he did not always feel the need to do this. While practitioners would encourage residents to do things and to expand upon their efforts, practitioners considered levels of readiness and boundaries were respected. During observations levels of challenge varied considerably between residents yet challenge always felt appropriate. By way of example, an eager and able Dorothy was invited to entertain the group with her stories and to stand in the middle of the room and dance for the group (textbox 6.2, the horse bridle, part 1; textbox 6.5, making moves). By comparison, a more reticent Pam was tentatively invited to engage in a seated dance with Zara in the first dance therapy session and was asked to share her thoughts during one-to-one interactions with Jane in poetry sessions. Expectations about levels of readiness also influenced the sorts of invitations or

offers a practitioner would make at the start of their sessions. Several practitioners explained that they always started their sessions with something easy. Kenneth for example explained that he would start his sessions by reading some poems of a light-hearted nature and would invite residents to repeat lines from the poem. Kenneth considered that anything of more demanding or serious nature at the start of a session, would overwhelm residents.

The diverse and changing moods, needs and desires of residents meant that practitioners would adapt their approach and modify the arts space according to what residents wanted and needed. A resident's need to rest was an important consideration. When working with those who were fatigued, practitioners explained that they would engage the person in a shorter activity, incorporate plenty of opportunities to rest or encourage the resident to dip in and out of the activity as they desired and as their energy permitted (textbox 7.1, making choices).

### 6.5.3. Group size and composition

Group composition was also an important consideration for scaffolding. Many practitioners reported that care staff could assist them by encouraging and supported residents to engage. Susan encouraged and supported residents during poetry and dance therapy observations (textbox 6.4, the balloon; textbox 6.8, the leaf in my hand). Sometimes Susan's input could be pivotal. For example, Susan knew that Rachael had lived on a farm all her life, and she used this information to encourage Rachael's participation in the first poetry session (see textbox 6.2, the horse bridle, part 1). Furthermore, it was Susan who helped Zara identify the tune that Helen was singing during dance therapy (see textbox 7.3, the solo). Susan would celebrate the achievements of residents or would give compliments in ways that affirmed a resident's sense of identity. Residents could also be a source of encouragement and support for their peers. It was evident that the inclusion of Dorothy and Rachael had benefited the group sessions. Rachael reassured an embarrassed Annie when she forgot her words in the first poetry session, while Dorothy praised Bessie when she headed the balloon in the first dance therapy activity (textbox 6.4, the balloon). Dorothy unintentionally modelled a movement with the band for Helen to copy (see textbox 6.3, the band). In interviews, Susan and Jane explained that the inclusion of one or more residents who were more competent and confident could be a useful strategy for engagement.

Several practitioners explained how they could sometimes struggle to support residents in groups where residents had conflicting wants and needs. A common example was a resident who had a high desire or need for attention, so that they would want to dominate the session to the detriment of the others. Practitioners explained that they tried to manage the group and accommodate the needs of all residents as best as possible in these situations. Rachael, the music therapist explained that she would sometimes organise a one-to-one session if a resident demonstrated a strong need and desire for her full attention.

Dorothy was not deliberately disruptive, yet she was so enthusiastic that she dominated the first poetry session. Jane had encouraged and supported Dorothy to continue sharing her stories for much of this first session, and it was lovely to see. Yet Dorothy frequently interrupted Jane's interactions with the other residents, wanting to talk more about the war. I noticed a shift in Jane's approach in the second poetry activity, when Jane did not encourage Dorothy to expand upon her responses quite so much. Afterwards, Jane confirmed my observation, explaining that she had wanted to avoid a situation where Dorothy would dominate the group. Jane also explained that she had brought the flowers and fruit as inspiration to avoid any obvious connection to the war. Yet Jane stated that she wanted to find time to sit with Dorothy one-to-one to hear all her stories.

Group size could also impede a practitioner's ability to scaffold. While bigger group sizes were deemed permissible in performance-based activities, in participatory sessions, practitioners tended to prefer working with small to moderately sized groups (between 6 and 15 in this study). Practitioners explained that they could then give individual residents the encouragement and support they needed and could build relationships. Several practitioners explained that group composition also an important consideration here, so that in a group that was largely composed of residents with high support needs, smaller group sizes were needed:

*'About 8 people is the most one can manage of a varied group. Sometimes I'm brought a group of people who have serious difficulties with speech .... 8 people who have got real difficulties - that is too many'*

Kenneth, (Poet)

## 6.6. Context

Three contextual conditions were found to influence the scaffolding process. These were time, the activity environment, and the care home.

### 6.6.1. Time

Time influenced scaffolding in several respects. Time firstly refers to the time a practitioner would spend interacting with a resident during a session. In poetry and dance therapy observations, residents seemed to become more competent through repeated interactions with the practitioner, needing less encouragement and support to engage over time. In the second poetry session for example, Jane initially needed to support residents to explore the fruit and flowers by directing their attention to salient features. Yet with repeated interaction, residents started to examine the fruit and flowers independently, even making unprompted observations (textbox 6.8, the leaf in my hand). The shift from dependence to independence and self-directed engagement was also observed in dance therapy sessions. Zara gave encouragement and support to residents by guiding movements and modelling movements. It was notable that while residents copied Zara's movements very closely initially, over time many of the residents seemed to have internalised Zara's repertoire, so that they were moving freely and needed less encouragement and support. Some of the residents also started to create their own movements. Consistent with scaffolding, residents appeared to internalise the knowledge and skills needed to engage independently with repeated interactions over time.

#### The leaf in my hand

Jane approaches Helen with some fuchsias and kneels in front of her, *'look what I brought Helen, I brought flowers'*! Helen is in a buoyant mood and is laughing to herself. I notice how Jane becomes more animated and joyful as she speaks to Helen - mirroring Helen's mood. Helen is clearly enjoying the interaction with Jane, yet she seems oblivious to the flowers. Jane tries to make Helen aware of the flowers by waving them a little in front of her, before gently brushing the flowers against her hands. Jane then prompts Helen, *'Can you see them if you*

*look down?'* Helen eventually looks but stares blankly at the flowers. Susan, who is seated next to Helen, rubs the lavender between her fingers, inviting her to smell, and asking if it reminds her of anything. Helen smells the lavender and smiles but doesn't say anything. Jane prompts her *'it's lavender'*, to which Helen says quite dramatically *'yes, not bad'*. Jane mirrors her, *'YES, not bad indeed'*. Helen laughs.

Towards the end of the session, Jane brings some Virginia Creeper leaves and places them on Helen's skirt. Helen appears more focused each time she interacts with Jane. This time Helen notices the leaves immediately and picks up a single leaf without any prompting. Helen turns the leaf over, examining it closely before exclaiming, *'oh look, a leaf in my hand, isn't it lovely, so pink'*. After a few moments Helen places the leaf on her knee with great care, saying *'I'll put it there'*.

**Text box 6.8: Narrative description of an observation of a poetry session at Hawthorne House on 18/12/2018**

Time also related to the length of time practitioners had spent working with residents. Several practitioners explained that some residents could be harder to engage than others, but that by working with these residents over a longer time-period, they could sometimes have significant breakthroughs in terms of engagement. Sometimes this was a consequence of experimenting with lots of different offers to eventually find something that appealed to the person. Jane explained that had sessions continued, she would have liked to have developed her approach with members of the group who were less verbal. Jane explained that over time, she would *'make guesses about what might persuade them to talk more'*. When inviting engagement several practitioners explained that they would initially be more experimental in their approach to gain a better understanding of what worked. Over time, practitioners could better tailor invitations to the individual or the group:

*'I was able to develop art that I knew that he would enjoy doing ... but you can only do that if you get to know somebody over a length of time'*.

Julie (Visual artist)

In participatory arts sessions, the idea of working with the same residents over time was also deemed important in terms of developing relationships. In post activity reflections, Zara explained that she was in the early phases of developing relationships with the residents:

*'Relationships are starting to build ... currently it is very surface level... but the longer you work with individuals... the deeper you can go with that... it is about building that therapeutic relationship in order for individuals to feel they can trust you ... and express their emotions.'*

Zara (Dance Movement Psychotherapist)

#### 6.6.2. The activity-space

The activity space could also influence resident engagement and the practitioner's ability to work well. Some practitioners explained that if possible, they preferred working in a more private space without distractions. Others did not mind working in more communal spaces when this meant that other residents could look on. The layout of the space was deemed important for many practitioners who preferred to use a circular seating arrangement. This circular arrangement could help to foster a sense of togetherness and being in a group when residents could see each other and interact with greater ease.

*'Having this circle then becomes valuable ... people can then make eye contact, they can mirror, they can communicate.'*

Ruth (Singing facilitator)

In observations it became apparent that the position and proximity of residents in relation to the practitioner was also an important consideration. In poetry sessions, those with more support needs like Pam, Helen, and Annie seemed to engage more when they were seated beside or directly facing Jane. In the first poetry session, the layout of the room was such that Helen was at the end of a row of seats. The door was in Helen's direct line of vision. Neither

Helen nor Jane could see each other clearly. Helen did not engage much in the session. Yet in the second and third sessions, Helen was seated beside Jane and directly facing Jane. Helen engaged much more in these sessions. Jane reflected after the second activity:

*'(It was) immensely better that she was sitting beside me because I could just look to my side and make eye contact to get her attention.'*

### 6.6.3. The care-home

Finally, the research data indicated that the care home itself could facilitate and constrain the practitioner's ability to do their job. Practitioner explained that 'good' care homes, that cared for their residents and that understood the value of arts activities, were more inclined to cooperate and collaborate. Arts practitioners often had requirements for their sessions in terms of continuity of residents, group size, room layout etc. Cooperation or lack of cooperation, could therefore have a considerable impact on the practitioner's ability to run the session well:

*'The care home can make all the difference ...if they like you and they value it. If they don't, you will have different people each week, and you won't start on time...'*

(Simon, Dance movement psychotherapist).

The research data showed that care homes that were willing and able to work in more collaborative ways, could also have a positive impact on engagement. Several practitioners also explained that care staff could play an important role in recruiting the interest of residents and generating enthusiasm in the lead up to a session. Staff could generate interest by building a sense of anticipation about a session, or by communicating the value of a session. Clarissa, an opera company director for example, explained that staff could build anticipation before her sessions, telling residents that a special performance would be taking place:

*'Some of the places, the residents have been so looking forward to it... knowing that ... it is something really special ...and that builds into an excitement you know'.*

Clarissa (Director Opera Company)

Hawthorne House was a 'good' care home, reflected in a CQC rating of outstanding. Residents were well cared and catered for. Management and staff understood the value of arts activities. Susan was an excellent activity coordinator who loved her residents, something noted by Jane in a post-activity interview; *'They are in a very good care home. It is very caring...Susan is possibly one of the two best activities organisers I've ever come across and she is outstanding'*. The impact that a 'good' care home and a committed activity coordinator could have on sessions was evident during observations. Each week it was clear that the logistics of a preparing for a session were not easy from the perspective of the care home. Susan explained that the care home and residents had their routines, and residents had appointments. Susan invested a considerable amount of time coordinating with care staff to make sure that the six residents had their personal care needs and appointments scheduled around the activity. While Susan insisted that this was entirely possible, I wondered if a less well organised home, or a home that was less invested in arts activities would be as able or as inclined to make this effort.

Several arts practitioners in this study took steps to try to get the commitment of the home. They did this by communicating the purpose and value of their arts sessions with management and care staff, and by inviting management and staff to attend sessions, so that they could see the value of sessions for themselves.

*'We would always want a meeting with the care home management... so you know dropping into the office to say hello and encouraging them to come to sessions'.*

James (Musician)



## 6.7. Conclusion

With reference to the academic literature on scaffolding, this chapter explained why the metaphor of a scaffold was relevant for arts engagement in care homes. Observational and interview data were used to illustrate how social, material, and cultural resources enabled residents to engage more intensively and extensively during arts activities than might otherwise have been possible. The chapter broke down of the overarching process of scaffolding into three sub-processes: (1) inviting and inspiring engagement, (2) cultivating connections, and (3) nurturing change. These subprocesses showed how arts practitioners generated interest and enthusiasm, how they encouraged and supported individual, interpersonal, and collective engagement, and how they enabled change through the relationships they formed with residents. The chapter also revealed how scaffolding was influenced by the following factors: (1) time, (2) the care home, (3) the activity space, (4) practitioner differences, (5) resident differences, and (6) group size and composition.

**Table 6.2: Summary of scaffolding subprocesses and their associated action and interaction strategies**

Subprocess	Category	Action/interaction strategies
Inviting and inspiring engagement	Generating interest and stimulating capacities	<p>Appealing to beauty; Using novelty; Connecting to the familiar (using culturally/personally significant resources).</p> <p>Encouraging sensory exploration.</p> <p>Showing enthusiasm; Communicating value; Building anticipation; Arousing curiosity.</p>
	Getting the fit right	<p>Using diverse and multifaceted opportunities; Using a multisensory approach; Experimenting; Tailoring.</p> <p>Creating open-ended opportunities: Inviting and supporting choice; Taking inspiration/following; Allowing for interpretation/experimentation.</p> <p>Appropriate challenge</p>
	A gentle persuasion	<p>Foot-in-the-door; Communicating benefits; Being playful/using humour; Using flattery/focus on past success; Appealing to need.</p> <p>Giving a nudge/coaxing/direct encouragement.</p>

Cultivating meaningful connections	Creating a facilitating environment	Extending/expanding relevant opportunities; Rearranging the space; Matching (emotions, moods, energy); Holding space.
	Encouraging and supportive interactions	<p>Withholding/giving time; Encouraging more (movement, feeling, thought). Affirming contributions; Giving reassurance/being a reassuring presence.</p> <p>Intensifying support: Simplifying tasks; Modelling/demonstrating behaviours; Physically holding/ guiding; Making suggestions; Giving prompts; Directing attention.</p> <p>Tapering support/Stepping back.</p>
	<p>Cultivating connections in the group</p> <p>Cultivating personal connections</p>	<p>Directing attention (to a resident); Turn-taking; Highlighting common ground; Modelling interactions; Dropping out (of the group).</p> <p>Noticing and reflecting (personality, identity, likes/dislikes, beliefs); Joining- in; Mirroring (words, facial expressions, body language, actions); Turn-taking; Sharing/finding common ground; Giving personal attention; Using eye contact and proximity.</p>

Nurturing change	Communicating value	Recognising contributions; Celebrating achievements; Communicating appreciation- giving thanks; Complimenting the person/ affirming identity.
	Communicating understanding and acceptance	Acknowledging (feelings/frustrations/challenges); Validating feelings; Accepting- not correcting; Validating contributions.
	Communicating deep admiration and care	Showing affection/love; Providing reassurance and comfort.

# Chapter 7: Findings 2: Causal Conditions and Consequences of Scaffolding

## 7.1. Introduction

Chapter 6 provided an account of the core category of scaffolding. The usefulness of scaffolding as a metaphor for arts activity engagement in dementia was discussed and was supported by the research data. The subprocesses of scaffolding, and the action and interaction strategies associated with scaffolding were detailed, as well as the conditions and contextual influences that shaped, facilitated, and constrained the scaffolding process. This chapter will focus on the causal conditions (box a) and consequences of scaffolding (box f), as illustrated in figure 6.1 (chapter 6).

## 7.2. The Causal Conditions of Scaffolding

Causal conditions refer to the influences that contribute to the development of the core phenomenon. Four conditions were identified as fundamental to scaffolding in this study: a safe and supportive space; the availability of meaningful engagement opportunities; a thoughtful and responsive approach; and authentic and nurturing relationships. Each of these categories will now be examined in turn.

### 7.2.1. A Safe and Supportive Space

Arts practitioners explained that activities had the potential to be stressful and anxiety provoking for some residents. Some stated that anxiety could stem from nervousness about the unknown. Residents could become unsettled if they were uncertain of what was happening or when they were unsure of what to expect. Some explained that residents could have concerns about their ability and what would be expected of them. Anxiety could stem from negative prior experiences of the arts, often from school. Several stated that the social

nature of group activities could be anxiety provoking for some, while some residents could become overwhelmed in a loud and busy arts space.

To avail of engagement opportunities, arts practitioners wanted residents to feel safe and at ease. A range of strategies were adopted with the aim of creating a safe space for engagement (see table 7.1 for a summary). Practitioners explained that they tried to create a relaxed, non-pressured environment. Practitioners did this by adopting a failure-free approach – there was no right or wrong way to engage in their sessions. In dance therapy sessions Zara always started the activity by explicitly telling residents this, assuring residents that they could engage in any way they pleased (textbox, 7.1, making choices). Some practitioners talked about the importance of not being coercive and giving a more reluctant resident time to engage on their own terms. In phase-1 data collection, Julie, a visual artist, had described the importance of using non-dominant body language with residents; *'You're sitting down next to them if they're sitting, you're never standing over somebody, that's daunting I think'*. In dance therapy and poetry observations I noticed how Zara and Jane adopted a friendly and non-threatening demeanour during interactions, often sitting on the floor or crouching beside residents. Susan the activity coordinator explained that, in her experience, residents tended to be more comfortable and responsive with practitioners who were mindful of their body language in this way. Finally, some arts practitioners tried to create a relaxed and non-pressured environment by transitioning or easing into their sessions, chatting with residents, or starting with something easy to help residents feel comfortable:

*"The Yorkshire Sculpture Park. Forget about it being a sculpture park. Yorkshire. What do we know about Yorkshire? ...Yorkshire tea, Yorkshire puddings .... it's getting them to feel comfortable... building the bridge if you like to the creative arts bit'.*

Gavin (Visual artist)

Practitioners also managed anxiety by instilling residents with a sense of control. Some reminded residents of their choice to engage as they wanted and to leave if they preferred. Zara frequently reminded residents of their choice in her dance movement sessions (textbox, 7.1, making choices). Some practitioners instilled a sense of control by allowing residents to

keep their distance so that more nervous residents could sit at the back of the room or on the periphery where they could watch at a safe distance:

*'There might be people who are sort of outside the circle ...they want to be far away because they may be a bit nervous ...then one week they'll eventually kind of come in'*

Kelly (Dance Movement Psychotherapist)

### Making Choices

In the second dance therapy session and Rachael, Bessie, and Annie are notably tired. Annie seems particularly tired, and Zara spends some time with her at the start of the session, explaining that she should just rest as she needs to. Zara makes it clear that the session belongs to residents, and that they should do what feels right for them. Zara always explains at the start of a session that there is no right or wrong way to engage, yet I notice that Zara takes extra care to remind residents of the optional and flexible nature of engagement in this session. Zara suggests that residents can watch or listen or sleep if they prefer.

After several songs, Zara opens-up the session and invites ideas for songs, dance moves or themes. The group is silent. Zara asks Rachael if she would like to make a song choice. Rachael looks a little fretful and weary and says she cannot think of anything. She apologises for her lack of enthusiasm. Zara warmly assures Rachael that she is joining in simply by being there, and that she should rest if she needs to. Rachael seems to visibly relax. Zara opens-up to the group again, asking for ideas for a dance movement this time. After a lengthy period of silence, Dorothy offers an original dance movement, clasping her hands and making the shape of a star. Zara says that she loves this movement and asks the group what song they would like to hear. After some time, Dorothy suggests *In the Mood* by Glen Miller. This seems to be a popular choice. Annie starts to tap her hand to the music, with her eyes closed. Zara and Susan copy Dorothy's star movement. Rachael's mood seems to lift as she watches Dorothy and the others dance.

Dorothy declares that *In the Mood* was used to lift spirits during the war and starts to reminisce. Zara lets this go on for a while before suggesting that the group might like to hear a war song. There is a period of silence before Rachael suggests *'It's a Long Way to Tipperary'*.

The group sing this together with gusto. The war theme continues with *Pack up your troubles; There'll be Bluebirds Over* (chosen by Rachael); and *Wish Me Luck*, with time for talking and sharing between songs. Annie has been resting with her eyes closed, but she joins in the singing. For *Wish Me Luck* Zara kneels in front of Annie, and gently strokes her hand with a scarf. Annie opens her eyes. They smile warmly at each other and sing together.

Engagement has been exceptionally high for nearly everyone during this war segment. Rachael's mood and engagement has shifted substantially. Almost everyone has been singing, and Dorothy has enjoyed giving a commentary about the war between songs. I notice how Zara has dipped in and out of the group for this segment. At times, she sits out of the circle. The residents seem to focus more on each other (as opposed to Zara) when this happens. There seems to be a real sense of togetherness in the group.

Bessie is the only member of the group who has not engaged with the singing and she seems to have slept throughout. Yet when Zara comments on this, Bessie opens her eyes and informs us that she has been listening.

