Dementia and Meaningful Activity

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Contents

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Completing PhDs late in life seems to run in the family. My mother, Sali Dening, undertook her doctoral studies between 1949 and 1953, in Hamburg and in Oxford. As it happened, when she presented her thesis on the life and works of the German polymath Justus Möser, she was pregnant with her first child and unable to travel to her degree ceremony. In consequence, her DPhil certificate was never awarded, something we did not know until we were tidying her house contents in 2016. After we wrote to Oxford University, the Registrar promptly supplied the missing certificate, which (at the age of almost 90) she proudly hung on her wall at last. This thesis is therefore dedicated to her and to late scholarship wherever it may happen to bloom.

Statement on joint authorship

The included papers all have either three or four authors. My name most frequently occurs as the last, senior author (five times), as second author three times, and as first author just once. The first authors of the other papers were medical students (four papers), PhD students (two), and postdoctoral researcher (one) and a professorial colleague (one).

I played an active role in the design, conduct, supervision and reporting of each of these publications. The details for each included paper are described in Appendix 1.

Glossary

AD	Alzheimer's disease
AOTA	American Association of Occupational Therapists
BMedSci	Bachelor of Medical Science, degree attained by year 3 medical students at Nottingham, which involves completion of a research project
CMOC	Context-Mechanism-Outcome Configuration
EU	European Union
GEE	Groups of Experts by Experience
MinD	Designing for People with Dementia: an EU funded programme
NICE	National Institute for Health and Care Excellence
RCT	Randomised controlled trial
TAnDem	The Arts and Dementia: Alzheimer's Society funded doctoral training centre
UN	United Nations

Abstract

Aim: This thesis presents nine of my published papers based around a common theme of meaningful activity in dementia. The papers and the accompanying text will explore the concept of meaningful activity and whether it is relevant to dementia; the use of meaningful activities for people living with dementia in various settings; and the experiences of people with dementia participating in such activities.

Background: An overview of the published literature regarding four areas of meaningful activity is presented in Chapter 2. These areas, which reflect topics of the included papers, comprise: access to the outdoors; exercise and other group activities; dementia and the arts; and involving people with dementia in mindful design.

Chapter 3 is a critical discussion of the concept of meaningful activity. Meaningful activity is a concept with considerable limitations but remains useful in psychosocial research and practice in dementia.

Methods: The methods of each study are described in each of the nine included papers but the overall methodological approach is summarised in Chapter 4. In general, the approach is exploratory and qualitative, and places a strong emphasis on the voices and experiences of people living with dementia.

Results: As with the methods, the detailed results are included in each study. Chapter 5 provides an overall summary of the results, and combines results from those papers with similar methods. Altogether, over 100 people living with dementia have contributed to the data, either as study participants or in the process of co-design.

The nine papers included appear in Chapter 6, with the abstract as published and a commentary on each one. The full texts of the papers are reproduced in Appendices 2 to 10. The nine papers fall into four broad groups: Paper 1 is about outdoor access; Papers 2 to 5 concern exercise and other group activities; Paper 6 to 8 are studies of arts interventions; and Paper 9 is about design for and with people living with the dementia. The individual papers are as follows:

Paper 1 is an invited editorial that argues for improved access to outdoor space for all people with dementia, whether resident in their own homes or in care homes. This argument is based upon a human rights perspective.

Paper 2 reports a qualitative study of a community based sports and exercise group for men with young onset dementia. Four main themes were identified, with enjoyment, anticipation and the creation of a ‘dementia-free’ environment, set alongside less positive themes of loss and lack of other appropriate resources.

Paper 3 is a qualitative study of using multisensory boxes as the basis for a storytelling group intervention for care home residents with dementia. The themes generated in our

analysis included engagement, curiosity about the contents of the boxes, and the opportunity for self-expression.

Paper 4 describes a qualitative study of a Boccia (modified indoor bowls) group for people with dementia. Four main themes were identified, three of them positive: the family nature of the group, the characteristics of Boccia as a sport, and the sense of equality and freedom from dementia in the group.

Paper 5, another qualitative study, investigated a weekly swimming group for people with dementia. Themes included the impact of dementia, the pleasure of swimming, and how the group created a sense of equality or being ‘all in the same boat’.

Paper 6 reports two case studies of arts interventions for care home residents that were provided as part of a larger arts project. The case studies explored the perceptions of the artists and care home staff and draws attention to the crucial role of care home activity co-ordinators.

Paper 7 includes more than one individual study (focus groups and case study) that were used to create a taxonomy of arts interventions in dementia. The paper presents a striking visual model with twelve descriptive dimensions, thus providing a common language for description and future research.

Paper 8 is a single case study of a person with advanced dementia and her interaction with a visual art installation in an exhibition, using video analysis. The study was an exploration of capturing the in the moment experience of the participant but also as to whether a person with profound disability could engage with visual art.

Paper 9 is a report on a European programme of work around mindful design with and for people with dementia, which provides a background to the work, a description of the models and the approach to co-design that were used, and concludes with a series of design guidelines for different stakeholder groups.

Discussion and Conclusions: The main findings and the contribution of the work as a whole are presented and discussed in the final chapter of the thesis. Collectively, the papers present several positive findings. Participation in groups providing exercise or stimulating activities is enjoyed and valued by those taking part. Under the right circumstances, such activities have powerful effects, such as levelling things up for people with dementia, creating equality between group members, and reducing the sense of ‘us and them’ (that is, people with and without dementia). These effects act to enhance the dignity and confidence of participants and reduce the stigma of dementia.

In addition, establishing meaningful collaboration with people with lived experience of dementia requires attention to several elements: how and why people are approached initially; how the invitation to participate is framed; observing relevant rights, permissions and consent; creating an equitable and inclusive working environment; and accessible communication and participatory activities that include everyone. There is much common ground across the nine papers, which may be described as an overriding theme of rights, empowerment, liberty and activity, all of which aim at enjoyment and social interaction.

The studies included in this thesis have certain strengths, which include the exploratory nature of the studies, the collection of data in naturalistic surroundings, and the emphasis on recording the experiences of the participants with dementia. Possible limitations include the relatively small sample sizes and lack of quantitative data, though it is argued that these are not really required in exploratory studies looking at people's personal experiences.

As a body of work, the nine papers in this thesis make a significant contribution to research and scholarship in the area of meaningful activity in dementia. Future research will need to explore the mechanisms by which interventions 'work' and to continue exploration of studying in the moment experiences. Involvement of people living with dementia is essential in order to design products or activities that they may value, and in order to ascertain that allegedly meaningful activities actually do have personal significance.

Chapter 1: Introduction

1.1 Dementia

Dementia is a syndrome arising from a variety of diseases of the brain, the most common being Alzheimer's disease. Dementia is an age-associated condition with its prevalence and incidence increasing sharply in each decade from middle age onwards. Reflecting the ageing global population, numbers of people with dementia are increasing in most countries in the world. There are currently over 50 million people with dementia in the world, predicted to double approximately every 20 years (Alzheimer's Disease International, 2021). A recent estimate of the number of people with dementia in the UK is 850,000, growing to 1.5 million by 2040 (Wittenberg et al., 2019). Further information on dementia, including causes, symptoms, diagnosis and management can be found in a series of papers published in the Nursing Standard (Dening and Sandilyan, 2015a,b; Sandilyan and Dening, 2015a,b,c).

Potential pharmacological treatments for conditions such as Alzheimer's disease are much sought (Scheltens et al., 2021) though so far no drug with genuinely disease-modifying properties has been licensed. Therefore, the most important aspects of treatment and care include dementia prevention (Livingston et al., 2020), the assessment and diagnosis of dementia (Arvanitakis et al., 2019), and non-pharmacological approaches to support people with dementia and their families (McDermott et al., 2019).

Other aspects of dementia that have received more attention in recent years concern such matters as decision making around health and social matters, e.g. advance care plans (Dening et al., 2019) and end of life care (Lloyd-Williams et al., 2017). The representation of dementia in the media and creative arts has also attracted research (e.g. Bailey et al., 2021). There has also been a welcome growth in the voice of people with dementia, for example dementia activists such as Kate Swaffer and Wendy Mitchell, as well as increasing numbers of news stories featuring celebrities and sports stars with dementia. The human rights of people with dementia is also an important topic (Cahill, 2018), with recognition that dementia falls within the remit of the UN Convention on the Rights of People with Disabilities (United Nations, 2006).

This thesis concentrates on a particular area of psychosocial research in dementia, that is around activities undertaken by people with dementia, and the idea of meaningful activity. Rights and autonomy for people with dementia are an important theme in the thesis. The remainder of this chapter contains a reflexive account of the personal background to this body of my research, and then summarises the plan for the rest of the thesis. A critical discussion of the concept of meaningful activity will be found in Chapter 3.

1.2 Personal background

A doctoral thesis is primarily a contribution to research, evidencing original work in a particular field and a contribution to scholarship. It is of course other things too. A good thesis will have a powerful narrative that brings together the context in which the work is set, and how the research questions have been addressed. It describes the implications for future research, practice and policy, and it leaves the reader with a sense of having encountered something worthwhile. The research, thesis preparation, examination and graduation form an important rite of passage, that in many cases opens portals for career progression, not to mention adding 'Dr' in front of the candidate's name. The thesis also forms a journey, both temporal and intellectual, which for most PhDs spans about three or four years and equates to around 10% of the life so far of most younger candidates. This thesis aims to address these four axes – advancing research, strong narrative, rite of passage, journey – though the journey described here is probably over at least 30 years rather than the average three to four.

I obtained my medical degree just over 40 years ago. I was attracted into psychiatry by its common ground with neurology and brain sciences, and my MD thesis (Dening, 1989) was very neuropsychiatric in its orientation. I studied a large cohort of patients with Wilson's disease (Dening, 2020). My subsequent career in old age psychiatry reflected these interests but in over 30 years as a consultant I have noticed a change in my approach. I gradually became more focused upon the lives of people rather than just their brains. Although the relationships between brain pathology and mood and behaviour remain of interest, I became increasingly fascinating by the narratives of people's lives and aware that hearing these was among the main motivations for doing my job. Similarly, as time went on, I became less preoccupied with the idea of future cures for dementia and more intent on what happens now. There are already nearly a million people living with dementia in the UK. They don't spend most of their time seeing doctors; indeed, over several years of having dementia, they may have very little contact with doctors at all. Therefore, actually it's what they do most of the rest of the time that will have the most influence on the outcomes for them and their families.

So, by the time I had the privilege of moving to an academic post at Nottingham in 2012, I was much more interested in psychosocial and epidemiological aspects of dementia research than I was in more biological topics. The papers that I am submitting for this PhD reflect these interests. A second theme reflects my role as head of the newly-formed Centre for Dementia and the need to develop young researchers and increase research capacity. Thus, the first authors of four included papers were medical students, and two more papers emerged from PhD research with students from the TAnDem (The Arts and Dementia) doctoral training centre funded by the Alzheimer's Society, and hosted jointly by the universities of Nottingham and Worcester.

1.3 Summary of included papers

This selection includes a total of nine publications. They relate in various ways to a common theme of meaningful activity in dementia. The papers fall into four unequally sized groups, reflecting a range of topics: dementia and the outdoors; exercise and group activities for people living with dementia; the arts and dementia; and design for and with people with dementia. All nine papers were co-authored and my contribution to each is set out in the statement of joint authorship (see page 6) and in the more detailed statements agreed with, and signed by, my fellow authors included in Appendix 1.

Paper 1, though not the earliest, opens the collection as it is an invited editorial and sets out some of my views on the importance of activity – in this instance, specifically about access to the outdoors. The paper started with limited aims about how care home residents rarely get out of doors. It became clear that we could be bolder than this and we broadened the scope to people living in their own homes. In particular, we argued that 'care at home' should not mean incarceration. I also invited Peter Bartlett, an academic lawyer, to join us and we set the paper in a frame of human rights. The idea for the title was also mine. I am surprised that we got away with it, as one might have expected the phrase to be copyright.

Papers 2 to 5 report research from four consecutive years of Nottingham BMedSci projects, involving a total of five students. The papers are quite similar methodologically as they involved the student making contact with an organised activity, acting as a participant-observer, and conducting interviews with people involved, including people with dementia. The main method of analysis was thematic analysis of the interview data. I was indebted to my colleagues, Victoria Tischler and Charlotte Beer, who had much more competence in qualitative methods than I did. My contribution was usually around developing the research idea and making contact with the activity providers. For example (Paper 2), the contact with Notts County Football in the Community followed my attending a presentation that they gave to a high-level meeting at Nottinghamshire Healthcare NHS Foundation Trust and approaching them afterwards about a possible project. Paper 3 was made possible by contacts that Victoria Tischler had made at Boots UK, but I found a suitable and welcoming care home location for the study to run in. The contact for the study in Paper 4 arose when the organiser of the Newark Boccia group happened to call into a Radio Nottingham phone in that I was doing one morning. I called him back straightaway about doing a project with them. Paper 5 also arose from opportunistic contacts with Nottingham City Council and Swim England. All four studies were fun to conduct, the students had a great experience, and the hosts were also delighted to collaborate as it helped them with publicity for their activities. For all five students, the journal paper was their first publication and not only were they delighted but it materially improved their job options.

Papers 6 to 8 are arts-based studies of differing kinds. This reflects how important the arts are as a potential activity for people of dementia, whether they live at home or in residential care. Papers 6 and 7 arose from work done by two talented PhD students (Emma Broome and Emily Cousins), for whom I acted as the primary supervisor. Paper 6 is a case study of participative arts sessions in two care homes. This research was nested within another grant-funded project, Imagine Arts, funded by the Arts Council and the Baring Foundation, for which I had played a crucial role in bringing together the two main partners, Abbeyfield and Nottingham City Council, with University of Nottingham having a smaller, evaluative, role. Paper 7 is more complex as it brought together several components of the PhD alongside the theoretical discussions we had conducted, to generate the elegant graphical models. These were ultimately Emily's creation but arose from a lot of interplay with her supervisors. Paper 8, funded by a small grant from Alzheimer's Research UK, ingeniously used gallery space at the University to expose people with dementia to new art – somewhat poignantly, the last final year exhibition of Nottingham Fine Art students. My contribution to this was around the dementia aspects, facilitating the gallery visits, and of course in writing and editing the paper.

Paper 9 forms a suitable concluding piece as it looks to the future. It is a report from a large European project (MinD – Designing for People with Dementia), summarising several years work on codesign with people living with dementia. The full document is over 20,000 words long, so here is included just the executive summary. The design guidance was the deliverable from one of the work packages, which was led by the Nottingham group. The authorship of the report reflects this as the only non-Nottingham author is the chief investigator for the whole project. We were proud of our work on this, which included several involvement groups across the partner groups, though the most active leadership was provided by Nottingham, especially by my colleague Julie Gosling. Pulling the report together, with approval from all partners, was a big task for several months in mid-2019.

1.4 Thesis plan

The following chapters of this thesis include an account of the research background relevant to my four groups of papers (Chapter 2); a critical discussion of the concept of meaningful activity in dementia (Chapter 3); summary descriptions of the methods and results of the nine papers (Chapters 4 and 5); the papers themselves, each with a commentary (Chapter 6); and lastly discussion and conclusions from the body of work as whole (Chapters 7 and 8).

In conclusion, I suggest that these nine publications portray the commitment that my research has shown to promoting meaningful activities for people with dementia. I am pleased to develop these ideas further in my PhD thesis.

Chapter 2: Background literature

This chapter provides an overview of the research literature relevant to the topics explored by the papers in this thesis, which as mentioned in Chapter 1.3, fall into four broad groups. Paper 1 deals with access to the outdoors; Papers 2 to 5 with exercise and other activities; Papers 6 to 8 with dementia and arts; and Paper 9 with participatory design.

The purpose of this chapter is to review briefly the research literature on each of these four topics in context by way of introduction. An overview is a summary of the literature that surveys the literature and describes its characteristics (Grant and Booth, 2009). Neither a systematic search nor a quality assessment of included papers is required, and synthesis is usually in the form of a narrative.

Chapter 3 follows on from this chapter by providing a critical discussion of the concept of meaningful activities, since that is the overarching theme of this body of research.

2.1 Access to outdoors

Most research about the environment and people with dementia focuses on care homes and much more attention is paid to the internal and built environment than to outdoor spaces, e.g. Barrett et al. (2019). Where outside spaces are considered, this is therefore usually the garden of the care home. Two reviews (Whear et al., 2014; Gonzalez and Kirkevold, 2014) examined, respectively, the impact of access to gardens, and the effects of sensory gardens and horticultural activities for people with dementia. Inevitably, they included some of the same papers in their review, and reported similar conclusions, which were that the studies included showed some evidence of benefits, especially in terms of behaviour such as agitation. Whear et al. (2014) also reviewed eight studies with qualitative data and identified five themes: the nature of the activity; interaction with other people; impact; possible mechanisms; and negatives (safety concerns and lack of staff time). The review by Gonzalez and Kirkevold (2014) was not solely limited to care homes because of their interest in horticultural activities, which can of course be accessed by people dwelling in the community. They did not report outcomes for horticultural activities separately from the more passive exposure to sensory gardens, which seems unfortunate, though their data seem to suggest that horticultural activity was frequently associated with improved mood and/or sleep.

D'Cunha et al. (2020) reviewed the effects of activities provided outside of the care home for residents with dementia. Not all studies described outdoor activities but there were four studies of wheelchair cycling, horse riding, horticulture and supervised walks. There was evidence of benefits in terms of psychological and physical outcomes. However, there was only a small number of studies to include, which suggests that such initiatives are not common. Also, several barriers were identified, such as concerns about safety, the need to plan ahead, and resources needed to provide travel to and support during the activity.

An alternative approach to research is to investigate the relationship between characteristics of the local environment and the risks of cognitive decline or dementia. This is complex, for example, deciding which environmental measures to use and how to control for variables such as deprivation or individual risk factors for dementia (Wu et al., 2015). Wu et al. (2017) found that high land use mix, a measure of the diversity of types of environment, and (in conurbations) access to the natural environment, were associated with lower risks of developing cognitive decline and dementia. Access to green spaces and parks has also been associated with lower risks of other common mental health disorders (Wu et al., 2015, Hystad et al., 2019). These results suggest that access to outdoor space and to nature are important in even the early part of the dementia journey.