**Text 7.1: Narrative description of an observation of a poetry session at Hawthorne House on 08/12/2018**

Practitioners who felt that nervousness could stem from the unknown, tried to make residents feel more comfortable by reducing levels of uncertainty. Some explained that they would take time to introduce themselves and explain what would happen in the session. Zara needed to re-introduce herself to Bessie several times in dance therapy sessions (textbox, 6.4, the balloon). Some practitioners who worked with residents on a more regular basis said that they would use a recognisable structure so that sessions would feel familiar to residents. This sense of familiarity could help residents feel at ease:

*'You do go through the same process each time and that develops a sense of familiarity, a kind of rhythm and a pattern that people can identify and get used to... the more things can be expected... the safer the environment is.'*

Michelle (Activity kit developer and trainer)



Yet the research data showed that arts practitioners were not creating a safe environment so that residents would participate in a predetermined way. They were creating a safe and supportive space so that residents would feel free to express themselves and to engage in ways that were meaningful to them. They were creating a safe and supportive space where residents would feel welcomed and accepted for who they were. Practitioners understood that residents would all engage and choose to express themselves in different ways. This meant that they practiced non-judgement and showed unconditional acceptance; *'I just love the people I work with even those who are disruptive. Even the lady who was disruptive... I thought she was wonderful'*. (Kenneth, poet). It meant that they welcomed and valued diversity of expression:

*'It might be that there are some people in the group who are doing lots....it might be that another person is just sitting very quietly and taking everything in, and that is seen as equal in terms of value'*

James (Musician)

Finally, the notion of a safe space also applied to arts practitioners themselves. Arts practitioners explained that they needed to feel relaxed and at ease in a session. Some practitioners explained that they allowed themselves time to ease into their sessions, and to feel comfortable in the care home environment and with residents. Some said that working to a loose plan could be helpful when a plan could give some sense of control in a session.

*'It's helpful to have a structure...partly it's about what makes me feel comfortable because I've learned that if I don't feel comfortable then the session won't work.'*

Kelly (Dance Movement Psychotherapist)

While practitioners took action to create a safe and supportive environment, the importance of this was stressed more by those who ran participatory arts activities. In participatory sessions residents were being invited to actively participate and there was a perception that

this could be anxiety provoking for some. Yet performers also explained the importance of being sensitive to resident comfort. Claudia, the cellist, offered performances in a resident’s bedroom if the resident experienced social anxiety. Rhonda (an artistic director for a theatre company), explained how she took time to introduce her show and to explain what would be happening to more nervous residents. Clarissa, an opera company director, explained how she was mindful of overstimulation, when residents could become overwhelmed by singing during a performance.

**Table 7.1: Summary of action and interaction strategies to create a safe and supportive space.**

<b>Causal condition</b>	<b>Category</b>	<b>Action/interaction strategies</b>
A safe and supportive space	Taking a gentle and relaxed approach	Transitioning/easing in; Giving time and space; Adopting a failure-free approach (no right or wrong); Using non-dominant body language.
	Instilling control	Reminding of choice; Having a safe zone/keeping a distance.
	Reducing uncertainty	Using a recognisable structure; Introducing oneself and the session.
	Being inclusive	Welcoming and valuing diversity of expression; Being non-judgemental; Respecting choice.
	Feeling safe	Having a plan; Easing in

## 7.2.2. Meaningful engagement opportunities

To encourage and support engagement, practitioners needed to generate meaningful engagement opportunities, that were attractive, accessible, and actionable. Table 7.2 contains an overview of the strategies used by arts practitioners to create meaningful engagement opportunities. Practitioners explained that their ability to create such opportunities depended to a large degree upon their repertoire. Repertoires included the songs, poems, materials, images, tools, ideas, objects, props, games, activities, skills, techniques, approaches etc. that practitioners had at their disposal. The development of a varied, extensive, and attractive repertoire was considered a useful strategy for engagement.

Many practitioners spoke of the importance of diversifying their repertoire to accommodate for different abilities, interests, and limitations. Ruth the singing facilitator had more cognitively demanding activities (e.g. sequence songs) in her repertoire to challenge residents who were more able. Julie, the visual artist, had acquired special paintbrushes that she used to support the creativity of residents with very advanced dementia; *'You don't need to dip the brush into the paint, they are paintbrushes where the paint is actually in the brush'*. Claudia the cellist made sure that her musical repertoire could cater for a broad range of interests so that her collection included wartime songs, classical music, songs from operas and ballets, childhood songs, folk music etc. Louisa the drummer had different instruments or various shapes and sizes that could accommodate for different abilities:

*'Some of it is about your repertoire of resources... make sure you've got something for people with greater and lesser physical ability and concentration sustainability... it's also about having a repertoire of games and approaches'*

Louisa (Drummer)

Arts practitioners in this study came to the field with well-developed repertoires that had been acquired through their professional training and experience. Yet practitioners also continued to develop their repertoires over time. Some expanded their repertoires by consulting with residents about their interests. Claudia the cellist for example explained that she was in the process of adding songs from the musicals and hymns to her repertoire after discovering that

residents particularly enjoyed these genres of music. Some practitioners explained that they were always on the look-out for things to add to their collection. Jane the poet for example explained that she would rummage through her garage and home to find items that might be of interest to residents. Louisa the drummer described how she had learned a trick from a science teacher that she planned to show residents. Some practitioners explained how they would incorporate new approaches into their repertoires by trialling them to see how residents responded. Some practitioners expanded their repertoires by developing their cultural awareness. When working with a resident from Africa, Simon the dance movement psychotherapist spoke with the gentleman's family to grow his collection of African songs. Zara was well-versed in songs that were culturally significant for residents, including songs from the war, while Jane's knowledge of rural life and cultural practices and customs meant that she was able to converse with the group about Shire horses and Rag and Bone men.

*'It's about making yourself au fait with certain aspects of life and culture'*

Gavin (Visual artist)

Several practitioners commented that quality was also an important consideration when developing a repertoire. Some held the belief that activity provision in care homes could be substandard and patronising when low quality or childish materials were used and when sessions were 'dumbed down'. To counter this, practitioners explained that they sourced quality materials and invested resources (time, talent, and money) in their sessions. One practitioner commented that she gave the best performance she could because residents were deserving of the very best.

*'We want it to be a professional performance because I believe we often dumb things down for people we think are not capable. I wanted to challenge things a bit more. I really wanted quality performers, in terms of the operatic output. They needed to be good singers.'*

Clarissa (Director Opera Company)

A varied, extensive, and attractive repertoire meant that practitioners had more options to draw upon to engage residents and to accommodate for different abilities and limitations. Yet practitioners could also make opportunities more accessible and more appealing when they communicated in clear and compelling ways. The importance of verbal and non-verbal communication was evident during poetry and dance therapy observations. Zara and Jane spoke clearly and projected their voices well to the group. When engaging the group, they usually positioned themselves so that residents could hear them and see them (though Helen could not see Jane, nor Jane Helen in the first poetry session). When speaking, they also made use of gestures, body language, tone of voice, and facial expressions to communicate. Yet they were also compelling communicators and made opportunities seem fascinating or fun. (see the jam, textbox 7.2).

**Table 7.2: Summary of action and interaction strategies used to generate meaningful opportunities.**

Causal condition	Category	Action/interaction strategies
Meaningful engagement opportunities	Developing a varied, extensive, and attractive repertoire	Drawing on professional training and experience; Diversifying resources; Developing cultural awareness; Consulting with residents; Acquiring new ideas and resources; Trialling new approaches.  Sourcing quality materials; Investing resources (time, talent, money)
	Being a clear and compelling communicator	Being expressive (body-language, gestures, facial expressions, intonation, sounds); Positioning; Pacing communications; Projecting.

### The Jam

Just over half-way through the second poetry session Jane takes a quince from her basket and gives it to Rachael who holds it up for inspection, examining it with apparent fascination.

Dorothy interrupts to ask where the quince comes from. Jane replies that while she isn't sure, she thinks it possibly originated in Europe. Jane hands Dorothy a quince, before inviting her to smell it and share her thoughts. Dorothy states that while it reminds her of something, she *'can't christen it'*. Jane exclaims that this is a wonderful expression and writes it in her book. Dorothy seems chuffed with herself. Dorothy is clearly still thinking about quinces when she loudly declares that *'in the Mediterranean they are this big!'*, indicating an improbably large quince. Jane accepts Dorothy's unlikely assertion and says that she hasn't seen these very large quinces herself. Dorothy confirms that she has and proceeds to ask Jane a series of questions about her garden, where she lives etc. Jane always indulges Dorothy's curiosity.

Jane takes two quinces to Bessie and explains what they are. Jane asks Bessie if she can put one in each hand before asking what she thinks. Bessie doesn't reply but she is laughing and seems amused by the weight of the quinces, holding them in front of her. Jane explains that her garden has a tree that grows quinces and that she uses them to make jam. Pam is watching intently. Jane seems to notice this and so she turns to face the group, speaking loudly for all to hear. Holding a quince in the air Jane demonstrates how the wind had blown the fruit from the tree so hard that it hit the ground with a *'thud'*. Jane then demonstrates the vigorous sawing action she used to cut the quinces with *'a great big knife'* describing how they made a *'squeak squeak'* noise. Jane mimics the various noises as tells the story. She describes the lengthy boiling process, how she dripped the liquid into a jam jars using a muslin cloth, and the wonderful ruby red colour of the jam, (showing a picture to the group). Jane is a clear and compelling communicator. She is vivid in her storytelling and uses her body, the quince, images, and her speech to communicate with the group. Dorothy and Rachael seem to be fascinated by the jam-making process, making comments like *'how interesting'*. While it is not clear that the others follow Jane's story to the same extent, Pam, Bessie, and Annie all watch and laugh as Jane demonstrates her sawing motion and the *'squeak squeak'* noise of the quinces. Helen laughs heartily when Jane dramatically describes the thumping noises of the falling quinces.

**Text box 7.2: Narrative description of an observation of a poetry session at Hawthorne House on 18/12/2018.**

### 7.2.3. A thoughtful and responsive approach

Arts practitioners in this study were thoughtful and considered in their approach. In interviews, practitioners demonstrated clarity of vision and purpose and were able to articulate their intentions well. Practitioners also reflected on their approach to sessions. Some practitioners explained how they prepared for activities by making a loose plan. This helped them to incorporate different elements in their sessions to be inclusive. It also helped them to work to their goals. A more structured and somewhat planned approach contrasts with the highly improvised approach that was described by James, the musician. Yet James was still being thoughtful and intentional. Equality and agency were key priorities in his practice. By approaching sessions in an open way, James created space for residents to initiate and take the lead if they desired to do so.

All practitioners put some degree of forethought into their activities. Many practitioners also had preferred ways of working (e.g. maximum group size, room layout, care staff support), so that planning and preparation could also involve the care home. Yet while practitioners could prepare for sessions, they explained that they also needed to be responsive to the care environments they worked in. Care homes were busy and complex and unpredictable places where anything could happen. Practitioners explained that they needed to stay flexible and adaptable when working in these settings. Ruth, the singing facilitator for example, explained that while she had certain ideals for her sessions, care staff could be overworked and unable to accommodate her requests at times, or the activity spaces in care homes could be less than ideal. Ruth explained that she had learned to adapt and work with the situation that presented itself on the day. Louisa the drummer explained that unexpected situations, such as an emergency or bereavement in the home could crop up, causing her to abandon her plans when she felt that a loud drumming session was not appropriate. Gavin, the visual artist, explained that his sessions would frequently be interrupted when family arrived or when residents needed to be taken for appointments, so that he had to allow for this. To stay responsive in these settings, practitioners spoke of the need to manage their expectations of the care home and to accept a degree of uncertainty.

To optimise engagement, practitioners also explained that they needed to be responsive to the residents they worked with. Practitioners needed to have room in their plans to improvise and adapt. Practitioners also spoke of the need to accept the unpredictability of resident

responses, and to manage any expectations about what engagement should look like or what should happen in a session. Some practitioners explained that they had learned over time to relinquish the need to control what happened in a session, to go with the flow, and to be receptive to what residents wanted to do:

*'In care homes often spaces will arise where people will start talking or reminiscing and you have to allow for that much more ... there's no expectation you know that, oh we're here to sing...it's more dynamic. It's more geared around who is there and what arises within that space'.*

Ruth (Singing facilitator)

To be responsive to residents, practitioners also needed to understand the needs and desires and beliefs of those they worked with. Practitioners did this in several ways. Some felt that basic dementia awareness training helped them to understand needs in dementia to support residents. Arts therapists all drew upon theoretical knowledge to understand and support residents (e.g. attachment theory). Everyone who was asked in this study engaged in consultation with care staff about residents to anticipate needs and/or interests. Yet there were differences. Some sought only basic information that allowed them to anticipate support needs relating to mobility or sensory impairments. Others sought more information. Rachael the music therapist consulted with care staff and care plans to form an understanding of residents and to gain insights about what sort of music they might like. Julie, the visual artist, sought information about health and dementia diagnoses and symptomatology where possible, finding that this information helped her to better support residents. Julie also sought information about behavioural issues because she had been hit by residents in the past.

Interestingly, several practitioners expressed reservations about prior consultation with staff (or family) beyond basic health information. These practitioners stressed that they wanted to respond to the person, and not to judgements or labels or assumptions about the person. Some had found that information about residents had been unhelpful or misleading in the past, claiming that care staff (and family) could misjudge the things a resident would enjoy or be capable of. Others felt that information could affect how they would interact with someone who was labelled as difficult or aggressive, when they would become guarded in their



interactions. One practitioner was particularly angered by the suggestion of attaining knowledge of a resident's dementia diagnosis or symptomatology, stating a need to see the person and not the dementia. Regardless of a practitioner's beliefs, those who consulted or made a deliberate choice not to consult extensively with staff or family, did so because they wanted to be responsive to the person. Moreover, those who did consult gave precedence to their own experience, acknowledging that information could be unhelpful at times:

*'I was told all sorts of things about what she liked... and what we found over the weeks is that there doesn't seem to be any predictor of what she's going to respond to... all these things are just kind of clues...'*

Rachael (Music Therapist)

Interestingly, there was greater consensus around consultation with staff to interpret resident behaviour. Biographical information could sometimes help a practitioner interpret a resident's responses in a session. By way of example, upon learning that a lady who had been wrapping her in scarves had been a dressmaker, Kelly was able to make sense her behaviour, and encouraged and supported more of this in subsequent sessions. Rachael the music therapist discovered that a gentleman she worked with had been a boiler engineer. Rachael explained that knowing piece of information helped her to make sense of his behaviour when he started to dismantle an instrument; *'being able to interpret you know what he was doing, instead of just thinking, oh he is just taking the instruments apart, he's obviously destructive and not interested'*. Consultation with staff could also help practitioners to interpret subtle behaviours that could seem insignificant or ambiguous when they did not know a resident (especially in advanced dementia). In these instances, care staff could provide useful insights about what a meaningful response looked like for a person.

*'I get told, Mrs A looked up at you and made eye contact, we are blown away ... to me I wouldn't think that that was an unusual response- but then I don't really know the person'*.

Louisa (Drummer)

All practitioners in this study stressed the importance of forming an understanding of residents by attending and attuning to resident responses in a session. Practitioners described how they were constantly attending to the verbal and non-verbal cues that were given by residents to understand what residents wanted or needed. With repeated sessions, practitioners explained that they could get to know residents over time. Several practitioners explained that they would reflect after a session about what had worked well and less well. In doing so, practitioners could anticipate needs and desires and speculate about what approaches might be effective in future sessions.

To be responsive to the wants and needs of residents, several practitioners also talked about the importance of understanding themselves. Practitioners used self-reflection in slightly different ways. Kelly, the dance movement psychotherapist, and Rachael, the music therapist, both gained insights about how residents were feeling by paying attention to their own emotional reactions during activities. Some practitioners used self-reflection as a way of identifying their weaknesses and areas for improvement. Claudia the cellist recognised that her need for approval was a barrier in her practice when it caused her to react more favourably towards some residents than others. Lisa the opera singer reflected her personal barriers to connecting with residents, explaining that she did not always find it easy to connect in more intimate ways. Ruth, the singing facilitator, and Elizabeth, the dance practitioner both engaged in self-reflection during a session to ensure that they were being truly responsive to residents and not acting out of their own desires. Elizabeth for example explained the need to check that she was not acting out of her own ego and desire to show off. In dance therapy observations, Zara explained that she would have loved for Helen to have engaged more with the dance-movement aspect of her sessions. Yet Zara said that she needed to reflect on this, recognising that this was her desire and not necessarily Helen's. Zara encouraged and supported Helen to do what she seemed to enjoy most – sing (textbox 7.3, the Solo).

*'It's also about recognising your own feelings, not acting out of your own feelings... so you're acting in light of the individual that you are meeting, rather than your own perspective of what do I want to achieve for that person'*

Ruth (Singing facilitator)

## The Solo

Helen has had her eyes shut for some time when she spontaneously starts to sing a tune 'la la la la'. Zara stops what she is doing, and watches Helen – trying to work out what the song is, before turning to Susan to ask if she knows it. Susan says it's Underneath the Arches. Susan who is a fabulous singer, starts to sing the chorus. Dorothy joins in. Helen still has her eyes closed, yet she starts to sing the words. Zara lets the singing continue and looks for the song in her collection, before playing it for the group. When the song ends, Helen continues to sing with gusto, but on her own this time. Everyone is watching her. Helen stops, and most clap and cheer. Helen opens her eyes and looks round laughing – *'it's brilliant, it's absolutely brilliant'*.

**Text box 7.3: Narrative description of an observation of a dance therapy session at Hawthorne House on 01/12/2018**

Finally, to remain responsive, practitioners needed to be somewhat resilient. Several practitioners explained that they could be emotionally impacted by the nature of their work; *'If you are a softer soul, you probably are going to take on stuff and that can become too much.'* (Clarissa, director opera company). Some stressed the tiring nature of their work when they needed to be constantly vigilant and responsive to residents; *'We are emotionally exhausted. You just need to give them 100% focus and attention, that it is exhausting'*. (Rhonda, artistic director, theatre company). One practitioner stated that sessions did always go as well as she would have hoped. To cope with these challenges and to stay responsive, some practitioners talked about the importance of self-care. Rachael the music therapist took time between her sessions to unwind and regenerate. One practitioner spoke about the importance of practicing self-compassion and learning not to be so hard on herself when a session had not gone as well as she would have hoped. One practitioner practiced self-care by talking about the emotional impact of their work with a counsellor. Some spoke about the value of a support network or mentorship or supervision to share challenges – emotional or otherwise. Table 7.3 contains an overview of the strategies used by practitioners to ensure a thoughtful and responsive approach.

*'You can't not be emotionally affected by doing this work. You need to realise that and get support of some kind'*.

**Table 7.3: Summary of action and interaction strategies used to develop a thoughtful and responsive approach**

Causal condition	Category	Action/interaction strategies
A thoughtful and responsive approach	Being intentional	Reflecting on purpose and approach; Preparation and planning, Liaising with the care home.
	Staying Flexible/ Being Adaptable	Room to improvise and adapt; Managing expectations; Accepting uncertainty; Relinquishing control (going with the flow).
	Forming an understanding (self and others)	Training and development; Consulting with care staff; Drawing upon relevant theories; Getting acquainted; Attending and attuning to resident responses. Post-activity reflection.  Self-reflection
	Developing resilience	Practicing self-care; Getting support (e.g. mentorship, supervision)

#### 7.2.4. Authentic and Nurturing relationships

Authentic and nurturing relationships were also fundamental to an effective practice. An overview of the actions that underpinned these relationships is shared in table 7.4. The word authentic captures the deep and genuine care and respect that practitioners had for residents. Practitioners explained that they had great admiration for the people they worked with; *'they're still valuable as a person and they are still very precious'* (Claudia, cellist), and a genuine care and interest in residents as persons. Moreover, relationships were authentic in the sense that practitioners claimed that their lives had been enriched by residents. In observations, the deep care that Zara and Jane had for residents was evident. Both practitioners claimed to derive immense benefit and satisfaction from their interactions with residents. Residents seemed to recognise and respond to this (textbox 6.6, the horse bridle, part 2). Some practitioners explained that their interactions with residents involved an opening up to each other. Gavin, the visual artist, explained that an exchange of information was essential to build trust. In poetry and dance therapy I saw how Zara and Jane were both open and willing to share things about themselves with residents. Both also took time to answer Dorothy's repeated questions (textbox, 7.2, the jam; textbox, 6.2, the horse bridle, part 1).