Overall, existing research suggests that there are benefits for people with dementia having access to outdoor spaces. So far, studies have focused on rather limited contexts, mainly care homes and their gardens. Also, it appears that outdoor access is often limited by concerns about safety and staff factors. There is a need to take a wider perspective and do more to enable people with dementia to be outdoors whenever they wish.

2.2 Exercise and activities

The scope of all psychosocial activities for people with dementia is vast and beyond the scope of this discussion. McDermott et al. (2019) conducted a synthesis of systematic reviews of psychosocial interventions in dementia, which included 22 reviews and 197 individual studies. Most of these were concerned with cognitive and psychological interventions, but there were nine reviews of exercise interventions. This section will discuss research on dementia and exercise in order to set in context the papers included in this thesis.

It is generally accepted that physical inactivity is a risk factor for developing dementia. Longitudinal studies have found, for example, that moderate to vigorous exercise (Zotcheva et al., 2018) and higher physical fitness in midlife (Hörder et al., 2018) were associated with lower risks of dementia in later life. Sommerlad at al. (2020) found that exercise levels in the participants’ mid 60s was associated with lower dementia risk, but this was not so for exercise levels in mid 50s. They also noted a decline in physical activity preceding the onset of dementia, suggestive that inactivity may be a prodromal manifestation of dementia. Overall, physical inactivity has been estimated to be an independent risk factor contributing about 2% of the total population attributable risk of dementia (Livingston et al., 2020).

There are numerous trials of exercise interventions aimed at the prevention of dementia, and several systematic reviews have been published (e.g. Brasure et al., 2018; de Souto Barreto et al., 2018). Overall, these concluded that there was no evidence that exercise programmes prevent dementia, though a systematic review of tai chi did find modest evidence of benefit in cognition and executive function, both in comparison to non-intervention and control groups receiving other exercise interventions (Wayne et al., 2014). The main limitations of studies included in systematic reviews were that the intervention was too short or that the follow-up period was insufficient to show any differences that might arise.

Turning to exercise for people with diagnosed dementia, a Cochrane review (Forbes et al., 2015) found evidence of improved activities of daily living in a subset of six of the 17 trials in their review. However, the was no evidence of improvement on other outcomes, such as cognition. Notably, all but two of the included trials took place in institutional settings, so there is little information about exercise activities in community settings.

So far, trials of exercise interventions in community-dwelling people with dementia have been conflicting. Pitkälä et al. (2013) reported slower functional decline and fewer falls over 12 months follow-up in groups receiving either home-based or group-based exercise compared to controls receiving usual care. Hoffmann et al. (2016) reported decreased neuropsychiatric symptoms in the intervention group receiving moderate-to-high intensity exercise over 16 weeks compared to controls, but no differences in cognitive or functional outcomes. Yoon et al. (2018) reported a 4-month trial of resistance exercise training for people with cognitive frailty, with the intervention group having significantly better cognitive and physical outcomes compared to controls. However, Lamb et al. (2018) found no improvement in cognitive decline or any other outcomes apart from physical fitness from a 4-month exercise programme compared to usual care. Another noteworthy trial currently underway is the Nottingham-led PrAISED (Promoting Activity, Independence and Stability in Early Dementia) study, which includes a 12-month supervised exercise intervention, and so far has completed a feasibility study for the main trial (Goldberg et al., 2019).

Thus far, the evidence is unclear and several questions remain unanswered, for example, which types of exercise may be most effective. The strongest evidence appears to be in favour of resistance training, meditative movement interventions (such as tai chi) and exercise-based active video games (Di Lorito et al., 2021). Other issues to be resolved include the possible benefits of group interventions, the characteristics of professionals delivering the intervention and how this may affect outcomes, and the impact of motivational factors, both the motivation of the person with dementia but also that of their carers (Di Lorito et al., 2021).

Most studies have involved relatively straightforward exercises, often delivered or supervised by an instructor. Less attention perhaps has been paid to the effects of exercise and interaction through pursuing sports or other specific pursuits. There have also been fewer studies exploring the experience of people participating in exercise, sports or other leisure pursuits. An exception is the study of Long et al. (2020), which used focus groups to evaluate an exercise class for people with dementia, and found that factors associated with success included access to the exercise venue, opportunities for socialisation and the presence of staff with experience in working with people with dementia. However, in general, the literature is rather top down, in that the exercise interventions are largely prescribed and the individual motivational and experiential factors may be overlooked; for example, whether there is a relationship between the level of enjoyment experienced and the other outcomes being measured.

2.3 Dementia and the arts

There is increasing recognition of the beneficial effects of the arts for health and well-being across the life course (Gordon-Nesbitt and Howarth, 2020). The benefits include both physical and mental health (Fancourt and Finn, 2019) and also arts engagement is associated with lower mortality, independent of demographic, social and other factors (Fancourt and Steptoe, 2019). Arts engagement may be helpful both in a preventive or protective sense or else may be used within the management and treatment of existing illness (Fancourt and Finn, 2019). The arts in relation to medicine and health form a major component of the emerging discipline of health humanities (Bleakley, 2020; Crawford et al., 2020).

Research and practice involving dementia and the arts has reflected this general appreciation of the positive effects of arts engagement and arts participation. Several reviews have been published that all suggest that the arts may have benefits for people with dementia (e.g. Beard, 2012; McDermott et al., 2013; de Medeiros and Basting, 2014; Zeilig et al., 2014; Young et al., 2015; Cavalcanti Barroso et al., 2020). These have some common findings, for example that included studies were variable in nature and design, they often had small sample sizes, and they often used general outcome measures, such as quality of life, without reference to meaning of the experience for the individual. De Medeiros and Basting (2014) reviewed creative arts interventions alongside pharmacological and other psychosocial interventions, and they were critical of the paradigm of randomised controlled trials (RCTs) as a way of assessing the impact of arts experiences. Their recommendations included: new types of study design; better description of the interventions; consideration of the social as well as the individual aspects of the intervention; the importance of assessing whether the participant is likely to be interested in what is being offered; and better, more appropriate outcome measures.

The limitations of the RCT paradigm are reflected when looking at the Cochrane Database of Systematic Reviews for reviews of arts interventions. There are just three reviews, of music-based therapeutic interventions (van der Steen et al., 2018), art therapy (Deshmukh et al., 2018), and dance movement therapy (Karkou and Meekums, 2017). Van der Steen et al. (2018) reviewed 22 trials and found that music-based interventions probably reduced depressive symptoms and improved overall behaviour, but there was limited or no evidence of effects on other outcomes. Deshmukh et al. (2018) identified just two studies for inclusion but the quality of evidence was low and there were no clear effects on outcomes. Karkou and Meekums (2017) could find no studies that met their inclusion criteria. Overall, therefore, this literature does not provide inspiring evidence to guide practice. There seem to be two possibilities: either arts interventions simply do not ‘work’ or else this methodology is not the best or most appropriate way of collecting evidence about the effects of arts for people with dementia. It may also be helpful to move away from using the concept of arts interventions as being too medical in nature, or implying too much interference or disruption of a person's life. Terms like arts experience or participatory arts seem preferable.

Recent research has responded to these methodological challenges by using novel methods or by selecting new questions for investigation that explore more individual responses to arts experiences. For example, the question of what creativity means in the context of dementia has been explored by Camic et al. (2018). Conventionally, creativity is regarded as a cognitive process and judged according to its outcome, e.g. a work of art, such as a painting, but in dementia this notion becomes problematic. Therefore, it is important to consider other aspects, which include the process and the experience, alongside the social interaction that is required to support a person with dementia. These aspects of process and experience are arguably more appropriate measures for research than traditional outcomes (Camic et al., 2018).

Another indication of growing diversity and methodological advance has been the funding of several recent programmes of arts and dementia research, which include Mark Making, Dementia and Imagination, and Created out of Mind. Mark Making was a review of participatory arts and dementia research, with illustrative case studies and collected views of people living with dementia on cultural and arts based approaches (Zeilig, 2016). Dementia and Imagination was a longitudinal, mixed methods study of a visual arts programme, looking at well-being, communication and quality of life among people with dementia both in community and residential settings (Windle et al., 2018). Created out of Mind was an interdisciplinary project aimed to change perceptions and understanding of dementia by a variety of creative activities hosted at the Wellcome Collection in London (Brotherhood et al., 2017).

A fourth project, the Dementia Arts and Well-Being Network (DA&WN), was led by and hosted at the University of Nottingham (Tischler et al., 2019). DA&WN consisted of four interdisciplinary workshops, actively involving people with dementia and their carers, as well as creative practitioners. Each workshop featured a different art form: dance movement, visual art, theatre and music. Guided participatory sessions were combined with group reflective discussions, with a focus on the elements that promoting well-being among people with dementia. The workshop model offered promise as a method for future research.

To summarise, research on arts and dementia has made significant progress, moving away from rather mechanical studies that provide group interventions and apply standard outcome measure. Instead, contemporary research focuses more on the process and experience of involvement with the arts, and looks at a broader range of useful outcomes which should be meaningful for the individual participants. There remain significant problems, for example the challenge of capturing or measuring a person's experience in the moment (Strohmaier et al., 2021), and the relative values of in the moment experience versus longer-lasting benefits. Another problem relates to terminology, for example that ‘music’ applies to a wide range of activities from personal playlists (Cunningham et al., 2019) to music therapy delivered by a highly trained specialist (Schneider, 2018).

It was in this context that our research into dementia and the arts took place, and it formed the background to the TAnDem (The Arts and Dementia) doctoral training centre, which is described in Chapter 4.

2.4 Design and dementia

The word design has several usages but its definitions include: ‘The … process, practice, or art of devising, planning, or constructing something (as a work of art, structure, device, etc.) according to aesthetic or functional criteria; (also) this as a subject of study or examination’; and ‘The completed product or result of this process; the arrangement of features in something planned or produced according to aesthetic or functional criteria; a particular shape, style, or model’ (Oxford English Dictionary, 2021). Thus the word includes a process, an academic discipline and a set of models or products. All three of these aspects are relevant to dementia.

Design is ubiquitous and surrounds our everyday lives (Niedderer et al., 2017). Most of the time, we are unaware of the process that has operated in designing the items that we use in home life, at work or in leisure time. However, in developing a novel product or service, the concept of personal design is central. Thus companies use volunteers or testing panels to assess new products, and amend them in response to the comments and reactions of the people using the prototypes. Although our response to design is often automatic, it may be helpful in the design process to increase our attentiveness, so as to make a link between use of an object and its consequences. One example of this uses the concept of mindfulness, hence the notion of mindful design (Niedderer, 2014).

Another key topic in contemporary design is that of end-user participation. It is generally accepted that involving consumers, users or members of the public in design and development of products is valuable, as it is a means of improving factors such as acceptability and usability. Such involvement may be at any stage of the design process from conception of the idea, through its development, and even includes post-marketing feedback. Three commonly used terms are co-creation, co-design and co-production, but other terms have been used as well, such as participatory design (Sanders, 2002). These three ‘co-‘ concepts are often used with various and overlapping definitions, and sometimes more or less interchangeably. McDougall (2012) defined them thus: co-design attempts to define a problem and then its solution; co-production is the attempted implementation of the proposed solution; and co-creation is the process by which people do both. In contrast. Blanco (2020) defined co-creation as the active involvement of end users in the different phases of the production process; co-design as synonymous with user-centred design and participatory development; and co-production as simply the process of engaging customers in an organisation’s work. The core of the problem is whether co-creation is seen as an overarching term that includes co-design and co-production, or whether co-creation is regarded as a subset of co-design (Blanco, 2020).

In relation to dementia, probably the earliest examples of person-centred design centred on assistive technology, and included three EU-funded projects: TED (Technology, Ethics and Dementia) (Bjørneby et al., 1999); ASTRID (A Social and Technological Response to meeting the needs of Individuals with Dementia and their carers) (Marshall, 2000); and ENABLE (Enabling products for people with dementia) (Hagen et al., 2004; Orpwood et al., 2004). These projects were not very participatory in their approach but they did provide some experience in design with people with dementia and their carers. Key elements described were: promoting a sense of independence; supporting people to make choices; focus on positive aspects of life; supporting and maintaining skills rather than emphasis on lost abilities or on disability; supporting the person’s self-image; building on existing solutions; and ensuring that information about a product’s use is always visible (Cahill et al., 2007).

Assistive technology remains an active area of research. However, evidence of user participation is often limited. For example, Gibson et al. (2016) categorised assistive technologies as being used ‘by’, ‘with’ and ‘on’ people with dementia, with many technologies falling into the third category. Meiland et al. (2017), in a literature review of assistive technology for community-dwelling persons with dementia, found that users (i.e. people with dementia) were often not involved in development or evaluation of technologies and that although ethical issues were often mentioned they were not often explored.

There is also a literature on environmental design and dementia, often featuring the architecture and fittings of care homes, though more recently there has been a focus on more person-centred aspects, e.g. Ludden et al (2019). Another approach has examined how design and technology can contribute to ‘autonomous ageing’ (van der Cammen et al., 2017) to promote more independent living and help compensate for functional deficits associated with ageing or long-term conditions.

Co-design involving people with dementia has become more common in the last decade. Wang et al. (2019) reviewed 26 studies, the oldest published in 2007 but the great majority since 2010. Studies were quite mixed but generally showed benefits for the participants, as well as there being a trend over time towards designing with people who had moderate and severe dementia.

However, the bulk of research has focused on design aimed at supporting function, and relatively few studies have had higher aims, for example to promote pleasure, enjoyment, social interaction and well-being. Exceptions to this have included the work of Treadaway et al. (2019), who described a design model known as compassionate design that actively involves people with advanced dementia; Tsekleves et al. (2020), who emphasised the importance of play and playfulness in achieving co-creation; and Rodgers (2018), who described the involvement of people with dementia in a project to produce a new tartan, from the development of the project brief right through to commercial production.

The MinD programme was aimed to combine several of these elements: mindfulness, personal design, user involvement, and products that would be enjoyable and help to promote independence and social interaction.

Chapter 3: Meaningful activity in dementia

Meaningful activity is a term that is often used in the field of dementia care. It is generally taken as a vital component of person-centred care. It is a term that people use freely, almost automatically. Perhaps there is good agreement as to what is meant when meaningful activity is spoken of. A current widely used definition is included in the NICE guidance on mental wellbeing of older people in care homes (NICE, 2013): 'Meaningful activity includes physical, social and leisure activities that are tailored to the person's needs and preferences'. The nature and scope of these activities are then listed, and I will return to discuss these aspects later in this thesis.

However, various questions may be asked. Where does the term come from? How long has it been in use? How is it measured? Do normal people concern themselves about engaging in meaningful activities, or is it just when there is a health condition or disability (such as dementia) that it becomes relevant that an activity is 'meaningful'? If so, why is that? Is meaningful activity a useful concept or simply a platitude? Would another word be a better alternative than 'meaningful'?

3.1 The concept of meaningful activity

Meaningful activity derives from the occupational therapy literature. It originates from discourse about the purposes of occupation and occupational therapy in the second half of the last century, moving away from simply looking at occupational therapy as a means of rehabilitating deficits to looking at such things as the human need for occupation (Wilcock, 1993) and links between activity and happiness (Csikszentmihalyi, 1993).

The notion of purposeful activities appears to have preceded that of meaningful activity, as evidenced by a consensus statement of the American Occupational Therapy Association (AOTA) (Hinojosa et al., 1993). Purposeful activity was defined as 'tasks or experiences, in which the person actively participates'. This requires co-ordination of a person's physical, emotional, and cognitive systems. It also requires that attention is directed to the task Itself, rather than to the internal processes required for achieving that task. Purposeful activity could yield one-off, immediate results or require to be sustained over a period of time. Finally, according to AOTA purposeful activities would be influenced by an individual's context and would have a unique meaning for that person. Some aspects of what would now constitute meaningful activity can be recognised here; for example, the unique meaning of the activity for the person. However, as defined by the AOTA, purposeful activity seems more focused on getting the task done, by whatever means, and there does not appear to be any mention of the individual's choice or autonomy, or whether they experience any pleasure.

Trombly (1995), in a published lecture to the AOTA, did make a distinction between 'purposeful' and 'meaningful' occupation. Purposeful was seen as a way of organising behaviour, while meaningful was more about motivating performance. Trombly suggested that occupation could be seen both as a means and as an end, which gave four combinations of purposeful/meaningful and occupation as a means or an end. Occupation as an end is aimed at achieving functional goals, whereas as a means it is more about the therapy and the journey to bring about change. Some of the other points made by Trombly (1995) also still remain relevant; for example, that no activity is intrinsically meaningful, and that meaningfulness is individual in nature, that is, it is a construction between the therapist and the person. Trombly recommended assessing whether an activity was meaningful by using measures of motivation, essentially the behavioural response, such as the time spent on the activity or the number of times it was repeated.

Other strands relevant to meaningfulness come from the spiritual dimension of occupational therapy and also concerns about occupational justice and injustice. For example, Egan and DeLaat (1997) have discussed how occupational therapy shares a belief in the inherent value of all beings, and how this spiritual dimension contributes to the holistic nature of assessment and practice. In their analysis, deriving meaning from activities acts alongside occupation to enhance relationships, whether to other people or some larger entity. Townsend and Wilcock, in a series of publications (e.g. Townsend and Wilcock, 2004), applied ideas from social justice to formulate the idea of occupational justice/injustice, where occupation is defined as participation in various forms of everyday life. Although this work is not specifically concerned with meaningfulness, it is difficult to see how occupational justice can occur without personal meaning to the individual.

Perhaps the first paper to use the term ‘meaningful activity’ in its title was that of Goldberg et al (2002) in a study of 32 people attending a community mental health programme. The participants were all aged between 27 and 64, and two-thirds had a diagnosis of schizophrenia, none with dementia. These authors explored the relationship between engagement in meaningful activities and quality of life in people disabled by mental illness, examining correlations between questionnaire responses regarding participation in activities, overall symptoms and quality of life. The main finding was that, although engagement in activities was correlated with overall satisfaction with life, most of the variance was explained by depression.

3.2 Measuring meaningful activities

There now exist at least five scales of meaningful or related (purposeful or pleasurable) activities that are applicable to people with dementia or older people with mental health problems, and these are summarised in Table 3.1. Two of them, the Pleasant Events Schedule-AD (PES-AD) (Teri and Logsdon, 1991) and the California Older Person's Pleasant Events Schedule (COPPES) (Rider et al, 2016) derive from an earlier scale, the Pleasant Events Schedule, which was originally used for people with depression. Although the COPPES has quite a recent publication date, it had an earlier phase when it was simply known as the Older Person's Pleasant Events Schedule (OPPES) (Gallagher and Thompson, 1981). Other variations of the Pleasant Events Schedule also exist, e.g. a version for nursing home residents published by Meeks et al. (2009).

The construction of most of them is similar, with varying numbers of possible activities listed and endorsed according to such parameters as frequency and enjoyability of the activity. The EMAS (Goldberg et al., 2002) is slightly different in that it enquires about activities in general without presenting a list of specific activities.

Most of these scales have not been extensively used, and the publication of the most recent (Tuijt et al., 2020) is too recent to determine if it will be widely taken up. One problem may be that the purpose of such scales is not entirely clear. For example, are they a suitable outcome measure, or are they better used as a measure of process? Use of a meaningful activities scale as an outcome could be problematic, since it would merely measure whether a person was undertaking more (or a wider range of) activities, but this would be insufficient to demonstrate that this was of genuine benefit, or indeed that the activities were genuinely meaningful for the participants.

Another issue is that studies have shown that scores on meaningful activities scales are heavily influenced by other variables, such as depression (Logsdon and Teri, 1997; Goldberg et al., 2002), severity of cognitive impairment (Logsdon and Teri, 1997) or functional independence (Tuijt et al., 2020). Thus the scales might simply be checklists or else complex composite variables, that act as proxies for other processes, such as depression or more severe dementia.

Table 3.1: Scales of meaningful or related activities

Authors	Name of scale	Content	Intended application
Teri & Logsdon (1991); Logsdon & Teri (1997)	Pleasant Events Schedule-AD (PES-AD)	53 items rated by carer or jointly with person with dementia – frequency, availability, pleasurability of each item	Dementia, mild to severe
Goldberg et al (2002)	Engagement in Meaningful Activities Survey (EMAS)	12 self-rated items, a series of statements about the quality of activities, each scored on a 5-point Likert scale	People disabled by mental illness; not dementia
Eakman et al (2010)	Meaningful Activities Participation Assessment (MAPA)	28 activities, each rated by frequency and degree of meaning – multiplied to give score of 0-672	Older people
Rider et al (2016)	California Older Person's Pleasant Events Schedule (COPPES)	66 items, each self-rated by how often they occurred and how pleasurable they were	Treatment of depression in older people
Tuijt et al (2020)	Meaningful and Enjoyable Activities Scale (MEAS)	20 meaningful and enjoyable activities rated by carers on an ordinal scale (0-4) of frequency, from ‘almost daily’ to ‘never’	Mild dementia

3.3 Meaningful activity and dementia

The earliest paper identified in a PubMed search for dementia and meaningful activity/ies was by Mayers and Griffin (1990), which was a study of using toys and other playful objects to provide stimulation for patients with dementia on a geriatric psychiatry ward. The study made a single mention of how agitation could result from a loss of purposeful and meaningful activity. As with many other studies, mention of meaningful activity was made largely in passing, rather than being the main focus of the paper.

The first papers to look specifically at the notion of meaningful activities in dementia were published by Phinney and colleagues (Phinney 2006; Phinney et al., 2007). Phinney et al. (2007) used interpretative phenomenological analysis of interview and observational data from eight people living with dementia in the community. The main contribution to meaning seemed to arise from activity, being as active as possible, in a wide range of activities. The authors described three themes: feelings of pleasure and enjoyment; a sense of connection and belonging; and retaining a sense of autonomy and personal identity. Phinney (2006) also examined the strategies used by the family carers to support meaningful activity, and identified three approaches: reducing demands; guiding; and accompanying. Reducing demands described how families were able to structure the activities, thus reducing cognitive demands upon the person with dementia and reducing the impact of their disability. Guiding included two aspects, reminding the person of what they were supposed to do and providing instruction to keep them on track. Accompanying comprised several strategies, e.g. taking the person with dementia alongside while doing everyday tasks, seeking new activities to give stimulation, or engaging other people to give support to give the carers some time to themselves.

Another relatively early publication with meaningful activities mentioned in the title was by Vernooij-Dassen (2007), an editorial discussing the findings of a programme of sustained activities in long-term care. This illustrates how adhering solely to the idea of meaningful activities tends to ignore other important work during this time on various kinds of activities and psychosocial interventions, which used different terminology.

Harmer and Orrell (2008) addressed the question of what was meant by meaningful activity for people with dementia living in care homes, by means of a qualitative study of focus groups involving a total of 17 residents, 15 staff members and eight family members from three care homes. Harmer and Orrell identified four themes underlying meaningful activity: reminiscence; family and social; musical; and individual. They found an interesting difference between residents on the one hand and family and staff on the other, with residents finding meaning in the quality of the experience from an activity, rather than from the nature of the activity itself. In contrast, relatives and staff tended to regard activities that aimed to preserve function as being more meaningful. This difference is similar to the distinction made by Trombly (1995) (see previous section on the origins of the concept) between meaningful and purposeful activities, the one type being more concerned with the journey and the other focusing on the desired outcome.

Beyond this point, the number of studies that make reference to meaningful activities increases and it is probably unhelpful to attempt to discuss them all. Instead, as there are now several systematic reviews of activities studies in dementia, a brief narrative overview of relevant systematic reviews is provided in the next section.

3.4 Narrative overview of reviews: meaningful activity and dementia

This section provides a brief overview of systematic reviews on meaningful activity and dementia, with the purpose of summarising the literature to date. It is not a formal systematic review of reviews, though that would be a useful project to undertake in the future. Instead it is intended to be exploratory in nature.

3.4.1 Question

What evidence is available about the use and impact of interventions aimed at providing meaningful activities for people with dementia?

3.4.2 Methods

The design of this brief review is a narrative overview of systematic reviews. One only data source was used: PubMed systematic reviews. The search strategy was a simple search for titles on “meaningful activity AND dementia”. All titles and abstracts were read.

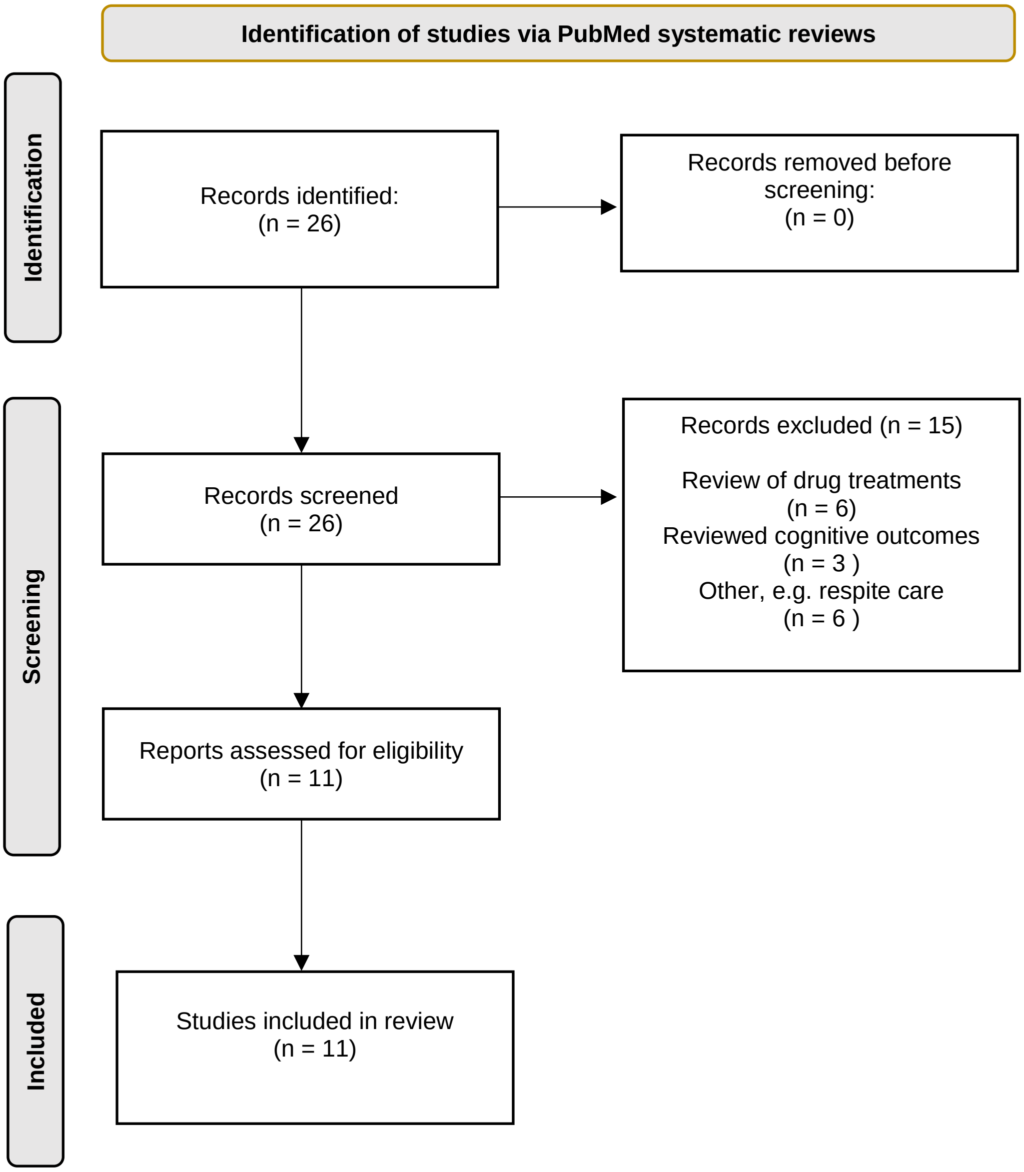
The inclusion criteria were: mention of ‘meaningful activity’ in title or abstract; mention of conceptually similar terms, e.g. pleasurable activity. There was no date or language restriction. Exclusion criteria were a failure to meet the inclusion criteria, and also reviews looking at other specific outcomes, e.g. cognition, rather than enjoyment or quality of life, were excluded.

Full texts of all included papers were read. A summary table was constructed to show their main findings. A narrative approach was taken for integrating main findings.

3.4.3 Results

The search results are summarised in a PRISMA flow chart (Page et al., 2021) (Figure 3.1). Twenty-six papers were identified by the initial search, of which 11 met the inclusion criteria and were included in the review. Of the 15 papers discarded, 6 were reviews of drug treatments, 3 reviewed cognitive outcomes, and 6 reviewed other outcomes (such as behaviour and respite care).

Figure 3.1: PRISMA flow diagram of systematic reviews of dementia and meaningful activity



PRISMA flow diagram template from: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. (2021) The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 372: n71. doi: 10.1136/bmj.n71.

The 11 included papers are summarised in Table 3.2. All but two reviews were published since 2016. Four reviews were published from Australia, four from mainland Europe, two from the UK, and one from the USA. The authors derive from a range of academic disciplines, including nursing, psychology, occupational therapy, and social gerontology.

The reviews are quite heterogeneous, as they often examine different populations, and explore different research questions. For example, Irving et al. (2017) reviewed studies using purpose of life measures in older people, not specifically with dementia. Alsawy et al. (2017) reviewed communication involving people with dementia, though this review was eligible for inclusion in my overview because they made a strong link between good communication and establishing meaningfulness for people with dementia. Marshall and Hutchinson (2001) provided a critique of the existing literature on activity interventions, rather than dwelling upon the findings of these studies.

Four reviews examined people with dementia residing in care homes (Lawrence et al., 2013; Travers et al., 2016; Möhler et al., 2018; Jones et al., 2020). Three reviews dealt with the application of technology, including the use of computers to create meaningful activities for people with dementia (Liapis and Harding, 2017; Goodall et al., 2020), and also the involvement of people with dementia in the design and development of supportive technology (Suijkerbuijk et al., 2019).

The methodologies of the reviews are also variable. There are two Cochrane reviews (Möhler et al., 2018; Möhler et al., 2020), which also provide the only meta-analyses. Travers et al. (2016) conducted a Janet Briggs Institute review, with a quantitative synthesis of included studies. Most of the other reviews used systematic search methods, with usually a flow chart to illustrate the search process and selection of included studies. Eight of the reviews employed a quality rating tool for included studies, with two each using the GRADE system (Guyatt et al., 2008) and the Mixed Methods Assessment Tool (MMAT; Hong et al., 2018).

The outcomes of interest were varied, which reflects the mixed nature of this group of reviews. The commonest were quality of life, behavioural and psychological symptoms of dementia (BPSD) and mood. None of the reviews appears used any of the scales of meaningful activity described in the preceding section of this thesis. Most reviews provided a narrative or descriptive synthesis.

In view of this heterogeneity, the findings of the 11 reviews are difficult to combine. However, there probably are consistent messages to be derived from their results. First, the idea of meaningful activities (or alternative terms like individual activities or personally-tailored activities) is a powerful and attractive concept. Meaningful activity can be either facilitated, in which case it may be regarded as therapy or as a therapeutic intervention, or non-facilitated, which includes the provision of a range of things, such as animals, dolls, or robot pet devices like Paro the Seal (Hung et al., 2019).

There is some evidence that engaging people with dementia in meaningful activities may be of benefit against various outcomes, of which challenging behaviour or BPSD have been most frequently examined. Evidence for benefit against other outcomes, such as mood or overall quality of life, appears weaker.

The use of technology appears promising, including involvement of people with dementia in co-design and development of technology. Using personal computers to create and deliver meaningful activities seems feasible, acceptable and enjoyable.

Other factors that help to promote meaning and purpose in life, including through better communication, also seem to be important. Good communication requires that people with dementia are treated with due respect, but it enhances relationships, activities and meaningfulness.

Table 3.2: Systematic reviews of meaningful and related activities in dementia

(AD = Alzheimer's disease; BPSD = behavioural and psychological symptoms of dementia; LTC = long term care; PWD = people with dementia; QoL = quality of life; RCT = randomised controlled trial)

Authors and country	**Description of review**	**Number of papers**	**Number of participants**	**Type of activities reviewed**	**Outcomes studied**	**Findings**
Marshall & Hutchinson (2001) USA	Systematic review and critical analysis of the literature	33	n/a	A range of therapeutic activities provided for people with Alzheimer's disease	Conceptual basis & methodology of studies, including sampling, design & measurement, description of interventions and outcomes	Although there is much interest in activities for people with AD, current research has numerous shortcomings. Authors suggest ways in which this could be improved
Lawrence et al. (2012) UK	Systematic review and meta-synthesis of qualitative research	39	n/a	Psychosocial therapies designed to improve outcomes for people with dementia in care homes	Beneficial elements of a psychosocial intervention; conditions required for successful implementation; & challenges to successful implementation	Beneficial interventions enable PWD to connect with others, make a meaningful contribution, and reminisce. Successful implementation needs active input from staff and families, and also to be continued over time
Travers et al. (2016) Australia	Janet Briggs Institute review, with quantitative synthesis	34	n/a	Individualised activities for PWD living in residential care facilities v. control or usual care	QoL, BPSD, mood, cognition, function, sleep	Meaningful or individualised activities for PWD in LT care appear to be effective for various BPSD, e.g. preferred music for agitation, depression & anxiety; reminiscence for mood

						and cognitive functioning. However, the relative contribution of the activity v. 1:1 social interaction is unclear
Alsawy et al. (2017) UK	Mixed methods systematic review	15	n/a	Communication specifically involving PWD	Feedback on experiences and perspectives of communication, obtained from participants	Communication difficulties often affected interpersonal relationships and activities of daily living. Conversely, personhood strategies and strong underlying relationship facilitated communication. Only one study examined perspectives of PWD and emphasised the importance of retaining valued relationships and feeling respected during communication
Irving et al. (2017) Australia & New Zealand	Systematic review with narrative synthesis	31	>10,000	Physical and psychosocial effects of purpose in older people and variables associated with higher reported purpose	Quantitative measures of purpose in life	Greater reported purpose is related to better health and well-being outcomes for older adults. Purpose generally declines with age, but it can be maintained, e.g. by continuing social roles, meaningful activities, etc.
Liapis & Harding (2017) Australia	Systematic review with descriptive synthesis	9	13130 in population risk studies 59 in feasibility/	Preventive or therapeutic benefits of computer use among people with	Prevalence of MCI or dementia (population risk studies); QoL; engagement,	Computer use associated with decreased risk of dementia. Computer-based activity interventions are feasible and enjoyable for PWD

			intervention studies	or at risk of dementia	acceptability or feasibility of computer use	
Möhler et al. (2018) Germany	Cochrane review with meta-analysis	8	957	Personally tailored activities for improving psychosocial outcome for PWD in LTC	QoL, challenging behaviour, positive & negative affect, mood	Personally tailored activities for PWD in care homes may slightly improve challenging behaviour when compared with usual care, but no evidence that this is better than offering non-personally tailored activities. No evidence of benefits for other outcomes
Suijkerbuijk et al. (2019) Netherlands	Systematic review with descriptive synthesis	49	n/a	Active involvement of PWD in design of technology	Phase of technology development, role of PWD, research methods & materials, impact of involvement on technology & participants	PWD can influence the development of supportive technology including the initial idea, content and design. More work needed to establish appropriate methods and materials for active involvement of PWD
Goodall et al. (2020) Norway	Systematic review with narrative synthesis	29	231	Use of technology in creating individualized, meaningful activities for PWD	Nature and extent of use of technology to enhance meaningful activities; effects of technology on outcomes such as memory, mood, well-being, social engagement	Using technology to create individualised, meaningful activities appears promising in terms of improving behaviour & promoting relationships with others
Jones et al. (2020) Australia	Systematic review with descriptive synthesis,	6	628	Non-facilitated meaningful activities for PWD in LTC facilities	Psychological outcome measures, e.g. QoL, loneliness, mood & BPSD	Meaningful non-facilitated activities (e.g. music, stimulated family presence, animal-like social robot

	RCTs or quasi-experimental controlled trials					PARO/plush toy, lifelike dolls) may have beneficial effects on agitation, emotional well-being, feelings of pleasure, engagement, & sleep quality
Möhler et al. (2020) Germany	Cochrane review, RCTs and quasi-experimental designs with controls, meta-analysis	5	262	Personally tailored activities for improving psychosocial outcomes for PWD in community settings	Challenging behaviour & QoL (primary outcomes), plus range of secondary outcomes	Personally tailored activities may reduce challenging behaviour and may slightly improve QoL. Few effects on any secondary outcomes apart from slight reduction of carer distress. All evidence was of low certainty

3.4.4 Narrative overview: discussion

This overview suggests that meaningful activity for people with dementia is an important topic for research. However, it is not entirely straightforward. The definitions of meaningful activity used are not always specified, or alternative terms like personally-tailored activities are used. For various reasons, the effects of meaningful activity are difficult to evaluate by more formal methodologies, such as randomised controlled trials. In particular, it is difficult to find a suitable control condition. But also, by their nature, meaningful activities are individual, so it may be difficult to ensure that a treatment group allocated to an intervention is indeed having a meaningful experience. Also, as noted by Travers et al. (2016), providing a meaningful activity is usually associated with increased individual time with staff or a family member, and it is difficult to distinguish between any specific effect of the meaningful activity and the powerful, non-specific effect of increased human contact.