*'It's love, and if you haven't got that and it's just mechanical, then you might as well go home'.*

Kenneth, poet

The relationships described by arts practitioners were also nurturing ones. The word nurture means to care for and protect something while it grows and captures how practitioners helped residents to reach their potential by exposing them to opportunities for growth and change, in the context of a secure and supportive relationship. Arts practitioners in this study believed in the potential of residents, and felt that with the right opportunities and support, residents were still very capable of thinking, feeling, and acting, contributing to others, and reaching their potential:

*'It's acknowledging that somebody still capable of development, because you know people with dementia can do some amazing things.... it's finding ways to enable them to do that'*

Ruth (Singing facilitator)

Practitioners in this study did not dwell on limitations, but instead looked for possibility and potential. Many explained that different forms of engagement, including creative engagement, were still very possible even in advanced dementia. In seeing possibility and potential, practitioners continued to find ways to encourage and support engagement and change. In seeing residents as capable and recognising capabilities, practitioners encouraged residents to use their capacities and reach their potential. Finally, practitioners demonstrated their belief in residents when they showed commitment and persistence. Several practitioners described how they continued to expose residents to opportunities, even when previous attempts had been unsuccessful, or when it was unclear that a resident was benefiting from a session.

*'You don't know, you might be getting through. It's like singing to someone who is dying isn't it? They might be hearing me, they might not, but they are worth the effort aren't they?'*

Lisa (Opera singer)

**Table 7.4: Action and interaction strategies to develop authentic and nurturing relationships**

Causal condition	Category	Action/interaction strategies
Authentic and nurturing relationships	Valuing the person	Seeing the person; Being interested; Being open– a willingness to receive and share.
	Believing in the person	Seeing possibility and potential; Recognising capabilities; Being committed and persistent.

### 7.3. The Consequences of Scaffolding

Four consequences of scaffolding were identified from the research data. These consequences were: being in the world; an enhanced sense of self; a sense of belonging and attachment; and a sense of wellbeing.

Being in the world is intended to capture how arts sessions encouraged and supported residents to connect with their capacities for engagement and to engage with the world around them. Residents could more fully experience themselves as thinking, feeling, and acting persons. They could: feel emotions more deeply; fulfil their creative potential; experience sensory pleasure; express themselves more fully; explore their imaginations; reminisce; engage their minds; and connect with their bodies. They could communicate and interact with others.

*'It's trying to waken things up again ... to stimulate to make people feel more alive'*

Elizabeth (Dance practitioner)

Residents could also develop an enhanced sense of self through arts activities. When residents could use their capacities and fulfil their potential, some practitioners explained that residents could surprise themselves by what they were capable of. Residents could experience a growth in self-confidence. A sense of self-worth and self-confidence could be further enhanced when practitioners (and others) made the effort to recognise and compliment residents on their accomplishments. During observations I continually noticed how residents looked pleased and proud when they were recognised for their achievements in the group activities. A resident's sense of self could also be enhanced when they were recognised and respected as an autonomous and unique individual. Practitioners in this study respected the choices a resident made. They recognised and reflected things about the person. Practitioners also explained that a resident's sense of self-worth could be enhanced when they felt significant to others. Residents could make contributions in a session. Practitioners also explained how their lives were enriched by their interactions with residents. Sessions were an opportunity to show residents how wanted and needed they were.

A further consequence of scaffolding was the sense of belonging and attachment that could result. Practitioners explained how residents could experience a sense of togetherness when they participated in group sessions; *'it can bring people together...I've seen friendships develop'* (Kenneth, poet). Several practitioners explained that arts sessions had the potential to enhance relationships beyond the activity, by encouraging and supporting family and care staff to find new ways of relating to residents. Some practitioners described how the relationships they developed with residents over time could be a source of intimacy, comfort, and emotional reassurance for residents, so that residents could feel a sense of closeness with another person, and able to share their troubles.

Finally, improvements in resident wellbeing were a potential consequence of scaffolding. The ability to engage in activities could be a source of great joy for residents. Mood was certainly enhanced during dance therapy and poetry observations, and this was evidenced by the laughter and playfulness that often filled the room. Residents also articulated their joy at times, with Helen declaring; *'We are having a good time here aren't we!'* (see Making moves, textbox 6.5). In observations, the mood could be buoyant at times, yet at other times, residents seemed to experience a sense of relaxation and contentment. Annie for example, seemed soothed at times when she listened to Jane read her poems, or when Zara would gently stroke her hand with a scarf.

Improvements in wellbeing could also result for those who were anxious or frustrated or angry. Arts activities could be a safe and facilitating space where residents could express their emotions. Music, images, and materials could be used to soothe those who were anxious or to enable relaxation for those who were stressed. Therapeutic relationships could enable residents to unburden themselves from their worries, or activities could simply provide a nice distraction. Dorothy seemed to confirm this in one of the dance therapy sessions:

*'If anybody has a worry, they bury it... it takes your mind off .... most don't have worries, but somebody could be short of money, short of brains ... but we enjoy your company – come again!'*

Dorothy, Resident, Dance therapy observation at Hawthorne House.



## 7.4. Conclusion

This chapter presented the causal conditions and consequences of scaffolding. Observational and interview data were used to demonstrate four causal conditions that were essential to scaffolding: (1) a safe and supportive space; (2) the availability of meaningful engagement opportunities; (3) a thoughtful and responsive approach; and (4) authentic and nurturing relationships. Examples from interviews and observations were also used to demonstrate the consequences of scaffolding: (1) being in the world; (2) an enhanced sense of self; (3) a sense of belonging and attachment; and (4) a sense of wellbeing.

## Chapter 8: Discussion

### 8.1. Introduction

The research question guiding this study was: *'How do arts practitioners engage the person with dementia in a care home setting?'* In the previous two chapters, findings from the investigation were presented in the form of a grounded theory. This chapter will provide a focused discussion about the more noteworthy aspects of the theory and will consider how the theory relates to existing research. Three major areas of importance will be discussed: (1) engagement, (2) scaffolding, and (3) person-centredness. Future avenues of research will be identified, and the chapter will end with a discussion of the strengths and limitations of the research.

### 8.2. Engagement

#### 8.2.1. Engagement as a process

The lack of research examining engagement as a social process provided some of the impetus for this study. Yet while outcomes focused research has dominated the arts and dementia field, some studies have considered arts engagement as a process. It therefore seems important to consider how my findings relate to these studies. In chapter two, Kontos et al. (2017), and Pavlicevic et al., (2015) described and advocated an improvised approach, so that engagement was a synchronous and emergent phenomenon that manifested between arts practitioners and residents in unpredictable ways. More recently 'co-creativity' has been an emerging concept of interest in the arts and dementia field. Zeilig et al., (2018) explain that the term signifies a *'democratic and non-hierarchical notion of creativity'* (p.138). It is characterised by improvisation, shared leadership, and the absence of a pre-determined plan (Zeilig et al., 2018 & 2019). Those who advocate for this way of working seek to create a 'level playing field', where people with dementia are in control and recognised as creative agents and equals in the creative process (Zeilig et al, 2018). Given the trend towards more 'co-creative' working styles, findings in this study need to be considered against the notion of co-creativity.

Following the definition offered by Zeilig et al (2018), some arts practitioners in this study took what could be described as a 'co-creative' approach. These practitioners had a very open-ended way of working, so that activities (or parts of activities) were undecided and highly improvised. Crucially, persons with dementia were explicitly or implicitly invited to take the lead/take control. For instance, Zara demonstrated a democratic leadership style when she repeatedly asked residents what they wanted to do, and when she followed Helen's lead each time she burst into song. Consistent with the findings of Zeilig et al. (2018) findings supported claims that persons with dementia can be capable of taking the lead. Moreover, the opportunity to do this seemed to have a positive impact on engagement (see Making Choices, textbox 7.1; the Solo, textbox 7.3).

Yet more practitioner-led and pre-determined approaches were prevalent in this study. Kontos et al. (2017), have been particularly critical of more structured approaches, claiming that they overlook creative capacities, '*thwart creative expression*', and deny agency in dementia (p.60). Based on findings in this study, I would argue that this is not necessarily the case. It seems that arts practitioners can adopt a leadership role, have a plan, and set a defined task or theme for an activity, while still allowing freedom and space for creative self-expression. By way of example, Julie the visual artist set the defined task of making masks, yet residents were still free to make choices and to experiment with different approaches. Furthermore, all practitioners in this study acknowledged agency by respecting a resident's right to engage (or disengage) as they pleased.

This study also indicates that co-creative approaches are not without their challenges. It seems that opportunities to take control might cause anxiety for some. During observations for instance, Rachael seemed to experience some embarrassment and uneasiness at first when she was asked to make choices for the group. Findings therefore suggest that practitioners adopting this working style might need to be mindful of potential overwhelm to give direction if needed. Indeed, some practitioner accounts suggest that more structured and practitioner-led approaches might provide a sense of reassurance when residents feel guided and supported and when they know what to expect. This is consistent with the findings of Broome et al, (2019) who found that repeating structures or a familiar pattern to sessions could lessen participant anxiety. It also seems important to note that interview data revealed that working without a plan could be daunting and unrealistic for some practitioners, and especially for those with less experience.

While pre-planned approaches were prevalent in this study, some flexibility, and a willingness to follow a resident's lead, were still considered important features of an engaging arts session. It therefore seems while more pre-planned activities can still be engaging, practitioners should not be too dominant and too prescriptive about what happens. This finding is supported by Robertson and McCall (2020) who noted a detrimental impact on engagement when '*facilitation was too rigid*', and when a resident's input was downplayed or ignored if it was perceived as '*going off task*' (p.1166 & p.1167). Similar insights were offered by Byrne and MacKinlay (2012).

### 8.2.2. Engagement as an outcome

Chapter two revealed that engagement outcomes are often used to judge the efficacy of arts programs. The prevalence of high intensity engagement behaviours and positive affect, and the absence of disengagement and negative affect, are typically viewed as markers of success (e.g. Sauer et al., 2016; Rentz, 2002). Yet the literature review indicated a possible tension between evaluation studies and arts-based practice (also see Pavlicevic et al., 2015). Findings in this study suggest that observational tools might not reflect the values and aims of arts practitioners if they ascribe higher values to intense, sustained and 'positive' displays of engagement.

The issue of engagement outcomes is relevant to this study because practitioner values and expectations about engagement influenced how they interacted with residents. Arts practitioners did not have rigid expectations about what engagement should look like. They engaged residents in ways that were mindful of differences, and of the realities and complexities of dementia. Different levels of cognitive ability and different dispositions meant that practitioners expected engagement to vary. The simple act of momentarily responding to stimuli could be significant for those with very advanced levels of cognitive decline, while more subtle engagement behaviours could be meaningful for those who were more reserved by nature. Periods of disengagement were reported as common and expected for those who were frail or easily fatigued. Rather than trying to sustain the attention of these residents, practitioners encouraged rest. Practitioners therefore stressed the importance of valuing all contributions equally no big or small these were. They did not place a higher value on one person's engagement over another's. Furthermore, 'negative' displays of engagement were

not unusual for residents and were accepted. Indeed, some practitioners highly valued and actively encouraged these sorts of expressions.

These findings suggest that what is valuable in terms of engagement outcomes should be contextualised in terms of the arts practice and the residents who participate. Researchers might therefore need to exercise caution when using observational tools to make value judgements about activities based on engagement outcomes.

### 8.2.3. Influence of the care home culture on engagement

Findings in this study indicate that the care home culture can impact how arts practitioners engage residents. Practitioner reports suggest that the task of engaging residents can be easier in 'good' care homes, where resident wellbeing is prioritised and where residents benefit from regular interaction and stimulation. By contrast, reports suggest that a lack of meaningful interaction and stimulation in 'poor' homes can mean that residents might be harder to engage due to apathy and lack of stimulation. Residents in these settings might also be more likely to present as anxious and fearful if they are not used to activities or if they do not feel safe and secure in the home more generally. Based on the accounts provided in this study, practitioners might therefore need to adapt their approach when working in more challenging care home environments. Progress might be slower, and expectations might need to be managed more. Extra care might be required to help residents feel comfortable in a session. For instance, practitioners talked about taking more time for introductions or easing into activities slowly.

Interview accounts also indicate that practitioners might be impacted in terms of their ability to deliver engaging sessions in homes with a poor culture. It seems that practitioners might encounter more practical and psychological challenges when working in these settings. The research data suggests that such care homes might be less inclined to value arts activities. Practitioners might be caused to feel unwelcomed, and management and staff may be less inclined to cooperate. Reports of hostile attitudes and unfriendliness from staff, unnecessary interruptions, late start times, and different residents each week, all impacted a practitioner's ability to do their job well. This finding is consistent with the reports given by artists in a study by Evans et al. (2019) who found that the '*overarching culture of a care home*' was a key contributing factor in how well artists could facilitate engagement during arts activities (p.333).

It seems that practitioners therefore need to have or acquire a level of resilience to work in more challenging care environments, and reports indicate that a range of strategies might be adopted to avoid disillusionment and feelings of overwhelm. For instance, practitioners might need to manage their expectations of the home more, accept uncertainty, and stay flexible. They might also need to manage expectations of themselves and what they can achieve more when working in these settings.

Given the focus of this research, it was not possible to examine the influence of the care home on engagement in any great depth. Yet the question of how arts practitioners effectively engage residents in their sessions seems to depend to at least some degree on the wider care home culture and the extent to which the home is supportive (or unsupportive) of the practitioner. The question of how an arts practice is impacted in different care settings and how practitioners can work more effectively in less cooperative environments, is worthy of further attention.

#### 8.2.4. The ethics of engagement

Despite the assertion that ethics are of *'paramount'* importance *'in the provision of aesthetic experiences'* for care home residents with dementia (DSDC, 2012), there has been surprisingly little mention of ethics in the arts and dementia research literature. The question of what constitutes an ethical arts practice in care homes has gone largely unaddressed. Yet findings in this study indicate that ethics can play an important role in how arts practitioners engage residents.

Firstly, the study revealed that practitioners are often motivated by ethical concerns and perceived moral failures. Practitioners reported that care homes could be places that lacked meaningful stimulation and interaction, where residents were 'abandoned' and 'forgotten about' by society. There was a belief that residents were no longer recognised, valued, and respected as persons. There was a perception that residents could be disempowered when they lacked control over their lives, and infantilised when they were treated as useless and dependent. Arts practitioners tried to address these perceived moral failures through their practice. Yet paradoxically, the study also revealed that arts sessions can perpetuate some of these problems. By way of example, it was acknowledged that sessions could reinforce feelings of loss or inadequacy if residents felt their artistic abilities were subpar or if they were

reminded of a loss when they were unable to participate in some way (e.g. if eyesight problems prohibited participation in a visual aspect of an activity). There was also a concern that a perceived loss of agency and control could be further compounded if residents felt compelled to attend and participate in an activity. It therefore seems arts practitioners need to consider the possible ethical implications of their practice.

This study has revealed some areas that might present ethical dilemmas in an arts practice. The first relates to times where practitioners might need to persuade or coax residents in some way. The use of persuasion and coaxing was prevalent in this study, and it was not unusual for practitioners to face resistance when inviting residents to attend or participate in their sessions. This presented an ethical dilemma when practitioners did not want to impose on residents but believed they would benefit from participation. While others have noted the need for cajoling and coaxing (McPherson et al. 2009; Broome et al., 2018;), the ethics of this seem to have gone unaddressed in the literature. In this study, coaxing was deemed acceptable in certain contexts, for example if reluctance was attributed to uncertainty or a lack of confidence rather than a genuine aversion to an activity or the need to be left alone. Or when it prevented the isolation and withdrawal of those who would likely enjoy an activity yet would never engage of their own volition. The acceptability of this also seemed to exist on a continuum of resident readiness where signs of discomfort were monitored, and outright refusals were respected. It therefore seems that there might be an ethical argument for persuasion in certain contexts, so long as boundaries are respected.

The study also raises the possibility that certain forms of persuasion might be more ethically acceptable than others, or more acceptable in certain contexts than others. For instance, one practitioner appealed to need by asking reluctant residents to attend sessions as a favour to her. Yet another practitioner felt this was coercive. One practitioner thought that goading and teasing residents was inappropriate, except for in care homes where banter was the norm and a part of the culture. The question of what forms of persuasion are permissible and in what contexts is a question that could be unpicked further.

A second ethical dilemma relates to the impact of an activity on the wider care home. As noted in chapter 7, section 7.3.4., practitioners had requirements for their sessions. Yet practitioner accounts indicated that care homes were busy, complex, and unpredictable environments with competing demands. Findings showed that some practitioners recognised care homes as communal living and workspaces and managed their expectations so as not to

distract from other care priorities, or to be a source of stress for already overburdened staff. Interestingly, some practitioners in this study were critical of negative attitudes and disruptive/unhelpful behaviours from care staff, yet others argued that it was morally wrong to criticise and judge staff in these ways. They attributed poor attitudes or hostility to a lack of training and awareness, embarrassment, nervousness about the unknown, and fatigue from overwork. Accounts therefore suggest that arts practitioners have a moral duty not only to their activity participants, but to the wider care home. What is best for the activity needs to be balanced with the needs of others living and working in the space.

A further ethical dilemma uncovered in this study relates to the issue of consultation with care staff, family members and care plans. While some practitioners found that it could occasionally be helpful to find out information about residents (e.g. life history, prior interests, dementia diagnosis, behavioural issues) others made an ethical argument against this, arguing that misjudgements about a resident's likes or dislikes or capabilities could lead to the unnecessary exclusion of the person. Artists in a study by Evans et al (2019), also expressed apprehension about care staff misjudgements, indicating that the concern is not an uncommon one. Some practitioners in this study revealed that accounts of 'difficult' behaviour could prove irrelevant in an activity context, yet negatively impact interactions with a resident. There was a concern that knowledge of dementia diagnosis and symptomatology might lead to too great a focus being placed on the dementia rather than the person, and that knowing the details of a resident's life could perpetuate power imbalances when residents did not have access to information about practitioners. Accounts therefore suggest that the seemingly innocuous act of engaging in prior consultation about residents (beyond information needed for health and safety), might be questioned on ethical grounds.

The question of how arts practitioners ethically engage residents (and the wider care home) is one that has gone largely unaddressed in the research literature. This study has started to shed some light on possible ethical implications of arts engagement in care homes, yet the terrain is still relatively unexplored. Given the ethical complexities and ambiguities identified here, and the implications of ethics for the wellbeing of residents (and the wider care home), this is an area that warrants further research.



## 8.3. Scaffolding

### 8.3.1. The usefulness of scaffolding as a metaphor for arts engagement

The major finding of this research was the usefulness of scaffolding as a metaphor to explain the engagement process. The concept of scaffolding has received some attention in the dementia literature more generally. Hyden (2011) for example, considered the concept in relation to the case of a couple, one of whom had Alzheimer's disease, showing how a wife was able to include her husband in conversations about their life together by scaffolding his involvement. McCabe, Robertson, and Kelly (2018) demonstrated how the scaffolding metaphor could explain how families and support services could increase support (or scaffolding) to enable people with dementia to live well. Merrick, Camic, and O'Shaughnessy (2016) used the term 'flexible scaffolding' to describe how carers adjusted levels of support according to the changing abilities of the person with dementia. Yet the concept of scaffolding has received little attention in the arts and dementia literature. The exception being one outcomes-focused study that compared artistic outputs in a scaffolded and non-scaffolded drawing activity for people with dementia (Ramsey, Webb and Ellis, 2018).

The analogy of the 'scaffold' as developed by Wood, Bruner and Ross (1976) is closely related to Lev Vygotsky's sociocultural theory which emphasises the importance of the social context in learning (Vygotsky, 1978). In this study, parallels with the work of Vygotsky and Wood, Bruner and Ross were most obvious in participatory arts sessions. The approach to engagement described and demonstrated by participatory arts practitioners, showed how the social context played a crucial role in arts engagement. Consistent with sociocultural theory, residents seemed to acquire the knowledge needed to engage at a higher level through their on-going interactions with 'more knowledgeable others' (either a practitioner or a more competent peer). Participatory arts practitioners adjusted levels of challenge and support according to the abilities and on-going progress of a resident, consistent with the structuring of tasks within a learner's Zone of Proximal Development (ZPD). They balanced autonomy and freedom with guidance and support and intervened only as needed with 'scaffolding' strategies (modelling, prompting, directing attention etc). Consistent with the temporal and adjustable nature of scaffolding, they faded support over time (Van de Pol, 2010). Crucially, observational evidence indicated that residents became more competent through the course of repeated scaffolded interactions, seeming to internalise the knowledge that was needed to engage independently and at a higher level over time.

This study therefore suggests that the application of scaffolding theory might help participatory arts practitioners to optimise engagement in their sessions. Ongoing scaffolded interactions that are both suitably challenging, and cognitively and emotionally supportive of residents seem to positively impact engagement. Consistent with socio-cultural theory, the research data also showed evidence of peer support. It therefore seems that group composition can impact the engagement of the individual. The inclusion of more competent residents in activities might therefore be a useful strategy for engagement. Yet the arrangement of the arts space also seems to be an important consideration here. Peer support was more obvious during observations when a more competent resident was seated next to or directly facing a less competent peer.

While the term 'scaffolding' is not prevalent in the arts and dementia literature, it should be noted that some of the core principles and strategies of scaffolding are. The importance of relating to people with dementia as capable individuals (Kontos et al, 2017; Zelig et al. 2018, Windle et al., 2018) and using appropriate challenge has been acknowledged (Humphrey et al, 2019; Tietyen and Richards, 2020). The need to give support only as needed, has also been noted (Pavlicevic et. al., 2015; Windle et al., 2018; Robertson and McCall, 2020). Strategies consistent with scaffolding are prevalent in the literature including the use of prompts (Rentz, 2002; Lancioni et al., 2015), the modelling of behaviours (Cohen-Mansfield et al, 2011), and the direction of attention (Luyten et al., 2017), along with the need to provide positive reinforcement (Burnside et al, 2017), and reassurance where needed (Robertson & McCall, 2020). This study has therefore contributed to research knowledge by making the link between scaffolding theory and arts engagement in dementia, and by demonstrating how the scaffolding metaphor can encapsulate and elucidate the engagement process.

While the scaffolding metaphor developed by Wood, Bruner and Ross is most obviously applicable in participatory arts sessions, this thesis has argued that the metaphor can have a wider application. A broader conceptualisation of a 'scaffold', as posited by Colombetti and Krueger (2015) and Maiese (2016) means that any resource can be considered a 'scaffold' if it succeeds in encouraging, supporting, and enhancing cognitive and/or affective capabilities. Taking this definition, all arts practitioners were scaffolding when they successfully used material and cultural resources to help residents concrete, remember, communicate, express emotions, and achieve certain affective and arousal states. Moreover, all arts activities

scaffolded relationships when they encouraged and supported communication and collaboration in dementia.

While cultural and material resources are not referred to as 'scaffolds' in the arts and dementia literature, there is some acknowledgement of the role these resources can play in enhancing cognition (Young, Camic & Tischler, 2016), affect (Clare et al., 2020; Treadaway and Kenning, 2016), and relationships (Cousins et. al, 2020; Garabedian and Kelly, 2020). Again, this research has contributed to research knowledge by making the link between the broader scaffolding literature, (and more specifically the work of Colombetti and Krueger, 2015, and Maiese, 2016), and arts engagement in dementia. The metaphor of a scaffold might help arts practitioners to reflect upon their work and articulate what they are doing when they use resources to amplify cognitive and affective capabilities, and when they use these resources to develop and maintain relationships in dementia.

The metaphor of a scaffold seems to provide a useful explanation for arts activity engagement for care home residents living with dementia. Yet it seems likely that scaffolding might also hold relevance for arts activities that take place in the community, or for non-arts-based activities in dementia, potentially opening-up additional avenues of research. The scaffolding metaphor warrants further examination and elucidation as applied in other settings and for other activities in dementia.

### 8.3.2. Practitioner differences and scaffolding

This study included a range of professionals (arts therapists, artists, performers). Despite the diversity of the sample, 'scaffolding' could explain arts engagement and how practitioners used resources (personal, social, cultural, and material) to encourage and support meaningful engagement and change in dementia. The three sub-processes of scaffolding were relevant across different practices. Practitioners all 'invited and inspired' engagement. They all cultivated connections when they encouraged and supported residents to connect to themselves and others. They all 'nurtured change' through the relationships they formed with residents - whether these were short-lived relationships, or longer-term therapeutic relationships developed over many sessions. Numerous action and interaction strategies identified in the study also spanned different arts practices. To give some examples, it was common for practitioners to experiment with different approaches, or to include diverse and multifaceted engagement opportunities in their activities (e.g. different props, music, smells).

Mirroring, proximity, eye contact, touch, were all commonly used. All practitioners stressed the importance of showing residents they were cherished, valued, and respected as persons. Yet the study also revealed important differences in how different arts professionals scaffolded due to different backgrounds, beliefs, and values.

There was a clear distinction between the work of participatory and non-participatory arts practitioners. As discussed in section 8.4.1, non-participatory practitioners (i.e. performers) scaffolded cognition and affect by using cultural and material resources. The arts were valued primarily for their ability to evoke feelings like nostalgia, to profoundly move residents, to inspire feelings of awe and joy, to stimulate memories, to energise residents or to help them relax. Performers scaffolded in more indirect ways when the arts space itself functioned as a kind of scaffold (e.g. when music encouraged and supported relaxation). While participatory arts practitioners (artists and therapists) scaffold indirectly, for example by using music and props, they also scaffolded in more direct ways by challenging residents to participate, and by supporting their active participation using prompts, modelling, and giving reassurance etc.

It also seems important to distinguish between the work of arts therapists and artists. For therapists in this study, the arts were primarily valued for their ability to scaffold emotional self-expression and the formation of therapeutic relationships. This meant that therapists used resources (e.g. music, objects) to understand residents, to connect with them on an emotional level, and to cultivate trusting and emotionally supportive relationships. It meant that therapists invited residents to share their thoughts and feelings. It meant that they encouraged and supported the expression of challenging emotions when these emerged (through talking, music, movement, objects etc.). By comparison, participatory artists primarily valued the arts as a scaffold for imaginative thinking, play, communication, exploration, experimentation, and creative self-expression.

It should be stated that while performers, artists, and therapists all stressed/valued different things, there was a significant overlap between these groups. For instance, non-therapy sessions could clearly hold therapeutic value when artists or performers provided emotional comfort to residents, or when aspects of their sessions provided emotional release. Art therapists certainly encouraged and supported play, experimentation, and creative self-expression in their sessions. Yet the difference was a matter of emphasis and practitioners were all primarily driven by different values and goals.

The study also revealed how differences in practitioner beliefs influenced their approach to scaffolding. For instance, one practitioner who stressed how residents experienced a loss of self in dementia took care to notice and reflect things about the person. Those who believed residents lacked control or were underestimated and treated as incapable, stressed the importance of equality and empowerment by sharing leadership and following a resident's lead. Those who believed that residents could experience isolation, stressed the importance of communication and interaction in the group (e.g. by introducing turn-taking activities).

## 8.4 Person-centredness

### 8.4.1. The relevance of person-centred philosophy for arts engagement

Another important finding in this study was the relevance of person-centred philosophy for arts engagement. The Dementia Services Development Centre have noted that *'the key test for the therapeutic value of engagement with any form of art in a care home setting, like for so much else, is whether it is person-centred'*. (DSDC, 2012). The literature review in chapter two indicated the potential significance of person-centredness for arts engagement. Yet the question of what person-centredness means in an arts and dementia context, and its implications for practice have been somewhat superficially explored in the literature. This study allowed me to give more extensive consideration to the relevance of person-centred ideas for arts engagement, and the implications of person-centredness for arts practices in care homes.

The concept of person-centredness as applied in dementia care originates from the pioneering work of Tom Kitwood (1937-1998). In the 1990's, Kitwood challenged the dominant biomedical approach to dementia care, and the prevailing narrative of dementia as *'the death that leaves the body behind'* (Brooker & Latham, 2016, p.18). Kitwood's person-centred care was founded on the idea of personhood, something he defined as *'a standing or status...bestowed upon one human being, by others, in the context of a relationship and social being. It implies recognition, respect, and trust'* (Kitwood, 1997a, p.8). This represented a paradigm shift towards a more humanistic ethical approach to dementia care that aimed to recognize and prioritize the status of people with dementia as persons worthy of dignity and respect (Terkelsen, Petersen, and Kristensen, 2019). Kitwood (1997b) asserted that relationships were integral to person-centred care, and that personhood was upheld through 'positive person work', or interactions that involved recognition, warmth, celebration, validation etc. Conversely, Kitwood thought that personhood could be undermined by 'malignant social psychology', or interactions that involved infantilisation, disparagement, objectification etc. (Kitwood, 1997b).

While person-centredness in dementia is most often associated with the work of Tom Kitwood, the philosophy predates his work. Indeed, Kitwood was heavily influenced by the person-centred approach of humanistic psychologist Carl Rogers (1902- 1987). Again, in person-centred therapy, it is the relationship between the therapist and the client that is of fundamental importance. Relationships are based on genuineness, empathy, and unconditional positive regard (Rogers, 1961). In recognizing the inherent worthiness and capabilities of the person, the person-centred therapist takes a non-directive approach, enabling the client to realise their own potential for growth and change (Rogers, 1961).

In this study there were very clear parallels between accounts of arts practitioners and the work of Kitwood and Rogers. While the term 'person-centred' was not prevalent in the research data, the humanistic values and ethics that underpinned the work of Kitwood and Rogers were evident. Arts practitioners recognized personhood in dementia, and they were concerned that others did not. They expressed a concern that residents were no longer seen as persons of value, or as whole persons with needs, desires and capabilities. They felt residents could be ignored, objectified, infantilised, and disempowered in their everyday interactions. Arts practitioners recognized 'personhood' by relating to every resident as valuable and capable. The sorts of interactions that were documented in this study align well with positive person work as outlined by Kitwood (1997b), so that arts practitioners conveyed warmth and affection, recognized residents as unique persons, celebrated achievements, and validated experiences.

The relevance of person-centred theory and positive person work has been noted in other arts and dementia studies (e.g. Windle et. al 2018; McDermott, Orrell and Ridder, 2014). Yet this study builds on previous work by showing how practitioner ethics and a recognition of 'personhood' in dementia are fundamental to a person-centred arts practice. The study also builds on previous work by showing how scaffolding can help arts practitioners to work in person-centred ways. By taking a non-directive approach and encouraging residents to engage as freely and independently as possible, residents could realise their own capacities for growth and change. Practitioners could then celebrate achievements, recognize uniqueness, and validate experiences.

Because person-centredness is typically associated with Tom Kitwood, it is not surprising that his work is usually referenced in arts studies that have considered person-centredness. Yet while Kitwood's work was ground-breaking, the literature on person-centredness has continued to evolve since his time. Since Kitwood, some called for greater clarity about the meaning of person-centredness and how it can be implemented in practice (McCormack, 2004; Brooker, 2007). Some also claimed that important aspects of person-centredness were overlooked or not sufficiently emphasised in Kitwood's work (Dewing, 2008, Kontos, 2005). As such, any consideration of the relevance of person-centredness in an arts and dementia context must also consider more recent developments in the person-centred literature.

#### 8.4.2. Person-centred frameworks and arts engagement

Some researchers have offered definitions and frameworks to give more clarity and structure to Kitwood's ideas. Brooker (2007) for example developed the VIPS to help service providers implement person-centredness in practice. The framework is summarised by the equation: PCC (person-centred care) = V + I + P + S, meaning that person-centred care is underpinned by a value base (V) that recognises the value of all human lives. It involves an individualised approach that recognises the uniqueness of the service user (I). It attempts to understand the perspective of the person (P). Finally, it provides a social environment that is supportive of individual psychological needs (S). More recently Wilberforce et. al. (2016) have provided a threefold operational definition of person-centred care for older adults. This definition posits that person-centredness is characterised by an understanding of the person (and their perspective and experience), by the empowerment of the service-user in decision-making processes, and by relationships and interactions that are positive and respectful. McCormack and McCance's (2006, 2010) person-centred nursing framework has also contributed to an understanding of person-centred care.

The prime importance of relationships, and a value base that recognizes the inherent worthiness of every human-being, is restated in these frameworks. Yet they build on Kitwood's work in several respects. Firstly, they all elevate perspective taking as a crucial component of person-centredness. In a nursing context, McCormack and McCance, (2010) state the importance of '*developing a clear picture*' of what the person values and how they '*make sense of what is happening*', as well as the need for '*a sympathetic understanding of the patient's losses and present limitations*' (p.37, p.100). Brooker (2007), states that perspective taking



involves asking the person their consent, attending to non-verbal cues, and using empathetic skills and imagination to consider what the experience of the person might be.

Arts practitioners in this study were being 'person-centred' according to the criterion of 'perspective taking' when they extended offers or 'invitations' to engage and did not assume consent, when they attended to verbal and non-verbal cues to consider a resident's experience, and what they seemed to want or need. Interestingly, in an arts context it seems that explicitly asking for consent might be problematic at times. Practitioners explained that a verbal invitation could sometimes provoke an immediate refusal if a resident did not understand the offer or if they were unsure of what to expect (so that it was safer to just refuse). Conversely one practitioner found that residents could accept a verbal offer, yet not truly appreciate what they were consenting to. As such, the importance of constantly attending to responses was deemed more important as a way of understanding consent. Consent was seen as an on-going process and not a one-time event.

Practitioners also demonstrated perspective taking when they made the effort to understand how a resident made sense of what was happening, and when they entered into the resident's reality (e.g. when Rachael the music therapist dismantled instruments with a gentleman who had been a boiler engineer). They also demonstrated perspective taking by acknowledging a resident's losses and frustrations (e.g. when Gavin described how he expressed sympathy for a resident who was frustrated by her visual impairment).

Individualisation is also emphasised as a defining feature of person-centredness in these frameworks. Brooker (2007), states that individualisation means treating people as individuals and recognising that each person differs in terms of their health and neurological impairment, personality, and life history. Arts practitioners in this study certainly recognised individual differences explaining that residents would engage and express themselves differently due to different dispositions, preferences, and abilities. They interacted with residents in ways that took account of these differences. By way of example, in observations, Zara and Jane challenged a confident, verbose, and energetic Dorothy to entertain the group with her stories and dance moves. By comparison, they engaged in more intimate, gentle, and tactile interactions with an affectionate and sweet-natured Annie, given her disposition and frailty.

Yet there is perhaps some divergence between findings in this study and the literature on individualisation as it relates to life history/biography. The application of biographical knowledge is typically seen as an integral component of individualization. Wilberforce et al.

(2016), note that person-centredness is often associated with knowledge of a person's biography or personal narrative so that services can be delivered in ways that are congruent with their values and identity. It is thought that biography can provide clues from the past about what is likely to be familiar and enjoyable to a person (Brooker, 2007). When a sense of self can start to erode in dementia, it is also reasoned that biographical knowledge can help service providers maintain personhood by holding a person's '*narrative*' for them (Brooker, 2007, p.58). While it is advocated that biographical information should be sought from the person with dementia, consultation with family members is advised where the person with dementia is unable to communicate this information (Brooker, 2007).

Findings in this study suggest that consultation with family/care staff/care plans might be problematic if biographical information is not treated tentatively. Practitioners reported that biographical information could be misleading when past interests and behaviours did not necessarily predict what would be meaningful for a person in the present. Some revealed that it was not unusual for family to express shock when a relative engaged in activities they would have previously avoided. Changing interests in dementia is supported by Cohen-Mansfield et al. (2010) who found that content that aligned with current interests had a more potent impact on engagement than content rooted in past interests (Cohen-Mansfield et al., 2010). It therefore seems that while biographical information gathered from staff, care plans or family members might sometimes prove useful, assumptions about what a person will or will not enjoy should be avoided.

The study does however suggest that what is pertinent to a resident in terms of their biography might become apparent over the course of an activity. Brooker (2007) advises that biographical information should be sought from persons with dementia where possible. Practitioner accounts suggest that arts activities can provide a useful vehicle for residents to reveal what is important to them in terms of their life story. Findings indicate that it is not unusual for persons with dementia to spontaneously reminisce and re-enact meaningful experiences from their past. It therefore seems that rather than facts, what might be more important to the person in terms of their biography is how they integrate their past in ways that give meaning to the present. By paying close attention, practitioners can understand what is most pertinent about a resident's biography, and how this has shaped and continues to shape who they are.

Arts practitioners in this study used these insights to be person-centred in two ways. Firstly, they shared information with care staff (and family), thus facilitating person-centred care by helping staff to better understand and relate to the person. Secondly, some arts practitioners used these insights to recognise and reinforce the person's narrative and their personhood during activities. By way of example, the lady in Kelly's dance therapy sessions chose to engage by dressing her in scarves. Kelly recognised that the lady's experience of being a dressmaker was still an integral part of her narrative and so she continued to encourage this ritual in her sessions. This approach is consistent with the ideas of Sabat and Harre' who stressed the importance of understanding how the person with dementia sees him or herself in the present, to actively cooperate in the co-construction of self with the person, rather than focusing on what was lost (Batra et al., 2016).

Perspective taking and relating to persons with dementia as unique individuals are important elements of person-centredness, and these features of person-centredness were evident in the research data. A third aspect of person-centredness involves a recognition of agency and the empowerment of the individual. Indeed, Wilberforce et. al. (2016) state that empowerment is the pinnacle of person-centredness. While Tom Kitwood certainly recognized agency in dementia, some consider that this need was not sufficiently emphasized in his work. Kaufmann and Engel (2016) have therefore extended Kitwood's model of needs to include agency (or the need for self-determination, freedom of action, and independence). In an arts and dementia context, a recognition of agency means that persons with dementia should be free to make choices, to act independently, and empowered to take control.

Again, these aspects of person-centredness were evident in the study. Practitioners recognized agency when they respected a resident's right to decide if and how they would engage. They facilitated freedom of action when they included an abundance and diversity of engagement opportunities and when they extended open-ended opportunities so that a resident had freedom of choice in terms of their response. When participatory arts practitioners scaffolded engagement during interactions with residents, they empowered residents to use their capacities and to act as independently as possible.

Importantly, the sensorimotor-based nature of an arts environment meant that the arts space itself could act as a kind of scaffold, so that residents could sometimes engage independently. Pia Kontos (2005) has argued that social interactionist perspectives of personhood have tended to overlook the significance of the body as a means of expressing agency and self in

dementia. Kontos asserts that person-centred care must therefore find ways of recognising agency and responding to personhood as it is expressed through the body. Findings in this study suggest that the sensorimotor based nature of an arts space can provide an accessible means for persons with dementia to assert and express themselves. This was evident for example when Bessie asserted her will and revealed her wicked sense of humour in dance therapy, teasing everyone with the balloon, and when Helen tried to influence the course of the session with her singing. It therefore seems that arts activities can not only provide an avenue for residents to express personhood through the body, but that personhood can also be upheld when arts practitioners recognise and respond to the embodied expressions of the person.

Finally, arts practitioners empowered residents to take control in their sessions. McCormack and McCance (2010) state that empowerment involves a willingness to be led, so that the person's behaviour '*directs the focus of action*' (p.94). The research data in this study showed arts practitioners empowered residents to take control to varying degrees, with some encouraging residents to take the lead, while others were willing to stand aside if a resident expressed a desire to take charge. Yet empowerment also happened in more subtle ways when residents influenced the course or content of the session in some respect. For instance, while Jane brought objects and images to poetry sessions, she let residents dictate the content of the conversation. Clarissa explained how residents would influence the content of her operatic production when singers would improvise and go off script in response to audience input. It therefore seems that arts practitioners can empower residents when they are willing and able to let residents direct the focus of action in some way.

To conclude, findings in this study suggest that person-centred philosophy is highly relevant to the question of how arts practitioners ethically engage persons with dementia in care homes. Findings indicate that activities provide a way of recognizing and upholding personhood in dementia when they serve as a vehicle for positive and affirming interactions, when they facilitate perspective taking, and when they can help practitioners (and others) to better understand and relate to the person as an individual. Furthermore, arts sessions can also uphold personhood when they residents can exercise their agency by making choices, acting independently, and by directing the actions of others. Yet findings also suggest that person-centred arts practices might also be more impactful in terms of engagement. Observational data showed that residents were more responsive and more engaged when they were valued

as individuals, when their contributions were acknowledged and celebrated, and when they experienced a sense of choice and control.

## 8.5. Strengths of the grounded theory

I believe that the grounded theory developed in this study meets the quality standards as laid out by Corbin and Strauss (2015). Corbin and Strauss advise that, even when using the same data set, different researchers will create somewhat different theories, yet these theories might all offer explanations that are plausible and useful, so that credibility and applicability should be the criteria by which quality is judged (Corbin and Strauss, 2015). Credibility indicates that findings of a theory are believable or plausible, while applicability indicates that the theory is useful (Corbin and Strauss, 2015, p.346). Corbin and Strauss offer a range of checkpoints for researchers and others to consider when ensuring and assessing quality according to these criteria, and these checkpoints are considered below.