This overview has certain strengths in that it brings together a diverse group of reviews that, in turn, have included over 200 individual studies, with several thousand participants. The overview's findings suggest that there is an identifiable corpus of work around meaningful activity for people dementia but also considerable vagueness about the boundaries of the concept and its application. The inclusion criteria used here have been relatively wide because of the exploratory nature of this overview.

Clearly, the overview has some major limitations. It is deliberately quite brief and exploratory in its current form, mainly for reasons of time and personal resource. Only one database has been used (PubMed) and only a single search has been conducted by a single reviewer, so clearly some key references may have been overlooked. No formal quality assessment of the reviews included has been performed, so there is no measure of the relative confidence to be had from the conclusions of each review. However, as the purpose here is exploratory, this is not crucial at this stage. It will be possible to revisit this overview as a collaborative project, e.g. with Masters students, in which case the review would be conducted at a higher level of rigour, with a view to later publication.

3.5 Meaningful activity in 2021

This section considers the current status of the concept of meaningful activity and then discusses some of the questions posed at the beginning of this chapter.

The most readily accessible definition of meaningful activity is that provided by NICE (2013), in the Quality Standard (QS50) on mental wellbeing of older people in care homes. NICE provides six quality statements, most of which relate to recognition of mental, sensory and physical health problems, and access to health care. However, the first quality standard is entitled Participation in Meaningful Activity, and the following definition is provided:

> *Meaningful activity includes physical, social and leisure activities that are tailored to the person's needs and preferences. Activity can range from activities of daily living such as dressing, eating and washing, to leisure activities such as reading, gardening, arts and crafts, conversation, and singing. It can be structured or spontaneous, for*

> *groups or for individuals, and may involve family, friends and carers, or the wider community. Activity may provide emotional, creative, intellectual and spiritual stimulation. It should take place in an environment that is appropriate to the person's needs and preferences, which may include using outdoor spaces or making adaptations to the person's environment.* (NICE, 2013)

This is clearly a very inclusive definition. It certainly has face validity, as it gives specific examples of activities that are likely to be meaningful. However, the main weakness of this definition is that almost any activity could be regarded as meaningful. This creates two problems: one, that it raises the question as to whether any activity is in fact non-meaningful; and, two, it seems to imply that all meaningful activities are at the same level. The NICE definition doesn't tell us anything about the importance of an activity having personal significance for the person, even though in everyday language we might expect that, for an activity to be meaningful, it must carry some significance for the person involved. Therefore, it seems to make no distinction between, for example, a Wagner devotee making a trip of a lifetime to Bayreuth versus simply deciding to have jam on one's piece of toast. Both of these instances meet the NICE criteria as meaningful, yet they are clearly worlds apart in what the degree of personal meaning that is involved.

Tierney and Beattie (2020), also troubled by the variable use of the term meaningful activity and by the tendency to use other overlapping concepts alongside it, undertook a concept analysis of meaningful activity. They reviewed a total of 29 papers from a range of studies, including quantitative and qualitative data as well as studies attempting to measure meaningful activity, as long as the papers contained a definition of meaningful activity in the text. They noted that there was considerable variation in the content of the definitions used by different authors. From their analysis they identified five key attributes of meaningful activities from the terms used in other studies: they are enjoyable; suited to an individual's skills, abilities and preferences; related to personally relevant goals; engaging; and they express and reinforce the person's identity. An individual activity may have any combination of these attributes, e.g. may be engaging without being especially enjoyable, but the optimum is to have all five qualities.

The model developed by Tierney and Beattie (2020) also included antecedents, consequences and empirical referents for meaningful activities. Antecedents included (a) individual factors, such as role identity, physical and cognitive abilities, familiarity, and available support if required, and (b) opportunities, such as the availability of an activity and the resources (e.g. financial, transport, staff) to enable participation. The main consequences were meeting various psychological needs, for example, self-esteem, autonomy, connection, continuity, and quality of life in general. Empirical referents can provide evidence that an activity is meaningful, and these include signs of full participation, sustained attention, enjoyment, and working towards a personal goal.

In addition to a diagrammatic model, Tierney and Beattie (2020) provided a concise definition of meaningful activity as ‘those activities which engage the individual and provide a sense of enjoyment’. They also commented that specific activities would be different for different individuals. It is noteworthy and slightly puzzling that, despite considering other possible attributes of meaningful activity, Tierney and Beattie have apparently prioritised enjoyment and engagement ahead of other qualities. Their definition contrasts with that of NICE (2013) which emphasises the personal tailoring of activities. Nonetheless, theirs is an important contribution to making sense of a jumbled conceptual area.

Another approach was taken by Burke et al. (2021) who examined best practice in delivering a physical activity programme in a residential care setting, and produced guidelines for good practice. This consisted of four main themes (environment, atmosphere, communication and adaptation) linked to a set of outcomes (engagement, inclusivity, social interaction, recognition and physical activity). The main conclusion of this work was that attention to detail was essential as small differences to how an activity was delivered had notable effects on the quality of the residents’ experiences.

3.6 Critique

Although there are now available definitions to help clarify what is meant by meaningful activity, there remain several problems, which are outlined in this section.

The first is that there is a long list of terms that are sometimes used as alternatives to meaningful activity or else as near synonyms. It is unlikely that this list is comprehensive, but competing or overlapping terms include: enjoyable, pleasurable, worthwhile, useful, valuable, serious, important, significant, individualised, personalised, preferred, engagement (also productive engagement and engagement in life), leisure, purposeful, and fulfilling a goal or purpose. It may be that ‘meaningful’ should be regarded as top of the hierarchy and the other terms can be seen as providing components that contribute to meaning. However, there is no a priori or empirical reason to favour the dominance of meaningfulness over, say, purposefulness, or even simply choice, in relation to activities. It may be a challenge to achieve consensus on terminology.

A second problem that does not seem to be addressed in the literature is under what circumstances does it start to be considered whether an activity should be assessed as being meaningful or not. In normal circumstances, we do not consider whether our activities are meaningful or not. I watch television, I go for a walk, I go to the pub: for none of these things does it cross my mind whether the activity has meaning or not. However, if I take a relative with dementia to the pub, suddenly this becomes a meaningful activity (for them). Therefore, what is different between the two cases? Clearly, the relative has dementia, a long-term condition, so there is an element of care and also of dependence, since the relative might not get to the pub on their own. However, it does not seem like simply a matter of disability or long-term conditions, since we may equally talk about meaningful activities for older people in general, including those who do not have dementia. If the only salient quality of the older person is being old, rather than having a disability or needing care, then this is a bit uncomfortable. Are we in fact reflecting on an imbalance of power between us? Perhaps troubling ourselves about whether an activity is meaningful for someone else maybe actually be rather patronising and demeaning.

This links with a third issue, which is the constant failure of research to demonstrate that providing a meaningful activity is any better than providing any form of activity. No studies have demonstrated that value has been added to any intervention by badging it as meaningful. As mentioned in the discussion of the overview above, it is not usually possible to distinguish between any effects of the meaningfulness per se and the non-specific effects of closer human contact that is required to provide that activity.

Fourth, the idea of meaningfulness implies that there is a judge who decides on whether an activity is meaningful or not. However, as shown by Harmer and Orrell (2008), the perspectives of people with dementia living in care homes differed from those of family members and care staff. The residents valued the quality of the experience rather than its specific content, whereas relatives and staff were much more focused on the purposes and goals of the activity. So, who decides? In principle, it should be presumed that the view of the person with dementia should be paramount, though it is clear that this does not always happen. Doubtless, in more advanced dementia, the person has less capacity to choose what they want to do, but this does not stop them demonstrating whether or not they are engaging with an activity or enjoying it. The issue of ‘who decides?’ is also tied up with the possible imbalance of power mentioned above.

Finally, another dimension missing totally from the discourse on meaningfulness is any reference to culture. All the quoted papers arise from Europe, North America and Australia. It is likely that meaningfulness is being applied from a context of individualism, where seeking one’s personal meanings is an important goal in life. However, not all cultures necessarily share this viewpoint. It may be that, in some societies, it is simply not important for an older person to be seeking individual meaning. Other goals, for example more rooted in family roles, may be more highly valued than this Western perspective. Even within a Western frame of reference, the focus on individual meaningfulness may only supply part of the picture as it overlooks the ways in which collective meaning may be sought. This is not to say that meaningful activities cannot be delivered in group contexts. Indeed, they often are, e.g. group singing sessions for people with dementia. The point is more that the individual is not necessarily the focus, and the power and importance of the collective identity should not be ignored. An example might be, for a football fan, attending a match is certainly a meaningful activity at an individual level; but his allegiance as one of a crowd of thousands is probably more important and transcends the simple individual experience of going to the game.

3.7 Conclusions

Meaningful activity is a complex and elusive concept. It contains several important elements. Others have tried to characterise what these are, but my own suggestion is that they offer some or all of these following five components: choice and preference; value to the individual; engagement; pleasure; and they may be associated with certain personal goals.

Other researchers have attempted to coin alternative terms but none has gained predominance. In consequence, we are probably stuck with meaningful activity, despite all its imprecision, ambiguity and shortcomings.

Chapter 4: Methodology

This chapter describes the general methodological approach to the included papers. However, details of the methods used are described in the individual papers themselves, so it is unnecessary to repeat the information here. The same applies to the next chapter, entitled Results. Both these chapters are intended as a preview to the individual papers.

4.1 Methodological approach

Overall, the intention has been to seek the voices of people with dementia as much as possible, alongside other important stakeholders, especially family carers, but also staff involved in delivery of the intervention being studied in each project. The studies are quite small scale and most were delivered with no additional funding (medical student projects) or relatively small grants. The exceptions were the two papers from the Alzheimer's Society TAnDem (The Arts and Dementia) doctoral training centre (papers 6 and 7) and the EU-funded MinD programme (Paper 9). The outcomes being measured were not the usual quantitative measures used in clinical trials (cognition, mood, quality of life, etc) but what we were interested in was primarily the experience of participation and how this affected people living with dementia and those around them.

The data collected were usually from interviews, either individual or dyads of person with dementia and carer, or group interviews and focus groups. Data analysis largely used qualitative methods, such as thematic analysis. This was appropriate since the studies were quite exploratory in nature, rather aiming to test whether specific outcomes were being achieved.

Qualitative research uses an interpretative, naturalistic approach to research, and aims to investigate the meaning that individuals and groups ascribe to human and social issues, in this case dementia. The collection of data should be in a naturalistic setting that is sensitive to the participants, and the analysis should establish (inductively, deductively or both) patterns or themes in the data. Reporting of qualitative research will contain the voices of participants, the reflexivity of the researcher, and an interpretation of the findings in relation to the research issues being addressed (Creswell and Poth, 2018, pages 7-8).

Furthermore, qualitative research not only has distinct aims but also needs to be assessed by its own criteria. The assessment of rigour and research quality in evaluating qualitative research has a long history (e.g. see Lincoln and Guba, 1986) and multiple viewpoints (FitzPatrick, 2019). Important concepts include trustworthiness and authenticity. Trustworthiness is analogous to the idea of validity in quantitative research, and includes criteria such as credibility, transferability, applicability and consistency. In short, it is an adequate explanation of the purpose, methods, data collection and analysis used in the research (Hammarberg et al., 2016).

Authenticity is a more radical approach to evaluation, but is perhaps less fully developed than trustworthiness (Amin et al., 2020). Authenticity addresses issues like power, pluralism, multiple values, representation, empowerment, and accountability, and has criteria around such concepts as fairness and ontological authenticity (the extent to which participants access more information and increase their consciousness of the issues, as a result of participating in the research) (Amin et al., 2020). Authenticity is thus further removed from the conventional positivist paradigm of quantitative research, and it reflects the important role of the participants in actively shaping the outcomes of the research.

The other methodological approach, which was just used in one paper (Paper 7) was that of realist enquiry. Realist methods are based on theories of critical realism, and reflect the notion that knowledge is a social and historical product, so social and contextual factors will influence the outcomes of interventions or policies. Realist methods in social sciences trace back to the work of Pawson and Tilley (1997) and they are increasingly used for reviewing or evaluating complex health and psychosocial topics (e.g. Rycroft-Malone et al., 2012; Crosbie et al., 2019).

Realist methodology places much emphasis on the concept of 'mechanism'. Mechanisms are viewed as a combination of resources offered by the programme under study and stakeholders' reasoning in response (Dalkin et al., 2015). They operate as an intermediary between the context in which an intervention takes place and the outcomes observed, so that realist inquiry often formulates its findings in terms of hypotheses known as Context-Mechanism-Outcome configurations (often abbreviated to CMOC). Mechanisms are imputed rather than directly observed, and they are essential in addressing the typical questions of realist studies, namely 'What works for whom, under what circumstances, how, and why?' (Ellaway et al., 2020).

4.2 Summary of methods in Papers 1-9

Paper 1 is an invited editorial. The methodological issues here were about defining the scope of the paper. The invitation was to write about access to outdoor space for care home residents, a topic that had been the subject of a PhD thesis I examined in 2018 (King, 2018). However, we decided that it would be more salient to write about access to the outdoors for people with dementia living at home, as this aspect has not attracted so much attention. The other choice was to take a human rights angle, so we invited an academic lawyer, Peter Bartlett, to join the first two authors.

Papers 2-5 are a series of papers arising from BMedSci projects with University of Nottingham medical students. They are methodologically quite similar. All four arose from opportunistic contacts, in three instances with providers of activities for groups of people with dementia and in the other case (Paper 3) with an archive of company resources that could be packaged and used in a group activity. The medical students participated as members of the groups, acting as observers, and then interviewed as many of the participants and supporters of the groups. The four papers shared the same analytic method, thematic analysis, following the stages described by Braun and Clarke (2006). The students performed the data analysis, under supervision, and wrote up the findings for the required dissertations as well as drafting the papers, which were published jointly with their supervisors. The projects took place in consecutive years, from 2013 to 2016. As it happened, three of the papers were eventually published in print in the same issue of the journal Dementia, so they have consecutive page numbers.

Papers 6 and 7, as mentioned earlier in this chapter, contain the work of two students from the TAnDem doctoral training centre. TAnDem was a joint enterprise between the universities of Nottingham and Worcester. It provided direct funding for two studentships in each centre, and matched funding could be used for further students. Altogether, four students from Nottingham undertook and successfully completed, on time, TAnDem PhDs. Each student had at least one supervisor from each university. I was the primary supervisor for Emma Broome and Emily Cousins, examples of whose work are included in this thesis.

Paper 6 is a case study of participatory arts sessions provided in local care homes as part of a larger project, Imagine Arts. Imagine Arts was one of four programmes in England funded by Arts Council England and the Baring Foundation's Arts and Older People in Care fund. The partners in the Nottingham programme included Abbeyfield, City Arts Nottingham, and University of Nottingham. The case study methodology was based on the work of Yin (2014), which provides a justification of the contribution of case studies to explore complex interventions within given settings, such as care homes. Most of the data were obtained from interviews with arts practitioners, care home managers and activities co-ordinators in the participating homes.

Paper 7 is more complex, as it describes using different elements to build upon an earlier phase of the research. The aim of the project was to develop a taxonomy of arts interventions for people with dementia. Phase 1 of the taxonomy development was published by Cousins et al (2019). Phase 2 included a case study, undertaken in six sites in Denmark, and a Delphi study of 24 participants, with a wide range of academic, professional practice and lived experience. In both Paper 6 and Paper 7, thematic analysis was employed, because of the flexibility between deductive and inductive coding offered by this method (Braun and Clarke, 2006) and its reflexive nature indicates the researcher's central role in knowledge production (Braun and Clarke, 2019).

Paper 8 reports an exploratory study of visual art appreciation by people with dementia. A person with severe dementia was guided through an art exhibition by a member of the gallery staff. Discreet filming was performed in front of certain exhibits and video analysis was used to examine patterns of interaction between the person with dementia and the staff member. As the person with dementia had very little spoken language, the emphasis was on the non-verbal aspects as well as any attempts at verbalisations. The study was mainly about the methodology and whether this was a practical way of exploring interactions in a non-care setting. There were some novel features, for example, the way the gallery, which was on the university campus, could be made available for an individual viewing of this nature. Also, a student art exhibition was used, so the participant could have no previous acquaintance with the works on display. The participant was severely disabled, and relied on a wheelchair as well as having advanced dementia. Video analysis has not been commonly used to investigate interpersonal behaviour in people with dementia, especially in a setting that is not providing care.

Finally, paper 9 is a report rather than a piece of primary research, but it does include sections for which new data were collected by the research group, especially in partnership with people with dementia. MinD was funded by the EU Horizon 2020 programme, and was intended to bring to the fore issues around design with and for people with dementia. Although there has been a lot of attention paid to technology and dementia (see, for example, Meiland et al., 2017), there has been less research focusing on design and co-design issues. MinD was led by Kristina Niedderer, then at University of Wolverhampton, and comprised academic and non-academic (mainly designers) partners from several European countries. The grant provided for staff exchange visits between the centres, including Nottingham. Nottingham hosted several visits over a four-year period and our most significant contribution was probably to organise a series of public engagement workshops. We also had responsibility for one of the work packages in the grant, which was charged with producing guidelines for good design, both with (co-design) and for people with dementia. Paper 9 provides a background to the MinD programme and summarises how it operated. It then introduces the MinD framework for mindful design, and the largest part of the report describes in some detail the participatory workshops that involved people with lived experience, who are here referred to as Groups of Experts by Experience (GEE). Altogether about 70 people with a diagnosis of dementia were involved. Several other papers from the MinD programme are in progress, including one that will highlight the lived experience contribution.

The methods and processes used by MinD are described in detail in section 4 of Paper 9 (pages 24-49). The work included here comprised the first two of the three overall stages of the MinD programme, that is, data collection and participatory design, with evaluation of the prototype designs being covered by other MinD outputs. Data about areas of daily life were collected from people with dementia across participating centres by various means, for example using purposefully designed visual cards and activity books. Several models were used to stimulate participatory design, for example the Panton models of ideation and of persona development (see pages 30-32) and mindful scenario task analysis (page 33). The next stage was production by the research group of a long list of possible design areas to address the areas of challenge identified by the data collected. This list was then subjected to scrutiny and refinement by GEE participants. Detailed descriptions are provided of some of these participatory design sessions and the methods that were used in the workshops that were held. The outcomes from the data collection and design phases of MinD were the development of prototype products for evaluation, further refinement and possible commercial development.

Chapter 5: Results

The results of each individual paper are, obviously, included in the text of that paper, so the purpose of this chapter is to bring together and present those findings that apply across the selected papers.

Table 5.1 provides a summary of the nine papers, including the numbers of participants in each and the methods of analysis used. Papers 2 to 5 may be considered as a group, as they investigated various activities for people with dementia, and they used similar methods and analyses (see Table 5.2). Papers 6 to 8 may also be considered as a group, since they concerned dementia and the arts, though their methods, settings and purposes were quite different from each other. Papers 1 and 9 do not group with the others, as the first was about access to outdoor space and the latter about co-design with and for people with dementia. Indeed, Paper 1, being an editorial, summarised other research but did not present any original data, so it will not be discussed further in this results chapter.

Overall, the studies were conducted in a wide range of settings. Two studies gathered data in care homes, but other settings included sports, cultural and leisure facilities. Two studies (Papers 7 and 9) were conducted not only in multiple settings but also in more than one country. In total, over 100 people with a diagnosis of dementia contributed data, including from individual interviews but also from group public participation events, which were a regular feature of the MinD project (Paper 9). Only one study (Paper 6) did not gather data directly from people with dementia; in this case study, interviews were conducted with arts practitioners, care home managers and care home activities co-ordinators. Numbers of participants with dementia varied from one (Paper 8) to around 70 (Paper 9).

Table 5.1 Summary of studies included

Paper no	First author	Year of publication	Journal	Type of paper	Funding	Setting	Total no of participants	No of participants with dementia	Method(s) of analysis
1	Argyle	2017	Aging & MH	invited review	none	n/a	n/a	n/a	n/a
2	Carone	2016	Dementia	peer-reviewed	UoN	sports centre	20	5	thematic analysis
3	Griffiths	2019	Dementia	peer-reviewed	UoN	care home	19	13	thematic analysis
4	Ovenden	2019	Dementia	peer-reviewed	UoN	indoors bowls club	22	6	thematic analysis
5	Hobden/ Swallow	2019	Dementia	peer-reviewed	UoN	swimming pools	14	4	thematic analysis
6	Broome	2018	Dementia	peer-reviewed	Alzheimer's Society	2 care homes	6	not recorded	case studies
7	Cousins	2020	Gerontologist	peer-reviewed	Alzheimer's Society	various	62	14	case study; Delphi study
8	Schneider	2019	Ageing & Society	peer-reviewed	ARUK	art gallery	1	1	video analysis
9	Dening	2020	MinD website	research report	EU H2020-RISE	various	>120; 52 research contributors listed	approx 70	various, including participatory development

Table 5.2 Summary of themes in the four exercise and activities studies

Paper	Activity	Theme 1	Theme 2	Theme 3	Theme 4
Carone 2016	Indoor football and other sports	Loss (related to the condition of dementia and its impact upon relationships)	Lack of resources (lack of age-appropriate services for people with young onset dementia)	Enjoyment and anticipation	The Notts County effect (the brand of the football club plus individualised activities in a dementia-free environment)
Griffiths 2019	Memory boxes and story telling	Engagement (including inclusiveness and emotional involvement)	What's in the box (including contents stimulating memories, mystery & variety, olfactory stimuli)	A conversation starter (opportunity for self-expression)	
Ovenden 2019	Boccia	The struggle of being a carer	This group is a family	The unique nature of Boccia	Here everyone is the same (treated as equals, with being hindered or defined by dementia)
Hobden/ Swallow 2019	Swimming	The pleasure of swimming (and its benefits as exercise and improving confidence of participants)	The importance of insight and empathy in creating a safe and secure experience	The impact of dementia	'All in the same boat' (value placed on being part of the group)

5.1 Activities for people with dementia

The findings from Papers 2 to 5 are summarised in Table 5.2, which sets out the themes generated in each study. One study (Paper 3) was conducted with care home residents, who therefore tended to have moderate to severe dementia, whereas the other three studies were all in community settings and participants had mild to moderate dementia. They also tended to be younger and in better overall physical health. For example, the group in Paper 2 was for men with young onset dementia and the mean age of those interviewed was 61 (range = 59-64). These differences between the settings and participants in Paper 3 and in Papers 2, 4 and 5 are probably reflected in the themes shown in Table 5.2.

Papers 2, 4 and 5 generated some similar themes. For example, all three had at least one theme about the impact of dementia and the difficulties in coping with it (loss, lack of resources, the struggle of being a carer, the impact of dementia). A corresponding theme was not seen in Paper 3, perhaps because the participants were further removed from the time of receiving a diagnosis and also they were no longer trying to maintain their independent lives in the community.

A second type of theme that was described in Papers 2 and 5 (and also in Paper 3) was about enjoyment and the pleasure obtained from the activity. Participants in the Notts County group (Paper 2) were also noted to show anticipation ahead of each weekly meeting of the group, which was described by one carer as the highlight of the week ('Is it Wednesday yet?').

Third, all three of Papers 2, 4 and 5 had a theme that reflected the special nature of the activity – 'the pleasure of swimming', 'the unique nature of Boccia' and 'the Notts County effect'. The latter reflected several elements, among which was the strong brand of the football club. In addition, these themes reflected appreciation of the non-stigmatising nature of the activities and the venues in which they were conducted.

The fourth and last theme generated in more than one study was seen in Papers 2 and 4. This was about the creation of a feeling of equality among the members of the groups, to the extent that dementia was no longer relevant, or the sense of there being a 'dementia-free zone' (see Paper 2) during the time of the group. In Paper 4, this sense was reflected in the choice of the paper's title: 'Here everyone is the same'. In Paper 5, one of the themes was titled 'all in the same boat', which is probably describing something similar. However, all being in the same boat does not quite capture the way that the other two studies were describing a more active process by means of which dementia was temporarily put aside.

5.2 Arts and dementia

As mentioned above, Papers 6 to 8 used different methodologies, so a similar form of comparison cannot be used. There are, however, areas of common ground between these three studies. The first is that in various ways they make a methodological contribution to the study of dementia and the arts. This is explicit in Paper 8, which reports an exploratory case study of a single individual with advanced dementia viewing original art works. The study aimed to examine the moment of interaction during a facilitated viewing of the art work, and the main result was that there was evidence that, despite the participant's severe language and physical impairments, she was able to engage in an interaction with the gallery attendant who accompanied her. Paper 7 is also methodological in its aim of developing a taxonomy of arts interventions in dementia. The outputs of the study were both a list of 12 dimensions (e.g. art form, artistic focus, arts approaches, competencies, principles) and a visual representation of the dimensions. These can be used either to enhance communication and to develop future hypotheses and research in this area.

A second commonality is a focus on the 'in the moment' experience. This is self-evident in Paper 8 as that was being filmed and video analysed. In Paper 6, the five themes had a temporal sequence, two of which related to the time within the session. These were opportunities for (self-)expression and the role of staff in supporting engagement in the arts sessions. Opportunities for expression included not only enjoyment for the residents but also for the arts practitioners and the staff involved in the sessions. For the residents, expression seemed to take a number of different forms, including reminiscence, social interaction and simply having fun. For Paper 7, the dimension of most interest to the research group was that of principles, which were defined as 'elements present in, or enabled by, arts interventions and identify how they operate and produce their effects'. They therefore represent the mechanisms by which arts interventions might 'work' and, as such, they will operate mainly at in the moment, during the encounter with the arts experience. Altogether, eight such principles were identified and described in a companion paper (Cousins et al., 2019).

5.3 Design and dementia

Paper 9 is not a single study but a report from an international, interdisciplinary programme of work based on applying principles of mindfulness to design for dementia. The original project brief mentioned design for people with dementia, but as MinD progressed it was changed to with and for people with dementia, in order to reflect the importance of co-design and co-production as opposed to a more top-down process. The report summarises work that was undertaken in several different countries at different times during the period of the grant. It is also not comprehensive of all the activities undertaken by the MinD consortium (see Niedderer et al., 2019 for overview) but focuses on the aspects of public involvement and actively engaging people with a diagnosis of dementia in the design process.

Paper 9 begins with sections on the background to the project and the development of what is referred to as the MinD framework. This incorporates elements of mindfulness and a commitment to well-being, social interaction and personal independence. As part of this, the Nottingham researchers proposed the AIR model, standing for Activities, Internal World and Relationships, as a means of bringing together nine themes that had been generated from an initial period of data collection. The AIR model (see pages 20-22) depicted how these themes could be organised, how they interact with each other, and how its components may be affected by enhancers or barriers operating on the person, their relationships and their activities. The longest section of Paper 9 describes the phases of data collection and design, including participatory design, from the MinD programme, and its final section is a set of recommendations for good practice in design and dementia.

The work reported in Paper 9 does not report results in a conventional manner, as its aim was to describe the learning about the co-design process and to summarise this as a set of guidelines about good practice. As it happens, the design product outputs from MinD included an interactive board game (This Is Me), a mindfulness handbook, and a social network decision aid system, which are all undergoing further work. The design guidelines in Paper 9 form another significant output. They are also accompanied by a second document which provides a set of policy recommendations (Niedderer et al, 2020).

The next chapter of the thesis presents the nine included papers, followed by Chapter 7, which will discuss the findings and their implications.

Chapter 6: Selected papers

This chapter comprises the nine selected papers, each of which is accompanied by a commentary. Papers 2 to 8 have abstracts, which are included in this chapter, in full size text above each commentary. The full text papers are reproduced in Appendices 2 to 10. Because of the length of the full document, only certain chapters from Paper 9 are included in Appendix 10.

Paper 1: Space, the final frontier: access to outdoors

Argyle E, Dening T, Bartlett P. (2017) Space, the final frontier: access to outdoors for people living with dementia. Aging and Mental Health 21(10): 1005-1006. doi: 10.1080/13607863.2016.1222351. (for full text, see Appendix 2)

Commentary

This editorial paper does not have an abstract. It was invited by the journal's editor and reflected local research interest in outdoor activities for care home residents (King, 2018). However, in planning the paper, two considerations became apparent. The first of these was that issues about access to the outdoors do not only apply to residents of care homes, but also people with dementia living at home may also have restrictions on their opportunities to leave home. Perhaps they live alone and maybe also have limited mobility. Or there may be concerns about them becoming lost if they venture out alone, so it is deemed necessary to escort them.

The second issue that arose for us was that there was an element of human rights that needed to be addressed. Even prisoners have an entitlement to time in the open air that is not accorded to people with dementia. We identified two articles of the UN Convention on the Rights of People with Disabilities (United Nations, 2006): Article 9 (accessibility) and Article 19 (living independently and being included in the community).

The paper made several recommendations, aimed at different levels, including the individual and their care plan, commissioning and providing of more imaginative services, the enhancement of dementia friendly outdoor spaces, and an end to the social and physical exclusion of people with dementia.

I was somewhat surprised that we were able to use the title for the paper, as I thought that the phrase may have been subject to copyright.

Paper 2: Football and dementia

Carone L, Tischler V, Dening T. (2016) Football and dementia: a qualitative investigation of a community based sports group for men with early onset dementia. Dementia 15(6): 1358-1376. doi: 10.1177/1471301214560239. (for full text, see Appendix 3)

Abstract

This study investigates the impact of a weekly group providing sport and physical activities for men with early onset dementia established by Notts County Football in the Community (NCFC). There were three aims: to investigate the effect of early onset dementia on individuals with the condition and their carers; to examine the perceptions of current levels of service provision for people with early onset dementia; and to analyse the impact of the group. Men with dementia (n=5) attending the sessions, their carers (n=5), NCFC coaching staff (n=5) and people organizing/facilitating the sessions (n=5) were interviewed. Semi-structured interviews explored the participants' experiences of dementia, their opinions on current service provisions and on the sessions. Data were analysed using thematic analysis. Four main themes were found: loss related to the condition of dementia and its impact on relationships ('Loss'); lack of age-appropriate services for people with early onset dementia ('Lack of Resources'); enjoyment and positive anticipation related to the group for all involved ('Enjoyment and Anticipation'); and 'the Notts County Effect' which attributed the success of the sessions to the strong brand of the football club, and to personalized service in a ''dementia-free'' environment. The NCFC sessions provided a safe low-cost intervention with positive effects upon quality of life for both people with early onset dementia, their carers and the staff involved. This suggests that the service may be valuable to a wider range of people living in different areas.

Commentary

This project was an important one for me in my early days at Nottingham. It was the first project that I initiated in my new post. I was appointed to the chair from October 2012. I was invited to join the Nottinghamshire Healthcare NHS Trust (as it then was) Executive Leadership Council, which was a large monthly meeting for senior managers and clinicians. The first meeting I attended was in November 2012, which was entitled 'The Health and

Wellbeing Challenge: Sport for Health and Esteem'. The meeting included a presentation by two staff members from the Notts County Football in the Community, who talked about their On The Ball programme for people with mental health problems, including a group they had set up for men with young onset dementia. Interestingly, the dementia group had come about as it became evident that men with dementia had different needs and levels of performance from men with long-term mental illnesses, so they took the decision to separate the two groups.

I was enthused by their talk and arranged to meet them as soon as I could. From our discussion arose the idea of developing a student project as a way of evaluating the activity. I was aware that there was limited published literature on football and dementia available at the time. We identified one observational study (Solari and Solomons, 2012) and one reminiscence project (Tolson and Schofield, 2012) to cite in our paper. In designing the project, I collaborated with Victoria Tischler because of her expertise with qualitative methods, and she was keen to be involved with more dementia projects. We were able to attract an enthusiastic medical student, Laura Carone, to undertake the project as part of her BMedSci degree. The data were collected in autumn 2013 and contributed to her dissertation. Laura attended several of the weekly session of the group during this time and conducted interviews with men attending the group, their carers, and others involved in delivering the group. The paper was published online in 2014 only appeared in print two years later.

The paper described four main themes, of which perhaps the most interesting was the one we referred to as the Notts County effect. This had two aspects: first, the strong, instantly recognisable brand of the football club; and, second, the ability to create a 'dementia-free' environment. This last quality was something that has continued to impress me when we have observed it in subsequent projects.

The project was a very enjoyable one to organise and supervise. We were made to feel very welcome by the group organisers and participants. The group was supported by trainees from the football club's coaching staff, which enabled quite a high level of individual attention for the participants. The trainees were most impressive in how they related to the men with dementia, even though they had had limited, if any, training for this purpose. Sadly, the funding for the group had never been secure and eventually it folded. There was also a problem in attracting new members and, as would be expected, several of the group members showed deterioration in their dementia as time progressed. Laura Carone not only published her first paper, but presented at two conferences, in the UK and abroad. She also allocated time in her final year student selective period to help with other dementia projects, and was involved in designing and setting up the swimming project that led to paper 5.

Paper 3: Mementos from Boots

Griffiths S, Dening T, Beer C, Tischler V. (2019) Mementos from Boots memory boxes - a qualitative evaluation of a multisensory intervention for people with dementia: innovative practice. Dementia 18(2); 793-801. doi: 10.1177/1471301216672495. (for full text, see Appendix 4)

Abstract

This qualitative study explored a multisensory (including olfactory) intervention for people with dementia. Six themed boxes (e.g. Childhood) containing items chosen from the Boots archive designed to encourage conversation were used in weekly group sessions. Session participants were people with dementia and care staff from a local care home, a trained facilitator and archivists from Boots UK. Semi-structured interviews explored participants' experiences of the sessions. Interviews were analysed using thematic analysis. The three major themes Engagement (subthemes: Inclusiveness; Emotional involvement; Factors that supported engagement), What's in the box (subthemes: Contents stimulate memories; Mystery, variety and age of items; Value of olfactory stimuli), and A conversation starter (subtheme: Opportunity for self-expression) reveal the success of the intervention and the value of olfactory stimuli. Multisensory boxes including olfactory stimulation can be an engaging intervention with scope to refine it for people with dementia and their carers in the wider community.

Commentary

Another opportunistic contact was the origin of this project, which formed Sarah Griffiths' BMedSci project in 2014-15. On this occasion it was a social contact between Victoria Tischler and the head of the company archives at Boots UK. It led to us designing a project artefacts from the Boots archive as the basis of a multisensory group intervention for people living with dementia.

In contrast to the Notts County project, where the group being studied already existed, for this research we needed to create the group. For this purpose, we worked with a local care home and a local freelance artist, who had previous experience of facilitating groups for people with dementia. Archivist colleagues at Boots UK allowed access to the archive to choose suitable materials for the group sessions. A key decision was to use a theme for each week that the group was to run and to design a box for each session with a range of contents. These are listed in the paper (see page 795) and the themes had titles like 'daily routine', 'childhood' and 'out on the town'. The boxes were collectively named 'Mementos from Boots'.

We could only schedule six groups because of the tight timescale of the BMedSci, which means that data analysis and dissertation writing have to be completed with about six month of starting the project. The procedure of the groups was that the facilitator would use any of the items from the box with a view to promoting story-telling. Some degree of reminiscence inevitably occurred but this was not the main aim of the group. This is because we wanted to achieve a more creative atmosphere within the group and we felt this would be better achieved by story-telling rather than the more mechanical process of trying to excavate memories. The student researcher attended all the groups as a participant observer and then conducted interviews with some of the residents and staff as well as two archive staff and the group facilitator.