Firstly, the credibility or believability of a grounded theory can be enhanced through methodological consistency and transparency. This means that a grounded theory study should ideally follow the core procedures of the method, and readers should be able to follow the application of these procedures to see how conclusions were reached (Corbin and Strauss, 2015). My approach to data collection and analysis, and the development and integration of categories around a core category was described in some detail in chapters 6 and 7. An account of how I used grounded theory procedures to aid theory development and integration (including the constant comparison technique, theoretical sampling, and memo writing), was provided.

Secondly, the credibility of a grounded theory can be enhanced when sufficient description and detail is provided so that readers can judge the believability of the theory for themselves (Corbin and Strauss, 2015). Corbin and Strauss advise that a grounded theory should combine *'conceptualisation with sufficient descriptive detail to allow the reader to reach his or her own conclusions'* (p.347). To enhance credibility, the concepts and categories of the theory (as reported in chapters 6 and 7), were supported by the words of research participants and by detailed observational accounts. Finally, by including multiple comparison groups the credibility of a grounded theory study can be enhanced *'because the findings are based on*

*more than one group*' (Corbin and Strauss, 2015, p.345). This study included arts therapists, performers, artists, arts mentors/trainers, artistic directors, care staff, and care home residents.

In terms of the applicability or the usefulness of the grounded theory, I wanted to produce a pragmatic theory of arts engagement. Corbin and Strauss (2015) advise that *'theories are not just abstract notions'* but can have *'direct application to the real world'* (p.367). They refer to four features of a grounded theory, explicated in the original grounded theory text, that are relevant when considering applicability (Glaser and Strauss, 1967). Firstly, a grounded theory should 'fit' or correspond closely with the realities of the substantive area. Secondly, the theory should be accessible and comprehensible for laypersons and for professionals. Thirdly, the theory should be applicable under diverse and varied situations. Fourthly, the theory should enable the user to experience some sense of control when applying the theory.

When considering the first criteria of fit, the grounded theory needed to capture the realities of arts-based practice. It needed to resonate with arts practitioners and others who had experience of the phenomenon. While not every action and interaction strategy in a theory will hold relevance for every person, the major categories of a theory should provide a recognisable account of a phenomenon (Corbin and Strauss, 2015). To ensure fit, researchers can therefore check a grounded theory with research participants, and with others who have experience in the substantive area (Corbin and Strauss, 2015). Several actions were taken in this regard. The significance of the emerging categories of the theory were checked with research participants during phase one interviews (e.g. the importance of being responsive). The core category scaffolding was not determined until after phase-one data collection was complete. I was however able to check the suitability of the concept as a core category in the theory during phase 2 data collection. Persons who had not participated in the study, but who worked in the substantive area, were also consulted about the theory. The theory with a focus on the core category was presented to arts practitioners and care staff at two conference workshops in late 2018. Findings with a focus on the causal conditions of the theory were presented by my Director of Studies at an arts and dementia event in 2019. Feedback from discussion groups at these events indicated that findings resonated with those who worked in the field. Findings were also sent to research participants. Feedback was positive and included the following comments:

*'Thank you for the insight, sensitivity and articulation of these processes, they are a great addition to helping us articulate what we do as artists in the field'.*

*'It's such a positive model that really gets to the process underpinning practice.... I think it will give practitioners opportunity to reflect on and improve their own practice'*

Corbin and Strauss advise that researchers can also consult with colleagues who have experience of the substantive area (Corbin and Strauss, 1990). Findings were therefore discussed with fellow TAnDem students to check insights. Theory development also benefited from the perspectives of my supervisors who have research experience in dementia, care homes, and in the use of the arts for dementia in care homes. My ideas were scrutinised during supervisory meetings and through written work. I was challenged on occasions, for example, when my supervisors were unconvinced about the suitability of a suggested core category, or when I had conceptualised or labelled something in a way that was considered unsuitable or unclear. Challenge and constructive criticism helped me to produce a theory that was coherent, and the resulting theory resonated with my supervisors' experiences of the substantive area.

Persons that might wish to apply the theory must also be able to understand the concepts of the theory. In the original grounded theory text, Glaser and Strauss (1967) advised that *'understanding the theory tends to engender a readiness to use it'*. Corbin and Strauss (2015) reason that because the concepts of a grounded theory are developed from empirical data and often contain the actual words of participants, this should render the theory more comprehensible because it is likely to *'consist of terms that are familiar and usable to practitioners'* (p.359). In vivo codes (concepts that reflect the actual words of participants) were used in this study where practitioners conceptualised something well, like *'creating a safe space'* or *'getting the fit right'*. Other concepts of the theory such as *'validation'*, *'mirroring'*, *'prompting'*, *'reflecting'*, *'joining-in'*, *'matching'*, *'suggesting'*, and *'modelling'*, were all terms used by arts practitioners. I also tried to incorporate the language of participants in concepts where possible. By way of example, the concepts *'developing a repertoire'* and *'cultivating meaningful connections'* captured the prevalence of the terms *'repertoire'* and *'connections'* in the interview data. Finally, I tried to ensure that all concepts in the theory

were likely to be understandable and accessible to arts practitioners. This included the concept of scaffolding, an every-day metaphor that most people can relate to.

To be useful, a grounded theory also needs to be applicable under diverse and varied situations, while any potential users should experience some sense of control over its application. The involvement of multiple comparison groups, theoretical sampling, and the constant comparison technique helped to build variation into the theory. A suitable core category was identified that was sufficiently broad enough to be used by therapists, participatory arts practitioners, and performers. The process of scaffolding was explicated according to three subprocesses that were all relevant for these groups. The action and interaction strategies associated with each subprocess were examined under different conditions, building variation into the theory, and broadening its applicability. For example, the inclusion of practitioner differences as an intervening condition, showed how scaffolding could vary according to differences in practitioner motivations, values, preferences, beliefs. The inclusion of resident differences showed how practitioners could scaffold in a way that accounted for different abilities, moods, levels of readiness etc. In terms of control, the theory places a heavy emphasis on practitioner judgements. The theory captures how practitioners make on-going judgments about how best to invite and inspire, cultivate engagement, and nurture change. Similarly, in a group scenario, it is the practitioner who makes judgements about how to balance resident needs and desires, and when and to what extent they should encourage and support the engagement of an individual group member. While the contextual influence of the care home is less controllable, some strategies are offered that practitioner may wish to use to manage this influence.



## 8.6. Limitations of the study

Limitations of the study relate to the focus of the research project, the design and methods of data collection used in phase two of the study, my relative inexperience as a researcher, and the grounded theory itself.

Firstly, I do not claim that the theory developed in this study is *the* definitive theory of arts activity engagement in care homes. Rather, the theory is one of potentially many theories that could advance understanding of the phenomenon. The complex nature of arts engagement, and the subjective and creative nature of theory development means that the grounded theory is imperfect and incomplete. The theory represents my best attempt to conceptualise and explain arts engagement. Theory development involved ongoing subjective decisions about how best to organise the categories of the theory around a core category. It is very possible that there might have been a more insightful and useful core category, and a better way of organising the categories of the theory.

While I believe that most of categories of the theory were well developed, there were also limits to what I could accomplish in a single research project. Indeed, Corbin and Strauss (2015) advise that a grounded theory is never really done, and that researchers could go on collecting data and developing their categories indefinitely. Some categories of the theory were less well developed than others. The category '*a safe and supportive space*' could have been explored more in terms of the strategies used by arts practitioners to feel at ease themselves in a session. In the final interview the dance therapist described the importance of having personal boundaries, citing the example of a resident (not in this study) who had been inappropriate in a way that made her feel vulnerable. I would have liked to have explored the issue further to see if other practitioners experienced these sorts of situations, and how they managed them. The influence of the care home on engagement is something that could have been explored in more detail. The grounded theory developed in this study would therefore benefit from further research and scrutiny. Other researchers might wish to challenge, adapt, develop, and refine the theory.

A further limitation of the theory relates to the design followed in phase two data collection. The grounded theory is ambitious in scope. I wanted to produce a theory that might be useful and applicable for a broad range of arts practices.

While not every strategy will hold relevance for every practitioner, the major categories of theory are intended to be applicable across a variety of art forms and approaches. Yet an in-depth exploration of poetry and dance therapy activities in phase two data collection to validate the theory, meant that the same level of attention and scrutiny of the theory was not applied to other art forms and approaches. The decision to focus phase two data collection on two activities, each repeated three times, was taken to examine the influence of time. Yet three observations of each session were insufficient to examine this influence in any depth. Both arts practitioners had wanted to continue their work with residents. Jane wanted to find ways of encouraging more verbal contributions from quieter residents. Zara wanted residents to open-up emotionally. Three sessions were not enough to observe the kinds of emotional and creative breakthroughs Zara and Jane were describing. In retrospect, I should have observed 3 arts activities, each on two occasions. This would have generated plenty of material for illustration, while the inclusion of a third arts activity could have further validated and enhanced the applicability of the theory. The theory would therefore benefit from further examination when applied to a variety of other arts activities in care homes.

Two additional limitations of phase-two data collection were the absence of video-data and the absence of interviews with residents. Video-data would have allowed me to document the nuances of interactions more effectively and would have ensured that important incidents in activities were not overlooked. My inability to interview residents was also a weakness when resident perspectives or insights about sessions were not communicated— though some profound insights were shared during observations.

My relative inexperience as a researcher was another limitation in the study. I did come to the PhD with some research knowledge and experience gained through a master's degree in social research methods. I had also completed an assignment for my master's degree using a grounded theory approach that had resulted in the beginnings of a theory about retirement decision-making processes. Yet I still considered myself a novice researcher. The quality of the grounded theory developed in this study depended to a large degree upon my interview and observational skills, and my proficiency in applying the procedures of grounded theory. A more experienced researcher and grounded theorist would likely have produced a more nuanced and insightful theory.

## 8.7. Conclusion

This chapter discussed research findings across three major areas: (1) engagement, (2) scaffolding, and (3) person-centredness. It revealed how the process of arts engagement (as described and demonstrated by arts practitioners), showed clear parallels with scaffolding as documented in the research literature. The chapter also revealed how research findings showed clear parallels with the research literature on person-centredness, when arts practitioners were motivated by humanistic ethical values, when they developed positive and affirming relationships with residents, when they treated residents as individuals, and when they recognised agency.

In terms of engagement, the chapter highlighted how different care home cultures might impact a practitioner's ability to engage residents, and how practitioners might need to adapt their approach when working in more challenging care settings. The chapter also discussed the ethics of engagement. It revealed how a practitioner's ethical obligations also extend to non-participating residents and care staff in homes. It further considered how engagement strategies like persuasion and consultation with care staff might present ethical dilemmas for arts practitioners.

## Chapter 9: Conclusion

### 9.1. Introduction

In this final chapter I will share some reflections about the research. I will start by clarifying how the study has made an original contribution to research knowledge. I will then offer some reflections about reflexivity. As stated earlier in the thesis, I consider that my prior experiences, interests, and assumptions will have influenced this research study. I kept a reflexive diary throughout the study to consider my influence. While I do not claim to be aware of all the ways I impacted the research, I will share some reflections in this chapter. I will also share my thoughts about how this research has changed me, and how my position on various matters changed over the course of the study.

### 9.2. How this study has contributed to the existing evidence base.

This study has added to the existing evidence base in several ways. Firstly, while theoretical frameworks for the arts in dementia have started to emerge in recent years, these theories have focused on a particular art form or a specific arts intervention (Camic, Baker and Tischler, 2016; Windle et al, 2018; Clare et al, 2020; McDermott, Orrell and Ridder, 2014). Yet some have called for research to consider the components of effective arts-based activities more broadly (de Madieros & Basting, 2014). Indeed, Cousins et al. (2020), recently developed a taxonomy that identified the common attributes of a wide variety of arts interventions in dementia. This study has contributed to the evidence base by developing a grounded theory that explicates the process of arts engagement across a wide variety of art forms and approaches.

A major contribution of this study to research knowledge is the finding that sociocultural theory (Vygotsky, 1978), and the scaffolding metaphor (Wood, Bruner and Ross, 1976) can help to explain arts engagement as a social process. Previous chapters have revealed the socially mediated nature of arts engagement and have demonstrated clear parallels between practitioner behaviours and scaffolding behaviours. The research has also demonstrated how a broader conceptualisation of scaffolding, as outlined by Colombetti and Krueger (2015) and

Maiese (2016), holds relevance in an arts and dementia context. Yet despite the relevance of scaffolding, it has not been considered in an arts and dementia context (the exception being one outcomes-focused study by Ramsey, Webb and Ellis, 2018). To my best knowledge, this study has been the first to note the relevance of sociocultural theory and scaffolding as a way of encapsulating and elucidating the process of arts engagement in dementia.

The study has also contributed to research knowledge by demonstrating how person-centred ideas are relevant for an effective and ethical arts practice. While some arts and dementia studies have acknowledged the significance of person-centred ideas, these studies have tended to give a somewhat superficial account of what person-centredness means in an arts context. This study has therefore added to existing knowledge by considering how the hallmarks of person-centredness as identified in the broader person-centred literature are evidenced in the ways that arts practitioners engage residents.

Finally, this research has contributed to the evidence base by considering the ethics of arts engagement. The ethics of engagement in care homes seem to have gone largely unaddressed in the arts and dementia literature, yet this study has shown how an arts practice can raise ethical dilemmas for practitioners and how the wellbeing of residents and care staff might be negatively impacted if practitioners do not consider the ethical implications of their work.

### 9.3. Reflections on how I impacted the research.

My prior experiences, interests, and assumptions will have impacted on all stages of this study, including my initial decisions about what to investigate and how to focus the study, my choice of research questions, my interactions with research participants, my analysis of the research data, and my construction of the grounded theory. For the sake of transparency, I will share some of the ways I influenced the research here.

In chapter one, I explained how my biography informed my decision to develop a pragmatic theory of arts in engagement in care homes. My first experience in a care home and my work in Age NI, shaped how I thought about care homes and people with dementia. I saw how residents could be ignored and disrespected, and how they could be treated as patients and not persons. I saw how they could be denied opportunities for meaningful engagement and self-fulfilment. Charmaz (2006) states that what a researcher brings to their research as a person will influence what they can see in their data. My experience provided a lens for analysis, and I was sensitised to incidents in the data that aligned with my own beliefs. Arts practitioners shared my concerns. The final grounded theory therefore places a heavy emphasis on concerns about loss in dementia (e.g. loss of respect, loss of visibility, loss of opportunity etc). These concerns were prevalent in the research data and were shared spontaneously during interviews. Yet it is very possible that another researcher might not have given the same prominence to loss in their own theory. My own experiences and beliefs about care homes played a part in what struck me as most pertinent in my data and in how I framed my findings.

Person-centred ideas are also heavily reflected in the theory. I came to this study with some limited awareness of person-centred theory and an interest in the topic. This probably stemmed from a belief that care home residents and persons with dementia could often be treated as a homogenous group, rather than unique and valuable individuals. I was motivated to consider the individual in my study. I also anticipated that person-centred theory would be relevant for engagement. During my Churchill Fellowship, I had seen how respectful and affirming interactions could positively impact engagement. I had seen how practitioners had adapted for different preferences, needs and abilities. The early review of the arts and dementia literature (chapter two) also indicated the relevance of person-centred ideas.

My interest in the person with dementia and person-centred ideas certainly influenced this study. It was reflected in my overarching research question; *'How do arts practitioners engage the person with dementia in a care home setting?'.* It was reflected in my participant information sheet and my line of questioning when I asked interviewees if they ever struggled to engage a resident, if they ever needed to adapt or tailor their approach for different persons, and if they needed to know anything about a resident to engage them. My belief that person-centred theory would prove relevant also influenced my approach to analysis, and a reading of person-centred literature alongside the research data sensitised me to incidents in the data that indicated a person-centred approach. Person-centred ideas did prove relevant and were prevalent in the research data. As such, the resulting grounded theory and the presentation of the theory places a strong emphasis on person-centredness. Yet it seems likely that a researcher who had not shared my interest might not have given prominence to person-centred ideas in their theory.

For reasons outlined in chapter one, I was motivated to produce a pragmatic theory of engagement. This impacted the choices I made in this study in several ways. Firstly, it meant that I set very clear boundaries for the study from the outset. I was interested in how arts practitioners engaged residents during their activities. A detailed participant information sheet meant that participants came to interviews primed to explain the engagement process. My decision to focus the research this way also meant that I redirected interviewees at times if I felt the person was straying too far off topic (for instance if they started to talk at considerable length about their relationships with care home management or care staff). My intention to produce a pragmatic theory also influenced my decision to use scaffolding as the core category. The concept was grounded in the data of course, yet I believed it would provide a very practical and accessible metaphor to inform practice. The theory developed in this study was therefore heavily influenced by my motivations. I set out to produce a very practical theory. I fully appreciate that other researchers would likely have chosen a different core category and constructed their theory in a different way.

Some of the decisions I made in this research project also related to my experience as a researcher. Prior to the PhD I had completed a master's in research methods. I found that I preferred using quantitative methods and my master's dissertation was purely quantitative in nature. My preference for following a systematic process partly influenced my decision to use

Straussian grounded theory. For instance, at one point I had considered using Realist Evaluation to construct a theory using context, mechanism, and outcome configurations (or CMOs) (Pawson and Tilley, 1997). Yet nothing matched the level of guidance and structure given by Corbin and Strauss (2015). Likewise, my desire for structure and guidance influenced my decision to use the paradigm as a framework for theory construction. While Corbin and Strauss stress that researchers do not have to use the paradigm, this framework gave me confidence when constructing the grounded theory. My decision to use Straussian grounded theory and the paradigm obviously impacted upon the grounded theory that was produced.

#### 9.4. How this study has changed me.

I came to this PhD with expectations and assumptions about engagement before I started data collection. Some proved valid, while others did not. I tried to keep track of my expectations and assumptions in a reflective diary to challenge my own thinking and to guard against overt bias. Yet in doing this, I also learned how I have changed over the course of this study. Just as I shaped the PhD, the PhD also has shaped me. It has challenged my thinking about engagement and has given me a more nuanced perspective on certain matters. It has made me realise things about myself that I was previously unaware of. It has also shaped me as a researcher. I will try to provide an account of this change here.

As mentioned in chapter one, I had observed plenty of arts activities during my Churchill Fellowship and informally at the start of the PhD. I had inevitably started to make judgements about what 'good' and 'bad' engagement looked like. To give some examples, when a resident expressed criticism during an activity, I considered this a negative outcome. I questioned the inclusion of those with more advanced dementia in group activities, when they seemed to engage intermittently. I considered that overt displays of engagement would be more valued by practitioners than subtle displays. I started to encounter ideas that challenged this way of thinking during the early literature review. Papers by Pavlicevic et. al. (2015) and Kontos et al. (2017) revealed that more subtle and fleeting displays of engagement, and even 'negative' emotions were not necessarily undesirable. Interviewees confirmed this and helped me to develop a more nuanced perspective about what was realistic and valuable in terms of engagement. I came to understand that momentary engagement could be significant for a person with more advanced dementia, and that quieter forms of engagement were just as



valid as more demonstrative displays. I came to understand the value of showing residents that they were seen and heard, and valued and accepted, regardless of how they chose to engage and express themselves.

A major assumption I made at the outset of this study was that practitioners would want to know as much as possible about residents prior to working with them. I reasoned that advanced knowledge of residents would help practitioners modify or adapt their sessions according to the abilities and needs and interests of those present. In my mind, this was being person-centred. I had expected that practitioners would want to gather information from care staff and family members. I assumed that they would benefit from knowing the facts about a resident's biography, dementia diagnosis and neurological impairment. This assumption was reflected in early interviews when I asked practitioners if they liked to find out information about residents to engage them. Yet I was challenged by some who thought that prior information (beyond basic health and safety related information) was not necessary, helpful, practical, or even ethical.

The process of keeping a diary forced me to consider my assumptions/expectations and my emotional reactions to things I had seen and heard in this study. My assumptions were challenged in all sorts of ways, and my viewpoint changed when I was exposed to other perspectives. I was not overly attached to my ideas. Yet for some reason I was incredulous when I was told that prior information about residents was not important or useful. I found it difficult to accept what I was being told. Indeed, I tried to impose my viewpoint with several interviewees, by questioning them repeatedly on this. My emotional response forced me to confront my own bias. With reflection I realised that I needed to revisit my assumptions and better understand other perspectives. Over time, I came to accept that information could sometimes present a barrier to person-centredness if this information was misleading, if it altered relationship dynamics, and if it caused a practitioner to focus on the dementia and not the person. Arts practitioners taught me that being person-centred was more about paying attention to what a person revealed about themselves during an activity (their interests, abilities, and needs), rather than making assumptions based on facts about a person's past, a dementia diagnosis, or the perspectives of others.