The project ran very well because of the excellence of the facilitator, the care home management and the archivists. In writing the paper, we acknowledged that the skill of the facilitator had probably contributed greatly to the outcomes. From the outset, Boots UK was interested in the potential of the Mementos boxes for wider use in many care homes, and this work has been taken forward (Boots UK, 2018; Tischler and Clapp, 2020). Victoria and I also have been supervising a PhD student at University of West London (Federica D'Andrea) looking at olfaction as a component of multisensory interventions for people with dementia. This latter project has been in collaboration with the fragrance manufacturers Givaudan, so it is gratifying that our small 2014 project has stimulated further research.

Paper 4: Boccia

Ovenden I, Dening T, Beer C. (2019) “Here everyone is the same”- A qualitative evaluation of participating in a Boccia (indoor bowling) group: innovative practice. Dementia 18(2): 785-792. doi: 10.1177/1471301216675988. (for full text, see Appendix 5)

Abstract

This qualitative study explored the impact of a Boccia (modified indoor bowls) group on the lives of people with dementia and their carers. Semi-structured interviews with people with dementia (N=6), carers (N=10) and the group organisers (N=6) analysed using thematic analysis revealed four main themes. ‘The struggle of being a carer’ was relieved by participating in the group and benefitting from the caring support and social aspects of ‘’This group is a family’’. ‘’The unique nature of Boccia’’ helped it to provide physical and mental stimulation as well as being an inclusive and enjoyable group. These aspects contributed to many participants describing the group as a Dementia friendly environment where ‘’Here everyone is the same’’: treated as equals, without feeling hindered or defined by dementia. Boccia appears an exciting initiative but further research is needed to see if these findings can be replicated with other groups.

Commentary

This paper is the third BMedSci student project, undertaken in 2015-16. Once again, its origins lay in a chance contact. In November 2014, I did a live phone-in session on dementia for Radio Nottingham. It was quite a lively session, with several callers asking pertinent question or sharing moving accounts of their experiences. One man rang to mention the work that he was doing with a dementia group running at the Newark Indoor Bowls Club. Alert to the opportunity, I arranged to meet him and we set up the first meeting to be covered by the radio team.

The group met on a weekly basis and had a dedicated slot at the bowls club, which lies a little way of the town on the edge of the Newark showground. They play a modified form of bowls called Boccia, which was originally designed for people with physical disabilities and is an official Paralympic sport (International Paralympic Committee, 2021).

Our study followed a similar methodology to the two previous ones, with the student joining the group as a participant and observer, and conducting semi-structured interviews with as many people as possible. In all of these studies, we have managed to interview people with a diagnosis of dementia, something that I think is crucial. We generated four main themes, which are listed in Table 1 of the paper (Table 1, page 787). Of these, one was named ‘Here everyone is the same’, which refers to the levelling effect of the activity and corresponds to the dementia-free theme in the Notts County study.

The importance of this theme was reflected by a couple of informal observations that I made on the occasions when I visited the group. The first of these was that, before the session started, people with dementia would be sitting with their accompanying carers. The carers would interact with each other but there was little such interaction between the people with a diagnosis. However, after playing Boccia, when the participants retired to the bar area of the club for tea and cake, the people with dementia were much more animated and engaged more with those around them. According to carers, this stimulated state remained for some time, often the rest of the day.

My second observation was that, in play, people with dementia became totally engaged and it was no longer possible to tell who had dementia or not. Because of the modified nature of Boccia, they could compete with a reasonable chance of winning, and they were delighted when they did. Perhaps this was at variance with their everyday experience of having to be prompted and reminded. Thus, during the time of playing Boccia, the impairments of dementia were set aside and, in a way, it could be said that dementia had been temporarily abolished. In which case, it was no wonder that the participants enjoyed the game.

We were not only able to get the paper published, a first publication for yet another delighted student, but also Imogen was able to present her findings as a poster at the 2016 Alzheimer Europe conference in Copenhagen.

Paper 5: Swimming for dementia

Hobden T, Swallow M, Beer C, Dening T. (2019) Swimming for dementia: an exploratory qualitative study of an innovative practice. Dementia 18(2): 776-784. doi: 10.1177/1471301218768372. (for full text, see Appendix 6)

Abstract

Swimming is a non-weight bearing form of exercise that can be enjoyable and promote physical fitness. This qualitative study investigated a local group established as part of a national dementia swimming initiative. Semi-structured interviews with people with dementia (N=4), carers or companions (N=4) and the organisers and facilitators of the group (N=6) were analysed using thematic analysis. This revealed four main themes: (1) the pleasure of swimming and its benefits as a form of exercise and for building confidence and empowering participants, (2) the importance of insight and empathy in creating a safe and secure experience, (3) the impact of dementia and (4) how participants valued being part of a group 'all in the same boat'. 'Dementia friendly swimming' appears to be a valuable form of exercise, but it requires considerable preparation and support to make it happen.

Commentary

The origins of work in this paper were in 2014, with the award of a government voluntary sector grant to the Amateur Swimming Association (now Swim England) and the Alzheimer's Society to promote swimming for older people with dementia. The grant was for sessions in eight cities, one of which was Nottingham, so Nottingham City Council was a partner in the local implementation of this project. The intention was to have supported dementia-friendly swimming sessions at three pools across the city. In 2015 and early 2016, we had several meetings to discuss how a student research project could be conducted. The research was conducted in the autumn and winter of 2015-16.

We were allocated two medical students for this project, which worked well as they were able to support each other, and also they proved very helpful in some the swimming sessions too. One instance was where other pool users had become resentful that some of the pool was roped off for the dementia session. As in other projects, the students acted as participant-observers and conducted interviews with as many participants and supporters of the sessions as possible. Each student was writing their own dissertation, one looking at features contributing to a dementia-friendly environment and the other at the social benefits of taking part in the swimming, though the work of both was combined in the writing of this paper.

A challenge for the swimming initiative as a whole was recruitment of participants with dementia. One of the three intended pools had no sessions at all. A second pool had been expensively refurbished by the Council with a lot of thought given to its internal layout and suitable signage. However, the pool is located in a sports centre with a long drive and access by public transport is somewhat limited. Again, this pool struggled to attract sufficient attendees. The third pool was older but more integrally located at the heart of its community, so the group here thrived. Even so, recruitment both the swimming sessions and to the research project was initially slow until additional funding from the Alzheimer's Society enabled the appointment of a very effective swimming co-ordinator who was able to help people overcome their reluctance to attend and/or to get into the water.

Among the themes described in our analysis were the pleasure and benefits of swimming, and how participants valued being part of a group ('all in the same boat'), though there was not a theme corresponding to the elimination of dementia that we had seen in the Notts County and Boccia projects. There were perhaps three practical learning points, namely: first, there are perhaps more barriers that make older people with dementia less likely to use swimming sessions than attend other types of activities; second, that the location of the facility matters more than how smart its appearance is; and, third, that without the right people involved it can be very difficult to recruit participants to attend activities.

Curiously, because of delays with papers appearing in print in the journal Dementia, this paper and papers 3 and 4 were all published together on consecutive pages of the same issue, making a nice hat-trick. They had of course been published earlier online at different times.

Paper 6: Participatory arts in care homes

Broome E, Schneider J, Dening T. (2020) Participatory arts in care settings: a multiple case study: Innovative practice. Dementia 19(7): 2494-2503. doi: 10.1177/1471301218807554. (for full text, see Appendix 7)

Abstract

This paper describes two case studies of arts interventions in UK care settings. Visual arts and dance movement interventions were regularly held in two settings. This paper draws on data from qualitative interviews, reflective diary sheets and narrative monitoring reports to examine the content, context, and process of the arts interventions within the care settings. Activity coordinators play a crucial role in the success of arts interventions in care setting through their knowledge and support of residents. We recommend that preparatory consultations should take place between arts practitioners and care personnel, as this seems to improve participation and overall satisfaction.

Commentary

Papers 6 and 7 were both published from PhD studentships forming part of the Alzheimer's Society funded TAnDem (The Arts and Dementia) doctoral training centre. TAnDem was a partnership between the Universities of Nottingham and Worcester and ran from 2015 to 2019. It included studentships that were funded directly and also from matched funding. Altogether four students graduated from Nottingham and three from Worcester. I acted as principal supervisor for Emma Broome and Emily Cousins (first authors of Papers 6 and 7).

Emma's PhD research was conducted in care homes participating in Imagine Arts, a three year programme funded by Arts Council England and the Baring Foundation with the theme of arts and older people in care. It aimed to enrich the lives of older people in care settings through the provision of an innovative programme of arts. The key partners in Imagine Arts were Abbeyfield, City Arts Nottingham, Nottingham City Council, and the University of Nottingham.

Paper 6 is one of three peer-reviewed papers published from this PhD (see also Broome et al., 2017; 2019) along with two articles in the Journal of Dementia Care. It provides two case studies of providing arts activities from the Imagine Arts programme in two separate care homes. The choice and scope of the homes and of the activities was slightly limited by the fact that Imagine Arts was well underway by the time that data could be collected for the research, but nonetheless the two cases yielded valuable insights. As well as the five themes presented in the results, it was evident from this study as well as from the other studies we undertook with Emma just how critical is the role of the activity co-ordinator in a care home.

It is also worth commenting that both Imagine Arts and TAnDem only came about because of my longstanding personal connections with two of the key individuals, Marsha Tuffin from Abbeyfield, and Professor Dawn Brooker from Worcester.

Paper 7: A taxonomy of arts interventions

Cousins E, Tischler V, Garabedian C, Dening T. (2020) A taxonomy of arts interventions for people with dementia: A framework to describe and explain the theory and practice of arts activities. Gerontologist 60(1): 124-134. doi:10.1093/geront/gnz024. (for full text, see Appendix 8)

Abstract

Background and Objectives: The current evidence base for the arts and dementia has several limitations relating to the description, explanation, communication, and simplification of arts interventions. Research addressing these challenges must be multidisciplinary, taking account of humanities and science perspectives. Consequently, this research aimed to produce a taxonomy, or classification, of arts interventions for people with dementia as a contribution to this growing field.

Research Design and Methods: This research was underpinned by taxonomy and realist methodology. Taxonomy, the science of classification, produces a common language to name, define, and describe the world around us. Realist theory explains how interventions "work" and produce their effects. The main findings in this paper were generated from a case study and a Delphi study.

Results: An arts and dementia taxonomy of 12 dimensions was developed: Art Form, Artistic elements, Artistic focus, Artistic materials, Arts activity, Arts approaches, Arts facilitators, Arts location, Competencies, Complementary arts, Intervention context, Principles.

Discussion and Implications: Arts interventions can be classified according to their contexts, mechanisms, and outcomes. A range of stakeholders could benefit from the taxonomy, including people with dementia, artists, practitioners, carers, care staff, funders, commissioners, researchers, and academics. Language relating to the arts and dementia can be adapted depending on the audience. This is a foundational model requiring further development within the arts and dementia community.

Commentary

Paper 7, from the other TAnDem student I supervised, is rather more conceptual, though data were collected from focus groups, a case study and a Delphi study. The purpose of the research was to introduce some clarity to the variable use of language around the arts and dementia. For example, research literature about the arts and dementia often lacks detail about the components of the activities being used, the underpinning theoretical frameworks are often not specified, and there is no common language to describe the mechanisms and outcomes of arts activities between the various stakeholders, who include artists, researchers, care staff and people with dementia themselves.

It was however, by no means certain what a suitable taxonomy would look like, or indeed if one could be created. There was a certain mistrust or even hostility in some quarters as parties probably felt that their artistic and therapeutic work defied being classified. As a result, supervision discussions were often quite lively as we circulated various ideas, e.g. would a taxonomy look like a menu, or an IKEA catalogue, or a map of the world? We also decided that a framework of realist enquiry would be appropriate, as we were interested in what 'worked' (whatever that may mean in terms of arts activities in dementia) and, if so, what were the mechanisms underlying a good outcome.

The paper summarises the steps that took place to create version 1 of the taxonomy, which had six main principles, and then the development of version 2. The visual presentation of the 12 dimensions in version 2 of the taxonomy is shown in Figure 1 on page 128. Of the dimensions, possibly the one of most interest is that of principles. The principles correspond to the mechanisms, in realist terms, by which the arts activities have their action, and they include such elements as connection, engagement, selfhood and transformation. A full list and operational definitions of the Principles appears in Table 2 on page 130. A separate paper on the principles was also published (Cousins et al., 2019).

It was a challenging paper to write and to bring a significant amount of thesis content into a journal sized paper. It also required some careful thought as to which journal might look favourably upon such an unusual piece of work. Fortunately, we guessed right first time with the Gerontologist. The 12 dimensions and eight principles lend themselves readily to further work. For example, they would form a good basis in designing a new arts activity for people with dementia as they would enable the creator to check that they had incorporated as many elements as possible, or they could be used to assess the outcomes of an activity. I have continued to work with Emily to apply for a postdoctoral fellowship to take some of this work forward.

Paper 8: Interaction with visual art

Schneider J, Hazel S, Morgner C, Dening T. (2019) Facilitation of positive social interaction through visual art in dementia: a case study using video-analysis. Ageing and Society 39(8): 1731-1751. doi: 10.1017/S0144686X1800020X. (for full text, see Appendix 9)

Abstract

The aims of this exploratory study were: to investigate the process of visual art appreciation in a person with dementia, in real time; and to test the feasibility of using video-analysis as a method to explore this process by and with a person who has minimal verbal expression. Gallery personnel guided a woman with severe dementia around an exhibition. Audio-visual recordings of the interactions were analysed. Patterns were identified, and interpreted in the light of conversation analysis theory and research. Evidence was found of turn-taking vocalisations on the part of the research participant. Her participation in a dialogical process was facilitated by the skilled and empathic gallery personnel in ways that the analysis makes clear. We argue that this supports the inference that successful communicative acts took place, contrary to expectations in the light of the participant's level of disability. We demonstrate in this paper how a woman with minimal speech due to dementia was enabled to engage with visual art through the facilitation of an expert guide, attuned to her needs. This is a novel example of a person-centred approach, because it takes place outside the context of caring, which is the typical setting for examining person-centred ways of relating to individuals with dementia.

Commentary

Although it is well recognised that people even with quite advanced dementia can respond to contact with various art forms, such as visual art or music, there is relatively little direct observational research and most of this has been focused on events after the exposure took place. However, this overlooks the importance of what happens in the moment, which, as we know from our own experiences, is at least as important as what happens later. This study, which was funded by a small grant from Alzheimer's Research UK, was therefore aimed at capturing and analysing the moments when a person with dementia came into contact with an art work, in this instance visual art.

The study was carefully designed to collect the intended data. It was decided to use newly produced art so that the participants would not be familiar with it and so recognition would not form part of their response. Poignantly, we were able to use the last exhibition of the University’s Fine Art students, which was taking place at the Djanogly Gallery on the Park Campus. We were able to book a session in the late afternoon for our work. Altogether three individuals with dementia were guided around the exhibition, though this paper reports in detail on just a single case. The participants had moderate to severe dementia but were living at home with a family carer. They would arrive with their carer, be offered tea and refreshments, and then a member of gallery staff would take just the person with dementia around the exhibition. The gallery staff were asked to take the participant to see two works in particular, as these had three camcorders arranged to record the person’s face while looking at the featured works. In front of the art work, the pair would pause and interact in any way they chose. In the meantime, the carer waited in the gallery café with members of the research team until the viewing was completed. Video analysis was performed.

The participant in Paper 8 was of interest as she was physically disabled and had severe dementia. She was no longer able to speak and her husband thought that she would be unable to engage with the exhibition or interact with the gallery attendant. However, the video analysis did show evidence of interaction, turn-taking and attempts at vocalisation by the participant. It left open the question as to the role of the art work in generating this interaction, but we argued in the paper that the art had at least brought the two people together and made them halt in the same place. Certainly, too, the gallery attendant was behaving as if taking part in a meaningful interaction.

The remaining data were reported in another paper (Morgner at al., 2019). The gallery project itself was a spin-off from a 12-month interdisciplinary programme of varied arts activities, the Dementia, Arts and Well-Being Network (DA&WN; Tischler et al., 2019).

Paper 9: MinD Design guidelines

Dening T, Gosling J, Craven M, Niedderer K. (2020) Guidelines for designing with and for people with dementia. MinD: Designing for people with dementia. At: https://designingfordementia.eu/ (for extended extract, see Appendix 10)

Commentary

The preceding papers in this thesis have been divided between physical and arts activities for people with dementia. Paper 9 explores a different strand, which is about how people living with the condition can be involved in design with a view to promoting meaningful activity and social contact, and therefore enhancing well-being and personal independence. The emphasis in MinD was on mindful design and the process of co-design and co-production, rather than on applications of technology.

MinD was an EU Horizon 2020 funded project in the Research and Innovation Staff Exchange programme. As such, money was available to support secondments across the partner organisations, though not to pay for researcher salaries. Altogether, the MinD project brought together 18 organisations from eight countries, including nine universities, one healthcare policy partner, four healthcare partners, and four design/ICT partners. It involved about 40 secondments from 2016 to the end of 2019. The programme was led by Professor Kristina Niedderer, then at the University of Wolverhampton. The Nottingham group participated as a health, rather than as an academic, partner; therefore under the title of Nottinghamshire Healthcare NHS Foundation Trust. This was slightly ironic as, although we tried to recruit employees of the Trust to take part, they felt unable to do so because of the length of the secondments. In the event, the Nottingham contingent were actually University employees or associates with Trust honorary contracts.

The Nottingham group consisted of four people, Dr Mike Craven, Dr Dons Coleston, Dr Julie Gosling and myself. We were responsible for hosting several secondments in Nottingham, as well as undertaking secondments in other countries. I personally spent a total of six weeks in Luxembourg and a full month in Dresden, Germany. The Nottingham group had responsibility for Work Package 6, which comprised Implementation and User Testing. We were able to draw upon our existing patient and public involvement contacts, as well as the involvement groups in the NIHR MindTech collaborative, and the extensive experience of

Julie Gosling in working with people with lived experience. Several of the Nottingham secondments included public involvement events to present and develop design ideas.