A variety of other beliefs were also challenged in this study. Interviewees challenged my thinking around ethics and consent (particularly my belief that residents should always be

explicitly asked for consent, and that persuasion was a form of coercion). I came to see that that it might not always be appropriate to seek consent in this way (if the person would always decline opportunities due to poor comprehension), and that persuasion could be necessary and ethically justified at times. Whilst I had believed that it was unethical to 'subject' a resident to an activity they had previously disliked or shown no interest in, I learned that it was not unusual for a resident to engage with enthusiasm when given time and repeated opportunities.

Perhaps the biggest lesson I learned from this study was how much I had underestimated people with dementia. Getting to know Dorothy, Rachael, Helen, Pam, and Bessie over the course of the six observations was the highlight of the PhD, and they enriched my life in ways I hadn't expected. I had also underestimated what these residents were capable of and each week I was surprised by what they had achieved. In the dance therapy for instance, I questioned Zara's judgement when she asked residents to make choices for the group, thinking that her expectations were much too high. Yet with repeated opportunities, and to my amazement, some of the residents did do this. In poetry sessions, I expected that Pam and Annie, would not contribute to the group poems, given their language struggles. Yet both residents were able to contribute some words and seemed to gain immense satisfaction from doing so. Helen was the biggest surprise for me. Despite having the most advanced dementia in the group, Helen led the group in song on numerous occasions, and offered profound insights for the poetry. I never would have believed this would have been possible from my first meeting with Helen.

This research therefore made me reconsider ideas I thought were logical and ethical and 'person-centred'. The study also challenged assumptions I was not even aware I held, for example, that persons with dementia should not experience struggle, or that they would not be capable of leading a group. Furthermore, the study gave me more positive experience of a care home when my experience in Hawthorne House was far removed from my first encounter with a care home. I looked forward to my visits and always left feeling uplifted. My time there showed me that care homes can be joyous places and that arts activities can play an important role in supporting residents to flourish in these settings.

## 9.5. Conclusion

This concluding chapter highlighted the ways in which the study has made an original contribution to research knowledge. The most significant contribution to knowledge was the finding that the scaffolding metaphor holds relevance for arts engagement in care homes.

The chapter revealed how my motivations, interests and beliefs shaped the theory that was constructed. I revealed how my interest in the person and person-centred theory was reflected in the final theory, and I explained how my decision to use scaffolding as the core category of the theory was informed by my desire to produce a pragmatic theory of engagement. Finally, I shared how my assumptions had been challenged, and how my position on engagement had changed during the research process. The study challenged my beliefs about what was logical and ethical and person-centred. It also caused me to reflect upon how I routinely underestimated persons with dementia.

## References

Algar, K., Woods, R. T., and Windle, G. (2016). 'Measuring the quality of life and wellbeing of people with dementia: A review of observational measures', *Dementia*, 15 (4), pp.832-857.

Allen, P. (2018). *Arts in Care Homes: A Rapid Mapping of Training Provision*. London: The Baring Foundation.

All-Party Parliamentary Group (APPG) on Arts, Health and Wellbeing (2017). *Creative Health: The Arts for Health and Wellbeing*. London: APPG on Arts, Health and Wellbeing.

Bailey, J. (2008). 'First steps in qualitative data analysis: transcribing', *Family Practice*, 25 (2), pp. 127–131.

Basting, A. (2018). 'Building creative communities of care: Arts, dementia, and hope in the United States', *Dementia*, 17 (6), pp. 744–754.

Batra, S., Sullivan, J., Williams, B. R., and Geldmacher, D. S. (2016). 'Qualitative assessment of self-identity in people with advanced dementia', *Dementia*, 15 (5), pp. 1260–1278.

Beard, R. (2011). 'Art therapies and dementia care: A systematic review', *Dementia*, 11 (5), pp. 633-656.

Bigelow, A. E., MacLean, K., and Proctor, J. (2004). 'The role of joint attention in the development of infants' play with objects', *Developmental Science*, 7 (5), pp. 518–526.

Birks, M., and Mills, J. (2015). *Grounded theory- a practical guide*. Second Edition. SAGE Publications, Inc.

Brinkmann, S. (2013). *Qualitative Interviewing: Understanding qualitative research*. Oxford: Oxford University Press.

Brooker, D. (2005). 'Dementia Care Mapping: A review of the research literature', *Gerontologist*, 1 (1), pp. 11-8.

Brooker, D. (2007). *Person Centred Dementia Care: Making Services Better*. London: Jessica Kingsley Publishers.

Brooker, D., and Latham, I. (2016). *Person-centred dementia care*. Second Edition. London: Jessica Kingsley.

Broome, E., Denning, T., and Schneider, J. (2018). 'Participatory arts in care settings: A multiple case study: Innovative practice', *Dementia*, DOI: 10.1177/1471301218807554.

Broome, E., Denning, T., and Schneider, J. (2019). 'Facilitating Imagine Arts in residential care homes: the artists' perspectives', *Arts & Health*, 11 (1), pp. 54-66.

Bryman, A. (2008). *Social research methods*. Third Edition. Oxford University Press.

Burnside, L. D., Knecht, M. J., Hopley, E.K., and Logsdon, R.G. (2017). 'here:now – Conceptual model of the impact of an experiential arts program on persons with dementia and their care partners'. *Dementia*, 16 (1), pp. 29-45.

Byrne, J. A. (2016). 'Improving the peer review of narrative literature reviews', *Research Integrity and Peer Review*, 1 (12).

Byrne, L., and MacKinlay, E. (2012). 'Seeking Meaning: Making Art and the Experience of Spirituality in Dementia Care', *Journal of Religion, Spirituality & Aging*, 24 (1-2), pp. 105-119.

Camic, P. M., Baker, E. L., and Tischler, V. (2016). 'Theorizing how art gallery interventions impact people with dementia and their caregivers', *Gerontologist*, 56 (6), pp. 1033-1041.

Campbell, S., Ponsillo, N., Budd, P., and Keady, J. (2017). 'Music in Mind and Manchester Camerata: an exploratory qualitative evaluation of engagement in one care home in Northwest England', *Quality in Ageing and Older Adults*, 18 (1), pp. 69-80.

Cevasco, A. M. (2010). 'Effects of the Therapist's Nonverbal Behaviour on Participation and Affect of Individuals with Alzheimer's Disease During Group Music Therapy Sessions', *Journal of Music Therapy*, 47 (3), pp. 282-299.

Charmaz, K. (2006). *Constructing Grounded Theory. A Practical Guide Through Qualitative Analysis*. London: Sage Publications Ltd.

Clare, A., Camic, P. M., Crutch, S. J., West, J., Harding, E., and Brotherhood, E. (2020). 'Using Music to Develop a Multisensory Communicative Environment for People with Late-Stage Dementia', *Gerontologist*, 60 (6), pp. 1115–1125.

Cohen-Mansfield, J., Dakheel-Ali, M., and Marx, M. S. (2009). 'Engagement in persons with dementia: The concept and its measurement', *The American Journal of Geriatric Psychiatry*, 17 (4), pp. 299-307.

Cohen-Mansfield, J., Marx, M. S., Thein, K., and Dakheel-Ali, M. (2010). 'The impact of past and present preferences on stimulus engagement in nursing home residents with dementia', *Aging and Mental Health*, 14 (1), pp. 67-73.

Cohen-Mansfield, J., Marx, M. S., Freedman, L. S., Murad, H., Regier, N. G., Thein, K., and Dakheel-Ali, M. (2011). 'The Comprehensive Process Model of Engagement', *The American Journal of Geriatric Psychiatry*, 19 (10), pp. 859-870.

Colombetti, G., and Krueger, J. (2015). 'Scaffoldings of the affective mind', *Philosophical Psychology*, 28 (8), pp. 1157-1176.

Corbin, J. and Strauss, A. (2015). *Basics of Qualitative Research- techniques and procedures for developing grounded theory*. Fourth Edition. SAGE Publications, Inc.

Cousins, E., Tischler, V., Garabedian, C., and Dening, T. (2020). 'A taxonomy of arts interventions for people with dementia', *Gerontologist*, 60 (1), pp. 124-134.

Cridland, E. K., Phillipson, L., Brennan-Horley, C., & Swaffer, K. (2016). 'Reflections and Recommendations for Conducting In-Depth Interviews with People with Dementia', *Qualitative Health Research*, 26 (13), pp. 1774–1786.

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. London: Sage Publications.

Cupchik, G. (2001). 'Constructivist realism: An ontology that encompasses positivist and constructivist approaches to the social sciences', *Forum qualitative social research*, 2 (1).

Cutler, D., Kelly, D., and Silver, S. (2011). *Creative Homes. How the arts can contribute to quality of life in residential care*. London: Baring Foundation.

Davidson, J. W., and Fedele, J. (2011). 'Investigating group singing activity with people with dementia and their caregivers: Problems and positive prospects', *Musicae Scientiae*, 15 (3), pp. 402-422.

de Laine, M. (2000). *Fieldwork, Participation and Practice: Ethics and Dilemmas in Qualitative Research*. SAGE Publications.

de Medeiros, K., and Basting, A. (2014). 'Shall I compare thee to a dose of donepezil?: cultural arts interventions in dementia care research', *Gerontologist*, 54(3), pp.344-353.

Department of Health. (2009). *Living well with dementia: a national dementia strategy*. London: Department of Health.

Department of Health. (2016). *Prime Minister's Challenge on Dementia 2020. Implementation plan*. London: Department of Health.

Dewing, J. (2008). 'Personhood and dementia: Revisiting Tom Kitwood's ideas', *International Journal of Older People Nursing*, 3, pp. 3-13.

Diener, E., and Crandall, R. (1978). *Ethics in Social and Behavioural Research*. Chicago: University of Chicago Press.

Dröes, R. M., Chattat, R., Diaz, A., Gove, D., Graff, M., Murphy, K., Verbeek, H., Vernooij-Dassen, M. Clare, L., Johannessen, A., Roes, M., Verhey., F., Charras, K., and the INTERDEM sOcial Health Taskforce (2017). 'Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice', *Aging & Mental Health*, 21 (1), pp. 4-17.

Evans, G. L. (2013). 'A novice researcher's first walk through the maze of grounded theory: rationalization for classical grounded theory', *Grounded Theory Review: An International Journal*, 12 (1).

Evans, S. C., Garabedian, C., Bray, J., and Gray, K. (2019). 'Challenges and enablers for creative arts practice in care homes', *Journal of Applied Arts & Health*, 10 (3), pp. 333-345.

Findji, F. (1998). 'Infant attention scaffolding at home'. *European Journal of Psychology of Education*, 13, 323.

Garabedian, C. E., and Kelly, F. (2020). 'Haven: Sharing receptive music listening to foster connections and wellbeing for people with dementia who are nearing the end of life, and those who care for them', *Dementia*, 19 (5), pp. 1657–1671.

George, D. R., and Houser, W. S. (2014). "I'm a Storyteller!": Exploring the Benefits of TimeSlips Creative Expression Program at a Nursing Home', *American Journal of Alzheimer's Disease & Other Dementias*, 29 (8), pp. 678- 684.

Glaser, B. (2013). 'Introduction: Free Style Memoing', *Grounded theory review: An International Journal*, 12 (2).

Glaser, B., and Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Mill Valley, CA: Sociology Press.

Grant, M., and Booth, A. (2009). 'A typology of reviews: an analysis of 14 review types and associated methodologies', *Health Information and Libraries Journal*, 26, pp. 91–108.

Green, B. N., Johnson, C. D., and Adams, A. (2001). 'Writing Narrative Literature Reviews for Peer-Reviewed Journals: Secrets of the Trade', *Journal of Sports Chiropractic and Rehabilitation*, 15, pp.5-19.

Hallberg, L. R. M. (2010). 'Some thoughts about the literature review in grounded theory studies', *International Journal of Qualitative Studies on Health and Well-Being*, 5, 5387.

Humphrey, J., Montemuro, M., Coker, E., Kilgour-Walsh, L., Moros, K., Murray, C., and Stanners, S. (2019). 'Artful Moments: A framework for successful engagement in an arts-based programme for persons in the middle to late stages of dementia', *Dementia*, 18 (6), pp. 2340–2360.

Hyden, L. (2011). 'Narrative collaboration and scaffolding in dementia', *Journal of Aging Studies*, 25 (4), pp. 339-347.

Jung, J., and Recchia, S. (2013). 'Scaffolding Infants' Play Through Empowering and Individualizing Teaching Practices', *Early Education & Development*, 24 (6), pp. 829-850.



Kaufmann, E. G., and Engel, S. A. (2016). 'Dementia and well-being: A conceptual framework based on Tom Kitwood's model of needs', *Dementia*, 15 (4), pp. 774–788.

Kenny, M., and Fourie, R. (2015). 'Contrasting classic, Straussian, and constructivist grounded theory: Methodological and philosophical conflicts', *Qualitative Report*, 20 (8), pp. 1270-1289.

Kent, M., and Rose, L. (2013). *The Arts and Aging: Building the Science*. Washington: National Endowment for the Arts.

Kitwood, T. (1997a). *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press.

Kitwood, T. (1997b). 'The experience of dementia', *Aging & Mental Health*, 1 (1), pp. 13-22.

Kitwood, T. and Bredin, K. (1992). *Person to Person: A Guide to the Care of those with Failing Mental Powers*. Essex: Gale Centre Publications.

Kontos, P. (2005). 'Embodied Selfhood in Alzheimer's disease. Rethinking Person-Centred Care', *Dementia*, 4 (4), pp. 553–570.

Kontos, P. Miller, K., Mitchell, G. J., Stirling-Twist, J. (2017). 'Presence redefined: The reciprocal nature of engagement between elder-clowns and persons with dementia', 16(1) 46–66.

Kvale, S. (1996). *Interview Views: An Introduction to Qualitative Research Interviewing*. Thousand Oaks, California: Sage Publications.

Lancioni, G. E., Bosco, B., De Caro, M. F., Singh, N. N., O'Reilly, M. F., Green, V. A., Ferlisi, G., Zullo, V., D'Amico, F., Addante, L. M., Denitto, F., and Zonno, Z. (2015). 'Effects of response-related music stimulation versus general music stimulation on positive participation of patients with Alzheimer's disease', *Developmental Neurorehabilitation*, 18 (3), pp. 169–176.

Levers, M. D. (2013). 'Philosophical Paradigms, Grounded Theory, and Perspectives on Emergence', *SAGE Open*.

Luyten, T., Braun, S., Jamin, G., van Hooren, S. and de Witte, L. (2017). 'How nursing home residents with dementia respond to the interactive art installation 'VENSTER': a pilot study', *Disability and Rehabilitation: Assistive Technology*, DOI: 10.1080/17483107.2017.1290701

MacPherson, S., Bird, M., Anderson, K., Davis, T., and Blair, A. (2009). 'An Art Gallery Access Programme for people with dementia: 'You do it for the moment'', *Aging & Mental Health*, 13 (5), pp. 744–752.

Maiese, M. (2016). 'Affective Scaffolds, Expressive Arts, and Cognition', *Frontiers in Psychology*, 7, 359, DOI:10.3389/fpsyg.2016.00359.

Mansbach, W., Mace, R., Clark, K., and Firth, I. (2017). 'Meaningful Activity for Long-Term Care Residents with Dementia: A Comparison of Activities and Raters'. *Gerontologist*, 57 (3), pp. 461–468. McCabe, L., Robertson, J., and Kelly, F. (2018). 'Scaffolding and working together: a qualitative exploration of strategies for everyday life with dementia', *Age and Ageing*, 47 (2), pp. 303–310.

McCormack, B., and McCance, T. (2006). 'Development of a framework for person-centred nursing', *Journal of advanced nursing*, 56 (5), pp. 472 – 479.

McCormack, B., and McCance, T. (2010). *Person-centred Nursing: Theory and Practice*. Oxford: Wiley Blackwell.

McDermott, O., Orrell, M., and 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), pp.706-716.

Merrick, K., Camic, P., and O'Shaughnessy, M. (2016). 'Couples constructing their experiences of dementia: a relational perspective', *Dementia*, 15 (1), pp. 34–50.

MRC Ethics Guide (2007). *Medical research involving adults who cannot consent*. London: Medical Research Council.

National Institute of Health and Care Excellence (NICE) (2013). *Mental wellbeing of older people in care homes*, Quality standard [QS50]. Available at: <https://www.nice.org.uk/guidance/QS50> (Accessed: 30th November 2020).

National Institute of Health and Care Excellence (NICE) (2019). *Dementia*, Quality standard [QS184]. Available at: <https://www.nice.org.uk/guidance/qs184> (Accessed: 30th November 2020).

Nyman, S.R., and Szymczynska, P. (2016). 'Meaningful activities for improving the wellbeing of people with dementia: beyond mere pleasure to meeting fundamental psychological needs', *Perspectives in Public Health*, 136(2), pp. 99-107.

Patton, M., Q. (2015). *Qualitative Research & Evaluation Methods* (4<sup>th</sup> ed). SAGE Publications, Inc.

Pavlicevic, M., Tsiris, G., Wood, S., Powell, H., Graham, J., Sanderson, R., Millman, R., and Gibson, J., (2015). 'The 'ripple effect': Towards researching improvisational music therapy in dementia care homes', *Dementia*, 14 (5), pp.659-679.

Pawson, R., & Tilley, N. (1997). *Realistic Evaluation*. Sage Publications, Inc.

Pols, J. (2005). 'Enacting Appreciations: Beyond the Patient Perspective', *Health Care Analysis*, 13 (3), pp. 203-221.

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., Adelaja, B., Hu, B., King, D., Rehill, A., and Salimkumar, D. (2014). *Dementia UK: Update*. Second edition. King's College London and the London School of Economics.

Ramsey, A., Webb, S., and Ellis, M. (2018). 'Scaffolding for artistic success: comparing structured and unstructured art activity for people with dementia', *Journal of Dementia Care*, 26 (4), pp. 20-23.

Ray, K. D., and Fitzsimmons, S. (2014). 'Music-assisted bathing: Making shower time easier for people with dementia', *Journal of Gerontological Nursing*, 40 (2), pp. 9-13.

Rentz, C. A. (2002). 'Memories in the Making: Outcomes-based evaluation of an art programme for individuals with dementing illness', *American Journal of Alzheimer's Disease and Other Dementias*, 17 (3), pp. 175-181.

Rieger, K. L. (2019). 'Discriminating among grounded theory approaches', *Nursing Inquiry*, DOI: 10.1111/nin.12261.

- Robertson, J. M., and McCall, V. (2020). 'Facilitating creativity in dementia care: the co-construction of arts-based engagement', *Ageing & Society*, 40 (6), pp. 1155–1174.
- Rogers, C. R. (1961). *On Becoming a person: A psychotherapists view of psychotherapy*. Houghton Mifflin.
- Roulston, K., deMarrais. K., and Lewis, J. B. (2003). 'Learning to Interview in the Social Sciences', *Qualitative Inquiry*, 9 (4), pp. 643-668.
- Sabat, S. R., and Harré, R. (1992). 'The Construction and Deconstruction of Self in Alzheimer's Disease', *Ageing and Society*, 12 (4), pp. 443–461.
- Sauer, P. E., Fopma-Loy, J., Kinney, J.M., and Lokon, E. (2016). 'It makes me feel like myself: Person-centered versus traditional visual arts activities for people with dementia', *Dementia*, 15 (5), pp. 895-912.
- Schneider, J. (2018). 'The Arts as a Medium for Care and Self-Care in Dementia: Arguments and Evidence', *International journal of environmental research and public health*, 15 (6), 1151.
- Shin, M. and Partyka, T. (2017) 'Empowering infants through responsive and intentional play activities', *International Journal of Early Years Education*, 25 (2), pp. 127-142.
- Silverman, D. (2017). 'How was it for you? The Interview Society and the irresistible rise of the (poorly analyzed) interview', *Qualitative Research*, 17(2), pp. 144–158.
- Sixsmith, A., and Gibson, G. (2007). 'Music and the wellbeing of people with dementia', *Ageing & Society*, 27 (1), pp.127-145.
- Slaughter, S., Cole, D., Jennings, E., and Reimer, M. A., (2007). 'Consent and assent to participate in research from people with dementia', *Nursing Ethics*, 14, pp. 27–40.
- Social Care Institute for Excellence (SCIE) (2010). *A definition of excellence for regulated adult social care services in England*. Social Care Institute for Excellence: London.
- Stiel, S., Pestinger, M., Moser, A., Widdershoven, G., Lüke, U., Meyer, G., Voltz, R., Nauck, F., and Radbruch, L. (2010). 'The use of Grounded theory in palliative care: methodological challenges and strategies', *Journal of Palliative Medicine*, 13 (8), p. 997-1003.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. First edition. Newbury Park, CA: Sage Publications.