Among the outputs of MinD are several designed products, which include: ‘This Is Me’, a story board game; ‘Living the Life’, a mindful reflective booklet; You and Me, an interactive decision-making tool; and ‘Let’s Meet Up!’**,** a digital platform for social interaction with chosen family or friends. Alongside these are several papers at various stages of completion, and the proceedings of the end of project conference (Niedderer et al., 2019). A further output, and part of our contribution from WP6, are the Guidelines that form Paper 9, together with a set of policy recommendations (Niedderer et al., 2020). The Guidelines document is quite lengthy but gives a comprehensive description of some of the models developed and methods used in the collaborative design process across so many organisations and people. The list of accredited authors is quite short but there is a much longer list of people who contributed. The AIR model described in section 3.2.2 (pages 20-22) was originally my idea. I became the first author as I spent most of my one-month secondment in Dresden editing successive drafts of the report.

The main message from MinD can perhaps be summed up thus. There is a lot of interest and considerable research on technology to support people with dementia. However, much of this is focused on devices for more advanced dementia and there is little evidence of end user contributions to the design of products (see Meiland et al., (2017) for a review, to which we contributed). Instead, more attention is required for design at an earlier stage, with specific aims around independence and quality of life, and especially with the involvement of people with lived experience. If Paper 1 suggests that people with dementia should get outside more often, Paper 9 suggests that they should be involved and consulted more often, which brings the cycle of papers to a fitting conclusion.

Please note that this document is over 60 pages long so, rather than reproducing the whole document in Appendix, I have omitted Chapters 2 and 4 from the extract included. Chapter 2 contains the background literature, much of which is discussed in Chapter 2.4 of this thesis, and Chapter 4 is a lengthy description of the methods used to develop the design guidelines. My own contributions form part of Chapter 3 and much of Chapter 5, especially.

Chapter 7: Discussion and conclusions

7.1 Main findings

This thesis has brought together nine papers that deal with various aspects of meaningful activities in relation to people with dementia. Between them, the papers cover four areas: namely, access to outdoor space, group activities including various forms of exercise, the effects of arts activities, and the importance of co-design and co-production in promoting social interaction and personal independence. The papers present a number of largely positive findings:

1. Access to the outdoors is often denied to people with dementia, whether living in the community or in care homes. However, being outdoors is important and ways of enabling this can have important benefits for people with dementia.
2. Participation in groups providing exercise or stimulating activities is enjoyed and valued by those taking part.
3. Under the right circumstances, such activities have the effect of temporarily abolishing dementia and creating equality between group members.
4. There are also benefits in terms of social interactions following sessions of group activity, and group members may show eager anticipation of the next meeting.
5. The taxonomy of arts interventions and dementia described in Paper 7 provides a framework for better communication about research involving the arts and dementia.
6. The principles also described in Paper 7 act as potential mechanisms for how arts interventions 'work' and can be the basis for further investigation and research.
7. It is important to consider the impact of arts activities in the moment that they are being experienced, as well as their more lasting effects. In the moment experience can be observed, recorded and analysed, even in people with severe dementia and other impairments.
8. Establishing meaningful collaboration with people with lived experience of dementia requires attention to several elements: how and why people are approached initially; how the invitation to participate is framed; observing relevant rights, permissions and consent; creating an equitable and inclusive working environment; and accessible communication and participatory activities that include everyone.
9. Collecting the studies together adds another dimension to that provided by the individual studies considered in isolation, since it enables examination of the common ground between them and permits emphasis on those findings that appear in more than one study. Added to which is an overriding theme of rights, empowerment, liberty and activity, all of which aim at enjoyment and social interaction.

The individual studies described their own strengths and limitations but did not formally assess themselves against criteria of trustworthiness or authenticity (see Chapter 4 for description of these concepts). To take an example, consider the five studies that involved group exercise and care home activities (Papers 2 to 6) in relation to the criteria of trustworthiness, which include credibility, transferability, dependability and confirmability (Amin et al., 2020). The findings appear credible, in that the researchers had extended contact with the groups, while setting up the projects and while conducting the research. The themes generated in our analysis had meaning not only for the researchers but presumably also for independent peer-reviewers and journal editors. The findings were also presented at several conferences. Transferability refers to the extent to which the research methods and findings may be applicable to other settings or other areas of practice. Again, there are instances where this has occurred. Certainly, the notion of achieving a dementia-free environment or even temporarily abolishing dementia has gone down well when used in teaching or in other discussions about activities. Dependability and confirmability are measures of the consistency of the findings. Certainly the studies form a consistent set. The methods and analyses are consistent and, as shown in Table 5.2, there is consistency between several of the themes identified. All of these criteria were underpinned by the reflexivity of the researcher(s). All the student researchers had regular supervision and therefore the opportunity to reflect, as well as which they wrote their own accounts of personal reflection in their dissertations and theses.

It is harder to assess the studies in terms of measures of authenticity, as these are less robustly defined (Amin et al., 2020). However, the studies are aimed at achieving fairness by including the voice of people with dementia. Where there were usable quotes from participants with dementia, we used these ahead of comments from carers or other interviewees, since people with dementia tended to give shorter, less detailed interview responses and giving these priority seemed a way of redressing this imbalance.

Therefore, there is evidence that the studies may be considered trustworthy and at least to some extent authentic. This provides confidence that this is a robust body of work.

7.2 Strengths

The research described in these papers was largely conceived and carried out within the interdisciplinary Centre for Dementia at the University of Nottingham’s Institute of Mental Health. As such, it has drawn upon a common philosophy and interests in predominantly psychosocial research in dementia.

The studies are largely exploratory in nature, rather than seeking to test specific hypotheses. Therefore a mainly qualitative approach to data collection and analysis has been used, which is appropriate for a number of reasons. These include the exploratory nature of the studies, and the aim to understand the experiences of the people with dementia participating in the group interventions and in the research itself. It enables the derivation of important themes.

The data presented in most of these papers were collected in naturalistic settings, such as a sports centre, a swimming pool, and several care homes. It is highly likely that participants would be much more comfortable being interviewed in the same settings that the activities took place, as well as which those participants with dementia would be more likely to remember what they had been doing if interviewed in the same place and as soon after the session as possible.

It is also a strength of these collected papers that the majority of them included data collected from participants with dementia. This was deliberately an important part of the methods used. It would be difficult to establish much about the meaningful nature of an activity without hearing the voice of people with dementia. As mentioned in Chapter 5 (see Table 5.1), over 100 people with dementia have contributed directly as participants in the research, which is a figure to be proud of. Research participation by people with dementia is increasingly viewed as important, and more than solely an issue of capacity to give consent, with a focus on active involvement and incorporation of lived experience throughout the research process (e.g. Gove et al., 2018; Scottish Dementia Working Group Research Sub-group, 2014).

A similar method of analysis, thematic analysis, has been used in several of the papers in this thesis. This may be regarded as a limitation and will be discussed as such in the next section. However, on the other hand, it has enabled a tabulation (see Table 5.2, Chapter 5) of the themes generated in four studies, which would not otherwise have been possible.

7.3 Limitations

Most of the studies included in this thesis were on a small scale, notably Papers 2 to 5 and Paper 8. Several studies were not supported by external funding, so their development had not undergone the rigorous competitive process of obtaining research grants. The small sample sizes may limit the degree to which the findings may be generalised. The sample participants were recruited by convenience. For example, the Notts County (Paper 2), Boccia (Paper 4) and swimming projects (Paper 5) simply enlisted members of the groups in question. The three care homes (one in Paper 3 and two in Paper 6) were used as they were already partners in research. The individual participant in Paper 8 was recruited via personal contact. The larger MinD project (Paper 9) included a larger number of participants in several countries, so could be more confident of representing a wider population. In addition, for all the studies there is probably a lack of ethnic diversity. Nearly all the participants recruited in Nottingham were probably of White British ethnic origin, though we did not in fact record this for most of the studies.

These limitations are mitigated, however, as most of the studies were exploratory and qualitative in nature. The main aims were to explore the experience of people with dementia in relation to group activities, arts and participatory design, so therefore representativeness was not a primary issue. Also, sample size is less of an issue in studies of this kind, where what matters more is the depth of the exploration to be able to identify the salient themes.

The largely qualitative approach to the research studies in this thesis has certain implications, some of which may be perceived as limitations. For example, by not using quantitative study designs and standardised outcome measures, we are unable to demonstrate the magnitude of any benefits derived by people with dementia from participating in various activities. In some ways, it might be argued that these studies do not even show that the activities 'work', since there are no comparison groups and no before and after measures. Even if the activities do bring benefit, it may be argued that this is due to a non-specific effect of increased social contact and not directly resulting from the content of the activity (whether that is arts, exercise, or whatever).

This line of argument is not, however, helpful. As has been mentioned in the previous section (Strengths), qualitative methods have a different purpose from quantitative research. The research in this thesis is brought together by a focus on exploring the personal experience of the participants. It is to some extent taken as read that the participants derived benefit from the activities, but certainly many of their comments and the themes reported in the papers did reflect their profound engagement and enjoyment.

7.4 Contribution of this research

This section discusses how the research presented in the nine papers has contributed to the general field. Again, the papers are considered in four broad groups: access to outdoor space, group activities including various forms of exercise, the effects of arts activities, and the importance of co-design and co-production.

7.4.1 Outdoors

In relation to access to the outdoors, there remains relatively little research in this area, and what there is tends to concentrate around certain topics, notably sensory gardens in care homes, as mentioned in Chapter 2.1. An exception is the study by Phinney et al. (2016) who described a social day programme for community-dwelling people with young onset dementia that involved a regular walk to promote social citizenship.

There is however evidence that outdoor activities are being taken more seriously, for example by the National Trust working to make some of its properties dementia friendly (National Trust, 2019), and by numerous smaller projects involving wildlife organisations and other groups (e.g. Outside the Box, 2020). Dementia Adventure is a charity that provides days out or holidays for people with dementia with their families. Such initiatives are likely to be boosted by the introduction of 'green social prescribing' (GOV.UK, 2021). Social prescribing is a means for local agencies (health or social) to refer to a link worker, who can then make an assessment and connect people to community groups or statutory services for practical and emotional support. Green social prescribing is a refinement of this and will link people to nature-based interventions and activities. These may include: green exercise, such as local Walking for Health schemes and dementia walks, active travel (such as walking or cycling), local Park Runs, care farming, community gardening and food growing projects, as well as conservation volunteering, green gyms, and arts and cultural activities which take place outdoors (GOV.UK, 2021). So far, the initiative is running in just seven sites (one of which is Nottingham and Nottinghamshire), though doubtless the intention is to extend it if the uptake is good.

7.4.2 Exercise and group activities

Exercise and dementia remains an active area for research, with studies exploring a variety of outcomes (cognition, mood, physical fitness, falls prevention, etc.) and moving closer to consensus on the types of exercise intervention that appear to be most effective. Research in this field covers both exercise as possible dementia prevention and also exercise and group activities for people with an established diagnosis of dementia. There remain gaps in the field, for example a lack of studies about the particular needs of people with young onset dementia (Roman de Mettelinge et al., 2021).

As mentioned in Chapter 2.2, there has been less attention paid to the experience of participants with dementia in exercise and other group activities, and our studies (Papers 2 to 5) have definitely contributed to knowledge in this area. As well as maintaining function, it is important that people should enjoy what they are doing. In clinical trials of exercise interventions, it is generally necessary to standardise the intervention so that everyone is doing much the same things. However, this may have the effect of suppressing individual choice, which does not seem to have received much attention to date. The Notts County programme (Paper 2) was very flexible in its approach and could offer individual attention to group members, whose needs and abilities were in fact quite variable.

Another contribution of these papers (especially Papers 2 and 4) was to draw attention to how engagement with enjoyable and absorbing activities can create a 'dementia-free' space, by neutralising or abolishing the functional disability due to dementia. This seemed to result from the adaptation of the sports being played, e.g. Boccia, indoor football, so that all group members could contribute on an equitable basis. This observation was not made in the swimming group (Paper 5), maybe because being in water required a higher degree of supervision, so that the boundaries of dementia could never be entirely lowered. Other studies have made similar observations, using other terms such as 'non-medicalised environment' and 'keeping the focus off dementia' (Phinney et al., 2016).

The corollary of activity is to consider what happens in its absence, which has led us to undertake a more recent study on apathy. In particular, we were interested in the experience of apathy both for the person with dementia and for their carers. The project included interviews with six people with dementia and their carers (in the event, their spouses), which were conducted separately and simultaneously, and analysed using interpretative phenomenological analysis. The results for people with dementia (Baber et al., 2021) and the carers (Chang et al., 2021) were also published separately. The themes from both groups had some similarities and differences, but what was most noticeable was how apathy was largely a silent struggle for and between both parties (Dening et al., 2021). People with dementia remained keen to have personal contact but the effects of apathy prevented them from showing this in their behaviour. Another interesting theme illuminated how carers would try any reasonable means to get the person with dementia involved or more active, and they spoke of trying to 'reignite the spark' of their spouses. Igniting the spark is conceivably close to the 'dementia-free' moments that were described in the preceding paragraph.

7.4.3 Arts

Papers 6 to 8 have used diverse methods, which include case studies, focus groups, a Delphi study, and video-analysis. There are several important findings. Paper 6 contributes to how arts interventions are delivered in care settings, focusing on the central role of activities co-ordinators and on the importance of preparation and communication between the artists and the care staff. Paper 7 makes a theoretical and practical contribution to the literature, since the taxonomy can be of practical use but can also serve as a reference when designing new arts interventions.

In particular, the idea of principles described in Paper 7 and Cousins et al. (2019) by which arts interventions 'work' is akin to the notion of mechanisms in realist methodology (as described in Chapter 4.1). The eight principles described in our arts intervention taxonomy (e.g. connection, expression, involvement and transformation) are unseen but are likely to contribute to the success of any arts intervention. Paper 7 also points out that the principles could be used as outcomes, though this would require that there is a measure of, say, engagement that could be applied. In addition, some of the other dimensions of the taxonomy can potentially be regarded as mechanisms, for example artistic element such as rhythm, rhyme, sound or harmony.

Paper 8, as has been mentioned, makes a methodological contribution about using video analysis to explore the in-the-moment responses and experiences of people with dementia exposed to the arts, in this case visual arts. This is important, as studies that have looked for longer term benefits from arts interventions may have disappointing results, but they may also be missing the point altogether. For most people engaging in an arts activity, the impact is in the moment of attendance or shortly afterwards, so it may be unreasonable to expect significant improvements on relatively crude instruments such as quality of life scales. Other researchers have contributed recently to advances in thinking about in the moment experience and what it actually means. For example, Keady et al. (2020) suggested that 'being in the moment' consists of a continuum of moments that progress in a sequential and interlinked manner. The authors proposed four types of moment: creating the moment (anticipatory aspects and preparation), being in the moment (embodied engagement, creativity, flow), ending the moment (distraction, interruption, end of session), and reliving the moment (the potential subsequently to recall or share the experience, even if this recollection is partial or fragmented). Strohmaier et al. (2021) have evaluated the use of a very short well-being scale (the Canterbury Wellbeing Scales) that can be used before and immediately after sessions, and reported that the scale showed improved well-being nine varied community arts-based interventions. It is likely that future research will employ tools of this kind and develop further other ways of catching in the moment experiences.

7.4.4 Design and co-design

The field of design and co-design specifically for dementia is fairly new and is continuing to expand. The MinD project has played a part in this cultural advancement, bringing together as it did design researchers, dementia specialists, and commercial designers. The aim was to develop suitable methods for the engagement of people with lived experience of dementia and to use these for the creation of products that would enhance mindfulness, social interaction and well-being. Although the MinD project has now closed, the group is still writing papers using the data collected. There is now a MinD network, which meets to shape future developments, e.g. grants and symposia, and we are working on a proposal for a book that would draw on MinD experience but also connect with other people working in this field.

Another significant recent publication is a book (Tsekleves and Keady, 2021) that contains ten case studies of research involving design and dementia. One chapter features the MinD project. The other chapters describe a range of diverse projects: for example, three concern music-related interventions; and others describe social groups and neighbourhoods (see also Calvert et al., 2020; Phinney et al., 2016), clothing and playful products for residents in care homes (see also Iltanen-Tähkävuori et al., 2012; Treadaway et al., 2019); and co-creation of interior environments with technology and interior design (see also van Hoof et al., 2013). Some of these topics are more obviously design-related than others, but design has an important role to play in creating groups and networks that support people with dementia. It is not merely a question of creating new physical objects or applications.

In time, we should see more influence of co-design in the development and application of technology, since the end users (people with dementia) have often been excluded from the development process (Meiland et al., 2017). This will help to lead to products that are highly acceptable and usable by people with dementia and their families. Also, designers have an important role to ensure that technology, services and other products are attractive, simple and effective.

7.4.5 Meaningful activity revisited

The concept of meaningful activity was discussed at length in Chapter 3, which considered the origins of the concept and its roots in occupational therapy, the measurement of meaningful activity, research on the application of meaningful activity in dementia, and provided a critique of the concept. The problems highlighted included imprecision about the use of the term, what factors render an activity ‘meaningful’, who judges whether something is indeed ‘meaningful’, lack of research to show that meaningful activity is better than alternative forms of contact, and a lack of other cultural perspectives. Despite these difficulties, Chapter 3 conceded that, for the time being at least, there was no good alternative term. However, more precision about what is meant by meaningful activity can be achieved by considering its underlying components, which (I suggested) include choice and preference; value to the individual; engagement; pleasure; and possible association with personal goals.

The nine papers presented in this thesis have been considered as four groups, relating to the outdoors, exercise and group activity, the arts, and design and co-design. They therefore span a wide range of activities and settings, including people's own homes, their neighbourhoods, local sporting and leisure facilities, and care homes. Most of the activities featured in this body of research meet at least some of the criteria for meaningfulness listed at the end of the previous paragraph. For example, choice and preference were key features of the co-design sessions held during the MinD project (Paper 9). Engagement and pleasure were clearly described in several of the exercise and group activity studies (Papers 2 to 5). There are numerous quotes that reflect the value placed on the activities by the participants. The studies perhaps provide less evidence of progress towards meeting personal goals. This is perhaps because the studies were not designed as formal evaluations of the activities, so there was no before and after measurement that would help to set such goals and then ascertain if they were achieved. Personal goals could be very simple things though, like simply being able to leave the building and go for a walk in the fresh air, which is of course the topic of Paper 1.

Thus, the nine papers form a body of work that centres around meaningful activity, whatever the limitations of that concept may be. It is important to note, however, that for an activity to be meaningful does not require that something special has to be provided. Although I have criticised the NICE (2013) definition for being too wide, it does say something important about how even quite routine or trivial actions can be meaningful for the individual. The meaning is not necessarily even at a conscious level. For instance, consider the process of getting dressed. Much of the time, this is fairly automatic and we may not give much thought even to the choice of clothes. However, at other times, e.g. going to a big social event or a job interview, much more consideration is given. Though, even when little thought is given, we are still making a statement about ourselves and giving social signals to other people. It remains the case for people with dementia that clothes are meaningful, since what we wear is not merely just how we present ourselves in terms of outward appearance, but part of how we enact our being (Twigg, 2010).

In summary, the notion of meaningful activity is imperfect but it is in wide circulation, so it will probably continue to be used. It can be applied very broadly to encompass the meaning contained in everyday actions or more focused upon certain activities that may be provided for people.

7.5 Implications of this work

The implications of this work, and future areas for development may be considered under the three usual headings of implications for research, practice and policy.

7.5.1 Research

Each paper has contained ideas about future research that could be undertaken. In relation to access to the outdoors and outdoor pursuits for people with dementia, the focus needs to shift from care homes to people living in their own homes. There is a need for more studies that involve going out, walking, exploring the neighbourhood or exploring nature.

For exercise and group activities, the studies described here (Papers 2 to 5) could be extended to other leisure pursuits, to larger numbers of people and other locations. Future research should also explore ways of increasing access and means by which groups can be more inclusive or extend to members of minority communities, for which purpose ethnographic methods may be especially useful (Motta-Ochoa et al., 2021). In our own work, we have explored a possible project with a tennis club, which unfortunately did not progress, but have current plans with the Trent Bridge Community Trust and their Forget Me Notts programme (Trent Bridge Community Trust, 2021). It is crucial that the input of people with dementia should be sought in the design of activities, that they should have choice as to what they undertake, and that their experience should be explored when evaluating outcomes. Future research on exercise and dementia will establish more precisely the contribution that exercise can make to dementia prevention and also in maintaining health and well-being at all stages of dementia post-diagnosis.

Future research on arts and dementia is needed to explore further some of the issues covered by this thesis. This includes examination of the ways in which arts activities and interventions ‘work’ perhaps using realist methods, as discussed in 7.4.3. Future research is also required to focus on capturing the in the moment experience. Perhaps technical advances in video analysis will enable detailed observations in larger samples than the single case described in Paper 8. The taxonomy presented in Paper 6 has definite potential to be used as a means of communication between researchers as well as a source of future research questions. It is also a point of personal satisfaction that, through the TAnDem doctoral training centre, we have added to the pool of researchers who can potentially develop the ideas that they have worked on.

The future research agenda in design, co-design and dementia is likely to be busy. In 7.4.4, the future plans of the MinD network have been mentioned. There are many aspects of design where the input of people with lived experience of dementia will be required. Research can also examine how this is most effectively provided as well as contributing to the development of novel products and services. Design research should become a more prominent component of the larger field of dementia and technology. The MinD recommendations (Niedderer et al., 2020), which are published alongside Paper 9 on the MinD website, list three requirements for designers, design researchers and design educators: (1) the starting point for design should not be with a product but with identifying people’s needs, wants, wishes, dreams and aspirations; (2) all stages of the design process from start to finish should emphasise including or partnering with relevant stakeholders, including people living with dementia; and (3) design should be evidence-based and informed by relevant policy and legislation, with special attention to equality and accessibility.

7.5.2 Practice

The implications of the research in this thesis for care and practice can be summarised quite simply: just do more of it! A second theme is that we need to move beyond short-term initiatives and ensure that good practice is sustained. This requires not only that the intervention continues to be supported, continues to develop, and continues to provide benefit (Moore et al., 2017), but that it should be successfully implemented in the first place.

It needs to be a priority for service providers to find ways in which to enable people with dementia to access outdoor space and to enjoy the natural world. The health and social benefits are close to self-evident and besides, as pointed out in Paper 1, confining people with dementia indoors is probably in breach of their rights. Care plans should include statements about how people with dementia are to be helped to go outside, with due assessment of any risks, but without allowing safety issues to predominate over everything else. Providers and proprietors of natural environments, such as wildlife trusts and heritage bodies, need to make it routine that dementia-friendly spaces are provided. Despite several initiatives having been announced, disappointingly some of these appear to have lapsed, so that the relevant websites contain no new information, e.g. Natural England (2016). As mentioned previously, green social prescribing may have an important part to play, especially if it is introduced nationally beyond the initial pilot sites.

There is also plenty of scope for providers of leisure facilities, gyms and sports clubs to offer sessions suitable for people with dementia. Some activities are easier to access than others, and some require greater degrees of supervision and so are more labour intensive (e.g. swimming, Paper 5). For some, the provision of equipment or special premises is required, for example, golf (Shimada et al., 2018). This may mean that there is inevitably a cost of attending, which may be beyond the means of some people. Ensuring that activities take place at convenient times and giving thought to how participants are transported is also important. Proximity to public transport routes may be desirable, and seemed to be a factor of the success of one swimming pool location in Paper 5. However, in our Boccia study (Paper 4), the bowls club was out of town but the group organiser ensured that participants could all have lifts in private cars. Many groups rely on the goodwill of family carers but also recognise that the support and/or respite they provide to carers is an important part of their remit, as shown at Notts County in Paper 2. Not only are groups of this kind vulnerable either to limited periods of funding and/or the departure of key enthusiastic staff, but episodes such as the covid-19 pandemic can also be disastrous for the provision of social groups for people with dementia (Giebel et al., 2021).

A welcome development in the field of arts and dementia has been the rise of voluntary organisations, such as Arts 4 Dementia and the Creative Arts Dementia Network, that have championed the cause, advocating for services to provide more arts experience for people with dementia but also encouraging many creative artists or arts organisations to turn their attention to dementia. Room 217 is a Canadian social enterprise that seeks to place music at the heart of care, and has an international profile with events in the US and the UK. However, probably the largest single arts venture has been Singing for the Brain, developed by the Alzheimer's Society and operating in the UK since 2003 (Osman et al., 2016). This seems to have been widely adopted though there are other variations, such as local dementia choirs. Arts professionals, such as music therapists or dance movement therapists, are increasingly working with people with dementia. There is also a need for staff working with people with dementia, in whatever setting, to have greater awareness of the potential of arts activities and be able to signpost where opportunities exist.

As regards design, the main message is for designers and service providers to consider the input of people with lived experience of dementia at all stages of design. It is normal practice in most areas of commercial development to seek the views of potential users in the initial design stages and to undertake prototype testing. The same should apply in the case of design if items that are intended for use in the field of dementia. It would also be preferable if people with dementia are consulted at an early stage to explore their perceived needs and preferences, as too often products are designed for them rather than in collaboration.

7.5.3 Policy

Many of the policy implications of this research overlap with the impact upon practice, and it is difficult completely to separate them. Access to the outdoors – being able to leave a care home or indeed to step out from your own place in the community – is really a human rights and dignity issue. It requires constant reminders to policy makers and health and social commissioners. Initiatives like green social prescribing are to be welcomed, so long as they are accessible, evaluated and properly resourced.

This research has contributed to demonstrate the value of groups providing exercise and social activity. The value of these groups has been clear for many years but was thrown into harsh relief by the effects of covid-19 lockdown. Funders and policy makers need to be aware of the scope of local and national activities and to support them in a more consistent manner.

One of the obstacles to obtaining consistent funding for arts activities, and indeed other types of meaningful activities, in dementia has been the difficulty of providing evidence that is robust enough for guidelines and standards bodies such as the National Institute for Health and Care Excellence (NICE). The gold standard for evidence comes from randomised controlled trials and meta-analyses. Such studies can be difficult to achieve with arts interventions, because of the numbers of participants required, imprecise outcome measures, and the challenge of finding suitable comparison conditions to act as controls. Trials of arts interventions tend to be underpowered and unconvincing (e.g. Moreno-Morales et al., 2020). However, some large trials of music interventions are underway, e.g. the MIDDEL study (Gold et al., 2019) or the PRESIDE feasibility trial (Dowson et al., 2021), in an attempt to bridge this longstanding gap in the evidence. For this reason, the smaller scale studies described here have not focused so much on quantitative outcomes but have concentrated on producing different kinds of evidence, notably from the experience of the participants, which complements findings from clinical trials.

There are several factors that could serve to highlight the importance of design for and with people living with dementia (Niedderer et al., 2020). These include recognition of the importance of design in supporting all aspects of the lives of people and families affected by dementia. There is a need for increased funding for research in this area, and this should emphasise the importance of people with dementia in co-design and development. Design regulators and voluntary organisations should explore and develop the potential for dementia-friendly specification or standards for dementia-friendly products and services taking into account relevant guidance , and also promote awareness of how designs that have arisen from one user group may be transferred and applied to other groups and audiences. In practice, this could mean either that a product designed for people with dementia could have application elsewhere, or vice versa.

7.6. Summary of findings and implications

Meaningful activity is a term with no single agreed definition but, as it is widely used and there is no obvious better alternative, it probably remains applicable to describe activities of varied kinds that have personal significance. In Chapter 3.7, I have argued that the aspects that seems to contribute to making an activity meaningful are: choice and preference; value to the individual; engagement; pleasure; and they may be associated with certain personal goals.

The results from these papers show many positive findings, for example the importance of providing appropriate and accessible activities for people living with dementia, and how this can also support their carers. Under certain circumstances, the activity within a group can eliminate the disabling effects of cognitive impairment, thus creating a ‘dementia-free’ space, or in effect temporarily abolishing dementia altogether. This experience is extremely powerful and it does has some effects that persist beyond the confines of a group session.

The research has also made contributions to the methodology of dementia research. For example, the taxonomy from Paper 7 can help to position future research about the mechanisms by which arts activities have their positive effects, and Paper 9 offers extensive advice about co-design with people who have dementia.

As a clinician first and foremost, I think that what is most important about this body of work is how it offers evidence that meaningful activities of varying kinds are not merely important, but probably essential for the wellbeing of people living with dementia and their families. Having contributed in some tiny way to this cause is a reason for some personal pride, but also it has been a privilege to work in this area with these amazing people.

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Appendices

Appendix 1: Statements of joint authorship

Paper 1

Argyle E, Dening T, Bartlett P. Space, the final frontier: access to outdoors for people living with dementia. Aging and Mental Health 2017; 21(10): 1005-1006.

EA was invited to provide an editorial by journal editor. TD was approached as co-author and suggested PB to add legal and human rights expertise. EA led the writing but both TD and PB contributed to the initial structure of the paper and added text to successive drafts.

We accept this statement as a true reflection of our contribution to this paper.

Dr Elaine Argyle E Argyle Date: 26 March 2021

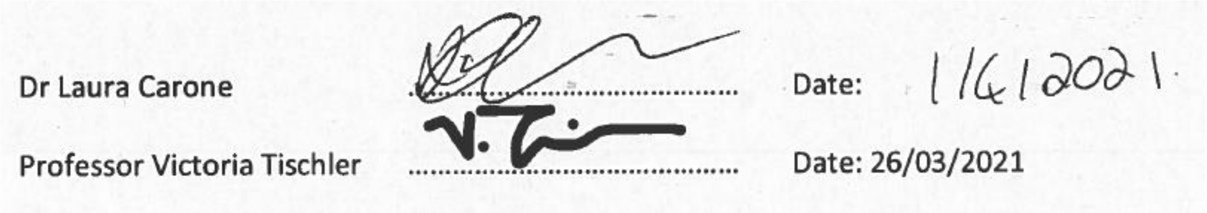
Professor Peter Bartlett Peter Bartlett Date: 26 March 2021

Paper 2

Carone L, Tischler V, Dening T. Football and dementia: a qualitative investigation of a community based sports group for men with early onset dementia. Dementia 2016; 15(6): 1358-1376.

TD initiated the project by making contact with Notts County Football in the Community. TD and VT developed the project proposal. LC was supervised by both TD and VT in conducting the research. LC attended group sessions, gathered the data and conducted the interviews with participants and others. VT supervised analysis of the qualitative data. LC submitted her BMedSci dissertation based on this work. All three authors wrote the paper.

We accept this statement as a true reflection of our contribution to this paper.



Dr Laura Carone .... Date: 1/6/2021.

Professor Victoria Tischler .... Date: 26/03/2021

Paper 3

Griffiths S, Dening T, Beer C, Tischler V. Mementos from Boots memory boxes - a qualitative evaluation of a multisensory intervention for people with dementia: innovative practice. Dementia 2019; 18(2); 793-801.

The project began with VT's contacts with archive staff at Boots UK. All four authors developed the project proposal. VT identified a facilitator for the group. TD negotiated with Church Farm at Skylarks for them to host the multisensory groups. SG was supervised by TD and CB in conducting the research. SG attended group sessions, gathered the data and conducted the interviews with participants and others. CB supervised analysis of the qualitative data. SG submitted her BMedSci dissertation based on this work. All four authors wrote the paper.

We accept this statement as a true reflection of our contribution to this paper.

Dr Sarah Griffiths S Griffiths ………………………… Date: 26/03/21

Dr Charlotte Beer Date: 26/03/21

Professor Victoria Tischler ……………………………………… Date: 26/03/2021

Paper 4

Ovenden I, Dening T, Beer C. “Here everyone is the same”- a qualitative evaluation of participating in a Boccia (indoor bowling) group: innovative practice. Dementia 2019; 18(2): 785-792.

TD initiated the project by making contact with the Newark Indoor Bowls and Boccia Club. TD and CB developed the project proposal. IO was supervised by both TD and CB in conducting the research. IO attended group sessions, gathered the data and conducted the interviews with participants and others. CB supervised analysis of the qualitative data. IO submitted her BMedSci dissertation based on this work. All three authors wrote the paper.

We accept this statement as a true reflection of our contribution to this paper.

Dr Imogen Ovenden ICOvenden **Date:** 6/4/2021

Dr Charlotte Beer Date: 26/03/21

Paper 5

Hobden T, Swallow M, Beer C, Dening T. Swimming for dementia: an exploratory qualitative study of an innovative practice. Dementia 2019; 18(2): 776-784.

TD initiated the project by making contact with Claire Sullivan at Sport & Leisure, Nottingham City Council, and Duane Newton, from the Amateur Swimming Association. TD and CB developed the project proposal. TH and MS were supervised by both TD and CB in conducting the research. TH and MS attended swimming sessions, gathered the data and conducted the interviews with participants and others. CB supervised analysis of the qualitative data. TH and MS submitted independent BMedSci dissertations based on this work. All four authors wrote the paper.

We accept this statement as a true reflection of our contribution to this paper.

Dr Tanya Hobden Date: 06/04/21

……………………………………… Date: 28/04/2021

Dr Mary Swallow

Dr Charlotte Beer Date: 26/03/21

Paper 6

Broome E, Schneider J, Dening T. Participatory arts in care settings: A multiple case study: innovative practice. Dementia 2020; 19(7): 2494-2503.

JS was co-director of the TAnDem doctoral training centre. TD (principal supervisor) and JS supervised EB's PhD research. The study reported in this paper was designed by all three authors. EB attended the two homes in the case study, and conducted observations and data collection. EB performed the initial analysis, to which TD and JS contributed in discussion. All three authors wrote the paper.

We accept this statement as a true reflection of our contribution to this paper.

Dr Emma Broome EBroome Date: 26th March 2021

Professor Justine Schneider Date: 30 March 2021

Paper 7

Cousins E, Tischler V, Garabedian C, Dening T. A taxonomy of arts interventions for people with dementia: a framework to describe and explain the theory and practice of arts activities. Gerontologist, 2020; 60(1): 124-134.

TD (principal supervisor), CG and VT supervised EC's PhD research. The research reported in this paper was designed by all four authors, and all authors contributed to discussions about the nature of taxonomy and its potential application to dementia and the arts. EC conducted focus groups, carried out a case study during an academic visit to Denmark, and undertook the circulation of questionnaires for the Delphi study. Data analysis was mainly conducted by EC, with input from supervisors, for example modifying the Delphi statements after each round of responses. EC designed the striking visual presentations of dimensions and principles. EC, VT, CG and TD wrote the paper.

We accept this statement as a true reflection of our contribution to this paper.

Dr Emily Cousins E. Date: 26.03.2021

Dr Claire Garabedian Claire Date: 26/03/2021

Professor Victoria Tischler V. ………………………………………… Date: 26/03/2021

Paper 8

Schneider J, Hazel S, Morgner C, Dening T. Facilitation of positive social interaction through visual art in dementia: a case study using video-analysis. Ageing and Society 2019; 39(8): 1731-1751.

The project was conceived by JS and CM. JS, CM and TD developed the protocol. JS provided brief dementia training for the gallery staff. JS, CM and TD organised and oversaw the gallery viewing sessions. This included greeting participants and carers on arrival and providing support and encouragement for the person with dementia and their carer during the art viewing session. SH performed the video analysis. All four authors contributed to the writing of the paper.

We accept this statement as a true reflection of our contribution to this paper.

Professor Justine Schneider Date: 30 March 2021

Dr Spencer Hazel Date: 26 March 2021

Christian Morgner

Dr Christian Morgner Date: 06 April 2021

Paper 9

Dening T, Gosling J, Craven M, Niedderer K. Guidelines for designing with and for people with dementia. MinD: Designing for people with dementia, 2020. At: https://designingfordementia.eu/

KN was the grant holder and led the MinD programme. The report was produced as a deliverable of the MinD project from work carried during numerous secondments during the MinD programme, which involved a large number of contributors, including people with dementia. Several sections describe work undertaken in public involvement sessions, several of which were held in Nottingham, and led by JG and colleagues. An initial draft containing much of the content of the report was produced by MC and JG. TD and KN completed an overall edit of the report in January 2020, and the final version was agreed with comments from all four authors.

We accept this statement as a true reflection of our contribution to this paper.

Dr Julie Gosling ………………. Date: 26/3/21

Dr Mike Craven M.P.Craven Date: 26/3/2021

Professor Kristina Niedderer Kristina Niedderer Date: 26/3/21