Terkelsen, A. S., Petersen, J. V., and Kristensen, H. K. (2019). 'Mapping empirical experiences of Tom Kitwood's framework of person-centred care for persons with dementia in institutional settings. A scoping review', *Scandinavian Journal of Caring Sciences*, DOI: 10.1111/scs.12709

Tietjen, A. C., and Richards, A. G. (2020). 'A Visual Arts Education pedagogical approach for enhancing quality of life for persons with dementia (innovative practice)' *Dementia*, 19 (4), pp. 1244–1251.

Treadaway, C., and Kenning, G. (2016). 'Sensor e-textiles: person centered co-design for people with late stage dementia', *Working with Older People; Brighton*, 20 (2), pp. 76-85.

Van de Pol, J. Volman, M., and Beishuizen, J. (2010). 'Scaffolding in Teacher–Student Interaction: A Decade of Research', *Educational Psychology Review*, 22, pp. 271–296.

Van Der Vleuten, M., Visser, A., and Meeuwesen, L. (2012). 'The contribution of intimate live music performances to the quality of life for persons with dementia', *Patient Education and Counselling*, 89 (3), pp. 484-488.

Vogl, S. (2013). 'Telephone versus face-to-face interviews', *Sociological Methodology*, 43 (1), pp. 133-177.

Vygotsky, L. S. (1978). *Mind in society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press.

Ward, K. (2015). 'Participants' views of telephone interviews within a grounded theory study', *Journal of advanced nursing*, 71 (12), pp. 2775 – 2785.

West, E., Stuckelberger, A., Pautex, P., Staaks, J., and Gysels, M. (2017). 'Operationalising ethical challenges in dementia research—a systematic review of current evidence', *Age and Ageing*, 46, pp. 678–687.

Wilberforce, M., Challis, D., Davies, L., Kelly, M., P., Roberts, C., and Loynes, N. (2016) 'Person-centredness in the care of older adults: a systematic review of questionnaire-based scales and their measurement properties', *BMC Geriatrics*, 16 (63).

Windle, G., Gregory, S., Howson-Griffiths, T., Newman, A., O'Brien, D., and Goulding, A. (2018). 'Exploring the theoretical foundations of visual art programmes for people living with dementia', *Dementia*, 17(6), pp. 702–727.

Wittenberg, R., Hu, B., Barraza-Araiza, L., and Rehill, A. (2019). *Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040*. CPEC Working Paper 5. Care Policy and Evaluation Centre: London School of Economics and Political Science.

Wood, D., Bruner, J. S., and Ross, G. (1976). 'The role of tutoring in problem solving', *Child Psychology & Psychiatry & Allied Disciplines*, 17 (2), pp. 89–100.

Young, R., Camic, P., and Tischler, V. (2016). 'The impact of community-based arts and health interventions on cognition in people with dementia: a systematic literature review', *Aging & Mental Health*, 20 (4), pp.337-351.

Zeilig, H., West, J, and Williams, M. (2018). 'Co-creativity: possibilities for using the arts with people with a dementia', *Quality in Ageing and Older Adults*, 19 (2), pp. 135-145.

Zeilig, H., Tischler, V., van der Byl Williams, M., West, J., and Strohmaier, S. (2019). 'Co-creativity, well-being and agency: A case study analysis of a co-creative arts group for people with dementia', *Journal of Aging Studies*, 49, pp. 16-24.

## Appendix 1: Practitioner information sheet, phase 1



### INFORMATION SHEET FOR ARTS PRACTITIONERS

Version 2

26/04/2017

**Study: *How do arts activities engage the individual living with dementia in a residential care setting?***

*This document is designed to give you more information about a research study I am undertaking. I would like you to consider taking part in the study. Before you consider this, it is important for you to understand why the research is being done and what it will involve. Please take some time to read the following information carefully. Please feel free to ask me if there is anything that is not clear or if you would like more information. My contact details are at the end of the document.*

#### **Why is this study being done?**

This research is being conducted as part of my PhD which is focused on how arts activities successfully engage individuals with dementia. The PhD is part of a larger programme of work. I am one of six PhD students based at the TAnDem (The Arts and Dementia) Doctoral Training Centre, which represents a partnership between the Association for Dementia Studies at the

University of Worcester and the Centre for Dementia at the University of Nottingham. The Doctoral Training Centre is funded by the Alzheimer's Society and has been established to improve the evidence base for the arts and dementia.

In recent years there has been a growing interest in the use of arts-based activities for people with dementia. The content and delivery of arts sessions is highly variable and we don't know what approaches are most effective when trying to engage individuals in a session. We know very little about the process of engagement, how engagement occurs and how engagement might vary between individuals. We also don't know how an individual's circumstances might influence their engagement in an arts activity and how we might need to tailor our approach depending on the individual. My study will therefore seek to develop a theory of engagement in arts activities that explains how to engage the individual living with dementia during an arts session.

**Why am I asking you to consider taking part?**

I would like you to consider taking part in this study as you are an arts practitioner who delivers activities to individuals living with dementia in a residential care setting.

As my study is focused on engagement, I am keen to hear your views on how to successfully engage the individual living with dementia during an arts session. I am interested in the process by which you go about engaging the individual, what the process of engagement looks like, and how this process might vary depending on the individual or individuals you are working with. I am interested your insights about how and why an individual will engage (or won't engage) during a session and how you might need to tailor your practice to the individual.

**What sorts of activities am I interested in?**

In my study I can look at a range of arts activities including dance, drama, poetry, reading, storytelling, music, singing etc.



**What are you aiming to find out?**

In the research I will be trying to understand the process by which we can engage an individual in an arts activity and also how this process might vary between individuals.

**How am I going to do this?**

My study will focus heavily on interviews with arts practitioners. I will also interview care staff. I will use the information gathered during these interviews to develop a theory of engagement that is based on the insights of those who have experience of arts activities.

**What am I asking from you?**

I am asking for around an hour of your time to conduct an interview with you. The interview may be slightly shorter than this, or slightly longer. The interview will take place at a time and place that is convenient for you. The interview will be audio recorded with your permission.

For the research to be fruitful it is important that I interview arts practitioners who recognise the value of what I am doing and who have insights about engagement that they are willing to share in terms of how to engage the individual during an arts session.

**Do I have to take part?**

No you are not obligated to take part and you can withdraw from the study at any point.

**Will my participation in the study be kept confidential?**

The information I gather will be published in my PhD thesis. I also intend to publish my findings in journals and other publications. I will present my findings at conferences and workshops. I will not name you or your practice in these outputs. I will not name the care home(s) you work in or the people you work with. I might quote from your interview when I write about it or when I present my findings, however your name will not be used so that you will not be

identified. I will also take precautions to protect your anonymity by limiting any other information from which you or the care home(s) you work in may be identified.

Information that I collect for the study will be taken to the university where it will be securely stored. All digital files will be stored on a secure area of the University of Worcester network with password protection.

Two types of participant information will be kept:

1. Personally identifiable data including your name and contact details, for data protection purposes and to enable contact during the study. This information will be recorded in an Excel spreadsheet and will be kept separately and securely at the University of Worcester. This information will only be seen by me and the Director of the Association for Dementia Studies. You will then be assigned a code to ensure that your participation in the study remains confidential.
2. Digital files of audio-recorded interviews and their transcripts. Written transcripts of our interview will be anonymised so that your name and any identifying information will be removed. A descriptive note will be kept, describing your role (e.g. dance therapist'). This will be linked to your interview files by your unique participant identification number.

Any personal or other data held in manual files will be stored in a locked facility at the University of Worcester. All identifying information on these files will be removed and will be marked with an anonymous code

Information disclosed in our interview will not be discussed with the care home. The exception to this would be if you were to tell me something that made me think that a care home resident was at risk. I would have to act on this. I would need to inform the Director of Studies at the Association for Dementia Studies and possibly the care home manager.

**How will my data be used?**

As stated, the information I gather will be published in my PhD thesis. I also intend to publish my findings in journals and other publications and to present my findings at conferences and workshops.

If you do decide to take part in this study, you and the other research participants will be volunteering your time and expertise. It is reasoned that any information gathered should be used to its fullest potential. If you agree to this, anonymised data (anonymised interview transcripts, not audio recordings) will be shared with other researchers who are undertaking similar research. Your name and any identifying information will have been removed from these transcripts. Use of the data would have to be agreed by the Director of the Association for Dementia Studies. If you would prefer that your interview is only used for the purposes of this study that is fine. We will discuss this.

#### **How long will the data be kept for?**

In accordance with the Data Protection Act we would keep your personal data and interview data for 10 years. Your contact details will only be used while I am engaged in the research and for the purposes of this study only. Your interview transcripts will only be used for the purposes of this study unless you consent to other researchers using the data.

#### **What are the benefits of participating in the study?**

By taking part in this study you will be supporting research which aims to increase our understanding of how best to engage individuals in arts activities. This could potentially help to inform the practice of other arts practitioners delivering sessions in care homes.

#### **What are the disadvantages of taking part?**

The interview will take time out of your day, but every effort will be made to minimise inconvenience and interviews will take place at a time and location that is convenient for you.

I will be conducting in-depth interviews that are likely to last around an hour and up to ninety minutes. This is a long time to take part in an interview and could be tiring for you. It will be

possible to take a break or stop at any point during the interview should you wish, or to finish the interview early if you would prefer to. You can withdraw from the interview at any point and do not have to answer questions you do not wish to.

**Who has reviewed the study?**

This study has been reviewed and has been ethically approved by the University of Worcester's Ethics Committee.

**What should I do next?**

If you are interested in taking part in the study, or if you have any further queries about the research, please contact me on the details below.

**Contact details**

Amy Veale

PhD Student, TAnDem/ Association for Dementia Studies

University of Worcester

Tel: 07921819521

Email: a.veale@worc.ac.uk

**Further information and contact details**

This study is being supervised by Professor Dawn Brooker at the Association for Dementia Studies. If you have any concerns or complaints about this study, please contact Professor Brooker on the details below:

**Professor Dawn Brooker**

Association for Dementia Studies

University of Worcester

Henwick Grove  
Worcester  
WR2 6AJ  
Tel: 01905 85 5250  
Email: [d.brooker@worc.ac.uk](mailto:d.brooker@worc.ac.uk)

If you would like to speak to an independent person who is not a member of the research team, please contact:

**Dr John-Paul Wilson**  
***Independent Sponsor***  
Graduate Research School  
University of Worcester  
Henwick Grove  
Worcester  
WR2 6AJ  
Tel: 01905 54 2196  
Email: [j.wilson@worc.ac.uk](mailto:j.wilson@worc.ac.uk)

**Thank you for taking the time to read this information leaflet.**

## Appendix 2: Information sheet for care staff, phase 1



### INFORMATION SHEET FOR CARE STAFF

Version 2.

26/04/2017

**Study: *How do arts activities engage the individual living with dementia in a residential care setting?***

*This document is designed to give you more information about a research study that am undertaking. Before you consider whether or not you should take part in the study it is important for you to understand why the research is being done and what it will involve. Please take some time to read the following information carefully. Please feel free to ask me if there is anything that is not clear or if you would like more information. My contact details are at the end of the document.*

#### **Why is this work being done?**

This research is being conducted as part of my PhD which is focused on how arts activities successfully engage individuals with dementia.

The PhD is part of a larger programme of work. I am one of six PhD students based at the TANdem (The Arts and Dementia) Doctoral Training Centre, which represents a partnership between the Association for Dementia Studies at the University of Worcester and the Centre for Dementia at the University of Nottingham. The Doctoral Training Centre is funded by the Alzheimer's Society and has been established to improve the evidence base for the arts and dementia.

In recent years there has been a growing interest in the use of arts-based activities for people with dementia. My study is focused on how arts practitioners can successfully engage the individual living with dementia in arts activities. Based on your experience, and what you might have observed in an arts activity, I am keen to hear your views. I am interested in your insights about how and why an individual will engage (or won't engage) during an arts session and what approaches work best for certain individuals.

**What are you aiming to find out?**

In the research I will be trying to understand the process by which arts practitioners engage an individual in an arts activity and also how this process might need to vary between individuals.

**How are you going to do this?**

I will conduct interviews with arts practitioners and care staff. I will use the information gathered during these interviews to develop a theory of how to engage individuals in arts activities.

**What am I asking from you?**

If you agree to take part in the study, I would ask you to take part in an interview. The interview will last no longer than 1 hour and will take place at the care home. The interview will take place during your working hours at a time that is convenient for you and the home, and with the agreement of management. The interview will be audio recorded with your permission and will focus on how residents in your home engage in arts activities and what influences their engagement.

For the research to be fruitful it is important that I interview care staff who recognise the value of what I am doing and who have insights about engagement that they are willing to share. You should be willing to share your insights and experience in terms of what influences the engagement of individuals in an arts session.

**Do I have to be involved?**

You do not have to take part in the study and you are free to withdraw at any time without giving a reason.

**Will my participation in the study be kept confidential?**

I will not reveal your identity or the identity of the home, the arts practitioners who work in your home, or any residents in any reports or documents. In transcriptions of interviews and any reports, all references to people's names, places or other identifying information will be removed.

The information I gather will be published in my PhD thesis. I also intend to publish my findings in journals and other publications. I will present my findings at conferences and workshops. I might quote from your interview when I write about it or when I present my findings, however your name will not be used so that you will not be identified. I will also take precautions to protect your anonymity by limiting any other information from which you or the care home you work in may be identified.

Information that I collect for the study will be taken to the university where it will be securely stored. All digital files will be stored on a secure area of the University of Worcester network with password protection.

The following information will be kept:

1. Personally identifiable data including your name and contact details, for data protection purposes and to enable contact during the study. This information will be recorded in an Excel spreadsheet and will be kept separately and securely at the University of Worcester. This information will only be seen by me and the Director of the Association for Dementia Studies. You will then be assigned a code to ensure that your participation in the study remains confidential.
2. Digital files of audio-recorded interviews and their transcripts. Written transcripts of interviews will be anonymised so that your name and any identifying information will



be removed. A descriptive note will be kept, describing your role (e.g. activity coordinator). This will be linked to your interview files by your unique participant identification number.

Any personal or other data held in manual files will be stored in a locked facility at the University of Worcester. All identifying information on these files will be removed and will be marked with an anonymous code.

Information disclosed in our interview will not be discussed with the care home. The exception to this would be if you were to tell me something that made me think a care home resident was at risk. I would have to act on this. I would need to inform the Director of Studies at the Association for Dementia Studies and possibly the care home manager.

#### **How will my data be used?**

As stated, the information I gather will be published in my PhD thesis. I also intend to publish my findings in journals and other publications and to present my findings at conferences and workshops.

If you do decide to take part in this study, you and other research participants will be volunteering your time and expertise. It is reasoned that any information gathered should be used to its fullest potential. If you agree to this, anonymised data (anonymised interview transcripts, not audio recordings) will be shared with other researchers who are undertaking similar research. Your name and any identifying information will have been removed from the transcripts. The use of the data would have to be agreed by the Director of the Association for Dementia Studies. If you would prefer that your interview is only used for the purposes of this study that is fine. We will discuss this.

#### **How long will the data be kept for?**

In accordance with the Data Protection Act we would keep your personal data and interview data for 10 years. Your contact details will only be used while I am engaged in the research and

for the purposes of this study only. Your interview transcripts will only be used for the purposes of this study unless you consent to other researchers using the data.

**What are the benefits of participating in the study?**

There are no direct benefits to you or the home. By taking part however, you would be supporting research which aims to improve the lives of people with dementia in care settings.

**What are the disadvantages of taking part?**

The interview will take time out of your working day, but every effort will be made to minimise disruption to your working routine and interviews will take place at a time that is most convenient for you in agreement with your manager.

I will be conducting in-depth interviews that are likely to last around an hour and up to ninety minutes. This is a long time to take part in an interview and could be tiring for you. It will be possible to take a break or stop at any point during the interview should you wish, or to finish the interview early if you would prefer to. You can withdraw from the interview at any point and do not have to give a reason. You do not have to answer questions you do not want to.

**Who has reviewed the study?**

This study has been reviewed and approved by the University of Worcester's Ethics Committee.

**What should I do next?**

If you are interested in taking part in the study, or if you have any further queries about the research, please contact me on the details below.

**Contact details**

Amy Veale

PhD Student

TAnDem/ Association for Dementia Studies

University of Worcester

Tel: 07921819521

Email: [a.veale@worc.ac.uk](mailto:a.veale@worc.ac.uk)

[www.worcester.ac.uk/tandem](http://www.worcester.ac.uk/tandem)

### **Further information and contact details**

This study is being supervised by Professor Dawn Brooker at the Association for Dementia Studies. If you have any concerns or complaints about this study, please contact Professor Brooker on the details below:

#### **Professor Dawn Brooker**

Association for Dementia Studies

University of Worcester

Henwick Grove

Worcester

WR2 6AJ

Tel: 01905 85 5250

Email: [d.brooker@worc.ac.uk](mailto:d.brooker@worc.ac.uk)

If you would like to speak to an independent person who is not a member of the research team, please contact:

#### **Dr John-Paul Wilson**

#### ***Independent Sponsor***

Graduate Research School

University of Worcester

Henwick Grove

Worcester

WR2 6AJ

Tel: 01905 54 2196

Email: [j.wilson@worc.ac.uk](mailto:j.wilson@worc.ac.uk)

**Thank you for taking the time to read this information leaflet**

## Appendix 3: Consent form for arts practitioners, phase 1



Participant Identification Number for this study:

**Study: *How do arts activities engage the individual living with dementia in a residential care setting?***

**Name of Researcher: Amy Veale**

### PRACTITIONER CONSENT FORM

#### Interview consent

I confirm that I have read the information sheet dated 26/04/2017 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

I agree to participate in an interview with Amy Veale and understand that data from this interview will be analysed as part of the study.

I agree for the interview to be audio-recorded.

I agree for anonymised data from the interview to be used in analysis, reports and publications.

I agree that anonymised data from the interview can be presented at conferences and workshops.

I agree that all personal data can be stored for 10 years after the study has ended in line with the Data Protection Act.

I agree that anonymised data from my interview may be used to support further research.

**OR**

I would prefer that data from my interview is only used for the purpose of this study.

I agree that I can be contacted again for a second interview if necessary.

\_\_\_\_\_  
Name of Practitioner                      Date                      Signature

\_\_\_\_\_  
Researcher                      Date                      Signature

## Appendix 4: Consent form for care staff, phase 1



Participant Identification Number for this study:

**Study: *How do arts activities engage the individual living with dementia in a residential care setting?***

**Name of Researcher: Amy Veale**

### CARE STAFF CONSENT FORM

#### Interview Consent

I confirm that I have read the information sheet dated 26/04/2017 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

I agree to participate in an interview with Amy Veale and understand that data from this interview will be analysed as part of this study.

I agree for the interview to be audio-recorded.

I agree for anonymised data to be used in analysis, reports and publications.

I agree that anonymised data can be presented at conferences and workshops.

I agree that all personal data can be stored for 10 years after the study has ended in line with the Data Protection Act.

I agree that anonymised data from my interview may be used to support further research.

**OR**

I would prefer that data from my interview is only used for the purpose of this study.

I agree that I can be contacted again for a second interview if necessary

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature



## Appendix 5: Excerpt from interview transcript with an arts practitioner

Interviewer: There is an educational concept that I'm interested in called scaffolding, and I think that some artists might do it. So, you can do it for a group or an individual – it's about challenging the person or group, but supporting them in the process to meet the challenge. So, you provide support but eventually you kind of step away and then they can do whatever it is independently.

Participant: Ok. Silence.

Interviewer: Do you ever challenge people in your sessions?

Participant: Oh yes. (emphasis).

Interviewer: Well maybe if you tell me how you challenge people and then we can work out if it's scaffolding?

Participant: Ok. I mean a lot of people still believe that people with dementia can learn anything new, can't be part of a creative process, and that they just need to be looked after. Who knows what Mrs Brown is capable of, I don't know until I try. So that's where I'm coming from. Some people might say, oh no I can't, and if they really don't want to, I respect that. But I might give them, I will model, 'can you do this', and I will give them something very simple, they'll do it. Then I'll say 'do it again and we'll all copy you' so they've actually succeeded in the task almost without realising. So, you give them something. Or I might sit and say ok then let's do it together, I will play on this part and you can play on that part, or if you have volunteers or staff I might say, can you two do this together, we will give you a little minute to work out what you're going to do.

Interviewer: When you play with someone- do you ever do that and then back away?

Participant: Oh yes. I do that in a group setting as well. I mean we might have got a rhythm going, it might have taken a lot of effort to get everybody handling their instruments, everybody engaged, but you've got something very simple going along, which is very much led by me, and then I might gradually withdraw my input and then, it's a bit like the child on the bike with the stabilisers and they think that dad is still pushing and then they turn round and he's back there somewhere. I actually stop playing and then they somehow they feel like they have launched into something cause they can do it without me.

## Appendix 6: Information sheet arts practitioners, phase 2



### INFORMATION SHEET FOR PRACTITIONERS

Version 1

30/09/2017

**Study: *How do arts activities engage the individual living with dementia in a care home setting?***

*This document is designed to give you more information about a research study I am undertaking. I would like you to consider taking part in the study. Before you consider this, it is important for you to understand why the research is being done and what it will involve. Please take some time to read the following information carefully. Please feel free to ask me if there is anything that is not clear or if you would like more information. My contact details are at the end of the document.*

#### **Why is this study being done?**

This research is being conducted as part of my PhD which is focused on how arts activities successfully engage individuals with dementia in a care home setting. The PhD is part of a larger programme of work. I am one of six PhD students based at the TAnDem (The Arts and Dementia) Doctoral Training Centre, which represents a partnership between the Association for Dementia Studies at the University of Worcester and the Centre for Dementia at the University of Nottingham. The Doctoral Training Centre is funded by the Alzheimer's Society and has been established to improve the evidence base for the arts and dementia.

In recent years there has been a growing interest in the use of arts-based activities for people with dementia. The content and delivery of arts sessions is highly variable and we don't know

what approaches are most effective and why. We know very little about the barriers and enablers of engagement, how engagement occurs and what approaches participants find more or less engaging. We also don't know how an individual's circumstances will shape their experience of an activity and how approaches need to be tailored to the individual. Yet by understanding these things, we can develop and deliver more effective arts-based activities that are appropriate for the individual, and this is what my research will seek to address.

### **Why am I asking you to consider taking part?**

I have already conducted a series of interviews with arts practitioners and care staff to understand how people with dementia can be successfully engaged in arts activities.

I now wish to conduct a small number of observations of arts activities. I want to gain a deeper understanding of how these activities unfold and how people with dementia engage in the activities. I will observe 2 different arts activities on 3 occasions. I am asking you to take part as you are an experienced arts practitioner.

### **What am I aiming to find out?**

In the research I will be:

- Interpreting the engagement and mood of individual participants during arts activities.
- Interpreting any changes in engagement and mood throughout the activity.
- Relating this to the practice of the arts practitioner and the content of the activity
- Identifying the active ingredients/components of arts activities and how these are delivered.
- Identifying important considerations for engagement as these relate to the individual and how approaches might need to be tailored to the individual.

### **How am I going to do this?**

This is phase 2 of my study. Phase 1 focused exclusively on interviews. In this phase of the study, I intend to observe 2 different arts practitioners engaging care home residents in their respective activities. I will observe each practitioner leading their session on 3 separate occasions. If you consent to take part, I will observe your activity 3 times over the course of 3 weeks.

For each observation, I will describe the arts practice in detail as it unfolds. I will also describe the engagement of each individual throughout the session. I will make my own interpretations about the individual's engagement and what has influenced their engagement. I will use a tool called Dementia Care Mapping to note the behaviour, engagement and mood of each individual participant, your actions, and what is happening in the activity.

Following the activity, I will conduct a short 30-minute interview with you to hear your views on how individuals engaged in the session. I will also seek the interpretations of key members of care staff, and the participants themselves where this is possible.

### **Who will I observe in the group and how will I select them?**

All individuals will be selected in the weeks and days before the activity. Individuals will only be approached to take part in the study if they have a history of taking part in arts activities and if they consent or (for those who lack the capacity to consent) family approve their inclusion. Individuals will be excluded on the day if they present with any acute mental or physical issues, or if they withdraw consent or give any indication they are uncomfortable with their inclusion in the study.

### **What will I ask from you?**

For the research to be fruitful it is important that I work with practitioners who recognise the value of what I am doing and can commit to the research process. I would ask that you are willing to commit to having your arts session observed on 3 separate occasions over the course of 3 weeks, and that you are willing to participate in 3 short 30 minute interviews to reflect on each of the sessions. The interview will be audio-recorded with your permission.

**How will my research impact on your practice?**

It is possible that my presence could be distracting for you and the participants. I will endeavour to minimise any disruption by being discreet in my observations and note taking.

The arts session that you run will be specifically set up for the purposes of the research. Only individuals who have consented (or for whom approval is gained) will participate in the session. It is therefore possible that you may have fewer numbers for your session than you are used to.

**Do I have to take part?**

No. You are not obligated to take part and you can withdraw from the study at any point.

**Will my participation in the study be kept confidential?**

I will not reveal your identity or the identity of the home in any reports or documents. The confidentiality of individuals resident in, working in or visiting the home will be maintained. In transcriptions of interviews and any reports, all references to people's names, places or other identifying information will be removed.

The exception to this would be if I was to witness or hear something that made me think that a resident was at risk. I would have to act on this. I would follow adult protection/safeguarding procedures which could involve me reporting concerns to the Local Authority.

Information that I collect for the study will be taken to the university where it will be securely stored. All data will be stored on a secure area of the University of Worcester network with password protection.

Two types of participant information will be kept:

1. Personally identifiable data including the name of the home and your name and contact details for data protection purposes and to enable contact during the study. This information will be recorded in an Excel spreadsheet and will be kept separately and securely at the University of Worcester. This information will only be seen by me

and the Director of the Association for Dementia Studies. All individuals will be assigned a code to ensure that their participation in the study remains confidential.

2. Digital files of audio-recorded interviews and their transcripts and written observational notes. The written transcripts of any interviews and observation notes will be anonymised so that the name of the home, your name and the name of any residents will be removed. A descriptive note will be kept, describing your role (e.g. arts practitioner'). Your data will be linked by a unique participant identification number. Any audio recordings of interviews will be stored in a separate and secure password protected area of the University of Worcester's network. Any audio recordings held on digital recording devices will be destroyed immediately after they are transcribed.

Any personal or other data held in manual files will be stored in a locked facility at the University of Worcester. All identifying information on these files will be removed and will be marked with an anonymous code.

#### **How will the data collected be used?**

The information I gather will be published in my PhD thesis. I also intend to publish my findings in journals and other publications. I will present my findings at conferences and workshops for academics, arts practitioners, carers, people living with dementia, and care professionals.

#### **How long will the data be kept for?**

As stated, personal data (names and contact details) will be kept for 10 years in line with the Data Protection Act and University of Worcester policy. This data will only be accessed by myself and my Director of Studies.

All other data will be destroyed as soon as the PhD is complete and will only be used for the purposes of the PhD.

#### **What are the benefits of participating in the study?**

By taking part in this study you will be supporting research which aims to increase our understanding of how we best engage individuals in arts activities. This could potentially help to inform the practice of other artists and arts therapists delivering sessions in care homes.

### **What are the disadvantages of taking part?**

Observations and interviews will require a time commitment from you. I will need to observe your activity 3 times over 3 weeks and I will need to conduct a 30-minute interview with you after each observation. In total this will mean that you will need to devote 4 ½ hours for the purposes of data collection. Every effort will be made to minimise inconvenience, and suitable times and arrangements for observations and interviews will be discussed with you.

As sessions will be arranged specifically for the purposes of the research, self-employed arts practitioners will receive payment to cover the costs of running these sessions.

### **Who has reviewed the study?**

This study has been reviewed and approved by the Social Care Research Ethics Committee (Ref: 17/IEC08/0048)

### **What should I do next?**

If you are interested in taking part in the study, or if you have any further queries about the research, please contact me on the details below.

### **Contact details**

Amy Veale

PhD Student, TAnDem/ Association for Dementia Studies

University of Worcester

Tel: 07921819521

Email: [a.veale@worc.ac.uk](mailto:a.veale@worc.ac.uk)



### **Further information and contact details**

This study is being supervised by Professor Dawn Brooker at the Association for Dementia Studies. If you have any concerns or complaints about this study, please contact Professor Brooker on the details below:

#### **Professor Dawn Brooker**

Association for Dementia Studies  
University of Worcester  
Henwick Grove  
Worcester  
WR2 6AJ  
Tel: 01905 85 5250  
Email: [d.brooker@worc.ac.uk](mailto:d.brooker@worc.ac.uk)

If you would like to speak to an independent person who is not a member of the research team, please contact:

#### **Dr John-Paul Wilson**

##### ***Independent Sponsor***

Graduate Research School  
University of Worcester  
Henwick Grove  
Worcester  
WR2 6AJ  
Tel: 01905 54 2196  
Email: [j.wilson@worc.ac.uk](mailto:j.wilson@worc.ac.uk)

**Thank you for taking the time to read this information leaflet**

## Appendix 7: Practitioner consent form, phase 2



Participant Identification Number for this study:

**Study: *How do arts activities engage the individual living with dementia in a care home setting?***

**Name of Researcher: Amy Veale**

### **PRACTITIONER CONSENT FORM**

**Version 1**

**30/09/2017**

#### **Interview and observation consent**

I confirm that I have read the information sheet dated 30/09/2017 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I do not have to participate in this study.

I understand that the data collected in relation to the observations of my practice, and through subsequent interviews with myself, care staff, and participants will be analysed for the purpose of this study.

I agree to participate in 3, 30-minute interviews with Amy Veale.

I agree for these interviews to be audio-recorded.

I agree that Amy Veale can conduct observations of my arts practice on 3-separate occasions and record her observations using Dementia Care Mapping.

I agree for anonymised data to be used in analysis, reports and publications.

I agree that anonymised data can be presented at conferences and workshops

I agree that all personal data can be stored for 10 years after the study has ended in line with the Data Protection Act.

\_\_\_\_\_  
Name of Practitioner

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Appendix 8: Consultee information sheet



### INFORMATION SHEET FOR RELATIVE/ PERSONAL CONSULTEE

Version 1

30/09/17

***Study: How do arts activities engage the individual living with dementia in a care home setting?***

#### **Who am I and why am I contacting you?**

I am a PhD researcher based at the Association for Dementia Studies at the University of Worcester. My PhD is focused on understanding how arts activities positively engage individuals with dementia in a residential care setting.

My PhD is part of a larger programme of work that is exploring the value of arts based activities for people with dementia, and I am one of six PhD students based at the TANdem (The Arts and Dementia) Doctoral Training Centre. The Doctoral Training Centre is funded through the Alzheimer's Society and represents a partnership between the Association for Dementia Studies at the University of Worcester, and the Centre for Dementia at the University of Nottingham

I am contacting you because your relative/ friend takes part in arts activities and I would like to include them in my PhD study. I would like to invite you to act as a 'personal consultee' on behalf of your relative/friend as they do not have the capacity to understand or retain information about the research long enough to consider whether or not they should take part.

You are not obliged to act as a personal consultee if you do not want to, but if you do, this is what would be involved: I will arrange a time to talk to you over the phone (or in person if you

prefer) to tell you more about the study. I will then ask your advice about whether your relative/friend should take part in the research. It is important for you to understand why the research is being done, and why I am asking people like your relative/friend to take part. They do not have to take part, but if your view is that they would be happy to be involved, I will approach them for consent. Please take time to read the information on this sheet carefully.

### **What is my study about?**

My PhD is focused on how arts activities provide positive engagement for people with dementia in a residential setting.

In recent years there has been an increased interest in the use of arts activities for people living with dementia. To make sure that people with dementia get the most out of these activities we need to understand what makes them worthwhile, and what approaches residents respond positively to.

### **Why are you asking my relative/friend to help?**

I believe that one of the best ways to know how arts activities engage individuals with dementia is to spend time observing the activities and talking to the people who take part. Much of the research in this field has not included the views of the people with dementia. I think it is important that their voices are heard where possible.

### **What will I do in my study?**

I will observe 2 different arts activities at the care home where you friend/ relative lives. I will observe each of the activities 3 times in total. The first activity will be observed 3 times over the course of 3 weeks. The second activity then be observed 3 times, again over a period of 3 weeks. Each session is likely to last around 1 hour.

The first activity will be one that is regularly offered in the home. Your friend/relative will have participated in this activity on a regular basis. The second activity will be a new activity that has

not been offered by the home in the past. Even though this activity will be new to the home, it will be delivered by an experienced arts practitioner. I will seek your advice and approval for each of these activities. It is possible that you might approve the inclusion of your friend/relative in one activity but not the other.

### **How will I collect data?**

For each activity, I will observe what happens and how the participants and your friend/relative responds in the activity. I will take detailed notes on the activity itself, what happens, and how the artist goes about engaging your friend/relative.

After the activity, I will speak to the individuals who took part (where this is possible) to find out what they think. I want to make sure that participants have the opportunity to discuss what they liked or disliked about the activity. I will do this after the artist/ therapist has left the room. I recognise that it may not be appropriate or possible to speak with your relative. The appropriateness of this will be discussed with you and care staff. After the activity, I will then interview staff and the artist/ therapist who delivered the activity to hear their thoughts about engagement and why they think your friend/relative and others responded in the way that they did.

If you advise that your friend/relative would want to take part in just one of the arts activities, they will be observed taking part in that activity on 3 occasions over the course of 3 weeks. If you advise that they would want to take part in both of the arts activities offered, they will be observed on a further 3 occasions over an additional 3 weeks. I will discuss the content of the new activity with you to see if you think it is suitable for your friend/relative.

I will always ask your friend/ relative if they are happy to take part and if they are happy to be observed. If they appear to be annoyed or distressed by the process, they will be removed from the study and will not be re-enrolled.

### **What am I asking from you?**

I am asking you to act as a Personal Consultee for your friend/ relative. You are under no obligation to do this, however if you do wish to act as Personal Consultee I would seek your advice about whether or not you feel your friend/ relative would want to contribute to this

study if they had capacity. It is important that you consider carefully how they would feel about taking part. Please consider what you know of their wishes and feelings. Please let me know about any advance decisions they may have made about participating in work of this kind as this should take precedence.

Please consider how your friend relative would feel about:

1. Being observed taking part in an arts activity.
2. Being asked some questions about their experience after the activity.
3. Taking part in a new arts activity that they will have not participated in before (I will discuss the nature of the new activity with you).
4. Contributing to a research study where anonymised data about their engagement will be disseminated in publications and reports, and at conferences and workshops.

**Will my friend's/relative's participation in the study be kept confidential?**

The information I gather will be published in my PhD thesis. I also intend to publish my findings in journals and other publications. I will present my findings at conferences and workshops. I will not name you or your relative in these outputs. I will not name the care home your friend/relative lives in. I might discuss my observations of your friend/relative when I write about my findings, however their name will not be used so that they will not be identified. In transcriptions of interviews and any reports, all references to people's names, places or other identifying information will be removed.

Information will be kept confidential. The exception to this would be if I was to witness or hear something that made me think that a resident was at risk. I would have to act on this. I would follow adult protection/safeguarding procedures which could involve me reporting concerns to the Local Authority.

Information that I collect for the study will be taken to the University of Worcester where it will be securely stored. All data will be stored on a secure area of the University of Worcester network with password protection.

Two types of participant information will be kept:

1. Personally identifiable data including the name of the home, your relative's name and your name and contact details for data protection purposes and to enable contact during the study. This information will be recorded in an Excel spreadsheet and will be kept separately and securely at the University of Worcester. This information will only be seen by me and the Director of the Association for Dementia Studies. All individuals will be assigned a code to ensure that their participation in the study remains confidential.
2. Observational notes about your relative's engagement in the activity and written interview notes if I interview them after the activity. The written transcripts of any interviews and observation notes will be anonymised so that the name of the home and the name of your relative will be removed. A descriptive note will be kept, describing their role (e.g. resident). Their data will be linked by a unique participant identification number.

Any personal or other data held in manual files will be stored in a locked facility at the University of Worcester. All identifying information on these files will be removed and will be marked with an anonymous code.

#### **How will the data be used?**

As stated, the information I gather will be published in my PhD thesis. I also intend to publish my findings in journals and other publications and to present my findings at conferences and workshops.

#### **How long will the data be kept for?**

In accordance with the Data Protection Act we would keep your personal data and your friend/relative's personal data for 10 years. Your contact details will only be used while I am engaged in the research and for the purposes of this study only. Any interview transcripts or observational notes will be destroyed after the PhD is complete.



**What are the possible benefits of taking part?**

The two arts activities will be in addition to those already offered in the home as they will be organised specifically for the purpose of the research. Your friend/relative might therefore benefit in terms of further opportunities to participate in an activity they already take part in, as well as a newer activity. Both activities will be delivered by experienced arts practitioners.

**What are the possible disadvantages of taking part?**

Your relative will be aware that they are being observed as I will ask if they are happy for me to observe their participation, however I will make every effort to be discreet. It is possible that your relative/friend may feel uncomfortable about my presence during the arts activity.

If they do appear uncomfortable at any point by my observation, I will discontinue the observation. I will inform the appropriate member of care staff to attend to them. They will be then be withdrawn from the study and subsequent observations. They will not be re-enrolled.

**What happens next?**

I will contact you by phone to discuss the study in more detail. We can also discuss any concerns that you might have.

After this conversation, if you decide your relative/friend would have no objection to taking part in the study, I would ask you to read and sign the consultee declaration which is enclosed. You also have a copy to keep. If you decide that your friend/relative would not wish to take part it will not affect the standard of care they receive in any way. I fully understand if you do not think it is appropriate for your relative/ friend to be included in the study.

You can change your advice about your relative/friend taking part in this study at any point. You do not have to give a reason.

**Who has reviewed the study?**

This study has been reviewed and approved by the Social Care Research Ethics Committee (Ref: 17/IEC08/0048).

**How do I contact you?**

If the care home advises me that you are happy to be contacted about this study, I will arrange a time to call you. If you wish to contact me before this time, or at any point after the study has started, my contact details are below.

Amy Veale

PhD Student

TAnDem / Association for Dementia Studies

University of Worcester

Tel: 07921819521

Email: [a.veale@worc.ac.uk](mailto:a.veale@worc.ac.uk)

**Further information and contact details**

This study is being supervised by Professor Dawn Brooker at the Association for Dementia Studies. If you have any concerns or complaints about this study, please contact Professor Brooker on the details below:

**Professor Dawn Brooker**

Association for Dementia Studies

University of Worcester

Henwick Grove

Worcester

WR2 6AJ

Tel: 01905 85 5250

Email: [d.brooker@worc.ac.uk](mailto:d.brooker@worc.ac.uk)

If you would like to speak to an independent person who is not a member of the research team, please contact:

**Dr John-Paul Wilson**

***Independent Sponsor***

Graduate Research School

University of Worcester

Henwick Grove

Worcester

WR2 6AJ

Tel: 01905 54 2196

Email: [j.wilson@worc.ac.uk](mailto:j.wilson@worc.ac.uk)

**Thank you for taking the time to read this information leaflet**

## Appendix 9: Consultee declaration form



Participant Identification Number for this study:

### RELATIVE/ PERSONAL CONSULTEE DECLARATION FORM

**Study: *How do arts activities engage the individual living with dementia in a care home setting?***

**Name of Researcher: Amy Veale**

I have been consulted about my relative's/friend's participation in this research project. I confirm that I have read the information sheet dated 30/09/17, version 1, and have had the opportunity to ask questions about the study and understand what is involved.

In my opinion he/she would have no objection to taking part in the above study.

I understand that I can request he/she is withdrawn from the study at any time, without giving any reason and without his/her care or legal rights being affected.

I believe that my he/she would want to participate in both of the arts activities that are the focus of the study

**OR**

I believe that he/she would only want to participate in the first arts activity

**OR**

I believe that he/she would only want to participate in the second arts activity

In my opinion he/she would have no objection to the researcher observing his/ her participation in the arts activity/ activities.

In my opinion he/ she would be happy to be interviewed briefly after the arts session.

I understand that the data gathered through observations and interviews will be used in publications and presented at conferences and workshops, but that all steps will be taken to protect the identity of my relative/friend.

I understand that personal data will be kept for 10 years after the study has ended in line with the Data Protection Act.

\_\_\_\_\_  
Name of consultee

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Relationship to consultee

\_\_\_\_\_  
Name of researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature