



UWL REPOSITORY

repository.uwl.ac.uk

Exploring the significance of clothing to people with dementia using sensory ethnography

Fleetwood-Smith, Rebecka (2020) Exploring the significance of clothing to people with dementia using sensory ethnography. Doctoral thesis, University of West London.

This is the Accepted Version of the final output.

UWL repository link: <https://repository.uwl.ac.uk/id/eprint/7758/>

Alternative formats: If you require this document in an alternative format, please contact: open.research@uwl.ac.uk

Copyright:

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy: If you believe that this document breaches copyright, please contact us at open.research@uwl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

**EXPLORING THE SIGNIFICANCE OF CLOTHING TO
PEOPLE WITH DEMENTIA
USING SENSORY ETHNOGRAPHY**

REBECCA FLEETWOOD-SMITH

A thesis submitted in fulfilment of the requirements of the University of
West London for the degree of Doctor of Philosophy

August 2020

List of Figures	i
List of Reflexive notes	iii
List of Tables	iii
Copyright Statement	iv
Dedication	iv
Acknowledgments	iv
Interdisciplinary approach	vi
Abstract	vii
Introduction to the project	ix
Organisation of the thesis	xi
CHAPTER 1 INTRODUCTION	1
1.1 Defining dementia	1
1.2 Dementia, selfhood and embodiment	6
1.3 The bodily turn and dementia care paradigms	10
1.4 The arts, creativity and dementia	14
1.5 Dementia care settings	17
1.6 Summary	20
CHAPTER 2 LITERATURE REVIEW	21
2.1 The material context of the care home	22
2.2 Textiles, objects and dementia	27
2.3 Clothing, dementia and the care home	38
2.4 Summary	59
CHAPTER 3 METHOD	61
3.1 Research paradigm	61
3.2 Conducting qualitative research with people with dementia	62
3.3 A consideration of qualitative methodologies	65
3.4 Sensory Ethnography	68
3.5 Research design	75
3.6 Research setting	79
3.7 Recruitment	81
3.8 Ethical considerations	84

3.9	Summary	87
CHAPTER 4	CYCLE 1: EXPLORING CLOTHING DURING WEAR	88
4.1	Introduction	88
4.2	Multisensory research encounters	89
4.3	Research encounters: Ethical and practical considerations	93
4.4	Recording the research encounters	98
4.5	Contact time with participants	99
4.6	Participants	101
4.7	Reflexive thematic analysis	103
4.8	Findings	110
4.9	Discussion	144
4.10	Limitations and recommendations	154
4.11	Summary	156
CHAPTER 5	CYCLE 2: TRANSLATING THEMES INTO OBJECTS	158
5.1	Introduction	158
5.2	STEP 1: Designing tools for elicitation	161
5.3	STEP 2: Carrying out the interviews: Thematic cards as elicitation tools	165
5.4	Interviews: Ethical and practical considerations	169
5.5	Recording the interviews	169
5.6	Participants	170
5.7	Thematic analysis	171
5.8	STEP 3: Findings	173
5.9	STEP 4: Designing the object handling sessions	187
5.10	Discussion	202
5.11	Limitations and recommendations	205
5.12	Summary	208
CHAPTER 6	CYCLE 3: THINKING WITH THINGS: A SERIES OF OBJECT HANDLING SESSIONS	209
6.1	Introduction	210
6.2	Object handling sessions as a research method	210
6.3	Structuring the object handling sessions	211
6.4	Carrying out the object handling sessions: Practical considerations	215

6.5	Video recording the object handling sessions	217
6.6	Participants	222
6.7	Audio-visual analysis	223
6.8	Findings	226
6.9	Discussion	249
6.10	Limitations and recommendations	255
6.11	Summary	258
CHAPTER 7	SYNTHESIS AND DISCUSSION OF FINDINGS	259
7.1	Introduction	259
7.2	The process of synthesising findings	260
7.3	Presentation and discussion of synthesised findings	262
7.4	Summary	308
CHAPTER 8	CONCLUSION	310
8.1	Sensory, creative and embodied research methods	310
8.2	Project findings	320
8.3	Strengths and limitations of this project	327
8.4	Implications for future research	336
8.5	Summary	342
REFERENCES		345
APPENDICES		383
APPENDIX A	Visual reflexive journal	383
APPENDIX B	Writing conventions	383
APPENDIX C	Glossary of key terms	384
APPENDIX D	Ethical considerations	388
APPENDIX E	Ethical approval	393
APPENDIX F	CYCLE 1 Recruitment advert (Care home staff)	395
APPENDIX G	CYCLE 1 Participant information sheet (Care home staff)	396
APPENDIX H	CYCLE 1 and CYCLE 2 Consent form	397
APPENDIX I	CYCLE 1 Participant information sheet (People with dementia)	398
APPENDIX J	CYCLE 1 Consent form (People with dementia)	402

APPENDIX K	CYCLE 1 Nominated consultee information and declaration form	405
APPENDIX L	CYCLE 2 Participant information sheet (Creative practitioners)	408
APPENDIX M	CYCLE 1 Accessible participant information sheet	409
APPENDIX N	CYCLE 3 Recruitment advert (Care home staff)	412
APPENDIX O	CYCLE 3 Participant information sheet (People with dementia)	413
APPENDIX P	CYCLE 3 Consent form (People with dementia)	418
APPENDIX Q	Consultee information and declaration form	421
APPENDIX R	Abuse protocol	424
APPENDIX S	Distress protocol	425
APPENDIX T	Participant sample identification	427
APPENDIX U	Notes from a participant consent process	429
APPENDIX V	CYCLE 1 Prompts: Participant with dementia	430
APPENDIX W	CYCLE 1 Prompts: Care home staff	431
APPENDIX X	CYCLE 2 Focus group discussion guide	432
APPENDIX Y	Designing textiles for the 'playful' object handling session	435
APPENDIX Z	CYCLE 3 Risk assessment - video recording	436
APPENDIX AA	Reflexive note - preparing for video recording	440
DISSEMINATION ACTIVITIES		441

LIST OF FIGURES

Figure 1. VISUAL REFLEXIVITY: Exploring repetitive touch	xi
Figure 2. Research participant's rings (Connellan, 2019:118). Image reuse permission obtained.	19
Figure 3. Overview of the literature review	21
Figure 4. Abstracted illustrations used as prompts with nursing assistants (Cleeve et al., 2020:129. Image reuse via CC BY-NC 4.0.	23
Figure 5. Example from the Napkin Project (2014). Photograph by Jim Wilemen. Image reuse permission obtained.	27
Figure 6. 'Bud sensory cushion' for people with dementia (Find, n.d.)	28
Figure 7. 'Fiddle muffs' (Alzheimer's Society e-shop, n.d.)	29
Figure 8. HUG™ created by the LAUGH project led by Professor Cathy Treadaway, Cardiff Metropolitan University. Image reuse permission obtained.	33
Figure 9. Clothing for people with cognitive impairments and / or problems with incontinence in Finland (Topo & Iltanen-Tähkävuori, 2010:1685). Image reuse permission obtained.	43
Figure 10. Interlinked cycles of study	76
Figure 11. Example from my visual reflexive journal	79
Figure 12. Extracted page from participant information sheet	85
Figure 13. CYCLE 1: Exploring clothing during wear	88
Figure 14. Example fall detector pendant (Folio, 2018)	114
Figure 15. VISUAL REFLEXIVITY: Exploring the 'inner workings' of garments	145
Figure 16. VISUAL REFLEXIVITY: Exploring communicative surfaces	148
Figure 17. VISUAL REFLEXIVITY: Exploring marks after wear	151
Figure 18. CYCLE 2: Translating themes into objects	158
Figure 19. Example thematic card	165
Figure 20. Using thematic cards	166
Figure 21. CYCLE 2 Synthesis of findings	174
Figure 22. Using a mind map to connect ideas: 'Playful object handling session'	188
Figure 23. 'Playful' Mood-board	191
Figure 24. Items selected and created for playful session	193
Figure 25. 'Curating objects' Mood-board	194
Figure 26. 'Birdseye view of two of the 'Playful' session boxes	195
Figure 27. Textile artist Celia Pym and Grayson Perry's teddy Alan Measles	196
Figure 28. 'Narrative-based' object handling session	197
Figure 29. Items selected and created for narrative session	198
Figure 30. Aran jumper with visible repair	199
Figure 31. Presenting items in 'Narrative-based' session	200
Figure 32. 'Dramatic' object handling session	200
Figure 33. Items selected for 'Dramatic' session	202
Figure 34. CYCLE 3: Thinking with things: A series of object handling sessions	209
Figure 35. Example layout of the space	216
Figure 36. Route to the room	217
Figure 37. Position of camcorder	220
Figure 38. Knitted sample used by P21 (PWD)	228
Figure 39. Tactile postcard used in 'Narrative' session	229
Figure 40. 'Alan Measles' tactile postcard	232

Figure 41. Textile sample used by P19 (PWD)	234
Figure 42. Textile sample used by P21 (PWD)	236
Figure 43. Necklace used by P20 (PWD)	237
Figure 44. Silk scarf used by P22 (PWD)	241
Figure 45. Tactile postcard used by P21 (PWD)	244
Figure 46. 'Playful' textile samples	245
Figure 47. Hand knitted mohair jumper	247
Figure 48. VISUAL REFLEXIVITY: Exploring pressure through repetitive marks	251
Figure 49. VISUAL REFLEXIVITY: Handling objects	255
Figure 50. Synthesis of findings	259
Figure 51. Modibodi® absorbent underwear (Modibodi, 2020). Image reuse permission obtained.	267
Figure 52. Essence fall detector pendant with Care@Home™ technology (Essence, n.d.)	269
Figure 53. GreatCall fall detector watch (GreatCall, n.d.)	269
Figure 54. Buller™ pulldown wardrobe rail (n.d.)	271
Figure 55: Nevernaked™ shower drapron® by Limon Attire. Image reuse permission obtained.	275
Figure 56. Seamless shorts from The Woolmark Company and NAGNATA 'The sensuality of seamless' collaboration. Image reuse permission obtained.	278
Figure 57. Mock laundry timetable	285
Figure 58. New Vision Health Environments 'Memory box' (n.d.). Image reuse permission obtained.	287
Figure 59. Cabinet created by Wallace et al. (2012). Image reuse permission obtained.	288
Figure 60. 'Tactile dialogues' (Industrial Fabrics Association International, 2014)	293
Figure 61. Dr Jenny Tillotson - Sensory Designer/eScent Founder wearable scented accessories. Image reuse permission obtained.	295
Figure 62. Collated inspiration for wearable items	296
Figure 63. Prototype tactile jewellery	298
Figure 64. Mao Tsen Chang (n.d.). Image reuse permission obtained.	300
Figure 65. Smart textiles, Atlas Institute, University of Colorado (2019)	301
Figure 66. The Dispensary by Tabatha Andrews 2016. Image courtesy RSS and Anne Purkiss. Private collection. Image reuse permission obtained.	303
Figure 67. Carvings with braille by Alistair Park (2016). Image reuse permission obtained.	303
Figure 68. © Frances Priest (n.d.), Tonic Arts, Edinburgh and Lothians Health Foundation. Photographer Shannon Toffs. Image reuse permission obtained.	304
Figure 69. My proposed 'tactile' artworks	304
Figure 70. Handrails matching different scenes Ludden et al. (2019:14). Image reuse permission obtained.	305
Figure 71. Prototype textile objects	307

LIST OF REFLEXIVE NOTES

Reflexive note 1: The use of pseudonyms	84
Reflexive note 2: Setting-up a research encounter	97
Reflexive note 3: Recording the observations and interviews	99
Reflexive note 4: Analysis process	110
Reflexive note 5: Covering a mirror	113
Reflexive note 6: Embodied clothing practice	125
Reflexive note 7: Comparing ages	141
Reflexive note 8: Designing thematic cards	164
Reflexive note 9: CYCLE 2 Carrying out the interviews	168
Reflexive note 10: Recording the interviews	170
Reflexive note 11: Thematic analysis process	173
Reflexive note 12: Facilitating Week 3's 'Dramatic' object handling session	214
Reflexive note 13: Setting up the room	217

LIST OF TABLES

Table 1. Participant groups and cycles of study	81
Table 2. Number of research encounters	100
Table 3. Participant contact log P1 (PWD)*	101
Table 4. CYCLE 1: Participant self-reported demographic information	103
Table 5. Reflexive thematic analysis framework	106
Table 6. Thematic findings: Care home staff	108
Table 7. Thematic findings: People with dementia	109
Table 8. CYCLE 1 Thematic findings	111
Table 9. CYCLE 1 Draft master and subordinate themes	163
Table 10. CYCLE 2: Self-reported demographic information	171
Table 11. (3) Tools for the session	185
Table 12. Object handling timetable	212
Table 13. Object handling session guide and prompts	213
Table 14. CYCLE 3: Participant self-reported demographic information	223
Table 15. CYCLE 3: Thematic findings	226
Table 16. Thematic synthesis of findings	263

COPYRIGHT STATEMENT

The copies of the thesis and published works and thesis submitted for examination shall remain the property of the University of West London, but the copyright in the thesis shall be vested in the candidate.

DEDICATION

This thesis is dedicated to my wonderful research participants and those who supported me in carrying out this work. Thank you for sharing your time with me - without your generosity this work would not have been possible. I feel extremely privileged to have been able to get to know and work with you all.

ACKNOWLEDGMENTS

Thank you to the University of West London for funding this research and to everyone at the Graduate School for supporting me over the course of my studies. Prof Victoria Tischler and Dr Deirdre Robson, thank you for your supervision. It has been a pleasure to work with you, I have learnt so much and will be forever grateful for your support, enthusiasm and dedication throughout this process. Thank you both.

I have met so many talented individuals over the course of this project, many of whom I am now lucky enough to call friends. Fred, Federica, Millie and Grace, it has been wonderful getting to know you, thank you for your support and encouragement. Robyn, you have been so generous with your time, thank you for all of your help.

Finally, I would like to thank my close family and friends. Mum, your fierce belief in me was never more needed, thank you for all that you do and thank you for teaching me to be strong. Dad, thank you for encouraging me to do what I love. Joe

and Rachy, when this process was all-consuming, thank you for not letting me forget myself. AP, your love and selflessness has been a source of inspiration and awe for as long as I can remember, thank you. Jan and Ant, your unwavering support has meant so much, thank you. My oldest friends, Andy, Jack, Hannah and Hannah thank you for always being there for me. Claire, your enthusiasm is infectious, and your notes of encouragement meant so much, thank you. My London family - Amber, Kate, Hattie and Steph, you enable me to do the things I love, thank you for always encouraging me, and for always being on hand with tea (or wine) and cake. And last but not least, Olly. I can't put into words what you mean to me. I could not have done this without you, (or your proof-reading skills), thank you.

INTERDISCIPLINARY APPROACH

My background in fashion textile design and psychology is inextricably connected with this project. Throughout the thesis I refer to explicit instances where my creative practice shaped the research. For example, I design and deliver creative workshops (both one-off sessions and weekly courses, e.g. textile screen printing workshops) in settings such as higher-education colleges, hospices, care homes and hospitals - and this informed the research design and the methods used. Moreover, prior to carrying out research, I volunteered both at the study site and further dementia care settings to deliver creative workshops for (and with) people with dementia. These experiences were invaluable in carrying out the research.

This research was both shaped by my background and the expertise of the supervisory team who are experts in dementia, arts and health, and fashion, textiles and contextual studies.

ABSTRACT

The World Health Organisation has identified the challenge of caring for those with dementia to be made a public health priority. Increasingly, literature from dementia care advocates creative approaches to aid those with dementia to live well. Greater importance is being placed on the significance of the physical and social aspects of dementia care environments. Whilst material and textile objects are used within the care of people with dementia, limited research has explored clothing within dementia care settings. Therefore, the research aims were to investigate the relationship between people with dementia and their clothing, by exploring the embodied and sensorial experience of clothing during wear to examine the potential of clothing in the care of people with dementia.

The research design was shaped by my background in fashion textile design and psychology, and employed a sensory ethnographic (SE) approach. SE draws on traditional ethnographic methods, such as observation and interviews, whilst employing less conventional techniques which involve, for example, designing an activity for (or with) participants. This project employed the use of sensory, creative and embodied research methods, designed to support people with dementia to participate as fully as possible in the research. Three iterative, interlinked cycles of study were carried out. CYCLE 1 consisted of multisensory research encounters, working with people with dementia and care home staff to explore clothing during wear. CYCLE 2 involved working with creative practitioners to translate thematic findings from the first cycle of study into a series of materials, objects and images. CYCLE 3 repurposed object handling sessions (typically used as a psychosocial intervention within dementia care) as a creative, sensory research method, working with people with dementia to explore their responses to the specific materials,

objects and images. The analytic process used varied according to each cycle of study, resulting in the use of reflexive thematic analysis (CYCLE 1), thematic analysis (CYCLE 2) and audio-visual analysis (CYCLE 3).

Findings demonstrate that clothing is important to people with dementia at a number of levels. Clothing supports selfhood, enhances spatial and temporal orientation, improves feelings of comfort, belongingness, security and privacy. The aesthetic and sensorial properties of clothing (and textiles) are important to people with dementia. For example, wearing the 'right' items of clothing can be empowering, whilst wearing the 'wrong' items of clothing can act as a barrier. Attending to such preferences can support relational approaches to care and the design and use of clothing and textiles within care homes. This research identifies the expressive capacity that clothing and textiles afford people with dementia, and demonstrates how this can inform relational approaches to care and activities provision within care homes. Not only do findings contribute multifaceted knowledge regarding the importance of clothing to people with dementia, they also demonstrate the significance of using novel sensory, creative embodied research methods when working with people with dementia.

INTRODUCTION TO THE PROJECT

This research focussed on exploring the significance of clothing to people with dementia living in a care home - and involved working closely with one study site. The site was selected due to the large proportion of people with dementia living there, and the Care Quality Commission (CQC) rated outstanding care it delivers. Care homes in the UK are divided into residential homes i.e. homes that provide personal care, and nursing homes - these may also be referred to as care homes with nursing i.e. homes that provide personal care and are a place where qualified nursing care is provided (NHS, 2018). For the purpose of this research, the term care home is used. Current figures estimate that between 70 - 75 per cent of the UK care home population is made up of people living with dementia (Alzheimer's Society, 2019), thus, this research specifically worked with people with dementia living in a care home. The rationale for working in a care home is detailed in the **Introduction** (see **1.5 Dementia care settings**) and the **Literature Review** (see **2.3 Clothing, dementia and the care home**).

This research explored the embodied and sensorial aspects of clothing to examine the ways in which clothing can be considered in the care of people with dementia. Thus, this research did not seek to provoke reminiscence, it sought to explore experiences 'in the moment'. The focus of this research corresponds with the broader 'bodily turn' in the social sciences and humanities (Martin, Kontos & Ward, 2013), which has led to focussing on the body as a way in which to generate knowledge and understanding. It is claimed that this can lead to enhancing understanding and, in turn, develop health and social care services and settings.

In order to carry out this research I sought an approach that would empower people with dementia and so I used methods that did not rely on recall and verbal expression. Drawing upon my experience of leading arts and textiles workshops and existing research methods, I used a series of sensory, creative and embodied research methods. The approach was underpinned by Pink's (2015) Sensory Ethnography, which I present in detail in the **Method** chapter. Over the course of the project I carried out three focussed periods of 'data' collection, in the form of three cycles of study: **CYCLE 1: Exploring clothing during wear**, **CYCLE 2: Translating themes into objects** and **CYCLE 3: Thinking with things: A series of object handling sessions**. The cycles of study were iterative, as each cycle of study built upon the previous one, to generate a series of rich multifaceted findings. Each cycle of study is presented as a stand-alone chapter in this thesis, detailing the research methods used, participants, the analysis process and the findings. Findings from each cycle of study are considered in the **Synthesis of Findings** chapter, in which findings are discussed alongside existing literature and recommendations are made with regard to the use of specific products and / or prototypes in dementia care settings.

Due to the focus of this project and the research methods used, this thesis contains visual references to existing products, artworks, pieces of design and my own creative practice. My engagement with reflexive practice involved both textual-based reflections and the use of sketchbooks i.e. visual reflexive journal. **Figure 1** contains an extract from my reflexive journal. I used the journal to explore ideas and reflect upon experiences through the use of various techniques, such as marking making, print making, and textiles practice. See **APPENDIX A** to access the full

sketchbook. There are a number of references to my visual journal throughout the thesis.

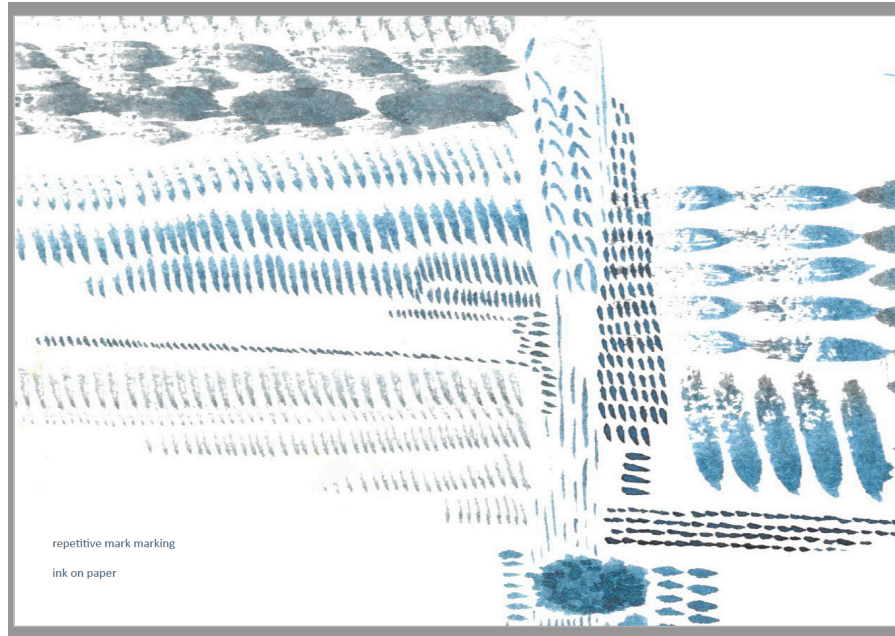


Figure 1. VISUAL REFLEXIVITY: Exploring repetitive touch

ORGANISATION OF THE THESIS

This thesis is comprised of eight chapters:

Chapter 1: Introduction outlines the context for the research, including key definitions and conceptualisations of dementia.

Chapter 2: Literature review brings together literature from a range of disciplines to explore existing research around the significance of clothing to people living with dementia in the care home setting.

Chapter 3: Method details the use of Sensory Ethnography (Pink, 2015) to explore the ‘in the moment’ embodied and sensory experiences of people living with dementia. The chapter examines other methods used when working with people with

dementia and explores novel approaches to carrying out research with people with dementia.

Chapter 4: CYCLE 1: Exploring clothing during wear details the first of three interlinked cycles of study used within this project. This includes the use of multisensory research encounters to explore clothing during wear, the participants involved in the cycle of study, the analytic process and findings.

Chapter 5: CYCLE 2: Translating themes into objects details the second of the three interlinked cycles of study used within this project. This includes the use of thematic cards as tools for elicitation (in order to select and create a series of materials, objects and images), the creative practitioners involved in the cycle of study and the analytic process. The findings represent three object handling sessions used in CYCLE 3.

Chapter 6: CYCLE 3: Thinking with things: A series of object handling sessions presents the use of object handling sessions as a creative research method. The method is detailed, including the use of video recording, the participants involved in the cycle of study, the approach to analysing audio-visual data and findings are presented.

Chapter 7: Synthesis of findings thematically presents findings from the three cycles of study to explore how clothing can be considered in the care of people with dementia. Findings are presented with reference to existing products, artworks, and initial prototypes that I created.

Chapter 8: Conclusions, limitations and recommendations brings together conclusions, discusses limitations associated with both the methods used and the

findings, and presents opportunities for further research and design-led ventures to enhance the care of people with dementia.

CHAPTER 1 INTRODUCTION

The purpose of this introductory chapter is to outline the context of this project. This includes defining dementia both in terms of biomedical and gerontological perspectives, exploring dementia and notions of the self and identity and the significance of this in relation to dementia care practices. The chapter then considers holistic approaches to supporting people with dementia through an exploration of the arts and creativity in dementia care settings.

1.1 Defining dementia

Dementia is an umbrella term for a number of types of disease that affect the brain. To date over 200 subtypes of dementia have been identified (Stephan & Brayne, 2010), including, but not limited to: Alzheimer's disease, dementia with lewy bodies, and vascular dementia. In general terms, dementia is characterized by the progressive decline in cognition which interferes with activities of daily living (Knopman, DeKosky, Cummings et al., 2001). Activities of daily living include, for example, bathing and getting dressed. Due to the progressive nature of dementia, stages i.e. early, middle and late, are used to understand the changes that occur over time (Alzheimer's Society, 2017). Although there are individual variations, common symptoms of early stage dementia include memory loss, difficulty concentrating, problems carrying out familiar daily tasks, issues with communication such as following a conversation and mood changes (NHS, 2020). As dementia progresses symptoms often include memory problems such as difficulty recognising family members, challenges with verbal communication, problems with mobility, incontinence, and reduced appetite (NHS, 2020). People with dementia may also

develop certain behavioural and psychological symptoms, such as agitation, depression, anxiety, aggression and hallucinations (NHS, 2020).

According to the Alzheimer's Society, 850,000 people currently live with dementia in the UK, with that number set to rise to over one million by 2025 (Alzheimer's Society, 2015a). At present, it is estimated that dementia costs the UK economy £26.3 billion per year in social care, health care and unpaid informal carers (Alzheimer's Society, 2015b). Of that cost, two thirds is spent by those affected by dementia (Alzheimer's Society, 2018). Socio-economic status affects access to care, and the types of services that people with dementia receive. In 2018 the Alzheimer's Society called for: major funding reforms (whereby the state covers the cost of dementia care), improved access to services, and enhanced quality of dementia care to address the vast inequity between dementia and other health conditions.

There is currently no cure for dementia and, with the number of people developing the condition increasing annually, enabling those affected to live as well as possible has become one of the biggest health and social care challenges faced in the 21st Century (World Economic Forum, 2017). In a Guardian article Brown, who at the time of writing was Chief Policy and Research Officer at the Alzheimer's Society, wrote that "the need for a cure for dementia is pressing, but practical solutions to benefit those with the condition are also vital" (Brown, 2018 [online]). In 2009, the UK government published the national strategy titled "Living well with dementia" (Department of Health, 2009). Yet the notion of 'living well' with dementia as a concept is becoming increasingly contested. For example, Dr Wendy Mitchell, who was diagnosed with early onset dementia in July 2014, has written extensively about living with dementia - and in her blog 'Which me am I today?' challenged the use of the term:

“We mustn’t hide this reality of their situation just because it doesn’t fit in with the current view of ‘living well with dementia’. My belief is that not everyone does live well, but with support and guidance we can teach people how to live as well as possible.” (Mitchell, 2016)

Arts and gerontology researcher Zeilig (2013) speculated that dementia is not only a neurological condition, it is a societal construction which is exacerbated by fear surrounding the loss of memory and identity. Rhetoric surrounding the condition is often dehumanising, sensationalised and affecting, for example ‘join us in the *fight against* dementia’ (Alzheimer’s Society Strategy, 2017 [emphasis author’s own]). The aggressive notion that one has to ‘fight’ dementia is something that Zeilig (2013) has argued provokes fear and powerlessness, and is indicative of a biomedical approach. The medicalisation of dementia perceives the condition as something to be diagnosed and treated, involving, for instance, the management of ‘difficult’ behaviours. Camp claims that this has led to “a paradigm of learned helplessness while waiting for “the cure”” (Camp, 2019: 221). Additionally, Zeilig (2013) claims that the condition has become a ‘cultural metaphor’ for tragedy in Western culture. This can exacerbate the stigma associated with dementia, which is further intensified by pervasive notions surrounding the condition and ageing.

Dementia and the ageing body

Over the past two centuries life expectancy has risen more than two years every decade, meaning that children born in the West have over a 50 per cent chance of living to be over 105 (Gratton & Scott, 2016). Although this means that millions of people will live a long life, it is important to consider that dementia is the most age-related of all conditions affecting older people. At present 30 per cent of 85-year-olds live with dementia (Gratton & Scott, 2016).

Age, much like gender, race, class, sexuality and disability, is a key social division affecting how a person is perceived, ranked and evaluated within society (Twigg, 2013). Whilst youth is perceived as good and desirable, ageing is typically perceived as bad, repulsive and ugly (Hurd Clarke & Griffin, 2008). As such, ageing involves moving away from 'the ideal' (i.e. youth), towards a form of degeneration. Thus, physical manifestations of older age, for example, wrinkles, grey hair and changes in body composition, deviate from societal standards of beauty, therefore 'othering' the ageing body. Whereby visible signs of ageing are typically perceived as a personal failure and are also encoded with moral associations, for example, a lax attitude (Twigg, 2013). This is particularly evident for women (e.g. Hurd, 2000; Hurd Clarke & Griffin, 2008), as normative femininity is associated with youthfulness and personal grooming e.g. dressing, hairstyle and make-up. Twigg (2013:32) wrote that "derogation from it [femininity] erodes a woman's status...so that ageing is experienced by many women as a form of cultural exile from femininity".

The 'othering' of the ageing body and ageism i.e. discrimination on the grounds of the person's age, is prevalent in Western culture. Nelson (2011) refers to derogatory phrases e.g. 'over the hill' and cartoon imagery associated with frailty and death, often found on birthday cards, as one way in which to demonstrate that ageism is normative within Western culture. Ageism is exacerbated by changing demographics and socio-economic developments, which has led to conceptualizations of ageing such as the 'Third age' and 'Fourth age'. These metaphorical realms are not associated with specific chronological ages, they are instead associated with factors such as health, lifestyle, and financial opportunity. Laslett (1987), a social philosopher and historian, argued that a shift in demographics and socio-economic development has produced a generation of

retired people who find themselves in a position of greater potential agency. Agency is defined as, “the ability to control personal life in a meaningful way, to produce, to achieve, to make some mark upon others and the world” (Kitwood & Bredin, 1992: 283). The ‘Third Age’ allows for the development of a distinct and personally fulfilling lifestyle and is marked by pleasure and self-development, such as the pursuit of personal interests - it is in stark contrast with the ‘Fourth Age’. The Fourth Age, positioned by Gilleard and Higgs (2011) as a “social imaginary” (Higgs & Gilleard, 2014:13), represents not a particular age group or stage of life, but is defined as a state of ‘unbecoming’, in which forms of agency are stripped away. They state that ‘going into care’ is central to the central social imaginary of the ‘Fourth Age’. The Fourth Age is a metaphorical ‘black hole’ (Gilleard & Higgs, 2011), meaning that once the conceptual threshold, a diagnosis of high-risk frailty i.e. overall poor health and worsening morbidity and disability, is passed, there is little chance of return (Higgs & Gilleard, 2014). People with dementia conceptually ‘fall’ into the category of the Fourth Age due to associations with risk and frailty, which in turn negates their agency.

There is vast potential to enhance the lives of older adults (including older adults living with dementia) and to challenge pervasive rhetoric and stigmatisation. For example, in 2019 Research England awarded £4m to Lab4Living’s ‘100 year-life project’ (The CCRI Impact Blog, 2019) to develop age related products, new housing models and care technologies to support older people to lead more independent and fulfilled lives. Such investment is crucial in order to enhance older adult’s quality of life and, in turn, challenge pervasive ageism.

1.2 Dementia, selfhood and embodiment

Dementia is stigmatised not only through its links with ageing, but the decline of cognitive function has led to a prevalent view that the condition leads to a loss of self. In broad terms, selfhood is considered to be the quality that constitutes one's individuality and one's state of having identity; it is what makes each person unique. Yet, the self is inherently difficult to define, for instance, when carrying out a systematic review exploring the impact of dementia on selfhood, Caddell and Clare (2010) reported using "self", "identity", "personhood" and "selfhood" as interchangeable terms when approaching selfhood.

Despite difficulty in defining the self, Vidal (2009) purports that the dominant notion is that selfhood is located in the brain i.e. "we are our brains" (Vidal, 2009:7). Vidal (2009) claims that in principle it could have been attached to any part of the body, but, with the rise of the modern self in the 17th Century, identity became implicitly intertwined with the brain, as the brain is the organ responsible for the functions that the self was identified with, for example, intellectualism.

The conceptual 'location' of the self within the brain, and the progressive decline in cognitive function symptomatic of dementia, has "led to much debate in the literature as to the extent to which selfhood persists or diminishes in people living with dementia" (Caddell & Clare, 2010: 113). Some researchers claim that the self erodes in people living with dementia, for example, Davis (2004: 375) wrote that: "what is so devastating about the relentless nature of dementia is the very splintering of the sedimented layers of being". Some researchers argue that while selfhood remains it is compromised in some way (e.g. Cohen-Mansfield, Parpura-Gill, Golander, 2006). Others, however, reason that the self remains throughout the course of dementia (e.g. Fazio and Mitchell, 2009). Notably, in recent years, social

scientists have argued that the body has a pivotal role in the construction and manifestation of the self in people with dementia i.e. embodied selfhood, (e.g. Kontos, 2005; Kontos & Martin, 2013; Katz, 2013) thus, challenging the notion that cognitive decline equates with diminishing selfhood.

Embodied selfhood

Gerontology's emerging theoretical subfield of embodiment and dementia, specifically 'embodied selfhood' (Kontos, 2004, 2005; Kontos and Martin, 2013; Katz, 2013) examines the experience of the lived body by distinguishing primordial and socio-cultural ways of being in the world i.e. that bodily gestures and movements are formed through exposure to particular social conditions. The notion of embodied selfhood, as posited by Kontos (2005), takes its theoretical bearings from phenomenological philosopher Merleau-Ponty (1962) and Bourdieu's (1990) sociological theory of the logic of practice.

1.2.1.1 The primordial body

Merleau-Ponty (1962) argued that embodied consciousness is a fundamental level of existence which does not involve a cognitive form of consciousness. Thus, he claimed that the pre-reflective body is intentional, as it is directed towards the world without requiring a reflective understanding as to the way in which it is directed and so does not involve a cognitive form of consciousness. In order to explain the pre-reflective body, Merleau-Ponty (1962) referred to the experience of being bitten by a mosquito. In this case a person does not need to look for where they have been bitten, they can find it straight away, reaching with their hand to scratch the itchy bite. Therefore, they experience a direct relationship between their hand (and its scratching potential) and the part of the body bitten by the mosquito. This, Merleau-Ponty claimed, illustrates the coordination of all movements involved in scratching

the mosquito bite without requiring reflective thought. Therefore, pre-reflective thought is not learnt, it is bodily-knowledge. This means a person knows through their body, and their body knows how to act or respond.

Drawing on the work of Merleau-Ponty, Kontos (2005) claimed that selfhood emanates from the body's power of innate expression, which is expressed in the movements of the body. When carrying out research with people living with dementia, she observed, for example, how a woman would reach behind her neck to pull from beneath her bib (worn to protect her clothing whilst eating) a string of pearls so that they could be seen. Kontos claimed that such moments illustrated how residents would intend a certain outcome by their actions (e.g. in this case, that the string of pearls were made visible) and that their actions were performed through their bodies (e.g. the person reaching behind her neck).

1.2.1.2 Habitus

Despite this, Kontos (2005) argued that the capability of Merleau-Ponty's primordial body did not explain the style or content of bodily movements and gestures i.e. bodily practices. Kontos (2005) drew upon Bourdieu's concept of habitus (1977, 1990) that addresses the ways in which being a member of a particular social class is instilled in individuals' bodily dispositions. These are enacted by the body through postures, gestures and movements affecting, for example, the way one walks and the way one eats. Therefore, Bourdieu claimed that bodily practices are formed through exposure to social conditions associated with being part of a particular social group/class. Habitus consists of dispositions and forms of know-how, all of which function below the threshold of consciousness, and as such, are at a pre-reflective level.

Drawing upon the aforementioned work of Merleau-Ponty (1962) and Bourdieu (1977, 1990), Kontos (2005) argued that selfhood, in addition to having a primordial source, resides in the dispositions and schemes of habitus and thus, in the same way that dispositions are embodied and materialized in practice, selfhood is also embodied and established in a socio-culturally specific way of being-in-the-world.

An embodied understanding of selfhood places the body at the centre of a reconceptualization of how dementia is represented and experienced, and so focuses on the sensory and lived experience of being in the world. In practice, embodied selfhood requires disregarding the body as secondary, embracing the holistic notion that a person *is* their body, including their brain/mind, its gestures, movements and habits. Thus, it requires viewing the body as intentional and significant, rather than as an object that a superior mind orders to perform.

Whether researchers align with Kontos' notion of embodied selfhood (Kontos, 2004, 2005, 2015; Kontos & Martin, 2013) or not, her work has been significant in shifting the discourse to embrace the role of the body in the construction and manifestation of selfhood in people with dementia. An embodied perspective of selfhood recognises that a person is unique, and that their wishes and desires are experienced and communicated through the body. This is particularly important for people with dementia who may struggle with verbal communication (Downs, 2013). This is also significant as it demonstrates the need to attend to the embodied actions of people with dementia as expressive, rather than behaviours to be managed.

1.3 The bodily turn and dementia care paradigms

This recent emphasis on the body, in terms of both representing and understanding the experiences of those living with dementia, also corresponds with a broader 'bodily turn' in the social sciences and humanities (Martin, Kontos & Ward, 2013), whereby a focus on the body has become a significant way in which to generate knowledge and understanding. Furthermore, researchers (e.g. Downs, 2013; Ward, Campbell & Keady, 2014) have claimed that attending to the body could have vast implications for health and social care services and settings, as the approach can be juxtaposed with biomedical task-oriented models of care, necessitating a more flexible approach to care (Cohen-Mansfield & Bester, 2006). Moreover, as Herron & Wrathall (2018) note, dementia researchers, carers, and people with dementia advocate the need to understand the actions and expressions of people with dementia as responsive behaviours (Dupuis, Wiersma & Loiselle, 2012b). For example, a person with dementia who attempts to strike someone may be expressing an unmet need, fear, confusion or distress at a particular social or physical setting (Herron & Wrathall, 2018) rather than their behaviour being symptomatic of the condition.

This in turn has implications when considering dementia care paradigms, as traditionally the social and clinical care of people with dementia has been characterised by a biomedical model of care and deficit model of dementia e.g. losses associated with cognitive impairments, and the management of 'difficult' behaviours, through control, containment and pharmacology (Dupuis et al., 2012b). The traditional 'dementia sufferer' (them) was distinct and different to the cognitively intact (us). Concerns around the dehumanising and pathologising nature of such

approaches have led to, most notably, the person-centred care model (Kitwood, 1997).

Person-centred care

Kitwood (1997) described the ways in which treatment contexts and caregiving relationships could be infantilising, stigmatising and objectifying, creating a 'malignant social psychology' (Kitwood, 1997). As a corrective to the dehumanizing tendencies of some treatment contexts and caregiving relationships, Kitwood (1997) founded the principles of person-centred care. The approach involves enabling individuals with dementia to exercise choice, to use their abilities, to express their feelings, and to develop and maintain relationships. Kitwood's (1997) person-centred approach derives from a number of traditions in psychiatric counselling and psychotherapy. The psychosocial approach is centred on the premise of attaining a state of wellbeing (which is equated with the maintenance of selfhood), regardless of cognitive status and is dependent upon fulfilling various psychological needs, including a sense of identity, "attachment", "comfort", "occupation", and "inclusion in groups" (Kitwood, 1997:7). Kitwood's model of dementia emphasises psychosocial factors that can deprive an individual with dementia of their selfhood: thus the approach recognizes the intrinsic value and uniqueness of the individual. The impact of Kitwood's person-centred care cannot be underestimated and has become pervasive in UK dementia care provision. Recognising the selfhood of people with dementia has become a definitive feature of policy and practice in dementia care (NICE, 2018), including the development of person-centred outcome measures e.g. Dementia Care Mapping (Bradford Dementia Group, 2005).

The concept of person-centred care is widely accepted, yet there is often a gap in its implementation in care homes (Edvardsson, Winblad, Sandman, 2008).

The approach has been criticized, as it focusses on the person with dementia as a 'recipient of care'. This centres on the person with dementia and neglects the experiences of family and formal partners in care (e.g. Dupuis, Gillies, Carson et al., 2012a; Nolan, Davies, Brown, et al., 2004). Likewise, the approach does not recognise the agency of people with dementia, or that they are important catalysts of their own well-being (Kaufman & Engel, 2016).

Relationship-centred care

Building upon the notion of person-centred care, relationship-centred care (Adams & Gardiner, 2005) was developed to include those caring for the person living with dementia. The approach conceptually shifts away from focusing on the individual with dementia and their autonomy, and instead moves towards interdependence and relationality (Dupuis et al., 2012a). Additionally, the approach highlights that the person with dementia retains status and has an active role in their care. Despite this, the approach still positions the person living with dementia as someone living in need of care, and therefore places them conceptually in a care setting (Bartlett et al., 2010).

A citizenship perspective

Bartlett and O'Conner (2007) claim that employing a citizenship perspective addresses some of the gaps inherent in both person-centred and relationship-centred approaches to care. Applying a citizenship lens involves attending to the power imbalance that occurs within dementia care and wider society, as it focusses on improving the status and treatment of people living with dementia (Bartlett & O'Connor, 2010). Moreover, it extends the notion of relationship-centred care to incorporate the person with dementia's relationships with others and the broader society, thus it addresses access to, and the experiences within, health and social

institutions and provision. The model centres on “people getting what they are entitled to or have a right to expect as an equal citizen” (Bartlett et al., 2010: 108). The lens is therefore viewed as “rights-based”, as opposed to “needs-based” (Bartlett et al., 2010: 35) and thus shifts the discourse away from the notion that a person with dementia is living in need of care. A rights-based approach to developing dementia care is increasingly advocated see e.g. Hughes and Williamson (2019).

The relational citizenship-model

Despite the advancement of dementia care paradigms, Kontos, Miller and Kontos (2017a), posit that the intentionality of the body remains neglected within the aforementioned paradigms. Kontos et al. (2017a) claim that embracing embodied selfhood in dementia care practice could result in shifting practices away from approaches that silence or ignore bodily expressions of selfhood to approaches that recognize and respond positively to such expressions. Such approaches, in turn, have less to do with strategies to manage and control the behaviour of care recipients and more to do with the development of new principles of care (Kontos 2005). Thus Kontos et al. (2017a) propose the ‘Relational Citizenship-Model’ of care, the principles of which draw upon: (1) the concept of citizenship (i.e. interdependence, reciprocity); (2) treating the person with dementia as active partners in their own care and; (3) the theory of embodied selfhood i.e. that the body is expressive and communicative of the self. They argue that “relational citizenship more inclusively and unconditionally provides for the recognition and support of membership in, and contributions to, social collectivity” (Kontos et al., 2017a:194). This model recognises the role of the self beyond cognitive impairment and, despite

being in its infancy, provides a way in which to view the person with dementia both as an individual and a social being.

Referring to elder clowns as an arts-based approach to dementia care, Kontos, Miller, Mitchell et al. (2017b) claim that creativity is a central tenet of relational citizenship and that the expressive capacity of art can support people with dementia at an embodied level. Elder clowns are specialist clowns, who use humour, song, dance and music to work with people with dementia. Kontos et al. (2017b) explain that such techniques can facilitate engaging with a person with dementia 'in the moment'. Keady, Campbell, Clark et al. (Accepted/In press:11) define being 'in the moment' as:

“a relational, embodied and multi-sensory human experience. It is both situational and autobiographical and can exist in a fleeting moment or for longer periods of time. All moments are considered to have personal significance, meaning and worth.”

The improvised, creative techniques used by elder clowns are distinct from common approaches to communicating with people with dementia, which often focus on 'bringing the person with dementia back' and therefore emphasise losses associated with the syndrome and reinforce normative concepts of selfhood. Creativity provides opportunities for interacting with people with dementia 'in the moment', attending to what a person can do, rather than what they cannot do.

1.4 The arts, creativity and dementia

A burgeoning area of research demonstrates that creativity, arts-based activities and engagement with culture e.g. visiting museums and galleries, can enhance people with dementia's wellbeing and enable social inclusion and empowerment (see e.g. Clift, 2012; Craig & Killick, 2011; Killick & Craig, 2012;

Young, Camic & Tischler, 2016). A seminal report from the All-Party Parliamentary Group on Arts, Health and Wellbeing (APPGAHW) (2017) highlighted the many ways in which engagement with the arts can help people with dementia. For instance, it was reported that the arts facilitate “a style of communication and self-expression that is able to capitalize on the emotional and social capabilities of people with dementia” (APPGAHW, 2017:133). Engagement with the arts, the inquiry suggested, shifts focus away from treating the symptoms of dementia to engaging with the creative potential of a person. Similarly, both Craig (2012) and Swinnen and de Medeiros (2018) highlight the expressive capacity that textiles and objects can have in supporting people with dementia in meaning-making and expression.

Despite this, the majority of arts programmes for people with dementia view arts activities as ‘interventions’ and focus on the role that the arts have in enhancing the wellbeing and quality of life of people with dementia (Zeilig, West & van der Byl Williams, 2018; Bellass, Balmer, May et al., 2019). Thus, it is assumed that there is a measurable impact - pre and post the intervention. However, focussing on the measurable before and after effects of arts activities leaves little room for understanding the personal experiences of those taking part ‘in the moment’ i.e. during the arts activity. Thus, as Bellass et al. (2019:5) note, there is often “a lack of attention to the material, sensory and embodied nature of creating.”

An interventionist approach to the arts also results in creative engagement being limited to a pre-set schedule and therefore negates engagement with art for art’s sake. Zeilig et al. (2018) claim that this is, in part, due to the ways in which creativity is traditionally entrenched with notions of the ‘creative genius’ and is therefore limited to the realm of the select few. They argue that a shift in the way in which creativity is viewed for people with dementia can challenge dominant

biomedical and social paradigms, in order to consider people with dementia as “embodied, emotional, desiring, creative agents, embedded in relationships and a social context” (Zeilig et al., 2018:141). Similarly, Dowlen (2018) argues that attending to the ‘in the moment’ experiences of people with dementia can lead to greater understanding of the possibilities that, in the case of her research, music “outside of the remit of cognitive enhancement or symptom reduction” can have for people with dementia (Dowlen, 2018:59). Likewise, Zeilig, Tischler and van der Byl Williams et al. (2019) describe how a series of co-creative arts sessions i.e. improvised music making sessions, supported the ‘in the moment’ experiences of people with dementia. They posit that the sessions facilitated shared collaborative processes and enabled people to be “interdependent, creative agents with equal potential to explore (and get lost) together” (Zeilig et al., 2019:22). Such co-creative approaches are therefore in stark contrast with arts interventions that are delivered ‘to’, rather than ‘with’, people with dementia, thus emphasising the strengths of people with dementia and potential opportunities for e.g. creative expression, and challenging the biomedical and deficit model of dementia which emphasises the losses and decline associated with the syndrome.

Moreover, Bellass et al. (2019) posit that the notion of everyday creativity or little-c creativity can be considered particularly meaningful for people with dementia. Little-c creativity is defined as engagement with creative practice that is meaningful to everyday life (Beghetto & Kaufman, 2007). For example, a care home resident using their bag to transition from a private space e.g. their bedroom, to a public space of the care home e.g. the lounge (Buse & Twigg, 2014a). Similarly, Stephens, Cheston and Gleeson (2013) described the ways in which tangible material objects may be appropriated within the care home setting (e.g. transitional objects). Such

objects transcend their functional use and are instead used by an individual to feel calm and secure. Attending to spontaneous moments of everyday creativity (Bellass et al., 2019) can offer new insights into the ways in which people with dementia, and those that surround them, adapt to changes associated with the condition and their experiences of dementia care settings.

1.5 Dementia care settings

Engagement with the arts has been found to enhance health and social care environments (e.g. APPGAHW, 2017; Arts Council England, 2007), whilst the installation of artworks within such settings can transform how the spaces ‘feel’. ‘Paintings in Hospitals’, an arts and health charity that specialises in installing high-quality artworks within, for instance, hospitals, hospices and care homes, has been recognised by The Department of Health, NHS England and, Arts Council England as a leading provider of arts in social care and health services (Paintings in Hospitals, n.d. [online]). The impact that the design of health and social care settings can have on those living with dementia is reflected in the growing number of ‘dementia friendly design’ guidelines and recommendations (see e.g. Halsall & MacDonald, 2015; Greasley-Adams, Bowes, Dawson et al., 2012; Timin & Rysenbry, 2010).

This is important as despite the prevalence of domiciliary care (CQC, 2019) i.e. paid care-workers that support people in their own homes, and informal carers i.e. unpaid care provided by relatives or friends, at present 400,000 older adults in the UK live in care homes (Laing Buisson, 2018). Current figures estimate that between 70 - 75 per cent of the UK care home population is made up of people living with dementia (Alzheimer’s Society, 2019). In light of the growing numbers of people living with complex care needs (including dementia), and recent figures estimating

that 1.5 million older people do not have access to the care and support that they need (Age UK, 2020), the Alzheimer's Society (2018) anticipates increased demand for care home places.

At present, the Care Quality Commission (CQC), the independent regulator of health and social care in England, reports that 72 per cent of nursing homes and 82 per cent of residential homes are rated as 'good' (CQC, 2019). This meaning that the services are performing well and meeting the required CQC expectations. Despite this, care homes are often scrutinised in the media and inquiries into cases of abuse and neglect, widespread funding cuts and high staff turnover (Lloyd, Banerjee, Harrington et al., 2014) have led to largely negative public perceptions e.g. "Britains are living in 'real fear' of moving into care homes" (Borland, 2019).

The fear and uncertainty associated with moving into a care home is reinforced by the ambiguity of the setting. Care homes are complex due to the transition to communal living and the blurred 'boundaries' between public and private spaces (Buse & Twigg, 2014a; Cleeve, 2020; Nakrem, Vinsnes, Harkless et al., 2012). A care home resident is allocated their own bedroom and access to public shared spaces e.g. lounge, dining room, activity room and garden. Yet, there are also spaces such as kitchens, laundry rooms, staff rooms, and offices, that are for the sole use of care home staff. This necessitates that residents negotiate the meaning and use of different spaces and highlights tensions between organisational priorities i.e. the care home as a place of work, and the care home as a home (see e.g. Craig, 2017; Kenkmann, Poland, Burns et al., 2017). For example, Craig found that people "struggled to navigate a place that was called home, but which resembled more of a hospital" (Craig, 2017: S2343).

Connellan (2019) claims that on moving into a care home it is a person's bedroom, rather than the entire care home, that becomes their home. She found that the objects that people move into a care home with can enable a sense of belongingness and support selfhood. For example, she wrote that:

“There is sadness and trauma in the displacement of moving; therefore, it can often be small remnants of material pasts that help to shape fragile presents and uncertain futures” (Connellan, 2019:104).

Connellan (2019) found that such objects may be decorative items that a person displays in their bedroom e.g. a painting or a tapestry, or they may be items of dress, such as jewellery. See **Figure 2** - a person wearing her late husband's rings. The notion that the proximity of certain objects can be significant and hold particular importance for individuals within care homes has also been found by e.g. Buse & Twigg, 2014b; Craig, 2017; Stephens et al., 2013. Likewise, Lovatt (2020) found that material and social interactions within care homes shape feelings of belongingness and homeliness. For instance, she found that engaging with housework activities enabled people to feel 'at home' within such settings.



Figure 2. Research participant's rings (Connellan, 2019:118). Image reuse permission obtained.

This project builds upon such notions, examining clothing as a person's most immediate physical environment (Twigg, 2010) and thus the potential importance of clothing in a care home setting and within the holistic care of people with dementia. This research is pertinent given the need to enhance the psychosocial care of people with dementia in care homes. The following chapter, the literature review, identifies how this research address gaps within existing knowledge.

1.6 Summary

This chapter presented the contextual background to this research, including definitions and conceptualisations of dementia, psychosocial interventions and the significance that the arts can have for people with dementia. This chapter also considered the prevalence of dementia within UK care homes and the impact that the arts, creativity and materiality can have in enhancing the lives of people with dementia in such settings. The following chapter explores existing research within the area of clothing, dementia and the care home.

CHAPTER 2 LITERATURE REVIEW

This chapter contains a comprehensive discussion of literature within the under-researched area of clothing and dementia. The approach to research was informed by my background in fashion textile design and psychology. This influenced the assimilation of literature which references fields including, but not limited to; gerontology, fashion theory, social psychology and sociology. **Figure 3** visually represents the assimilation of literature.

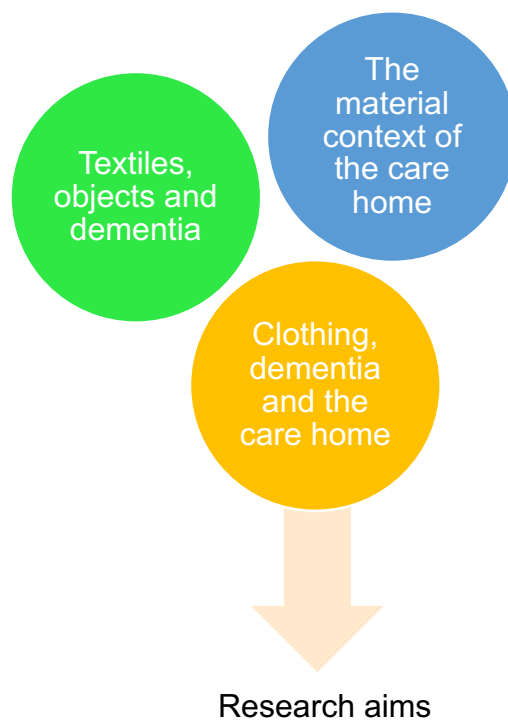


Figure 3. Overview of the literature review

Drawing upon the introduction, the literature review first explores care home settings and the impact of the built environment and the materials/objects within such settings on people living with dementia. This includes examining items ranging from purpose-made objects such as tactile items designed to provoke sensory engagement, to a person's personal possessions e.g. their handbag, within settings.

Clothing within the care home is then considered with regard to its appearance, clothing during wear, clothing and shared experiences and clothing attachment. The literature review concludes by exploring opportunities to reimagine clothing within health and social care settings and identifies the research aims that underpin this project.

2.1 The material context of the care home

Studies focussed on the social and material context of dementia care environments, demonstrate that materialities i.e. engagement with material things, for example, the built environment, everyday objects and health technologies are significant and impact care practices (Buse, Martin & Nettleton, 2018a; Cleeve, Borell & Rosenberg, 2020; Latimer, 2018). Social and material interactions are fluid and processual with interactions shaping meanings and associations within care home settings (Lovatt, 2020; Lupton, 2017). For example, Cleeve et al. (2020) used a series of illustrations of everyday objects (see **Figure 4**), to explore nursing assistants' (who work with people with dementia) understanding and engagement with materialities in the care home. They found that nursing assistants engaged with items in a number of ways whereby, in some instances materialities were described from a functional perspective e.g. a bed used to enable a resident to rest and sleep, yet in other instances, materialities were found to facilitate dignified care e.g. drawing curtains to support privacy. Thus, materialities contribute to the ways in which care is delivered and impact the quality of life of those within health and social care settings (Latimer, 2018).



Figure 4. Abstracted illustrations used as prompts with nursing assistants (Cleeve et al., 2020:129. Image reuse via CC BY-NC 4.0.

The notion that materiality is important in care homes is significant in light of increased recognition surrounding the impact that the design of health and social care settings can have in the lives of older adults (including older people with dementia) (e.g. APPGAHW, 2017; Arts Council England, 2007; Chaudhury & Cooke, 2014; Chaudhury, Cooke, Cowie et al., 2017; Craig, 2017; Ludden, van Rompay, Niedderer et al., 2019). Due to the prevalence of people with dementia living in care homes, the setting should support and enable those with dementia to live as well as possible. The Department of Health (DH) reported that dementia care environments should:

“Enhance positive stimulation to enable people living with dementia to see, touch, hear and smell things such as through the use of sensory and tactile surfaces and walls, attractive artwork, soothing music, and plants, that give them cues about where they are and what they can do.” (DH, 2015:26)

The report contained comprehensive design guidance on the layout and sensory aspects of dementia care environments. Yet the language used within the report, for instance, that the care setting should provide people with dementia “cues about

where they are and what they *can* do” [italics author’s own], refers to the losses associated with dementia (the deficit model). Thus, rather than considering the experiences of the person with dementia and the enabling opportunities that the setting can provide, recommendations seemingly focus on addressing deficits associated with the syndrome.

In order to enable people with dementia to live as well as possible care settings must move beyond traditional environments designed for the purpose of control and containment e.g. designed to reduce behaviours such as restlessness and aggression, towards ‘enabling environments’. The concept of an enabling environment is not a place that attends simply to functional and practical needs of residents living there e.g. access, but one that facilitates enjoyable interactions (Chalfont & Rodiek, 2005). Davis, Byers, Nay et al. (2009) claim that attending to the lived experiences of people with dementia within care settings i.e. in the case of their research, this involved exploring specific experiences e.g. meal times, can support the creation of dementia-friendly environments. Dementia-friendly environments are broadly defined as settings that consider the organisational, social and physical places which impact upon the experiences of the person with dementia, in order to support the meaningful engagement of the person in everyday life (Davis et al., 2009). Niedderer, Tournier, Colesten-Shields et al. (2017) note that it is also important to consider the forms of engagement that such settings offer. For example, they claim that deficit-orientated perspectives have led to the use of activities (or interventions) that occupy people with dementia i.e. give people ‘something’ to do, rather than focussing on meaningful activities. Davis et al. (2009) suggest that care homes should enable spontaneous meaningful engagement through, for instance, the use of varying objects and materials within the setting e.g. vases with flowers for

residents to arrange. Similarly, Craig (2017) positioned that the careful design of such settings can be an 'enabler' due to the material and social interactions it can facilitate. Interestingly, Davis et al.'s (2009) recommendations regarding the provision of opportunities that are not formally structured within, for example, an arts intervention, concur with notions of everyday creativity as suggested by e.g. Bellass et al. (2019) and Zeilig et al. (2018) and indicate the potential that materialities have in supporting spontaneous, meaningful engagement.

The design-led project 'Design for Dementia', carried out by researchers at the Royal College of Art (Timin & Rysenbry, 2010), demonstrated a different approach to re-imagining the dementia care environment and included ways in which to support the independence of those living within care settings. For instance, the researchers suggested redesigning bedroom furniture such as wardrobes to facilitate greater accessibility through the use of e.g. compartments separating different types of garments. The redesigned wardrobes were proposed to support independence through enabling people to see, choose and access their clothing. Moreover, Ludden et al. (2019) found that redesigning functional furniture such as handrails, both enhanced the look and feel of the care home setting whilst also improving orientation, encouraging purposeful walking and providing opportunities for multisensory stimulation. Both projects demonstrate how attending to the experiences of people with dementia can support understanding and reveal opportunities that can enable people to live as well as possible with the condition.

Institutional priorities impact upon the look, feel and atmosphere of a care home by dictating: the aesthetic of the home e.g. what a care home looks like; the layout e.g. long corridors; and the sensory properties e.g. the fabrics within the setting, of the care setting. In order to comply with legislation, organisations include

objects such as hand sanitising gel dispensers, latex gloves and stainless-steel medicine trolleys, all of which engender an institutional feel rather than a sense of home (Campbell, 2019). Moreover, the carpets, tiles, upholstery, and soft furnishings used can drastically affect the look and feel of the environment (Brawley, 2006; Chaudhury & Cooke, 2014). Surfaces within care homes are often easy to clean i.e. wipeable, enabling staff to maintain hygiene standards and yet this dramatically impacts the look, 'feel' and atmosphere of the setting. Where the use of materials such as vinyl, due to its easy-clean, hardwearing properties, typically provoke a sterile and institutional 'feel' (Brawley, 2006). This is, in part, due to the notion that textiles are imbued with associations and meanings according to the tactile fabric (e.g. Barnard, 1996). For example, the connotations of silk as smooth, lustrous and luxurious, have been harnessed by the hair and beauty industry to promote and sell products. Such pervasive connotations are no less powerful in dementia care settings, This, shapes what Lupton (2017) discusses as the affective atmosphere i.e. the ways in which material and social interactions affect how spaces and places are encountered, shaping how people think and feel about the spaces that they inhabit.

The use of materials such as vinyl within care homes not only affect the intangible atmosphere of the setting but, as Brawley (2006) claims, also provide limited opportunities for haptic stimulation due to the cold, synthetic texture. However certain upholstery fabrics could provide opportunities for tactile and haptic stimulation whilst also enhancing the look of the setting. Brawley's (2006) suggestions connect with Davis et al.'s (2009) findings recommending that dementia care settings should provide opportunities for everyday unprompted enjoyment via aesthetic pleasure through for instance, artwork, décor and windows with views to the garden. Similarly, Jakob, Collier and Ivanova (2019) claim that attending to the

sensory needs of people with dementia, through the use of specific objects and materials within health and social care settings, can lead to personal, meaningful engagement. Moreover, Collier and Jakob (2017) claim that the richness of textiles, and the diverse ways that they can be used, offer opportunities for sensorial exploration and engagement for people with dementia. This, they state, is particularly important as people living with dementia can be at risk of sensory deprivation due to age-associated declining performance of the senses, and difficulties in initiating their own sensory stimulating activities.

The use of textiles could therefore take on particular importance in care homes, as researchers have found that people with dementia often negotiate and re-imagine the setting through engagement with and the use of material objects (Brawley, 2006; Campbell, 2019; Chaudhury et al., 2017; Collier & Jakob, 2017; Lupton, 2017).

2.2 Textiles, objects and dementia

The notion that people with dementia may enjoy engaging with different textiles and fabrics has been demonstrated by the work of, for example, the Napkin Project (2014), devised by artist Deirdre Nelson and produced by Willis and Newson (see **Figure 5**). The project invited members of the public to embroider napkins that



Figure 5. Example from the Napkin Project (2014). Photograph by Jim Wilemen. Image reuse permission obtained.

were then donated to care homes. The initiative was inspired by Nelson's observations in a care home - that fabric was particularly important to some residents e.g. she noted that residents would spend time smoothing a napkin, touching its edges and refolding it. Feedback from care home staff and those involved in the Napkin Project suggested that the tactile qualities of the donated napkins were particularly engaging and meaningful for people with dementia (Napkin Project, 2014).

Similarly, Pajackowska (2012) found that certain textile activities, such as untangling skeins of wool, knitting and plaiting yarns, sorting, folding and handling lengths of fabrics, evoked positive and emotional responses from care home residents. For example, she described residents recalling memories, and speaking, singing and humming when taking part in the activities. Additionally, Souyave, Treadaway, Fennell et al. (2019), recently presented the potential that activities such as folding lengths of fabric or paper, can have in providing positive moments for people with dementia. Handling fabric has also been used in reminiscence activities in which fabrics such as fur, satin and velvet, have been found to be meaningful for people with dementia. It is suggested that the feel of such items can provoke



Figure 6. 'Bud sensory cushion' for people with dementia (Find, n.d.)

reminiscence as such fabrics have the ‘feel’ of the past (Schweitzer, Bruce & Gibson, 2008).

The potential benefits of engaging with textiles and the haptic engagement (via handling items) that everyday material objects can provide within dementia care



Figure 7. 'Fiddle muffs' (Alzheimer's Society e-shop, n.d.)

settings has been advocated by Jakob and Collier (2017). They found that exemplary Multi-Sensory Environments¹ used cushions specifically designed to provide haptic and visual engagement through the use of ribbons, buttons, zips, and embroidery. See **Figure 6**, an example of a sensory cushion designed for people with late stage dementia.

Such items share similarities with 'twiddle muffs' (also known as 'fiddle muffs') which are often used in dementia care settings. Twiddle muffs are typically a double-muff, with items such as, beads, buttons and zips attached to both the inside and outside of the item in order to provide tactile stimulation. The Alzheimer's Society e-

¹ MSEs are sometimes referred to 'Sensory Rooms' or 'Snoezelens' – they are specific spaces that provide sensory enriched experiences and activities. The rooms were first established by Dutch therapists for people with learning disabilities and have been applied to a range of users including people with dementia.

shop sells ‘fiddle muffs’ (see **Figure 7**), which are marketed as providing the following benefits: “it can be used to exercise hands and fingers, calm agitated hands and minds, relieve stress, act as an interactive companion and reduce the use of medication” (Alzheimer’s Society, n.d.). Despite anecdotal reports that state the benefits that twiddle muffs can have for people living with dementia, there is little evidence-based research that examines the specific benefits of using them. Moreover, such objects are often infantile in design and thus could be considered stigmatising.

Further purpose-made objects for people with dementia include the use of dolls (there is a specific body of literature that explores the potential benefits that ‘doll therapy’ has for people with dementia) and material objects such as ‘PARO’ a robot designed to look like a seal. The robot includes tactile and light sensors and voice recognition meaning that it seemingly ‘responds’ when interacted with. There is research to suggest using PARO is enjoyable for people with late stage dementia (Jøranson, Pedersen, Rokstad Mork et al., 2016).

Nevertheless, it is important to note that not all individuals with dementia would benefit from engaging with such items – as argued by Collier and Jakob (2017), perception of material objects and textiles is influenced by one’s cultural background and personal experiences and therefore differs for each individual. Moreover, as Campbell (2019) found, the use of particular objects and décor often ‘feminise’ dementia care settings e.g. the use of embroidered napkins (Napkin project, 2014), creating “gendered atmospheres” (Campbell, 2019: 162), thus potentially compromising the experiences of other care home residents.

Person-centred material objects

Recent design-led projects have seen the further development of person-centred material objects (often also referred to as textile artefacts) for people with dementia (e.g. Mann & Oatley, 2017; Treadaway & Kenning, 2016, 2018; Wallace, Wright, McCarthy et al., 2013). Such projects have used co-design strategies which involve, for example, working with people with dementia, their relatives, friends and care-workers, in order to create objects that reflect, for instance, an individual's interests. For example, Mann and Oatley (2017) embedded aprons with an electronic device that played the person's favourite music. They (Mann & Oatley) argue that in order for such artefacts to support meaningful engagement and enjoyment for people with dementia they should contain personalised elements.

The extensive work of The LAUGH (Ludic Artefacts Using Gesture and Haptics) research project (Treadaway, 2018; Treadaway, Fennell, Taylor et al., 2018; Treadaway & Kenning, 2016, 2018) has demonstrated the affective dimension that personalised objects can have for people with dementia. The project develops bespoke objects designed to promote engagement 'in the moment' to amuse, distract and comfort, those who interact with them. The textile objects often contain the use of different textures and fabrics, fastenings such as, buttons, zips and poppers, and decorative textile techniques such as applique and embroidery to facilitate fiddling, touching and stroking (Treadaway & Kenning, 2016). Using participatory qualitative methods such as co-design workshops working with care home staff and family members, Treadaway and Kenning (2018), found that the personalised objects, e.g. co-designed personalised blankets, had the capacity to facilitate tactile and sensory enjoyment for the person with dementia, whilst also providing a means of shared engagement and distraction for loved ones during their

visits. For example, they described the experiences of participants Bill and his wife, whereby a co-designed blanket stimulated emotional memories, and provided an ‘in the moment’ experience that they could share. Thus, they proposed the blanket shifted the focus away from Bill’s condition to support positive experiences for he and his wife. They claim such objects can be used to support both people with dementia and their loved ones (Treadaway & Kenning, 2018).

Purpose-made textile items have also been created to facilitate shared moments between people with dementia and care-workers. For example, the project ‘Tactile Dialogues’ (Industrial Fabrics Association International, 2014), a collaboration between Eindhoven University of Technology, De Wever Borre Akkersdijk, Optima Textiles BV and Metatronics, resulted in the creation of a tactile pillow. The pillow consists of integrated elements that vibrate when rubbed, stroked or pushed. These vibrations occur across the pillow, so that those interacting with the piece follow the patterns of vibration. This may create moments of togetherness and connection through the material, sensory interactions.

Drawing upon the notion of the ‘in the moment’ experience, recent developments from the LAUGH project have seen the creation of innovative material objects (Treadaway, 2018; Treadway et al., 2018), for example, the object HUG™ (see **Figure 8**). The long-armed, soft, wearable object contains embedded electronics to mimic the vibrations of a beating heart and was designed to imitate the feel of being hugged. The person HUG™ was designed for reportedly reacted very positively to the object - the researchers stated that she:

“Snuggled into it, rested her head and closed her eyes ... A few moments later, to the amazement of the care staff, she spoke a few words for the first



Figure 8. HUG™ created by the LAUGH project led by Professor Cathy Treadaway, Cardiff Metropolitan University. Image reuse permission obtained.

time in many weeks... Her hands that had initially been twisted into tight fists had opened and relaxed over the three months of the study and she had regained the use of her fingers” (Treadaway et al., 2018:282).

Despite the seemingly affective responses that such objects can have for people with dementia, it is important to note that their perception and sensorial qualities are subjective. For example, where HUG™ was designed specifically for one individual who reacted positively to the object, another person may not have had the same response. The affective responses that objects can induce are, as such, not inherent to the object itself, they are shaped by personal meanings (as demonstrated in the work of the LAUGH project) and social and material interactions (Lovatt, 2020).

Transitional and precursor objects

The notion that material objects can be affective is not only applicable to bespoke objects designed for an individual: everyday objects can be appropriated (e.g. Buse & Twigg, 2014a; Stephens et al., 2013), transcending their functional use to become something that a person becomes emotionally invested in, and this is no less true for people with dementia. The emotional attachments and relationships that people form with objects have been studied and theorised (e.g. Belk, 1988; Bowlby, 1969; Winnicott, 1953).

In 1953, Winnicott introduced the term 'transitional object' to describe any object that a child uses to help them separate from the primary caregiver and support them on their journey to individuation. It is important to emphasise here that people with dementia are not children and should not be infantilised, yet that attachment concepts, such as transitional objects, can be considered relevant throughout the lifespan (Bowlby, 1969). The concept of transitional objects has been used in relation to people with dementia (e.g. Loboprabhu, Molinari, & Lomax, 2007; Stephens et al., 2013). Examples of transitional objects may include blankets, material objects and repetitive words or phrases (Winnicott, 1953). Yet Winnicott (1953) claimed that it is not *what* the object is, it is *how* the object is used that is important. Loboprabhu et al. (2007) suggest that transitional objects can act as an 'anchor' within care settings, aiding the person with dementia with their 'transition to dependence'. Despite the highly problematic notion of 'transitioning to dependence', the use of transitional objects by people with dementia can help to negotiate their changing environment, whether that is their physical environment (i.e. from home to care home) or their psychological environment (Stephens et al., 2013).

Stephens et al. (2013) carried out a focussed ethnographic study to explore the relationships people with dementia have with objects. Results from the study were presented using Winnicott's criteria of a transitional object. They found that many behaviours within the care home demonstrated that residents with dementia had transitional objects that were meaningful to them. Therefore they suggested that transitional objects could be important within dementia care settings, adding that, as people with dementia have had a lifetime of attachments, the transitional object can represent one or more of these attachments. For example, one participant named a doll after her husband and another participant said that playing cards reminded her of her children. The notion that people with dementia in care settings may use transitional objects as a tool for comfort and support could be said to demonstrate a form of everyday creativity (Bellass et al., 2019).

Furthermore, Gaddini's (1978) concept of precursor objects i.e. objects that have the capacity to console a child but were not discovered or invented by the child, could also be considered significant within dementia care settings. Precursor objects are distinctly different to transitional objects as they are given to the individual by another person. As such, the strength of attachment to the precursor object is weaker than the strength of attachment to a transitional object. It is instead theorised that it is something about the tactile quality of the object that is significant (Gaddini, 1978). Therefore, unlike Winnicott's (1953) transitional objects, it is what the object *is* that is significant. Stephens et al. (2013) found that some participants demonstrated precursor object behaviours, whereby they found that people with dementia often rubbed parts of their bodies, others' hands, and items in their immediate vicinity, in what they suggested was a tactile and soothing fashion. For example, they observed a resident rubbing the fabric of her skirt against her skin, she stopped and then

handled the cuffs of her sleeves. Therefore, the notion of precursor objects may be applicable when considering both textiles and clothing within the dementia care setting, for example, when considering everyday objects such as soft furnishings, or when considering the fabric that a person's clothing is made from.

The nature of precursor objects and the proximity of tactile items to the body in dementia care settings is notable when considering Treadaway and Kenning's (2016) findings. Treadaway and Kenning (2016) reported that one of the most significant aspects of the personalised textiles created during the LAUGH project was that the items assisted in bringing the world to the person with dementia through proximity with the body. In a further paper, Treadaway and Kenning (2018) suggest that textiles that are in close proximity to the body can support people with dementia to access something meaningful to them, as their world is 'ready to hand'. Similarly, Van Steenwinkel, Van Audenhove and Heylighen (2014) reported that textiles including items such as blankets, pillows and cushions can be significant for people with dementia in care home settings, due to the intimate closeness between the material objects and the body. They suggest that the closeness of items to a person's body can help support a person's sense of selfhood, as they claim that a person's selfhood is intertwined with their environment.

The concept that material objects in close proximity to the body can be particularly meaningful for people with dementia is also supported by Buse and Twigg (2014b), who found, for instance, that handbags were important for women with dementia living in a care home. Used for an array of purposes, the handbags facilitated a means with which to create a sense of privacy in the care home, a tool for distraction e.g. through sorting items in the bag, and enabled the sharing of stories e.g. through using items contained within the bag such as photographs and

letters as prompts. Thus, handbags within the care home setting transcended their functional use, symbolising aspects of the women's selfhood, whilst providing a sense of agency through allowing the women to create their own private space in an environment in which limited spaces can be considered private. Buse and Twigg's (2014b) findings connect with those of Van Steenwinkel et al. (2014) and Treadaway and Kenning (2018), demonstrating the significance that material objects 'close to hand' can have for people with dementia living in the care setting. Additionally, the use of items 'close to hand' connects with what Harnett (2014) termed 'interactional respite' whereby care home residents 'carve out' space from institutional life by e.g. engaging in social and material interactions unrelated to life in the care home. Such practices e.g. the use of handbags to create privacy were referred to by Bellass et al. (2019) as forms of everyday creativity within the setting.

Drawing upon the aforementioned literature that has demonstrated that textiles can be considered meaningful in dementia care settings (e.g. Brawley, 2006; Campbell, 2019; Collier & Jakob, 2017; Jakob et al., 2018), that engagement with textiles and material objects can be affective for people with dementia (e.g. Buse & Twigg, 2016a, 2016b; Treadaway & Kenning, 2016, 2018; Van Steenwinkel, 2014), and that material objects in close proximity to the body can be particularly significant for people with dementia (e.g. Stephens et al., 2013; Treadaway & Kenning, 2018), it can be posited that clothing (during wear) could be considered especially important to people with dementia at an embodied and sensorial level. As Bovone (2012:73) writes:

“among the objects surrounding us... it [clothing] plays a special role. Among the different non-verbal language modalities, clothing is the most typically

human because it belongs to any age and culture. We usually present ourselves to others and, even to ourselves, dressed”.

It is important to affirm here that the focus of this research is not to evoke reminiscence i.e. to explore memories associated with clothing or to explore items of clothing that are no longer worn. Rather, this research focuses on the embodied experiences of people with dementia and is therefore not centred on losses associated with the syndrome. Thus, rather than attend to, for instance, dress and appearance practices as symptomatic of dementia, this research focusses on clothing during wear, shifting attention from clothing as a fixed static appearance, to something that is fluid, embodied and sensory (Lovatt, 2020). In order to develop this notion further, clothing and appearance in care home settings is explored in the following section.

2.3 Clothing, dementia and the care home

Historically, clothing within health and social care settings consisted of institutional garments and overalls. Yet whilst clothing practices in care environments have moved on (Twigg & Buse, 2013), researchers have argued that much greater attention to clothing needs to be given when considering improving care (e.g. Buse & Twigg, 2015; Topo and Iltanen-Tähkävuori, 2010; Timin & Rysenbry, 2010), with Buse and Twigg (2018) recommending that clothing should be considered when reimagining dementia care.

Clothing and appearance

A lack of interest in clothing and deviations from normative standards of dress are often viewed as symptomatic of dementia (Buse & Twigg, 2016a). For example,

Caldwell, Falcus, and Sako (2020) found that pictorial depictions of dementia in children's literature often used clothing to indicate cognitive decline:

“The first inkling that there is something wrong with Nana is when her clothes do not match – she is pictured wearing a striped shirt, incorrectly buttoned up, and flowered trousers” (Caldwell et al., 2020 [online]).

An emphasis on the appearance of the person with dementia has been reported as significant for care-workers and informal caregivers alike (e.g. Mahoney, LaRose & Mahoney, 2015; Ward et al., 2014). For example, Mahoney et al. (2015) found that maintaining continuity of appearance was extremely important for informal caregivers. They reported an example of a family caregiver whose father had always worn a belt; the family caregiver therefore continued to help her father wear a belt every day in order to maintain that aspect of his appearance, despite the belt becoming problematic for him to fasten and unfasten. This could be said to concur with and represent an aspect of Ward et al.'s (2014) findings, where relatives associated helping their loved one achieve a particular appearance with the strength of their relationship. Similarly, Mahoney et al. (2015) found that informal caregivers associated particular items of clothing with what Twigg (2010) terms a 'moral charge'. Twigg's (2010) notion that clothing can attract a language associated with a potent moral charge demonstrates, for instance, the ways in which particular items of clothing or aspects of appearance can be deemed shameful. For example, Mahoney et al. (2015) found that informal caregivers felt it would be neglectful to dress their loved one in pyjamas during the day as they would then look like 'a care home resident'. Yet, Tseelon, when talking of the contextual and psychological factors regarding clothing and what they may communicate, wrote:

“It is rarely the outfit that conveys the messages, but usually the sum total ingredients that make the look, as well as the fit and manner in which it is worn. The same outfit can look sublime on one person and ridiculous on another” (Tseelon, 2012:118).

Dressing has been reported as one of the most pressing daily concerns by informal caregivers of people with dementia (Nichols, Martindale-Adams, Greene et al., 2009). People with dementia are often supported when getting dressed because of difficulties in perception, short-term memory, and mobility (Mahoney et al., 2015). Dressing within health and social care settings is often subsumed into task-orientated routines, which respond to institutional priorities and typically signify the ways in which the bodies of those in care settings are ‘processed’ (Kelly, 2014). As Buse and Twigg (2018) note, a garment’s style, construction, fabric and fastenings can constrain the dressing process and reduce the body to a series of discrete parts. Moreover, specific clothing practices are often adopted in care settings with the use of for instance: “polyester easy-care fabrics that require no ironing; trousers that are permanently fastened to prevent exposure, and clothing or overalls that open at the back for ease of toileting” (Kontos, 2015: 178). The wearing of such garments, Twigg (2010) claimed, results in the look of the ‘classic’ dementia patient, stigmatising the wearer through their appearance (Gove, 2013). Moreover, Kricton and Coch (2007) argue that those making decisions regarding a person’s clothing and appearance, for example, care-workers, ‘curate’ the appearance of the person with dementia.

The notion that a person with dementia’s appearance is curated by others is notable when considering the concept that clothing is a ‘situated and bodily practice’ (Entwistle, 2015), meaning that preparing the body - getting up and getting dressed - is a deeply personal experience that prepares the figure for the social world and its

public presentation. Such preparation is a complex process (Woodward, 2007), as clothing imbues the body with layers of cultural, social and personal meanings (Entwistle, 2015). Using the example of a person wearing a suit, Entwistle (2015) claims that the suit instils the body with 'masculinity' and results in the wearer being perceived as masculine. This demonstrates the ways in which clothing, the body and the self are perceived as one (Entwistle, 2015). It is therefore near impossible to decipher between the meanings or associations attached to the clothing, and the identity of the wearer. Thus, where clothing in care homes is often a complex negotiation of others' e.g. care-workers and relatives, decision making, this results in the appearance of those being 'cared-for' being invested with meanings that reflect others' perspectives (Ward, Vass, Aggarwal et al., 2008).

Clothing and appearance within the care home is not only affected by care-workers' perceptions, relative's expectations e.g. what their loved one 'should' look like, and institutional routines e.g. that a resident must be dressed at a particular time, it is also affected by institutional restrictions. For example, Armstrong and Day (2017:117) reported care home guidelines that stated, "numerous clothes are not necessary" (when moving in to the care home) and that "clothing should reflect the resident's current lifestyle". Likewise, Buse and Twigg (2016a) found that care homes often recommended clothing such as easy stretch garments e.g. jogging bottoms, to replace smart trousers, or trousers for women rather than skirts to avoid "dealing with tights" (Buse & Twigg, 2016a:89).

Contributing further to such constraints around clothing, institutional laundering regimes can also affect the garments that residents are advised to bring into the care home with them. Laundry practices involve the separation of items into categories such as bedding and towels, outer clothing, underwear and hand-wash

items e.g. woollens (Buse et al., 2018b). Care home guidelines often discourage residents from wearing delicate hand-wash items such as woollen jumpers or silk blouses, due to the careful laundering processes required (Buse & Twigg, 2016a). Therefore, researchers (Armstrong & Day, 2017; Buse et al., 2018b) claim that laundering practices are important for both care home residents and relatives, due to the impact that they can have upon a person's identity at a material and embodied level e.g. through influencing clothing choices. Consequently, Buse et al. (2018b) argue that rather than positioning laundry workers as additional labour in the care home setting, they often in fact provide an important aspect of care through attending to resident's personal clothing practices. They reported instances in which laundry workers spoke of getting to know the individual style of residents, for example, "Eddie likes shirts with tank tops over the top" (Buse et al., 2018a: 721).

Restrictions placed on clothing could be said to not only stigmatise the wearer through their outer appearance (Gove, 2013), but may also reinforce notions of dependency both tangibly - through practical restrictions, and psychologically - e.g. through the negative associations imbued within particular items of clothing. For example, in their research exploring clothing designed for institutional settings, Topo and Iltaanen-Tähkävuori (2010) found that patient clothing created limited possibilities for being active. They found that people associated wearing patient clothing (see e.g.

Figure 9) with their lowly status in the hospital setting. Despite finding that clothing can support the independence of the wearer, they also found that clothing can often be used to prevent exposure and hence can become a tool for managing the body (Iltanen-Tähkävuori, Wikiberg & Topo, 2012) - thus connecting with the notion that bodies within care settings are processed and contained (Kelly, 2014). Moreover, (Iltanen-Tähkävuori et al., 2012), report that clothing designed to meet the functional or cognitive needs of people 'receiving' care, often neglects aesthetics in order to prioritise effectiveness and cost-efficiency.

The notion that particular items of clothing can be stigmatising and symbolise notions of dependency during wear, connects with the work of Adam and Galinsky (2012) who coined the term 'enclothed cognition' to explain the systematic effect on the wearer's psychological processes through physically wearing a garment imbued with meaning. Thus, it could be said that, for instance, the capacity for an item of clothing to enable a person to feel active, resides both within the embodied



Figure 9. Clothing for people with cognitive impairments and / or problems with incontinence in Finland (Topo & Iltanen-Tähkävuori, 2010:1685). Image reuse permission obtained.

sensation of wearing the garment, but also within the meanings both at a societal and personal level, associated with that item of clothing. The concept of enclothed cognition could therefore support Topo and Iltanen-Tähkävuori's (2010) claim that material artefacts such as clothing need to be given particular attention when considering enhancing care practices.

This, in turn, is supported by researchers' claims (e.g. Buse & Twigg, 2018; Ward et al., 2014) that the significance, placed by others, on the appearance of people with dementia, is problematic. For example, Buse and Twigg (2018) presented the experiences of a care home resident who used to feel comfortable wearing her dressing gown at home in the evening, but who felt that care-workers wanted her to remain dressed in the evening in the home. Not only does this example illustrate the ways in which a person's appearance is 'curated' (Krichton & Coch, 2007) by care-workers and institutional priorities, the example also highlights the multifaceted complexities when considering clothing in the care home. For instance, the example demonstrates the notable tensions between what is considered a public and private space, the ways in which clothing practices are often subsumed into formal caring routines, and the interrelationship between the care home setting, clothing practices and the affective impact on those within the space.

The emphasis on the appearance of people with dementia within care home settings is socially contingent and the subsuming of clothing within institutional practices e.g. care routines and laundering regimes negates understanding how clothing and appearance feel (Ward & Campbell, 2013a) for individuals. Ward and Campbell (2013a), in their study exploring the hairdressing experiences of people with dementia, demonstrated that it was the process of achieving the appearance that was meaningful for people with dementia, rather than the appearance itself, as it

provided opportunities for engagement, interaction and connection i.e. it was the hairdressing process that was significant rather than the final hair style. Therefore, this project focusses on the embodied and sensory experiences of clothing within the care home setting, exploring specifically clothing during wear rather than exploring the importance of clothing and appearance as e.g. a visual indicator of care.

Clothing during wear

Drawing upon Ward and Campbell's (2013a) emphasis on understanding how appearance 'feels' for people with dementia, this project attends to the sensorial and embodied dimensions of clothing within the dementia care setting. Hence, rather than viewing clothing as a fixed, static entity, clothing during wear is explored in order to encompass the multifaceted aspects of wearing clothing. This involves shifting focus away from what clothing looks like, and, the gaze of others, to explore what clothing *feels* like for the wearer. For example, as Barnes and Eicher wrote (1993:3) "clothing is imbued with meaning not only through how it appears, but also through how it feels, smells and sounds". Hence, focussing on clothing during wear connects with the growing emphasis placed on the 'in the moment' experiences of people with dementia, as approaching clothing during wear attends specifically to the experiences of the person with dementia at that time. This also connects with growing interest in sensory approaches to design that shift emphasis away from the visual to attend to the multisensory experience (Lipton & Lipps, 2018).

Despite the sensory and embodied materiality of clothing, clothing studies have traditionally ignored the body and thus the wearer. This conceptual separation of clothing from the wearer has typically removed clothing from the complex world in which the body resides (Entwistle, 2015). This has resulted in a dearth of literature surrounding the differing experience of wearers. For example, despite extensive

literature exploring gender and clothing, there are limited studies exploring ethnicity and clothing and ageing and clothing. Recent years have seen an attempt to address the lack of literature within the area of clothing and ageing (e.g. Buse & Twigg, 2018; Hurd Clarke et al., 2009; Holmund, Hagman & Polska, 2010; Peters, Shelton, & Thomas, 2011; Twigg, 2013, 2015) and clothing design for older women (Townsend, Sadkowska, Sissons, 2017). For example, Hurd Clarke et al.'s (2009) study carried out with women aged 71-93 reported women's tensions in negotiating clothing preferences, with socially instilled norms surrounding garments and the ageing female body. For instance, participants reported the need to hide increased weight and to cover up their wrinkles. The researchers concluded that women's clothing choices were limited by both the clothing choices on offer to them e.g. available, affordable and desirable clothing, and pervasive social norms surrounding the ageing female body e.g. whether they were dressed 'correctly' for their age. Despite Hurd Clarke et al.'s (2009) study exploring older women's clothing choices and preferences, they did not specifically attend to clothing during wear and, therefore, the experience of wearing the clothing.

Within her analysis of fashion and age, Twigg talks of "adjusting the cut" (Twigg, 2013:131), which is the need for manufacturers to alter the cut of garments to respond to the changes that occur as the body ages. This is similarly reflected in research from Townsend et al. (2017), who explored older women's (in the case of their research women aged 62-67) experiences surrounding clothing fit, examining the physical sensation of wearing particular items of clothing. The study aimed to develop pattern cutting techniques in order to design clothing that met the sizing and clothing fit needs of older women, and as such attended closely to the embodied experiences of participants.

Recent attempts to explore the significance of clothing and age are often to the exclusion of men and so represent something that Twigg (2015) terms 'the gender bias', in which women are implicitly represented as the norm in clothing studies. Moreover, it is also notable that within the aforementioned studies that the health of participants is often implicit, meaning that although clothing and ageing studies may explore participants experiences of, for example, clothing fit and clothing sizes, they typically treat older people as homogeneous. This is particularly significant, as in older age people often develop different health conditions and can experience several health conditions at the same time, and these can impact clothing needs. Common conditions include sight impairment, difficulties with mobility, osteoarthritis, diabetes and dementia (WHO, 2018). However dementia is the most age related of all disabling conditions affecting older people, but only a limited number of researchers have explored the impact that clothing has in the lives of people with dementia.

At present, the most substantial work within the area of clothing and dementia was carried out by Buse and Twigg (2015, 2014a, 2014b, 2016a, 2016b), in their sociological 'Dress and Dementia' study. During the study they worked with people with dementia living at home, people with dementia living in care homes, care-workers and informal caregivers. Their research demonstrated that clothing offered a means with which people with dementia maintained selfhood at a material and embodied level. They reported that individuals engaged with their clothing at multiple levels, for example clothing was imbued with biographical meanings, associations and memories and that clothing was used expressively by people with dementia. Their research incorporated clothing that was no longer worn by individuals, vintage items of clothing used within reminiscence sessions and techniques such as

wardrobe interviews whereby clothing in the wardrobe was explored. However, the study did not focus specifically on clothing during wear or focus exclusively on clothing within the care home setting.

Notably, Buse and Twigg (2018: 349) argue the role that clothing has in supporting people with dementia's identity through items that "look and 'feel' right". This is particularly interesting given that they (Buse & Twigg, 2015, 2018) found that people with dementia engaged with Woodward's (2007) notion of 'aesthetic fit' which Woodward termed as the extent to which clothing embodies a person's sense of self. In her work, Woodward attended to the material properties of clothing, exploring women's processes of selecting and choosing items from their wardrobes and how clothing *felt* on the body and, therefore, the importance of the garment, fit, style and texture when worn. Clothing, for Woodward, continues the self through the material object (the clothing), she talks of getting dressed as a process of considering identity through the "material form of clothing" (Woodward, 2007: 83). Woodward notes that this is complex as "dressing is also an act of making present aspects of a former self, as a woman may wear an item of clothing from her past in a new combination" (Woodward, 2007: 158).

Buse and Twigg found that participants engaged with the notion of 'aesthetic fit', stating for example; "I don't like big patterns... no, it's not me" (Buse & Twigg, 2015:79), with some refusing to wear particular items of clothing. For example, one participant would not wear Velcro shoes, as he felt that they looked like "old people's shoes" (Buse & Twigg, 2015:83). Thus, for this participant the style of shoes indicated a look of ageing and frailty that he wanted to avoid. The notion that the self is continued within the clothing, Twigg (2013) noted, connects with Gell's (1998) account of 'distributed personhood', whereby he talked of humans not being simply

in their singular bodies, but their personhood being distributed between everything within their surroundings. Likewise, Belk (1988) talked of the self being extended through possessions which become vessels for meanings, thus connecting with further research surrounding clothing and the effect that wearing particular items of clothing can have on the wearer (Adam & Galinsky, 2012; Fleetwood-Smith, Hefferon & Mair, 2019).

Similarly, in their study exploring the significance of appearance to people with dementia, Ward et al. (2014), found that appearance related practices e.g. shirt sleeves rolled up and hairstyles, remained significant to people with dementia. For instance, they reported that one participant would have found it unbearable to leave his shirt collar unbuttoned. Ward and Campbell (2013a) suggested that it is how appearance *feels*, at a sensory and embodied level, that can be considered particularly important for people with dementia, as appearance-related practices can become embedded over time (Ward et al., 2014) and can create a sense of who one is (Crossley, 2006). In light of Ward et al.'s (2014) findings, it may therefore be interesting to extend Woodward's notion of 'aesthetic fit', as the term seems to emphasise the fit of the appearance to a person, to incorporate the impact that the physical sensation of clothing and the intangible *feel* of the clothing has for the wearer. As Ash (1996) posited, clothing, through its appearance, materiality, and the meanings imbued within it, has a strong affective dimension. This has been found to be no less important for people with dementia (e.g. Buse & Twigg, 2015, 2018; Twigg, 2010, Ward & Campbell, 2013a; Ward et al., 2014).

Clothing and shared embodied experiences

Considering clothing, rather than through appearance, but exploring the embodied, sensory and affective dimension of how it *feels*, could be an opportunity

with which to understand the experiences of people with dementia as it can involve relating to people at an embodied level. For example, Buse and Twigg (2018) suggest that clothing can enable care-workers to relate to people with dementia as a person rather than as a body to be cared for and processed (Kelly, 2014).

Clothing in Western culture is ubiquitous, all engage with clothing and wear it on a daily basis. Wearing clothing involves the intimate proximity of body and material. As such, differing fabrics and garment styles influence a person's movement, their posture, the way they sit, stand and their demeanour (Sweetman, 2001), for example, as Twigg wrote:

“How we sit, or move is affected by the clothes we wear: for women, trousers prompt different ways of sitting and walking from a skirt; you dispose of your limbs in a long loose dress differently from a short tight one” (Twigg, 2010: 225).

Therefore, it could be said that to an extent all share in their embodied understanding of how it feels to wear, e.g. tight, items of clothing that restrict the body.

The notion that clothing practices can be informed by shared embodied understanding and that this could enable care-workers to interact with and relate to people with dementia at an embodied level, may be supported by findings that demonstrate the ways in which care-workers draw upon their own bodily experiences when delivering care. For example, Kontos and Naglie (2009) described the ways in which care-workers drew upon their own bodily knowledge when caring for people with dementia. They described a care-worker's account of assisting a resident get out of the bath, whereby she “would wrap them in a towel quickly and rub their arms

and back as she knew how it felt to be cold and wet” (Kontos & Naglie, 2009: 694). This behaviour, Kontos and Naglie suggested, connects with Merleau-Ponty’s shared embodied experience in understanding the ways in which knowledge can be formed through bodily understanding e.g. drawing upon the feeling of being wet and cold, and that this informed the care-worker’s empathetic approach.

The concept of shared embodied experience could challenge assumptions in the care setting, surrounding, for example, the use of polyester easy-care fabrics. Clothing, through its appearance, can be considered stigmatising for people with dementia (Gove, 2013), yet the *feel* of clothing could also exacerbate notions of dependency, through embodying institutional priorities and potentially deepening synthetic and sterile connotations associated with health and social care settings. Drawing upon embodied understanding and care-workers attending to how wearing such garments *feels* could challenge the use of particular types of clothing e.g. polyester easy-care fabrics that require no ironing, or clothing selected for the ease of supporting a person to dress. For example, Stokes (2008) presented a troubling account of a gentleman with dementia who was required to wear pyjamas all-day every day when in hospital. Nurses’ notes detailed that he:

“dressed inappropriately, wearing two shirts, refused any assistance from nursing staff. Getting verbally abusive when told to take one of his shirts off.” The day after he became very aggressive, hitting and kicking out at staff when they attempted to change his wet clothes. “Clothes removed to prevent Stanley re-dressing in day clothes. Mattress removed from bed as patient continually laying down trying to sleep” (Stokes, 2008:26).

Stokes (2008) notes, that the man had arrived in hospital smartly dressed (wearing a navy suit), and yet he was required to wear his pyjamas all-day on the hospital ward. As Stokes (2008) claims, a desire to control his behaviour negated attempts to understand and meet his needs. It is also possible that wearing pyjamas during the day impacted his spatial and temporal orientation (Buse & Twigg, 2013, 2014a). This demonstrates that clothing is important to a person's sense of self, agency, autonomy, and spatial and temporal orientation and that attending to how the clothed body *feels* may offer valuable opportunities to enhance the care of people with dementia.

Attending to clothing during wear, and how the clothed body *feels* could develop insights that a focus on the appearance of a person negates. For example, a care-worker wrote an online post to The Dementia Centre at Stirling University (2011), asking the Centre to recommend retailers where 'un-rippable' clothing could be purchased for a care home resident who repeatedly ripped and pulled at her clothing. Rather than considering *why* the resident may be pulling at and ripping her clothing, the care-worker sought to control the woman's behaviour. The emphasis on control could be said to have prevented the care-worker from considering what the resident may have been expressing. For instance, the woman's actions may have been her way of indicating that she was distressed or uncomfortable - e.g. she could have been too hot, the clothing could have irritated her skin, or the clothing could have been unfamiliar to her. This example highlights Davis et al's. (2009) notion that focussing on understanding the experiences of people with dementia, rather than focussing on the condition itself, is significant and can impact upon the ways in which care settings can be enhanced.

In the case of the above example, it is not possible to know whether other items of clothing provoked similar responses and whether the woman's expressions were to do with the items of clothing themselves or to do with her feelings about other issues. Yet, it does illustrate the ways in which clothing is a person's most immediate physical environment (Twigg, 2010) and that the ways in which a person engages with their clothing during wear can be a form of everyday creativity (Bellass et al., 2018; Zeilig & Almila, 2018). For example, Bellass et al. (2019) suggested that clothing in a care home setting is used by people with dementia expressively, whereby they talked of participants signifying that they wanted to leave the care home and go outside through putting on their coat or jacket. Thus perhaps the woman's use of her clothing and her actions of ripping and pulling at her clothing was the most accessible tool with which to express her needs/ emotions.

Clothing attachment and clothing as a transitional object

The multifaceted ways in which the woman's actions of ripping and pulling at her clothing can be interpreted reveal some of the complex ways in which clothing functions for the wearer. For example, Bovone (2012) claims that clothing is not only used in connection with a person's needs, e.g. to keep a person warm, but it is also appreciated as something that can enrich a person's life. This phenomenon is not new: in 1890 psychologist William James considered clothing to be a fabric extension of the flesh and, as such, inextricably connected to a person's identity and their sense of self. Much like James' claim, rather than view clothing as a 'second skin' Twigg (2013) reasons that a person is almost as embodied by their clothing as they are their bodies, as it is first and foremost a person's clothing that interacts directly with the world. The inextricable connections between the wearer and their clothing could be said to be demonstrated by the ways in which items of clothing are

often kept, despite no longer being worn (Masuch & Hefferon 2018), thus signifying the intimacy between a person and their clothing and the ways in which clothing is appropriated due to the meanings associated with it. People form relationships with material objects (including clothing), and this is no less true for people with dementia (e.g. Stephens et al., 2013).

Buse and Twigg (2016a) found that objects they talked of as 'small items of dress' such as handbags, necklaces, cufflinks and further accessories, acted as transitional objects in the dementia care setting. Similarly, much like findings from Treadaway and Kenning (2016) (see **2.2 Person-centred material objects**), the items were significant due to the connections ascribed to them e.g. specific associations with people, places and personal narratives. This is notable when considering what the items *felt* like for participants, as Buse and Twigg (2016a) claim that the connections were accessed through touching and handling 'small items of dress' e.g. jewellery, scarves.

Interestingly, Buse and Twigg (2016a) noted that many participants had favourite items of clothing that were worn and re-worn. Their findings, in turn, could connect with the work of Fleetwood-Smith, Hefferon and Mair (2019), who found that garment fit and the appearance of attachment garments i.e. clothing that participants described themselves as being emotionally attached to, was not as significant as the meanings associated with the items. Fleetwood-Smith et al. (2019) found that whilst wearing their attachment clothing, participants were able to access the personal meanings that they associated with their specific items of clothing. Many participants in their study reported wearing their attachment items frequently, hence through wear the clothing became moulded to the wearer's body, both tangibly and intangibly, via the emotional connections that the clothing evoked. Moreover, such

findings are further supported by Adam and Galinsky's enclothed cognition (2012) whereby wearing attachment clothing enables the wearer to access and shape meanings associated with the garment.

The notion that clothing can be charged with meanings that are not innate to the items themselves, but that are shaped by both personal and social meanings and material interactions e.g. the specific time, place and culture in which it is worn, are little disputed (e.g. Belk, 1988; Bovone, 2012; Twigg, 2013) and that these meanings can be accessed through touching, handling and wearing clothing has been demonstrated by researchers (e.g. Adam & Galinsky, 2012; Buse & Twigg, 2016a; Fleetwood-Smith et al., 2019). Considering clothing as being infused with meanings that are accessed through wear allows one to shift focus away from the gaze of others to considering clothing through the perspective of the wearer in order to examine embodied, sensorial and affective experiences.

Re-imagining clothing in health and social care settings

The consideration of clothing and how it feels for the wearer, drawing upon the complex ways it can be considered significant, could have multiple implications when considering the holistic care of people with dementia. Many researchers advocate that clothing practices and clothing design should be considered when re-imagining health and social care settings e.g. Buse and Twigg (2018) and Mahoney et al. (2015). The following examples demonstrate some of the ways in which renegotiating clothing within healthcare settings can impact those within such settings.

Firstly, the NHS #EndPJPParalysis campaign, an initiative founded by Professor Brian Dolan, a visiting Professor of Nursing at Oxford Institute for Nursing,

Midwifery and Allied Health Research, aimed at achieving one million days of patients being up, dressed and moving by encouraging people to get changed out of their pyjamas and into their own clothes. During the campaign it was reported that the number of patients up and mobile increased. Narratives collected from patients during the campaign highlighted feelings of dignity, agency and autonomy when being dressed in their own clothes (End PJ Paralysis, n.d.). Notably, these findings may support previous research that suggests that patient clothing creates limited possibilities for being active, symbolises the low status of patients (Topo and Iltanen-Tähkävuori, 2010) and reinforces the patient's notion that they are sick (Pratt & Rafaeli, 1997). However the campaign seemingly assumes that patients wearing pyjamas is negative and it is not clear if this is how all patients felt. Nevertheless, the concept that clothing could be used creatively (Bellass et al., 2019; Zeilig & Almila, 2018) at an institutional level is interesting to note when considering Twigg and Buse's claim that the embodied and material closeness of clothing to a person with dementia can help support their sense of "spatial and temporal orientation" (Twigg & Buse, 2013:329).

The notion that attending to the design of clothing can contribute to care practices was demonstrated within the design-led project Garment+ (Chan, Lempp, Peabody et al., 2018). The project sought to explore the potential of clothing in supporting people with musculoskeletal conditions e.g. rheumatoid arthritis. Such conditions can cause difficulties in dressing due to restricted joint mobility, pain and fatigue. The project, a collaboration between designer Chan, academics from King's College London, and adults from a rheumatology outpatient clinic, explored the role of fashion to promote positive-wellbeing in patients. Employing a collaborative design process, clothing prototypes were developed and refined with patients to address

their concerns with clothing fastenings, comfortable fabrics, and the accessibility of garments (how easy they were to put on). Findings reported that participants felt a sense of empowerment after having their views considered throughout the design process and also began adapting their existing clothing based on designs developed within the project.

Chan et al's (2018) process of working with patients identified how the visual appearance of the items was secondary to the fit and feel of the garments. This is interesting when considering the growing interest in sensory approaches to design. As Lipton and Lipps wrote:

“Sensory design activates touch, sound, smell, taste, and the wisdom of the body. Sensory design supports everyone’s opportunity to receive information, explore the world, and experience joy, wonder, and social connections, regardless of our sensory abilities” (2018:9).

In recent years the potential of attending to the senses with regard to the design of health and social care settings (including the objects within them) has been recognised both nationally and internationally. For example, the UK Research and Innovation Future Leaders Fellowship recently funded the project ‘Sensing spaces of healthcare: Rethinking the NHS hospital past and present’. The project explores how attending to the senses may enhance the design of future NHS hospitals (Bates, n.d.). Whilst, the Social Science and Humanities Research Council of Canada recently awarded the University of Concordia’s Centre for Sensory Studies funding to carry out ‘Explorations in Sensory Design’ (Centre for Sensory Studies, n.d.). The project aims to explore sensory experiences within spaces such as museums, parks, and hospitals in order to enhance design. The researchers claim that sensory design

can have “incalculable health, recreational, educational and ethical benefits” (2020 [online]).

Although these examples focus on the sensory design of spaces as opposed to clothing, they demonstrate the vast potential that attending to sensory experiences, as opposed to privileging the visual, can have in design practice and in turn to people’s lives. As Jakob et al. (2019) claim, attending to the sensory needs of individuals with dementia can result in more holistic, user-centred, and inclusive approaches and this can lead to personal, meaningful engagement. This is important as clothing designed to meet the functional or cognitive needs of people ‘receiving’ care often neglects aesthetics in order to prioritise effectiveness and cost-efficiency (Iltanen & Topo, 2007a, 2007b). This is also the case for material purpose-made objects for people with dementia, such as twiddle muffs. Yet, in order to facilitate independence, and demonstrate respect for people with dementia, Mahoney et al. (2015) advocate the creation of ‘fashionable’ innovative clothing for people with dementia. In order to do so, it could be argued that approaches that support the strengths of people with dementia should be employed e.g. through the use of participatory techniques as demonstrated in the work of Chan et al. (2018) and the use of approaches to explore the ‘in the moment’ sensory experiences of individuals (Lipton & Lipps, 2018).

In order to understand and enhance the lives of people with dementia approaches that seek to explore their experiences are crucial. To date, limited studies have attended to the significance of clothing to people with dementia living in care homes. Clothing could be considered particularly significant during wear for people with dementia, given (1) the affective dimension that textiles and material objects in close proximity to the body can have for people with dementia, (2) the

embodied, sensory and affective dimension of wearing clothing e.g. how clothing *feels* for the wearer and (3) that people with dementia use their bodies and senses (including their clothing and appearance) to create meaningful worlds (e.g. Van Steenwinkel et al., 2014; Ward & Campbell, 2013a; Ward et al., 2014).

2.4 Summary

This literature review has sought to weave together the ways in which clothing (including material objects) can be considered significant to people with dementia. Existing research has demonstrated that clothing is not incidental in the lives of people with dementia, nor for those with dementia living in long term care settings (e.g. Buse & Twigg, 2014a, 2016a; Twigg, 2010; Ward et al., 2014;). Thus, researchers have suggested that materials (including clothing) should be given greater attention when reconsidering dementia care provision and re-imagining dementia care settings (e.g. Buse & Twigg, 2018; Mahoney et al., 2015). The current research seeks to explore the significance of clothing during wear to people with dementia living in a care home and in turn address the potential of clothing in the holistic care of people with dementia. The research aims are therefore:

- To explore the relationship between people with dementia and their clothing, through addressing the following:
 - What is the embodied experience of wearing clothing in people living with dementia?
 - How do particular sensory qualities i.e. aesthetics, specific colours, patterns, fabrics effect clothing wear?
- To address the potential of clothing in the holistic care of people with dementia.

Due to the focus on clothing during wear, this research utilised a number of sensory, creative and embodied methods to explore the embodied and sensorial experiences of participants. The following chapter presents the methods used to carry out this research.

CHAPTER 3 METHOD

This chapter situates the approach to research, explaining the methodology used, details about the design, the study site, and the study participants involved in the research. A discussion of ethical considerations is also included. The research was underpinned by an interpretative-constructivist paradigm (see **3.1 Research paradigm**) which informed the design and methods used.

Throughout this chapter and the subsequent chapters I have used the first person e.g. “I”, “we” and “me”. This was considered imperative due to the embodied approach to the research. Rather than using the traditional ‘disembodied’ third person, Ellingson (2017) advocates the use of the first person to enhance how embodied research is communicated and disseminated. I have therefore used first person within this **Method** chapter and subsequent chapters. I have also included extracts from my reflexive diary throughout this and the subsequent chapters. Within qualitative research, transparency is deemed a sign of quality and it could be argued that the inclusion of the reflexive extracts demonstrates a commitment to rigour within the research (Yardley, 2000). The extracts included attempt to illustrate and share with the reader my experiences related to the research taking place.

3.1 Research paradigm

The research paradigm underpins the approach to study and is thought of as the foundation from which the project is formed. A paradigm is a “basic set of beliefs that guides action” (Guba, 1990:17): it is constructed from the ontological, epistemological and axiological views of the researcher. Ontology includes one’s view of the nature of reality; epistemology addresses how that reality is known, as

well as the relationship between the knower and the known (researcher and participants); and axiology is concerned with the place of values in research.

This research was underpinned by an interpretivist-constructivist paradigm, meaning that the project was informed by the notion that knowledge is co-constructed by both participants and researcher, consequently this implies a transactional and subjectivist epistemology (Guba & Lincoln, 1994). Interpretivist-constructivist approaches to research have the intention of understanding "the world of human experience" (Cohen & Manion, 1994:36). The interpretivist-constructivist researcher tends to believe that contextual factors need to be understood when pursuing findings: this suggests that there are multiple realities and that these are socially constructed. Moreover, it is thought that knowledge is value laden and that such values need to be made explicit. Therefore, in this paradigm, my values can be embraced, meaning that my background and experiences are incorporated. Consequently, the approach to research is subjective. Interpretivist-constructivist researchers are concerned with the inductive generation of patterns or meanings within the research process (Creswell, 2003). Thus, interpretivist-constructivist research is context specific, and generalisability is not sought.

3.2 Conducting qualitative research with people with dementia

This project sought to explore the significance of clothing to people with dementia living in a care home and to examine the ways in which clothing can be considered in the holistic care of people with dementia. This is an under-researched area of study, therefore an exploratory qualitative approach to research was warranted (Smith, 2015).

Traditionally research has largely ignored the perspectives of people with dementia and has relied upon care-worker and family caregiver reports (Hubbard, Downs & Tester, 2003; Taylor, DeMers, Vig, & Borson, 2012). In recent years, guides that promote inclusive research and the participation of people with dementia have been published with strategies to include ways in which to support the consent process and ensure people with dementia have positive experiences when participating in research (Murphy, Jordan, Hunter et al., 2015).

However, despite recommended adaptations, people with dementia are still often excluded from research. Fletcher, Lee and Snowden (2019) in their paper 'Uncertainties When Applying the Mental Capacity Act in Dementia Research', highlight the ongoing need for researchers to share their experiences of carrying out research with people with dementia. They suggest that people with dementia are often excluded from research due to differing interpretations, e.g. between the care home manager and researcher, regarding capacity (see **3.8 Ethical Considerations** later in this chapter for a discussion of the consent process within this study). Excluding people with dementia from research can result in limited understanding of their lived experience and needs (Heggestad, Noetvedt & Slettebo, 2010). Thus, it is imperative that people with dementia are enabled to participate in research.

In order to support the involvement of people with dementia in qualitative research, Phillipson and Hammond (2018) advise that researchers move away from traditional methods that focus on recall and verbal expression as these can be challenging due to cognitive impairments. Instead, they advocate the use of innovative qualitative methods such as: ethnographic observation, photo elicitation, visual and sensory adaptations to interviews, and participatory techniques, as these can support people with dementia to partake in research (Phillipson & Hammond,

2018). For instance, a sensory adaptation to an interview may involve the introduction of objects: this can encourage both verbal and nonverbal responses, thus shifting the focus away from verbal expression alone. Phillipson and Hammond (2018) suggest that the use of such methods can lead to rich findings. Kontos and Martin (2013) similarly support the use of novel creative methods when working with people with dementia. Furthermore, Campbell and Ward (2017) used a video ethnographic approach to understand the role of hairdressing in dementia care settings. They found that the use of video enabled them to employ a multidimensional approach to data collection whereby they were able to explore visual narratives of participants and interactions within the hair-dressing setting. Some researchers (Campbell & Ward, 2017; Kontos & Martin, 2013; Phillipson & Hammond, 2018) claim that sensory and creative research methods can enable and empower people living with dementia to partake in studies and, as such, can generate multifaceted findings.

Further considerations when undertaking research with this population are to examine what the research is asking and why. For instance, researchers (e.g. Smith & Mountain, 2012; Mountain, 2018) have claimed that studies carried out with people with dementia often focus on cognitive impairment and losses associated with the syndrome (the deficit model). Furthermore, Smith and Mountain (2012) found that new technologies designed for people with dementia typically focus on addressing issues such as safety or security and monitoring rather than, for instance, facilitating enjoyable engagement. Thus, Smith and Mountain (2012) argue that a radical rethink is needed when approaching research with people with dementia, in order to include strength-based approaches whereby emphasis is placed on the assets of individuals.

Carrying out research with people living with dementia can be challenging due to issues around informed consent, varying levels of communication and the progressive nature of the condition. These factors, combined with a reliance on traditional methods that emphasise recall and verbal expression, and the frequent focus on loss and cognitive impairments associated with the syndrome, can make taking part in research highly problematic for people living with dementia. As such, a research design that does not focus solely on verbal expression and recall was important in order to involve people with dementia as fully as possible in this project.

3.3 A consideration of qualitative methodologies

Due to the concerns outlined above, I sought a qualitative methodology that would be flexible and support the participation of people with dementia, whilst addressing the phenomenon under study i.e. the significance of clothing to people with dementia. Thus, I explored the potential use of a number of qualitative methodologies, specifically: Interpretative Phenomenological Analysis (IPA), Grounded Theory (GT) and Participatory Action Research (PAR). These methodologies were considered due to their shared focus on the lived experience of participants, the concern with context-specific details, and the iterative approaches to data collection employed (specifically GT and PAR).

Interpretative Phenomenological Analysis

The use of Interpretative Phenomenological Analysis (IPA) was considered, due to its inductive methodological focus, the ability to reflect the richness and depth of the participants' lived experience and its flexibility. Moreover, IPA is increasingly used by those working in the social and health sciences, as the methodology is committed to understanding the lived experiences of a specific group of people, within a certain context. An IPA researcher explores, describes, and interprets the

means by which participants make sense of their experiences (Smith, Flowers & Larkin, 2009).

IPA is theoretically underpinned by hermeneutics (the theory of interpretation) and the hermeneutic circle (the relationship between the parts and the whole). In analytical terms this offers IPA researchers a process of non-linear interpretation. Some aspects of this process, for example, analysing the single word within the sentence, analysing the whole sentence, analysing the whole text extract and so forth, would not seem appropriate when working with people with dementia. A person with dementia may repeat themselves due to the nature of their condition; this repetition, within an IPA analysis and abstraction process, could be deemed as meaningful, though this may not in fact be meaningful to the individual with dementia. Despite this, IPA has been used to explore people with dementia's lived experience's (Harman & Clare, 2006; Johnson 2016). Within Johnson's (2016) study, interviews were carried out during creative sessions with participants i.e. whilst participants created collages of objects that were important to them, thus adding a sensory element to the interview. Yet, previous use of this method, in exploring the experience of clothing attachment (Fleetwood-Smith, Hefferon & Mair, 2019) suggested that the IPA interview, with its focus on verbal expression and recall, did not account for or allow 'room for' the author to explore nonverbal responses or experiences. Therefore it was deemed unsuitable for the current study. It is however important to recognise that there are overlaps between IPA and Sensory Ethnography due to the inductive approach to research, the focus on the lived experience, and similar phenomenological underpinnings i.e. Merleau-Ponty's 'Phenomenology of Perception', (2002 [1962]).

Grounded Theory

Grounded Theory (GT) was considered due to its inductive approach to inquiry. GT exists in a number of different forms, the underpinnings originally being a methodology that offered researchers a systematic guide to qualitative research and analysis (Robson, 2011). GT researchers aim to generate a theoretical account of a particular phenomenon (Smith et al., 2009). The process of GT seeks to generate a theory and, despite being inductive, tends to offer broader claims whilst working with a greater number of participants (Smith et al., 2009) however, this was not the focus of this research. Rather, this research aimed to give a rich, detailed account of the significance of clothing to people living with dementia. Moreover, the explanatory claims often sought in GT did not seem appropriate for this body of research. People's experiences of dementia can differ as dementia affects each person differently, I therefore sought an approach that embraced nuances and differences within the data.

Participatory Action Research

A further methodology considered when designing this project was Participatory Action Research (PAR) (Koch & Kralick, 2006). The approach was considered due to the iterative, cyclical, and collaborative research process and previous examples of PAR research carried out with people living with dementia (e.g. Goeman, Dickins & Iliffe et al., 2017). PAR involves planning, action and reflection within an iterative research process. The process involves researchers and participants working together in cycles to explore concerns and issues that impact upon participants' lives. The cyclical research approach means that the researcher and participants work together to decide what counts as data. Moreover, the process promotes reflection and focusses on developing solutions that may lead to the

enhancement of people's lives either at an individual, group, or macro level (Koch & Kralick, 2006). PAR is therefore often used when developing a new service or programme within a community. Although not deemed suitable as an overall method, the focus of PAR influenced the cyclical way of working in the current study, and the ways in which participants were viewed as collaborators within the process, and so helped to shape and inform the design of this research.

This project's focus on the lived and embodied verbal and nonverbal experiences of participants, meant that sensory, participatory and creative methods that are inductive and iterative were especially suitable. Researchers (e.g. Campbell & Ward, 2017; Craig, 2014; Kontos & Martin, 2013; Phillipson & Hammond 2018) claim that the use of flexible and creative methodologies can be a powerful way in which to engage people with dementia (and older adults living in care homes) in the research process and support their participation. Therefore Sensory Ethnography (SE) (Pink, 2009, 2015) was selected as a flexible, creative, and sensory method that was deemed particularly empowering for the population of interest.

3.4 Sensory Ethnography

Pink (2015) proposed that Sensory Ethnography (SE) is a re-thinking of ethnographic methods that attends to sensory perception and sensory experience. Sensory Ethnography is informed by an understanding of the interconnected senses, it incorporates innovative approaches to research that go beyond listening and watching to employ the use of multiple media. Pink (2009, 2015) proposed that Sensory Ethnography (SE) is open to multiple ways of knowing and forming understanding, claiming that it would be erroneous to view SE as simply a method for data collection; she instead refers to SE as a route to ways of knowing and understanding. The SE researcher forms understandings through engaging with

participants and reflecting on their own experience of this engagement (the research encounter): this could involve for example, taking part in an activity with a participant.

In practice SE involves drawing on traditional ethnographic methods such as observation and interview, whilst also employing less conventional techniques such as creative research methods. The term creative research methods (Kara, 2015) can be used to describe approaches that draw upon both arts-based research methods and design-led research methods. Arts-based approaches invite people to engage with creative practice e.g. sketch an image, whilst design-led techniques typically focus on the design of e.g. objects, services or interventions, involving people in the design process (Woodward, 2020). Despite these distinctions, the approaches are similar as both methods actively bring participants 'into' the research, inviting them to interact with things e.g. prototypes, or engage with raw materials to create things, e.g. to produce a collage (Woodward, 2020). Thus, within SE research creative methods could involve, for example, collaboratively producing a film, or co-designing objects with participants. SE involves the researcher using and developing established research techniques alongside new, participatory, creative approaches to generate knowledge. Campbell and Ward (2017) claim that such approaches can support exploring the embodied experiences of people with dementia.

SE seeks to draw out and understand the everyday realities of a person's life whereby the sensory experiences of the researcher and participants are emphasised within the research process. Thus Pink (2015) claimed SE could have a key role to play in applied research, as the understandings generated could be used to explore how a person's everyday experiences could be made more pleasurable and affective. For instance, this could result in the design of a new product, service, or inform ways in which to make care settings e.g. more comfortable. This applied way

of working is particularly important when considering how research findings can be used to enhance the care of people living with dementia. The approach is shaped by the view that the body is a source of knowledge and understanding. This is underpinned by the founding principles of SE research, which in turn informs how SE research is designed and carried out.

The principles of Sensory Ethnography

The principles of SE, and the theoretical approaches it draws from, despite being rooted in social anthropology, derive from human geography and philosophy (Pink, 2009, 2015). Pink (2009, 2015) drew on theories of human perception and theories of place, to propose a framework for understanding SE methodology as a process and practice. SE is underpinned by the concept that knowledge is formed through the body, consequently it involves attending to sensory experience, sensory perception and the interconnected nature of the senses. Therefore, the approach emphasises the experiences of researcher and participant within the environment in which they are situated, drawing upon the sensory experience of the 'in-situ' research encounter i.e. attending to the time, place and location of the interview; what it looks like, what it feels like, what it smells like, and so forth. This project draws upon Pink's principles for SE (2009, 2015), and is further informed by Ellingson's (2017) notion of embodiment within qualitative research.

Embodiment and embodied knowing

The privileging of the mind over the body is deeply ingrained in Western culture and hence within traditional research methodologies. This stems from the historical divide between the mind-body, in which the mind is equated with the self, and the body is portrayed as a metaphorical vessel for the mind. This divide, combined with traditional positivist assumptions about researcher neutrality and

objectivity, has resulted in viewing the mind as rational and where data derives meaning (Brady, 2011). Thus, the body has traditionally not been considered as a source of knowledge, and so not often acknowledged within research. Ellingson (2006) claims that this can limit understanding of experiences. For example, she reported that although qualitative health research is seemingly all about bodies i.e. patients' bodies or health care providers' bodies, the research is virtually bodiless. This, she claims leads to omitting "vital information and insights" (Ellingson, 2017:18).

An embodied approach to research foregrounds the notion that individuals encounter the world through their bodies and, as such, understand and learn through their body. Both Pink and Ellingson draw upon the notion of embodied knowing, which repositions the body as a source of knowledge and agency. To quote Perry and Medina (2011:63), this means that "the body is our method, our subject, our means of making, representing and performing". Ellingson (2017) claimed that such an approach to research can develop new insights and lead to knowledge that would be otherwise unknowable.

Furthermore, employing an embodied approach to research can open new possibilities for analysis and representation in qualitative research. This could involve creative ways in which to represent research findings i.e. using sensory cues (textures, sounds, smells, tastes) to move beyond written texts. Consequently, this can engage multiple audiences with research findings, moving beyond academia to public engagement: this in turn can increase the impact of the research. Ellingson (2017) posits that active engagement with embodiment can enhance a researcher's ability to understand, disseminate and, in turn, potentially spark social change, especially when working with those from marginalized communities. Ellingson's

(2017) claim supports Pink (e.g. 2015), who suggested that sensory research methods can generate new understandings that could, for instance, lead to the developments that could enhance peoples' lives.

Attending to the corporeal within the research process can also be particularly important in understanding and empathising with the experiences of research participants (Ellingson, 2017). Dominant cultural views of the body and the self conceptualise identity and physicality as a stable and static construct. Yet it could be argued that a more useful understanding of bodies and selves would be to view them in continuous movement or in a state of flux. This could be especially important when one considers people living with dementia, as the progressive and fluctuating nature of the condition means that a person with dementia may change day-to-day (e.g. fluctuations in capacity). An approach that supports the notion of embodied knowledge may facilitate the participation of those living with dementia in the research process, as it promotes understanding through the body 'in the moment' i.e. at the specific time of the research encounter. Therefore, attending to and foregrounding the significance of the body within the research process could be particularly meaningful when working with those living with dementia. This is also notable given the recent emphasis on the significance of embodied selfhood in people with dementia (see **Chapter 1, 1.2 Dementia, selfhood and embodiment**).

Interconnected senses, sensory perception and phenomenology

Theories of sensory perception underpin SE. The notion that 'perception' is central to good ethnography (Howes, 2003), and to practicing an embodied approach to research (Ellingson, 2017) is rarely disputed. For the purpose of this research, human perception is viewed as a holistic process, underpinned by Pink's principles of Sensory Ethnography (2015), Ellingson (2017), Howes (2004; 2013)

and the work of Merleau-Ponty (1962). Merleau-Ponty's work framed the body as a holistic system in which all functions are linked together.

In Western culture we are taught that we possess five senses; sight, hearing, touch, taste and smell, each of these is associated with a specific organ of the body (Ellingson, 2017). For instance, using the example of children's picture books, Howes (2013) explains how this notion is reinforced and suggests that "each sense has its proper sphere - sight is concerned with colour, hearing with sound, smell with odours" (Howes, 2013:15). These associations have vast implications when considering how we approach sensory experiences as adults: for instance, he suggests that "options appear limited to either going to an art gallery to treat our eyes, a concert hall to enjoy our ears" (Howes, 2013:15). Thus, he argues that treating the senses as discrete processes is inaccurate and negates the interrelation of the senses (Howes, 2003). Similarly, neurobiologists Newell and Shams (2007:1415) posit that "our phenomenological experience is not of disjointed sensory sensations but instead, a coherent multisensory world, where sounds, smells, tastes, lights and touches amalgamate".

In his work 'The Phenomenology of Perception', Merleau-Ponty examined the holistic and integrated ways in which sensation is perceived. For Merleau-Ponty, sensation could only be realised in relation to other elements. For example he wrote,

"one sees the springiness of steel, the ductility of red-hot steel, the hardness of a plane blade, the softness of shavings. The form of objects is not their geometrical shape: it stands in a certain relation to their specific nature and appeals to all our other senses as well as sight (2002 [1962]:267)."

Therefore, he proposed that sensations are produced through our encounters with 'sense-data', but that to be realised sensations are overlaid by a body of knowledge since it (the sensation) cannot exist in pure form (2002 [1962]:5). Thus meaning, as depicted in his example, looking at an object involves not just sight, it involves understanding the tactile qualities of the object. Therefore, what we perceive is formed by our different sensory modalities that combine and integrate and, as Howes and Classen (2014) identified, are given meaning by human experience. Attending to the senses involves attending to the bodies of researcher and participants within SE research.

Emplacement

The notion of embodied knowledge has been extended to incorporate the ways in which information and understanding are shaped by the environment. Howes' (2005) notion of 'emplacement', an idea central to SE methodology, suggests the interrelationship between the body-mind-environment. Drawing upon Howes' (2005) definition, Pink (2015) uses the term 'emplacement' to suggest that the 'emplaced ethnographer' accounts for and attends to relationships between bodies, minds and the material and sensorial environment. Pink connects this with the work of ecological psychologist Gibson (1966), who wrote that perception is not the achievement of the mind in a body but of the being as a whole, situated within its environment. Adding to this, Ingold (2000:261) stated that "looking, listening and touching ... are not separate activities they are just facets of the same activity: that of the whole organism in its environment". For example, Pink (2015:80) wrote that:

"by sitting with another person in their living room, in their chair, drinking their coffee from one of their mugs, or when drinking together in a café, one begins in some small way to occupy the world in a way that is similar to them."

Thus, she identifies that knowledge is formed through the researcher being 'emplaced' in the environment and sharing experiences with participants.

As noted in the above quote from Pink, the concept of emplacement refers to the researcher and participants' experiences within the specific research context. Therefore, the SE process requires the researcher to engage with and reflect upon their own sensory experience of the research setting, whilst also attending to their participants' experiences. For instance, in the case of the current project, this involved attending to the care home environment during the research encounter i.e. what the room feels like, looks like, smells like and so forth.

The SE approach is underpinned by the notion that knowledge is formed through the body, that the knowledge formed is context specific, and is co-created by researcher and participants. The term co-create (Zeilig et al., 2018) is used within this thesis to illustrate the collaborative nature of knowledge production within the SE process (researcher and participant). Moreover, the SE approach emphasises attending to the interconnected sensory experiences of both the participants and researcher. To reveal and investigate such experiences the SE researcher may use a range of methods.

3.5 Research design

In order to carry out this Sensory Ethnographic study, I drew upon the work of Pink (2009, 2011, 2015), further SE studies (Hatton, 2016), Ellingson's (2017) 'Embodiment in Qualitative Research' and also upon co-design (Chamberlain & Claire, 2013, 2016, 2017) and PAR practices (e.g. Koch & Kralick, 2006), to develop a series of interlinked-cycles of study. **Figure 10** is a visual representation of the

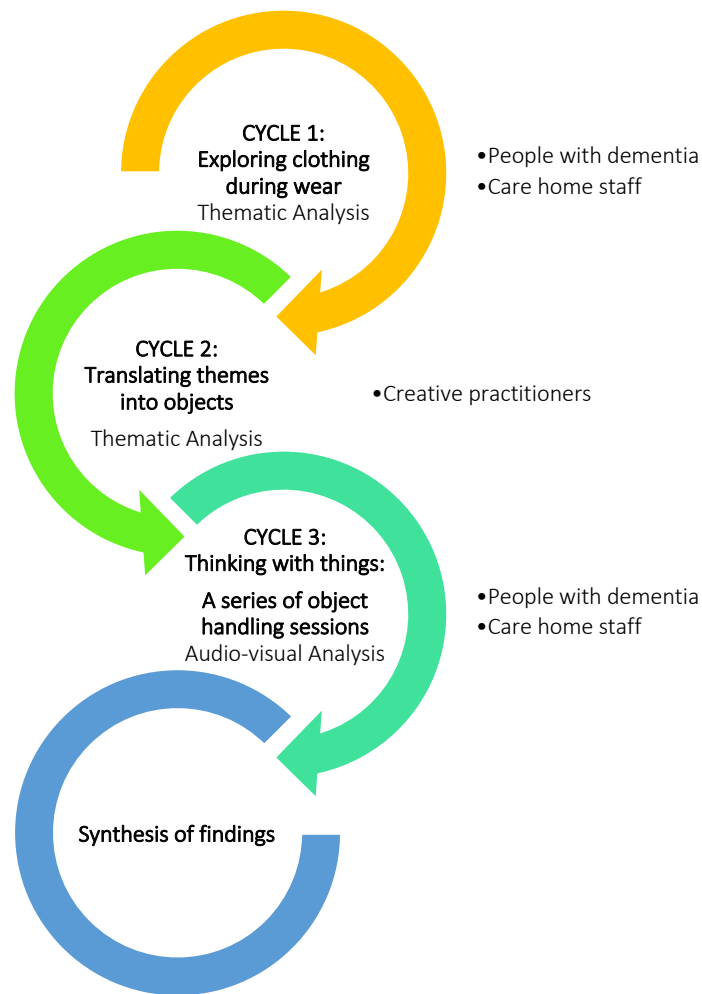


Figure 10. Interlinked cycles of study

cycles of study, it is used throughout the thesis to signpost each cycle of study as they are presented.

Traditional ethnographic research involves the researcher spending long periods of time in the field whilst living in the same environment as their participants. Yet in practice, and particularly within contexts, including design research or applied uses of ethnography, the method instead involves ‘excursions’ into participants’ lives in order to reveal what is important to the research aims (Pink & Morgan, 2013). In

practice, short term ethnography, or ‘focussed ethnography’ (Knoblauch, 2005), is concerned with periods of intense data collection. Such periods may involve a series of focussed observations through the use of prompts e.g. observations guided by prompts devised to reflect the aims of the research, or the use of methods such as videography (video-recording) to capture data. This project employed focussed periods of data collection through the use of interlinked cycles of study.

The interlinked cycles of study involved the use of malleable methods that were created and shaped within the specific context of the research (Pink, 2015). The cycles of study were designed to be inductive, forming knowledge through attending to the body rather than focussing solely on verbal expression and recall, i.e. sensory and creative methods were used to support nonverbal responses. There were three iterative cycles of study, each building upon the previous one. The cycles of study were informed by existing literature (e.g. Chamberlain & Craig, 2013; Pink, 2015; Koch & Kralick, 2006), and my experiences of volunteering in dementia care settings. Pitts-Taylor (2015) claims that an embodied approach to research necessitates an interdisciplinary approach to the research process, whereby the researcher employs a range of tools and methods to explore and generate knowledge. This aligns with Pink’s (2015) SE approach in which one method is not privileged, instead multiple methods, both conventional and innovative, can be drawn upon to generate knowledge.

The multi-method approach was designed to empower participants living with dementia, as the methods sought to enable participation at different levels and in varying ways and forms. Secondly, as a holistic understanding of clothing in the dementia care setting was sought, an approach that encompassed different methods was employed in an attempt to generate rich understanding. Each cycle of study i.e.

CYCLE 1: Exploring clothing during wear, CYCLE 2: Translating themes into objects and CYCLE 3: Thinking with things: A series of object handling sessions, is presented respectively in a stand-alone chapter which details the methods used, participants involved in the study, the data analysis process, and the study findings.

The aim of the research was not to generalise or generate one truth, but instead to co-create findings with participants. Acknowledging the ways in which my experience shaped the design of the research demonstrates an engagement with reflexivity, which is an integral aspect of the SE approach.

Reflexivity

Reflexivity is deemed to be particularly significant when carrying out SE, as the approach calls for the researcher to engage with how their own experiences are shaped within the research encounters. For example, the research encounter may involve interviewing a participant whilst sitting in the lounge of a care home. This would involve the researcher attending to the feel of the chair, the scents, sounds and sights experienced during that research encounter. The researcher's experiences may assist in understanding the experiences of others i.e. research participants, as the researcher can draw upon the experiences shared with the participant through being 'emplaced' within the environment (see **3.4 Emplacement**), thus, demonstrating the generation of knowledge through being 'emplaced' in the environment and sharing experiences with participants. The SE approach emphasises that the generation of knowledge is participatory and collaborative and where the researcher is an integral part of the knowledge formation. Therefore engaging with reflexivity is essential to support knowledge formation.

Practicing reflexivity typically involves writing, yet both Pink (2015) and Ellingson (2017) posit that an arts-based or applied means of engaging with reflexivity through, for instance, the use of sketchbooks, can invoke broader understanding and can be a way in which to make sense of the embodied experience. Similarly, La Jevic and Springgay (2008) suggest the use of reflexive visual journaling e.g. drawing, painting or collage, to aid in emphasising and articulating thoughts that are 'messy' and complicated to explain. Throughout each cycle of study, I engaged with both written and visual forms of reflexivity. **Figure 11** is an extract from my reflexive journal, in which I used mixed media techniques (e.g. using tissue, ink, and acrylic paint) to explore notions of touch.



Figure 11. Example from my visual reflexive journal

3.6 Research setting

The research was carried out in a care home in Greater London. The large site provides both nursing and residential care for older adults (stated by the site as people aged 60 and over). At the time of carrying out the

research, the care home was rated as 'outstanding' by the independent regulator of health and social care in England, the CQC. Thus, the care home was selected as the site for the research as it was deemed an exemplar of best practice. Moreover, there were a substantial number of people with dementia living there.

This research involved working in a care home due to (1) the prevalence of people with dementia living in care homes (Prince, Knapp, Guerchet et al., 2014); (2) existing literature that has identified that possessions can be particularly evocative and meaningful for people living in care homes (Buse & Twigg, 2014a, 2018; Cleeve et al., 2020; Craig, 2017; Stephens et al., 2013); and (3) the notion that clothing can be considered a person's most immediate environment (Twigg, 2010). As explained earlier it is increasingly recognised that the design of health and social care settings are important to the wellbeing of those accessing care, yet limited attention has been given to clothing within such settings. Consequently, unlike previous research within the area of clothing and dementia that worked with participants living both in their own homes and care homes (Buse & Twigg, 2014a, 2014b, 2016a, 2016b), this project focused on the significance of clothing to people with dementia living in a care home.

Volunteering at the research site

Throughout my PhD studies I have engaged with volunteer work, assisting with one-off events created for people with dementia and their carers', and assisting with delivering creative workshops in care homes. I volunteered at the research site on a weekly / bi-monthly basis for approximately seven months prior to the start of the research. This was invaluable in terms of getting to know residents, staff, and other volunteers and also understanding the ways in which the care home worked.

Fletcher et al. (2019) claim that such 'hanging out' periods are crucial when carrying

out research with people with dementia. Due to the nature of my research, I did not seek an objective stance and so volunteering supported my research process.

3.7 Recruitment

Carrying out research, especially in a health or social care setting, is a sensitive process which requires extensive understanding of ethical concerns. Ethical approval was granted for all procedures and materials associated with this research from the University of West London's College of Nursing Ethics Committee (CREP Reference 00465) and the London - Camden and Kings Cross NHS Research Ethics Committee (Reference 18/LO/1707). The research protocol guided the method of sampling and recruiting participants. See section **3.8 Ethical Considerations** for further details.

Due to the aims of the research, the focus of SE, and the holistic approach to research, a number of participant groups were included in the research including people living with dementia, care home staff, and creative practitioners working in health and social care settings. Each cycle of study (see **Table 1**) equated to a recruitment phase: thus there were three stages of recruitment.

Table 1. Participant groups and cycles of study

Cycle of study	Participant groups recruited
CYCLE 1: Multisensory research encounters	<ul style="list-style-type: none"> • People with dementia • Care home staff
CYCLE 2: Translating themes into objects	<ul style="list-style-type: none"> • Creative practitioners
CYCLE 3: Thinking with things: A series of object handling sessions	<ul style="list-style-type: none"> • People with dementia

All participants were sampled purposively. The SE method is not prescriptive and does not specify recruitment or sampling strategies, yet the approach calls for the researcher to engage with participants who have experience of the phenomenon under study. Purposive sampling can be particularly useful in exploratory qualitative studies as it involves recruiting a certain group of participants that give access to a particular phenomenon (Denzin & Lincoln, 1994). Therefore, those recruited had relevant life or professional experience related to the research aims.

Participant identification

Different tools and strategies were employed in order to identify participants. Methods included face-to-face meetings with potential participants in which the research was explained to them through written and visual materials, staff fora, managers' meetings, and the use of recruitment adverts such as posters and leaflets. In order to recruit participants who might give access to the phenomena under study i.e. the significance of clothing to the lives of people with dementia, a number of inclusion criteria were employed.

Inclusion criteria for people with dementia:

- People living in a care home with a confirmed diagnosis of dementia (as reported by the care home team managers). I relied upon the opinion of the appropriate manager regarding the dementia status of residents and did not view medical records.
- The capacity to understand and consent to participate in the research or had a nominated or personal consultee who was identified and approached if the individual was not able to consent.
- Ability to converse in English.

- Participants were **excluded** from the research if they were deemed too unwell or vulnerable to continue participating. This decision was made in close collaboration with the appropriate care home team manager, myself, the PhD supervisory team and, where applicable, the person's consultee.

Inclusion criteria for care home staff:

- Staff working at the research site with people with dementia.
- Ability to converse in English.
- **CYCLE 3 only** – able to attend 1 Object Handling Session and follow-up interview.

Inclusion criteria for creative practitioners:

- Individuals working as a practicing artist or designer.
- Working with or experience of working with people with dementia.
- Ability to converse in English.
- Over 18 years old.

Participant confidentiality

Codes, as opposed to pseudonyms, are used throughout the thesis in the place of participants' names, to protect confidentiality. It was originally thought that pseudonyms would be used for the purpose of this project as they are widely used in qualitative research. However, they were not used due to concerns around selecting names on behalf of participants. When working with people with dementia it is important to be sensitive to the needs of research participants and to acknowledge the potential power imbalances that occur, asking participants to select their own

pseudonyms (Lahman, Rodriguez, Moses et al., 2016) can avoid such issues, yet this was not possible at the time of writing the thesis (see *Reflexive note 1*).

Reflexive note 1: The use of pseudonyms

I coded all participant data for the purpose of storage and analysis and had planned on replacing codes with pseudonyms in the final presentation of the thesis. Yet, when it came to selecting pseudonyms, I felt uneasy, as though I was inferring characteristics about participants. I began to read more widely around the process of selecting pseudonyms and grew more uncomfortable with ‘making-up’ names. Due the COVID-19 pandemic it was not possible to approach the study site to see if it would be possible to ask participants to select their own pseudonym.

Although the use of codes may seem dehumanising, this is not my intention. The codes have been used in an attempt to keep my participants voices/experiences as their own without adding a layer of potential meaning through the use of certain names.

3.8 Ethical considerations

There were a number of ethical concerns that were considered for this research including voluntary participation, privacy, confidentiality and consent. One of the most substantial ethical considerations within this research was seeking and receiving consent from people living with dementia. Due to the progressive nature of the condition, capacity in people with dementia can fluctuate. I was guided by the Mental Capacity Act (2005) and the training provided by the National Institute for Health Research that I undertook prior to starting the research.

During the consent process every effort was taken to involve the person with dementia in the consent process. According to the Mental Capacity Act (2005) capacity is defined as a person's ability to understand the information about the research, retain the information to consider if they wish to take part, weigh up the consequences and communicate their decision. Thus, the study was explained to potential participants with dementia, verbally with the use of written and visual information (Participant information sheets were created with reference to the Dementia Engagement and Empowerment Project (DEEP) guidelines (DEEP Guide, 2013) (see **Figure 12**).

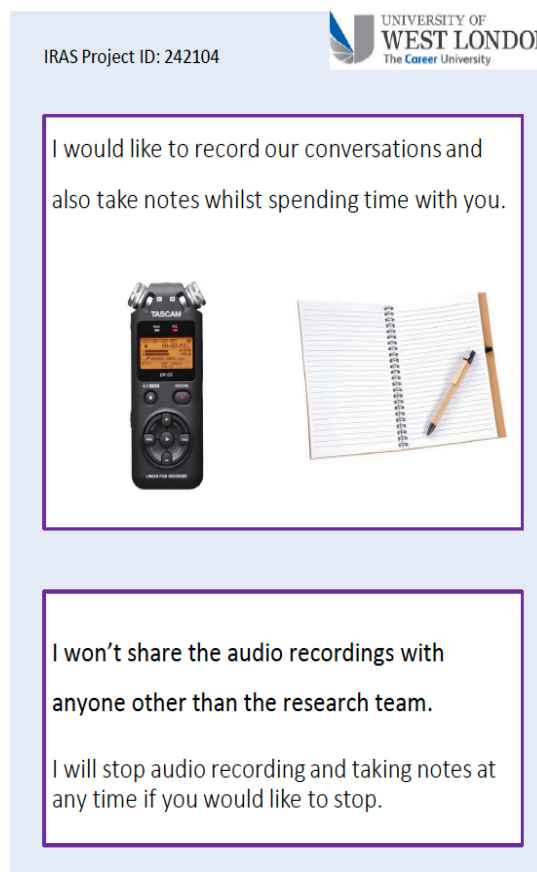


Figure 12. Extracted page from participant information sheet

Due to their dementia some people found it difficult to understand the study and were unable to express their views unequivocally in order to give fully informed consent. Where this was the case assent from a nominated or personal consultee

was sought. Consultees were asked to consider the person with dementia's past wishes and views, and their situation at the time of the research before making a decision regarding participation. Participants who lacked capacity were given an accessible Participant Information and Consent Booklet (see APPENDIX M). I referred to the British Psychological Society (2008) 'Conducting research with people not having the capacity to consent to their participation' to guide this process.

Consent was considered an ongoing process and was guided by the process consent method (Dewing, 2008). I reiterated consent at each inclusion in the research (i.e. in CYCLE 1 before each research encounter) and where appropriate during the research encounter. I kept detailed notes of the consent processes (see APPENDIX U for an example). Due to the sensitive ethical considerations, communication with key stakeholders (participants with dementia, team managers, personal/nominated consultees, and the PhD supervisory team) was integral. If a person with dementia was thought to be too unwell or vulnerable, they were excluded from the study at that time but, if appropriate, they were approached at a later date to continue participating in the research. The decision to include people with dementia who lacked capacity was made in close collaboration between myself, the personal or nominated consultees, the care home team manager, and the PhD supervisory team.

Further ethical concerns regarding participant distress during the research process, the invasion of privacy in the care home setting, data protection, confidentiality, participant distress and abuse disclosures were considered in detail (see APPENDIX D). I also made a note of any unanticipated ethical concerns in order to discuss these with the PhD supervisory team and develop my practice as a researcher. For example, one personal consultee found the use of the word

'dementia' problematic and considered it to be labelling. After discussion with the PhD supervisory team I assured the consultee that the project's focus was to explore the experiences of those living with dementia. Participation was not pursued as the consultee decided that they did not want their relative to be involved in the project.

3.9 Summary

This chapter has detailed the Sensory Ethnographic (SE) design of the research. The use of sensory, creative and visual research methods, when working with people with dementia, can generate rich and nuanced understandings of their experiences. Moreover, the methods used can empower people with dementia to take part in research. This chapter has also detailed the setting in which the research took place and the ethical considerations that applied to each cycle of study.

The subsequent chapter details the first cycle of study, **CYCLE 1: Exploring clothing during wear**, including the methods used, the data analysis process, and the findings.

CHAPTER 4 CYCLE 1: EXPLORING CLOTHING DURING WEAR

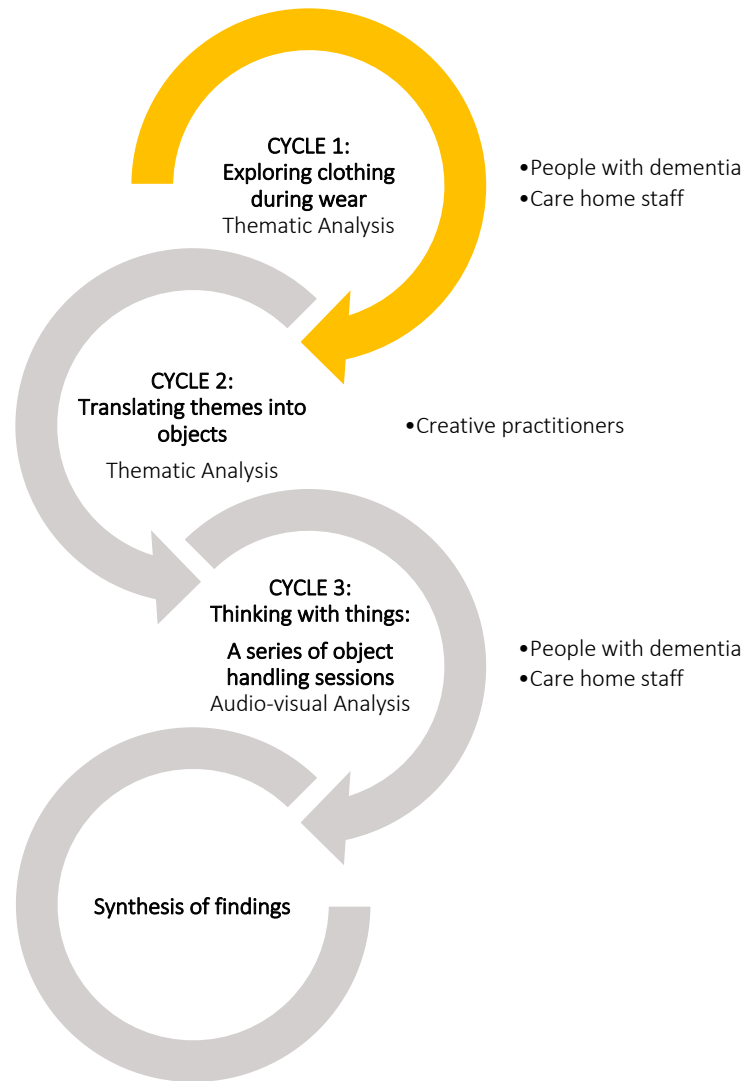


Figure 13. CYCLE 1: Exploring clothing during wear

4.1 Introduction

This chapter details the methods used, and findings from the first cycle of study, **CYCLE 1: Exploring clothing during wear**. This is informed by the **Literature Review** and the research aims, which are as follows:

- To explore the relationship between people with dementia and their clothing, through addressing the following questions:
 - What is the embodied experience of wear in people living with dementia?
 - How do particular sensory qualities i.e. aesthetics, specific colours, patterns, fabrics affect clothing wear?

This cycle of study focussed on exploring clothing during wear in the care home, working with care home residents living with dementia and care home staff.

4.2 Multisensory research encounters

This cycle of study employed the use of concurrent observations and interviews. For the purpose of this study, the term 'research encounters' is used when discussing the combined observations and interviews. Within social anthropological studies it is common to find that interview and observation coexist, rather than the interview occurring separately to the observation (Skinner, 2012). Hockey and Forsey (2012) positioned the interview as an engaging participatory encounter between the researcher and the interviewee. They suggest that viewing the interview as a moment of engagement allows the researcher to access knowledge that may be otherwise inaccessible. Similarly, Pink (2015) suggests that the combination of interview and observation can allow for different elements of experience to be understood. Rather than categorising the research encounter as either being solely verbal or, in the case of traditional observations, solely visual it can involve multiple forms of communication, and attend to haptic, auditory, visual and olfactory experiences. For instance, an emphasis on solely verbal expression can neglect different forms of communication e.g. gestures and facial expressions

and can therefore curtail what the research encounter is and limit understanding. This dependence on talk, especially when working with those who may experience verbal language challenges e.g. people with dementia, should be reconsidered. Attending to multiple forms of communication is particularly significant given that verbal expression makes up only a small percentage of communication, with nonverbal communication (all human communication excluding the spoken word) making up between 65% - 95% of information conveyed (Matsumoto, Frank & Hwang, 2013).

The use of concurrent observations and interviews sought to shift focus away from the visual, i.e. traditional observation methods, and the verbal i.e. traditional interview methods, in order to view the research encounter as a multisensory experience. This shift in emphasis attempted to form understanding through attending to the interconnected senses (Howes, 2003), meaning that, for instance, visual observations are relevant due to the connection with the other senses. This is particularly significant in the case of this research, where clothing and appearance are typically perceived visually. Focussing on the research encounters as experiential moments enabled me to draw upon how something may feel by sharing moments or experiences with participants. Moreover, as presented by Hubbard et al. (2003), carrying out interviews alongside observations can allow participants with dementia to communicate with the researcher on their own terms, through their own pattern of communication. Additionally, participants may draw on artefacts, objects, or photographs to help communicate their experiences. For example, when exploring personal items of clothing and accessories, participants with dementia often invited me to hold, handle or explore items with them. This enabled me to investigate multiple ways of knowing through incorporating various forms of communication i.e.

through the introduction of objects or materials to help elucidate their experience. Concurrent interviews and observations can therefore provide different forms of knowledge through verbal explanations and embodied ways of knowing e.g. through handling items within the encounter.

The use of material objects to support responses in anthropological research is well established. Within this research, clothing was the focus of the study and so, during research encounters, participants were invited to engage with their clothing, exploring its sensory properties of their clothing e.g. the tactile, visual and olfactory, and how their garments made them feel. The approach drew upon and extended the interview method that I previously used (Fleetwood-Smith et al., 2019)² to explore embodied, sensory aspects of wear. For example, when talking with one participant about the scarf that she was wearing, the participant proceeded to take her scarf off, handing it to me to allow me to understand how the scarf felt. She then proceeded to handle the scarf, slowly moving the fabric in her hands, twisting and distorting the shape before folding and refolding it. Thus, as demonstrated in this brief example, the use of clothing during wear as a tool for elicitation was particularly powerful and provided both shared moments of interaction and communication and also facilitated different forms of understanding.

The use of clothing during wear as a tool for elicitation has been little discussed in the literature, with existing studies often using clothing e.g. in a wardrobe, as a prompt (Woodward, 2007, 2015; Woodward & Greasley, 2015). Guy and Banim (2000) developed the notion of the 'wardrobe interview' in their work.

² The study involved exploring actively worn attachment garments whereby the participant was interviewed whilst wearing their attachment clothing.

Drawing upon this, in her work 'Why Women Wear What They Wear', Woodward (2007) used wardrobe interviews to explore the everyday clothing of women, and participants were interviewed alongside their wardrobes and asked to choose and discuss items of clothing therein. Rather than use a method such as a wardrobe interview, I sought to explore clothing during wear (i.e. the embodied and sensory aspects of clothing) 'in the moment', within the specific context and place of the care home. As found by researchers (e.g. Masuch & Hefferon, 2018), clothing is often kept for nostalgic reasons, remaining in the wardrobe despite no longer being worn. However, the aims of this research were not to provoke reminiscence or ask participants to talk about clothing that they no longer wore. Thus, informed by the work of Ilanen and Topo (2015), who displayed clothing on a rail and invited participants to interact (and try on) clothing to explore the embodied, visual and tactile properties of the items, this current project explored participant's clothing (during wear) at the specific time of the research encounter.

Research encounter prompts

The use of prompts rather than structured guides can allow for flexibility and create space for the researcher to be responsive to the participant (Pink, 2011). The prompts used to guide the research encounters consisted of a series of bullet points and were not numbered consecutively. They derived from the literature e.g. Buse and Twigg (2016a), Woodward (2015) and Guy and Banim (2000) and from my experience of volunteering in care homes and sought to explore the experience of clothing during wear. e.g. Please can you describe your clothing today? What does your clothing feel like? Is there anything that you like about your clothing today? See APPENDIX V and APPENDIX W for the full list of the interview prompts. The prompts were designed to focus the research encounters - this aligns with the notion

of 'focussed ethnography' which can generate rich data (Knoblauch, 2005; Pink & Morgan, 2013). Focussed research encounters are particularly suited to health and social care settings, as it would not be appropriate for the researcher spend prolonged periods of time at the sites due to the care home being both a person's home and one in which personal and clinical care is provided.

Flexibility has been advocated when working with people with dementia (Hubbard et al., 2003) and when working in health and social care settings (Buse & Twigg, 2018) and this involves not only considering e.g. the structure of an interview but also, for instance, where, when and how the research encounters are carried out. For instance, Buse and Twigg (2018) found that it was difficult for staff in a care home to 'come off the floor' in order to participate in their research and due to this reason they conducted interviews in empty corridors or in quiet corners of communal spaces within the care home. This demonstrates that adaptability can be important when carrying out research and can support the participation of those taking part.

4.3 Research encounters: Ethical and practical considerations

Involving people with dementia in research involves the careful consideration of a number of ethical and practical issues. Researchers such as McKeown, Clarke, Ingleton et al. (2010), Tanner (2012) and Rivett (2017) have discussed the importance of: considering researcher-participant rapport prior to conducting research, carrying out research at the 'best' time(s) of day for participants and ensuring participants feel comfortable e.g. using a space that is familiar to them, in order to enable people to take part. This section details how such considerations shaped the research and attempted to support participants as fully as possible. The following sub-section i.e. **Developing a routine** specifically details the procedure involved in carrying out the research encounters.

Firstly, although I typically arranged with participants when research encounters would take place, these were under constant negotiation as they were dependent on participants' health, availability and their desire to take part on a given day. For instance, there were approximately ten instances where encounters were cancelled or postponed due to ill-health, a participant attending an appointment, or not wanting to take part at that time. A flexible approach to meeting the needs of participants was essential in order to fully support participation and meet ethical requirements and so I made every attempt to do so.

Nevertheless, the extent to which I could be flexible was subject to the ethical constraints of the research protocol. For example, the protocol stipulated that research encounters must take place within the public spaces of the care home (i.e. not in a person's bedroom) and yet confidentiality must be ensured. Therefore, research encounters with both participants with dementia and care home staff typically took place in small rooms such as a 'Namaste room' (i.e. small rooms used specifically for namaste sessions³ for people with dementia), and staff rooms where privacy could be assured. These spaces were quiet and had a sign on the door to say that when the door was closed the room was in use. These rooms were situated on each floor of the care home (there were multiple floors of the care home) which made them accessible to participants as they were not required to travel too far from

³ Namaste Care is a programme of care for people with dementia (see e.g. Stacpoole et al., 2017). The programme requires a designated space i.e. 'the namaste room', within the room namaste activities such as, hand massage and reminiscence may take place.

e.g. the lounge area or their bedroom. This was particularly important for some participants where mobility e.g. walking or using a walking aide, was difficult; where participants were already on their 'floor' i.e. for participants with dementia the floor on which their bedroom was; or for staff, where they worked and for those who found moving between the different spaces of the care home difficult, for instance, some participants did not like particular areas of the care home.

Despite the complexity involved in finding and navigating between appropriate spaces, inviting participants to join me in a particular room was a useful way in which to frame the research encounter. The transition from one space to another indicated a natural start and end to the research encounter and was powerful in supporting the process consent method (see **Method, 3.8. Ethical considerations**, (Dewing, 2008)). Additionally, the movement between spaces provided rich and nuanced reflections. For instance, one participant insisted on putting perfume on and then bringing the fragrance to the research encounter, whilst on two occasions another participant chose to change her clothes.

Although the movement between spaces often helped to frame research encounters, it also proved challenging, and I relied heavily on the relationships that I had built with members of staff and their understanding of the research protocol. For example, securing appropriate research spaces could be difficult as they could not be booked in advance. I often had to find alternative suitable spaces at different times. It is important to note that the use of different rooms was only possible due to the large size of the care home and that I was familiar with the spaces available due to my volunteering experience. The training that I received when volunteering also supported the process as I had received wheelchair training and training in supporting someone who walked with an aide e.g. Zimmer frame and so could

support certain participants. Nevertheless, in some instances, I relied upon staff support e.g. one participant was a wheelchair user and preferred to transfer from her wheelchair into a chair for each research encounter, which involved staff support at the beginning and end of each research encounter.

Developing a routine

I usually arrived at the care home no earlier than 10am because the residents that I worked with typically had breakfast until 9:30am. Before approaching a participant with dementia, I spoke with my point of contact 'on the floor' (e.g. the team leader or team manager who was responsible for the specific floor of the care home that I was working on), or, if they were not available, to the most senior member of staff on the floor e.g. senior healthcare assistant. I would talk with the member of staff regarding the participant(s) and this would involve asking how the participant was and whether they felt that it would be suitable for me to spend time with the participant that day. For example, if a participant had not slept well the member of staff might advise that I come back in the afternoon. These interactions also gave me the opportunity to ask which rooms may be available to use for the research encounter.

The routines within the care home greatly impacted upon the ways in which I worked with participants: for example, lunch was served at 12:30pm and this meant that participants were usually only available before 12:15pm or after 2pm. Afternoon refreshments were served at 3:30pm and so participants often wanted to be in the lounge at that time. By 4:30pm staff advised that participants were often quite tired and so the majority of the research encounters took place between 10am-12:15pm and 2pm-4:30pm. In deciding when to conduct the research encounters, I was guided by each individual taking part in the research. For example, one participant

who slept late into the morning was content to take part in a research encounter between 4:30pm-5:15pm. As the project progressed, I became more attuned to the nuanced routines of each participant and the associated processes within the care home. When working with care home staff participants, I was advised by a team manager that weekends were quieter times at which I could meet with them. Thus, if staff agreed, I carried out encounters on weekends.

A 'typical' research encounter could vary greatly depending on each participant (see e.g. *Reflexive note 2*). For example, one participant, was happy to walk with me to the room which we often used for the research as soon as I approached her. For another participant leaving her bedroom could be a lengthy process as she often wanted to change her clothes and bring items with her to the research encounter. This could take up to forty minutes due to staff needing to support her in changing her clothing.

Reflexive note 2: Setting-up a research encounter

I checked in at the desk on the floor with the team leader who was busy with the medical round but who said that I could go and talk to the participant at that time. I went around and knocked on her bedroom door which was locked. I tried to explain through the locked door who I was and why I was there, but she struggled to hear. She walks with a Zimmer frame and so slowly approached the door, as she did so, she was talking to me, but I struggled to hear her. As I was waiting for her to open the door, a resident, whose room is opposite to the participant's started talking to me. She was interested in why I was going to be talking to the participant. Eventually the participant opened the door, at this point a healthcare assistant, who was walking past, offered to support me. On opening her door and seeing the healthcare assistant, the participant began to complain to the member of staff. Moreover, on seeing the resident whom I had been talking to, the participant began a conversation with her. This was difficult to navigate - I didn't want to take the participant away from her friend but equally I had already begun

to explain to her that I was there for research purposes. Eventually the situation was resolved as the healthcare assistant had been coming to support the other resident to go and join an activity.

I spoke to the participant in the corridor explaining who I was and why I was there, and she agreed that she was happy to spend time with me again for the research. The staff room was immediately next door to the participant's bedroom - this was something that was particularly important in supporting her to participate in the research as she often voiced her concerns at falling over if walking for long distances.

4.4 Recording the research encounters

In order to capture the research encounters I used the following techniques: (1) Field notes were written as soon as possible after the research encounter (see *Reflexive note 3*). These recorded specific observational aspects of the encounter, drawing upon observational tools from Morse and Chatterjee (2018); (2) the initial field notes were expanded to include further details within 24 hours of the research encounter; (3) an audio-recording device was used to record verbal communication with participants; (4) I used a reflexive journal to record text-based and visual reflections.

An unanticipated tool that I found valuable when writing field-notes was using the 'note' function on my phone. I often spent time in the café within the care home between research encounters, and although I sat alone, I felt that it would have been inappropriate to sit with my notebook or laptop on the table. Instead I chose to make notes on my phone to record immediate reflections and fieldnotes from research

encounters⁴. This meant that I was able to quickly record reflections and fieldnotes but avoid potential confusion that I may be observing and making notes about those sitting in the café.

Reflexive note 3: Recording the observations and interviews

The process of writing field notes at the time of the research encounter was often problematic as the encounters involved me spending time with participants one-to-one, making note-taking difficult at the specific time. There were however some participants who seemed concerned that the recorder may not capture all of the information and so they would often insist on me “taking notes”. This varied according to the participant, and many were concerned about me asking all of the questions that I had. Moreover, many participants interacted with their clothing, materials or objects within their proximity, and often invited me to interact with them e.g. handle a cardigan that they had draped over their walking aide, smell the perfume they were wearing. I had the same exchange with two participants whereby they wanted to try my ring on. Sharing the experience of exchanging the ring with participants, them trying the ring on, often on different fingers, exploring where it may fit best was a particularly powerful experience. Taking notes of these instances would not have been appropriate and would have been disruptive. I would have missed aspects of the experience.

4.5 Contact time with participants

Previous studies, employing observational methods, have reported differing durations of contact time with participants: for example, Kelley (2017) reported carrying out just under two hundred hours of observations at one study site (with observations ranging from half an hour to six hours), whilst Ward et al., (2013a) report collecting three hundred hours-worth of observational data, yet exact figures per participant are not clear. Hubbard et al. (2003) recommend carrying out

⁴ My phone was password protected and I did not include any identifiable information in the notes on my phone.

observations over approximately thirty minutes to two hours, depending on the participant's needs. For example, if a participant became tired and went to their room, an observation or interview would be terminated. Guided by the aforementioned timings, each research encounter was planned to last between thirty minutes to two hours. However due to the varying needs of participants with dementia e.g. becoming tired or wanting to take a break, research encounters typically lasted between twenty to sixty minutes. Each participant with dementia took part in multiple research encounters ranging from three up to six encounters over the course of the twenty-week study period (see **Table 2**). In the case of staff, the research encounters were longer but there were fewer of them.

Table 2. Number of research encounters

Participant	Number of research encounters	Total per participant group
Participants with dementia	3 < 6	22
Care home staff	1 < 3	9
Total number of research encounters		31

An unanticipated aspect of the research process was the time that I would spend with each participant with dementia prior to and after each research encounter. This could be as long as 40 minutes, as discussed earlier in this chapter (see **Research encounters: Ethical and practical considerations**). I made detailed reflexive notes of the varied processes involved in setting-up the research encounters and kept contact logs for each participant to record the time spent with individuals for the research encounter (see **Table 3**).

Table 3. Participant contact log P1 (PWD)*

Research Week Number	Approx. Minutes	Location
Week 3 Informed Consent Process	30 minutes	Omitted for confidentiality
Week 4	110 minutes	Staff room
Week 6	90 minutes	Staff room
Week 7	45 minutes	Namaste room
Week 9	50 minutes	Namaste room
Week 12	40 minutes	Namaste room
Week 15	30 minutes	Staff room

*Codes are used for all participants in the study to ensure confidentiality.

4.6 Participants

Participants were sampled purposively according to the sampling method detailed in **Chapter 3, Method, 3.7 Recruitment**. The total number of participants recruited for CYCLE 1 was twelve, equating to an equal number of participants with dementia (six) and care home staff participants (six). Previous completed doctoral ethnographic studies have used no less than three participants and no more than twelve participants when working with people living with dementia (Hatton, 2016; Kelley, 2017). These numbers were used as a guide for recruitment, yet despite approaching at least twelve potential participants only six people with dementia were recruited to take part in the research. There were a number of reasons why potential participants did not take part: not wanting to take part in research, illness, not wishing to complete the necessary consent form, and, in one case, a personal consultee did not wish for their relative to take part. An equal number of care home staff were recruited to take part in the research. It was considered important that the number of staff did not exceed the number of participants with dementia, to ensure

that the lived experiences of participants with dementia remained the focus of the study.

All participants with dementia involved in CYCLE 1 were female (see below); this was not intentional and male residents were approached to take part in the research. Three potential male participants were initially identified. However, at the time of approaching the participants, two of the potential participants were too unwell to participate and did not go through the consent process, whilst one potential participant began the consent process but decided not to proceed as he found the images on the consent form upsetting. It is possible that audio-recorded consent would have supported participants during this process, however this was not possible due to the ethical requirements. With regard to care home staff no male members of staff expressed interest in participating in the research, this was perhaps due to the topic of study, as Twigg (2013) notes clothing is often perceived as the realm of women rather than men.

The lack of male participants in CYCLE 1 is of interest and yet is representative of broader care home demographics in which the majority of care home residents and care home staff are female. Figures estimate that there are around 2.8 women for each man living in care homes (ONS, 2014) and women are disproportionately affected by dementia (Alzheimer's Society, 2014), whilst, 87 per cent of the dementia care workforce is female (Hussein & Manthorpe, 2012).

Table 4 contains the self-reported demographic information for people with dementia and care home staff. This information was gathered during their first research encounter. In the case of participants with dementia some were unsure of the information and so where an approximate age/ages were given this is noted. The

term ‘undisclosed’ is used where information was not given. Moreover, one member of care home staff did not state her actual age but that she was 30-40. Demographic information was collected in order to support the interpretation of findings.

Table 4. CYCLE 1: Participant self-reported demographic information

Participant code*	Gender	Age	Ethnicity
Participants with dementia (PWD)			
P1 (PWD)	Female	81	White American
P2 (PWD)	Female	87	White British
P3 (PWD)	Female	89-90	Egyptian
P4 (PWD)	Female	80	Turkish
P5 (PWD)	Female	Undisclosed	White British
P6 (PWD)	Female	82-86	Undisclosed
Care home staff participants (CHS)			
P7 (CHS)	Female	30-40	Asian
P8 (CHS)	Female	63	Asian Filipino
P9 (CHS)	Female	76	White British
P10 (CHS)	Female	26	White British
P11 (CHS)	Female	47	Ukrainian
P12 (CHS)	Female	36	Mauritian
*Note that codes have been used for participant confidentiality, see Method, 3.7 Participant confidentiality .			

4.7 Reflexive thematic analysis

SE is not prescriptive in its analytic approach, Pink (2015) claims that analysis is intertwined within the SE research process as the researcher continuously reflects upon experiences and is required to be analytical whilst carrying out the research. Nevertheless, Pink (2015) does explore the situated nature of the analysis process both spatially and temporally i.e. that analysis is typically carried out away from the fieldwork sites. Although Pink (2015) argues that

analysis is not a distinct phase in the research process, the iterative and reflexive approach that she outlines draws parallels with Braun, Clarke, Hayfield et al.'s (2019) reflexive thematic analysis. For the purpose of this project I engaged with a reflexive thematic analysis process (Braun & Clarke; 2006; 2013; Braun, et al., 2019; Terry, Hayfield, Clarke & Braun, 2017).

Thematic analysis is a method for identifying, analysing, and reporting patterns (themes) within data (Braun & Clarke; 2006, 2013; Braun, et al., 2019; Terry et al., 2017). Unlike Interpretative Phenomenological Analysis (IPA), Grounded Theory and other methods such as Discourse Analysis, thematic analysis is not bound by any pre-existing theoretical framework and so can be used flexibly (Braun & Clarke, 2006, 2013). Despite this it is important to note that reflexive thematic analysis is distinct from other thematic analysis processes. As Braun et al. (2019) suggest:

“Thematic analysis (TA) is often mis-conceptualised as a single qualitative analytic approach. It is better understood as an umbrella term, designating sometimes quite different approaches aimed at identifying patterns (“themes”) across qualitative datasets” (Braun et al., 2019: 2).

Within their recent work they identify three ‘schools’ of thematic analysis - “coding reliability, codebook, and reflexive” (Braun et al., 2019:1). Each ‘school’ is distinct meaning that they employ different approaches to coding, identifying themes and conceptualisations as to what a theme is. A reflexive thematic analysis (Braun et al., 2019) is contextual / situated and is underpinned by the concept that there are multiple realities i.e. one truth is not sought. Moreover, researcher subjectivity is

considered a resource and so the researcher is viewed as having an active role in knowledge production.

The reflexive thematic analysis process carried out within this cycle of study was guided by Braun et al., (2019) and thus driven by the data (Braun & Clarke, 2006, 2013; Braun et al., 2019; Terry et al., 2017). Analysis was an inductive non-linear process with themes under constant revision. Therefore, the approach moved beyond examining the semantic content of the data and sought to identify and examine underlying ideas, assumptions and conceptualisations. The development of the themes was interpretative, meaning that the analysis moved beyond description. Van Manen (1997) suggests that thematic analysis is not a rule-bound process but is a way of forming and creating meaning. For example, DeSantis and Ugarriza (2000) emphasise the ways in which themes are actively created by the researcher and do not passively 'emerge' from the data. My views and background, e.g. as a textile designer with an expertise in psychology, therefore shaped the analysis - this connects with the SE approach which emphasises the presence and influence of the researcher within the whole research process.

The interpretative approach to analysis employed the following phases, see **Table 5**. The table includes figures which illustrate the different techniques used i.e. working on paper and the use of NVivo (a qualitative data software package that can be used to support data analysis). The two methods involved in the analytic process i.e. carrying out analysis by hand and the use of NVivo, supported the iterative and reflexive analysis process and enabled me to continuously reflect upon and critically engage with analysis.

I first carried out analysis by hand. Ellingson (2017) claims that this process involves harnessing the materiality of analysis, whereby researchers interact physically with their data through e.g. highlighting, moving, cutting and pasting their data. I used hard copies of the transcripts and field notes, highlighting and making notes to create initial codes. I then transferred this process to NVivo (see **Table 5**, Phase 2) to securely store the work. I used the software's coding functions to create embedded links between codes, themes and transcripts and fieldnotes. I also used further techniques, such as creating mind maps to cluster codes together (examples of these can be seen in **Table 5**).

Table 5. Reflexive thematic analysis framework

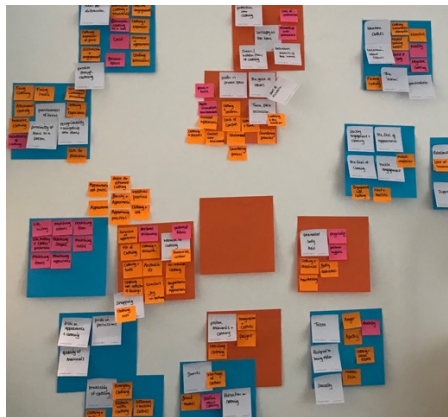
(adapted from Braun & Clarke, (2006, 2013), Braun et al., (2019) and Terry et al., (2017))

Phase	Process
Phase 1	Interviews and field notes were transcribed as soon as possible after each research encounter (e.g. the same week) and memos were written. The transcription process is considered part of the SE analysis process, as it allows the researcher to re-engage with the research encounter. Once all of the research encounters were complete and the transcriptions made, all of the transcriptions were then read and re-read to immerse myself in the data and further memos were written to use during the later analysis stages
Phase 2	Line by line coding was conducted and notes were made of any alternative codes. Coding means marking sections of the data and assigning labels or names (Holloway & Galvin, 2016). Line by line coding was done by hand on paper copies of transcripts and was then copied to NVivo, as can be seen in the figure below.

The screenshot shows the NVivo software interface. On the left, there is a list of codes (nodes) under the 'Name' column, with 'Files' and 'References' columns. The codes include: adopted clothing habits (1 file, 1 ref), aesthetic fit (1 file, 3 refs), anger (1 file, 1 ref), apathy (4 files, 5 refs), appearance (4 files, 6 refs), appearance not static or f... (3 files, 5 refs), appearance related practi... (2 files, 2 refs), appearance very important (1 file, 2 refs), Attachment to clothing (6 files, 19 refs), Beauty and appearance (1 file, 7 refs), bodily awareness (3 files, 6 refs), Brand names (3 files, 16 refs), care for possessions (3 files, 7 refs), Clothing and cleanliness (5 files, 8 refs), clothing and experiences (3 files, 3 refs), Clothing and expression (3 files, 5 refs), Clothing and fabric, texture (3 files, 6 refs), clothing and occasion (1 file, 1 ref), and clothing and sense of self (2 files, 5 refs). On the right, there is a 'Brand names' node selected, showing a 'Summary' and 'Reference' tab. The 'Reference' tab is active, displaying a transcript snippet: 'Gren...gren...', 'Mhmm yeah an', 'Wear it like a b show off ... oh same and ... I c er... I would ge and nice earrin', and 'At the end of Si I still have som'.

Name	Files	References
adopted clothing habits	1	1
aesthetic fit	1	3
anger	1	1
apathy	4	5
appearance	4	6
appearance not static or f...	3	5
appearance related practi...	2	2
appearance very important	1	2
Attachment to clothing	6	19
Beauty and appearance	1	7
bodily awareness	3	6
Brand names	3	16
care for possessions	3	7
Clothing and cleanliness	5	8
clothing and experiences	3	3
Clothing and expression	3	5
Clothing and fabric, texture	3	6
clothing and occasion	1	1
clothing and sense of self	2	5

-
- Phase 3 Initial themes were created through linking together similar codes to become themes. This was done by hand, as can be seen in the figure below.



-
- Phase 4 Themes were reviewed, this involved reading and re-reading initial themes, exploring any themes that did not 'fit' across the whole data set. These were negotiated, they were not discarded - they were re-considered to explore whether they conveyed a nuanced or divergent theme. This was done using NVivo to create mind maps as be seen in the figure below.



-
- Phase 5 Themes were renamed to convey the 'essence' or interpretative meaning of each theme.

-
- Phase 6 Writing up is the final opportunity for analysis. Extracts were selected to support the presentation of themes.

Thematic findings were separated into master themes and subordinate themes. The master theme represents the central concept or 'story' of the theme, whilst the subordinate theme connects with the concept or story but offers a different meaning and nuanced aspect connecting with the master theme.

The phases detailed above were carried out in the following three steps of analysis:

STEP 1: Data analysis care home staff: Firstly, I analysed data from care home staff using the reflexive thematic analysis framework (see above). See **Table 6** for the master themes and the subsequent subordinate themes.

Table 6. Thematic findings: Care home staff

Master Theme	Subordinate Theme
(1) Clothing as a symbol of care (1)	(1.1) Unseen aspects of care
(2) The feel of clothing and appearance	(2.1) The care home as a work place
	(2.2) Bodies in flux: Supporting and maintaining appearance
(3) Clothing as a tool for creative expression	(3.1) Clothing and engagement
(4) Clothing and possession attachment	

STEP 2: Data analysis people with dementia: I analysed data collected working with people with dementia using the reflexive thematic analysis framework (see **Table 5**). Master themes and the subsequent subordinate themes are presented in **Table 7**.

Table 7. Thematic findings: People with dementia

Master Theme	Subordinate Theme
(1) Bodily awareness: The feel of appearance	(1.1) Revealing / concealing the body (1.2) Practicality, cleanliness and mobility
(2) Clothing: The (Im)perceptible fit	(2.1) Embedded / habitual clothing practices (2.2) Situated clothing practices
(3) Everyday creativity and clothing: Clothing as vehicle for expression (active)	(3.1) Innate engagement with clothing (passive) (3.2) Stories told and facilitated through clothing
(4) Clothing attachment	(4.1) Ownership in the care home
(5) Clothing a tool to explore the unacknowledged (divergent)	

STEP 3: Synthesising thematic findings: Finally, I explored thematic findings together i.e. thematic findings: care home staff and thematic findings: people with dementia. This involved examining similarities and differences between the findings. Where thematic findings were underpinned by a shared concept, I combined the themes. Where thematic findings diverged the thematic findings were kept separate.

The multi-step approach to analysis aimed to ensure the lived experience of participants with dementia remained prominent within the findings. Analysing the data collected with care home staff and participants with dementia in isolation allowed me to focus on each group of participants experiences separately. I was

then able to explore where these experiences overlapped and mapped on to one another or where experiences differed i.e. where thematic findings did not combine and remained distinct. See *Reflexive note 4* which details the concerns that I had regarding the analysis process and how the multi-step approach attempted to address potential issues.

Reflexive note 4: Analysis process

Analysing the data separately attempted to avoid attending solely to participant verbatim. My past research processes have only used participant verbatim and I was concerned that I would tend to focus on what was said rather than what was 'not said'. This was particularly important for people with dementia. I was concerned that combining the whole data set i.e. care home staff and participants with dementia, may lead to concentrating on the experiences of care home staff. Data from care home staff typically followed clear structures and patterns of conversation whereas data i.e. verbatim and observational data from research encounters with participants with dementia, was 'entangled' - I often found it harder to decipher and explore meanings within this data. Thus, analysing the datasets in separation enabled me to attend to the experiences of care home staff and participants with dementia separately, to then critically bring findings together in. I think this strengthened the analysis process.

The collated thematic findings are presented in below **CYCLE 1 Findings**. Themes are presented as master and subordinate themes.

4.8 Findings

The findings presented here were formed from data collected with members of care home staff and people with dementia. Master and subordinate themes (see **Table 8**) are presented below alongside verbatim extracts from the research encounters, indicated by the use of speech marks (""). Observational notes are

included (in *italics*) to illustrate e.g. nonverbal actions, gestures, responses, in some instances these are presented as distinct extracts and, in some cases, observational notes are presented alongside verbatim quotes. Where necessary within the extracts I have added omitted words in [brackets] to support the reader's understanding e.g. if a participant missed a word in a sentence, without changing their meaning.

Identification codes have been used to ensure participant confidentiality, with accompanying brackets to signpost whether the participant was a member of care home staff (CHS) or a person with dementia (PWD) e.g. P1 (PWD) and P7 (CHS).

Within extracts staff refer to their experiences of working with residents in the care home setting: in some instances, staff explicitly recognise that the resident had dementia, in some cases they talked more generally about clothing within the care home. It was considered important for the research that such insights were valuable in giving an overview to clothing within the care home.

Table 8. CYCLE 1 Thematic findings

Master Theme	Subordinate Theme
(1) The (im)perceptible fit: The feel of clothing and appearance	(1.1) Bodies in flux: Supporting and maintaining appearance (1.2) Revealing / concealing the body (1.3) Practicality, cleanliness and mobility
(2) Embodied, habitual clothing practices	(2.1) Situated clothing practices
(3) Everyday creativity and clothing: Clothing a tool for expression	(3.1) Clothing and engagement 'in the moment' (3.2) Clothing and moments of respite
(4) Clothing and possession attachment	(4.1) Clothing and ownership in the care home
(5) Clothing a tool to explore the unacknowledged	(5.1) Clothing: An unseen aspect of care

(1) MASTER THEME 1: The (im)perceptible fit: The feel of clothing and appearance

This theme describes how both the physical aspects of clothing, including its appearance e.g. the texture of the fabric or the fit of an item of clothing, and the imperceptible aspects e.g. the extent to which a person felt happy in what they were wearing, impacted individuals. This applied to people with dementia and care home staff. The use of the word 'imperceptible' not only refers to the effect of wearing particular items but also highlights the ways in which clothing is not only something visual, perceived by the wearer and others, it is something that affects the wearer due to a multitude of factors, as illustrated in the below examples:

"I feel just comfortable in it. I like to feel comfortable in my clothes... I don't like anything sort of pouncy [flouncy] or anything like that." *Gesturing - she created large fluid movements as though surrounded by billowing fabrics.* P2 (PWD)

"I buy [size] 18 because I like room, I don't like to wear anything too tight." *She pulled her top away from her body demonstrating how 'roomy' it was. She used a wheelchair and so looser fitting clothes may have been more comfortable for her.* P6 (PWD)

"What I like best about it – it's different! It's different! You know usually materials are either flowers or leaves and this is sort of like abstract." P4 (PWD)

"Yes, everything is wrong! Yes! Everything! This is daily [for everyday wear]– this is, I don't know what and this colour is wrong." *She said as she pointed to her dark plum coloured top.* "You do not put that colour on in the

morning...you ...you put that colour in the morning – daytime, fresh.” *She pointed to a light duck egg blue colour on a poster in the room, indicating that the colour would be her preferred colour as it was ‘fresh’.* P3 (PWD)

P3 (PWD) also spoke of wearing the particular fragrances at certain times of the day. She brought two perfumes to one research encounter and described the differences:

“Now this is a fresh scent it’s [perfume name], which is very nice, it is fresh – you want to smell? It is heavy now you see and the other one ... [second perfume name] now this is a woman ahh - you see, you see it is different? It has more ...acidity I think ... more captivating, I don’t know.” *We passed the two bottles between us smelling each in turn.* “This is [for the] evening, and this is [for the] morning, morning - blue matin [morning] ... est c’était le soir [and this was for the evening].”

P3 (PWD) associated specific fragrances and colours with certain times of day, such preferences demonstrate how particular practices are embedded and impact much more than a persons’ appearance.

The notion that the ‘feel’ of appearance is important to individuals is important to consider in light of *Reflexive note 5* made in response to a participant seeing herself in a mirror prior to the start of a research encounter.

Reflexive note 5: Covering a mirror

There was a dressing table and mirror in the room and on seeing herself in the mirror she exclaimed. She was immediately uncomfortable, and I offered to cover the mirror with a towel, which she agreed to. We spoke for a while and began the research encounter once she was happy to. When talking about her outfit she was comfortable in her clothing and pleased with her outfit, despite being distressed at her appearance in the mirror.

Staff spoke in-depth about how clothing feels for many of the residents that they care for, and the ways in which their knowledge of different residents impacted how they supported residents to feel comfortable in what they wear. For example, one participant spoke of a visually impaired resident who had been advised to wear a fall detector pendant i.e. (fall detector pendants are wearable devices worn like a necklace that give off an alarm if the wearer falls over, see **Figure 14**).



Figure 14. Example fall detector pendant (Folio, 2018)

Staff spoke of how despite her visual impairment the resident would attempt to hide the device:

“She will put it inside.” She said, mimicking lifting up a scarf or opening a cardigan to hide it. “Then her own necklace or choker is on the outside... usually she is using a scarf... she doesn’t want anything hanging or showing.”
(P8 CHS)

Additionally, P12 (CHS) spoke of how heavier clothing supported an individual to feel comfortable:

“She is always cold and wants to wear heavier materials.” P12 (CHS) gestured to her top and her skirt, both made from a light jersey, and lifted them letting them fall through her fingers to demonstrate the lightness of the fabrics – “Not like these. She wears at least three layers of clothing despite

the season. I think the layers of clothing make her feel comfortable.” P12
(CHS)

The above examples demonstrate the ways in which wearing particular items of clothing seemingly evoked feelings of either discomfort or comfort, familiarity and security for residents. The theme **(1) The (im)perceptible fit: The feel of clothing and appearance**, focusses on the ways in which clothing affects people with dementia, both tangibly through the physical sensation of wearing particular items of clothing and imperceptibly through the affective impact that wearing or not wearing particular items of clothing can have for the individual. Rather than focus on the visual, the theme focusses on how clothing and appearance feels for both staff and residents. This connects with the subordinate themes, **(1.1) Bodies in flux: Supporting and maintaining appearance**, **(1.2) Revealing / concealing the body** and **(1.3) Practicality, cleanliness and mobility**.

(1.1) SUBORINDATE THEME: Bodies in flux: Supporting and maintaining appearance

The theme **Bodies in flux: Supporting and maintaining appearance** explores the ways in which the body is not a fixed or static entity and the impact that this can have on clothing and appearance needs within the care home. Moreover, the theme examines changes to the ageing body, as participants talked of difficulties associated with recognising and understanding such changes. For example, on respective instances two female participants talked of being able to feel facial hair and the want to remove it as it did not feel ‘right’:

P4 (PWD) stroked her chin and seemed to notice hairs on her chin which she asked if I could see. She explained that they felt prickly. She then proceeded

to try hold on to them and pull them out. P4 (PWD)

Touching her face whilst talking P6 (PWD) said: "I have got a long hair here...see it? Just there darling - I don't how it has got so long... I was pulling it and it hurts." P6 (PWD)

These mundane, small aspects of body modification e.g. personal grooming, represent an intuitive notion of how the body should feel, a further example of which was a participant who was wearing nail varnish:

"The girls put it on me - I was sitting there the other day and they were putting it on a few of us. It is not that I like wearing nail polish and I have been trying to pick it off. I'd rather someone to do it with the... to clean." She wiped her fingernails as though trying to clean them. "I don't like it. I just don't like nail polish. I never wear polish and I've been picking at it and now it isn't nice..." P2 (PWD)

Alongside mundane aspects of personal grooming, participants discussed more overt physical changes to the ageing body. Staff explained difficulties associated with residents needs changing during their time living in the care home e.g. the transition to permanently using a wheelchair. For example:

"Her chair was very uncomfortable and it got to the point where she couldn't really wear waisted – she liked skirts but they were not actually... a djellaba⁵ type of thing would be good...she couldn't wear shoes and she couldn't wear slippers so we made knitted in-between socks." P9 (CHS)

⁵ A djellaba is a long, loose-fitting robe with full sleeves.

“Stretch fabrics are best, especially for people with advanced dementia who may find it difficult to co-ordinate their hands and arms as we have to help them with the movement. Also, we have to be careful with their skin care as if they are dehydrated this affects their skin and then tight clothes, or clothes difficult to put on, can hurt them.” P12 (CHS)

Communicating, adapting to, and enabling a resident to understand and accept changes to their body seemed particularly challenging to navigate for staff. For instance, staff spoke of the different strategies that they used to support residents who often did not understand and struggled to adjust to their changing body. For instance, P8 (CHS) talked of how she would show residents items of clothing in order to support understanding:

“The bra sometimes they want to wear it but sometimes...err...because they are you know wearing the wired bra, to explain to them that some boobs are bigger than the bra...” *She demonstrated that she would show the person the bra and show where the wire would dig in to their body and hurt them.* P8 (CHS)

A further concern discussed by staff was a resident’s ability to use the toilet independently. In some instances, certain items of clothing supported independence, for example:

“This resident wanted to go to the toilet independently and had difficulty undoing the trousers and the zips so he preferred jogging bottoms which have got elastic and so he could just drop it down and use the toilet independently and pull it up no fuss.” P7 (CHS)

Yet, there were also cases of tensions between staff's judgement of a resident's level of independence and the person's own perceptions. This was particularly sensitive when it came to the type of underwear a person wore. For example, in many instances staff expected residents to wear incontinence underwear:

"Sometimes with the pads they say that it is uncomfortable...They will tell you, "I can still go to the loo"...I will just explain it is in case - because of your mobility it is less than before...By the time you will be there you will be dripping wet so we don't want your knickers to be wet." P8 (CHS)

The tension between staff's duty of care and a resident's wishes, including the extent to which the resident felt comfortable was highly dependent on each individual. Where one person may not want to wear the incontinence pad, another person may feel reassured wearing them.

As demonstrated in the above examples, clothing can be a tool with which to support change, to communicate change and to empower and enable someone to retain their independence. Moreover, mundane aspects of maintaining appearance e.g. supporting people to remove facial hair or supporting someone to remove their nail varnish can be important in enabling individuals to feel 'right' and comfortable.

(1.2) SUBORDINATE THEME: Revealing/concealing the body

The subordinate theme **(1.2) Revealing / concealing the body** explores how the clothed body feels. This theme is nuanced as it refers to participants preferences about their bodies and their agency e.g. through their want to exert control over their appearance. The type of clothing worn, and the fit of the garment(s), were important

in covering the body and supporting residents to feel comfortable, for instance, P2 (PWD) demonstrated her discomfort at wearing a low scooped neck t-shirt:

“Well I don’t feel that comfortable in the shirt because the neck seems...I don’t like these dropping necks ... and I feel I want to pull it. I am doing this all the time to straighten it out.” *She pulled the t-shirt higher around her neck.* “I don’t want to choke myself with it... this is about right ... that feels about right...”

Throughout the research encounter the top slipped down making it lower and exposing more skin.

Whilst, P12 (CHS) talked about a resident who preferred to wear trousers:

“She told me that she feels naked in a skirt, she always wears trousers.”

In contrast, P1 (PWD) expressed her frustration at being prevented from leaving her bedroom when wearing only a shirt:

“I have tried and failed to leave not this room but the one behind us, wearing a slightly longer shirt than this at one time...slightly longer...mmmm... it was probably about the same length...” *She looked down, pulling at the hem of her shirt that fell at her waist and said:* “But anyway [my] legs were sticking out and it was too much for them!” P1 (PWD)

P1 (PWD) also talked of being prevented from being naked on a hot day:

“You [referring to herself] are close to naked as they will let you get - it is just my t-shirt and my skin!” *She pulled her top away from her body and looked down her front, seemingly checking whether or not she was wearing a bra.* *The room we were using was stiflingly warm. The vinyl covered chairs*

exacerbated the heat and the air was thick and heavy - the research encounter was curtailed because of this.

The naked body in the care home highlights complex tensions regarding agency, privacy, sexuality, vulnerability, and choice. For example, P12 (CHS) explained that when a resident first arrived at the care home, she found personal care very difficult:

“When she first came here, she would stay in the same clothes day and night and she would say that when someone helped her with her personal care, like removing clothes and showering, it was like rape. “I feel raped” she would say. So, I make sure no male healthcare assistants help her”.

P12 (CHS)’s account demonstrates the potential distress caused when being supported with personal care and highlights the power imbalance that can occur i.e. the naked resident and the clothed member of staff. Nakedness is typically associated with intimate, sexual relationships and as Twigg (2003:150) claimed, nakedness in personal care “breaches some of the most profound of social expectations, requiring people to cope with new situations”.

(1.3) Practicality, cleanliness and mobility

This subordinate theme **(1.3) Practicality, cleanliness and mobility** explores the ways in which participants experienced practical issues connected with their clothing. The following examples demonstrate participants’ varied clothing preferences. For instance, P4 (PWD) spoke of always needing to have pockets, notably she often carried lots of belonging with her, precariously balanced on her Zimmer frame:

“I always have pockets because I put everything into my pockets – what do they say? - She has got something in her pocket – She has got a rocket in her pocket!” P4 (PWD)

Similarly, P1 (PWD) discussed the importance of pockets:

“I am so overwhelmed with the joy of having them on - I do like them because they have pockets” *She said this as she plunged her hands into her pockets.*

Whilst, P2 (PWD) explained that clean clothes were important to her:

“It is clean. It is important to me to have clean things on, I don’t like stains or anything on my clothes.” P2 (PWD)

P3 (PWD), similarly, talked of the importance of wearing clean clothing but went on to discuss personal care and how she sprayed perfume in her underwear to mask the smell of urine:

“Always clean except now when you are 89 you pee pee - you always have to re-change now what I do is I put a serviette that doesn’t come out to pee and put toilet paper on and put perfume on - not on the side... because you can create an infection... the less the better... then you throw it away.” P3 (PWD)

P3 (PWD) demonstrated the importance of wearing the correct footwear in order to support her feet:

“These are the socks and shoes that I wear that are comfortable for my feet they must be properly protected... Especially Pisces [zodiac sign] always the feet ... Yes, the weakest point the feet - yes because of the fish, the tail.” *She put her hands together and moved them, imitating a fish swimming through water, as her hands swam, she whistled.* P3 (PWD)

Mobility was not only mentioned by P3 (PWD), P5 (PWD) spoke of her shoes not being comfortable, and although not explicitly articulating that her shoes were too big, she suggested that she and I swapped footwear:

“Yes, and the pink shoes they don’t really cover anything”. She wriggled her feet in her shoes which gaped, when moving her feet one of her shoes slipped off a little – wriggling her toes she tried to get the shoe back on ... “No, that is quite uncomfortable!” She said, as she tried to put the shoe back on her foot. At the end of the research encounter I offered to walk with her to the lounge as we walked, she complained about her shoes not having laces saying that she thought that we should swap (I was wearing laced boots). Her shoes seemed too big, they only stayed on because she moved slowly, shuffling, only lifting her feet slightly off the floor. P5 (PWD)

Not only were practical considerations and strategies voiced by people with dementia, care home staff similarly spoke of decisions that they made when considering their clothing. For example, P7 (CHS) discussed the way in which, despite her managerial role, she often had to be “hands-on” with residents and that this determined the clothing that she selected to wear to work:

“I wouldn’t necessarily put something on that has got all the beads or it’s got all those, I don’t what they are called but all those other materials” - She motioned, seeming to represent tassel like embellishments that may hang low on a top or skirt... “Where it might sort of harm the residents if I am supporting them ... I am very conscious about those things - we might be required at any level to support a resident”. P7 (CHS)

P7 (CHS)'s careful consideration of her clothing, demonstrated an empathic and embodied understanding of what her job required and the way in which her clothing could hinder her ability to support residents.

This theme highlights mundane aspects of clothing preferences and connects with the master theme **(1) The (im)perceptible fit: The feel of clothing and appearance**, the examples presented, demonstrate the ways in which small aspects of clothing and appearance can be particularly important for individuals.

(2) MASTER THEME: Embodied, habitual clothing practices

The master theme **(2) Embodied, habitual clothing practices**, is defined as enduring clothing habits. Such practices could include e.g. the specific way in which clothing was worn e.g. rolling sleeves up, tying a scarf in particular style, wearing certain pieces of jewellery. The extracts presented typically focus on participant's nonverbal actions and gestures. For example, P3 (PWD) wore her scarf in a specific style:

"Ah the scarf always, always a scarf! You have many scarves big ones, small ones ... over the years you... you buy something not just to buy just think and this is what happens - this one, second-hand...not second- hand...synthetic darling. But it is so cute, it is fresh, it is young and then you can put it here."

She untied the scarf holding it out, examining it but as she went to tie it in place, she seemed to find it difficult to know where to start. At the end of the research encounter she realised her scarf remained undone and innately knotted her scarf around her neck. Her hands knew the well-trodden path of creating the perfect bow. She didn't say a word on tying her scarf. It was a swift natural action that was not for the benefit of the research, but for herself.

As demonstrated in the above example, P3 (PWD)'s tying of her scarf was embodied and habitual, her hands knew how to tie her scarf intuitively. This demonstrates retained procedural memory i.e. the long-term memory that is responsible for knowing how to do things. Similarly, P5 (PWD) always wore bangles, notably these changed regularly, and it seemed the feel and sound of wearing the bangles were important for her (rather than the specific items). During a research encounter she noticed some bangles on the table in the Namaste room and wanted to put them on, yet struggled to, getting her fingers and thumb stuck and so she was unable to slide them on to her wrist. I offered to show her:

Rebecka: "Shall I show you?"

P5 (PWD): "Ok"

Rebecka: "So, if you tuck your thumb underneath your hand like that". *I showed her, tucking my thumb under my hand so that it touched my palm, keeping my fingers together and sliding the bangle over my hand and onto my wrist.*

P5 (PWD): "Yes, oh I see ok ... I understand what you are doing, yep." *She tried again but wasn't able to put the bangles on, she instead placed the bangles on the table.*

Rebecka: "We can leave them there or you can keep hold of them" ...

P5 (PWD): "I don't want to lose them."

The research encounter proceeded, and after a few moments she picked the bangles up and instantly slid them onto her wrist - seemingly without thinking about the action. She did not say anything about putting them on. The sound of the metal bangles clinking together was heard throughout the rest of the audio recording.

The notion of embodied, habitual clothing practices, was discussed by P10 (CHS) who drew upon her own understanding of what it feels like to habitually wear something when she explained a gentleman's experience of losing his watch:

"He was a bit misplaced that he didn't have his watch...he can look [at] and touch his watch quite a lot and I wonder if... I know people can experience this if they don't have dementia, but I wonder if he also wasn't sure about the feeling of it not being there." *She held her wrist as though holding an imaginary watch.* "Because he is used to feeling it on his wrist." (P10 (CHS))

P10 (CHS)'s articulation of how it can feel to not wear something that you typically wear every day, demonstrated an empathic embodied response to the resident's sense of misplacement. Furthermore, when volunteering I observed a care home resident engage in embodied, habitual practice (see *Reflexive note 6*).

Reflexive note 6: Embodied clothing practice

I volunteered to help with an outing to a local garden / café and whilst sitting with residents, I became aware that one woman had started to unbutton her cardigan. We were sat outside; the café was quite busy, and I was worried that she may be undressing. She was quiet in her actions - she didn't seem uncomfortable or upset as she unbuttoned her garment, once it was all unbuttoned, she then began to rebutton it. I walked over to sit near her and as I approached, I realised that the cardigan was missing a button – her repetitive actions suggested that this felt wrong and she seemed to be (repeatedly) trying to correct it.

The examples of embodied, habitual clothing practices demonstrate the ways in which certain clothing practices are embedded and support a person's sense of self through maintaining specific aspects of their clothing and appearance. In some cases, wearing a specific item was important to the individual, yet in other cases it was the feel (and sound) of wearing specific items that was important i.e. the

sensation of wearing the watch, the feel and sound of the bangles. Moreover, not wearing an item or (in the case of *Reflexive note 6*) an item feeling wrong was important to individuals with dementia and affected their actions and behaviour.

(2.1) SUBORDINATE THEME: Situated clothing practices

It can be argued that each of the master themes and subordinate themes are context specific and emplaced i.e. situated within the care home. This subordinate theme offers a nuanced exploration of clothing practices that have been adapted or adopted, seemingly as a result of living in the care home. For example, P6 (PWD) discussed wearing a fall detector pendant. A member of staff had explained to me that fall detector pendants were not given to all residents, only those who may be 'at risk' of falling or who may have recently had a fall. Despite this it was P6's (PWD) understanding that everyone in the care home wore them:

"They gave it to everyone, everyone has one... This is my second one because sometimes I forget to wear it and some people sleep with it but when it goes off - it is like hell to remember how to do it [turn it off]." P6 (PWD)

It seemed to be important for P6 (PWD) that all residents wore the fall detector pendants. Similarly, P5 (PWD) reflected that her clothes were comparable to other residents', situating herself alongside other residents in the care home:

"I think that my clothes are on par with everyone else that is in the same position as me ... well here and nearby here... not everybody has big earrings and things like that, so you have to counter that in." P5 (PWD)

I was wearing large resin hoop earrings that the participant had talked about with me earlier in the research encounter. She seemed to insinuate that she did not need to think about wearing jewellery like mine, as other residents did not.

Much like P5 (PWD), P3 (PWD) distinguished the care home from other places when, during a research encounter, she commented on the shoes that I was wearing:

P3 (PWD): "And the shoes, beautiful - very nice and they are wasted here."

She said, as she pointed to my bronze coloured boots.

Rebecka: "Wasted here?"

P3 (PWD): "Yes, you should keep them for some smart place darling."

The above examples demonstrate something of an unspoken 'uniform' within the care home. Interestingly, staff spoke of creating their own uniforms, when discussing their clothing choices in the care home, for instance:

"It can be very hot on the floor as we have no air conditioning and the windows only open a little bit for safety reasons. For residents it is ok, but for us it is very hot as we are always moving...Also when you give someone a shower it is very hot in your clothes. [But clothing] has to be appropriate and covered and not open, as we are at work. You can't be half naked."

She motioned as if she were wearing a strappy or sleeveless top. P11 (CHS)

Similarly, P7 (CHS) who was a team manager talked of ensuring that her staff looked professional:

"Any kind of t-shirts with logos ... you know like "sexy" "babe" or anything like that, we don't accept that because we just want to be [professional]." P7 (CHS)

P7 (CHS) explained that healthcare assistants received funding each year to purchase clothes suitable for work. Thus, highlighting the complexity of the care

home as a place of work and also as the residents' home. This subordinate theme **(2.1) Situated clothing practices**, focusses on how the care home affected both residents and staff's clothing implicitly creating clothing norms within the home and something of a uniform - one for staff and one for residents.

(3) MASTER THEME: Creative use of clothing: Clothing a vehicle for expression

The theme **(3) Creative use of clothing: Clothing a vehicle for expression** explores how clothing was used by both, staff and residents, as a form of every day creativity, this draws on the notion of little-c creativity and creative expression as presented in the **Introduction, 1.4 The arts, creativity and dementia**. Many of the examples presented highlight small moments and interactions between members of staff or residents with theirs or others' clothing. For instance, clothing was used as a form of protest by P1 (PWD) who did not want to be in the care home:

P1 (PWD) showed me that she kept clean pairs of knickers in the bag on her Zimmer frame. "Yes, that is what it is – knickers. Yeah which others which have the skins fetishes they don't want me to have knickers anywhere in sight ... It is in their heads, they are offended by knickers in general so these are more or less visible and if anything terrible such as my taking a pair out and putting it on the dining table that I am sitting at, at the time, hysteria breaks out..."

Clothing was also used to indicate movement between spaces in the care home, for example:

P4 (PWD) instinctively removed her scarf on sitting down for the research encounter – it was an intuitive action and seemed to signal moving to a

different space. We had walked together from the lounge to the room for the research encounter.

Similarly, on numerous occasions respective participants spoke of altering their appearances (including clothing) prior to leaving their bedroom to join a research encounter. Practices included, putting on lipstick P3 (PWD) and P6 (PWD), brushing their hair P6 (PWD), putting their shoes on P6 (PWD), and changing their outfit P1 (PWD) and P6 (PWD).

Additionally, P3 (PWD) used perfume to seemingly 'mark' a space at the end of a research encounter:

As we got up to leave the Namaste room [used for the research encounter] P3 (PWD) sprayed perfume into the air. The room was hot, and the scent lingered. As we left, she said that this was so "people remembered", she then carefully placed the perfume in the bag on her Zimmer frame.

In a different form of expression, staff spoke of residents expressing themselves through undressing. For example, staff talked of a gentleman who would repeatedly take his trousers off:

"Whenever somebody put on the trousers, he would undo it and then try to get it off. It took a very long time to understand the whole concept behind it because this resident wanted to go to the toilet independently." P7 (CHS)

The above examples demonstrate the way in which clothing (and perfume) may be used as a form of expression for residents. This could be considered particularly meaningful especially where verbal expression may be difficult for residents living with dementia. A further example was discussed by a member of

staff who talked of knowing a resident well and because of this perceived the person's actions as a form of sexual expression. Yet, her acknowledgment that the resident did not want to live in the care home could also suggest that her actions were a form of protest:

“She has started to take her clothes off in the communal areas, I think it is because she is younger than the other residents and it is to do with her sexuality...maybe she missed out on things in life...she doesn't want to be here and doesn't like being here.” P12 (CHS)

Interestingly, the use of clothing as a vehicle for expression could be said to be reliant on the staff's ability to interpret what that person may be expressing at that time. In cases where residents undressed, staff acknowledged that the act of undressing was a tool with which the resident could express themselves e.g. whether that be the wish to change a specific item of clothing, or something more nuanced and complex such as their sexuality. This is important as Joller, Frank, Gibson et al. (2013) note a lack of clothing or wearing inappropriate clothing is not necessarily a sign of sexual disinhibition (a behaviour symptomatic of dementia) although it is often perceived as such. It is important to highlight that the members of staff who discussed these respective instances were experienced - one a team leader and one a team manager - and so perhaps their experience and knowledge of the respective individuals enabled them to form such insights.

In summary the theme **(3) Everyday creativity and clothing: Clothing a vehicle for expression** is multifaceted and examines the varied ways that participants used clothing to express themselves.

(3.1) SUBORDINATE THEME: Clothing and engagement 'in the moment'

This theme draws upon **(3) Creative use of clothing: Clothing a vehicle for expression** and highlights how clothing was used by both care home staff and residents to create informal moments of engagement and social interactions that were distinct from task-oriented discussions. These casual, often intuitive, forms of engagement demonstrate how clothing, accessories and appearance can be a unifying tool for people to communicate and engage at different levels, both verbally and nonverbally e.g. sensory engagement through touch. For example, staff talked of residents initiating interactions and touching their clothing or hair:

“She often looks at pattern or colours on my clothing and she often wants to feel my hair – she often wants to touch my hair. I think appearance in general is something that she is interested in and initiates conversation quite a lot.”

P10 (CHS)

“When wearing bright clothes or flowery and colourful clothes residents give staff compliments – it makes them and us happy.” P11 (CHS)

Staff talked of the ways in which they initiated positive moments of engagement with residents surrounding their clothing and appearance.

“One of the things, particularly here, is greeting people wherever you go you are always greeting people. So, one of the things I always do is say, “Oh you look lovely today ... your hair is really nice or oh what a lovely blouse you are wearing or oh that colour suits you”. And how you just see somebody's face change... They respond and that can be somebody who doesn't... who perhaps doesn't have good communication or perhaps is asleep a lot.” P9

(CHS)

“Quite often [you] can distract someone who is often quite anxious and going on and on about something, but you can usually alter it, quite often about clothes.” P9 (CHS)

Engaging with a person with dementia through their clothing could, as indicated by accounts from staff, provide positive ‘in the moment’ interactions. Such positive moments were expressed by participants: for instance, on examining my resin ring and trying it on P1 (PWD) recited a rhyme from her childhood:

Rebecka: “That is wonderful - could you translate it for me please?”

P1 (PWD): “This is wonderful, oh this is getting more difficult that is why it is wonderful! [participant’s name] behave yourself!”

She had put my ring on her thumb and then said the rhyme. “Oooft!”

She moved my ring between her fingers as she translated the rhyme.

“This is the thumb that shakes the plum tree, this one picks it up - a lot of plums have fallen down - and this one is ...these fingers are still fairly strong drags the plums home and this one smaller and smaller - darling baby one eats them all!” P1 (PWD)

Such momentary forms of engagement seemed to be uplifting and supported being with the person(s) with dementia ‘in the moment’ rather than, for example, asking the person to draw upon past thoughts and feelings that may prove difficult to recall. Engagement with clothing can also support nonverbal interactions e.g. gesture, touch, and so can be particularly meaningful for those who may struggle with verbal communication.

(3.2) SUBORDINATE THEME: Clothing and moments of respite

The subordinate theme examines the nuanced ways in which clothing and accessories provided opportunities for sensory enjoyment, distraction and ‘respite’ from the care home. The theme draws upon Harnett’s (2014) notion of ‘interactional respite’ whereby participants created moments of distraction and respite from institutional settings. For example, P10 (CHS) spoke of the ways in which residents adopted certain pieces of furniture within the lounge as their own, and noted that this enabled them to feel secure in communal spaces in the care home:

“That is where they usually sit and make out that it is like their possession, it is not, but it is just where they have chosen to sit but I think the routine with where they sit I think that helps gives them a sense of stability ... I think that it makes them feel placed.” P10 (CHS)

Seemingly mundane observations such as this demonstrate how residents spend time in and interact with their immediate environment, appropriating items. The appropriation of such items could be said to conceptually move the items outside the realms of the institutional setting, as they become something that ‘belong’ to the resident. Similarly, clothing was used creatively to provide respite, through engaging with the tactile qualities of specific items and therefore providing moments of distraction:

“When she is not occupied and then she’ll be quite tactile with her hands with her jumper or be playing with the bangles on her wrist.” P10 (CHS)

When working with participants with dementia I similarly found that items within a participants’ immediate vicinity provided moments of respite through sensory engagement:

She stroked the lining of her coat repeatedly. She fiddled with the materials of her clothes, her sleeves and the hem of her jumper as we spoke. P4 (PWD)

P5 (PWD) repeatedly rubbed the bobbled texture of her jumper, which she described as: “Grey, and it is generally looked at as something ... interesting combination... because of the spotted glass... the spotted erm ...the spotted these things... the spotted material...”

Moreover, clothing and accessories enabled participants to keep small items e.g. loyalty cards and business cards, close to hand, for instance:

I went out of the room to get a drink for the participant and she started looking through her handbag, when I came back into the room, she had found a loyalty card for a club that she used to go to. P6 (PWD)

Much like P6 (PWD), P1 (PWD), kept her business cards in her pocket, this seemed to provide respite from the care home setting:

“I mean it is hell living here, in this place, in this particular building, but” ...

She reached into her pocket and said: “Having pockets means that I can carry my business cards.” P1 (PWD)

Thus, the items within a persons’ immediate vicinity were important and often provided moments of respite, through what they symbolized e.g. a sense of identity (business card, loyalty card), ownership, and through tactile engagement.

(4) MASTER THEME: Clothing and accessory attachment

The theme **(4) Clothing and accessory attachment** highlights the attachments that residents formed to particular items of clothing and small items of dress e.g. accessories such as handbags, jewellery and watches. Over the course of

the research encounters (approximately twenty weeks), I became accustomed with specific items of clothing or accessories that participants typically had with them. For example: P1 (PWD), always had her small rucksack in the bag on her Zimmer frame, whilst P4 (PWD) (who often carried multiple items with her) had a large handbag precariously placed on the top of her Zimmer frame. P2 (PWD) had a scarf tied to her walking aide. Similarly, P6 (PWD) and P3 (PWD) wore the same items of jewellery (multiple bracelets and rings). Notably, P5 (PWD) always wore bangles however they were not always the same bangles, thus suggesting that it may have been the sensation of wearing and hearing the items (as they clattered together) that was significant to her. This may link to the earlier theme **(1) The (im)perceptible fit: The feel of clothing and appearance**. In some instances, participants acknowledged that they always had specific items with them:

“I have this coat with me everywhere I go because I am freezing, I like this - the shape, keeps you warm” P4 (PWD)

P2 (PWD): “Well this scarf ... it belonged to a carer here who’s now gone. Left. And because of that I keep it here because she gave it to me...It is one of those things and it was a sort of present and I keep it with me. So, it is on there all the time, they all fiddle with it.

Rebecka: “Other residents?”

P2 (PWD): “Yes... But I don’t care because it is not coming off as far as I am concerned.” *The scarf was tied to the handle of the participants’ walking aide, and when she held on to the aide, she touched the scarf.*

P2 (PWD) talked of not wanting other residents to remove the scarf, seemingly wanting to protect the attachment item. Similarly, participants also discussed a wish to repair and preserve their attachment items:

“I need to sew it I didn’t notice it - today I noticed it. I am very sorry that this happened.” P4 (PWD)

P3 (PWD) spoke of how she had repaired her bracelet in the past, in the research encounter she showed me the stitches that held the bracelet together:

“Look at how beautiful it is inside, outside. Yes, yes threads because it was not proper, I did not want it to [break] ... I sewed it with a bit of thread. It is solid.” P3 (PWD)

Additionally, staff recognised that residents were often attached to specific items. P12 (CHS) suggested that the use of the handbags by residents was habitual and acknowledged the significance of handbags to residents, for example:

“Handbags are very important to female residents – even in advanced stages [of dementia]. It is something that belongs to them... Their room is like their home and so when you leave home you always take your handbag with you - you always need your handbag. It is a sense of habit. They don’t hold much but they always have them.” P12 (CHS)

Similarly, P9 (CHS) spoke of residents’ concerns at not knowing where items were:

“His hat, he always has got to have his hat on... he always has got to have his cap on. “Is my cap in there...is my cap in there?” It is funny how things are ... it is a bit like a woman’s bag... isn’t it? ... “Is my bag there? Is my bag on the back of the trolley [Zimmer frame].” P9 (CHS)

Clothing and accessory attachment items were typically in close proximity to participants and were recognised by members of staff as being important to individuals. The items seemed to provide a sense of familiarity, comfort and security. Yet, there was also an underlying sense of vulnerability surrounding possessions in the care home, this is discussed in the following subordinate theme.

(4.1) SUBORDINATE THEME: Clothing and ownership within the care home

This subordinate theme examines the ways in which participants presented concerns around the location of their clothing. Staff often spoke of residents' distress and fear of losing particular items e.g. residents were sometimes reluctant to send items to the laundry:

“Some residents are very attached to their clothing – “Where is my shirt?” their attachment with their clothing is difficult when it comes to the laundry, they don't want their clothes to get washed.” P8 (CHS)

Another member of staff spoke of a resident who would purposefully put her clothing back in the wardrobe, despite it being soiled, so as to avoid her clothing going to the laundry. Residents fear of misplacing items and losing items of clothing and accessories was referred to as problematic by staff. Although not explained in detail, staff spoke of laundry being collected and delivered to each floor of the care home, with the items laundered in the basement of the care home.

Participants with dementia talked about particular items of clothing being lost or stolen. For instance, P6 (PWD) spoke of trousers that she thought had been lost:

“My red [trousers] are Marks and Spencer’s ... got lost and they keep telling me – “Oh you’ll get them back you’ll get them back” – get them back my foot!”

P6 (PWD)

Whilst P4 (PWD) spoke of a coat that she presumed had been stolen:

“I used to have another one and it was stolen - it was much lighter, lighter not in colour... in... in heaviness or whatever you call it...” *She lifted her coat up and down, demonstrating the weight of the material.* P4 (PWD)

Similarly, P1 (PWD) explained the ‘hidden’ laundry process:

“Because there has been such a chopping and changing here as to what goes in or out of the drawers which they, whoever they are.... So, I was quite grateful that there was anything in there that I could recognise. You have no idea when they might be taken away.”

Rebecka: “Ah taken away... where would they go?”

P1 (PWD): “That I don’t know, they can’t go on their own obviously, but they might wind up in the laundry.”

Whereas, P5 (PWD) talked of the joy at finding bracelets that she thought were lost:

“Well I was quite pleased that I found my bangles, always nice to find something isn’t it ... and I haven’t done very much today at all...” P5 (PWD)

Although not a specific example of a clothing practice, P1 (PWD) when talking about her clothing, often spoke about a need and want to be in control of her body:

“At other times they wanted to do other things really... other things that I said that they must not, could not and should not. They wanted to take my blood pressure and I said no you can’t, it is mine!” P1 (PWD)

Each of the above extracts depict a sense of vulnerability and lack of control in the care home, with participants’ uncertainty around the location of their clothing and possessions highlighting a lack of agency within the home. Furthermore, this theme identifies tensions between the needs of individuals and the institution e.g. mass laundering processes and individual’s needs e.g. knowing where their belongings are.

(5) MASTER THEME: Clothing: A tool to explore the unacknowledged

This master theme examines the ways in which clothing was used by residents to explore potential unseen and unacknowledged aspects of life in the care home. As discussed within the literature review (Entwistle, 2015) clothing can be considered an extension of the self, used to portray and indicate aspects of a person’s identity. This theme could be said to highlight the opportunity that clothing provides to explore specific topics, as during the research encounters participants discussed issues around e.g. sexuality, youth and ageing. Clothing often prompted discussions around life events, relationships and occasions. For example:

P4 (PWD) spoke of relationships: “But you get older you just quieten down - ç’est finis [it is over], it is not exactly ç’est finis ... I could still have boyfriends if I want to, but I don’t because men drive you up the wall.”

Whilst P1 (PWD) talked of finding a resident in the care home attractive:

“She is beautiful and there is no escaping being born with a bone structure like that so whenever anybody sees her, they’re like oh I’d like a bit of that...

Yeah, she is one hell of a good-looking woman.” P1 (PWD)

Moreover, P12 CHS talked of a resident in the care home who was very private about their sexuality and did not discuss this with residents or staff, however she felt that the way that they used particular items of clothing and accessories subtly expressed their sexual identity. Although there is not space here to discuss the significance of sexuality / sexual relationships within care home settings and the potential connections with clothing, these examples demonstrate that clothing can provide a tool with which to explore a person’s identity and intimacy needs.

A further nuanced example of how clothing was used as a tool to explore the unacknowledged was how participants compared themselves to staff, other care home residents and visitors, and reflected upon their own appearances. For example, participants often made reference to my appearance:

“You have nice legs; some people have a thick ankle, you don’t.” P3 (PWD)

“You are tall and very pretty...Because I was very pretty a few years ago! Not now – don’t look at me now.” P4 (PWD)

These moments highlight the divide between younger and older bodies, and the negative associations residents made about older bodies e.g. thick ankles, no longer being pretty. (see also *Reflexive note 7*).

Reflexive note 7: Comparing ages

Over the course of the research and during my time volunteering participants often talked about how young I was, including how lucky I was to be young. They often talked about my appearance, clothing and the jewellery that I wore. These instances were often difficult to navigate, although participants and residents alike were quick to give compliments, they were often veiled in negative perceptions about their own appearance, status and 'position' in the care home.

(5.1) SUBORDINATE THEME: Clothing an unseen aspect of care

This subordinate theme connects with the master theme **(5) Clothing: A tool to explore the unacknowledged**, as it underpins the notion that clothing was a route to unknown knowledge e.g. clothing offered insights into unseen aspects of care. This theme focusses specifically on staff experiences, exploring the multiple mundane tasks involved in supporting and caring for residents e.g. helping to pair a resident's socks or finding misplaced items. Despite these tasks seeming unimportant, staff explained that they were a significant part of care. The following extracts demonstrate the various strategies employed by staff when supporting residents dressing in the morning:

"[She] will try on maybe six tops before choosing what she will wear in the morning. She often comes back to a top that she said she didn't want to wear. Appearance is a must for her." P7 (CHS)

"You know they even tried to show her [by pointing] out of the window - [that] it is very cold and that the clothes are not warm enough for you because it is flimsy." P7 (CHS)

“Even if the resident says: “Oh darling you can get it for me” We would say “Well what you like to wear?” If they say you can get anything for me... I don’t think that staff would go and pick something randomly, that is inappropriate they would go: “Ok it is a bit cold today so let me put something nice and warm”. You know so something like a full sleeve not like a half sleeve or something... “You know it is about working with the resident, you know at the end of the day so the clothing the we have picked, or they have picked, is appropriate and that they feel comfortable in it as well.” P8 (CHS)

Supporting residents to choose their clothing was often described as a lengthy process, however such support is ‘unseen’ and not apparent in a person’s appearance i.e. their outfit. This is significant as clothing was considered to be a visual representation of the care that residents receive and associated with e.g. high-quality or low-quality care. For example, clothing was associated with cleanliness:

“Family were concerned when the resident was wearing the same clothes that she hadn’t had a shower or washed. She had had a shower, but she wished to wear the same clothes.” P11 (CHS)

Despite the negative associations with wearing the same clothing, this example, demonstrates staff supporting a resident’s agency i.e. selecting their own clothing.

A further aspect of ‘hidden’ work within the care home was the laundry system and the scale of the laundry process. Countless examples were given that reflected residents’ distress and in turn the difficulties that staff encountered, due to issues surrounding the laundry:

“There is a gentleman here, he can get very depressed and very down... erm and erm...there was one week when he was just obsessed by his laundry...

He said, “I have seven pairs of pants, I have so many t-shirts, I have so many pairs of trousers and there’s nothing there. There’s nothing!” And he was depressed for the whole week until we sorted out where his laundry was and got it back and he said to me - “Just thank you so much this is just so important to me””. P9 (CHS)

In an attempt to support residents, one member of staff gave an example of handwashing a resident’s underwear:

“Do you want me to do it for you – I can wash it if it is only knickers or brassiere or socks?” She said, “Is it true?” “Yeah, it is not a big deal I can do it for you” and that is when she said, “Oh you are so nice!” P8 (CHS)

Alongside laundering, staff also gave many examples of the need to alter, repair or buy new items of clothing for residents. For instance, two members of staff spoke of repairing or altering items of clothing for residents:

“Yeah, if not we can get the thread or something to repair it if we got time.” P8 (CHS)

“Well the length of her inside leg is 23 inches and she had trousers that were 29 and 30 inches – she was obviously taller at one point and obviously your muscles go when you are in a wheelchair and of course you shrink a bit. I do them on the sewing machine, I do them quite quickly.” P9 (CHS)

Interestingly P6 (PWD) spoke of caring for staff. For instance, she spoke of giving a member of staff a top:

“She is very nice, and I give her things. I had a lovely white top and ... I let her have it - I am not supposed to do it. The t-shirt she wears sometimes has

holes in it... and I said, “but it has holes in it” so she said it has holes, but it is comfortable, and she walks around in it.”

The concern shown by P6 (PWD) about the holes in the member of staff’s t-shirt highlight how residents similarly make assumptions about and judge care home staffs’ clothing (including appearance). Whilst, P6’s (PWD) generosity in wanting to give her own items of clothing away reveals the reciprocity involved in caring relationships.

The ‘unseen’ aspects of supporting someone with their clothing and appearance, were discussed by all staff who participated in the research. Although the frequency of themes is not something that the reflexive thematic analysis process advocates (Braun et al., 2019), the multiple times in which each participant discussed such matters demonstrated the importance of invisible aspects of care that seemingly go unacknowledged. For instance, handwashing items of clothing and the repair and alteration of items carried out in a member of staff’s spare time reveal the blurred boundaries between paid care work and the emotional and mental labour involved in working in a care home setting. Moreover, the example of a resident wanting to give a member of staff an item of clothing further highlights the complexities involved in caring relationships.

4.9 Discussion

This discussion explores findings related to the research aims and existing literature. I have also included a number of examples from my visual reflexive sketchbook that were made in response to certain findings. Findings in regard to specific applied / practice-based implications e.g. potential design solutions, are presented in **Chapter 7 Synthesis of Findings**.

This cycle of study focussed on the embodied and sensorial aspects of clothing through a series of multisensory research encounters, examining clothing during wear. This responds to Buse and Twigg's (2018) recommendation that research could explore the physical sensation and sensory engagement that clothing offers, and Ward and Campbell's (2013a) notion that the feel of appearance (including clothing) practices should be examined. This acknowledges a shift away from visual appearance to attend to how wearing clothing felt for people with people with dementia.

The physical sensation(s) of clothing i.e. the sensory properties of clothing during wear, were significant to people with dementia and were affected by numerous factors. **Figure 15** (taken from my reflexive journal) shows fabric 'rubblings' created to examine the sensorial properties of different garments.

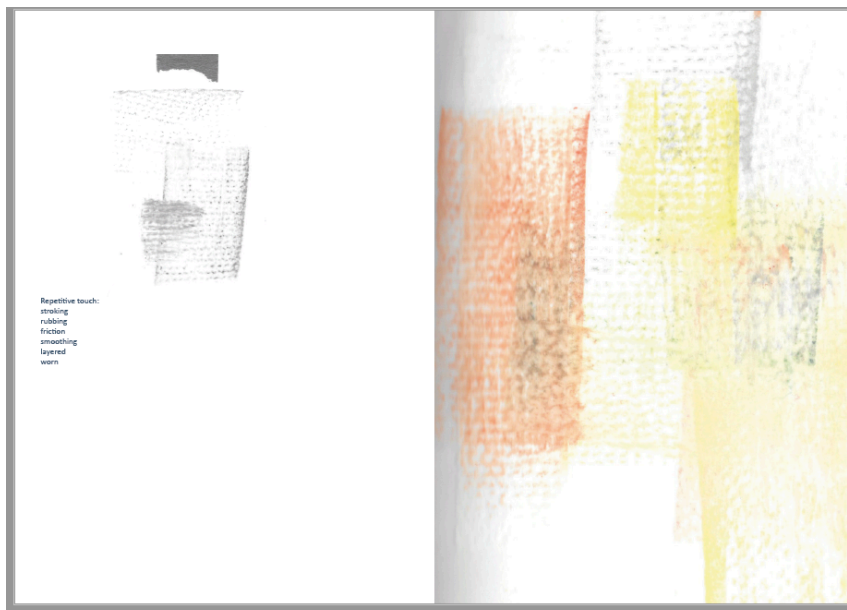


Figure 15. VISUAL REFLEXIVITY: Exploring the 'inner workings' of garments

The finding **(1) The (im)perceptible fit: The feel of clothing and appearance**

extends Woodward's (2007) notion of the 'aesthetic fit' i.e. the extent to which clothing embodies a person's sense of self. This finding develops the notion of 'aesthetic fit', through focussing on the nuanced aspects of clothing during wear, and the embodied aspect of clothing supported a person's sense of self and thus, the extent to which a person felt comfortable. For example, one participant demonstrated (through gestures) that she did not like lightweight fabric and so would not feel comfortable wearing clothing made of such fabric. Whilst for others the time of day, the season, the weather and the place in which the clothing was worn affected the extent to which they felt comfortable in their clothing e.g. the want to wear a specific colour in the morning rather than the evening. This demonstrates the negotiated interactions involved in clothing practices. As found in existing studies (Buse & Twigg, 2018), clothing preferences e.g. wearing trousers as opposed to skirts were particularly important as, for instance, one member of staff talked of a resident who would not leave her room wearing a skirt as she preferred to wear trousers. Clothing practices and the extent to which a person felt comfortable varied, some practices were habitual and embedded in a person's sense of self, whilst others were adopted during a person's time at the care home becoming situated clothing practices. These were important for both people with dementia and care home staff.

Care home staff spoke of how they created their own 'uniform'. The 'uniforms' were negotiated through individuals' consideration of their embodied actions when e.g. supporting a resident with personal care. Thus the 'uniform' was created not only through attending to their visual appearance e.g. the appropriateness of clothing in the care home as their place of work, but also the physical sensation of clothing

e.g. how they were required to move their bodies and how this could impact others. For instance, staff demonstrated how they may be required to move their body when supporting residents e.g. bending down to be at the same level as someone in a wheelchair or allowing someone to lean on them should they need to. Such actions required clothing that allowed movement and did not harm residents e.g. embellished clothing that may scratch residents. Such considerations highlighted staffs' embodied knowledge and also their empathic understanding of how their clothing choices could impact those that they supported. This concurs with Kontos and Naglie's (2009) finding that care home staff draw upon their own embodied knowledge when supporting people with dementia. Moreover, this finding demonstrates how clothing can be used to signify an 'unseen' aspect of care, as careful selection of garments by staff combined multiple factors including how their clothing would feel to others. This is novel, as clothing is typically considered in light of how a person may be perceived by others, as opposed to how clothing may feel. Inspired by staff's creation of their own 'uniforms' I explored 'communicative' surfaces, see **Figure 16**.

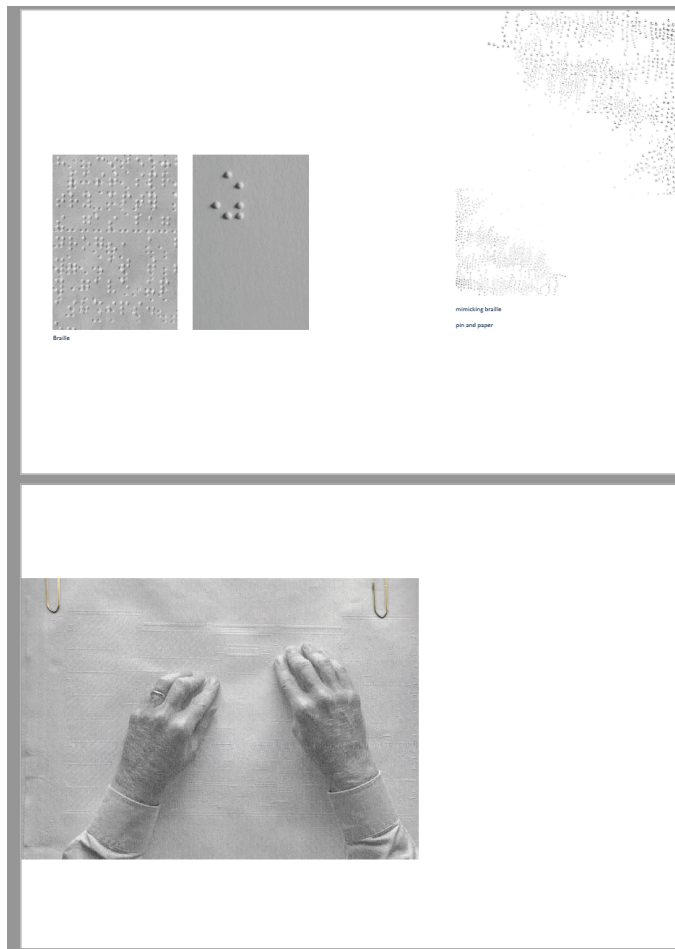


Figure 16. VISUAL REFLEXIVITY: Exploring communicative surfaces

Focussing on clothing during wear, enabled the exploration of embodied and habitual clothing practices through understanding e.g. how participants engaged with their clothing and accessories ‘in the moment’. This allowed me to observe, for instance, the ways in which participants intuitively knew how to tie their scarf or how to put bangles on. These examples were not ‘show and tell’ moments i.e. participants did not discuss their actions. Instead these moments happened intuitively at the respective participants’ own pace, during which they were not focussing on or talking about their actions. Such instances connect with Kontos (2004, 2005, 2015) work on embodied selfhood and are important to consider when supporting people with dementia with their clothing. For example, understanding embodied clothing practices could support people when dressing e.g. supporting an

individual's agency through allowing them space, time and the ability to move at their own pace was important during the above respective examples.

Much like Woodward's (2007) notion of 'aesthetic fit', embodied and habitual clothing practices are important to consider when supporting a person's selfhood. For example, wearing particular items and having certain possessions close to hand often provided a sense of comfort, familiarity and security for people with dementia. As Van Steenwinkel (2014) found with textiles e.g. cushions, pillows and blankets, clothing can also support people with dementia due to the closeness between the body and material. Wearing specific items can therefore enable a person with dementia to feel secure and comforted. This finding challenges the emphasis on an individual's visual appearance, as it requires attending to how appearance feels (Ward & Campbell, 2013a). For example, one participant often wore pyjama trousers with a shirt, whilst another typically wore multiple layers of clothing (often, including a coat), with staff explaining that these practices supported the respective individual to feel comfortable. This finding therefore supports Tseelon's (2012) notion that an outfit rarely conveys the whole message, as in the above examples, clothing preferences were specific to each person e.g. wearing pyjama trousers and a shirt may be comfortable for one person, but not be for another.

Attending to how appearance feels is dependent on each individual. For example, one participant found her reflection distressing, yet this would not necessarily be the case for someone else. For instance, there is evidence to suggest that the use of mirrors in residents' bedrooms can help maintain independence as they can enable people with dementia to engage with specific clothing practices and personal grooming (Kelsick & Freysteinson, 2013). Thus, this finding does not suggest that a person's appearance is unimportant but instead emphasises that the

gaze of others e.g. care-workers and relatives (Mahoney et al., 2015; Ward et al., 2014) should not compromise a person with dementia's ability to achieve the appearance (including clothing) that they feel most comfortable in (and with). Clothing functions at multiple levels for all, including people with dementia, and recognition of this within dementia care practice is important in order to avoid for instance, ignoring an individual's clothing practice (see the example from Stokes (2008), **Chapter 2, Literature Review**).

As found by Buse and Twigg (2014b, 2016b) 'small items of dress' e.g. handbags, jewellery and further accessories, were important for people with dementia. Such items were also part of participants' habitual and embodied clothing practices. For example, staff spoke of a gentleman feeling misplaced when not wearing his watch, due to the feeling of not having his watch on. Additionally, one participant always wore bangles, yet the bangles worn were often different. For her it seemed that the feel and sound of wearing metal bangles was important rather than the specific items. This is interesting in light of the concept of precursor objects (Gaddini, 1978), as it is what the object is that is significant, not the possible meanings associated with it (unlike transitional or attachment objects). The examples are interesting to note, when considering that clothing practices become sedimented over time and are important to a person's sense of self (Ward & Campbell, 2013a). Thus, wearing a specific type of accessory such as multiple metal bangles is important for an individual rather than wearing specific items of jewellery. Awareness and supporting individuals to maintain specific clothing practices is important in order to support selfhood at an embodied and material level. Within my reflexive journal, I explored how clothing physically impacts the wearer see **Figure 17**.

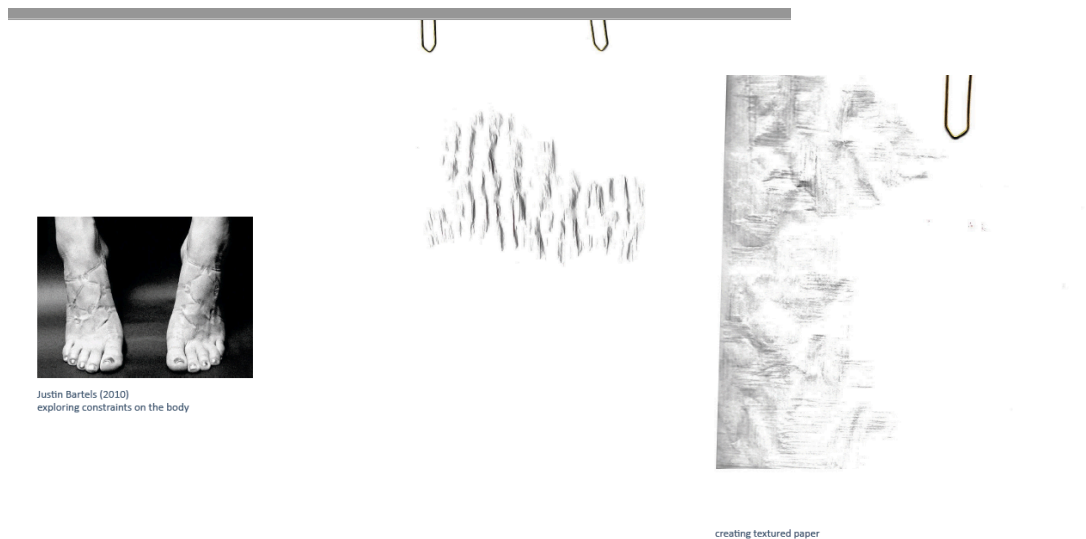


Figure 17. VISUAL REFLEXIVITY: Exploring marks after wear

Embodied and habitual clothing practices differed from the notion of attachment items. Attachment items are imbued with sentimental associations. People with dementia were found to access the meanings imbued within their pieces through wear and through close proximity with the items e.g. handling, touching, interacting with the items. This finding therefore connects closely with existing literature (Buse & Twigg, 2014a, 2016a; Stephens et al., 2013). Similarly, as found in my previous work (2019), participants viewed their attachment items as precious and expressed their desire to preserve these items. Related to this, the way in which staff helped to maintain certain items of clothing, through handwashing, repairing e.g. sewing buttons on, and altering clothing is important. Although staff did not explicitly discuss the items as being attachment clothing, their actions recognise the significance of specific items for residents. This finding is not only important when considering the role that attachment items can have for people with dementia e.g. supporting selfhood this also indicates how through maintaining items of clothing staff support selfhood. This is important to consider in light of relational approaches to care and how such practices build relationships between staff and residents. This

finding is also important in view of restrictions placed on clothing in the institutional settings including care homes. For example, mass laundering processes restrict the types of clothing a person can have in the care home e.g. items that require handwashing are not advised (Armstrong & Day, 2017; Buse et al., 2018b). Additionally, health and safety restrictions and limited storage space restricts the amount of clothing that a person can have (Armstrong, 2017). This is important as attachment items may not be practical despite still being worn. Thus it may be necessary to have multiple items of clothing or repair attachment items so that they remain functional e.g. one participant's attachment item was her threadbare coat.

Clothing was found to be a tool for expression, used by both staff and people with dementia. Clothing is widely perceived as an expression of identity and is inextricably connected with selfhood. Twigg (2010) reasons that a person is almost as embodied by their clothing as they are their bodies. The finding that clothing was used as a tool for expression is distinct from this and extends the notion that clothing can be considered a form of little-c creativity (Bellass et al., 2019; Zeilig & Almila, 2018). As Bellass et al. (2019) present clothing practices such as, putting on a coat to demonstrate a desire to leave the care home can be considered a form of everyday creativity. Findings from this study refer to both overt expressions e.g. removing or putting on items of clothing (Buse & Twigg, 2018), and also 'mini' examples of expression e.g. engaging with the tactile properties of clothing to distract, soothe and create a form of intangible respite from the care home setting.

Clothing can be considered a person's immediate physical environment (Twigg, 2010), the proximity of clothing enabled people with dementia to express themselves in a variety of ways. For instance, clothing was used as a form of protest e.g. one participant, who often spoke of not wanting to be in the care home, kept

knickers in the bag on her Zimmer frame, placing her underwear on the dining table to disrupt the setting. Similarly, a member of staff spoke of a resident who wanted to leave the care home, and would remove clothing when in communal spaces.

Clothing was also used to provide moments of distraction and respite from the care home setting. For example, some engaged with the tactile properties of their clothing and accessories e.g. bracelets. In keeping with Buse and Twigg's (2014b) work people with dementia used their handbags to store personal belongings 'close to hand'. Extending Harnett's (2014) findings, storing personal belongings close to hand, either in: pockets, handbags or bags on Zimmer frames, enabled people with dementia to renegotiate the care home environment as they provided moments of respite i.e. the physical act of looking through, investigating and handling the items provided unstructured moments of engagement for instance, looking at a business card held in a pocket. This finding is also notable in light of Davis et al.'s (2009) notion that the care home setting should provide opportunities for spontaneous engagement.

The expressivity of clothing as found in this research extends existing literature see e.g. Bellass et al. (2019). Staff explained that attending to embodied actions e.g. a person removing specific items of clothing, helped them to understand a person's needs and draw upon their own embodied knowledge e.g. empathising with how wearing something may feel. This relates to the work of Kontos and Naglie (2009), who found that care-workers used their own bodily knowledge when supporting people with dementia. For example, staff used embodied knowledge to support people with dementia to understand and feel supported with changes to their body e.g. mobility. For instance, staff spoke of knitting socks/slippers for someone who transitioned to permanently using a wheelchair as they could no longer wear

their shoes. Staff also used clothing e.g. inviting people to touch and handle items to support understanding. Thus, staff used clothing to communicate and support understanding when working with people with dementia.

To conclude, these findings demonstrate the multifaceted and nuanced ways in which clothing is significant to people with dementia living in care homes, also indicating that clothing was important to care home staff. Specifically, the sensorial, embodied aspect of clothing was important to both people with dementia and care home staff. The findings both support and extend existing literature within this novel area, contributing to the enhanced use of creative research methods when working with people with dementia.

4.10 Limitations and recommendations

This section examines the strengths, limitations and recommendations in light of the findings and the research methods used. The multisensory research encounters used generated understanding through both verbal and nonverbal communication, to explore the significance of clothing in a care home setting. Clothing was both the focus of this cycle of study and the method used i.e. clothing during wear was used as an elicitation tool. As Woodward (2020) notes, the visual, embodied and tactile dimension of clothing can be used to draw out experiences. The use of clothing as a tool to engage and explore participants' experiences was powerful. The research encounters enabled people with dementia to take part at their own pace as advocated by Hubbard et al. (2003), and at their own level. Participants shaped the focus of the research encounters, as these were dependent on the person's clothing 'in the moment' i.e. on the day of the encounter.

The findings provoke a number of recommendations with regard to future research in this area. Firstly, due to ethical requirements research encounters were carried out one-to-one, yet it would be interesting to develop encounters to explore the intricate ways in which people with dementia and staff interact with clothing. This could explore the creative use of clothing in the care home and how it may promote relational approaches to care.

Secondly, the use of clothing during wear as a tool for elicitation provoked responses that were beyond the scope of this research through references to e.g. sexuality, relationships and ageing. Further research could use clothing as a tool with which to explore intimate experiences as Woodward (2020) notes, material objects (including clothing) can enable understanding that would otherwise be unknowable. This could be particularly important in regard to people with dementia as there remains a dearth of literature within the area of e.g. sexuality and dementia in the care home.

If multisensory research encounters are used in future in research, it is important to develop recording methods. I used field-notes, audio recording and also engaged with reflexive visual journals, yet it was challenging to capture the ‘full-bodied’ aspects of the encounters e.g. how participants handled fabrics. Future research could use multisensory encounters alongside visual methods e.g. the use of a camcorder, as used in **CYCLE 3 (Chapter 6, 6.6 Video recording the object handling sessions)**, as visual recording methods enable re-visiting and re-engaging with the research encounters (Pink, 2015).

With regard to future use of multisensory research encounters, it is also important to note that familiarising myself with the study site was an integral part of

the study. Despite working with only twelve participants, I carried out a total of 31 encounters over approximately four - five months. This meant that I spent a lot of time at the care home negotiating with participants if, when and how often they may participate. This was possible due to the rapport that I built with care home staff and residents. As advocated by dementia researchers, carrying out research is a sensitive process that necessitates specific understanding of the place(s) where studies are undertaken. As noted earlier, Fletcher et al. (2019), when discussing ethics in dementia research, highlight the importance of such 'hanging out' periods e.g. spending a period of time at a care home prior to data collection. I volunteered at the study site for approximately seven months prior to the start of the study. This was possible as I was able to volunteer alongside my PhD studies, however this prolonged period would not be possible in shorter studies. Researchers could instead engage with intensive periods of engagement that could be built into research protocols. My volunteering at the site, suited both the exploratory aims of this study and the situated and emplaced nature of the SE methodology.

4.11 Summary

These findings demonstrate that the embodied and sensorial aspects of clothing are important to people with dementia due to a variety of multifaceted reasons. Findings support and strengthen existing literature (Bellass et al., 2019; Buse & Twigg, 2014b, 2016a; Buse et al., 2018b; Harnett, 2014) and build upon existing work thus developing understanding within the novel area. Additionally, the method used was found to be a powerful way in which to engage people with dementia in research and develop rich understanding. The methods could be adapted for use in further studies to explore specific aspects of the lived experience of people with dementia e.g. sexuality, relationships and ageing.

Chapter 7 Synthesis of Findings discusses the ways in which findings from this cycle of study and the subsequent cycles of study, can be applied to support and enhance dementia care settings. The subsequent chapter builds upon findings from this cycle of study detailing how findings were presented to creative practitioners in order to select and create a number of materials, objects and images for use in CYCLE 3.

CHAPTER 5 CYCLE 2: TRANSLATING THEMES INTO OBJECTS

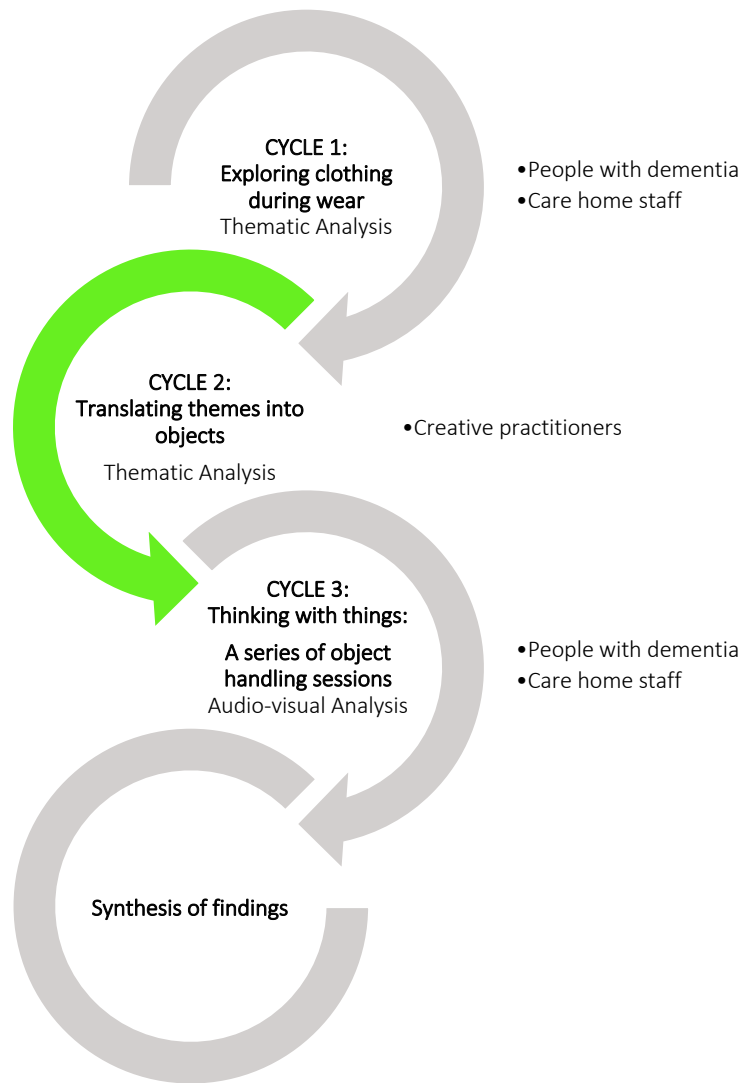


Figure 18. CYCLE 2: Translating themes into objects

5.1 Introduction

This chapter builds upon findings from **CYCLE 1: Exploring clothing during wear**, in which I worked with people living with dementia and care home staff to

explore clothing during wear in the care home. The current cycle of study involved working with creative practitioners to explore the thematic findings from CYCLE 1. For the purpose of this study creative practitioners were defined as artists, musicians or designers working in health and social care settings with people with dementia. I worked with practitioners to examine the ways in which CYCLE 1's findings could be envisaged and re-interpreted through a series of materials, objects and images. These were then used in a series of object handling sessions in CYCLE 3 (see **Chapter 6, CYCLE 3: Thinking with things: A series of object handling sessions**).

The novel methods employed in this cycle of study did not derive directly from Pink's SE (2009; 2015), instead it drew upon techniques used in co-design research approaches. Yet, the methods align closely with Pink's SE approach, as she advocates the use of both traditional and innovative methods to co-create knowledge with participants. Moreover, drawing upon Ellingson's (2017) approach to carrying out embodied qualitative research and Pink's (2015) SE, this method encompasses multiple ways of forming knowledge through:

- Text-based findings i.e. CYCLE 1 thematic finding, to elicit responses
- Visual and practice-based findings i.e. the creation of materials and objects for CYCLE 3.

CYCLE 2 was informed by the work of Chamberlain and Craig (2013, 2016, 2017) who, in their project titled: 'HOSPITAbLe: Critical design and the domestication of healthcare', used objects and artefacts to work with older people to explore healthcare services. Their methodology, 'Thinking with Things', utilised artefacts and objects to generate knowledge. The artefacts used were created in

response to interview and focus group data (Chamberlain & Craig, 2013). It is this aspect of their methodology that the current cycle of study drew upon, i.e. that the 'critical artefacts' created were borne out of interview and focus group data. Within Chamberlain and Craig's study (2013, 2016, 2017) the artefacts were then used to promote discussions and generate rich in-depth data, to further develop and shape understandings about older people's lives. The artefacts were not designed to be 'solutions' i.e. an object designed to meet a particular need, they were created as tools for discussion. Chamberlain and Craig (2013, 2016, 2017) claim that objects can be powerful, tangible ways with which to engage, promote discussions and lead to understanding the nuanced complexities of older peoples' lives. Similarly, the use of objects as tools for elicitation is presented by Woodward (2020) in her book 'Material Methods', in which she states that "to elicit means to draw out to prompt, to excite" and that "object elicitations can be helpfully thought out as a way of drawing out narratives, comments or experiences that would otherwise not have emerged" (Woodward, 2020:37).

Not only was this cycle of study (CYCLE 2) informed by the methods used by Chamberlain and Craig (2013, 2016, 2017) and Woodward's (2020) object elicitation, it was also influenced by the use of object handling sessions within dementia care settings. There is not a formal definition for object handling sessions (F. D'Andrea, personal communication, March 12, 2019), however such sessions are often themed in order to collate the objects used (e.g. Griffiths, Denning, Beer et al., 2019; Thomson & Chatterjee, 2016). For example, Griffiths et al. (2019) explored a multi-sensory intervention for people with dementia using themed boxes on topics such as, childhood, whilst Thomson and Chatterjee (2016) used objects from a museum's collection, and separated them into themed boxes such as zoology e.g. horns,

shells, teeth, or archaeological artefacts e.g. amulets, flint tools. Hence, this cycle of study was influenced by the work of Chamberlain and Craig (2013, 2016, 2017) and object handling sessions designed for people with dementia e.g. Griffiths et al. (2019).

The aim of this cycle of study was to work with creative practitioners to translate and re-interpret findings from CYCLE 1 into a series of themed materials, objects and images that were then utilised within object handling sessions in **CYCLE 3: Thinking with things: A series of object handling sessions.**

This cycle of study involved the following steps:

STEP 1: Designing tools for elicitation using thematic findings from CYCLE 1

STEP 2: Carrying out the interviews using thematic cards as elicitation tools.

The elicitation tools were used in one-to-one interview with creative practitioners

STEP 3: Thematic analysis of interviews

STEP 4: Designing the object handling sessions for use in CYCLE 3.

Each step is presented below.

5.2 STEP 1: Designing tools for elicitation

Firstly, elicitation tools were developed based on findings from CYCLE 1. As previously noted, elicitation involves prompting participants to provoke responses. The approach to designing the elicitation tools was informed by the use of probes within design-led research. Probes are used to elicit responses from participants and are designed for the purpose of the research project (Woodward, 2020). An example probe could be a photo album in which participants are asked to add photographs to

then explore a particular aspect of their lives (Woodward, 2020). Designing probes involves considering the connection between the probes and the aims of the research and the aesthetic, materiality of the probes e.g. what the probes look and feel like and how participants engage with them. Designing the tools for elicitation for this cycle of study involved considering: the presentation and accessibility of findings from **CYCLE 1: Exploring clothing during wear**, the aesthetic properties of the elicitation tools and their functionality in regard to informing CYCLE 3.

On reviewing findings from **CYCLE 1: Exploring clothing during wear** (see **Chapter 4, 4.8 Findings**) and after discussion with the supervisory team, it was recognised that an exhaustive presentation of each master and subordinate theme would not be possible given the length of time it would take to present and explore them within the participant interviews. It was therefore decided that only each master theme would be presented to participants. A master theme conveys an overarching concept or story which links to the respective subordinate themes. The latter sit under the conceptual umbrella of the respective master theme(s), therefore presenting the master themes from CYCLE 1 was deemed appropriate for the purpose of this cycle of study.

See **Table 9**, taken from **Chapter 4**, for a list of the master themes used. It is important to note that the findings used, although in the latter stages of refinement, were not final themes from CYCLE 1. They were master themes that had been developed and were subject to final analyses. The focus of this cycle of study was not to act as a validation or corroborative technique to ensure rigour, as can be found in some qualitative, quantitative and mixed-method approaches e.g. triangulation, but as a way in which to reimagine findings through the use of

materials, objects, and images. Thus, the use of findings in their final stages of development, was deemed appropriate for this cycle of study.

Table 9. CYCLE 1 Draft master and subordinate themes

Master themes	Subordinate themes
(1) Bodily awareness: The feel of appearance	(1.1) Revealing / concealing the body (1.2) Practicality, cleanliness and mobility
(2) Clothing: The (Im)perceptible fit	(2.1) Embedded / habitual clothing practices (2.2) Situated clothing practices
(3) Everyday creativity and clothing: clothing a vehicle for expression	(3.1) Innate engagement with clothing (3.2) Storytelling
(4) Clothing attachment	(4) Ownership in the care home
(5) Clothing as a tool to explore the unacknowledged	

Developing the format in which the themes were presented was a crucial aspect of the research method. It was important that the themes were presented succinctly and in an accessible format that enabled participants to engage with them within a short period of time i.e. the hour-long interview. Thus, firstly I wrote a synopsis of each master theme i.e. shortened versions of the themes presented in **Chapter 4, 4.8 Findings**, and selected participant extracts to illustrate the respective themes to foreground the perspectives of those taking part. Once the text was refined, I then developed the format in which the themes and extracts were presented.

In order to examine the most suitable way in which to present themes, I worked with peers including early career researchers and creative practitioners, to gather their feedback. For instance, I worked with a PhD student whose research is

based in the arts, health and dementia field, and who is also an arts workshop facilitator. These informal presentations, to people unconnected with this project, proved valuable in shaping the presentation of the themes. For example, feedback suggested that participants may prefer to use physical printouts rather than read from a screen. This concurred with research employing similar methods. For example, Sutton (2011) used 'concept cards' to explore the embodied experiences of female participants and found that the use of cards provided tangible ways in which participants could explore key topics within their research.

The elicitation tools, i.e. 'thematic cards', created for the purpose of this study were informed by the design of probes (Woodward, 2020), informal feedback and the use of tools such as 'concept cards' (Sutton, 2011). The thematic cards created were A5 in size and were designed to allow participants to physically interact with the themes and accompanying participant extracts, enabling them to read, select and order the cards. Cards were double-sided, with the theme on one side and an accompanying participant extract on the other. A total of ten cards were used, this equated to two-three cards per master theme, with no less than two supporting participant extracts per theme (see **Figure 19**).

Reflexive note 8: Designing thematic cards

Designing the cards was a lengthy process, and on reflection I feel that this process within the cycle of study was somewhat overlooked - it was initially considered a small part of the process, rather than an integral tool within the method. I enjoyed designing the cards and experimenting with the layout and format, however I think that the time it took to create and have the cards printed was underestimated and this proved difficult to manage given the short time period allocated for this cycle of study.



Figure 19. Example thematic card

5.3 STEP 2: Carrying out the interviews: Thematic cards as elicitation tools

The research protocol stated that this cycle of study would consist of up to two focus group discussions. The focus group discussion method consists of moderated group discussion based on the participants' perceptions and experience of a topic (Liamputtong, 2011). In the case of this research, the focus group was designed to explore thematic findings from **CYCLE 1: Exploring clothing during wear**, as outlined above. Each focus group was to be made up of up to six creative practitioners e.g. visual artists, ceramicists, who were working in health and social care settings and who were either working with people with dementia or had worked with people with dementia. It became apparent when recruiting participants that focus groups would not be suitable for this population of freelance creative practitioners who typically had varying schedules working across multiple locations

on any given week. Therefore, individual interviews were carried out. Interviews were guided by the adapted focus group discussion guide and lasted up to one hour.

At the start of each interview, participants were asked to briefly explain their practice and experience of working with people with dementia. Participants were then asked to read the thematic cards and select one or more to discuss how these could inspire the use of materials, objects and images with people with dementia in the next cycle of the research. The process of engaging with the thematic cards varied considerably according to each individual participant. For example, one participant chose to spread the cards across a table, systematically reading each card, and then re-visiting and picking up different cards throughout the interview. Another participant chose to read through the cards and selected three to focus on, handing the rest of the cards back to me. **Figure 20** shows re-created examples of two of the ways in which participants interacted with the thematic cards below i.e. sorting the cards into their themes, or the thematic cards with the participant extracts facing upwards:



Figure 20. Using thematic cards

I noted that the different ways in which participants engaged with the cards seemed dependent on the space in which we were in. As part of the SE approach, it is imperative that the researcher attends to and is emplaced within the research setting (even, in the case of this method, for a short period of time). Attending closely to the setting enabled me to explore how the interview setting/location may have impacted each participant's engagement with the thematic cards. For instance, in some cases I sat at a small table with a participant, and so there was not enough room to spread out the thematic cards in order to keep referring back to them, whereas in another interview we were sat in a participant's studio enabling her to spread the cards out across her large desk, selecting different cards as she spoke. This in turn affected the ways in which the interview was carried out. Due to the need for flexibility within the process, interview prompts were used, these were adapted from the original focus group discussion guide (see APPENDIX X).

Interview prompts

The prompts used were open-ended and sought to draw upon participants' experiences and practice in order to elicit responses regarding the thematic cards. The prompts were as follows:

- What are your initial thoughts / feelings about the theme selected?
- How do you think this theme could be represented?
- Can you name a material/object/image that you think may be used to represent this theme?

The prompts included follow-up questions such as:

- Could you describe that further?
- Could you explain your choice?
- Is there anything else that you think may be useful?

The use of prompts sought to create an openness to each interview (Pink, 2015), to allow participants the freedom to explore the thematic cards in depth, reflecting upon their practice. Each interview differed, depending on the individual's response to the thematic cards. In some instances, participants drew more broadly on their experiences, rather than stating specific ideas with regard to particular materials, objects or images. In other cases, participants spoke of the ways in which they felt certain themes were apparent in their own practice, for example, one practitioner spoke about sentimentality and how it was often particularly important in the music sessions that they run P18 (CP), whilst others were more explicit in their responses, for example, on reading one card, P13 (CP) listed a series of materials in response to one of the thematic cards. Thus, each interview varied, despite the use of the same thematic cards, and the different settings affected how individuals engaged with the cards (see *Reflexive note 9*).

Reflexive note 9: CYCLE 2 Carrying out the interviews

I found the interviews very challenging to facilitate. The thematic cards elicited rich responses, however guiding and facilitating these encounters was difficult in order to explore specific responses. I am concerned that my lack of experience working in this way may have affected the process and think that piloting the interviews would have helped improve my facilitation skills. I also think that multiple interviews would have been helpful, or perhaps the use of different methods, whereby, after the first interview, I then brought in a series of materials, objects and images and revisited participants to explore their thoughts relating to the items. There are many other opportunities and avenues that could be explored in order to develop this method, yet these were not possible due to time constraints.

5.4 Interviews: Ethical and practical considerations

It was not possible to facilitate a focus group at a mutually convenient time, therefore one-to-one interviews took place in different locations. In each case, the choice of interview location was selected by the participant. All participants were known to the PhD supervisory team or myself, and had been recruited through existing networks, thus ensuring the comfort and safety of both the participant and myself. For example, in one case the interview took place in a quiet room in a care home prior to the participant carrying out a workshop, whilst in other instances interviews took place in participants' own studios. Not only was flexibility important when considering where the interviews took place, I also had to respond to changes in availability, as due to the changing schedules of freelance creative practitioners there were multiple occasions where interviews needed to be re-arranged.

Before taking part in an interview I received informed consent from each participant. Each had been given a cover letter and participant information sheet no less than 48 hours prior to the interview. See **Chapter 3, 3.7 Recruitment** for a detailed discussion of the recruitment process.

5.5 Recording the interviews

In order to capture the interviews, the following techniques were used: (1) an audio recording device was used to record all verbal communication with participants; (2) field-notes were made immediately after the interview and these notes were expanded in detail within 24 hours of the interview; (3) a reflexive journal was used to record text-based and visual reflections, see *Reflexive note 10*.

Reflexive note 10: Recording the interviews

Audio-recording the interviews was valuable and captured all verbal-responses, however video-recording or photography may have provided further insights into the ways in which participants interacted with the thematic cards. The novel method was really interesting; however, I feel that audio-recording did not fully capture the processes undertaken within the interview. It was also difficult for me to reflect fully on these processes in order to make notes at the end of each interview. In order to have fully captured the interview, I would have needed to make notes during the interview, and this was not something that felt appropriate at the time as I was active in the interview i.e. handling the card with participants or offering and presenting new cards when prompted.

5.6 Participants

Creative practitioners were sampled purposively according to the sampling method detailed in the **Chapter 3, 3.7 Recruitment**. Participants were recruited using the PhD supervisory team's arts and health network, with the aim to recruit those from a range of different disciplinary backgrounds ranging from e.g. visual arts to music. Participants with a varied skillset were sought due to the multisensory aspects of their respective practices. Thus, it was reasoned that recruiting creative practitioners from a range of disciplines may support the translation of themes into a diverse array of materials, objects and images for use in CYCLE 3.

The participants recruited were practicing visual artists, ceramicists, musicians and designers and all worked in a range of health and social care settings with people with dementia. Six participants were recruited, these numbers were determined by numbers outlined as optimum for a focus group discussion i.e. six-ten participants (Liamputtong, 2011). Despite the use of interviews as opposed to a focus group, the PhD supervisory team and I agreed that six participants should enable rich insights in order to develop the object handling sessions i.e. CYCLE 3. It

was decided that more interviews would be carried out if additional insights were required or if the data collected was not sufficient to inform CYCLE 3.

Table 10. CYCLE 2: Self-reported demographic information

Participant code*	Age	Gender	Ethnicity
P13 (CP)	52	Female	Greek
P14 (CP)	29	Female	White British
P15 (CP)	30	Female	White British
P16 (CP)	31	Female	White British
P17 (CP)	45	Female	White British
P18 (CP)	34	Male	White British

*Note. Codes were used to ensure participant confidentiality, see **Chapter 3, 3.7 Recruitment, Participant confidentiality** for further discussion.

Recent figures on the arts and cultural sector workforce from Arts Council England (2019), report that 46 percent of all staff working in the sector i.e. permanent staff, volunteers and contractual staff, were White British and that women made up 50 percent of the workforce. Thus, the sample of creative practitioners recruited was not representative of the broader arts and cultural sector workforce. This may have been due to a number of factors including participants' roles, participants' employment i.e. four out six practitioners were self-employed.

5.7 Thematic analysis

Thematic analysis was used to analyse data from CYCLE 2. As discussed in **Chapter 4, 4.7 Reflexive thematic analysis**, thematic analysis is a method for identifying, analysing and reporting patterns i.e. themes within data. Yet, as critiqued by Braun et al., (2019), the analytic processes vary greatly according to the researcher and the focus of the research. Thus, the approach to analysis within this cycle of study differed from the reflexive thematic analysis carried out in **Chapter 4 i.e. CYCLE 1: Exploring clothing during wear**. The focus of this cycle of study

necessitated an alternative approach to analysis as the aim of the study was to identify particular strategies or techniques used by practitioners and to select specific materials, images and objects as opposed to exploring the data interpretively. Therefore, this thematic analysis examined the semantic content of the data using participant verbatim. The approach was deemed appropriate for this cycle of study in order to inform **CYCLE 3: Thinking with things: A series of object handling sessions**. In order to carry out this analysis, I followed an adapted version of Braun and Clarke's (2006) stages of analysis. The adapted process enabled me to attend to explicit meanings within the data that in turn could be used to develop **CYCLE 3: Thinking with things: A series of object handling sessions**. I employed the following stages of analysis:

1. All of the interviews were transcribed. Memos were written. The transcriptions were read and re-read.
2. Coding was carried out, this was not line-by-line, but rather 3-4 lines of text at a time, due to focus on the semantic content of the data. Codes were identified with specific reference to designing the object handling sessions e.g. identifying particular strategies and techniques, materials, objects or images, that participants discussed. Codes were assigned.
3. Initial themes were created through linking codes together.
4. Themes were reviewed, this involved reading and re-reading the initial themes.
5. Themes were named to convey the core essence of each theme, i.e. themes that were relevant to the design of **CYCLE 3: Thinking with things: A series**

of object handling sessions. Participant extracts were selected to support the themes created.

Despite the lack of reflexivity involved within this analysis process, Pink (2015) advocates that SE researchers engage with analysis processes that align with the focus of the research and with the methods used (see *Reflexive note 11*).

Reflexive note 11: Thematic analysis process

I found the thematic analysis process for this cycle of study particularly challenging. I wanted to explore the deeper, perhaps more nuanced meanings within the data, however the cycle of study necessitated an approach that drew specifically on the words of participants in order to design the final cycle of study (CYCLE 3). I think that this affected the presentation of themes, whereby master theme 1 and 2 present participants' broader experiences, whilst master theme 3 presents the 'tools' for the sessions.

5.8 STEP 3: Findings

The findings presented were derived from the one-to-one interviews carried out with creative practitioners using the thematic cards as tools for elicitation. Note that the terms 'sessions' and 'workshops' are used to refer to the activities that the respective participants discussed facilitating. This could refer to e.g. a painting class working with people with dementia. Where it is necessary, and without changing the meaning, I have added omitted words or details in [brackets] to support the reader's understanding. Themes are presented alongside illustrative extracts from participant transcripts.

The interviews were designed to gather responses that would in turn inform the materials, objects and images used in object handling sessions in the final cycle of study (i.e. CYCLE 3). Thus, findings are arranged around specific aspects of designing the object handling sessions (see **Figure 21**).

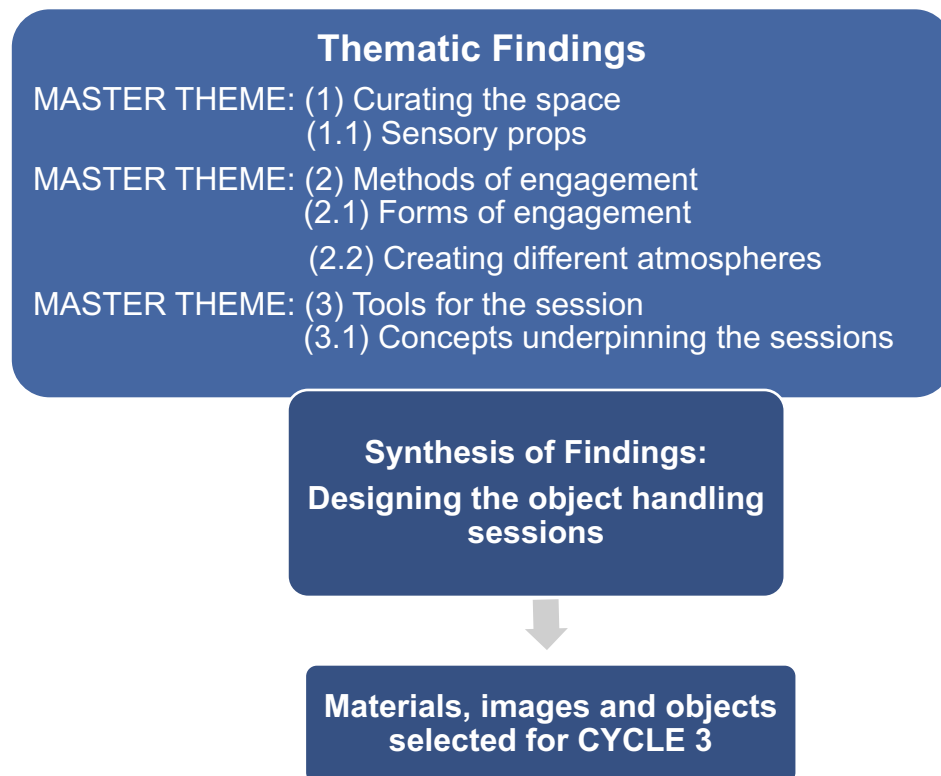


Figure 21. CYCLE 2 Synthesis of findings

(1) MASTER THEME: Curating the space

The first master theme, **(1) Curating the space**, presents techniques employed by creative practitioners in order to alter and enhance the spaces that they worked in (e.g. health and social care setting such as care homes, hospital wards) before carrying out their workshops. The term ‘curating’ was selected to emphasise the careful consideration that practitioners gave to organising, selecting, and in some cases, manipulating the spaces in which they worked in order to create a suitable environment. Techniques involved, for instance, re-arranging furniture and using props to transform the space from e.g. a health and social care setting, to

somewhere more conducive to creativity. This connects with Lupton's (2017) notion of affective atmospheres and the ways in which material and social interactions affect the 'feel' of spaces. For example, P14 (CP) discussed the importance of displaying the objects used during the workshops:

"When I display things, it is quite archival, but equally inviting people to engage and to touch - it can be very confusing having everything out at the same time, so I will be separating items into different sections." P14 (CP)

P14 (CP) also spoke of the ways in which she created individual workspaces for participants:

"I look at the curation of exhibitions and try and bring that into the experience of the sessions. So, looking at the materials that we are using - not just the [paint] pots in the middle, but really thinking about it before everyone sits down - everybody has their pot and paintbrush - it is almost like a dining experience, so everybody has their own curated space you know." P14 (CP)

Similarly, P15 (CP) also spoke of the importance of each person within a session having their own defined work space:

"We have had a couple of blow ups – [She explained when working with wet fabrics during a fabric painting session, people were worried about keeping their work separate from each-others] "You put your thing down and it is covering mine and it'll seep through" ... There is an intensity of being careful around your piece - especially when it is fabric." P15 (CP)

Practitioners spoke not only about curating the physical elements of the space but also about the different ways in which the atmosphere of the session can be

explored through the design and delivery of the session. For example, P18 (CP) spoke of his experience facilitating music sessions, during which people often become concerned at playing or listening to music on the hospital ward:

“I see that with the music stuff which is quite interesting saying “Oh I can’t listen to music here – I don’t want to disturb anyone” ... You know but that thing of like, but this isn’t what should be happening right now...” P18 (CP)

Moreover, he felt that there is a direct contrast between someone’s ability to express themselves through their clothing (referring specifically to the thematic card ‘Everyday creativity and clothing: clothing as a vehicle for expression’) as opposed to expressing themselves through music. He suggested that music needs someone to “create a space for it”:

“Music is not necessarily ... people can often sing but more often than not it doesn’t happen unless we go and instigate it or create a space for it ... it is different as it is almost like a fashion activity where you know it is something you own where you have decided how to put it together.” P18 (CP)

Thus, he talked of the ways in which curating the space involved assessing and manipulating the intangible feel of the space to ensure the comfort of those taking part, whilst being sensitive to “not upset the balance”. For example, he said that he often invited others e.g. patients not directly involved in the session and staff, to share their opinions, to create ‘more space’ for the session - opening the session up to more people on the hospital ward.

The relationship between the physical and intangible aspects of the space seemed integral when creating a space conducive for creative sessions, and

practitioners demonstrated that this was significant at both a group and an individual level.

(1.1) SUBORDINATE THEME: Sensory props

Connecting closely with the master theme **(1) Curating the space**, the subordinate theme **(1.1) Sensory props** explores how creative practitioners brought items into the spaces in which they work e.g. hospice, care home, hospital ward, to support different sensory experiences. For example, P17 (CP) spoke of altering the space:

“I am going to be delivering a session at a hospice so I am going to talk to the team beforehand about can we bring a kind of sensory element to it ... have like big bouquets of flowers ... and by the very nature of that you are changing the smell ... there is something about - this is a special session... this is a safe area and we can explore and exchange conversation.” P17 (CP)

P18 (CP) talked of how bringing unusual and unfamiliar objects into a hospital can be a powerful way to engage people as you create shared moments in which to explore a new object:

“You can have the sensuousness and that sense of intrigue with something that you haven’t seen before ... as a sort of err exploration of a new thing...”

However, he added the caveat this is often dependent on who is taking part in the session that day and that it becomes a case of exploring the extent to which people are open to exploring unusual items:

“How much novelty someone is comfortable with and this definitely applies with the sort of music stuff as well - a lot of the music group is very

improvisational, but that has to change depending on who is in the room.” P18 (CP)

Notably, P17 (CP) discussed using props to support people when viewing and discussing historic paintings. For example, she invited people to wear a replica ruff i.e. a starched frill worn round the neck, a typical characteristic of Elizabethan and Jacobean dress, in order to explore the posture of a subject within a painting. She explained how engagement with specific items can challenge and invite nuanced responses from those taking part.

Although a very different example, P14 (CP) similarly discussed using a range of sensory props and tools within sessions. She talked of the importance of connecting with different spaces within the care home e.g. chefs preparing food in the kitchen:

“It is bringing in different influences not just ok I am a creative I am doing a creative workshop - you know... “What about cooking?” – In one of my sessions we are not going to cook but equally thinking about the texture of food, the display of food, the feel of food, the aesthetics of food... you know, bringing in advertising in terms of a workshops and collaborating with other people in the care home [e.g. the chefs]”. P14 (CP)

The method of bringing in different and perhaps unexpected items to creative sessions seemed important for practitioners when considering transforming the spaces in which they work and thus impacting upon the intangible feel of the session.

(2) MASTER THEME: Methods of engagement

The master theme **(2) Methods of engagement** involves examining how participants drew on their respective practices e.g. visual arts, ceramics, theatre design, to employ different techniques that brought people conceptually 'into' the sessions and engaged them during workshops. For instance, P17 (CP) spoke of how to invite people into a session, encouraging them to look, observe, and focus by starting with a 'warm-up' activity:

"What I try and do is set up a warm-up activity for example, if I taught yoga (but I don't teach yoga!) - you would have to do a warm-up - and it is the same with art... you have to focus, and look, and engage." P17 (CP)

Participants spoke of particular techniques that they used when introducing objects, materials or imagery to people taking part in their sessions. For example, P14 (CP) spoke of presenting items to participants in order to elicit certain responses, inviting participants to be critical, as opposed to responses such as 'I like' or 'I don't like'. To do this she explored details within an item, to look at textures or features "out of context" as this provoked interesting responses:

"Zooming in on features that are intriguing they are not beautiful, so it is almost like remove the beauty, let's just almost have these out of context zoomed-in textures and things – erm, swatches of different fabrics that aren't clothing because when you start to put it into an identity or a function – a pair of trousers, a skirt, a top – it can kind of - it is almost diverting attention." P14 (CP)

Similarly, P18 (CP) discussed how the specific features of an item, as opposed to the object itself, could be particularly captivating or interesting:

“I bring a lot of small percussion instruments ... I have known it for people to become really fascinated by the texture of things and the weight of them - err in fact a woman in a group last week she erm err she was sort of err... she had this sort of wooden shaker and she was fascinated by the smoothness of it.” P18 (CP)

Moreover, P15 (CP) reflected on a series of fabric sessions that she had delivered in which she said some participants found it difficult to create a final piece:

“Saying that now makes me think how different those fabric sessions would have been if I had brought in a load of different fabrics; some of them patterned, some of them silk and some of them whatever, and said we’re going to make these bags...” P15 (CP)

Each participant spoke of differing techniques that they employed when facilitating sessions. This indicated that they drew upon on a range of methods and techniques when delivering sessions. The notion of situating the sessions and employing techniques that enabled people to look and engage in specific ways during the sessions seemed particularly important. Despite this finding not mentioning the use of particular objects, materials or images for CYCLE 3, the methods of engagement discussed by practitioners were useful when planning the use of objects with participants in CYCLE 3.

(2.1) SUBORDINATE THEME: Forms of communication

(2.1) Forms of communication, refers to the ways in which creative practitioners presented information, explored topics and communicated with people with dementia in sessions. For example, P17 (CP) spoke of how she viewed workshops as a collaborative and shared process as she said:

“I never assume any knowledge or experience or expertise from anyone... I will say we are going to explore this - can anyone tell me a little bit about it?”

She later went on to explain:

“I think people say “Oh no, no, no I don’t know about this”... and then you have someone that comes out with something so poignant or something you may not have thought of previously or just a facet of information that you aren’t aware of.” P17 (CP)

P15 (CP) discussed the importance of considering the questions used in workshops that enable a person to share as much as possible:

“It is like what we were saying about the blouse... “Oh I love your blouse, what a lovely colour” ... And they are closed questions, really aren’t they? ... And you could volunteer it like: “Oh my daughter gave me this blouse”, but you aren’t really being invited to [expand on this as] people are aware of all sort of niceties and how extensive their answers should be.” P15 (CP)

Furthermore, P16 (CP) spoke of how the items introduced can affect a person’s engagement. For instance, she spoke of a participant who didn’t want to take part in a weaving session because the fabrics being used were old clothes, which the person thought looked like rubbish:

“We were weaving, and I had said we were recycling, I thought it looked great weaving the basket and having strips of buttons from an old shirt, but she didn’t think so!” P16 (CP)

Yet, P15 (CP) spoke of referring to fabric as “scrap” in a deliberate attempt to shift focus away from creating a perfect finished piece: “I called them scrap deliberately”.

Although this subordinate theme is broad, the ways in which participants carefully considered approaching topics, introducing objects and asking questions was particularly useful to consider when preparing for CYCLE 3 and considering the use of prompts within the sessions.

(2.2) SUBORDINATE THEME: Creating different atmospheres

This theme examines the ways in which participants discussed how different materials, objects and images can create different atmospheres. For example, P13 (CP), in regard to the thematic card 'Creative expression through clothing' from CYCLE 1, discussed how participants could be encouraged to use gesture and fabrics to be dramatic within the sessions:

"Someone like her would love that... so that she has a big presence – you know like here I am with my big poncho scarf ... instead of always being a little thing that is personal and that you can fiddle with ..." P13 (CP)

Similarly, she suggested that participants could be encouraged to be playful through engaging with particular items of clothing:

"Also the thing with the pockets because I think it is also kind of... on the playful aspect of the clothes... like the lady with the rocket... like you can use the pocket to get a surprise out of it and you can be playful because... so many times the environment [care home] ... you know one says: "It is hell here"... it is so boring!" P13 (CP)

Some participants talked less explicitly about particular materials or objects possibly eliciting certain responses, but similarly talked of creating a particular atmosphere within the session. For example:

“Engaging with something beyond beauty that is quite interesting saying “Oh it is intriguing” ... because usually it is “Oh I don’t really like it” - and then kind of the conversation ends.” P14 (CP)

Similarly, P15 (CP) spoke of intentionally selecting “ugly” items to use within the sessions in CYCLE 3:

“I think this comes from the art discussion you sometimes have a juicier - not so based in nice things more about - passion... like a passionate response is better... like bring some ugly fabric in as well!” P15 (CP)

Interestingly, P15 (CP)’s response brings in the question of personal taste; a fabric that one person may find ugly, another person may think is beautiful. This could therefore be considered difficult to approach. Nevertheless, participants’ responses indicate the need for variety in order to shape the atmosphere of the sessions and create a sense of challenge to encourage detailed responses rather than closed, one-word answers. Although many of the examples focus on potential verbal responses to items, P13 (CP) concentrated on the possible feelings created within a session through gesture and touch e.g. “operatic impression, like being big”.

(3) MASTER THEME: Tools for the sessions

This theme encompasses creative practitioners’ specific references to materials, objects or images and also different sources of inspiration e.g. the work of particular artists, with specific reference to clothing and textiles. See the table below for participants’ suggestions, listed under the following categories:

Clothing / objects lists specific objects or items of clothing suggested by participants.

Types of fabrics refers to certain fabrics suggested by participants.

Features refers to specific details suggested by creative practitioners.

Colours lists specific colours suggested by participants.

Other refers to artists and designers or further sources of references suggested by participants.

In some instances, participants made suggestions in reference to specific thematic cards, where this was the case this is noted in the column 'Specific reference to thematic card'. See **Table 11. (3) Tools for the session**.

Table 11. (3) Tools for the session

Suggestion	Participant	Specific reference to thematic card
Clothing / object		
"Cape / poncho"	P13 (CP)	Everyday creativity and clothing
"Voluminous fabrics"	P13 (CP)	Everyday creativity and clothing
"Lengths of fabric"	P13 (CP)	Everyday creativity and clothing
"Scarf"	P13 (CP)	Everyday creativity and clothing
"Medals"	P13 (CP)	Clothing attachment
"Jewellery"	P14 (CP)	Clothing attachment
"Bag"	P15 (CP)	Clothing attachment
Types of fabrics		
"Suede"	P13 (CP)	Clothing attachment
"Faux fur"	P13 (CP)	Clothing attachment
"Leather / Leatherette"	P13 (CP)	
"Silk"	P17 (CP)	
"Wool"	P17 (CP)	
"Worn fabrics" (in need of repair)	P14 (CP)	Clothing attachment
"Crochet"	P13 (CP)	Clothing attachment
Features		
"Fringing"	P13 (CP)	Clothing attachment
"Contrasting textures"	P15 (CP)	
"Velcro"	P13 (CP)	Everyday creativity and clothing
"Zip"	P13 (CP)	Everyday creativity and clothing
"Pockets"	P13 (CP)	Everyday creativity and clothing
"Applique"	P15 (CP)	Everyday creativity and clothing
"Fringing"	P13 (CP)	Clothing attachment
Colours		
"Contrasting colours"	P13 (CP)	
"Colours of the 70s"	P13 (CP)	Clothing attachment
"Pops of colour"	P14 (CP)	
"Bright colours"	P13 (CP)	
Other		
"Textile artist, Celia Pym"	P16 (CP)	Clothing attachment
"Grayson Perry's Alan Measels"	P14 (CP)	Clothing attachment

The materials, objects and images suggested by participants were clustered to create a series of coherent pieces to be used within the themed object handling sessions. This process is discussed in the proceeding section **5.9 STEP 4:**

Designing the object handling sessions.

(3.1) Concepts underpinning the sessions

Not only did participants suggest specific materials, objects and images that could be used within the sessions as listed in **(3) Tools for the sessions**, participants spoke of ideas or concepts inspired by their engagement with the thematic cards. For example, participants suggested that sessions could be playful and provoke intrigue:

“It is something that is really fun and playful and it is really ...kind of to erm... kind of to... encourage this cheeky side of them, because I think everyone has that and it is still there you know - people want to laugh and they want to have fun you know.” P13 (CP)

“They can immerse themselves in and just experiment and be quite playful and that brings out a number of different responses in people.” P17 (CP)

“I think to get people in sometimes it is just ideas about being playful you know - we are going to have a go.” P17 (CP)

A further underlying concept that participants highlighted was the notion of clothing and attachment and the narratives that may be imbued within items:

“It is that nostalgic thing of touching it and remembering it somewhere. If something has got a stain on it – generally seen as a negative... but you remember where that stain came from... erm you know it is kind of like a map...” P14 (CP)

“Grandad also had a 90s style bucket hat that he always wore when gardening, it was oily and dirty from gardening and where it had worn on the top, he had stuck a piece of jay cloth in it to fix it.” P16 (CP)

P18 (CP), discussed the importance of sessions being group activities, whereby those taking part may be able to discuss similar or shared stories and experiences:

“Sentimental attachment ... it becomes when something turns in to errr... reminiscence - but in a social circle situation that is equally good I think.” P18 (CP)

A further and final concept outlined by participants was the notion of creating a sense of occasion, drama and challenge through the use of particular materials or objects within the sessions for instance:

“I think some people would really love it to be almost like operatic impression like being big and having lots of volume or being really long.” P13 (CP)

This concurs with P17's (CP) use of replica historic items of dress, and the ways in which such objects can challenge people to explore different characters:

“When you try it on you take the pose completely and suddenly people take on this gravitas as you can't breathe and suddenly you sit up straight and it is a way of ... and we talked of clothing nowadays and played around with these ideas.” P17 (CP)

The concepts discussed here informed the design of the three discrete object handling sessions. This is discussed in the following section. Images are also used to support the presentation of each object handling session.

5.9 STEP 4: Designing the object handling sessions

The findings presented above demonstrate the shared techniques and approaches that participants drew upon within their practice and when suggesting the ways in which the sessions for CYCLE 3 could be devised. Despite the more

specific suggestions presented in the theme **(3) Tools for the sessions**, participants often discussed multiple ways in which the thematic cards could inspire sessions. Thus, bringing together findings in order to design the object handling sessions proved challenging. The approach draws parallels with Ellingson's (2017) notion of crystallisation in qualitative research, whereby researchers engage with multiple representations in order to depict knowledge formed. The processes involved in designing the sessions are explained below.

Designing the sessions involved bringing together thematic findings. This involved, for example, connecting the ideas presented by participants i.e. **(3.1) Concepts underpinning the sessions** for instance, the notion of 'playfulness', with objects, images and materials that may evoke a sense of playfulness e.g. ambiguous textiles contrasting textures, and the use of bright colours. Mind maps were created in order to connect varying ideas for each object handling session (see **Figure 22**).

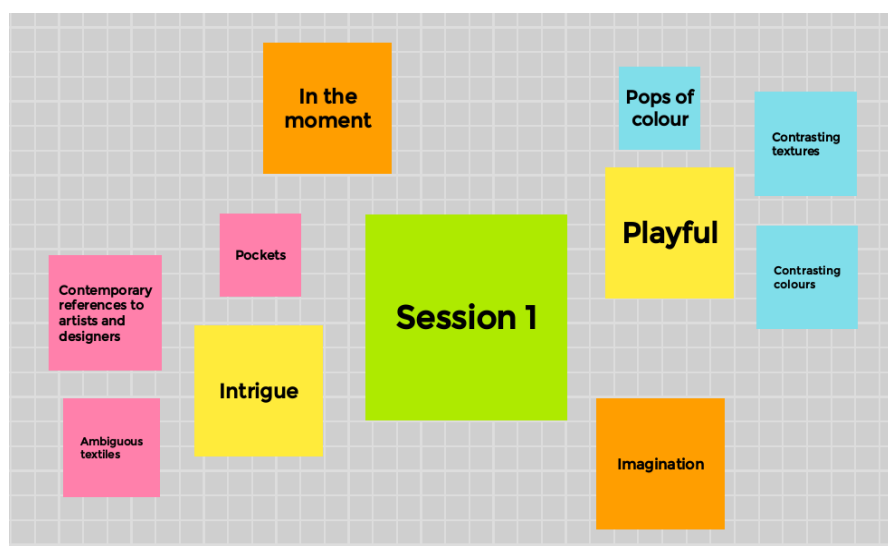


Figure 22. Using a mind map to connect ideas: 'Playful object handling session'

The mind maps resulted in refining the concepts i.e. themes, that underpinned each session. The following three sessions were developed:

‘Playful’ object handling session - this session was designed to provoke intrigue and encourage participants to be imaginative through the use of colourful, ambiguous objects and textile samples.

‘Narrative-based’ object handling session - this session examined the sentimental aspects of clothing and the way in which clothing can be imbued with stories and evoke storytelling. This session drew upon the work of artists Celia Pym and Grayson Perry using items that showed signs of wear e.g. threadbare or repaired items of clothing.

‘Dramatic’ object handling session - this session was designed to draw upon the expressive uses of clothing and the ways in which it affects a person’s posture through e.g. through the use of voluminous fabrics.

In order to explore and examine the above concepts i.e. ‘Playful’ object handling session, ‘Narrative-based’ handling session and ‘Dramatic’ object handling session, a mood-board was created for each session. A mood-board uses e.g. images, text and materials to depict a particular concept or certain topic. Mood-boards are often used in design disciplines e.g. graphic design, interior design, fashion and marketing, as a way in which to visually represent the overall ‘feel’ of an idea. Creating a mood-board for each session helped to refine ideas and depict how each session would be conceptually different. The mood-boards also inspired the types of objects, images and materials that may be used in each session.

The subsequent sections detail each object handling session illustrated with their representative mood-board alongside the objects selected for the session. Objects were selected, designed and created incorporating the findings from creative

practitioners, my background and experience as a workshop facilitator, and using feedback from my PhD supervisors.

‘Playful’ object handling session

The ‘Playful’ object handling session drew upon findings from creative practitioners whereby they suggested that sessions could be “playful” and “intriguing”, encouraging participants to use their “imagination”. Although play is commonly associated with children it occurs throughout the lifespan (Killick, 2013), thus the term has not been used to infantilise people with dementia.

The ‘Playful’ session drew upon creative practitioners’ suggestions of using a bright, bold colour palette alongside contemporary references to e.g. artists or designers. The session employed the use of familiar items and ambiguous textile samples to encourage participants to investigate and explore the items. The session therefore drew on different methods of engaging with items as advocated by participants, for example:

“Zooming in on features that are intriguing they are not beautiful, so it is almost like remove the beauty let’s just almost have these out of context zoomed in textures and things.” P14 (CP)

I selected the images for the moodboard⁶, see **Figure 23**. In the case of this session creative practitioners did not make direct reference to potential sources of

⁶ Images were selected from sources including: V&A Images i.e. Victoria & Albert Museum’s online repository: publications such as ‘Selvedge Magazine: The fabric of your life’ (a publication on textile craftsmanship): and design blogs, for instance, ‘POSTextiles’ i.e. a blog featuring works from postgraduate textile design students.

inspiration, unlike for instance, the 'Narrative-based' object handling session, whereby creative practitioners suggested the work of different artists.



Figure 23. 'Playful' Mood-board

Selecting the objects for the ‘Playful’ object handling session involved both sourcing existing objects and designing and creating a series of knitted textile samples (see APPENDIX Y for details). Items included:

- Contrasting textures in the form of different textiles
- Knitted samples that include pockets
- Brightly coloured large pieces of jewellery
- Tactile postcards - I altered the surface of the images using collage and embroidery techniques (this drew upon the collage technique suggested by P14 (CP) in **(3) Tools for the sessions**).

Due to the nature of the 'Playful' sessions, (it was decided using findings from creative practitioners, existing literature e.g. Chamberlain and Craig (2013) and discussions with the PhD supervisory team) that each participant would be given a box containing a similar set of items in order to potentially encourage and support participants' curiosity and imagination. Each box, although not identical, contained six similar items (following guidance from Johnson, Culverwell, Hulbert et al. (2017) on the amount of items used in object handling sessions) consisting of:

- Two handmade knitted samples
- A knitted pocket
- An item of resin jewellery
- Two tactile postcards
- Swatches of contrasting textiles

See **Figure 24** for the items created and selected for the session.

Tactile postcards



Resin jewellery



Knitted textile samples



Knitted pockets



Fabric swatches



Figure 24. Items selected and created for playful session

As presented in findings above see e.g. **(1) Curating the session**, selecting the objects to use within the session was not the only aspect of planning. I examined various ways in which I could present the materials, objects and images to participants. The research protocol stated that objects would be passed around the group, however this contrasted with the findings from creative practitioners, who talked of the need for participants to have their own individual work areas e.g. their own space to place items. I therefore explored different ways in which I could present the objects within the session. See **Figure 25** a mood-board created to examine how items could be displayed.

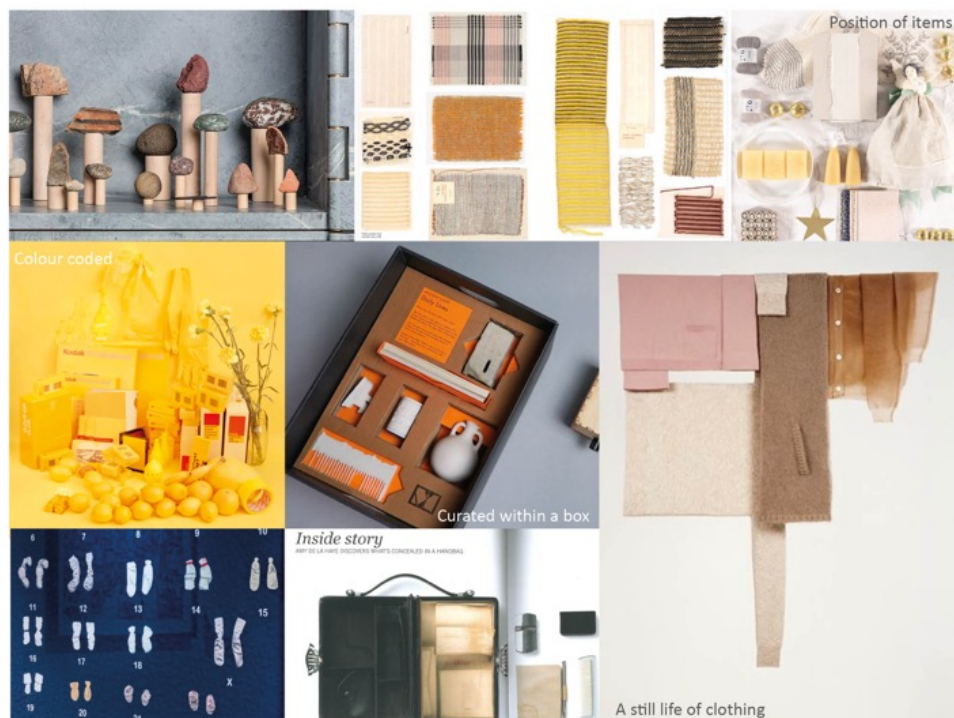


Figure 25. 'Curating objects' Mood-board

Figure 26 features two of the boxes created for the 'Playful' session.

Preparing the materials, objects and images for the 'Playful' session was arguably the most labour intensive of the three sessions, as preparation involved designing and creating knitted textile samples, sourcing suitable materials and imagery and creating tactile postcards. I also worked with contacts e.g. a jewellery designer, to source unusual items of jewellery as a way in which to provoke discussions. The subsequent chapter (**Chapter 6, 6.3 Structuring the object handling sessions**) details how the object handling sessions were carried out.



Figure 26. 'Birdseye view of two of the 'Playful' session boxes

'Narrative-based' object handling session

The 'Narrative-based' object handling session derives from findings whereby creative practitioners suggested that sessions could draw on the "sentimental" and "emotional" aspects of clothing, examining the ways in which clothing can evoke storytelling and the sharing of experiences. The session was inspired by artists suggested by practitioners i.e. the work of textile artist Celia Pym (see **Figure 27**), whose work includes collaborative projects in which she mends 'worn out' items of

clothing and Grayson Perry's teddy Alan Measles (see **Figure 27**). The session therefore contained images of both artists' works and also contained further items inspired by the concept of wear or worn out clothing e.g. P16's (CP) reference to her Grandfather's worn out hat which he wore when gardening. Thus, the session incorporated the use of items, fabrics, and clothing in which 'wear' was apparent. For instance, one creative practitioner spoke of the ways in which worn or threadbare items can explore notions of repetitive touch e.g. a worn-out cuff of a jumper or gloves with holes in:

"Threadbare can show that something has been touched a lot - it is like a patina of comfort that has been developed." P14 (CP)



Figure 27. Textile artist Celia Pym and Grayson Perry's teddy Alan Measles

Figure 28 is the mood-board created to inspire the selection of items for the sessions.



Figure 28. 'Narrative-based' object handling session

The items selected for the session were as follows (see **Figure 29**):

- Tactile postcards of Celia Pym and Grayson Perry's work - I altered surfaces to highlight areas of 'wear'
- Tactile postcards using images of clothing from 'Worn Stories' by Emily Spivack including embroidery and collage techniques
- An item of clothing with visible repair
- Accessories with signs of 'wear' e.g. handbag, wallet, scarf, brooch



Figure 29. Items selected and created for narrative session

Sourcing the objects for use within this session was a very different process to the 'Playful' session, as this session warranted objects with visible signs of use. I therefore sourced objects from vintage and charity shops. Although this process was not as time consuming as creating knitted textile samples, I also repaired an item of

clothing i.e. a woollen Aran jumper, adopting the style of textile artist Celia Pym in order to explore responses (see **Figure 30**).



Figure 30. Aran jumper with visible repair

The focus of the session was on the sentimental and evocative narrative aspects of such items. Participants were therefore encouraged to interact with the items as a group, passing items between each other, rather than having their own box in which items were contained (unlike the individual boxes created for the ‘Playful’ session). Thus, items were curated on a table with reference to the following layout techniques (see **Figure 31**).



Figure 31. Presenting items in 'Narrative-based' session

'Dramatic' based object handling session

The 'Dramatic' object handling session used suggestions from creative practitioners' that sessions might evoke the theatrical and "dressing-up" aspect of clothing, and the use of clothing to facilitate different feelings or presence see e.g.

(2.2) Creating different atmospheres. This session specifically drew upon the thematic card: 'Everyday creativity and clothing: Clothing as a vehicle for



Figure 32. 'Dramatic' object handling session

expression'. See **Figure 32**, the mood-board used to inform that materials, objects and images selected.

The session involved the use of lengths of fabrics as suggested by participants see **(3) Tools for the session**, that could be manipulated by participants to explore the drape, weight and texture of the fabric. This also referred to, for instance, P17's (CP) idea of using a replica ruff to explore the posture of a subject within a painting (see **(1.1) Sensory props**). Fabrics of differing lengths and weights were selected to explore how it may feel to wear different pieces. The fabrics were sourced from haberdasheries and selected from fabrics donated to the care home. A mannequin (a dressmakers stand) was used within the session to allow participants to explore manipulating fabrics to create shapes and forms. The objects selected were as follows (see below):

- Lengths of fabrics e.g. velvet, silk, satin, stiff cotton
- Tactile postcards.
- Mannequin

See **Figure 33** for the items selected.

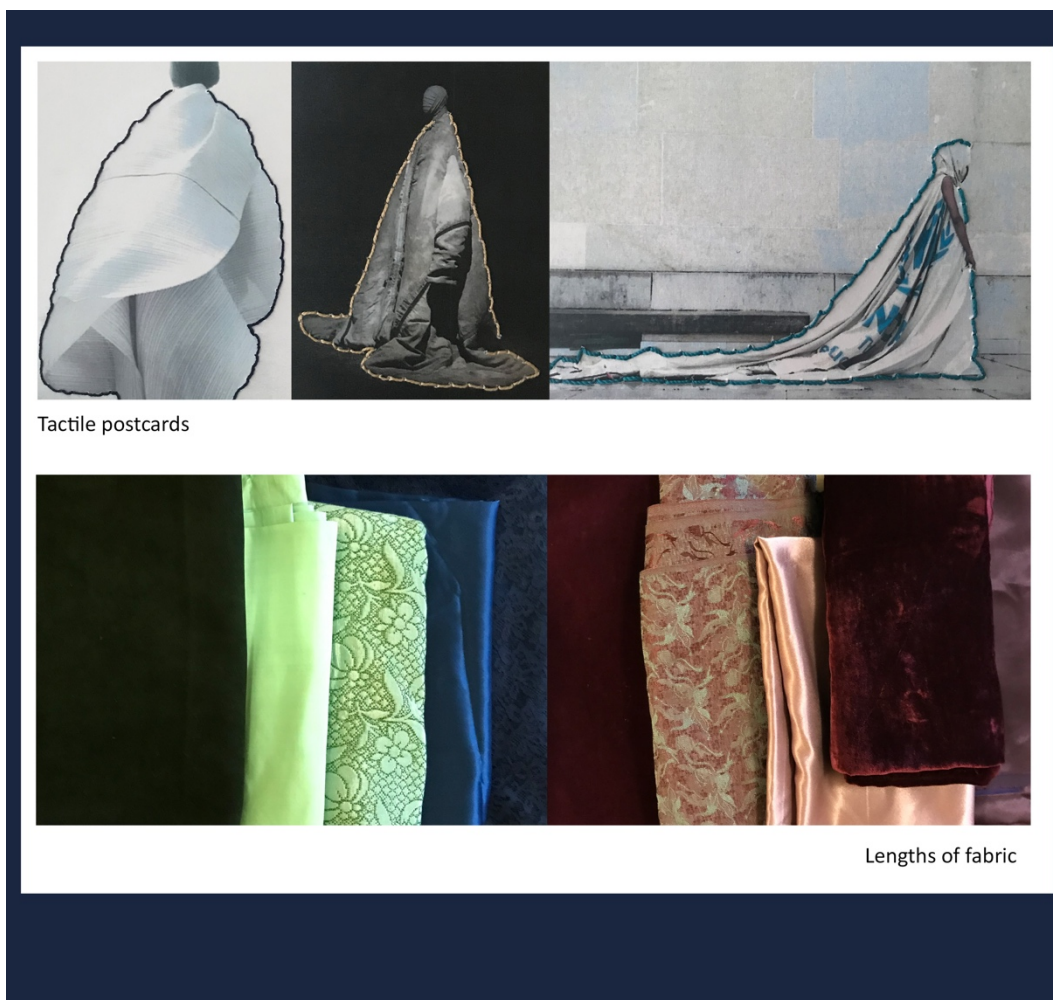


Figure 33. Items selected for 'Dramatic' session

The subsequent chapter (**CYCLE 3 Thinking with things: A series of object handling sessions**) details the ways in which the materials were used with participants within each of the three object handling sessions.

5.10 Discussion

Findings identified a number of techniques and strategies that were used to design and create three object handling sessions i.e. 'Playful' object handling session, 'Narrative-based' object handling session and 'Dramatic' object handling session. This discussion explores these findings in regard to holistic dementia care practices.

Firstly, findings demonstrate that the social and material context of health and social care spaces are important to people with dementia. For example, participants talked of creating spaces conducive to creativity through rearranging furniture, devising workspaces for groups and individuals and through bringing in sensory props, such as flowers, to transform the look and smell of the space. Additionally, participants discussed creating a supportive and enabling atmosphere through working with others within the setting. This finding contributes to the importance of the social and material context of health and social care settings (see e.g. Buse et al., 2018a; Campbell, 2019; Cleeve et al., 2020) through highlighting the complex spaces in care home settings and the impact that these have on individuals. With regard to clothing practices, this finding is of interest when considering how clothing can enhance temporal and spatial orientation (Twigg & Buse, 2013). Clothing can facilitate understanding, and this is often particularly important within certain spaces. For instance, anecdotally, I have found that the process of someone rolling up their sleeves or putting on an apron indicates the start of a creative session. Although seemingly mundane, these small acts can enable understanding, this is particularly important in care homes where it is often necessary to use the same room for multiple purposes e.g. the dining room may also be used for creative sessions.

Findings reveal a number of engagement and communication strategies employed by participants when working with people living with dementia. For example, one used a warm-up technique to bring people 'into' sessions. Such strategies demonstrate how practitioners sensitively encouraged and enabled people with dementia to join in with sessions. Participants also outlined how they supported people with dementia at an individual level e.g. providing individual workspaces, and at a group level, e.g. creating shared experiences through selecting music together.

This demonstrates an inherent relational approach (Zeilig, et al., 2019) to their practice. Interestingly, participants also explained the importance of challenging people with dementia through asking exploratory questions and inviting people to interact with specific items. For example, one participant discussed how they use unusual percussion instruments and ask people with dementia to decipher how they are played. The methods used by participants illuminate how creativity can support the strengths of people with dementia (Zeilig et al., 2019) and provide a sense of challenge and achievement.

Findings also indicate the expressive capacity that engaging with certain items can have for people with dementia. For instance, participants discussed how manipulating certain fabrics or putting on certain items of clothing can enable people to express themselves through e.g. adopting a particular posture or using gestural expressions. This connects with Killick and Craig's (2012) writing on the importance of creativity and communication:

“Each artform has its own language, and many of these do not require words for their expressive functioning, and we have found that people with dementia fall upon these languages with a new sense of purpose. They can be valuable for people to communicate with each other and with those without the condition.” (Killick & Craig, 2012:20)

Findings regarding the engagement strategies used and the expressive capacity that creativity affords people with dementia, are important to consider with regard to holistic dementia care practices. The notion of using creative approaches to enhance care practices is not new for instance, Clod Ensemble's Performing Medicine (n.d.) programme uses dance, theatre and voice coach training to develop

healthcare professionals' skills e.g. verbal and nonverbal communication.

Furthermore, there is an increasing body of literature that explores the role of the arts in medical education (Shapiro, 2012) and healthcare i.e. health humanities.

Despite this there is limited literature that explores the potential of the arts in enhancing care-workers practice. Future research could explore knowledge transfer between creative practitioners and care-workers and the potential impact on holistic dementia care practices. This could have implications regarding relational approaches to care, for instance, tasks associated with activities of daily living e.g. dressing, could be enhanced if informed by the engagement and communication strategies employed by creative practitioners.

5.11 Limitations and recommendations

Not only are findings applicable to holistic dementia care practices, this study highlights the potential use of thematic cards in future research. A number of recommendations are discussed in light of the limitations of this study.

Firstly, it is important to discuss the design of the thematic cards. The cards contained only text, as opposed to text and images, as the method sought to utilise the expertise of the creative practitioners to connect themes with specific images, objects and materials. The amount of text on each card was carefully considered so as not to be overwhelming, however participants often hypothesised about the context of the participant extracts and asked me to provide further details.

Additionally, the use of text inadvertently assumed participants' reading literacy i.e. their ability to understand, extract and reflect upon the information given. Participants were asked to engage with and reflect upon the thematic cards during the interview, and so may have felt pressurised to read and interpret the cards quickly. Although

participants were invited to take their time when reading through the cards, this is important to consider in order to develop the method.

Future use of the method may allocate a specific amount of time prior to the interview for participants to engage with the material. Alternatively, the method could be developed to use within a 'kit' that participants complete in their own time. The kit could contain e.g. instructions, thematic cards, and a sketchbook in which practitioners are invited to respond to the cards. Participants could then be invited to a follow-up interview (either face-to-face or over the phone) to discuss their responses. The developed method could support recruiting a broader group of participants, as the process may be more accessible to creative practitioners working across multiple roles / settings.

Despite the importance of meeting the needs of participants, it should be noted that the use of interviews within this study curtailed the open dialogue sought due to the lack of group discussion (Liamputtong, 2011). This was challenging and meant that I often needed to provide discussion points e.g. connect participants' ideas and ask participants to expand on them, as opposed to referring only to the prompts (see **5.3 STEP 2: Carrying out the interviews**). Therefore, when developing the method into e.g. a 'kit', participants could be invited to take part in a remote focus group discussion using e.g. Skype or Zoom. This could facilitate discursive dialogue whilst meeting the varied schedules of those taking part.

Not only is it critical to consider how participants interacted with the thematic cards, it is also important to note the extent to which I was able to respond to findings. The translation of the findings into images, materials and objects was subject to (1) my ability to source and create suitable items (both in terms of financial

resources and my skillset) and (2) the limited time (due to the use of multiple interviews as opposed to a focus group discussion) that I had to synthesise findings and design and create items. Future use of the method could allocate a longer period of time i.e. three – four months to the design, select and source the images, materials and objects. This would incorporate iterative feedback from creative practitioners as, although I worked closely with the supervisory team, continuous engagement with participants may have strengthened the design and development process. The method could also be adapted to facilitate multiple forms of engagement with the thematic cards. For instance, creative practitioners could be commissioned to respond creatively to one or more thematic cards and then be invited to discuss their pieces during e.g. a remote focus group. Such development of the thematic cards highlights the potential that this method has within design-led projects.

Despite the discussed limitations and subsequent recommendations, the thematic cards did elicit rich responses and participants interacted positively with the cards. For example, one participant said that the cards felt like “each individuals’ soul was on the table” P13 (CP). Similarly, multiple participants said that thematic cards felt familiar when reflecting upon their own experiences of working with people with dementia. This is powerful when considering how the thematic cards seemingly gave immediate access to CYCLE 1’s findings. The use of thematic cards could be developed into an accessible format for non-academic audiences, providing an alternative method with which to present findings and to explore opportunities for change.

5.12 Summary

This cycle of study resulted in the creation of three object handling sessions. Nevertheless, as presented in the discussion, the findings also have broader implications regarding the affective atmosphere of dementia care settings (Lupton, 2017) and the ways in which particular engagement strategies could be used to enhance relational approaches to care. Additionally, the novel method used could be developed to work with participants in different disciplines, across a variety of health and social care settings, to use within design-led projects, and be repurposed as a tool for dissemination of findings. The following chapter presents the use of object handling sessions as a research method and details how the sessions were informed by the current cycle of study (CYCLE 2) and the previous cycle of study (i.e. **CYCLE 1: Exploring clothing during wear**).

CHAPTER 6 CYCLE 3: THINKING WITH THINGS: A SERIES OF OBJECT HANDLING SESSIONS

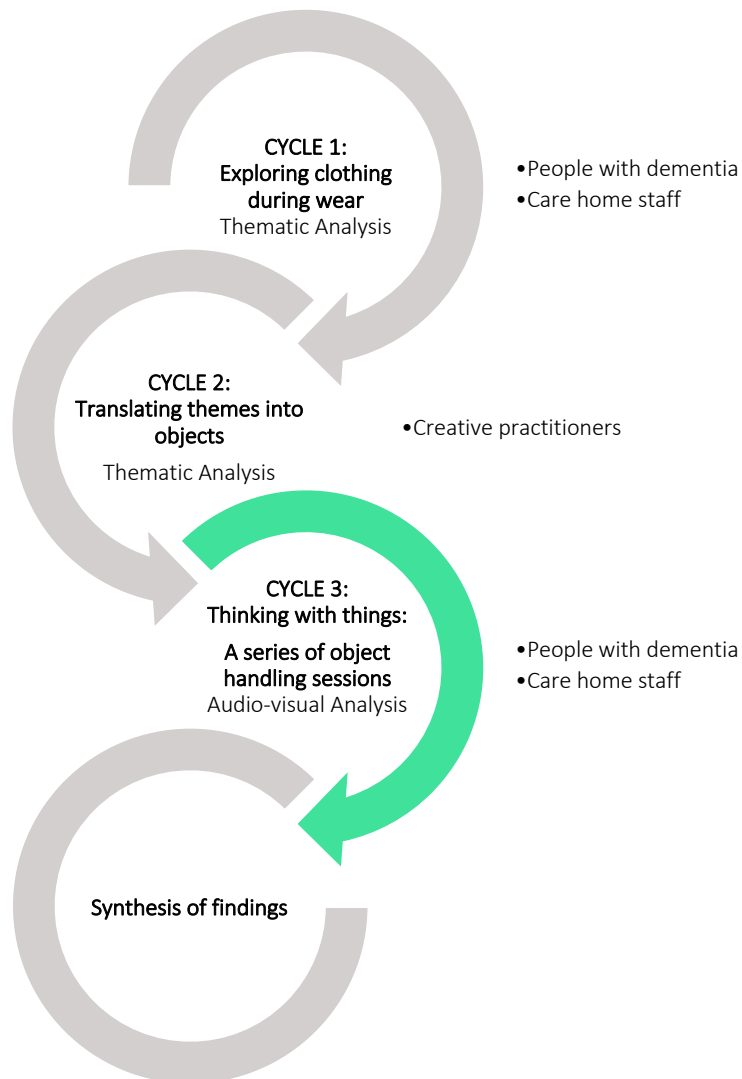


Figure 34. CYCLE 3: Thinking with things: A series of object handling sessions

6.1 Introduction

The title: '**Thinking with things: A series of object handling sessions**', is inspired by the work of Chamberlain and Craig (2013, 2016, 2017) and represents how this cycle of study invited participants to engage with, and respond to, a series of materials, objects and images. These were selected using the findings from the previous two cycles of study (i.e. **CYCLE 1: Exploring clothing during wear** and **CYCLE 2: Translating themes into objects**).

The aim of this cycle of study was to examine the potential of clothing in the holistic care of people with dementia. This was achieved by exploring participants' experiences within a series of object handling sessions.

6.2 Object handling sessions as a research method

As detailed within **Chapter 3, Method**, a Sensory Ethnographic (SE) approach to research necessitates that the researcher and participants engage in innovative forms of knowledge formation through e.g. the use of creative research methods. Object handling sessions were used within this study as a creative research method as the use of materials, objects, and images can be powerful in generating understanding of people's lives (Chamberlain & Craig, 2013; Woodward, 2020) and can support the participation of people with dementia in research. For example, although different in approach, Twigg and Buse (2013) worked with people with dementia in reminiscence groups to explore vintage items of clothing.

Object handling sessions involve engaging with and exploring sensory items, through for instance: interacting with items, selecting items, discussing, critiquing and reflecting upon the objects. Those taking part in object handling can engage with the activity in different ways through e.g. exploring the object's tactile qualities,

discussing its heritage or sharing stories relating to an item. Object handling studies carried out with people with dementia have been found to increase levels of wellbeing (Camic, Hulbert, & Kimmel, 2019), promote engagement (Griffiths et al., 2019) and prompt memories (Chatterjee, 2008; Thomson & Chatterjee, 2016).

The use of object handling sessions in this study aimed to explore participants' experiences and responses 'in the moment', as opposed to measuring the effects of taking part. The use of object handling sessions responds to the increased use of novel qualitative methods when working with people living with dementia (Bartlett & O'Connor, 2010; Twigg & Buse, 2013; Moss & O'Neill, 2019; Phillipson & Hammond, 2018) and the use of innovative methods within SE research (Pink, 2015). See **Chapter 3, 3.2 Conducting qualitative research with people with dementia**, for a detailed discussion.

6.3 Structuring the object handling sessions

The structure of the sessions was informed by object handling studies involving people with dementia (see e.g. Camic et al., 2019; Griffiths et al., 2019; Johnson et al., 2017). Therefore, each object handling session was designed to be up to one hour long, involving five - six objects (Johnson et al., 2017), with up to eight people (Johnson et al., 2017). Each session was themed as this has been found to be useful in guiding and structuring sessions (Griffiths et al., 2019). The format of sessions were derived from **CYCLE 1: Exploring clothing during wear** and **CYCLE 2: Translating themes into objects** and were themed as follows: 'Playful', 'Narrative' and 'Dramatic'. A detailed presentation of each theme can be found in **Chapter 5, 5.9 Bringing together findings: Designing object handling sessions**.

Object handling timetable

A total of seven object handling sessions were carried out using the following timetable, see below.

Table 12. Object handling timetable

Week No.	Session theme	Session length	No. Participants with dementia	Total in sessions (with supporting member of staff)
GROUP A				
Week 1	Playful	35 minutes	2	3
Week 2	Narrative	40 minutes	2	3
Week 3	Dramatic	55 minutes	2	3
GROUP B				
Week 4	Playful	30 minutes	1	2
Week 5	Narrative	40 minutes	2	3
Week 6	Dramatic	35 minutes	1	2
GROUP C*				
Week 7	Playful	15 minutes	1	2
*This session was offered on a one-to-one basis to enable a participant with dementia to participate as she had been unable to take part in the previous sessions.				

Previous object handling studies have reported differing numbers of sessions. For example, Griffiths et al. (2019) carried out object handling sessions over six consecutive weeks with each participant taking part in between two-six sessions. Repeating the same sessions, e.g. two 'Playful' sessions, enabled participants who were unable to participate in one session to join the following one if they wished to.

Object handling guide and prompts

Each object handling session followed the structure outlined in **Table 13**. The guide and prompts used were informed by the work of Thomson and Chatterjee (2016), object handling studies carried out with people with dementia (e.g. Griffiths et al., 2019) and my experience leading creative workshops in dementia care settings. The guide was used flexibly, as due to the distinct themes each session was structured slightly differently. For example, during the 'Dramatic' session I worked with participants to create designs on a mannequin and so prompts were adapted for use in the session.

Table 13. Object handling session guide and prompts

Structure	Prompts
Introduction (2-3 minutes)	
I introduced the session to participants, briefly talking through the research project and the session that day.	<ul style="list-style-type: none">• Do you have any questions before we begin?
Main activity (15-30 minutes)	
I led in handing items to participants. Whilst the objects were being handled, I asked questions about the items and encouraged conversations between participants. This typically continued until all items had been discussed.	<ul style="list-style-type: none">• What does the object feel / look /smell like?• What do you think about the object?• How do you feel about the object?• Do you have any other thoughts about the object?• Do you have any questions about the object(s)?
Extension activity (5-10 minutes)	
Participants were asked to select one of the items describing why they had chosen it.	<ul style="list-style-type: none">• Would you like to take a look at the objects and choose one to handle?• Why did you choose that object?• Can you think of any experience that might relate to the object?
Session close (2-3 minutes)	
I summarised the session. Participants were debriefed and thanked for taking part.	<ul style="list-style-type: none">• Would you like to take part in the next session?

Facilitating the object handling sessions

Studies using object handling sessions typically involve specialist facilitators: Camic et al. (2019) worked with museum staff who had received dementia-friendly training; whilst Griffiths et al. (2019) worked with an arts educator who was experienced at facilitating creative activities with people with dementia. As Leavy (2015) notes, there are close synergies between the qualitative researcher and arts-based practitioner whereby both engage with creative, malleable and iterative approaches to shape their practice. Therefore, for the purpose of this project, I facilitated the sessions. I drew upon my experience of carrying out creative workshops in a range of settings e.g. care homes, hospitals, hospices, and my experience of working with people with dementia (see *Reflexive note 12*) .

Reflexive note 12: Facilitating Week 3's 'Dramatic' object handling session

This session involved the use of multiple fabrics which I supported participants in draping and creating forms around a mannequin. It was a very powerful session and captured participants' imagination. It was also very challenging as it was particularly 'hands on'. Participants were enthusiastic and had many ideas. The member of staff supporting the session got very involved and helped with holding fabrics in place whilst I responded to the design ideas of participants, however if this hadn't had been the case, I would have struggled to create the designs. Creating participants' ideas on the mannequin was a wonderful experience but quite a significant shift from the previous two sessions, in which my role was a little more passive e.g. passing items between participants, sharing in handling an item, rather than creating forms on the stand. Different techniques could have encouraged other responses and it would have been interesting to have had table top mannequins for participants to use.

6.4 Carrying out the object handling sessions: Practical considerations

Alongside the structures presented above, further practical factors were necessary to consider when carrying out the object handling sessions. These were informed by carrying out research encounters during CYCLE 1, see **Chapter 4, 4.3 Research encounters** for a detailed discussion.

As found in **CYCLE 1: Exploring clothing during wear**, routines within the care home impacted the research. The dates and times that the sessions were carried out were selected in consultation with care home staff (including team managers, team leaders and activities staff) and participants. Sessions were carried out weekly on Monday afternoons, between 4pm-5pm, on the floor of the care home in which participants lived on i.e. the floor on which the participants' bedrooms were.

There were multiple processes involved in preparing for each respective session:

1. I arrived at the care home late morning to talk with either the team manager or team leader and asked how participants were that day and whether they may be well enough to participate in the session that afternoon.
2. Dependant on (1), I met with participants before lunch and asked if they would like to take part in the afternoon session.
3. I then met with the supporting member of staff and talked to them about the session that day and who may be participating.
4. I came back to the care home mid-afternoon and set up the room. This involved bringing items in to the space, moving furniture and ensuring

that there was enough seating in the room for participants, staff and myself.

5. Approximately 30 minutes prior to carrying out the session I met with participants and the supporting member of staff. I spoke to participants about taking part in the session and if they still agreed to participate, the member of staff and I assisted participants to the room.

A suitable space in which to carry out the research was important and so I worked with the team leader to ensure that the same room was available for each session. This met both ethical requirements and supported participation. See **Chapter 4, 4.3 Research encounters** for a discussion on the importance of space when supporting participants with dementia. Setting up the room involved attending to issues detailed in the risk assessment (see APPENDIX Z) such as ensuring walkways were clear and arranging furniture in the space. For example, each participant had a small table next to their chair which they could place objects on, enabling them to have their own space in which to explore items (see **Figure 35**). This utilised findings from creative practitioners who discussed the importance of

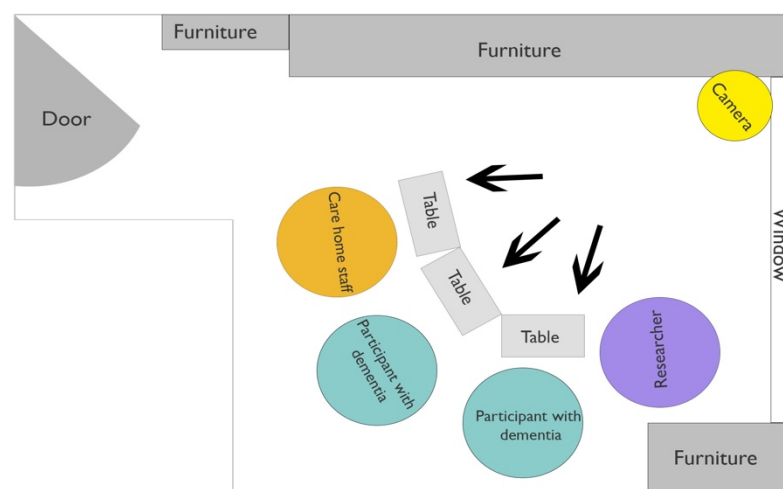


Figure 35. Example layout of the space

curating the space when working with people with dementia (see **Chapter 5, 5.8**

Step 3: Findings) (see *Reflexive note 13*)

Reflexive note 13: Setting up the room

The position of the room on the floor of the care home meant that I had to travel through communal spaces. The figure below shows my path - I had to walk through a seating area where people sat, facing the dining room. Walking through this space was challenging as I did not want to be disruptive. For example, on one instance, I had not been told that there was a birthday party taking place in the dining area, on arriving on the floor to prepare the afternoon session I saw the celebrations. I therefore delayed the start of the session until after the birthday party. Despite such challenges, carrying items through the space provoked lots of interesting feedback. People would often ask what was going on and if they could join in. This was difficult to manage as many of these people were not eligible to take part or had not been identified as potential participants by the team manager.

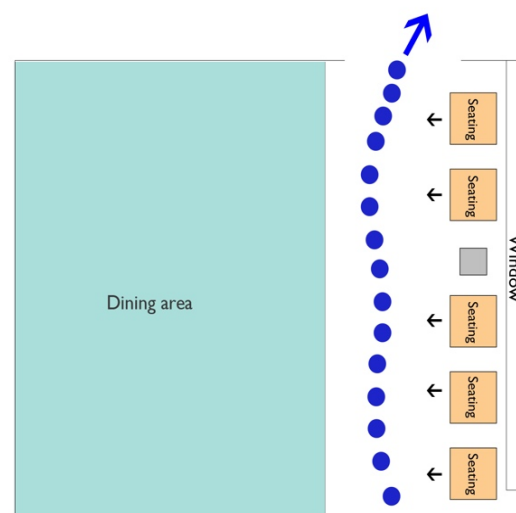


Figure 36. Route to the room

6.5 Video recording the object handling sessions

Video was used to record each object handling session. There is growing interest in the use of video to support qualitative researchers in making sense of experience and in acknowledging a variety of modalities such as, verbal, visual, and

touch (Reavey & Prosser, 2012). Yet research ethics committees e.g. NHS Research Ethics Committees, can be reluctant to approve the use of visual methods when working with people with dementia (Ward & Campbell, 2013b). For example, Ward and Campbell (2013b) received an unfavourable ethical opinion and were required to rewrite and resubmit their application, as the committee suggested that they did not give a clear rationale as to their use of video recording with people with dementia. This section explains the importance of video recording within this cycle of study.

As highlighted in earlier chapters, people with dementia may struggle to articulate themselves verbally due to cognitive impairments and language deficits so nonverbal expressions e.g. gesture and actions, are particularly important. The use of video can capture such expressions. Previous studies conducted with people with dementia have used video recording as a method of data collection, each with different foci, see e.g. Dowlen, (2018), Morse and Chatterjee (2018), Ward and Campbell (2013a). For instance, Dowlen (2018) video recorded participatory music sessions carried out with people with dementia in order to examine participants' 'in the moment' experiences. Not only has video been used when working with people with dementia, Pink and Leder Mackley note the worth that video recordings have within SE research:

“Video of course does not record invisible elements like smell, warm or cold air or the feel of the carpet or wooden floor. Yet in recording what is said about it, facial and bodily expressions and performance, the sound of footsteps and visible and spoken referents, it has the potential to invoke empathetic responses to these experiences” (Pink & Leder Mackley, 2012 [online]).

For the purpose of this research video recording was used to capture both verbal and nonverbal interactions within the object handling sessions. Recordings were only viewed by myself and the PhD supervisory team. The use of video recording enabled me to 're-visit' the research encounters i.e. object handling sessions and engage with continuous observation i.e. review the footage (Morse & Chatterjee, 2018).

To support the process of reviewing the video footage, field notes were made as soon as possible after each object handling session and expanded upon within 24 hours of the session(s) to ensure detailed recall. Additionally, I engaged with reflexivity. Contextual details recorded through field notes and reflexive engagement, can support the researcher when re-visiting the research encounter, for instance:

"I was reminded of the importance of the sensations of being there in the garden, for example of the ground underfoot, the weather. This embodied, sensorial and emotional engagement with the materials was crucial to my analysis." (Pink, 2015:146)

The combination of video recording, field notes and practicing reflexivity was therefore deemed appropriate considering the creative research methods used within this cycle of study. Nevertheless, the use of video posed a series of practical, technical and ethical considerations when working in a care home setting with people living with dementia.

Video recording: Practical and technical considerations

Video recording the sessions involved specific practical and technical considerations. As noted by Luff and Heath (2012), video recordings are subject to a series of factors including: what the camera is recording, where the camera is positioned, and the type of footage sought. These factors are crucial when using

video in qualitative research as they greatly impact upon the footage i.e. data, created.

Using the technical details presented by Luff and Heath (2012) and induction training carried out with UWL's School of Film, Media and Design, a Canon XF100 camcorder was selected to record the sessions. The built-in microphone was used to capture audio; however, an audio recording device was also used in the case of technical difficulties. The camcorder was lightweight, user friendly and compact. In order to capture the detail of the object handling sessions whilst focussing on the interactions of the three-four participant groups, a static mid-shot i.e. whereby the camera was held in a fixed position on a tripod, was selected. This enabled details and interactions to be captured whilst facilitating my 'hands-on' role during in the session. Heath, Hindmarsh, and Luff (2010) suggest that using a camcorder in a fixed position supports the researcher in 'joining in' as opposed to positioning the researcher behind the camera as the cameraperson. During each session the camcorder was positioned in the corner of the room, at a height to capture participants when seated (see **Figure 37**).



Figure 37. Position of camcorder

Due to the range of practical and technical considerations involved in video recording, I conducted a trial session (without participants) at the care home. See APPENDIX AA for *Reflexive note 14* on the session. Alongside the extensive practical and technical considerations involved in video recording in the care home, there were a number of ethical requirements to consider.

Video recording: Ethical considerations

Video recording poses a number of complex ethical issues when working in a care home with people with dementia, namely consent, confidentiality, and potential distress. This section provides an overview of the ethical considerations, however, see APPENDIX D for an exhaustive presentation.

Participant consent, or where appropriate consultee assent was received prior to carrying out the object handling sessions. As noted above, I worked closely with care home staff prior to approaching participants. These interactions were important in ensuring that I adhered to ethical considerations (see **Chapter 3, 3.7 Recruitment** for details regarding the consent process and ethical considerations). Participant consent was under constant negotiation (Dewing, 2008) and this included during video recording the sessions. Video recording only involved participants where informed consent or consultee assent had been received. Signage was used on the door of the room to ensure that it was apparent that videoing was taking place for the purpose of the research. I asked participants to confirm that they were happy for the session (and videoing) to start and told participants when the recording started. During the session I reiterated that the camcorder was still recording. The camcorder was immediately turned off at the end of the session.

The use of the camcorder was anticipated to potentially cause participants distress, consequently a protocol was developed to support participants (see APPENDIX S). In an attempt to avoid distress, the research protocol stated that a member of staff familiar to participants joined and supported participants during each session. The member of staff was asked to make me aware if they felt that a participant was showing signs of distress. It was reiterated at the start of each session that participants could stop taking part at any time and that they could let me know if they wanted the camera to be turned off. Although participant distress was anticipated, it did not occur and all participants, except one (due to health reasons), took part in multiple object handling sessions.

6.6 Participants

Participants were sampled purposively according to the method detailed in **2.7 Recruitment, Method Chapter**. Identifying potential participants involved the team manager and team leader's careful consideration of group dynamics i.e. who may want to take part in the same session and work together. The total number of participants recruited for CYCLE 3 was five people with dementia; the research protocol stated that no more than six people with dementia would be recruited for this cycle of study. Care home staff and relatives/friends were approached to take part however care home staff opted to support the sessions rather than participate, whilst, no relatives/friends expressed interest in participating.

See **Table 14** participant self-reported demographic information. As in CYCLE 1 all participants in CYCLE 3 were female; this was not deliberate and potential male participants were approached to take part. Two potential male participants were identified by the team manager; however, one participant did not wish to take part, and one took part in a fortnightly activity that took place at the same time as the object handling sessions. See **Chapter 4, 4.6 Participants** for a discussion of the care home population and how this may have impacted recruitment.

Table 14. CYCLE 3: Participant self-reported demographic information

Participant code*	Gender	Age	Ethnicity
GROUP A			
P19 (PWD)	Female	86	British
P20 (PWD)	Female	79	White British
GROUP B			
P21 (PWD)*	Female	81	White American
P22 (PWD)	Female	Undisclosed	British
GROUP C			
P23 (PWD)	Female	Undisclosed	Undisclosed
*Note, participant P21 also took part in CYCLE 1.			

6.7 Audio-visual analysis

Analysing audio-visual data is an interpretive method. Familiarisation with the context and setting in which the video recording was made enable researchers to make sense of the recordings (Knoblauch & Tuma, 2020). Pink (2009) claims that for the SE researcher, audio-visual data can be a way in which to re-engage with the specific research encounter as they can “re-encounter the sensorial and emotional reality of the research situation” (Pink, 2015:121). For example, Campbell and Ward

(2017), in their research exploring people with dementia's experiences of hairdressing salons, said that during their audio-visual analysis they were:

“Able to continue to construct knowledge and develop our understandings through our sensory and embodied engagement with the video captured in the field whilst watching back and re-experiencing the salon spaces and the feelings.” (Campbell & Ward, 2017:108)

In the case of this project, the video recordings enabled me to re-visit and re-engage with each object handling session. This reinforced re-living and remembering my embodied experience in my dual role as facilitator and researcher.

There are varying forms of visual analysis and the ways in which researchers engage with the analysis is context specific. I chose an analytic process that would enable me to explore and re-engage with the embodied and sensory experiences of the object handling sessions. Kristensen (2018) uses the metaphor of peeling an onion to describe an embodied analysis process, in which video data is engaged with as a series of layers, each layer is analysed in relation to the next:

1. Foregrounding bodies - the visible layer
2. Considering talk in combination with body - the audible layer
3. Including the environment - the material layer
4. Depth and adjustment through participant perspectives - the emic layer

(Kristensen, 2018:8)

Pink's work on visual analysis (2015), Kristensen's (2018) embodied video analysis process, and Braun et al.'s (2019) reflexive thematic analysis process influenced my approach to analysing the video data. I practiced reflexivity throughout

the analysis process, using visual journals to support this e.g. using sketchbooks including mark making, and creating textile samples.

The analysis process involved:

1. *Familiarisation with the data.* Initial review(s) of the video and initial note taking. Alongside reading and re-reading field notes and reflexive notes.
2. *Coding of video data without audio.* I watched the video at micro level i.e. making notes at 30-60 sec intervals following Kristensen's (2018) process of watching the video without audio to attend to nonverbal expressions.
3. *Coding of video data with audio.* I employed the same process as step 2 i.e. making notes at 30-60 sec intervals but watching the video with audio.
4. *Generating initial themes.* I looked for potential patterns between the coded data in order to create initial themes.
5. *Creating final themes.* I reviewed the initial themes and refined them, renaming and clustering them together under umbrella themes where appropriate.
6. *Writing up.* I wrote the final themes with supported extracts, the extracts included both transcribed verbatim and observational notes made from the video recordings.

6.8 Findings

Findings are presented as follows, each master theme and subsequent subordinate theme(s) (see **Table 15. CYCLE 3: Thematic findings**) are detailed alongside extracts from the object handling sessions. I have used both participant verbatim (noted by speech marks (“”)) and observational notes (presented in *italics*) taken from the video recordings to support the presentation of findings. Where necessary I have included notes in [brackets] to support understanding, for example, the words or actions of a member of care home staff involved as a supporter in the session. To support understanding I have included figures of the textile samples, postcards and objects that participants interacted with. Additionally, I have referred to the session that the extract derived from i.e. the theme of the session ‘Playful’, ‘Narrative’ and ‘Dramatic’ and the week e.g. Week 1’s ‘Playful’ session. See **Table 12. Object handling timetable** for the sequence of the sessions.

Table 15. CYCLE 3: Thematic findings

Master Theme	Subordinate theme
(1) Critical engagement	(1.1) Togetherness (1.2) Mini moments of engagement
(2) Improvisation and imagination	(2.1) Playful moments
(3) Embodied knowledge	(3.1) Haptic knowledge
(4) Taste: The look and feel	(4.1) Choice, selection and design

(1) MASTER THEME: Critical engagement

The theme **(1) Critical engagement** refers to the multiple ways in which participants engaged with the materials, objects and images used within the sessions. For the purpose of this project the theme characterises participants’ tendency to analyse and deduce information about the items within the sessions.

The theme encompasses the multifaceted ways in which participants engaged critically with the items through e.g. exploring the tactile qualities of an object or analysing the aesthetic qualities of a material. The example below details P20's (PWD) analysis of a knitted textile sample in week 1's 'Playful' object handling session:

P20 (PWD) held the knitted textile sample and turned it over, talking as she did so: "Something like that there..." She seemed to be exploring what the piece could be used for ... "What could we use it for?" ... She carefully analysed the textile sample, exploring the weight of it - balancing it across the palms of her hands. She ran her hands over the surface, examining the feel and texture of the knit... she then invited everyone to engage with the sample – holding the item up. "You see?" ... looking at the sample and talking quietly to herself... "It isn't a pocket." P20 (PWD)

Similarly, P21 (PWD) also engaged with a similar process of critiquing a knitted textile sample in Week 4's 'Playful' session, whereby she worked methodically from the top to the bottom of the knitted textile sample:

Laughing P21 (PWD), working meticulously across the surface of the knitwear, examining the lace hole pattern. “I can get my baby finger in this...” She smiled, raising her hand to show me, with the knitted sample dangling from her finger. “So, I presume I can get it in the other hole.” Laughing as she did so, she repeated the process moving from one lace hole to the next.



Figure 38. Knitted sample used by P21 (PWD)

P21's (PWD) process of examining the textile sample, may have been prompted by the defined sections of the knitted textile sample (see **Figure 38**). Notably, within the 'Playful' sessions, the textile samples used were ambiguous i.e. the textile samples did not have an apparent function and were not easily identifiable, and provoked interesting responses e.g. participants discussed what the samples could be used for. For instance, P20 (PWD) considered how practical and durable one of the textile samples was if it were to be a bedspread:

“Would not be practical as a bedspread – it wouldn’t last long enough” P20
(PWD) *gestured as though pulling at the decorative loops on the knitted textile sample, seemingly demonstrating that the loops could get caught or pulled.*

Participants demonstrated high levels of engagement with the textile samples, yet the tactile postcards evoked different critical responses. For example, in Week 5’s ‘Narrative’ session, P21 (PWD) was concerned that was she not able to deduce much information from the tactile postcard card (see **Figure 39**) as only the person’s shoes were visible:

P21 (PWD): “Yeah... I suppose talking about the lace up shoes. We don’t have much to say about the character because it’s cut off...”

Rebecka: “Mmmm.”

P21 (PWD): “We can’t see the rest of them, but I could ask you something about it because you may know – on the top of the toes - that’s snow?”

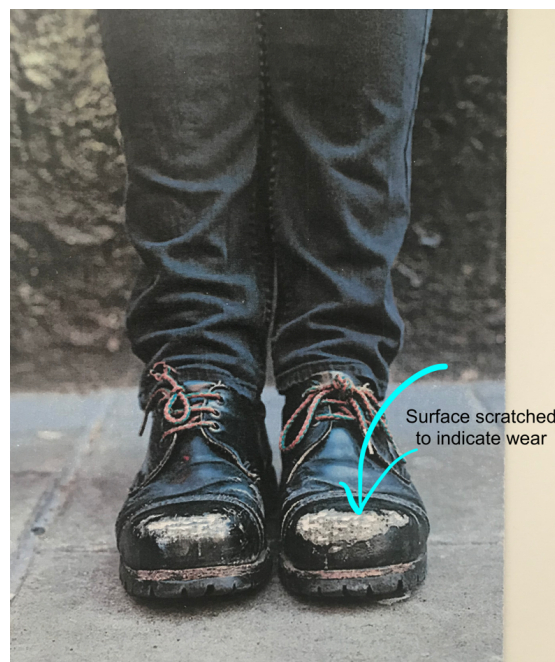


Figure 39. Tactile postcard used in 'Narrative' session

Interestingly, where the 'whole person' i.e. a full-length view of a person, was visible on the tactile postcards, participants hypothesised as to their identity, they also voiced opinions about the persons' character:

P22 (PWD): "Probably she has appeared in films ... As I really don't know who the hell she is, it strikes me that she looks as though she has performed as an actress and that she may well be British because of the stupid thing around her neck."

P23 (PWD): "She looks self-impressed!"

Thus, rather than exploring the tactile cards as an object, participants were drawn to the people featured on the cards.

Although the participant extracts presented here focus on individuals' one-to-one critical engagement with items, participants often invited others within the session to explore thoughts and ideas together. This social aspect of engagement was important as there were moments within sessions when participants collaboratively critiqued items.

(1.1) SUBORDINATE THEME: Togetherness

The subordinate theme **(1.1) Togetherness** explores how participants worked collaboratively to critique and develop ideas during the sessions. The theme also encompasses the ways in which participants invited responses from me (as the facilitator) and the supporting member of care home staff. The following example is taken from Week 3's 'Dramatic' themed session. During the session participants selected fabrics and I worked with them to create designs on a mannequin. The

example reveals how participants worked together, demonstrating the social interactions within the sessions. For example, P19 (PWD) typically reinforced P20 (PWD)'s ideas, as P20 (PWD) often took on a leadership role within the sessions yet sought affirmation from P19 (PWD).

P20 (PWD): "Am I being dogmatic?"

P19 (PWD): "No – you're giving suggestions..."

Rebecka: "Ok, so a dropped waist?"

P20 (PWD): "No waist."

P19 (PWD): "No waist at all."

P20 (PWD): "Straight down." *Motioning a column like shape with her hands.*

P19 (PWD): "Oh, yes alright." ... *the session continued and then moved on to consider the design created:*

P20 (PWD): "I think plain is elegant – don't twiddle it."

P19 (PWD): "No, quite right."

Although the example presented demonstrates how some participants worked together, the example also highlights a challenging dynamic i.e. whereby P20 (PWD) took the lead, potentially dominating the involvement of P19 (PWD). This highlights the need for individualised support to ensure the full participation of individuals in sessions.

A further interesting example, from Week 5's 'Narrative' session, details the moment that a participant took on a facilitator role within the session:

*P21 (PWD) picked up the 'Alan Measles' tactile postcard (see **Figure 40**)*

P21 (PWD): “Ok, I am going to interview the pair of you now...” *She held the card up for P22 (PWD) and me (Rebecka) to look at.*

P21 (PWD): “What does this remind you of?”

P22 (PWD) *smiled*: “Cuddly teddy bears we’ve had.”

P21 (PWD) passed the card to P22 (PWD) – P22 (PWD) held the card out in front of her and then wrapped her arms around her body, as though cuddling a teddy bear.

P22 (PWD): “Reminds me of my fluffy doll, it wasn’t a teddy bear it was a fluffy pillowcase you zipped up ... erm ... but this isn’t at all a doll, but it reminds me of her...”

P22 (PWD) passed the card to me and said, “How about you?”

Rebecka: “I didn’t have a teddy bear either; I had a cuddly toy elephant.”



Figure 40. ‘Alan Measles’ tactile postcard

Although not seemingly an example of 'togetherness', as P21 (PWD) directed the question at P22 (PWD) and myself, this moment conceptually brought me 'into' the session, shifting my role from facilitator to that of a participant enabling me to share my experiences with participants.

This theme identifies how participants worked together, bringing others 'into' the sessions, yet also demonstrates challenges faced e.g. group dynamics, leadership, agreeability.

(1.2) SUBORDINATE THEME: 'Mini moments' of engagement

Within the themes **(1) Critical engagement** and **(1.1) Togetherness**, it is apparent that participants varied in how they engaged with the materials, objects and images used within the sessions. For the purpose of this project, this subordinate theme i.e. **(1.2) 'Mini moments' of engagement** refers to fleeting, typically nonverbal moments within the sessions that were captured due to the use of video recording. The below example is taken from Week 1's 'Playful' session. During the session, participants were each given a box containing a series of themed knitted textile samples, fabric swatches, tactile postcards and items of sculptural jewellery (e.g. large necklace, resin ring). The example depicts participants individually exploring items at the same time as one another:

*P19 (PWD) held the knitted textile sample (see **Figure 41**) close to her face. Leaning her chin on the pompoms, slowly she gently rubbed the pompoms back and forth under her chin. She smiled slightly, as she repeated the motion. The action seemed to be comforting / soothing.*

Meanwhile, P20 (PWD) immediately lifted a textile sample up and then held it out in front of her, as if analysing the piece. She was very animated and

moved her arms in large, gestural, sweeping movements when talking about what the textile sample could be used for. [At this point she discussed making the textile sample into a bedspread].



Figure 41. Textile sample used by P19 (PWD)

As demonstrated within the example, participants differed in their responses in terms of both their actions and their pace of engagement. Whilst P19 (PWD) engaged slowly and nonverbally with the sample (i.e. a mini moment of engagement), P20 (PWD) was very animated in her response and moved quickly whilst talking – seemingly a more overt example of engagement.

There were many further examples of ‘mini moments’ of engagement whereby participants intuitively handled a material or object. For instance, P22 (PWD) whilst talking about a possible design that could be created in Week 5’s ‘Dramatic’ session, sat stroking a silk-like lining fabric on her knee. She didn’t comment on what she was doing, she continuously and innately stroked the fabric as she talked. Similarly, P21 (PWD), who on finishing talking about a resin ring that she had tried on, continued to handle the ring, moving it across the tips of her fingers she circled the tip of her

thumb as though about to put it on. Her actions seemed intuitive. A further, similar example, was when P19 (PWD) had the large, thick Aran (see **Figure 30**) jumper used during the 'Narrative' sessions (i.e. Week 2 and Week 5) on her knee:

P19 (PWD) pulled the jumper higher onto her knee as it had started to slide onto the floor. [I was concerned that the jumper was quite heavy on her knee and so asked if she was ok with it.]

Rebecka: "How does it feel on your knee?"

P19 (PWD): "Good."

Rebecka: "Not too heavy?"

P19 (PWD) didn't reply. The member of staff in the room asked if it was warm and P19 (PWD) nodded and tightly held on to the jumper on her knee.

Although, these nonverbal moments of engagement may seem mundane, the theme highlights the multifaceted ways of engaging during sessions i.e. that engagement can be meaningful despite limited outward signs (e.g. expressive gestures or verbal responses). The use of video was significant in capturing these momentary nonverbal forms of engagement.

(2) MASTER THEME: Improvisation and imagination

This master theme explores how the sessions provoked impromptu, spontaneous and resourceful responses from participants. It is important to reiterate here that each object handling session was introduced using open ended prompts, I did not refer to the session themes i.e. 'Playful', 'Narrative', 'Dramatic', when introducing the materials, objects and images, thus participants were not primed to have, for instance, a 'playful' response to an item.

The 'Playful' session evoked varied responses, perhaps due to the ambiguous textile samples used i.e. they did not have an obvious function and were not easily identifiable. The below example occurred when P21 (PWD) explored a textile sample that had a pocket attached (see **Figure 42**):

She put her hand inside the pocket, lifting her hand up, allowing the knit to fall around her wrist. She laughed as she did so and said: "One of my problems is that I never understood why anybody did puppets of any kind." She looked down at her hand inside the pocket, with her hand facing her, she waved, the textile sample dancing around her wrist. After a few moments, she removed her hand from the pocket and fiddled with the sample. I held a similar sample up for her to see and she said: "Shit! This is all so very exciting because this looks more like a mouth than you might think!" P21 (PWD)

P21 (PWD)'s immediate response i.e. that the knitted sample was a puppet and her attribution of a mouth to the textile sample, demonstrates a creative, imaginative response.

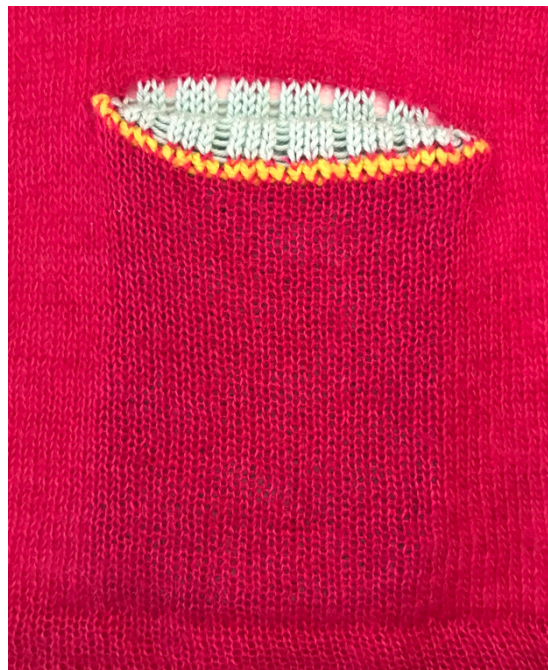


Figure 42. Textile sample used by P21 (PWD)

Although different in response, P20 (PWD) engaged creatively with an item of jewellery in Week 1's 'Playful' session. She explored alternative ways that the piece could be worn:

P20 (PWD) put the long necklace on over her head but almost immediately took it off. On removing the piece, she asked me to stand up.

P20 (PWD): "I wanted it around your waist..."

I stood up, visibly breathing in and standing on my tiptoes so that it was easier for her to try and place the necklace around my waist.

P20 (PWD) wrapped the necklace around my waist, fastening it in place. As she fastened the necklace, she held my loose-fitting top tightly around my back, seemingly wanting to create a more fitted shape.

"There..." P20 (PWD) said, as she stood back assessing the look of the necklace on my waist. She went on to say: "I think it is nicer there than around your neck – it doesn't matter where you wear it, it is the effect."



Figure 43. Necklace used by P20 (PWD)

Furthermore, similar responses were also found within the 'Dramatic' sessions. For example, P22 (PWD) demonstrated resourcefulness when discussing the types of accessories that could compliment a piece that we created on the mannequin:

P22 (PWD) looked down reaching for her handbag that, although sat down, she was still wearing across her body: "Here's my little handbag I brought with me." She held her bag out, looking at it closely: "Today - nothing in it at the moment so it's a spare handbag ... but would this do her?"

P22 (PWD) handed me the bag, and I carefully placed it across the mannequin as though wearing it across 'her' body.

P22 (PWD): "That bag is ideal as we are trying to keep it light."

Participants' response to items during the sessions and items within their immediate vicinity i.e. P22's (PWD) use of her handbag, demonstrated creativity, imagination and resourcefulness. Participants' spontaneous responses demonstrate the expressive capacity of materials and objects. The creative and imaginative ways in which participants engaged during the sessions shifted focus away from cognitive impairments associated with dementia, emphasising peoples' capacity.

(2.1) SUBORDINATE THEME: Playful moments

This subordinate theme connects closely with the preceding master theme **(2) Improvisation and Imagination** and captures how the sessions provided opportunities for play, enjoyment and humour 'in the moment' i.e. during the object handling sessions. For example, P21 (PWD) was playful in anthropomorphising the knitted textile samples (see **Figure 42**)

P21 (PWD) [laughing]: “I’m supposing that you don’t know anybody with green teeth?”

Rebecka [Laughing]: “No.”

P21 (PWD): “Or a hair-do like this?” *She held up the sample, showing me the purple tassels on the knitwear. She then turned to the supporting member of care home staff and asked: “Do you know anyone with a hair-do like this?... Look there’s more foolishness! It is my belief that none of each of us knows anybody with purple teeth or lavender teeth! ...I think it is useful occasionally to amuse each-other!”*

Similarly, P22 (PWD) when working with the mannequin, was humorous in her response. She anthropomorphised the mannequin, giving voice to the inanimate stand:

P22 (PWD) in a high-pitched squeaky voice said: “I want arms. Give me arms!” She made a shrill noise, then pursed her lips, still pretending to be the mannequin – “But I haven’t got any arms!” She had suggested designing sleeves for a dress but then realised the mannequin did not have any arms.

Moreover, P22 (PWD) was also playful at the end of the same session when she suggested that the dress we had created should be sold:

P22 (PWD): “She’s beautiful. In such a simple outfit... which cost her ten pence!”

The member of staff in the room joked that the price was too low and P22 (PWD) responded: “Well in that case £50.... £95.00 £95.07! A bargain at

£95.07... must be sold by November 31st and all money goes to P22 (PWD)
– this is mine!”

Participants’ playful and humorous responses within the sessions aligns with the notion of ludic artefacts i.e. artefacts designed to provoke joy and playfulness. The use of ludic artefacts within dementia care is not new (see e.g. LAUGH project Treadaway (2018)) yet interestingly the sessions were not designed to promote humour; participants’ playful responses occurred naturally. Seemingly the sessions allowed room for enjoyment and humour and thus supported participant’s self-expression as opposed to focussing on cognitive impairments associated with dementia.

(3) MASTER THEME: Embodied knowledge

This theme encompasses the multifaceted ways in which participants demonstrated embodied innate knowledge when interacting with the materials, objects and images during the sessions. For the purpose of this project, the theme is defined as intuitive or habitual actions and gestures e.g. where the body seemingly knew how to move or act. For example:

P20 (PWD) picked up one of the knitted textile samples that had a pocket. She stood up and asked me to stand. She then quickly began to explore the potential placement of the sample, using me as a ‘live’ model. She placed the pocket on my shoulder, considering the suitability of the placement. She then moved the sample across my shoulder, as though exploring the exact placement ... Her hands intuitively interacted with the knitted sample, her confidence in placing the sample and assessing where it may be ‘best’

seemed instinctive. Although she did not discuss her past experience, this process seemed to be very familiar to her.

Similarly, in Week 5's 'Narrative' session, the light-weight silk scarf was discussed, and I asked participants how someone may wear it. P22 (PWD) took the scarf (see **Figure 44**) and wordlessly demonstrated how she would wear it:

She folded the square scarf on the diagonal – creating a triangle. She then held the two ends, located on the longest side of the triangle, and twisted, wrapping the scarf on itself, leaning forward in her chair as she placed the scarf around the back of her neck. She loosely tied the scarf at her neck and gently tucked the ends of the scarf into her cardigan.

“Like that.” She said, in response to my earlier question about how one could wear the scarf. She then sat back in the chair and patted the scarf in place.



Figure 44. Silk scarf used by P22 (PWD)

P22 (PWD), articulated how the scarf could be worn through 'show and tell' rather than verbal explanation.

This theme shares some similarities with the subordinate theme **(1.2) Mini moments of engagement**, as there were many further examples of embodied habitual actions within the sessions. Whereby, participants often folded, re-folded and manipulated textile samples and fabrics. Such moments were made apparent through the use of video recording and were typically nonverbal.

(3.1) SUBORDINATE THEME: Haptic knowledge

This subordinate theme connects closely with the master theme **(3) Embodied knowledge** whereby on feeling an object or material participants deduced the potential use of the item or what the item was made from. The following extract is taken from Week 2's 'Narrative' session, at the point in which the participants explored a large, Aran knitted woollen jumper (see **Figure 30**):

P20 (PWD): "My goodness me – is this one? ... This is like a fisherman's jumper. That's what we used to call a fisherman knit." *She unfolded the sleeves to look at the jumper in full.* "It is what fisherman used to wear on the boat. Because it was so cold and wet – they wore thick jumpers." *She analysed the jumper holding it up... then balancing the jumper in her hands and said:* "You feel the weight of that. That is what they used to wear."

I ask P20 (PWD) to show P19 (PWD).

P19 (PWD): "Yes, I can see it". *She ran her hands gently across the jumper and then ran the back of her hand across the jumper and said:* "Cotton."

P20 (PWD): "It's wool isn't it?"

P19 (PWD): "No, it's not - it feels like cotton to me." *She squeezed the jumper and said:* "It feels a bit hard."

Mimicking P19 (PWD), P20 (PWD) also squeezed the jumper: "It's more of a practical item than a dressy...worn for warmth."

Similarly, P22 (PWD) when exploring fabric during Week 6's 'Dramatic' session, explored how the fabric felt and when it may be worn:

P22 (PWD): "Shiny and nice – you try it." She held the fabric out for the member of staff to feel. P22 (PWD) then continued to run her hands over the surface of the fabric, smoothing the fabric in her hands and said: "Soft and yes soft, well lovely and cool...lovely to wear in the summer time."

The relationship between the texture of different fabrics and seasons/weather was similarly discussed by P21 (PWD) who, on exploring one of the tactile postcards, spoke of the need for different clothing at different times of the year:

P21 (PWD): "If it really is cold outside - now this would be very useful for somebody – not any of the three of us!" P21 (PWD) looked closely at the tactile postcard, running her finger over the image of the jumper: "I don't know what has happened at the top, but it has been carefully disfigured."

Rebecka: "Carefully disfigured?"

P21 (PWD): "Yes! So, I don't think we should discuss the disfigurement – well I at any rate am hopeful that it is actually a warm sweater."

The disfigurement that P21 (PWD) talked of, was the embroidered area on the tactile postcard. The embroidery was designed to mimic the places where the jumper had been repaired (see **Figure 45**).



Figure 45. Tactile postcard used by P21 (PWD)

Participants' responses to handling the materials and objects during the sessions demonstrate their strong associations between the feel of something i.e. haptics, and the possible use of the item, when something may be worn e.g. type of weather or season, and the heritage of the item. Furthermore, participants invited others to share in the handling of the items, demonstrating the social aspect of working together to touch, handle and investigate pieces (as presented in detail in the subordinate theme **(1.1) Togetherness**).

(4) MASTER THEME: Taste: The look and feel

The master theme **(4) Taste: The look and feel** refers to participants sharing their personal preferences i.e. their likes and dislikes in response to the materials, objects and images used in the sessions. This theme refers to both the visual appearance of an item and how the items felt.

The textile samples used in the 'Playful' sessions (i.e. Week 1, Week 4 and Week 7 (see **Figure 46**) were polarising, many participants did not like them. For example, P23 (PWD), when handling and talking about one the samples said: "There's too much going on". Similarly, P19 (PWD) said that some of the samples were "too busy" with "too many colours". Moreover, when comparing a plain sample with a multicoloured one, P19 (PWD) preferred the former and said: "less is more".



Figure 46. 'Playful' textile samples

Not only did participants voice their preferences towards the textile samples, participants also talked about whether they would like to wear or use the items. For instance, when given a tactile postcard on which there was a pair of knitted woollen gloves, P20 (PWD) immediately said:

"Put it this way...I would only wear gloves like that for throwing snowballs! It's not dressy, it's very, very casual – very wide fingers as opposed to a dressy one which is always shaped." *As she was talking, she traced the shape of her fingers as though demonstrating a slim tapered glove.*

Furthermore, when P21 (PWD) and P22 (PWD) explored the light yellow, hand knitted mohair jumper in Week 4's 'Narrative' session (see **Figure 47**), they talked about who may wear it:

P22 (PWD): "Oh that's lovely! Oh, gorgeous yes." *She held the jumper up by the shoulders and then lay it across on her knee, stroking the soft mohair jumper.*

P21 (PWD), *watched P22 (PWD) explore the jumper and said:* "Lightweight and adorable and I haven't even touched it yet!" *P22 (PWD) then passed the jumper to P21 (PWD) for her to feel it.*

P21 (PWD), *laying the jumper on her knee and stroking it, said:* "It's lightweight, it feels very pleasant – very much more like baby clothes – I think that you may have noticed that I am not a baby!"

Rebecka: "Yes. What do you think about the colour?"

P21 (PWD): "Not my favourite." *She held the jumper up by the shoulders for P22 (PWD) to look at it – as though inviting her to comment on the colour as well.*

P22 (PWD): "Yes, I think it is lovely and certainly I would wear it myself if it fitted."



Figure 47. Hand knitted mohair jumper

P21 (PWD) and P22 (PWD)'s responses, demonstrate that participants may like a particular item, without wanting to wear it themselves, e.g. P21 (PWD) thought that the jumper was more suitable for a baby, whilst P22 (PWD) was more concerned that it may not have fit her.

Participants' opinions regarding the look and feel of items is of particular interest when considering purpose-made items for people with dementia, e.g. twiddle muffs, and the types of clothing and materials used within care settings, for instance, elasticated 'easy to pull' on trousers and synthetic easy-to-clean fabrics. Although such items were not explicitly explored during the sessions, participants' discernible preferences clearly demonstrated opinions regarding the specific items used.

(4.1) SUBORDINATE THEME: Choice, selection and design

This subordinate theme refers to the ways in which participants' preferences regarding the look and feel of fabrics influenced how they engaged with, and

selected fabrics during the 'Dramatic' sessions to then create designs on the mannequin (Week 3 and Week 6). During the sessions, participants were presented with a range of fabrics to explore, select and design with. For example, P20 (PWD) and P19 (PWD) discounted using a certain fabric due its weight:

P20 (PWD) leant over looking at P19 (PWD)'s fabrics and picked up a green jacquard fabric⁷: "Now, I don't think this is a dress material – this is more furnishing – I would not advise that for wearing..."

P19 (PWD): "No, you're correct...quite right"

P20 (PWD): "It is for furnishing..."

Rebecka: "How can you tell?"

P20 (PWD): "It is too heavy." She said as she held on to the fabric. She turned to P19 (PWD) letting her feel the fabric.

P19 (PWD): "Yes, I agree."

P20 (PWD): "And it's heavy, it's a heavy pattern." She patted the fabric firmly and placed it on the table.

Whilst in Week 5's 'Dramatic' session, P22 (PWD), had a clear vision for her design and ensured that I created the piece she envisaged:

P22 (PWD): "Have it as a pleated skirt"

She held the fabric up, assessing how much fabric there was... "Because there is quite a lot it."

⁷ Jacquard fabric is a patterned fabric woven on a weaving loom; the pattern is created during the weaving process.

She leant forward in her chair, reaching the waist of the mannequin and holding the fabric in place. I, and the supporting member of care home staff, proceeded to pin the fabric in place, creating pleats.

Rebecka: "What does that look like?"

P22 (PWD) pulled a face, as though she was unsure as to what to say.

P22 (PWD): "Well it looks as if you haven't finished it, I'm afraid..."

I altered the drape of the fabric on the mannequin, she watched closely and as I moved the fabric and said: "Yeah that's it!"

When selecting certain fabrics participants considering e.g. the suitability of the fabric, the amount of fabric available, and completing their designs i.e. what looked 'right'. Similar to the previous master theme, the subordinate theme is of interest when considering the design of items for people with dementia, given participants' discerning selections and attention to detail.

6.9 Discussion

This discussion explores findings considering the research aims (see **Chapter 2, 2.4 Summary**) and existing literature and includes extracts from my visual reflexive journal.

This cycle of study focussed on the embodied and sensorial aspects of clothing through a series of object handling sessions in order to examine the ways in which clothing can support the holistic care of people with dementia. The findings presented demonstrate the varied ways in which clothing can be considered significant to people with dementia and can be incorporated into dementia care practices within a care home setting.

Existing research has demonstrated that engaging with material objects e.g. object handling can increase levels of wellbeing (Camic et al., 2019), support positive feelings (Roe et al., 2016), and engage those taking part (Griffiths et al., 2019). The finding **(1) Critical engagement** demonstrated the varied ways in which participants engaged meaningfully with materials, objects and images during the sessions. Researchers such as Cohen-Mansfield, Marx, Thein et al. (2010), and Moyle, Jones, Murfield et al. (2017), have explored specific dimensions of engagement (not within object handling sessions) working with people with dementia and using particular items. For example, Moyle et al. (2017) measured participants' engagement with a robotic soft toy. Within this study engagement was not measured, yet the finding highlights the nuanced ways in which participants engaged critically, both verbally and nonverbally, at an individual and group level. This is interesting given what Morrissey, Wood, Green et al. (2016) discuss as embodied forms of participation e.g. 'holding' and 'giving'. For example, participants handled and analysed items, passing them back and forth to one another. This demonstrated not only interest in the items, but that the process of critiquing was purposeful e.g. participants strived to establish the use of an item. As Ludden et al. (2019) note it is imperative that activities provide opportunities for meaningful activity.

Awareness of, and the ability to attend to, varied forms of engagement is important when supporting individuals with dementia. For example, participants who engaged in mini moments of engagement i.e. nonverbal, momentary responses, often had items taken from them by the member of care home staff supporting the session. This may have occurred as a participant's engagement was not overtly obvious. When this happened, items were often placed out of the respective participant's reach, this in turn limited the person's agency i.e. the person's ability to

decide whether or not they wished to continue to engage with the item. In order to support engagement, it is necessary for care home staff to attend to the varied ways, i.e. not just verbal, in which people with dementia may interact and engage with items 'close to hand'. As discussed within the literature review, material objects and the ability to access them is significant in supporting people with dementia in the care home environment (see e.g. Stephens et al., 2013). I explored the notion of continuous tactile engagement through repetitive mark making techniques see e.g.

Figure 48.

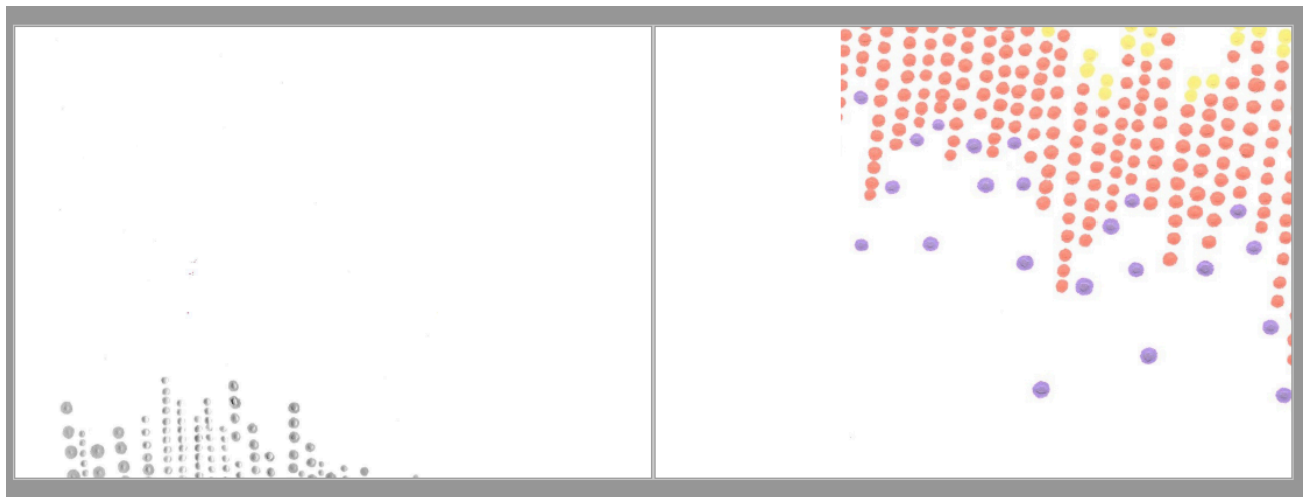


Figure 48. VISUAL REFLEXIVITY: Exploring pressure through repetitive marks

The notion that material objects and textiles are significant in dementia care settings is not new see e.g. the use of twiddle muffs (Alzheimer's Society, n.d.), therapeutic pet-type robots (Moyle et al., 2017), dolls (Stephens et al., 2013) and the use of textiles in MSEs (Jakob & Collier, 2017) and items are often designed and used to address and be responsive to particular behaviours symptomatic of dementia e.g. "agitated hands" (Alzheimer's Society, n.d.). Findings (see **(2) MASTER THEME: Improvisation and imagination**) presented in this study demonstrate the importance that materials and objects can have in supporting people with dementia in meaning-making and expression (Swinnen & de Medeiros,

2018), as opposed to solely addressing certain behaviours. As Craig (2012) notes, materials and textiles have a strong expressive capacity. The findings presented support this notion as participants were creative, humorous and imaginative during the sessions. For example, participants anthropomorphised textile samples and objects, and made connections between items used within the sessions and their own possessions e.g. in response to the Alan Measles tactile postcard a participant talked about a beloved childhood toy. The expressive capacity of items for people with dementia is important to consider in light of items designed for dementia care settings. For instance, findings support the use of ludic objects i.e. objects designed to evoke joy in dementia care settings (as previously noted by Treadaway et al. (2018). Additionally, findings build upon Smith and Mountain's (2012) and Ludden et al.'s. (2019) claim that researchers and designers should not solely focus on cognitive losses associated with dementia but they should design for enjoyment and engagement. Moreover, findings connect with Morgner, Hazel, Schneider et al.'s (2019:517) claim that engagement with the arts can enable "different channels of social interaction", as results demonstrate that material interactions invoked meaningful interactions between people with dementia.

Findings are also interesting to note when considering the use of person-centred objects in dementia care. The items used within this study's sessions were not designed to be person-centred nor ludic (except in the case of items used during the 'Playful' session). Yet, findings highlight the significance that textiles and material objects can have in supporting people with dementia to express themselves. Items do not need to be designed for specific individuals or designed to provoke specific forms of engagement in order to support expression and wellbeing. Textile samples that were ambiguous i.e. not designed for a specific purpose, and less recognisable

items, e.g. sculptural resin jewellery, provoked imaginative responses through participants engaging with the unusual tactile properties of the items, and aesthetics of the pieces. This concurs with findings from Griffiths et al. (2019) who reported that the use of unusual items during object handling sessions captured participants' imagination.

The sensory properties and aesthetics of clothing and material objects designed for people with dementia are important to consider in light of this study's findings. Such items are often created to meet cognitive and practical needs, and thus often neglect aesthetics (Iltanen & Topo, 2007a, 2007b; Mahoney et al., 2015). Yet, findings from this study (see master theme **(4) Taste: The look and feel**) established participants' discernible preferences regarding textile samples, items of clothing, and small items of dress as evidenced by participants comments on colour, texture, pattern and overall aesthetics of the items. For instance, participants indicated that particular textures and fabrics evoked certain associations and specific uses e.g. a soft light-yellow mohair jumper would be for a child. Moreover, when exploring the textile samples used in the 'Playful' sessions i.e. brightly coloured fabrics with different tactile features including pockets, tassels, pompoms and lace holes, participants said that the samples were "fussy" with "too much going on". This finding connects with existing research that demonstrates that when viewing artworks and visiting galleries people with dementia share aesthetic preferences e.g. (Windle, Joling, Howson-Griffiths et al., 2018). This is significant as it highlights that people with dementia should be involved in design processes and that e.g. the look and feel of items is important when creating items for their use. Moreover, this finding indicates that items should not focus solely on the cognitive losses

associated with dementia rather than pieces should be designed to support the strengths and residual capacity of people with dementia.

Findings are not only relevant in regard to the design of items, but also demonstrate how the embodied and sensorial properties of clothing can support people with dementia. For example, participants showed how their embodied, haptic knowledge enabled them to understand the use of a particular item, discuss when, how and where the item may be worn. These findings corroborate Twigg and Buse's notion that the embodied and material closeness of clothing can promote a person's sense of "spatial and temporal orientation" (Twigg & Buse, 2013:329). Additionally, findings connect with Stokes' (2008) example of a gentleman with dementia who would go to bed during the day as he was wearing pyjamas. For example, when handling a thick woollen jumper participants explained when, why and where it would be worn. Although seemingly mundane, such findings emphasise the value of people with dementia's knowledge and experience and could inform for example, dressing guidance for people with dementia see resources such as, 'Tips for helping a person with dementia to dress' (Alzheimer's Society, 2015c). Such guides typically focus on the visual appearance of people with dementia, and what clothing looks like, yet as found in this study enabling someone to touch and handle an item of clothing can elicit understanding. When exploring this notion, I created tactile objects that I manipulated and photographed see e.g. **Figure 49**.



Figure 49. VISUAL REFLEXIVITY: Handling objects

Findings from this cycle of study build upon existing literature by addressing gaps surrounding e.g. forms of engagement with material objects, the expressive use of textiles and clothing in dementia care settings and nuanced insights regarding e.g. the use of person-centred material objects.

6.10 Limitations and recommendations

This section presents both limitations and recommendations in light of the research methods used and the findings.

The use of object handling sessions supported both verbal and nonverbal expressions, through the use of carefully selected materials, objects and images. Similar methods have been used when working with people with dementia, for example, Twigg and Buse (2013) worked with reminiscence groups to explore responses to vintage items of clothing and sensory props. The method used was novel as (1) object handling sessions are typically used as a psychosocial intervention for people with dementia as opposed to a creative research method: (2) the sessions, and the materials, objects and images used were designed using

findings from the previous two cycles of study (CYCLE 1 and CYCLE 2): (3) audio-visual recording was used to capture responses during the sessions. There are a number of limitations and recommendations to consider when adapting this creative method for use in future research.

Firstly, object handling studies typically involve working in groups of up to eight people (Johnson et al., 2017) and so when planning the study, each session was to include up to eight people: three people with dementia, three relatives/friends of each person with dementia, one member of care home staff and a volunteer. Often, people with dementia work with relatives/friends and members of staff during sessions. Despite the efforts made to recruit participants e.g. I attended and presented at multiple staff meetings and discussed potential participation with staff informally, only five women with dementia were recruited. The limited sample impacted findings not only due to the all-female group of participants, I was also not able to carry out the planned follow-up interviews with care home staff and relatives/friends of people with dementia as neither group participated in the sessions.

In light of the impact of the participant sample on findings, it is important to reiterate (as presented in **Chapter 4, 4.6 Participants**), that there are many more women than men living in care homes and that women are disproportionately affected by dementia. However, the small numbers of participants meant that I was able to work closely with individuals. This provided multiple opportunities for engagement and enabled me to support and respond to participants' impromptu expressions e.g. the use of textile samples as puppets. Such creative, imaginative responses may have been supported by the small number of participants. For example, Annerstedt (1994) found that the dynamics of small groups were beneficial

to people with dementia. Additionally, when identifying eligible individuals, care home staff identified people who may work well together, thus this may also have supported participation.

Furthermore, my ability to work closely with individuals was supported by the use of the camcorder to capture the sessions. For example, I typically moved around a lot during the sessions to spend time with participants one-to-one. This 'hands-on' way of working was possible due to the use of video recording. Yet, moving around during the session meant that I was often out of 'shot'. This was also the case with one participant who often stood up during sessions. It would therefore be advisable for future researchers to capture sessions from different angles (as opposed to the use of one shot i.e. the static mid-shot as used in this study), either through the use of multiple camcorders or a 360 camera (Luff & Heath, 2012).

The use of object handling sessions as a creative research method in future research is important. As Woodward (2020) highlights, the capacity that objects (including clothing) have when exploring aspects of lived experience is vast. This study has demonstrated the multifaceted understandings that can be generated when carrying out object handling sessions with people with dementia. The careful selection and creation of specific items enabled the elicitation of responses around aspects of individuals' lives whereby participants shared stories, experiences and preferences. The use of object handling sessions along-with audio-visual recording methods is accessible, supporting people to engage and partake flexibly and at different levels, thus the method could support e.g. the inclusion of people with late stage dementia. This is important as people with late stage dementia are typically excluded from research due to both ethical and communication issues.

Specific potential design solutions are discussed and presented in the following chapter (**Chapter 7, Synthesis of Findings**).

6.11 Summary

To conclude, despite the limitations discussed, findings demonstrate that clothing and material objects are significant within the lives of people with dementia living in a care home. Items can support people to express themselves. Moreover, haptic engagement and the sensory properties of items provide opportunities for joy, playfulness and humour. Findings illustrate that items used in dementia care settings should be carefully designed. Items should not be designed with the sole purpose of meeting or addressing responsive behaviours rather they should be designed to support people with dementia and employ a strengths-based approach. As well as implications regarding the quality and aesthetics of items designed for people with dementia, findings can be considered in relation to broader conceptualisations of dementia e.g. loss of selfhood. Engagement with the arts, design (including aesthetics) supports positioning people with dementia as active embodied beings (Dowlen, 2018; Kontos et al., 2017b; Zeilig et al., 2019).

The findings support and extend previous research regarding clothing and textiles within the care home setting. Moreover, the use of object handling sessions as an accessible, creative and flexible research method was found to support people with dementia and could be adapted to use in future research projects.

The succeeding chapter (**Synthesis of Findings**), thematically combines and examines the findings from the three cycles of study carried out over the course of this research. Within the chapter I present a number of applied and practice-based recommendations centred on the findings.

CHAPTER 7 SYNTHESIS AND DISCUSSION OF FINDINGS

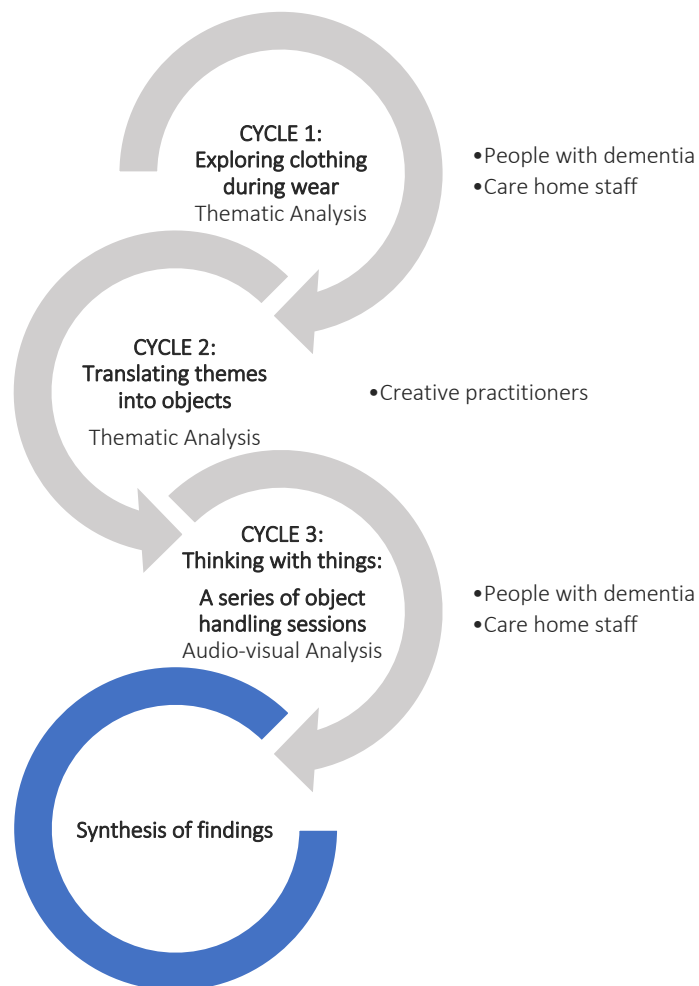


Figure 50. Synthesis of findings

7.1 Introduction

The purpose of this chapter is to synthesise and discuss overall study findings. Bringing together findings from: **CYCLE 1: Exploring clothing during wear**, **CYCLE 2: Translating themes into objects** and **CYCLE 3: Thinking with things: A series of object handling sessions**.

Findings are considered in light of the existing literature and where applicable, are explored with consideration to applied outcomes, e.g. the design of a new product or infographic. This connects with Pink's SE (2009, 2015), as she suggests that sensory research methods can generate new understandings that can lead to product development.

7.2 The process of synthesising findings

The process of bringing together findings from each cycle of study was informed by Ellingson's (2017) notion of crystallisation in qualitative research. She refers to Richardson's (2000) metaphor of crystallisation as an alternative to triangulation, i.e. the process of using multiple methods to ensure validity and rigour. Ellingson writes that:

"Crystallisation involves engaging multiple forms of analysis and multiple genres/media of representation within a research project, making and destabilizing knowledge claims, yielding a postmodern validity." (Ellingson, 2017:180)

Crystallisation involves multiple ways of presenting findings, for instance, Ellingson (2017) encourages researchers to engage with a 'large toolbox' of methods, as no single technique can capture everything. She highlights a number of ways in which researchers have engaged with such processes, for example, Jones and Woglom (2015) created a graphic novel to teach students about intersectionality, i.e. the presentation of bodies within specific circumstances, highlighting intersections of race, gender, class and age.

In order to synthesise findings, I drew upon Braun et al's. (2019) reflexive thematic analysis process (see **CYCLE 1, 4.7 Reflexive thematic analysis**) and

visually explored patterns within the findings (from each cycle of study) using methods such as creating mind maps and physically cutting up each theme to manipulate and cluster themes together. Each thematic finding (from each cycle of study) was explored at the macro level, i.e. at each master theme and at the micro level, i.e. at each subordinate theme (this process is described below). The process of thematically synthesising findings was also informed by PhD theses such as Dowlen's (2018), in which she presented a cross-case analysis, thematically bringing together data from six case studies.

The following stages were involved in synthesising findings (adapted from Braun et al., 2019):

1. Reading and re-reading each master theme (from CYCLE 1, CYCLE 2 and CYCLE 3) and supporting participant extracts and making notes.
2. Reading and re-reading each subordinate theme (from CYCLE 1, CYCLE 2 and CYCLE 3) and supporting participant extracts and making notes.
3. Themes were clustered together to explore overarching concepts to create initial umbrella terms.
4. Initial terms were renamed to convey the essence of each finding.
5. Findings were explored and visualised through the creation of prototypes and/or with reference to existing products, artworks and pieces of design.
6. Findings were written up and discussed in reference to existing literature and with reference to existing products, artworks and pieces

of design - and where applicable, I propose a number of potential applied outcomes, e.g. prototypes.

As a result of the six stages presented above, the following overarching themes were formed (see **Table 16**).

Thematic findings are presented alongside existing literature and figures. The figures used include existing products, artworks and design examples. I also created a number of prototypes (early samples of products that are created to test an idea or process) that sit alongside the findings. Although it was beyond the scope of this project to design new product(s) the prototypes illustrate a number of potential applied outcomes that respond to findings.

7.3 Presentation and discussion of synthesised findings

Table 16 represents the study findings as a whole, highlighting each master theme and how it is underpinned by a specific concept. The subordinate themes sit within the master theme and highlight nuanced aspects of each master theme. Each theme is discussed alongside existing literature and recommendations are made with regard to the application of specific products and / or prototypes. The proposed applications are not exhaustive and are not presented as a 'one size fits all approach', but they have been suggested in response to specific participants' experiences as detailed within this research.

Table 16. Thematic synthesis of findings

Master Theme	Subordinate Theme
(1) Embodied clothing and textile practices	(1.1) The right fit and feel (1.2) The changing body (1.3) Caring through clothing
(2) The significance of place	(2.1) Clothing and emplacement (2.2) Vulnerability
(3) Clothing and creativity	(3.1) Communication and expression (3.2) Respite and distraction (3.3) Imagination and playfulness

(1) MASTER THEME: Embodied clothing and textile practices

This research found that clothing was important at an embodied, sensorial and affective level for people with dementia. Embodied clothing and textile practices consist of, for instance, repeatedly wearing specific items of clothing, wearing clothing in a particular style, using clothing in a particular way, and the innate embodied ability to fold, drape and manipulate textiles. People with dementia engaged with embodied clothing practices through, for example, tying a scarf in a particular style, putting on jewellery, or folding items of clothing. These practices were intuitive, occurring at the respective individual's own pace. The unprompted and innate nature of these instances is important as they did not occur as a 'show and tell' moment, they were spontaneous. Moreover, the embodied feel of wearing particular items of clothing was important for individuals and affected people at multiple levels: for instance, care home staff spoke of the impact that not wearing certain items of clothing could have for people with dementia, as individuals could become upset, distressed and disorientated.

Embodied clothing practices were highlighted by Kontos (2005) when presenting the importance of bodily expressions e.g. actions and gestures, and selfhood. For example, she referred to a woman's action of moving her necklace to ensure that it was visible. This research found that wearing particular items of clothing and the style in which they were worn were important to people with dementia and could both support and disrupt selfhood, thus building upon existing literature (Buse & Twigg, 2016a; Ward & Campbell, 2013a). For example, Ward et al. (2014) found that clothing practices such as rolling sleeves up, are important in maintaining selfhood.

This project's finding identifies the numerous ways in which embodied clothing and textile practices are important for people with dementia and as such are significant when considering a person's mood, actions and behaviour. This is important when considering that clothing practices are not necessarily symptomatic of dementia. For example, as Joller et al. (2013) note a lack of clothing or wearing inappropriate clothing is not always a sign of sexual disinhibition (a behaviour symptomatic of dementia). For instance, findings from this research demonstrate that a lack of clothing was used to establish agency and autonomy within the care home setting.

Thus this research identifies the significance that attending to embodied clothing and textile practices have when considering (1) the design of clothing for people living with dementia, (2) the extent to which people have access to and are able to choose their clothing within care home settings, (3) how people with dementia are assisted with dress, and (4) relational approaches to dementia care. These implications are discussed within the following subordinate themes, which identify different aspects of embodied clothing and textile practices.

(1.1) SUBORDINATE THEME: Clothing: The right fit and *feel*

The fit and *feel* of clothing involves attending to both the tangible properties of clothing i.e. the sensorial, physical sensation of wearing clothing and intangible associations imbued within the clothing e.g. the affective impact of wearing particular items (how clothing made an individual feel). This research found that clothing often impacted a person's mood, behaviour and actions as a lack of appropriate clothing or wearing the 'wrong' item(s) of clothing acted as a barrier (Kabel, McBee-Black, & Dimka, 2016), and caused individuals to undress or want to change their outfit, refuse to wear items e.g. incontinence pads, refuse to leave their bedroom and to disguise items e.g. hide fall detector pendants in their clothing. Findings indicate that wearing the 'right' items of clothing enabled feelings of comfort, dignity and agency through maintaining aspects of selfhood. This finding extends existing literature (Buse & Twigg, 2016a) as it identifies how people with dementia engage with Woodward's (2007) notion of aesthetic fit, i.e. individuals with dementia judge the extent to which clothing is 'them' assessing both the intangible meanings e.g. the affective dimension of clothing and the physical fit i.e. the embodied sensorial dimension of clothing.

The physical, sensorial sensation of wearing clothing was important for people with dementia and this was demonstrated through both the preferences that participants shared and also the haptic knowledge that participants exhibited. Haptic knowledge, for the purpose of this research, explains how through handling items of clothing, textiles and jewellery people with dementia deciphered how they may be worn e.g. through gestures, through putting items on or through placing items on the body (in the case of textile samples). Participants with dementia also deduced when, where and why the items may be worn and who the wearer may be. Moreover,

participants shared preferences regarding the aesthetic and sensorial qualities of items, with regard not only to their design but also in reference to cleanliness detailing the rationale behind their preferences. For instance, participants talked of the importance of wearing clean clothing, and also masking unpleasant odours through the use of fragrance. This finding therefore has multiple implications when considering the potential of clothing within the context of care for people with dementia. A number of application-based opportunities are therefore presented below; these include the use or development of specialist products and opportunities for staff training and the development of dressing guidance in the care home.

Firstly, the use and development of certain specialist products are recommended in light of this finding. Disposable incontinence products are often used in care homes, yet staff stated that residents frequently refuse to wear them as they are uncomfortable. It is also possible that refusal may occur due to associations with lack of independence and / or control. Twigg (2000, 2001, 2003) has written extensively on issues surrounding bodywork (including incontinence) and writes how incontinence is a source of disgust, causing people to fall outside of societal norms as the body is no longer 'self-contained'. This stigmatisation is arguably epitomised within the design of incontinence products see e.g. 'adult nappies' sold by the trading arm of Age UK. In recent years, specialist urinary incontinence products made from innovative absorbent textiles have been designed to look and feel like conventional underwear see e.g. the brand Modibodi® (see **Figure 51**).



Figure 51. Modibodi® absorbent underwear (Modibodi, 2020). Image reuse permission obtained.

These products offer a more appealing, comfortable, dignified and familiar solution (due to feeling like regular underwear) to the items typically used, they are machine washable, guaranteed for six months and can last up to two years.

It is important to note that the often-pervasive use of incontinence products in care homes may meet institutional priorities (Twigg & Buse, 2013) rather than the needs of individuals. Nevertheless, the prevalence of incontinence increases with age, and age is the biggest risk factor associated with dementia. For example, Bardsley (2014) found that although people with dementia face the same risk of incontinence as the general population, the prevalence is higher, at approximately 53 per cent, and that those living in health and social care settings also have a higher prevalence compared to people living in the community. The negative impact that incontinence has on quality of life is widely recognised (e.g. Sims, Browning, Lundgren-Lindquist, et al., 2011), yet, as participants in this research demonstrate, products typically used to ‘manage’ incontinence can also negatively affect individuals. Thus, the improved design of products could be particularly powerful in

improving quality of life and elevating care. However, it is important to consider the cost implications involved – each pair of Modibodi® cost between £24.00 - £27.00, whilst a pack of fourteen Age UK's 'adult nappies' cost £5.49. Yet, as Modibodi® products can last up to two years, the two items are similar in their average 'cost per wear'. Nevertheless, the initial expense when using products such as Modibodi® may exacerbate health and care inequalities as socio-economic status may act as a barrier to access.

Another item that many residents were encouraged to wear in the care home was a fall detector pendant. At present literature surrounding the efficacy of fall detector pendants is varied (Ward, Holliday, Fielden et al., 2012), yet where such items are used, it is important to consider the extent to which they meet individuals' needs and preferences. For example, this research found that some people with dementia adopted the pendants as part of their clothing, whilst for others the items were unfamiliar and not viewed as part of their dress e.g. one individual hid the pendant within her clothing, which may have been both due to shame associated with wearing the item and the unfamiliar look and feel of it. It is possible that the design of such items could support wear if designed to look and feel like jewellery or watches, as opposed to medical devices, as this could be more appealing and acceptable to certain individuals. Møller (2018) proposes that an accessory approach to designing such items can enable a move beyond functionality and so support the wearer's physical, psychological and social needs. Existing products that could meet these needs include the 'Essence' fall detector pendant which looks and feels like a necklace (see next page, **Figure 52**), and 'GreatCall's' fall detector device which can be worn around the wrist and is designed to look like a 'smart' watch (see next page, **Figure 53**).

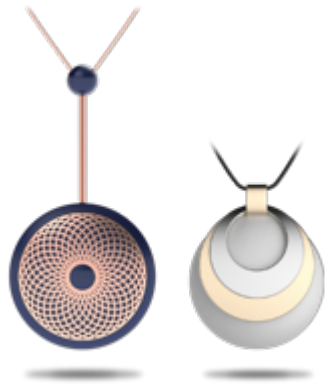


Figure 52. Essence fall detector pendant with Care@Home™ technology (Essence, n.d.)



Figure 53. GreatCall fall detector watch (GreatCall, n.d.)

It is also possible that fall detector devices could be attached to, or embedded within, items that a person already owns and wears, for instance Uran and Gersak (2018) have explored the integration of fall detector sensors within clothing. This could avoid the introduction of new, unfamiliar items and therefore may be more readily adopted by individuals (Chamberlain & Craig, 2013). Nevertheless, it is important to consider gender bias when embedding such technology into existing items. For example, in Criado Perez's book 'Invisible Women: Exposing data bias in a world designed for men' (2019) she presented the use of fall detector apps with women, noting that as women's clothing typically does not feature pockets or pockets large enough to carry a mobile phone (designed for the average man's hand) women often store their phones in their handbags, thus making a fall detector app redundant. Criado Perez (2019) therefore argues the importance of sex disaggregated data in research and design. Hence, the acceptability of items such as fall detectors / apps need to be carefully considered so that the use of such items is selected to specific individuals' needs.

It is not only possible that the use of certain products could enhance the holistic care of people with dementia through promoting feelings of autonomy, dignity and independence, adapting the physical care home environment could also improve care. For example, a participant who used a walking aide explained that she was unable to access her clothes in her wardrobe and had to rely on staff to help her. During two respective research encounters she said that she felt uncomfortable and wanted to change her outfit. It is possible that accessible furniture, such as a pulldown wardrobe rail (see **Figure 54**), could enable selecting clothing independently. This is important as care staffs' ability to enable choice is often limited by factors such as time pressures (Buse & Twigg, 2018). Adapting the physical environment to enhance choice, as noted by Førsund, Grov, Helvik et al. (2018), could be also be significant in transforming the intangible feel of the setting. As Lupton (2017) notes material and social interactions shape the affective atmosphere of health and social care settings. For instance, the use of a pulldown wardrobe rail may support independence and therefore promote feelings of autonomy and agency within the broader care home setting. Such products warrant the investment of institutions and thus necessitate raising awareness that the use of certain items can promote an accessible, enabling environment, fostering the autonomy and agency of residents and enhance the care provided.



Figure 54. Buller™ pulldown wardrobe rail (n.d.)

Existing research often describes tensions regarding what care home residents 'should' look like e.g. that residents should be dressed appropriately in public spaces of the care home (Buse & Twigg, 2018; Mahoney et al., 2015). Yet, this research found that care home staff often responded to and understood individual's preferences. For instance, care home staff talked of an individual who wore numerous layers of clothing to feel comfortable, whilst another individual typically chose to wear pyjama bottoms during the day. Although this demonstrated a holistic, relational approach to care, as Buse and Twigg (2018) found, this was often dependent on staffs' level of experience. It is therefore imperative that dressing guidance and staff training are delivered to ensure that all staff are able to support people with dementias' clothing needs. Without such training, awareness of the importance of clothing to people with dementia may be limited and so staff may be unlikely to offer the necessary support. This is illustrated by Stokes' (2008) example, of the gentlemen who arrived in hospital smartly dressed and yet was required to wear pyjamas all day demonstrating the importance of staffs' awareness and ability to attend to individual's' clothing practices.

Dressing guidance that currently exists emphasises choice and yet often focusses on clothing from a task-orientated perspective, to support informal caregivers, see e.g. the Alzheimer's Society (2015c) 'Dressing Guide'. As this research shows, clothing practices are important at a number of levels and vary greatly for individuals (see e.g. **CYCLE 1, (1) The (im)perceptible fit: The feel of clothing and appearance**). It is therefore imperative that dressing guidance challenges pervasive norms regarding what someone with dementia 'should' look like, to emphasise the fit and feel of clothing and the significance of this in maintaining selfhood and to enhance autonomy, agency, and dignity. In order to do so guidance should include a wide range of engagement methods to ensure that care home staff are able to respond to the needs and wants of individuals. For example, in CYCLE 2 creative practitioners discussed employing a number of nonverbal methods to enhance understanding and to support decision-making when working with people with dementia. Moreover, experienced members of care home staff talked of helping people with dementia handle different items of clothing to select an outfit. Incorporating creative approaches has been found to be effective in developing nonverbal communication skills. For example, as noted earlier, Clod Ensemble's 'Performing Medicine programme' (n.d.) uses dance and theatrical techniques when working with healthcare practitioners to develop embodied, nonverbal skills. Additionally, methods such as the use of visual cues e.g. photographs of favourite outfits within a person's bedroom could be used to illustrate a person's clothing preferences (Campbell, Buse, Twigg et al., 2015). This may also support staff's understanding regarding for example, specific items of religious dress, traditional garments, and further items of clothing that are of specific importance to the individuals that they care for. Yet it is important to recognise that an individual's

preferences and needs can change and thus it is essential that staff are able to be responsive 'in the moment' and support individuals with their clothing at any given time.

This finding **(1.1) Clothing the right fit and feel** demonstrates that strategies to enhance the holistic care of people with dementia involve the use of specialist products and changes to the physical environment, as well as staffs' ability to understand and meet individuals' clothing needs.

(1.2) SUBORDINATE THEME: The changing body

In recent years, Ellingson (2017) has challenged the ways in which the body is typically presented as a fixed static entity within health research. This subordinate theme draws upon such notions and identifies the importance that clothing can have in supporting changes to the body. This finding is novel, as it builds upon Woodward's (2007) notion of aesthetic fit by identifying the fluidity with which clothing practices must be viewed in order to address the unmet clothing needs of people with dementia. This in turn links to Lovatt's (2020) presentation of home and identity in care homes. She argues that viewing home and identity as fixed, does not account for the processual and fluid negotiation that occurs through material and social interactions. This finding **(1.2) The changing body** identifies how the adoption or introduction of specific items of clothing can support people with dementia at an embodied, affective and material level, thus clothing practices should similarly be viewed as processual and fluid.

Existing literature often refers to preserving the appearance (including clothing practices) of people with dementia (see e.g. Buse & Twigg, 2018; Mahoney et al., 2015; Ward et al., 2014). Clothing is intimately intertwined with the self and so the

preservation of clothing practices connects with the pervasive view that dementia equates with a loss of self, meaning that changes in clothing practices are often perceived as indicative of cognitive decline and loss of selfhood. Such views are exacerbated by visual depictions of people with dementia in which clothing practices such as ‘mismatched’ outfits are presented as symptomatic of the condition (Caldwell, 2020). Although certain clothing practices can remain important for people with dementia, as this study’s findings have affirmed, an emphasis on visual appearance excludes attending to embodied sensorial experiences and this in turn negates the positive opportunities that clothing practices afford people with dementia.

Firstly, as highlighted within the previous subordinate theme **(1.1) Clothing, the fit and feel**, certain garments can enable feelings of dignity and autonomy, thus enhancing the care of people with dementia in care homes. People with dementia often require help with personal care such as using the toilet and showering, which can be problematic for individuals and cause high levels of agitation and stress (Day, Carreon & Stump, 2000). This research identified strategies that care home staff employed in an attempt to alleviate distress, for example, only female care-workers supported a particular female resident who found showering difficult. Yet, as Twigg (2000, 2001, 2003) wrote, assisting someone with bathing or showering is complex, it involves nakedness, creating vulnerability, and this is significant when the experience is not shared i.e. the person being helped is naked and the member of staff is dressed. This reveals a potential role for specialist items of clothing to enhance care. For example, the ‘Nevernaked™ shower drapron®’ created by the brand Limon Attire, is designed to be worn in the shower (see **Figure 55**). The item is made of lightweight polyester, allowing water to pass through when showering.

Items such as the Nevernaked™ shower drapron® may support people at an embodied and material level as they promote feelings of dignity and security.



*Figure 55: Nevernaked™ shower drapron® by Limon Attire.
Image reuse permission obtained.*

Clothing can also enhance the comfort and dignity of people with dementia who experience changes in mobility. For example, care home staff altered clothing e.g. shortened trousers, to ensure that residents could continue to wear familiar items when transitioning to permanently using wheelchairs. Care home staff also knitted slippers for individuals who were no longer able to wear their shoes due to using wheelchairs. This demonstrates how existing clothing can be adapted and how bespoke items can be made to support people with dementia, yet these examples also demonstrate the dedication of certain members of staff as such activities were carried out in their own time. The resourcefulness and creativity shown by staff,

highlights the vast skillset that individuals working in care homes possess. Thus, indicating the potential for developing job roles, moving beyond traditional task-oriented models of care, to enable and empower staff to holistically attend to individual's needs. Additionally, these examples indicate the opportunity that, for instance, adaptable clothing could have in addressing certain unmet needs.

Clothing that is available on the high street is not suited to all types of bodies (Wilkinson & Wilkinson, 2019) and this is no less true for people with dementia. Buse and Twigg (2018) identified how fabric type, garment fastenings and clothing styles can constrain the dressing process and reduce the body to a series of discrete parts. Additionally, Kovach, Noonan, Griffie et al. (2002) report that ill-fitting and uncomfortable clothing is often a source of distress for people with dementia. Within this project clothing was examined during wear and the aesthetic, sensory properties of certain items were explored. This finding **(1.2) The changing body** identifies a number of opportunities for designers to enhance the lives of people with dementia.

People with dementia can have difficulties with mobility and may often sit for prolonged periods of time. Garment styles and fabrics impact the wearer's body (Sweetman, 2001), and this is particularly important when seated, as clothing can become distorted, twisted and creased. For instance, one participant, who was a wheelchair user, wore large items of clothing that hung loosely off her body to ensure that she was comfortable. Similarly, a member of care home staff suggested that (non-waisted) loose-fitting robe like garments could enhance the comfort of individuals who used wheelchairs. Moreover, a further participant found that when seated her top became distorted as it slipped off her shoulders revealing her skin and she spoke of her discomfort and manipulated the top into place throughout the research encounter. Thus, there are a number of opportunities for designers to

design for the seated body through e.g. specific pattern cutting techniques and the use of fluid fabrics such as jersey, which could improve comfort and avoid the use of ill-fitting garments. Alongside the fabric choice, size, cut and fit of garments the placement of seams and labels should also be considered. For example, there was an instance that a participant became upset as she thought that she was being bitten by an insect, but it was in fact a clothing label irritating her. Sensitivity to touch is not uncommon for people with dementia (Kovach et al., 2002), thus highlighting the potential that seamless garments and garments without labels could have in improving the fit and feel of clothing for people with dementia. For instance, The Woolmark Company, a not-for-profit organisation who work with Australia's woolgrowers to research, develop and certify wool, collaborated with the brand NAGNATA to create a collection of seamless activewear garments (see **Figure 56**). The combined use of Merino wool and Tencel™ fibres selected for their soft, breathable properties and the seamless construction technique, created garments with a "super soft second-skin" feel (The Woolmark Company, 2019 [online]). Thus, it is possible that innovative combinations of fibres and construction techniques could be utilised to create comfortable, attractive garments for people with dementia.



Figure 56. Seamless shorts from The Woolmark Company and NAGNATA 'The sensuality of seamless' collaboration. Image reuse permission obtained.

This finding has identified the need for clothing practices to be understood as fluid. Moreover, this finding has highlighted the opportunities that designers have in meeting the needs (and wants) of people with dementia through e.g. the use of innovative pattern cutting and garment construction techniques. As the literature review identified, clothing for older adults remains limited and is impacted not only by the lack of available, affordable and desirable clothing, but also pervasive social norms surrounding the ageing body (Hurd Clarke et al., 2009; Twigg, 2013). With the increasing ageing population and the health conditions that commonly occur in older age, it is imperative that designers employ innovative methods to meet the diverse clothing needs of people with dementia and older adults. Nevertheless, such innovative methods would need to take into account the vast health and care inequalities that can occur depending on socio-economic status. In order to enhance the care and quality of life of individuals with dementia innovative items of clothing combined with the cost of care needs to be carefully considered.

(1.3) SUBORDINATE THEME: Caring through clothing

The fit and feel of clothing was not only important to people with dementia, staff also engaged with specific clothing practices in the care home. Twigg and Buse (2013) posited that clothing enables care-workers to relate to people with dementia as a person rather than as a body to be cared for and this was similarly found within this research. Staff demonstrated empathic understanding of individuals' clothing practices and understood the importance of clothing (including accessories) in regard to a person's sense of self and their wellbeing. As discussed in the previous subordinate theme **(1.2) The changing body** staff altered, fixed and made items of clothing for residents and this demonstrated a holistic and relational approach to care.

Interestingly this finding not only demonstrates that clothing was used as a way in which to relate to individuals in 'receipt' of care (Twigg & Buse, 2013) but was also used as a way in which to practice relational care. For example, staff spoke of creating their own informal 'uniforms' through avoiding heavily beaded clothing which they said could potentially irritate someone's skin and cause harm. Staff also spoke of wearing items that they could easily move in, in order to provide optimal care. This finding not only determines care home staffs' embodied understanding of their caring roles, thus contributing to Kontos and Naglie's (2009) research, who found that care-workers drew upon their own bodily knowledge when caring for individuals, but also demonstrates how clothing enabled staff to enact holistic, relational care.

This finding is notable as although existing research has demonstrated that care-workers typically associate supporting someone with e.g. getting dressed as a sign of care (Mahoney et al., 2015; Ward et al., 2014), limited research has explored

care-workers use of clothing within the care home. For example, Mitchell (2018) discussed the potential of care-workers' clothing in enhancing person-centred care within a dementia care setting, whereby he presented the possibility that staff could wear nightwear during night shifts to enhance people with dementias' temporal understanding. Although there is limited understanding regarding the impact of such approaches, Mitchell's (2018) work concurs with this study, as it highlights the importance that care-workers' clothing can have within dementia care. The 'uniform' created by staff within this project is of interest and could be used to develop care providers dress code policies (where uniforms are not worn) and it could also be used to inform the design of uniforms for care home staff.

(2) MASTER THEME: The significance of place

This master theme refers to the impact of the care home both as a physical space e.g., the institutional priorities present within the setting, and conceptually e.g., the 'boundaries' between the public and private spaces and the position of residents living in 'need' of care, with regards to clothing practices. This finding demonstrates that the social and material context of the care home is important to people with dementia and affects clothing practices. For instance, the ambiguous 'boundaries' between public and private spaces (Buse & Twigg, 2014a, 2014b) and the movement between the private space (bedroom) to a public space (e.g. lounge) is akin to going outside and so effects what a person wears, and how and why they wear it. Existing literature identifies the importance of place, time and orientation for people living with dementia and how clothing can enhance temporal and spatial orientation (Twigg & Buse, 2013; Buse & Twigg, 2014a, 2014b). This finding extends knowledge by identifying the ways in which clothing took on particular associations,

meanings and importance within the setting, these are presented within the following subordinate themes.

(2.1) SUBORDINATE THEME: Clothing and emplacement

The theme **(2.1) Clothing and emplacement** identifies how people with dementia used theirs, and others, clothing practices to orientate and conceptually position themselves in the care home. As Entwistle (2015) notes clothing is a situated bodily practice whereby getting dressed prepares the body for the social world. This means that people typically engage with wearing the 'right' clothing in the 'right' setting. As is discussed below, this subordinate theme contributes nuanced understanding to Twigg and Buse's (2013) and Buse and Twigg's (2014a) notion that clothing supports people with dementia with temporal and spatial orientation.

Firstly, people with dementia associated particular sensorial qualities with temporal orientation. For instance, one participant related wearing particular colours with certain times of day, e.g. that dark rich colours should be worn in the evening and that light colours should be worn during the day. Particular fragrances were similarly connected with specific times of day for instance, light, fresh fragrances were associated with the morning whilst rich spice-like scents were associated with the evening. Moreover, participants linked the texture of particular items of clothing with distinct places, seasons and weather. This is interesting when considering that clothing is emplaced within the care home and that care home guidance (Armstrong & Day, 2017) often limits the number and types of items that residents have with them e.g. that thick woollen jumpers are unnecessary within the care home, and thus potentially limits application of such understandings.

This finding builds upon existing literature (Buse & Twigg, 2014a, 2014b) demonstrating that clothing within the care home can take on particular associations and both represent and mark transitions between public and private spaces. People with dementia used certain items within specific areas of the care home and also engaged with particular clothing practices such as removing a scarf to mark the movement between a public and a private space. This use of clothing demonstrates the complex boundaries within the setting (Cleeve, 2020) and also highlights the affective impact of these spaces on individuals' clothing practices. For example, certain items of clothing and accessories were used to enable feelings of privacy, security, comfort and belongingness within public areas of the care home. As such individuals often carried numerous items with them e.g. in or on their Zimmer frames. This enabled people with dementia to engage with items 'close to hand' such as handling small items of dress. This contributes to existing literature that identifies the importance that material objects 'close to hand' can have for people with dementia (e.g. Buse & Twigg, 2014a, 2014b; Treadaway & Kenning, 2018; Van Steenwinkel, 2014).

This finding demonstrates the significance that mundane clothing practices can have in creating a sense of occasion or marking a certain activity. For example, on two respective instances a participant insisted on changing her clothing before taking part in the research, this seemed to demonstrate a sense of occasion as the participant was to leave her bedroom to join the research encounter. Furthermore, whilst volunteering I noted that the embodied practice of rolling up sleeves or putting on an apron seemed to help mark the start of a creative activity.

This finding offers a further novel way in which clothing was used within the care home, as participants identified items that did and did not 'belong' in the setting.

For instance, a participant spoke of wearing a fall detector pendant because she thought that everyone else in the care home wore one, whilst another participant felt that she did not need to worry about wearing particular types of jewellery as other residents in the care home did not. She also spoke of being “on par” with those in the “same position” as herself. As Entwistle (2015) notes, people use clothing to both align themselves with and identify particular groups and communities, and participants engaged with this through their own clothing practices and their perceptions of others. For example, there were multiple instances in which participants told me not to wear certain items e.g. I wore bronze boots and was told by P3 (PWD) to save them for “some smart place”. Thus indicating a negative perception of the care home and that specific items did not belong in the setting. Similarly, although not a specific use of clothing, creative practitioners spoke of bringing unusual items and sensory props into health and social care settings to transform the ‘feel’ of the respective settings to create spaces conducive to creativity through disrupting the standardised look and feel of the spaces.

The identification of items that did or did not belong within the care home setting is of interest in relation to Cleeve’s (2020) exploration of boundaries in dementia care settings. She found that items are often tangibly ‘marked’ i.e. labelled to identify who the item(s) belong to. Yet the emplacement of clothing suggests that participants engaged with conceptually ‘marking’ items of clothing and accessories according to whether or not they belonged in the care home. This practice suggested that clothing was indicative of the standardised institutional setting, implying the lack of novelty within the setting. This metaphorical use of clothing is of particular interest when considering enhancing care home settings for people living with dementia as it

invites the reconsideration of standardised and task-oriented institutions to reconsider what a care home is, its purpose and design.

This theme identifies the significance that clothing takes on within the care home setting. For instance, wearing particular items enhanced feelings of belonging, security, and comfort and was used to mark or prepare the wearer for a particular occasion or activity. Furthermore, the metaphorical use of clothing to identify what and who belonged in the care home is interesting and contributes further understanding in light of existing literature (Buse & Twigg, 2014a, 2015; Cleeve, 2020; Lovatt, 2020). The following subordinate theme examines the precarity associated with items (including clothing) in the care home and tensions around ownership.

(2.2) SUBORDINATE THEME: Vulnerability

Clothing within the care home could enable residents to feel comfortable and secure and yet clothing and possessions were also deemed to be vulnerable. People with dementia often spoke of clothing disappearing, being lost, misplaced or hidden. This subordinate theme highlights the importance that a sense of ownership and control has to care home residents and the impact that e.g. laundering practices and public spaces can have on individuals. This theme also highlights a number of novel recommendations that could alleviate feelings of vulnerability and distress surrounding clothing and possessions.

The laundry process was often referred to as a source of concern, distress, and frustration by both people with dementia and care home staff. As Buse et al. (2018b) note, the laundering processes within care homes are typically unseen and it was seemingly the hidden nature of collecting laundry, the laundering itself and

return of laundry, that exacerbated feelings of distress, mistrust and uncertainty. It is possible that illuminating the process through e.g. the use of an infographic, could alleviate distress, as it visually identifies when clothing is returned. I created the mock laundry timetable (see **Figure 57**) to illustrate this idea.

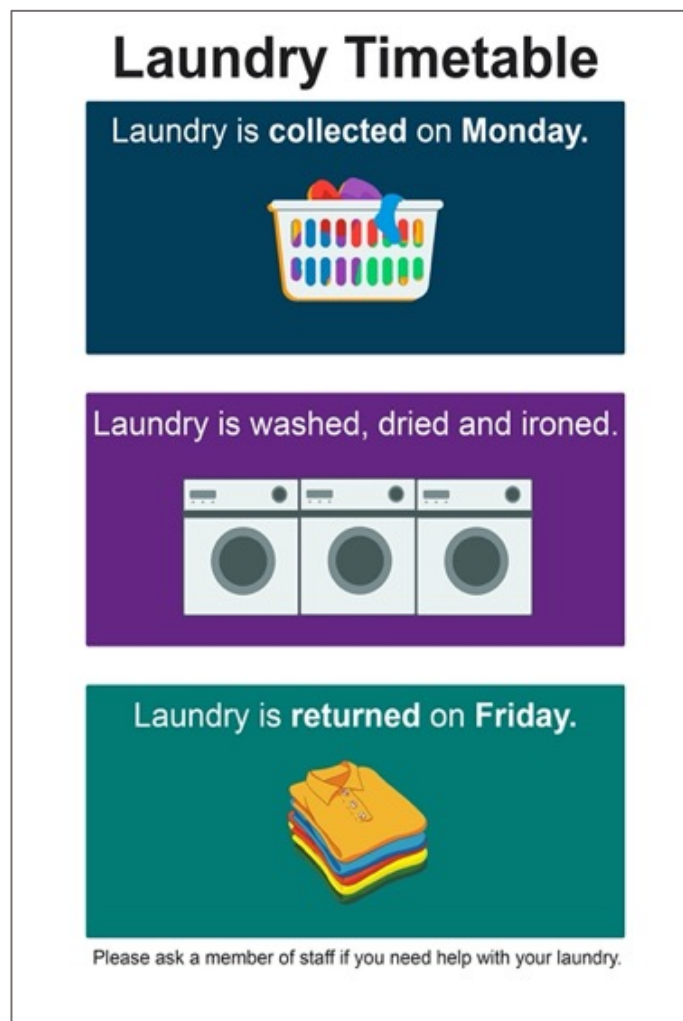


Figure 57. Mock laundry timetable

A further potentially more meaningful strategy could be to ask residents to assist with laundry processes. This could involve for example inviting residents to fold and put away their own clothing. This recommendation draws upon embodied clothing and textile practices and suggests that the process of folding clothing could enhance understanding and also provide a meaningful opportunity for enjoyment and

engagement. This recommendation connects with Lovatt's (2020) findings that suggest that engaging in housework can support care home residents and enhance feelings of ownership and homeliness. Moreover, Souyave et al. (2019), in a recent literature review, present the potential that folding activities can have in providing positive moments for people with dementia. Additionally, this recommendation also connects with increased interest regarding the use of Montessori-based activities in dementia care often involving the use of household materials, such as inviting people to fold and put away towels (Sheppard, McArthur & Hitzig, 2016).

The location of possessions in the care home and the fear of losing items was not only apparent through distress caused with regard to the laundry, it was also evident in how residents often carried numerous items with them. Walking aides enabled people to keep items 'close to hand'. Many people used Zimmer frames that were identical, and thus personalised their walking aides through habitually carrying specific belongings on (or in) them. For example, one participant precariously balanced numerous items on the top of her walking aide. The number of possessions that she carried appeared nomadic and seemed to provide a 'homelike' space when travelling through the different communal areas of the care home. The walking aide also acted as a physical barrier between the individual and others within the care home and so seemingly provided a sense of privacy. Campbell (2019) similarly found that whilst most personal possessions were kept in a person's bedroom, some personal items were kept 'close to hand' e.g. in a person's pocket. As Campbell (2019) noted, communal spaces in care homes lack the everyday clutter of homes such as photographs. It is possible that the care home setting could provide opportunities for individuals to have their own possessions 'close to hand' and this could enhance feelings of ownership within public spaces. Although in some

dementia care settings memory boxes are used (see **Figure 58**) Such boxes derive from reminiscence techniques and typically contain personal items associated with an individual's past. They are often positioned outside of a person's bedroom to provoke memories and support wayfinding, the boxes are typically made from glass or Perspex 'protecting' the items inside and preventing them from being touched.



Figure 58. New Vision Health Environments 'Memory box' (n.d.). Image reuse permission obtained.

Drawing upon the display of items within the care home, it is possible that personal possessions could be positioned within communal areas such as, the lounge, to enhance feelings of ownership, familiarity and comfort. For example, I worked alongside an artist who proposed the installation of a 'cabinet of curiosities' within the lounge of a dementia care setting. The cabinet was to be open to allow individuals to choose, select and handle items as they wished. The artist proposed that residents could contribute one or more possessions to the cabinet (that would rotate on a monthly basis) to provoke conversations and inspire the co-creation of artworks in response to the pieces. In a similar vein, Wallace, Thieme, Wood et al. (2012) installed a cabinet to create a home-like space and alleviate feelings of distress and

anxiety for people with dementia in hospital (see **Figure 59**). Although the cabinet did not house personal items, the pieces created were themed to provoke responses and engagement around selfhood. This also suggests the display of for instance, co-created artworks to enhance feelings of ownership within communal areas of the care home. When volunteering I held sessions in which people with dementia and care home staff brought in photographs, clothing and accessories, participants explored and handled the different items, and the sessions enabled individuals to learn about one another.



Figure 59. Cabinet created by Wallace et al. (2012). Image reuse permission obtained.

The notion of displaying and handling personal items within public areas of the care home could help to permeate boundaries between public and private spaces, fostering social engagement, enhancing relational approaches to care and promoting feelings of ownership and emplacement. Nevertheless, it is important to consider how the items contribute to and the extent to which spaces support individuals in the setting. For example, Campbell (2019) explored how communal spaces in care homes are often feminised to the exclusion of men. Strategies to enhance understanding around the 'hidden' processes and enable residents to

participate with activities, such as laundry, could similarly promote feelings of ownership and security.

(3) MASTER THEME: Clothing and creativity

This research found that clothing was used creatively by both people with dementia and care home staff: this extends limited literature that suggests clothing can be considered a form of little-c everyday creativity (Bellass et al., 2019; Zeilig & Almila, 2018). There were many ways in which clothing was used creatively by individuals ranging from the use of clothing as a prompt to tell stories and narrate aspects of identity (Buse & Twigg, 2016a), such as ageing, sexuality and relationships. Clothing was used by people with dementia creatively to demonstrate their agency. Embodied expressions included removing clothing, placing 'inappropriate' items of clothing in communal spaces and wearing limited items of clothing e.g. dressing 'inappropriately'.

The subsequent subordinate themes present how clothing was used creatively, to support communication and enable different forms of expression, to renegotiate and reimagine the care home setting, and to provoke imaginative moments of joy and humour.

(3.1) SUBORDINATE THEME: Communication and expression

Clothing and accessories have an expressive capacity and can enable people with dementia to express themselves in a variety of ways. This subordinate theme does not therefore refer to what an outfit may communicate about a person (Entwistle, 2015; Tseelon, 2012): it instead focusses on how people with dementia used their clothing as a tool with which to communicate and express themselves 'in the moment'. This builds upon existing literature (e.g. Craig, 2012; Swinnen & de

Medeiros, 2018) to highlight the expressive capacity that clothing and textiles afford individuals with dementia and the potential impact of this within dementia care practice and activities provision.

Clothing was used subversively through e.g. wearing 'inappropriate' items such as garments that revealed the body, removing items of clothing and placing 'inappropriate' items of clothing within public areas. This use of clothing as a form of protest and resistance connects with Ward, Campbell and Keady's (2016) notion that appearance practices can both support change and yet also be used as a form of defiance. The different ways in which people with dementia engaged with and used their clothing necessitates an ability to attend to multiple forms of expression and should be considered within holistic dementia care practices. Attending to nonverbal, embodied expressions connects with the need to understand responsive behaviours as expressive of an unmet need (Herron & Wrathall, 2018). For instance, if we apply this finding to the example used within the literature review in which a care-worker sought 'unrippable' clothing for an individual with dementia (The Dementia Centre at Stirling University, 2011), the person's use of their clothing was potentially expressive and communicative of their situation, mood, and/or an unmet need.

Clothing was not only used by people with dementia, it was also used by care home staff and creative practitioners to communicate with individuals and enhance understanding. For instance, a member of staff encouraged an individual to handle her (the resident's) underwire bra to enable her to understand that wearing it might irritate her skin. Similarly, creative practitioners spoke of inviting people with dementia to handle historical items of dress, to improve understanding through engaging with the aesthetic and tactile properties of items. Thus this finding connects with the subordinate theme **(1.1) Clothing the right fit and feel** to highlight the

importance that objects (including clothing) can have when using nonverbal methods of communicating with individuals with dementia and thus can be used to enhance guidance for care home staff.

Clothing was not only a tool with which individuals expressed themselves, or by which staff communicated with individuals, it also provided opportunities for social engagement and togetherness. For example, people with dementia and care home staff communicated with each other e.g. about their outfits. Moreover, exploring items of clothing and textiles within the object handling sessions (within CYCLE 3) presented an opportunity for people with dementia to work together, to share experiences and invite responses from each other. Additionally, staff who supported the object handling sessions often worked with residents to explore items and create designs. As creative practitioners highlighted, inviting people, e.g. staff and residents, to work together and explore novel items can create powerful shared moments. Such moments disrupt the power imbalance of the traditional caring relationship i.e. the position of the resident as a person to be 'cared-for' and the member of staff as the 'carer', permitting a sense of togetherness in which individuals are together outside the 'realm' of the care home. Thus, rather than task-orientated needs individuals engaged in more equal discussions around aesthetics, taste and style. The impact of such interactions may be powerful in enhancing relational approaches to care and this concurs with recent literature that recommends the use of arts interventions in developing the dementia care workforce (Windle, Algar-Skaife, Caulfield et al., 2020). Interestingly during the object handling sessions care home staff often seemed impressed (through comments that they made) at participants' interactions, discussions, and use of particular items, including

for example, their ability to manipulate and drape fabrics. Partridge similarly discussed the power of such moments when working with a woman with dementia:

“I handed the skein of yarn to a woman with limited mobility and no ability to verbalize. As soon as the yarn was in her hands, she seemed to have a new level of energy in her body...I held the loom closer to her, and she started weaving.” (Partridge, 2019: 58)

As much as staff were often surprised by such instances, participants with dementia were often equally surprised by e.g. a member of staff’s ability to create designs on the mannequin.

The accessibility of the object handling sessions (used in CYCLE 3), and the potential impact that sessions could have in enhancing relational approaches to care, indicate that such sessions could sit within activity provision in care homes. At present vintage items of clothing and textiles such as velvet, fur and silk, are often used in reminiscence sessions (Schweitzer, Bruce & Gibson, 2008) to provoke the ‘feel’ of the past. Yet, as the use of object handling sessions in CYCLE 3 demonstrate, and as I have recently discussed (Fleetwood-Smith, 2020), non-reminiscence-based clothing and textile handling sessions have vast potential in dementia care settings. The process of handling, exploring and sharing items within the sessions enable what Morrissey et al. (2016) discuss as embodied forms of participation e.g. ‘holding’ and ‘giving’ and provide opportunities for multisensory stimulation through smoothing, folding, and manipulating fabrics. Thus the sessions support multiple forms of expression from nonverbal engagement to storytelling, and also promote social engagement, and could be used to enhance relational approaches to care. Kits could be created, not dissimilar to the boxes created for

CYCLE 3's 'Playful' object handling session (see **Figure 26**) and they could provide meaningful one-to-one and / or small-group activities.

Furthermore, this finding also supports the creation of purpose-made objects designed to facilitate shared meaningful engagement between people with dementia and care home staff. For example, this finding connects with the use of the tactile, responsive pillow presented in **Chapter 2, Literature Review** (see **Figure 60**) to create shared moments. The pillow consists of integrated elements that when rubbed, stroked or pushed cause vibrations across the pillow so that those interacting with the piece follow the patterns of vibration, thus facilitating moments of togetherness and connection (Industrial Fabrics Association International, 2014).



Figure 60. 'Tactile dialogues' (Industrial Fabrics Association International, 2014)

This finding **(3.1) Communication and expression** identifies the potential that attending to the expressive capacity of clothing and textiles can have for people with dementia, and the impact that this can have on dementia care practices, activity provision within care homes and the design of textile items for use in dementia care settings.

(3.2) SUBORDINATE THEME: Respite and distraction

This theme, **(3.2) Respite and distraction**, explains how clothing and small items of dress were used by care home staff and people with dementia to create forms of engagement to renegotiate the care home setting. This develops what Harnett (2014) termed 'interactional respite'. Harnett (2014) found that people with dementia living in care home settings develop what can be considered creative strategies to renegotiate and reimagine their environment, providing distraction and respite from institutional life.

Findings indicate that clothing, as a person's most immediate physical environment (Twigg, 2010), provided considerable opportunities for respite and that this was created through material and social interactions (Lovatt, 2020). For example, staff spoke of the ways in which they would talk to residents about their clothing in order to lift a person's mood, distract them and also shift focus away from a person's 'current situation'. This connects with Buse and Twigg's (2018) notion that clothing can be used as an alternative 'talking point'. Similarly, people with dementia used their clothing and accessories 'close to hand' to provide moments of respite and distraction. This included physically interacting with items e.g. looking through the compartments of handbags, emptying pockets, exploring the tactile qualities of clothing through repetitive actions such as e.g. rubbing, stroking or smoothing clothing, and looking at items such as, business cards and loyalty cards. These practices demonstrate how people with dementia were resourceful and conceptually carved out 'space' from the institutional setting through the respite and distraction that interacting with items offered.

This finding develops the notion that care home settings should provide people with opportunities for spontaneous enjoyment (Davis et al., 2009), and while

interactional respite does not necessarily mean enjoyable moments, findings reveal the want and need for distraction from the institutional setting. As this finding demonstrates clothing, textiles and accessories have the capacity to provide stimulation and opportunities for creative expression (Bellass et al., 2019). It is possible that this finding could be harnessed to specifically design wearable items that provide such opportunities. It is important to acknowledge here that these proposed wearable items are oriented around the experiences of female participants in this research.

At present, small wearable items designed for people with dementia typically address issues around safety, security, and surveillance and emphasise technological developments as opposed to focusing on stimulation, meaningful experiences and wellbeing (Ludden, Rompaya, Niedderer et al., 2019). Drawing upon this study's findings i.e. that items 'close to hand' were used to create moments of respite and distraction, it is possible that small wearable accessories could be designed. Such items could draw upon the notion of precursor items as unlike attachment or transitional objects it is something about the tactile quality of the object



Figure 61. Dr Jenny Tillotson - Sensory Designer/eScent Founder wearable scented accessories. Image reuse permission obtained.

that is significant to individuals (Gaddini, 1978). The design of wearable items could be informed by the work of, for instance, Tillotson (see **Figure 61**), a sensory designer and founder of eScent, who embeds scented capsules into clothing and accessories, and jewellery and textile designers (see **Figure 62**).

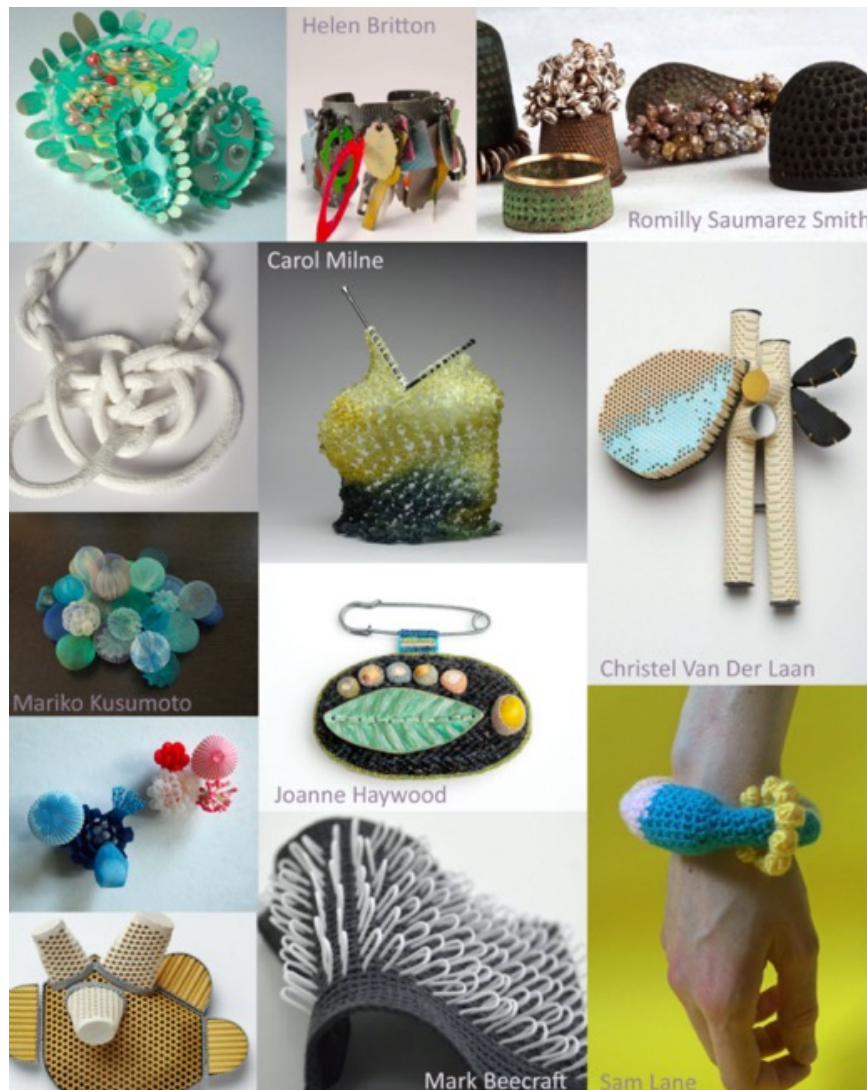


Figure 62. Collated inspiration for wearable items

Existing literature has explored the potential that co-designed wearable accessories have in the lives of people with dementia. For example, Wallace et al. (2013) created bespoke small wearable brooch-like accessories for women with

dementia and found that these can be important in maintaining selfhood.

Additionally, Treadaway (2018) created 'fidget jewellery' for a woman with dementia who enjoyed craft activities. The pieces contained shells and beads and were found to facilitate shared moments between the individual and care-workers.

I created the prototypes (see **Figure 63**), to explore possible tactile bracelets. It is important to acknowledge the gender bias apparent in the proposal of such wearable accessories, as they are typically 'female centric'. These examples are not presented as a 'one size fits all', they illustrate the potential that wearable accessories could have in providing opportunities for respite and distraction and the possible forms that such items could take. Moreover, the prototype designs were informed by female participants' experiences in this project.

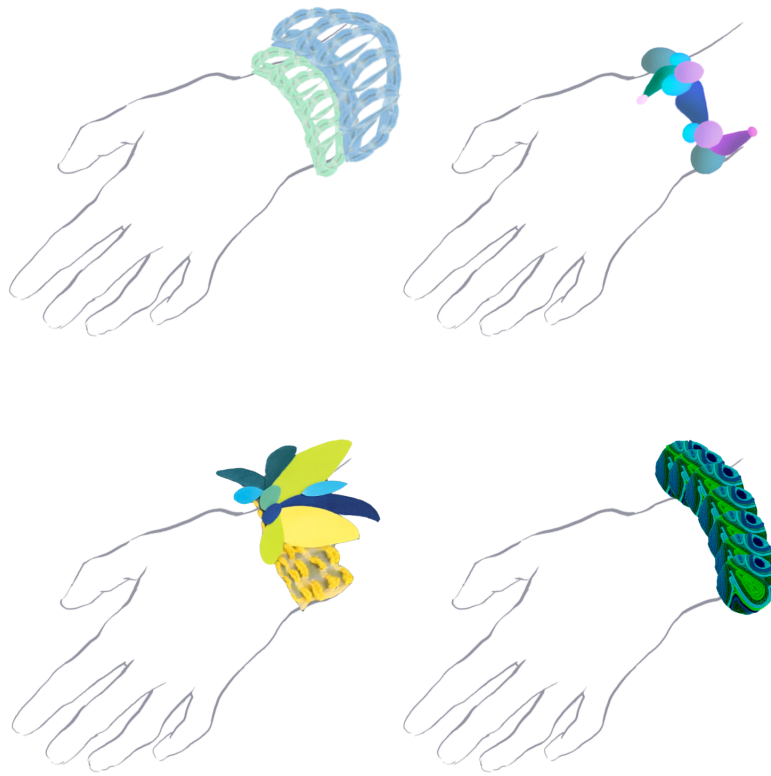


Figure 63. Prototype tactile jewellery

This finding **(3.2) Respite and distraction** reveals the potential that designers have in providing opportunities for meaningful engagement, distraction and respite. As Jakob et al. (2019) identify, attending to the senses when designing for people with dementia can enable meaningful personal engagement and address unmet sensory needs. Thus, employing a sensory based approach to creating small wearable items for people with dementia could be powerful and the immediacy of such wearable items could be particularly important for individuals in care homes.

(3.3) SUBORDINATE THEME: Imagination and playfulness

Clothing provided impromptu moments of joy and humour and was used imaginatively by participants with dementia. Participants demonstrated the

expressive capacity and the meaning-making opportunities of clothing and textiles (Swinnen & de Medeiros, 2018) through for instance, anthropomorphising items and animating the textiles, for example a participant gave voice to the mannequin when designing items on the stand. This finding indicates the importance that material objects (including clothing) can have in the lives of people with dementia and that such items can be designed to create joyful moments (e.g. Treadway & Kenning, 2016). This finding demonstrates the importance of focussing on the 'in the moment experiences' of people with dementia and that attending to these moments, as opposed to focussing on the losses associated with dementia, can enhance the care of people with dementia through creating opportunities for meaningful engagement and sensory stimulation. This finding can therefore be applied to: (1) inform the design of clothing for people living with dementia: (2) enhance the design of the care home settings: and (3) improve the design of purpose-made objects for use in care homes.

The notion that small wearable items can provide opportunities for stimulation was presented in the preceding subordinate theme **3.2 Respite and distraction**, yet findings can also be considered with regard to the design of clothing for people living with dementia. Typically clothing designed to meet functional or cognitive needs neglects aesthetics (Ilтанen & Topo, 2007a, 2007b) and is often stigmatising through the use of practical adaptations such as large Velcro fastenings, yet as this finding explains the look and feel of clothing and textiles can provoke joy. Thus, clothing could be reimagined and designed to facilitate joyful, playful and imaginative engagement. The use of techniques such as applique and embellishment along with the considered use of colour, fabric and textures could reimagine clothing design for people with dementia. For instance, playful elements could include the use of

oversized pockets made from contrasting colours and materials, or the cuffs of garments could be embellished to include tactile elements. Designers could look to examples from the work of fashion designers such as Mao Tsen Chang (see **Figure 64**), to inspire playful details. His designs include oversized tactile embellishments created from unusual contrasting textures e.g. the use of raffia on a cotton shirt.



Figure 64. Mao Tsen Chang (n.d.). Image reuse permission obtained.

The findings advocate for the increased use of smart textiles to enhance clothing design for people with dementia. Smart textiles combine traditional techniques such as knitting and weaving with fibre-based materials to create soft, flexible circuits resulting in materials that look and feel like textiles whilst integrating technology such as sensors. For instance, Devendorf et al. (2016) weave and crochet with conductive thread coated with thermochromic paint which changes colour when heated (see **Figure 65**). They examined wearers' responses and found that the smart textiles provided opportunities for engagement and yet felt familiar through the traditional techniques used.



Figure 65. Smart textiles, Atlas Institute, University of Colorado (2019)

It is possible that smart textiles could be used to provide playful opportunities and haptic stimulation for people with dementia and they could also be used for healthcare purposes. The communicative capabilities of smart textiles through e.g. displaying particular colours, may be of interest when considering the expressive use of clothing by people with dementia.

The notion that clothing could be designed to provoke playfulness, intrigue and curiosity develops similar concepts underpinning the LAUGH project (Treadaway et al., 2018) and responds to calls from Ludden et al. (2019) who advocate designing items that provoke meaningful engagement. This connects with Mahoney et al.'s (2015) notion that innovative clothing should be designed for people with dementia. This finding indicates that clothing could be viewed as an opportunity with which to provide joy, enhancing mood and increasing wellbeing as opposed to managing behaviours symptomatic of dementia.

When reimagining and renegotiating clothing for people with dementia it is important to consider the broader care home setting. As presented earlier (see **(2.1 Clothing and emplacement)**), clothing in the care home is emplaced i.e. items are

identified according to whether or not they belong in the setting. This indicates that it is necessary for there to be synergies between e.g. reimagined clothing design and care home settings and invites reconsidering what a care home is, its design and purpose. For example, creative practitioners spoke of disrupting the standardised spaces of health and social care settings through the use of sensory props. This highlights the need for novelty within such spaces and also indicates the limited opportunities for stimulation within existing spaces, as similarly found by Craig (2017). Jakob, Collier and Ivanova posit (2019) that multisensory stimulation should be considered essential in dementia care. The design of the built environment and the installation of particular objects within these settings can provide such opportunities. For example, sculptor Tabatha Andrews worked with people with dementia to create 'The Dispensary' (2016) (see **Figure 66**) Engagement with the piece provokes curiosity and multisensory stimulation as it involves exploring numerous drawers and compartments in order to discover the small sculptural items and musical instruments contained within. Similarly, carved wooden artworks within Bristol's Southmead hospital (2016) and tactile ceramics within the Royal Edinburgh Hospital (2000) provide opportunities for haptic stimulation, inviting people to touch

and engage with the artworks (see **Figure 67** and **Figure 68**) as they travel through the respective spaces.



Figure 66. The Dispensary by Tabatha Andrews 2016. Image courtesy RSS and Anne Purkiss. Private collection. Image reuse permission obtained.



Figure 67. Carvings with braille by Alistair Park (2016). Image reuse permission obtained.



Figure 68. © Frances Priest (n.d.), Tonic Arts, Edinburgh and Lothians Health Foundation. Photographer Shannon Toffs. Image reuse permission obtained.

Drawing upon findings, the preceding example artworks and the work of the LAUGH project (see e.g. Treadaway & Kenning, 2016, 2018; Treadaway, Fennell, Taylor et al., 2018) care home settings could be enhanced to enable spontaneous, joyful, multisensory experiences. For example, artists could be commissioned to create accessible 'tactile' artworks that would be interacted with when travelling through e.g. corridors (see **Figure 69**). Such artworks would need to be carefully



Figure 69. My proposed 'tactile' artworks

designed to avoid what Campbell (2019) discussed as the typically ‘feminised’ communal spaces within care homes. As Ludden et al. (2019) found when redesigning handrails (see **Figure 70**), such pieces can offer multiple benefits for people with dementia as they can enhance the look and feel of the setting whilst also improving orientation, promoting purposeful walking and increased mobility and providing opportunities for multisensory stimulation.

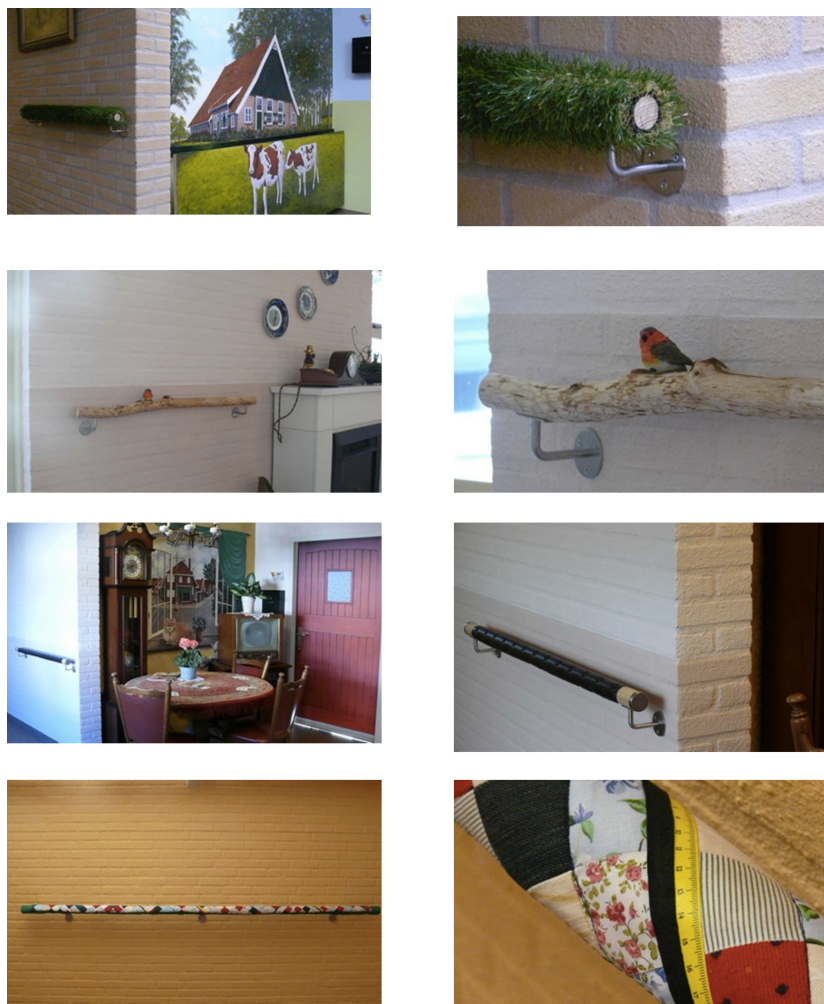


Figure 70. Handrails matching different scenes Ludden et al. (2019:14). Image reuse permission obtained.

This finding not only has implications with regards to reimagining clothing and the built environment, but it could also be used to inform the design of purpose-made objects for people with dementia. At present items such as twiddle muffs neglect

aesthetics and are designed to address responsive behaviours and thus typically centre on cognitive losses associated with dementia (Iltanen & Topp, 2007a, 2007b; Mahoney et al., 2015). Findings from this research indicate the importance that the aesthetic and tactile properties of clothing, textiles and objects have for people with dementia in promoting playful, creative and imaginative moments and the need to engage designers and design-led evidence when developing such items. For instance, some of the items used during the object handling sessions were designed to be ambiguous. This enabled individuals to interpret and assign their own meanings to the pieces (Gaver, Beaver & Benford, 2003) and was demonstrated through the ways in which they for instance, animated the textile samples as though they were puppets. Moreover, participants also manipulated textile samples to create their own design ideas placing items on the body to denote e.g. a hat or a sleeve. The ambiguous textile samples were therefore powerful in provoking curiosity, expressive, imaginative responses and purposeful engagement. Ambiguity could therefore be embraced within the design of multisensory objects for people with dementia. Such items could be informed by the textiles used in the 'Playful' object handling sessions (see **Figure 24**). I created a number of small textile objects to explore ideas in response to findings. The pieces created are designed to encourage different forms of engagement e.g. holding, stroking, squeezing and manipulation (see **Figure 71**).



Figure 71. Prototype textile objects

In the case of items that are not wearable, the placement and accessibility of such pieces are vital in supporting spontaneous engagement. For example, objects should be visible and 'within reach'. Such an accessible environment emphasises the strengths of those within the setting (as opposed to losses) and connects with burgeoning interest in the use of Montessori methods when working with people with dementia (Camp, 2010). The approach emphasises the autonomy, choice and agency of individuals and foregrounds the importance of all staff groups using communication that reinforces this. Thus it is possible that the introduction of such items within a care home could 'disrupt' the standardised setting, impacting the

setting both tangibly (altering the look and feel of the setting) whilst also intangibly shaping the affective atmosphere i.e. through the material and social interactions that such items may provoke (Lupton, 2017). Nevertheless, the potential introduction of items would need careful consideration in order to meet health and safety requirements in care settings.

Within this project clothing and textiles provided impromptu moments of joy and humour and were used imaginatively by people with dementia. These findings contribute to the novel area of creativity and clothing (Bellass et al., 2019; Zeilig & Almila, 2018) and identify the need to create wearable accessories for people with dementia, inform clothing design, enhance the design of care homes, and develop activity provision in care homes.

7.4 Summary

This synthesis of findings has thematically linked findings from the three cycles of study conducted over the course of this research. The findings have been presented alongside existing literature, identifying novel contributions, together with a number of application-based and design-led recommendations.

Findings reveal that clothing is an integral but under-explored part of life in care homes, providing a means for people with dementia to feel comfortable, secure, and express themselves. Clothing supported a number of important functions including enhancement of spatial and temporal orientation, whilst providing opportunities for those with dementia to renegotiate and reimagine the setting. Clothing promoted understanding including e.g. changes to body, it was a tool for embodied expression and communication, and it also provided opportunities for creativity, humour and playfulness.

The findings have a number of implications that can enhance relational approaches thus optimising dementia care. For example, findings can be used to enhance dressing guidance, to inform staff training and to develop activity provision within care homes. The expressive, communicative capacity that clothing affords people with dementia is vast and is important when considering alleviation of responsive behaviours such as agitation and wandering.

Findings demonstrate the potential that (1) certain specialist products, (2) items of dress, and (3) care-workers clothing can have in enhancing the care of people with dementia. Importantly the findings indicate many opportunities that designers have to enhance the lives of people with dementia. The aesthetic and sensory aspects of clothing remain important for people with dementia and should be considered to provide sensory stimulation and meaningful engagement in care home settings. Clothing and textile objects should be reimagined and renegotiated to be viewed as a means with which to enhance individuals' lives as opposed to managing responsive behaviours. The study findings have broader implications when considering the design of care home settings and enhancing spaces through for instance, using textiles to provide e.g. novelty, spontaneous enjoyment, meaningful engagement and sensory stimulation. These findings are therefore applicable to clothing practices but also with regard to enhancing dementia care settings more broadly.

The following chapter concludes this project, reflecting upon the research methods, research aims and findings, along with the study's strengths and limitations and recommendations for future research.

CHAPTER 8 CONCLUSION

This concluding chapter summarises this project, detailing how this body of work contributes new knowledge to the area of clothing and dementia and the ways in which clothing can be considered with regard to enhancing dementia care practice. I first consider the sensory, embodied and creative research methods used. This is followed by a summary of the findings in reference to the research aims and existing literature. I then discuss the strengths and limitations of this research. This is followed by a presentation of implications for future research including the impact of findings to dementia care practice, policy, design and future studies.

8.1 Sensory, creative and embodied research methods

This project consisted of three interlinked cycles of study, underpinned by a sensory ethnographic approach (see **Chapter 3, Method**). The iterative cycles of study involved the use of sensory, creative, embodied research methods that were created and shaped within the specific context of this project (Pink, 2015). As such the methods were designed to explore the phenomenon under study, whilst enabling people with dementia's participation in the research (Campbell & Ward, 2017; Phillipson & Hammond, 2018).

To summarise, the three interlinked cycles of study were as follows:

CYCLE 1: Exploring clothing during wear. This cycle of study explored clothing during wear and focussed on individuals' clothing practices 'in the moment' as opposed to exploring items of clothing that were no longer worn i.e. items in the wardrobe. This cycle of study responded to, Buse and Twigg's (2018) call that researchers should explore the physical and sensorial sensation of clothing when working with people with dementia, and Ward and

Campbell's (2013a) notion that how appearance feels is important for people with dementia. This cycle involved working with people with dementia and care home staff through a series of multisensory research encounters in which clothing was used both as the focus of study and as a tool for elicitation (Fleetwood-Smith et al., 2019; Hubbard et al., 2003; Pink, 2015; Woodward, 2020).

CYCLE 2: Translating themes into objects. This cycle of study, informed by the work of Chamberlain and Craig (2013, 2016, 2017), worked with creative practitioners to explore the thematic findings from CYCLE 1, examining the ways in which findings could be envisaged and re-interpreted through a series of materials, objects and images. This study employed the use of thematic cards as elicitation tools, working with creative practitioners in one-to-one interviews. Findings were then synthesised to create and select the materials, objects and images that were used in CYCLE 3.

CYCLE 3: Thinking with things: A series of object handling sessions. The final cycle of study explored the potential of specific items within the holistic care of people with dementia. Object handling sessions (e.g. Johnson et al., 2017; Griffiths et al., 2019) were repurposed as a creative, sensory and embodied research method and were video recorded to enable re-visiting and re-viewing each session.

Each respective method used in this project is discussed below, this includes presenting the strengths of the particular method and the ways in which it could be considered and developed for use in future research.

Multisensory research encounters (CYCLE 1)

The multisensory research encounters used in CYCLE 1, consisted of concurrent observations and interviews. The encounters enabled participants to partake at their own pace (Hubbard et al., 2003) and shape the focus of the encounter through the items that they chose to interact with and discuss. For example, participants often invited me to share experiences with them through e.g. handling items of clothing, looking at specific items of jewellery, smell certain perfume and so forth. Thus, as Woodward (2020) notes, the embodied and sensory aspects of clothing (including accessories) were powerful in eliciting experiences. Clothing was both the focus of this cycle of study and a prompt with which to explore experiences. Findings from CYCLE 1 indicate that using clothing as an elicitation tool can reveal complex aspects of a person's lived experience. Thus, this research contributes to existing literature (Twigg, 2019), demonstrating that personal possessions (including clothing) are powerful conduits with which to explore the lived experiences of people with dementia. For example, CYCLE 1's thematic finding **(5) Clothing a tool to explore the unacknowledged** revealed how when exploring items of clothing participants discussed relationships, sexuality, and views about ageing. This research demonstrates that engaging with materiality within research encounters can lead to in-depth understanding through the researcher and participant e.g. physically engaging with items together. In her recent book Woodward (2020) used the term 'material methods' to refer to such approaches and this project highlights the vast opportunities that such 'material methods' have in understanding lived experiences of people with dementia. This method therefore contributes to materiality focussed studies within dementia research (e.g. Buse et al., 2018a; Cleeve, 2019; Connellan, 2019, Lovatt, 2020). As demonstrated within this

project, such methods lead to rich understandings and can be applied to enhance the lives of people with dementia.

Despite the rich knowledge formed as result of the multisensory research encounters, there are a number of considerations that could impact the use of this method in further studies. Firstly, the site at which the research is carried out is important to consider. I carried out multiple research encounters (equating to a total of thirty-one working with twelve participants) over the course of CYCLE 1. Thus, due to the multiple research encounters over the concentrated period of study, it was important to build rapport with care home residents and staff prior to embarking upon the research. In order to do so I volunteered once a week for approximately seven months prior to starting the research. Fletcher et al. (2019) call this a 'hanging out period' and explain that this is good practice when working with people with dementia in care homes. Nevertheless, the lengthy volunteering period and the use of multiple research encounters may not be suitable for shorter projects and it may be that intensive periods of 'hanging out' i.e. three-four weeks and fewer research encounters / participants would be necessary. A shorter 'hanging out' period would however impact the ability to build rapport and may impact the ability to carry out the novel research methods. Therefore the prolonged period of 'hanging out' is a strength of this study.

The number of multisensory research encounters is not the only consideration involved when developing the method for future research, selecting the appropriate recording technique is crucial. As Campbell and Ward (2017) note, sensory and creative methods enable exploring rich full-bodied experiences and I found that such methods also warrant the use of creative, novel recording techniques. For instance, I used fieldnotes and an audio recording device to capture encounters during CYCLE

1, and although I engaged with creative reflexive practice this was not analysed alongside participant data, therefore, the recording methods limited what was captured. It is important to note that I did not seek an objective stance or align with the notion that there is one 'true' reality and so I do not believe that it is possible to capture the 'whole' experience. Nevertheless, alternative recording techniques could enhance the use of multisensory research encounters. For example, photography, video-recording techniques or practice-based approaches such as drawing or textile making - alongside the use of fieldnotes and audio recordings, could be used to enable researchers to 'fully' re-visit the multisensory research encounters during the analysis process. This, in turn, may enhance the knowledge formed as a result of the research encounters.

Despite the considerations outlined here, the multisensory research encounters used in CYCLE 1 resulted in a series of novel, multifaceted findings, through eliciting aspects of people with dementias' and care home staffs' experience of clothing during wear.

Thematic cards as elicitation tools (CYCLE 2)

The second cycle of study used findings from CYCLE 1 in a series of one-to-one interviews working with creative practitioners (who worked with people with dementia in health and social care settings). Data from the interviews was used to select and create, materials, objects and images that were then used in CYCLE 3's object handling sessions. This way of working was informed by Chamberlain and Craig (2013, 2016, 2017) who used focus group and interview data to create a series of objects to then explore older adults lived experiences.

The thematic cards created were informed by the use of probes within design-led research (Woodward, 2020). The process of designing the cards involved working with the supervisory team and peers outside of the research. Working with peers ensured that the thematic cards were accessible and understandable to individuals unrelated to the project. The use of thematic cards resulted in rich insights regarding creative practitioners' practice when working with people with dementia in various health and social care settings. This included understanding for instance, the ways in which they transformed spaces, created 'work spaces' for participants, selected materials and the nonverbal forms of communication that they employed. Findings also resulted in the development of three distinct object handling sessions that were used in CYCLE 3.

Despite participants' rich engagement with the thematic cards, it was initially anticipated that the cards would result in more 'direct' connections with specific materials, objects and images and as this was not the case (participants often referred more broadly to their practice). This necessitated that I engaged with multiple levels of analysis and synthesis to develop the object handling sessions. This may have been avoided if the interviews and use of thematic cards had been piloted. Additionally, it is also possible that multiple interviews would have enhanced this process. For example, two or more interviews might have allowed participants to engage with the content of their selected card(s) and to develop their ideas with regard to specific materials, objects and images.

The method could also be developed to be used as a remote research method i.e. thematic cards could be sent in a 'kit' to participants. This would allow participants to creatively respond to the cards as opposed to relying solely on verbal responses (as was the case in this project). For instance, the kit could contain

thematic cards, a sketchbook and art materials. Developing the use of thematic cards is timely in light of the COVID-19 pandemic see e.g. 'Doing fieldwork in a pandemic' (Lupton, 2020), a 'live' google document set up for researchers to share innovative ways of working when face-to-face to research is not possible. Moreover, the notion of inviting participants to respond creatively to the thematic cards also indicates the potential for creative practitioners to be commissioned to create prototype(s) in response to one or more of the thematic cards. Such prototypes could then be used with participants to explore potential design opportunities / solutions (Woodward, 2020).

The thematic cards could not only be developed to enhance the elicitation process or commission creative responses, the cards could be reimagined as a tool for dissemination. Participants' rich, evocative engagement with the cards in CYCLE 2 imply that the thematic cards offered immediate access to people with dementia's lived experiences and so could be reconsidered as tools with which to engage non-academic audiences. Nevertheless, it is important to recognise that practitioners' expertise informed their responses and so the use of thematic cards as a dissemination tool would need to be carefully developed in order to ensure meaningful engagement.

The use of thematic cards as elicitation tools resulted in the creation of three distinct object handling sessions. Thus, despite the limitations and opportunities for development, the method was powerful in engaging creative practitioners and developing ideas with regard to the use of specific materials, objects and images for use in CYCLE 3. Moreover, findings also elicited rich insights regarding creative practitioners' approaches when working with people with dementia. For example,

findings indicate the potential for knowledge transfer between creative practitioners and care-workers to enhance nonverbal communication skills.

Object handling sessions (CYCLE 3)

Drawing upon the work of Chamberlain and Craig (2013, 2016, 2017), the use of object handling sessions as a psychosocial intervention for people with dementia (e.g. Griffiths et al., 2019; Johnson et al., 2017; Thomson & Chatterjee, 2016), and object elicitation methods (Woodward, 2020), object handling sessions were repurposed as a sensory, creative and embodied research method. The sessions were video recorded to enable re-visiting and re-viewing the encounters during the analysis process (Campbell & Ward, 2017; Pink, 2015). The use of video recording alongside fieldnotes was particularly important in capturing the full-bodied experiences of participants (Campbell & Ward, 2017).

Using object handling sessions as a research method resulted in findings that would otherwise have been 'unknowable' (Ellingson, 2017; Pink, 2015). For example, participants interacted with and folded textiles demonstrating their embodied and haptic knowledge during the sessions. Engagement with specific materials, object and images not only elicited participant's preferences, they led to creative, imaginative and playful responses (verbal and nonverbal). Thus, the method highlights the importance that objects (including clothing) and textiles have in supporting the expressions of people with dementia.

The sessions involved working either on a one-to-one basis with participants (and a supporting member of care home staff) or working in small groups i.e. two participants with dementia (and a supporting member of care home staff). Working in this way demonstrated the potential that one-to-one creative activities have as a

research method. For instance, the sessions supported multiple forms of expression and shared experiences, whereby I worked with one or two participants to explore items and create designs i.e. in the 'Dramatic' object handling sessions. The use of the camcorder enabled this process as it meant that I could be 'hands-on' during the sessions.

Despite the novel findings generated there are a number of limitations to consider. Firstly, I had limited financial resources to source and create the materials, objects, and images used. This meant that although I was resourceful and used items donated, items from charity and vintage shops and my own textile materials, this impacted the sessions. Object handling interventions typically involve the use of loaned archive/museum objects (Griffiths et al., 2019), yet when adopting the use of such sessions as a research method it is crucial that items fit the scope and aims of the project and so appropriate funding is necessary so as not to limit the items used. Therefore, future use of this method necessitates appropriate funding in order to source and create high quality items for use in the sessions. It is also important to consider time as a resource. The use of interviews as opposed to focus groups in CYCLE 2 impacted the project timeline and meant that I had limited time to source and create the items used in CYCLE 3. Consequently, future use of this method must ensure a robust timeline to ensure an appropriate time frame in which to source and create the items used.

Future studies involving the use of object handling sessions as a research method could be developed for work with people with late stage dementia. Findings from this project demonstrate that the sessions were accessible, and participants interacted with the items at different levels thus suggesting that the sessions are valuable in exploring experiences with people with late stage dementia. This is

important as people with late stage dementia are often excluded from research due to difficulties with communication. Additionally, participants' meaningful, creative and imaginative engagement with items during the sessions suggests that the method could be developed to use within design-led projects. For instance, object handling sessions could be used to elicit design ideas and explore prototypes, thus involving people with dementia in design and development processes. This is significant given that findings from this research demonstrate that people with dementia discussed e.g. aesthetics, taste, style and potential applications for items (in the case of textile samples).

Summary

The respective methods used within this project demonstrate the potential that sensory, creative and embodied research methods afford in exploring people with dementias' lived experiences. Thus, this research concurs with Phillipson and Hammond (2018) and others e.g. Campbell and Ward's (2017) call for the use of innovative research methods when working with people living with dementia. Such methods are powerful as they move away from recall and verbal expression to support and elicit embodied, nonverbal responses. The capacity that objects (including clothing) have in exploring aspects of lived experience is extensive and this research has demonstrated that such knowledge can be used to address for instance, unmet needs through the creation or use of innovative products. Thus, sensory, creative and embodied research methods are important in developing understanding about the lived experience of people with dementia and can be embraced to design e.g. a new product, service or intervention, to enhance the lives of people with dementia.

The methods used within this project are also important when considering enhancing care practices within further health and social care settings and working with people with late stage dementia. Furthermore, such methods may be beneficial when working with people with different needs who may find taking part in traditional research problematic. For example, I will be developing the methods used within this project for another project involving children with visual / auditory impairments. This will explore their sensory experiences of specific hospital spaces in order to enhance the design of such settings (Bates, n.d.).

8.2 Project findings

Before summarising this project's findings and contribution to knowledge, I first return to the aims of this research as presented in the literature review.

The project's aims were as follows:

- To explore the relationship between people with dementia and their clothing, through addressing the following questions:
 - What is the embodied experience of wearing clothing in people living with dementia?
 - How do particular sensory qualities i.e. aesthetics, specific colours, patterns, fabrics effect clothing wear?
- To address the potential of clothing in the holistic care of people with dementia.

This research has demonstrated that clothing is not incidental in the lives of people with dementia and that attending to the embodied and sensorial aspects of wear offers rich opportunities with which to enhance the lives of people with dementia.

Moreover, this research demonstrated that clothing offered a nuanced means with which to explore the lived experiences of people with dementia.

The *feel* of clothing

Findings demonstrates that clothing practices should be viewed as processual and fluid in order to support people with dementia. This involves shifting focus away from what a person 'should' look like to how they feel. Explored the embodied and sensorial aspects of clothing elicited the nuanced ways in which clothing can contribute to the holistic care of people with dementia. Firstly, findings strengthen calls from Ward and Campbell (2013a) and Campbell and Ward (2014) that attending to the feel of appearance is important for people with dementia, as attending to the visual appearance solely negates understanding how a person's clothing physically and intangibly affects them.

Findings concur with and extend current literature and demonstrate that clothing is intimately intertwined with a person's sense of self and that this is no less true for people with dementia (Woodward, 2007; Buse & Twigg, 2018). This finding is important with regard to Woodward's (2007) notion of the 'aesthetic fit' i.e. the ways in which individuals distribute selfhood through their clothing and judge the extent to which items of clothing our outfits are 'really them'. Participants in this study, much like in Buse and Twigg's (2016a), engaged with Woodward's concept of 'aesthetic fit', and yet also demonstrated that not wearing specific items disrupted selfhood. Thus, findings offer a novel contribution illustrating that the *feel* of clothing can contribute to, or disrupt, selfhood. Thus, this research challenges the emphasis on preserving clothing practices and attending solely to an individual's visual appearance (see e.g. Buse & Twigg, 2018; Mahoney et al., 2015; Ward et al., 2014). For example, the feel of wearing particular items, rather than the items themselves,

were important to individuals i.e. the sensation of wearing a watch, bracelet, a cap, and the texture and weight of particular garments. Not having particular items close to hand was problematic and could disrupt selfhood, whilst wearing particular items and having them 'close to hand' could provide a sense of comfort, familiarity and security for people with dementia in the care home. As Van Steenwinkel (2014) found with textiles (e.g. cushions, pillows and blankets), clothing can also support people with dementia due to the closeness between the body and material, and wearing specific items can enable a person with dementia to feel secure and comforted. Moreover, the processual nature of clothing was demonstrated through the ways in which clothing practices were situated within the care home and were adopted and altered according to institutional practices, bodily changes and clothing 'norms' within the setting i.e. clothing was emplaced within the care home.

Attending to the embodied and sensorial experience of clothing is important for people with dementia as it affected individuals at both a physical and affective level. Focusing on the embodied and sensorial aspects of clothing offers vast opportunities to enhance the lives of people with dementia through e.g. improving the design of specific products, through the creation of wearable accessories and the enhanced design of clothing for people with dementia (and older adults).

The embodied and sensorial aspects of clothing were not only found to be important to people with dementia, they were also found to be important for care home staff. Clothing was found to be a tool with which to enact relational approaches to care through staffs' use of specific clothing practices e.g. whereby they selected outfits that allowed them to perform their caring role. Moreover, staff adapted and created specific items of dress for people with dementia, thus demonstrating their

understanding of the importance of clothing to individuals and demonstrating a relational, holistic approach to care that moves beyond task-oriented roles.

This research has identified that the embodied and sensorial feel of clothing impacts people with dementia both at a physical level, e.g. how wearing items of clothing feel, and at an affective level. Moreover, this research has found that clothing can be an important, yet often overlooked, aspect of relational dementia care. Thus, extending existing literature within the area of clothing and dementia.

Clothing and expression

This project identified that the expressive capacity of clothing should be considered and adopted within dementia care practice. As Joller et al. (2013) note, a lack of clothing, or wearing inappropriate clothing, is not always a sign of sexual disinhibition (a behaviour symptomatic of dementia). Similarly, as recent literature has demonstrated, it is important that responsive behaviours are viewed as expressive of, for instance, an unmet need (Herron & Wrathall, 2018). This research found that people with dementia used their clothing in multifaceted ways. Examples include expressions that were perhaps more readily identifiable as that of an unmet need e.g. a gentleman removing his trousers to demonstrate his need to wear elasticated waisted trousers so that he could continue to use the toilet independently, to more nuanced and creative forms of expression such as the subversive use of clothing as a form of protest e.g. to indicate a want to leave or a lack of agency within the setting.

Clothing practices denoted individuals' use and identification of boundaries within the care home setting. Findings concurred with Buse and Twigg's (2014b) notion that people with dementia use handbags to create privacy within public

spaces of a care home. Moreover, this research found that carrying multiple items 'close to hand' enabled individuals to create personal, private spaces within public areas of the care home. Additionally, certain clothing practices such as removing or putting on specific items of clothing marked transitions between areas of the care home. Clothing was also 'marked' according to whether or not it belonged within the setting. This extends Cleeve's (2019) finding that items within the care home are marked to denote who they belong to, identifying that items of clothing are implicitly marked according to whether or not they belong in the setting. Thus, clothing practices within care home settings are emplaced and situated.

Clothing was also used by care home staff to facilitate understanding, through e.g. enabling a person to handle a specific item of clothing. As Chamberlain and Craig (2013) discuss, material objects can generate understanding about older adults' lives and as this research has demonstrated can also be used to enhance older adults' understanding.

Reimagining and renegotiating clothing

Clothing was not only used as a tool to express e.g. an unmet need or to negotiate movement between spaces within the home, clothing was also used to reimagine and renegotiate the care home setting through providing social and material interactions outside the realms of the setting. Clothing also provided opportunities for social and material interactions (Lovatt, 2020) beyond task-orientated discussions. Mundane examples include the ways in which both staff and people with dementia would talk with each other about their clothing. Individuals would also use their own clothing and items close to hand to provide moments of respite from the setting through e.g. looking through pockets, handbags, and

engaging with the tactile properties of the textiles through handling, stroking or smoothing items. This finding develops Harnett's (2014) interactional respite.

Clothing was used creatively by individuals (Bellass et al., 2019; Zeilig & Almila, 2018) and this was particularly apparent through individuals' engagement with certain items of clothing. The materiality of clothing offered opportunities for people with dementia to be playful, imaginative and creative. Physically interacting with items enabled individuals to express themselves through gestures, actions and through narrating or anthropomorphising items. This enabled individuals to respond, 'in the moment' and did not focus on recall and verbal expression. As Twigg notes (2010) clothing can be considered a person's most immediate physical environment, this research highlights that clothing affords individuals with dementia an expressive capacity that can be playful and provide moments of joy, distraction and respite from the care home setting. This should be embraced and adopted as an important resource within dementia care practice.

As summarised earlier, findings demonstrated that clothing practices were enacted within the care home setting i.e. people with dementia judged the extent to which items did or did not belong in the care home. This research therefore has important implications when considering the broader care home setting, what the care home is, its purpose and design. As **Chapter 7, Synthesis of Findings** presented there are a number of application-based opportunities for designers to enhance care home settings and the lives of those who reside in them.

Summary

This research contributes new knowledge to the area of clothing and dementia. Findings demonstrate that clothing is important to the lives of people with

dementia and can enhance feelings of comfort, ownership and security and can both support and / or disrupt selfhood. Clothing is used by individuals in the care home to support spatial and temporal orientation (Twigg & Buse, 2013) and to enhance feelings of belongingness and privacy. Items ‘close to hand’ such as small items of dress and specific items of clothing provide meaningful opportunities for respite and distraction from the care home setting and enable people with dementia to be imaginative, playful and provoke moments of joy and togetherness through material and social interactions.

Reimagining and renegotiating the role of clothing and textiles within health and social care settings can have vast implications for individuals. Clothing should not be considered as simply a task-oriented activity or a tool with which to e.g. manage responsive behaviours, clothing should be considered an opportunity with which to enhance the lives of people with dementia. This research has proposed a number of application-based and design-led opportunities that could be used within dementia care settings to enhance the lives of people with dementia. Such opportunities range from the considered design of medical devices, to playful wearable accessories and garments. Moreover, this research has demonstrated how clothing can both enhance relational holistic approaches to care and how clothing can contribute to relational care practice e.g. care-workers’ creation of an informal uniform to provide optimal care. The findings from this project are novel, rich and multifaceted. Findings not only have multiple implications with regard to clothing, dressing guidance and activity provision within care homes, findings are also important when considering what a care home is, what it looks like, what it feels like, how care is provided and the processual and fluid material (including clothing) and social interactions within the setting. Section **8.4 Recommendations for future**

research of this chapter details specific implications with regard to policy, practice, design-led opportunities and future research according to this project's findings.

8.3 Strengths and limitations of this project

This section considers the strengths and limitations of this project. I first explore the study site and research participants, before considering the replicability of the research methods and the findings.

Study site

This project was carried out at one study site. Working closely with one site is not uncommon within ethnographic research nevertheless, it is important to consider when contextualising research findings. The study site was a large care home and had a considerable number of people with dementia living there. In recent years the organisation had received an outstanding rating from the CQC. Additionally, the research site often hosts commercial and non-commercial research projects. These factors are all important to highlight when considering (1) how this study was carried out, (2) the replicability of the research methods used and (3) interpreting findings.

Firstly, the large organisation had many volunteers who often worked closely with the activity team. The team delivered a comprehensive timetable of events ranging from gardening to arts and textiles activities. Thus, I was able to volunteer and work with the team to deliver textiles workshops. When volunteering I worked in a dedicated activities room that was used by residents across the care home, this was important as it meant that I was able to build rapport with care home residents and staff across the site. Volunteering at the site was invaluable in shaping my approach to research and how the research was carried out and thus was essential

for this project. Nevertheless, volunteering at differing or smaller research sites would need to be carefully negotiated to meet the needs of the site.

Additionally, the size of the site meant that I was able work across multiple floors; this was akin to working with multiple small study sites. For example, over CYCLE's 1 and 3 I spent a substantial amount of time at the care home, yet as I typically worked across two floors, I was able to split my time between the floors. This was important so as not to overburden participants, staff and care home residents and would not necessarily be possible at smaller study sites.

The CQC rated the care delivered at the site as outstanding which is crucial to consider when interpreting findings. For example, the site was recognised for the person-centred care it delivers, and so arguably staff at the site were more attuned to the holistic ways in which to enhance the care of people with dementia e.g. through supporting people with dementia with choosing their clothing. Although the strategies used at this site may therefore not be applicable across all care settings, they are important as they can be used to enhance clothing practices and dress guidance at other care homes. Moreover, despite the high standard of care delivered there were still a number of opportunities that could be adopted to enhance care, and existing products that may be used. This is of interest when considering potential barriers to implementation and the adoption of particular policies, products, and activity provision. For instance, with the regard to the use of existing specialist products such as accessible wardrobe rails it would be interesting to explore why such items were not already in use. The cost implications of such adaptations are important to acknowledge as such changes would require investment by the organisation, yet it is hoped that findings from this research provide an important evidence base to warrant such expenditure. Cost implications with regard to the use

of specific products for individuals are complex. For example, many of the recommendations centre on items of clothing or accessories that would not be shared objects, and thus it is probable that the cost would be incurred by the individual. It is therefore necessary that the adoption of specific products to enhance the lives of individuals are understood and implemented at both an organisational and individual level. The current study increases awareness regarding the importance of clothing and textiles in the care of people with dementia and the potential that such items have in enhancing quality of life. Nevertheless, it is important that the use of such products does not exacerbate health and social care inequalities.

The study site is important to consider in order to situate this research. Although the site is not representative it was selected as an exemplar of best practice due to the CQC rated outstanding care it provides. This project's findings include a number of examples employed by staff within the setting. Such findings are transferrable and may be readily adopted within other institutions. Additionally, the opportunities to enhance care practices in light of this study's findings demonstrate how holistic approaches to care are vital in enhancing the lives of people with dementia, as although participants with dementia were in an organisation providing 'outstanding' care, some needs (and wants) remained unmet.

Participants

There are a number of limitations to acknowledge with regard to the participants recruited over the course of this project. I worked with a total of twenty-three participants and yet this included only one male participant. As noted earlier within this thesis (see **Chapter 4, 4.6 Participants**), the lack of representation across the genders is a limitation and impacts findings, yet it does reflect the broader

demographic of social care settings. Women significantly outnumber men in UK care homes and women are disproportionately affected by dementia (Alzheimer's Association, 2014). Additionally, 87 per cent of the dementia care workforce is female (Hussein & Manthorpe, 2012).

The limitations with regards to recruiting male participants may be due to multiple factors. Firstly, when determining eligibility team managers only identified five potential male care home residents (across CYCLE 1 and CYCLE 3). This may have been due to the focus of the research i.e. clothing is often perceived as solely the realm of women (Twigg, 2013). Where team managers did identify potential male participants, one on starting the consent process did not wish to continue, one did not wish to take part, and three residents at the respective times of carrying out the studies were too unwell to take part.

When working with care home personnel, although male staff were supportive and often helped me with practical aspects of the research e.g. when inviting a participant with dementia to join a research encounter, none expressed an interest in taking part in the project. I did carefully approach staff on an individual basis (outside of staff fora and manager's meetings) and provided them with study information and yet this did not support recruitment. This could have been due to the focus of the research or more general concerns at taking part in research. For example, over the course of the project (CYCLE 1 and CYCLE 3) many female members of staff initially expressed interest in taking part and yet when I gave them the study information and explained the consent process, they were often reluctant to proceed. Despite the lack of male participants, care home staff did discuss male resident's experiences of clothing in the care home (during CYCLE 1) and although this is not comparable to individuals' own lived experiences, this did mean that some male experiences were

represented within this project. Nevertheless, this is a limitation of this project and as Campbell (2019) articulated care home settings are often gendered and feminised, thus future research could focus solely on men's experiences of clothing in the care home or other eldercare settings.

The respective samples of care home staff and people with dementia include diverse ethnic backgrounds, yet this project did not include any black participants. Under-representation of Black, Asian and Minority Ethnic (BAME) communities in the UK is often reported in research (Jutlla & Raghavan, 2017; Smart & Harrison, 2017), impacted by for instance, language barriers, socio-cultural barriers and scepticism regarding the research process. Anecdotally, I found that some staff who did not wish to take part in the project seemed to mistrust the research process. Such mistrust is complex, nonetheless pervasive systemic issues and societal inequalities impact those from BAME community's participation in research (Jutlla & Raghavan, 2017).

Uncertainty and mistrust regarding the research process were most apparent when attempting to recruit staff for CYCLE 3. No members of staff took part in the video recorded object handling sessions as participants, different staff members instead supported each session (due to ethical requirements see APPENDIX D), but their involvement was not analysed. It is possible that the media's scrutiny and largely negative public perceptions of care homes (Lloyd et al., 2014) contributes to scepticism surrounding the research process. This is particularly interesting with regard to the use of visual research methods as within this study the methods seemed to exacerbate such barriers. This is also of interest when considering that the study site had hosted many research projects prior to this project as such barriers were not anticipated.

With regard to ethical requirements, the rigorous consent process also hindered the participation of people with dementia and care home staff. Although this is a contested area, increasingly researchers claim that the stringent requirements of ethics committees can negate the needs of participants (Fletcher et al., 2019). For example, in this project if individuals (including care home staff and people with dementia) were able to give verbal (audio-recorded) consent this would have supported participant comfort and uptake in the study. Nevertheless, due to the limited project timeline it was not possible to approach the NHS research ethics committee to make the case for such an amendment. This would however be beneficial in future research.

Creative practitioners were recruited using the supervisory team's arts and health network, but this resulted in working with one male participant and a lack of diversity. An alternative recruitment strategy may have supported recruiting a diverse sample e.g. recruiting from multiple arts and health networks through social media platforms, arts and health fora and newsletters. This is important to acknowledge, as creative practitioners informed the materials, objects and images used in CYCLE 3. As Jakob et al. (2017) note one's perception of material objects and textiles is influenced by one's cultural background and personal experiences, hence working with a more diverse sample may have resulted in the creation and selection of different items.

Despite limitations with regard to this study's participants it is important to highlight that this project does not attempt to claim generalisability and that subjectivity was embraced within the approach to research. Moreover, the number of participants living with dementia who took part can be considered a strength of this research as people with dementia's experience is at the forefront of the research

findings. People with dementia equated to just under half the total number of participants in this project. Moreover, CYCLE 3 focussed solely on the perspectives and experiences of people with dementia.

Replicability of the research

This section considers the replicability of the research methods used. The research methods were designed for the specific purpose of this study and despite drawing upon existing approaches, the methods were novel and thus were unfamiliar to participants and the study site.

The perception of novel research methods in health and social care settings is crucial when considering the ethical approval process. For example, this study received NHS ethical approval subject to minor amendments yet, discussions with peers reveal that the use of similar creative and ethnographic research methods (when working with people with dementia) were not approved by NHS ethics committees in different parts of the UK. As Campbell and Ward (2013b) found, researchers are often required to provide substantial justifications regarding the use of 'unconventional' research methods. Thus, greater awareness and evidence is needed to increase the acceptability of such methods, and ethics policies must be modified to accommodate the use of such methods in order to support the participation of people with dementia in research.

The perception of such methods is not only important to consider with regard to ethical approval processes, views on the methods at the research site are important to consider. For example, although the site was familiar with research and had hosted researchers (including early career researchers), the novel methods meant that the research was often viewed as an 'engagement activity'. For instance,

during CYCLE 1 I worked with participants over multiple encounters and over the course of the study received comments from staff suggesting that I work with other residents who “needed engagement” or who “hadn’t had a visitor for a long time”. This was challenging to navigate and indicates that the position of the research / researcher needed to be more readily understandable. I presented at staff fora and manager meetings to introduce the research, yet continued engagement with such meetings to explain the research process and ethical constraints may have been beneficial. Furthermore, if staff and residents had been involved in the design of the research following e.g. a co-production or co-design model, this would have supported understanding and ownership.

In the previous section (i.e. **8.1 Sensory, creative and embodied research methods**) I discussed each respective method in detail, but it is important to note more generally that the methods used were ‘piloted’ within this project i.e. I had not previously carried out the exact procedures used. In order to design the research, I drew upon a number of approaches, from traditional qualitative research methods, to more creative, novel techniques (e.g. Chamberlain & Craig, 2013, 2016, 2017; Ellingson, 2017; Griffiths et al., 2019; Johnson et al., 2017; Pink, 2015). Each method was grounded in existing approaches, and yet was developed for the specific purpose of this project. It is therefore important to acknowledge the ‘untested’ nature of the methods used and how this may have impacted findings. For example, if time had permitted it would have been beneficial to work with care home staff, people with dementia (CYCLE 1 and 3) and creative practitioners (CYCLE 2) to refine the methods used prior to carrying out the research. Developing these methods for use in future projects could involve working with patient and public

involvement groups, or organisations such as DEEP, in order to develop the methods with specific participant groups.

It is notable that the sensory, creative and embodied research methods used drew upon my interdisciplinary background. For instance, I designed, printed and made the thematic cards used in CYCLE 2 and selected and made items for use in CYCLE 3. Thus, when considering the use of these methods in future research it would necessitate for instance: a researcher with a similar background, a multidisciplinary research team, or funding with which to commission the creation and production of specific items.

Despite the limitations associated with the approach to research and methods used, this research has highlighted how sensory, creative and embodied research methods can support people with dementia to take part in research and elicit rich, insightful findings.

Findings

As discussed above, it is important that the subjective nature of this project is embraced when considering the findings presented. The context in which this research was carried out should also be considered including participant characteristics and the overall approach to research when interpreting findings. Although a lack of generalisability is often cited as a limitation within qualitative research, recent discussions have seen this notion challenged as it negates understanding the valuable, multifaceted insights that are generated through qualitative projects (Clarke, 2020). The limitations involved in this research do not outweigh the strengths of this project or the contributions to knowledge that this research makes.

The findings progress the field of clothing and dementia. Findings build upon existing research and thus strengthen calls for clothing to be considered at a policy level in order to improve dementia care. Additionally, findings demonstrate tangible ways in which clothing and textiles can be harnessed to enhance the lives of people with dementia. Furthermore, findings highlight how the expressive opportunities of clothing and textiles can be incorporated within activity provision in care homes to enhance the lives of people with dementia. Moreover, findings can be used to enhance the design of specific items of dress or textile products created for people with dementia. Informing not only what items look like but also the ways in which the senses must be considered to create pieces that meet the needs (and wants) of people with dementia. This research also highlights the importance of attending to the senses in the design of items (including clothing and purpose-made textile items) used within health and social care settings.

8.4 Implications for future research

The findings of this project have a number of implications for dementia care practice, policy, research and design. This section will present the implications for each respectively.

Implications for dementia care practice

- This project demonstrates the nuanced importance that clothing, textiles and further items ‘close to hand’ have for people with dementia living in a care home. In light of the findings health and social care settings should be enhanced to more fully support individuals within these spaces. **Chapter 7, Synthesis of Findings** presents a number of possible strategies and products that could be adopted.

- Dressing guidelines for institutions should be developed as a result of this project, to respect and support the autonomy and independence of people with dementia through various strategies including developing nonverbal communication techniques.
- Clothing and material objects can be used to communicate with people with dementia and support understanding. Nonverbal, embodied forms of communicating with people with dementia are crucial in order to meet individuals' needs and this research has demonstrated that creative approaches should be adopted to enhance communication. Additionally, the expressive capacity that clothing and textiles afford people with dementia must be explained and shared through staff training and development processes.
- Key stakeholders should be directed to specialist, innovative products such as incontinence products or fall detectors, so that such items are more acceptable and appealing for people with dementia. Nevertheless, cost implications could prove a barrier to implementing the use of such products and this is congruent with the complexities regarding dementia care funding. At present people with dementia face vast costs to pay for the care and support that they need, costs that they would not face if living with a different condition (Alzheimer's Society, 2018). The proposed use of certain products to enhance dementia care does not seek to exacerbate health and social care inequalities and thus funding the use of such items has implications for the health and social care agenda.
- Activity provision within care homes should include non-remembrance-based clothing and textile sessions to support relational approaches to care.

- This research has identified the nuanced skills, creativity and resourcefulness that care home staff possess. This advocates the creation of roles that move beyond task-oriented models of care to provide holistic dementia care. This is complex and involves valuing care home staff, increasing pay and opportunities for staff development and progression in order to improve dementia care practice.

Implications for policy

- Attending to the embodied and sensory experiences of people with dementia can enhance care practice and is vital in enhancing the lives of people with dementia. Care providers policies around dressing must be altered in light of this project's findings. Institutional policies that state, for example, that multiple clothes are not necessary or that clothes should reflect a person's current lifestyle negate individual's needs must be adapted to avoid stigmatising people with dementia and to ensure that staff understand the importance of clothing to individuals.
- Traditionally social care settings centre on bio-medical models of care, hence institutions are often task-focussed and risk averse. This in turn limits opportunities for self-initiated (unprompted) engagement. This research has identified a number of ways in which spontaneous engagement and opportunities for creative and imaginative moments can be supported through, for instance, adaptations to the built environment, the use of specific objects, artworks, and the use of tactile items. Findings demonstrate the capacity that clothing and items within a person's most immediate physical space have in enabling individuals to express themselves, feel comforted, secure and safe, whilst also enabling them to reimagine and renegotiate the care home setting. Care providers' policies regarding public spaces within the care home should change to support the

‘personalisation’ of such spaces in order to enhance feelings of autonomy, ownership, and belongingness.

- Findings have identified that people with dementia retain embodied knowledge and that people with dementia are important agents in their own care. Mundane tasks such as putting away their own items of clothing can support feelings of autonomy, control, and understanding. This research indicates that the adoption of particular Montessori approaches within the care home may be beneficial in developing progressive health and social care agendas.
- Ethical policy surrounding the involvement of people with dementia in research is often complex and there is a need to address policy to ensure that people with dementia are empowered to participate in research at both non-NHS and NHS sites. This research received NHS ethical approval (subject to minor amendments) for the use of the novel research methods including video recording, and yet there is often disparity across ethics approvals. For example, at the Design for Health Conference 2018 design researchers spoke of the challenges faced when employing design-led and creative approaches that do not fit the standardised Health Research Authority’s IRAS system. Hence, developing ethical policy is crucial in order to embrace the opportunities that creative approaches afford in understanding and enhancing people’s lives (including people with dementia).

Implications for research

- This research has demonstrated the huge potential that sensory, creative and embodied research methods afford people with dementia and that such methods should be considered not only within research projects working within similar

topics but also more broadly. Objects (including clothing) offer numerous opportunities with which to explore aspects of peoples' lives (including people with dementia) (e.g. Chamberlain & Craig, 2013, 2016, 2017; Woodward, 2020).

- Research aims and questions should be developed to focus on the strengths of people with dementia. Sensory, creative and embodied research methods can focus on experiences 'in the moment' and so shift emphasis away from losses associated with dementia. This in turn shapes the research approach and aims. When working with people with dementia researchers should embrace novel research approaches that enable people with dementia to engage in the process as fully as possible.
- The use of thematic cards in this project suggest the potential that creative research methods have in developing approaches to disseminating research. Developing the ways in which research is communicated to non-academic audiences is crucial and can lead to changes at policy level. For example, Smith (2018) has presented that powerful knowledge transfer can occur through the use of narrative methods.
- CYCLE 3's 'Dramatic' object handling session demonstrates the potential that participatory textile making methods have when working with people with dementia. This contributes to the growing area of literature that emphasises the use of participatory textile research methods when working with people with dementia (see e.g. Robertson, Nevay, Jones et al., 2020; Shercliff & Twigger Holroyd, 2020).

- This research advocates working across disciplines and the importance of this when exploring the use of novel research methods and the application of findings.

Implications for design

- This research employed a sensory, creative and embodied approach to research in order to understand the significance of clothing to people with dementia living in a care home and examine how clothing could be reimagined and renegotiated in the holistic care of people with dementia. Although it was beyond the scope of this research to design e.g. specific products, I present a number of potential applied outcomes as a result of attending to individuals embodied and sensory experiences (see **Chapter 7, Synthesis of Findings**).
- Findings demonstrate that shifting focus away from the visual, in order to attend to embodied, sensory experiences has vast implications when redesigning and reimagining products (including clothing and textile items) within the care home and thus indicates that potential that sensory design has when renegotiating dementia care practice, interventions and activity provision. As Malnar and Vodvarka write:

“What if we designed for all of our senses? Suppose for a moment that sound, touch, and odour were treated as the equals of sight, and emotion considered as important as cognition.” (Malnar & Vodvarka, 2004: ix)

Designing for the senses could empower people with dementia, address unmet needs (and wants), enhance both dementia care and care home settings (Craig, 2017). Findings from this project advocate that designers engage with such sensory driven practices in order to enhance the lives of people with dementia.

- Findings demonstrate the ways in which people with dementia engaged with design practices through e.g. handling, draping and manipulating textiles. Contributing to evidence (e.g. Craig & Fisher, 2020; Ludden et al., 2019; Robertson et al., 2020; Treadaway, Fennell & Taylor, 2020) that supports people with dementia's active participation in design-led research projects.
- The prototypes proposed in **Chapter 7 Synthesis of Findings** could be developed in partnership with people with dementia living in care homes. The integration of people with lived experience is increasingly advocated to ensure that products and services are created 'with' rather than 'for' individuals. This is recognised across sectors ranging from health see e.g. 'Experience Based Co-Design' (Point of Care Foundation, n.d.) to the arts/cultural sector see e.g. the webinar 'Re-Imagining the Future' (Arts and Health South West, 2020) in which the co-production of projects was advocated. Involving people with dementia in the design process could draw upon approaches used within Lab4Living's 'Journeying through Dementia' project (Craig & Fisher, 2020), in which a series of resources were developed with people living with dementia.

8.5 Summary

This research explored the importance of clothing in the lives of people with dementia living in a care home by examining the embodied and sensorial aspects of clothing and the potential of clothing in the holistic care of people with dementia. The findings demonstrate that clothing is important to the lives of people with dementia living in care homes. Clothing supports selfhood, enhances spatial and temporal orientation, improves feelings of comfort, belongingness, security and privacy. Wearing the 'right' items of clothing is empowering, whilst wearing the 'wrong' items

of clothing acts as a barrier (Kabel et al., 2016). Clothing is used creatively (Bellas et al., 2019) by care home staff and people with dementia to create moments 'outside the realm' of the care home setting. Additionally, clothing supported and was used to enact relational holistic approaches to care.

The findings reveal enormous opportunities that designers have in enhancing the lives of people with dementia through reimagining wearable accessories and clothing. Yet this research not only contributes to the area of clothing and dementia, but also generates rich insights regarding material and social interactions within the care home. The introduction of specific garments, sensory props and further material items disrupted the standardised institutional setting. This resulted in identifying a number of ways in which care homes could be enhanced to provoke joyful, spontaneous moments of engagement.

Not only do the findings contribute multifaceted knowledge regarding the importance of clothing to people with dementia, it also demonstrates the importance of using novel sensory, creative embodied research methods when working with people with dementia. Focusing on sensory experiences shifts emphasis away from the visual to explore multisensory experiences and this elicited rich insights when working with people living with dementia.

Furthermore, exploring the sensory embodied experiences of people with dementia shifts emphasis away from losses associated with the syndrome to explore experiences 'in the moment'. This is powerful and has numerous implications when considering enhancing the lives of people with dementia. Clothing is important to people with dementia living in a care home and can be used to enhance dementia care practice and policy, the findings recommend a number of avenues for future

research and design-led ventures that could enhance the lives of people with dementia.

REFERENCES

- Adam, H., & Galinsky, A. (2012). Enclothed cognition. *Journal of Experimental Social Psychology, 48*(4), 918-925.
- Adams, T., & Gardiner, P. (2005). Communication and interaction within dementia care triads: Developing a theory for relationship-centred care. *Dementia, 4*(2), 185–205.
- Age UK. (2020, July 29). Care in crisis. Retrieved August 3, 2020, from <https://www.ageuk.org.uk/our-impact/campaigning/care-in-crisis/>
- All-Party Parliamentary Group on Arts Health and Wellbeing. (2017). *Creative Health: The Arts for Health and Wellbeing*. Retrieved from <http://www.artshealthandwellbeing.org.uk/appg/inquiry>
- Alzheimer's Society. (2014). Dementia UK Update. Retrieved from https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf
- Alzheimer's Society. (2015a). Dementia 2015: Aiming Higher to Transform Lives. Retrieved from https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_2015_aiming_higher_to_transform_lives.pdf
- Alzheimer's Society. (2015b). Dementia today and tomorrow: A new deal for people with dementia and their carers. Retrieved from https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_today_and_tomorrow.pdf
- Alzheimer's Society. (2015c). Dressing guide. Retrieved from <https://www.alzheimers.org.uk/sites/def>

ault/files/2019-09/510LP%20Dressing.pdf

Alzheimer's Society. (2017). Alzheimer's Society Strategy 2017-2022. Retrieved from

https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/alzheimers_society_2017-2022_the_new_deal_on_dementia.pdf

Alzheimer's Society. (2018). Dementia – the true cost: Fixing the care crisis.

Retrieved from <https://www.alzheimers.org.uk/sites/default/files/2018-05/Dementia%20the%20true%20cost%20-%20Alzheimers%20Society%20report.pdf>

Alzheimer's Society. (2019). Fix dementia care. Retrieved from

<https://www.alzheimers.org.uk/sites/default/files/2019-05/Dementia%20Fund%20Report.pdf>

Alzheimer's Society e-shop. (n.d.). Fiddle muff [Photograph]. Retrieved August 3,

2020, from <https://shop.alzheimers.org.uk/activities-and-sensory-stimulation/Fiddle%20Muff%20-%20Buttons%20and%20Beads>

Andrews, T. (2017). The dispensary [Image]. Retrieved August 9, 2020, from

<https://www.tabathaandrews.co.uk/3531420-the-dispensary#4>

Annerstedt, L. (1994). An attempt to determine the impact of group living care in

comparison to traditional long-term care on demented elderly patients. *Aging Clinical Experimental Research*, 6, 372–380.

Armstrong, P., & Day, S. (2017). *Wash, wear, and care; clothing and laundry in long-term residential care*, McGill-Queen's University Press. Retrieved from

<http://www.jstor.org/stable/j.ctt1n2tv88>

- Arts and Health South West. (2020, May 18). Re-Imagining the Future [webinar]. Retrieved from <https://www.youtube.com/watch?v=MIO-IPjYL-o>
- Arts Council England. (2007). The Arts Health and Wellbeing Strategy. Retrieved from <http://www.artshealthresources.org.uk/wp-content/uploads/2017/01/2007-ACE-Strategy-for-the-arts-health-and-wellbeing.pdf>
- Arts Council England. (2019). Equality, diversity and the creative case: A data report, 2017-2018. Retrieved from https://www.artscouncil.org.uk/sites/default/files/download/file/Diversity_report_1718.pdf
- Ash, J. (1996). Memory and Objects. In P. Kirkham (Ed.), *The Gendered Object* (pp. 219 – 224). Manchester: Manchester University Press.
- Bardsley, A. (2014, February 28). *Understanding incontinence in people with dementia*. Independent Nurse. Retrieved from <https://www.independentnurse.co.uk/clinical-article/understanding-incontinence-in-people-with-dementia/63430/>
- Barnard, M. (1996). *Fashion as Communication*. London: Routledge
- Barnes R. & Eicher J. (1993). *Dress and gender: Making and meaning*. Oxford: Berg.
- Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, 21(2), 107-118.
- Bartlett, R., & O'Connor, D. (2010). *Broadening the Dementia Debate: Towards Social Citizenship*. Bristol: The Policy Press.
- Bates, V. (n.d.). Sensing spaces of healthcare. Retrieved August 7, 2020, from <https://hospitalsenses.co.uk/>

- Beghetto, R. A., & Kaufman, J. C. (2007). Toward a broader conception of creativity: A case for "mini-c" creativity. *Psychology of Aesthetics, Creativity, and the Arts*, 1(2), 73-79.
- Belk, R. (1988). Possessions and the Extended Self. *Journal of Consumer Research*, 15(2), 139-168.
- Bellass, S., Balmer, A., May, V., Keady, J., Buse, C., Capstick, A., Burke, L., Bartlett, R., Hodgson, J. (2019). Broadening the debate on creativity and dementia: A critical approach. *Dementia*, 18(7-8), 2799-2820.
- Borland, S. (2019, March 6). Britain's elderly living in 'real fear' of moving in to care homes after they get worse in a third of local council areas. *The Daily Mail*.
<https://www.dailymail.co.uk/news/article-6775691/Britains-elderly-living-real-fear-moving-care-homes.html>
- Bourdieu, P. (1990). *The Logic of Practice*. Cambridge: Polity Press.
- Bourdieu, P. (1977). *Outline of a Theory of Practice*. Translated by Richard Nice. New York: Cambridge University Press.
- Bovone, L. (2012). Fashion identity and social actors. In M. Gonzalez & L. Bovone (Eds.), *Identities through fashion. A multidisciplinary approach* (pp.67-94). Oxford: Berg Publishers.
- Bowlby, J. (1969) *Attachment and loss: Vol. 1. Attachment*, London, UK: Hogarth Press.
- Brady, J. (2011). Cooking as inquiry: A method to stir up prevailing ways of knowing food, body and identity. *International Journal of Qualitative Methods*, 10(4), 321-334.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3(2), 77-101.

- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: Sage.
- Braun, V., Clarke, V., Hayfield, N., & Terry, G. (2019). Thematic analysis. In P. Liamputtong (Eds.), *Handbook of Research Methods in Health Social Sciences* (pp. 843-860). Singapore: Springer.
- Brawley, E.C. (2006). *Design Innovations for Aging and Alzheimer's: Creating Caring Environments*. New York: Wiley.
- Brown, D. (2018, February 19). Dementia research must study care as well as cure. *The Guardian*. <https://www.theguardian.com/social-care-network/2018/feb/19/dementia-research-cure-care>
- Buller™. (n.d.). Pulldown rail [Image]. Retrieved August 3, 2020, from <https://www.bullerltd.co.uk/motorised-lift-pull-down-wardrobe-rail.html>
- Buse, C., Martin, D., & Nettleton, S. (2018a). Conceptualising 'materialities of care': making visible mundane material culture in health and social care contexts. *Sociology of Health & Illness*, 40(2), 243– 55.
- Buse, C., & Twigg, J. (2014a). Looking “out of place”: Analysing the spatial and symbolic meanings of dementia care settings through dress. *International Journal of Ageing and Later Life*, 9(1), 69-95.
- Buse, C., & Twigg, J. (2014b). Women with dementia and their handbags: Negotiating identity, privacy and 'home' through material culture. *Journal of Ageing Studies*, 30, 14-22.
- Buse, C., & Twigg, J. (2016a). Clothing, embodied identity and dementia: Maintaining the self through dress. *Age, Culture, Humanities*, 2, 71-96.
- Buse, C., & Twigg, J. (2016b). Materialising memories: Exploring the stories of people with dementia through dress. *Ageing and Society*, 36(6), 1115-1135.

- Buse, C., & Twigg, J. (2018). Dressing disrupted: negotiating care through the materiality of dress in the context of dementia. *Sociology of Health & Illness*, 40(2), 340-352.
- Buse, C., Twigg, J., Nettleton, S., & Martin, D. (2018b). Dirty linen, liminal spaces, and later life: Meanings of laundry in care home design and practice. *Sociological Research Online*, 23(4), 711–727.
- Caddell, S L., & Clare, L. (2010). The impact of dementia on self and identity: A systematic review. *Clinical Psychology Review*, 30(1), 113-126.
- Caldwell, E.F., Falcus, S., & Sako, K. (2020). Depicting Dementia: Representations of Cognitive Health and Illness in Ten Picturebooks for Children. *Child Literature Education*. <https://doi.org/10.1007/s10583-020-09405-w>
- Camic, P. M., Hulbert, S., & Kimmel, J. (2019). Museum object handling: A health-promoting community-based activity for dementia care. *Journal of Health Psychology*, 24(6), 787–798.
- Camp. C. J. (2019). Denial of human rights: We must change the paradigm of dementia care. *Clinical Gerontologist*, 42(3), 221-223.
- Camp C. J. (2010). Origins of Montessori programming for dementia. *Non-pharmacological therapies in dementia*, 1(2), 163–174.
- Campbell, S. (2019). *Atmospheres of dementia care: Stories told through the bodies of men (Doctoral thesis)*. Retrieved from https://www.research.manchester.ac.uk/portal/files/122883145/FULL_TEXT.PDF
- Campbell, S., Buse, C., Twigg, J., Keady, J., & Ward, R. (2015). Appearance matters: It's integral to our sense of self. *The Journal of Dementia Care*, 2(3), 20-23.

- Campbell, S., & Ward, R. (2017). Videography in care-based hairdressing in dementia care: practices and processes. In J. Keady, L.C. Hydén, A. Johnson, & C. Swarbrick (Eds.), *Social Research Methods in Dementia Studies: Inclusion and Innovation* (pp. 96-119). Oxon: Routledge.
- Care Quality Commission. (2019). The state of health care and adult social care in England 2018/2019. Retrieved from https://www.cqc.org.uk/sites/default/files/20191015b_stateofcare1819_fullreport.pdf
- Centre for Sensory Studies. (n.d.). Explorations in sensory design. Retrieved June 19, 2020, from <http://centreforsensorystudies.org/explorations-in-sensory-design/>
- Chalfont, G. E., & Rodiek, S. (2005). Building Edge: An ecological approach to research and design of environments for people with dementia. *Alzheimer's Care Quarterly, Special Issue - Environmental Innovations in Care*, 6(4), 341-348.
- Chamberlain, P., & Craig, C (2013). Engagingdesign – Methods for Collective Creativity. In M. Kuruso (Ed.), *Human-Computer Interaction, Part I*, HCII 2013, LNCS 8004, (pp. 22–31), Springer-Verlag Berlin Heidelberg.
- Chamberlain, P., & Craig, C. (2016). HOSPITable: Domestication of healthcare. In P. Desmet, S. Fokkinga, G. Ludden, N. Cila, & H. van Zuthem, H. (Eds.), *Celebration & Contemplation: Proceedings of the Tenth International Conference on Design and Emotion*, (pp. 553-557). Amsterdam: Design & Emotion Society. Retrieved from <https://zenodo.org/record/2635727#.XzUdVRNKjKI>

- Chamberlain, P., & Craig, C. (2017). HOSPITAbLe: Critical design and the domestication of healthcare. *Research Through Design 2017 Proceedings*. Retrieved from https://figshare.com/articles/HOSPITAbLe_critical_design_and_the_domestication_of_healthcare/4746952
- Chan, A., Lempp, H., Peabody, G., Simpson, C., Souza de, S., Galloway, J., Milasevic, M., Prout, L., Ellam, I., Esterine, T., Gillingwater, E. (2018). Garment+ Challenging the boundaries of fashion for those with long-term physical disabilities. *The Journal of Dress History*, 2(1), 26-43.
- Chatterjee, H. J. (2008). *Touch in Museums* (Ed.). Oxford: Berg Publishers
- Chaudhury, H. & Cooke, H. (2014). Design matters in dementia care: The role of the physical environment in dementia care settings. In M. Downs & B. Bowers (Eds.), *Excellence in dementia care* (2nd ed.) (pp. 144-158). UK: Open University Press.
- Chaudhury, H., Cooke, H., Cowie, H., & Razaghi, L. (2017). The influence of the physical environment on residents with dementia in long-term care settings: A review of the empirical literature. *Gerontologist*, 58(5), 325-337.
- Clarke, V. [@drvicclarke]. (2020, May 10). I think my/my students' work gets rejected for being too qually or the wrong kind of qually, so in some ways the opposite problem - alien writing style (too much researcher voice, too informal). [Tweet]. Retrieved from <https://twitter.com/drvicclarke/status/1259551746491387905>
- Cleeve, H. (2020). Markings: Boundaries and borders in dementia care units, *Design and Culture*, 12(1), 5-29.

- Cleeve, H., Borell, L., & Rosenberg, L. (2020). (In)visible materialities in the context of dementia care. *Sociology Health & Illness*, 42(1), 126-142.
- Clift, S. (2012). Creative arts as a public health resource: Moving from practice-based research to evidence-based practice. *Perspectives in Public Health*, 132(3), 120-127.
- Clod Ensemble. (n.d.). *Performing Medicine programme*. Retrieved August 7, 2020, from <https://www.clodensemble.com/learning/performing-medicine/>
- Cohen, L., & Manion, L. (1994). *Research Methods in Education* (4th ed.). London: Routledge
- Cohen-Mansfield, J., & Bester, A. (2006). Flexibility as a management principle in dementia care: The Adards example. *The Gerontologist*, 46(4), 540-544.
- Cohen-Mansfield, J., Marx, M.S., Thein, K., & Dakheel-Ali, M. (2010). The impact of past and present preferences on stimulus engagement in nursing home residents with dementia. *Aging Mental Health*, 14(1), 67-73.
- Cohen-Mansfield, J., Parpura-Gill, A., & Golander, H. (2006). Salience of self-identity roles in persons with dementia: Differences in perceptions among elderly persons, family members and caregivers. *Social Science and Medicine*, 62, 745–757.
- Collier, L., & Jakob, A. (2017). The multisensory environment (MSE) in dementia care: examining its role and quality from a user perspective. *HERD: Health Environments Research & Design Journal*, 10(5), 39–51.
- Connellan, K. (2019). My room, my home, my self, *Home Cultures*, 15(2), 103-127.
- Craig, C. (2012). Textured journeys: Exploring the potential of textiles. In J. Killick & C. Craig (Eds.), *Creativity and Communication in Persons with Dementia* (pp. 84-91). London: Jessica Kingsley Publishers.

- Craig, C. (2014). Photography in care homes: Methods for a revealing practice. *SAGE Research Methods Cases*.
<https://doi.org/10.4135/978144627305013508506>
- Craig, C. (2017). Imagined futures: Designing future environments for the care of older people. *The Design Journal*, 20(1), S2336-S2347.
<https://doi.org/10.1080/14606925.2017.1352749>
- Craig, C., & Fisher, H. (2020). Journeying through dementia the story of a 14-year design-led research enquiry, In K. Christer, C. Craig, P. Chamberlain (Eds.), *Proceedings of the 6th International Conference on Design4Health* (pp. 105 - 117). Amsterdam: Lab4Living Sheffield Hallam University
- Craig, C. & J. Killick (2011). Why creativity and dementia go together. *Journal of Dementia Care*, 19(6), 20-22.
- Criado Perez, C. (2019). *Invisible Women: Exposing data bias in a world designed for men*. Vintage Publishing: London
- Creswell, J.W. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches*. (2nd ed.) Thousand Oaks: Sage.
- Crossley, N. (2006). *Reflexive embodiment in contemporary society*. Maidenhead: Open University Press.
- Day, K., Carreon, D., & Stump, C. (2000). The therapeutic design of environments for people with dementia: A review of the empirical research. *The Gerontologist*, 40(4) ,397–416
- Davis, D. H. J. (2004). Dementia: Sociological and philosophical constructions. *Social Science and Medicine*, 58, 369–378.

- Davis, S., Byers, S., Nay, R., & Koch, S. (2009). Guiding design of dementia friendly environments in residential care settings: Considering the living experiences. *Dementia*, 8(2), 185-203.
- Denzin, N. K., & Lincoln, Y. S. (Eds.). (1994). *Handbook of qualitative research*. Sage Publications, Inc.
- Department of Health. (2009). Living well with dementia: A national dementia strategy. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf
- Department of Health. (2015). Dementia-friendly health and social care environments. Department of Health. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/416780/HBN_08-02.pdf
- DEEP Guide. (2013). DEEP Guide: Writing dementia-friendly information. Retrieved from <https://www.dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf>.
- DeSantis, L., & Ugarriza, D. (2000). The concept of theme as used in qualitative nursing research. *Western Journal of Nursing Research*, 22, 351–372.
- Dewing, J. (2008). Process consent and research with older persons living with dementia. *Research Ethics Review*, 4(2), 59-64.
- Downs, M. (2013). Embodiment: The implications for living well with dementia. *Dementia* 12(3), 368-374.
- Dowlen, R. (2018). *The 'in the moment' musical experiences of people with dementia: A multiple-case study approach* (Doctoral thesis). Retrieved from

[https://www.research.manchester.ac.uk/portal/en/theses/the-in-the-moment-musical-experiences-of-people-with-dementia-a-multiplecase-study-approach\(48599400-3e3d-4871-a0e3-94d6b3692a5d\).html](https://www.research.manchester.ac.uk/portal/en/theses/the-in-the-moment-musical-experiences-of-people-with-dementia-a-multiplecase-study-approach(48599400-3e3d-4871-a0e3-94d6b3692a5d).html)

- Dupuis, S. L., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L., Sadler, L. (2012a). Moving beyond 'patient' and 'client' approaches: Mobilising authentic partnerships in dementia care. *Dementia* 11(4), 428–450.
- Dupuis, S., Wiersma, E., & Loiselle, L. (2012b). Pathologizing behavior: Meanings of behaviors in dementia care, *Journal of Ageing Studies*, 26(2), 162-173.
- Edvardsson, D., Winblad, B., & Sandman, P. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology*, 7(4), 362–7.
- Ellingson, L. (2006). Embodied knowledge: Writing researchers' bodies into qualitative health research. *Qualitative Health Research*, 16(2), 298–310.
- Ellingson, L. (2017). *Embodiment in Qualitative Research*, Oxon and New York: Routledge.
- End PJ Paralysis. (n.d.). Retrieved August 9, 2020, from <http://www.endpjparalysis.com/>
- Entwistle, J. (2015). *The Fashioned Body: Fashion, dress & modern social theory*, (2nd ed.). Polity Press: Cambridge
- Essence. (n.d.) Essence fall detector pendant with Care@Home™ technology [image]. Retrieved August 3, 2020, from <https://tech.essence-grp.com/smart-care/care-at-home-pers>
- Fazio, S., & Mitchell, D. B. (2009). Persistence of self in individuals with Alzheimer's disease. *Dementia*, 8(1), 39–59.

- Find. (n.d.). Bud sensory cushion [Image]. Retrieved August 3, 2020, from <https://findmemorycare.co.uk/product/bud-sensory-cushion/>
- Fleetwood-Smith, R. (2020). Fashion textiles. In P. Crawford, B. Brown, & A. Charise (Eds.), *The Routledge companion to health humanities* (pp. 262-267). London: Routledge.
- Fleetwood-Smith, R., Hefferon, K., & Mair, C. (2019). "It's like it's me": Exploring clothing attachment during wear. *International Journal of Fashion Studies*, 6(1) 41-62.
- Fletcher, J, R., Lee, K., & Snowden, S. (2019). Uncertainties when applying the mental capacity act in dementia research: A call for researcher experiences. *Ethics and Social Welfare*, 13(2), 183-197.
- Folio. (2018, February 26). Why fall detection devices are falling short [Image]. Retrieved August 3, 2020, from <https://www.folio.ca/why-fall-detection-devices-for-seniors-are-falling-short/>
- Førsund, L.H., Grov, E.K., Helvik, A. Juvet, L. K., Skovdahl, K., & Eriksen, S. (2018). The experience of lived space in persons with dementia: A systematic meta-synthesis. *BMC Geriatrics*, 18(33). <https://doi.org/10.1186/s12877-018-0728-0>
- Gaddini, R. (1978) Transitional object origins and the psychosomatic symptom. In S. Grolnick & L. Barkin (Eds.), *Between reality and fantasy: Transitional objects and phenomena* (pp.112–131). New York: Jason Arnoson Press.
- Gaver, W., Beaver, J., Benford, S. (2003). Ambiguity as a resource for design. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (CHI '03) (pp. 233-240). New York: ACM Press.

- Gell, A. (1998). *Art and Agency: Towards an anthropological theory*. Oxford: Clarendon Press.
- Gibson, J. (1966). *The senses considered as perceptual systems*. Boston, MA: Houghton Mifflin.
- Gilleard, C., & Higgs, P. (2011). Frailty, disability and old age: A re-appraisal. *Health, 15*(5), 475–490.
- Goeman, D. P., Dickins, M., Iliffe, S., Pond, D., & O’Keffe, F. (2017). Development of a discussion tool to enable well-being by providing choices for people with dementia: A qualitative study incorporating codesign and participatory action research, *BMJ Open, 7*. <https://doi.org/10.1136/bmjopen-2017-017672>
- Gove, D. (2013). *GPs, stigma and timely diagnosis of dementia: A qualitative exploration*. Bradford, UK: University of Bradford.
- Gratton, L., & Scott, A. (2016). *The 100-year life: Living and working in an age of longevity*. London: Bloomsbury Publishing.
- GreatCall. (n.d.). GreatCall lively wearable watch [image]. Retrieved August 3, 2020, from <https://www.safehome.org/medical-alert-systems/best/watches/>
- Greasley-Adams, C., Bowes, A., Dawson, A., & McCabe, L. (2012). Good practice in the design of homes and living spaces for people with dementia and sight loss. Retrieved from https://dementia.stir.ac.uk/system/files/filedepot/12/good_practice_in_the_design_of_homes_and_living_spaces_for_people_living_with_dementia_and_sight_loss_final.pdf
- Griffiths, S., Denning, T., Beer, C., & Tischler, V. (2019). Mementos from Boots multisensory boxes – Qualitative evaluation of an intervention for people with dementia: Innovative practice, *Dementia, 18*(2), 793-801.

- Guba, E. G. (Ed.). (1990). *The paradigm dialogue*. Newbury Park, CA: Sage
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks: Sage
- Guy, A., & Banim, M (2000). Personal collections: Women's clothing use and identity. *Journal of Gender Studies*, 9(3), 313-327.
- Halsall, B., & MacDonald, R., (2015). Volume 1: Design for dementia: A Guide with helpful guidance in the design of exterior and interior environments. Retrieved from http://www.hlpdesign.com/images/case_studies/Vol1.pdf
- Harman, G., & Clare, L. (2006). Illness representations and lived experience in early-stage dementia. *Qualitative Health Research*, 16(4), 484–502.
- Harnett, T. (2014). Framing spaces in places: Creating “respite spaces” in dementia care settings. *Dementia*, 13(3), 396 – 411.
- Hatton, N. (2016). *A cultural response to dementia: Participatory arts in care homes and relationship-centred care (Doctoral thesis)*. Retrieved from https://pure.royalholloway.ac.uk/portal/files/26452224/Thesis_final.pdf
- Heath, C., Hindmarsh, J., and Luff, P. (2010). *Video in qualitative research: Analysing social interaction in everyday life*. London: Sage.
- Heggestad, A., Noetvedt, P., & Slettebo, A. (2012). The importance of moral sensitivity when including persons with dementia in qualitative research. *Nursing Ethics*, 20, 30–40.
- Herron, R., & Wrathall, M. (2018). Putting responsive behaviours in place: Examining how formal and informal carers understand the actions of people with dementia. *Social Science and Medicine*. 204, 9-15.

- Higgs, P., & Gilleard, C. (2014). Frailty, abjection and the “othering” of the fourth age. *Health Sociology Review*, 23(1), 10-19.
- Hockey, J., & Forsey, M. (2012). Ethnography is not participant observation: Reflections on the interview as participatory qualitative research. In J. Skinner (Ed.), *The Interview: An Ethnographic Approach* (pp. 69-87). UK: Bloomsbury.
- Holmund, M., Hagman, A., & Polsa, P. (2011). An exploration of how mature women buy clothing: Empirical insight and a model, *Journal of Fashion Marketing and Management*, 15(1), 108-122.
- Howes, D. (2005) *Empire of the Senses: The sensual cultural reader*. Oxford: Berg.
- Howes, D. (2013). The Social Life of the Senses, *Ars Vivendi Journal*, 3, 4-23.
- Howes, D., & Classen, C. (2014). *Ways of Sensing Understanding the Senses in Society*. London: Routledge
- Hubbard, G., Downs, M., & Tester, S. (2003). Including older people with dementia in research: Challenges and strategies. *Ageing & Mental Health*, 7(5), 351-362.
- Hughes, J, C., & Williamson, T. (2019). *The dementia manifesto: Putting values-based practice to work*. Cambridge: Cambridge University Press.
- Hurd, L. (2000). Older women's body image and embodied experience: An exploration. *Journal of Women & Aging*, 12(3-4), 77-97.
- Hurd Clarke, L., & Griffin, M. (2008). Visible and invisible ageing: Beauty work as a response to ageism. *Ageing and Society*, 28(5), 653-674.
- Hussein, S., & Manthorpe, J. (2012). The dementia social care workforce in England: secondary analysis of a national workforce data set. *Aging and Mental Health*, 16(1), 110-118.

- Industrial Fabrics Association International. (2014, October 3). Tactile dialogues. Retrieved August 4, 2020, from <https://advancedtextilesource.com/2014/10/03/tactile-dialogues-a-medium-to-generate-interaction/>
- Iltanen, S., & Topo, P. (2007a). Ethical implications of design practices. The case of industrially manufactured patient clothing in Finland. In *No.2 Conference Proceedings Nordic Design Research: Design Enquiries*. Stockholm: University of Arts, Crafts and Design. Retrieved from <https://archive.nordes.org/index.php/n13/article/view/168/151>
- Iltanen, S., & Topo, P. (2007b). Potilasvaatteet, pitkäaikaishoidossa olevan ihmisen toimijuus ja etiikka – vaatesuunnittelijoiden näkemyksiä. [Patient clothing, agency of the persons in long-term care and ethics - Designers' views. Abstract in English]. *Gerontologia*, 21(3), 231–245.
- Iltanen, S., & Topo, P. (2015). Object elicitation in interviews about clothing, design, ageing and dementia, *Journal of Design Research*, 13(2), 167-184
- Iltanen-Tähkävuori, S., Wikberg, M., & Topo, P. (2012). Design and dementia: A case of garments designed to prevent undressing. *Dementia*, 11(1), 49-59.
- Ingold, T. (2000). *The Perception of the Environment*. London: Routledge.
- Jakob, A. & Collier, L. (2017). Sensory enrichment for people living with dementia: increasing the benefits of Multisensory Environments in dementia care through design, *Design for Health*, 1(1), 115-133.
- Jakob, A., Collier, L., & Ivanova, N. (2019). Implementing sensory design for care-home residents in London. In K. Niedderer, G. Ludden, R. Cain, C. Wölfel (Eds.), *Proceedings of the International MinD Conference: Designing with and*

for people with dementia (pp.109-122). Dresden: Technische Universität Dresden.

Johnson, H. F. (2016). Exploring the lived experience of people with dementia through interpretative phenomenological analysis. *The Qualitative Report*, 21(4), 695-711.

Johnson, J., Culverwell, A., Hulbert, S., Robertson, M., & Camic, P. M. (2017). Museum activities in dementia care: Using visual analog scales to measure subjective wellbeing. *Dementia*, 16(5), 591–610.

Joller, P., Frank, C., Gibson, M., & Sudeep, S. G. (2013). Approach to inappropriate sexual behaviour in people with dementia. *Canadian Family Physician* 59(3), 255-260.

Jones, C. A., & Woglom, J. F. (2015). Behind the body-filled scenes: Methodologies at work on the body in graphica. In M. Perry & C. L. Medina (Eds.), *Methodologies of embodiment: Inscribing bodies in qualitative research* (pp. 116-137). New York: Routledge.

Jøranson, N, Pedersen, I., Rokstad Mork M A., Aamodt, G., Olsen, C., & Ihebæk, C. (2016). Group activity with PARO in nursing homes: Systematic investigation of behaviours in participants. *International Psychogeriatric Association* (28)8, 1345-1354.

Jutlla, K., & Raghavan, R. (2017). Improving the recruitment of Black, Asian and Minority Ethnic (BAME) communities in health and social care research: A review of literature. *Mary Seacole Research Centre working paper 9*, Retrieved from <https://dora.dmu.ac.uk/handle/2086/13221>

- Kabel, A., McBee-Black, K., & Dimka, J. (2016). Apparel-related participation barriers: Ability, adaptation and engagement, *Disability and Rehabilitation*, 38(22), 2184-2192.
- Kara, H. (2015). *Creative methods in the social sciences*. Policy Press: Bristol
- Katz, S. (2013). Dementia, personhood and embodiment: What can we learn from the medieval history of memory? *Dementia*, 12(3), 303–314.
- Kaufmann, E. G., & Engel, S. A. (2016). Dementia and well-being: A conceptual framework based on Tom Kitwood's model of needs. *Dementia*, 15(4), 774–788.
- Keady, J., Campbell, S., Clark, A., Dowlen, R., Elvish, R., Jones, L., Kindell, J., Swarbrick, C., & Williams, S. (Accepted/In press). Re-thinking and re-positioning 'being in the moment' within a continuum of moments: introducing a new conceptual framework for dementia studies. *Ageing and Society*. Retrieved August 9, 2020, from [https://www.research.manchester.ac.uk/portal/en/publications/rethinking-and-repositioning-being-in-the-moment-within-a-continuum-of-moments-introducing-a-new-conceptual-framework-for-dementia-studies\(0197ff7f-a3a1-4e60-badd-7ac52f7b53db\).html](https://www.research.manchester.ac.uk/portal/en/publications/rethinking-and-repositioning-being-in-the-moment-within-a-continuum-of-moments-introducing-a-new-conceptual-framework-for-dementia-studies(0197ff7f-a3a1-4e60-badd-7ac52f7b53db).html)
- Kelly, F. (2014). Bodywork in dementia care: recognising the commonalities of selfhood to facilitate respectful care in institutional settings, *Ageing and Society*, 34(6), 1073–90.
- Kelley, R. (2017). *"Knowing the person" - The use of families' knowledge and expertise in delivering care and valued outcomes for people with dementia on acute wards (Doctoral thesis)*. Retrieved from <http://etheses.whiterose.ac.uk/18586/1/Kelley-RS-Medicine-PhD-2017.pdf>

- Kelsick, J., & Freysteinson, W. (2013). Who is that stranger in the mirror? The mirror experience for elderly patients with dementia, *Holistic Nursing Practice*, 27(5), 268-272
- Kenkmann, A., Poland, F., Burns, D., Hyde, P., & Killett, A. (2017). Negotiating and valuing spaces: The discourse of space and 'home' in care homes. *Health Place*, 43, 8-16.
- Killick, J. (2013). *Playfulness and dementia: A practice guide*. London: Jessica Kingsley Publishers
- Killick, J., & Craig, C. (2012). *Creativity and communication in persons with dementia*. London: Jessica Kingsley Publishers
- Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing and Society*, 12, 269-287.
- Kitwood, T. (1997). *Dementia Reconsidered, the person comes first*. Maidenhead: Open University Press.
- Knoblauch, H. (2005). Focussed ethnography, *Forum: Qualitative social research*, 6(3). <http://dx.doi.org/10.17169/fqs-6.3.20>
- Knoblauch, H., & Tuma, R. (2020). *Videography and Video Analysis*. In P. Atkinson, S. Delamont, A. Cernat, J.W. Sakshaug, & R.A. Williams (Eds.), *SAGE Research Methods Foundations*. <https://dx.doi.org/10.4135/9781526421036805699>.
- Knopman, D., DeKosky, S. T., Cummings, J., Chui, H., Corey-Bloom, J., & Stevens, J. (2001). Practice parameter: Diagnosis of dementia: An evidence-based review. Report of the quality standards committee of the American Academy of Neurology. *Neurology*, 56(9), 1143-1153.

- Koch, T., & Kralik, D. (2006). *Participatory action research in healthcare*. Oxford: Wildey-Blackwell.
- Kontos, P. (2004). Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing & Society*, 24(6), 829-849.
- Kontos, P. (2005). Embodied selfhood in Alzheimer's disease: Rethinking person-centered care. *Dementia*, 4(4), 553-570.
- Kontos, P. (2015). Dementia and Embodiment. In J, Twigg., & W, Martin., (Eds.), *Routledge handbook of cultural gerontology*, (pp.173-181). London: Routledge
- Kontos, P., & Martin, W. (2013). Embodiment and dementia: Exploring critical narratives of selfhood, surveillance, and dementia care. *Dementia*, 12(3), 288-302.
- Kontos, P., Miller, K. L., & Kontos, A. (2017a). Relational citizenship: Supporting embodied selfhood and relationality in dementia care. *Sociology of Health & Illness*, 39(2), 182-198.
- Kontos, P., Miller, K. L., Mitchell, G., & Stirling-Twist, J. (2017b). Presence redefined: The reciprocal nature of engagement between elder-clowns and persons with dementia. *Dementia*, 16(1), 46-66.
- Kontos, P. C. & Naglie, G. (2009), Tacit knowledge of caring and embodied selfhood. *Sociology of Health & Illness*, 31(5), 688-704.
- Kovach, R. C., Noonan, E. P., Griffie, J., Muchka, S., Weissman, E. D. (2002). The assessment of discomfort in dementia protocol, *Pain Management Nursing*, 3(1), 16-27
- Kricton, J., & Coch, T. (2007) Living with dementia: Curating self-identity. *Dementia*, 6(3), 365–81.

- Kristensen, L.K. (2018). "Peeling an onion": Layering as a methodology to promote embodied perspectives in video analysis. *Video Journal of Education and Pedagogy*, 3(3). <https://doi.org/10.1186/s40990-018-0015-1>
- Lahman, M., Rodriguez, K., Moses, L., Griffin, K., Mendoza, B., & Yacoub, W. (2015). A rose by any other name is still a rose? Problematizing pseudonyms in research, *Qualitative Inquiry*, 21(5), 445-453.
- Laing Buisson. (2018). Care homes for older people: UK Market Report. *Laing Buisson*.
- La Jevic, L., & Springgay, S. (2008). A/r/tography as an ethics of embodiment: Visual journal in preservice education. *Qualitative Inquiry*, 14(1), 67-89.
- Latimer, J. (2018). Afterword: Materialities, care, 'ordinary affects', power and politics, *Sociology of Health & Illness*, 40(2), 379–91.
- Laslett, P. (1987). The emergence of the Third Age. *Ageing and Society*, 7(2), 133-160.
- Leavy, P. (2015). *Method Meets Art: Arts-Based Research Practice*, New York: The Guildford Press.
- Liamputtong, P. (2011). Focus group methodology: introduction and history. In P. Liamputtong (Ed.), *Focus group methodology: Principles and practice* (pp. 1-14). London: Sage
- Lipton, E., & Lipps, A. (2018). *The Senses: Design beyond vision*, New York: Princeton University Press.
- Lloyd, L., Banerjee, A., Harrington, C., Jacobsen, F. F., & Szebehely, M. (2014). It is a scandal! Comparing the causes and consequences of nursing home

- media scandals in five countries. *International Journal of Sociology and Social Policy*, 4(1/2), 2–18.
- Loboprabhu, S., Molinari, V., & Lomax, J. (2007). The transitional object in dementia: Clinical Implications. *International Journal of Applied Psychoanalytic Studies* 4, 144–169.
- Lovatt, M. (2020). Becoming at home in residential care for older people: A material culture perspective, *Sociology of Health & Illness*, 40(2), 366–378
- Ludden, G. D. S., van Rompay, T. J. L., Niedderer, K., & Tournier, I. (2019). Environmental design for dementia care – towards more meaningful experiences through design. *Maturitas*, 128, 10-16.
- Luff, P., & Heath, C. (2012). Some ‘technical challenges’ of video analysis: social actions, objects, material realities and the problems of perspective. *Qualitative Research*, 12(3), 255–279.
- Lupton, D. (2017). How does health feel? Towards research on the affective atmospheres of digital health, *Digital health*, 3, 1-11.
- Lupton, D. (Ed.). (2020). Doing fieldwork in a pandemic [crowd-sourced online document]. Retrieved August 4, 2020, from <https://docs.google.com/document/d/1clGjGABB2h2qbduTgfrqribHmog9B6P0NvMgVuiHZCl8/edit?ts=5e88ae0a#>
- Mahoney, D. F., LaRose, S., & Mahoney, E. L. (2015). Family caregivers’ perspectives on dementia-related dressing difficulties at home: The preservation of self model. *Dementia*, 14(4), 494–512.
- Malnar, J., & Vodvarka, F. (2004). *Sensory design*. Minneapolis: University of Minnesota Press

- Mann, G., & Oatley, G. (2017). Positive design of smart interactive fabric artifacts for people with dementia. In *2017 IEEE 5th International Conference on Serious Games and Applications for Health (SeGAH)*, Perth. Retrieved from <https://doi.org/10.1109/SeGAH.2017.7939257>
- Martin, W., Kontos, P., & Ward, R. (2013). Embodiment and dementia. *Dementia*, 12(3), 283-287.
- Masuch, C., & Hefferon, K. (2018). 'It's like a souvenir of something that was important': The role of nostalgic memorabilia in psychological well-being. *International Journal of Fashion Studies*, 5(2), 347-361.
- Matsumoto, D., Frank, M. G., & Hwang, H. S. (2013). Reading people: Introduction to the world on nonverbal behaviour. In D. Matsumoto, M. G. Frank, & H. S. Hwang (Eds.). *Nonverbal communication: Science and applications* (pp. 3-15), Thousand Oaks, CA: Sage
- McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, 19, 1935–1943.
- Merleau-Ponty, M. (2002[1962]), *Phenomenology of Perception*. London: Routledge.
- Mitchell, G. (2018). Uniforms in dementia care: A barrier or a necessity? *Nursing ethics*, 25(3), 410-412.
- Mitchell, W. (2016, January 8). Children without a voice...Which me am I today? One person's experience of living with dementia. Retrieved from <https://whichmeamitoday.wordpress.com/2016/01/08/children-without-a-voice/>

- Modibodi. (n.d.). Modibodi adsorbent underwear [Image]. Retrieved August 4, 2020, from <https://www.modibodi.co.uk/pages/mo#shop>
- Møller, T. (2018). Presenting the accessory approach: A start-up's journey towards designing an engaging fall detection device, In R. Mandryk & M. Hancock (Eds.), *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems* (pp.1–10). New York: Association for Computing Machinery.
- Morgner, C., Hazel, S., Schneider, J., & Tischler, V. (2019). Conduct in dementia: Video analysis of arts interventions, *Sociological Research Online*, 24(4), 514–540
- Morrissey, K., Wood, G., Green, D., Pantidi, N., & McCarthy, J. (2016). “I’m a rambler, I’m a gambler, I’m a long way from home”: The place of props, music, and design in dementia care. In M. Forth, W. Ju, R. Schroeter, S. Viller (Eds.), *Proceedings of the 2016 ACM Conference on Designing Interactive Systems* (pp.1008-1020). New York: Association for Computing Machinery.
- Morse, N., & Chatterjee, H. (2018). Museums, health and wellbeing research: Co-developing a new observational method for people with dementia in hospital contexts. *Perspectives in Public Health*, 138(3), 152–159.
- Moss, H., & O’Neill, D. (2019). Narratives of health and illness: Arts-based research capturing the lived experience of dementia. *Dementia*, 18(6), 2008–2017.
- Moyle, W., Jones J. C., Murfield, J. E., Thalib, L., Beattie. R. A. E., Shum, D. H., T O’Dwyer, S. T., Mervin, C. M., Draper, B. M. (2017). Use of a robotic seal as a therapeutic tool to improve dementia symptoms: A cluster-randomized controlled trial, *Journal of the American Medical Directors Association*, 18 (9), 766-773

- Mountain, G. (2018, October 3). Redefining and measuring meaningful outcomes for people with dementia [Alzheimer Europe conference presentation]. Retrieved August 9, 2020, from <https://youtu.be/ei2Hh8ujbzc>
- Murphy, K., Jordan, F., Hunter, A., Cooney, A., & Casey, D. (2015). Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies. *Dementia: The International Journal of Social Research and Practice*, 14(6), 800–824.
- Nakrem, S., Vinsnes, A., Harkless, G.E., Paulsen, B., & Seim, A. (2013). Ambiguities: Residents' experience of 'nursing home as my home'. *International Journal of Older People Nursing*, 8(3), 216-225.
- Napkin Project. (2014, January 10). Celebration event [Image]. Retrieved August 3, 2020, from <https://thenapkinprojectblog.wordpress.com/>
- National Institute of Clinical and Health Excellence. (2018). NICE Clinical Guideline: NG974. Dementia: assessment, management and support for people living with dementia and their carers. Retrieved August 3, 2020, from <https://www.nice.org.uk/guidance/ng97>
- Nelson, T. (2011). Ageism: The strange case of prejudice against the older you. In R. Wiener & S. Willborn (Eds.), *Disability and Aging Discrimination: Perspectives in Law and Psychology* (pp.37-49). New York: Springer
- Newell, F., & Shams, L. (2007). *New Insights into Multisensory Perception*. *Perception*, 36(10), 1415–1417.
- New Vision Health Environments. (n.d.). Memory boxes [Image]. Retrieved from <https://www.new-vision.co.uk/health/products/memory-boxes>
- NHS. (2020). Dementia Guide: Symptoms of Dementia. Retrieved August 3, 2020, from <https://www.nhs.uk/conditions/dementia/about/>

- Nichols, L., Martindale-Adams, J., Greene, W. A., Burns, R., Graney, M. J., & Lummus, A. (2009). Dementia caregivers' most pressing concerns. *Clinical Gerontologist*, 32(1), 1-14.
- Niedderer, K., Tournier, I., Colesten-Shields, D., Craven, M., Gosling, J., Garde, J.A., Bosse, M., Salter, B., & Griffioen, I. (2017). Designing with and for people with dementia: Developing a mindful interdisciplinary co-design methodology. *Proceedings of the IASDR International Conference* (pp. 815-837) Cincinnati: University of Cincinnati
- Nolan, M. R., Davies, S., Brown, J., Keady, J. & Nolan, J. (2004). Beyond 'person-centred' care: a new vision for gerontological nursing. *Journal of Clinical Nursing*, 13, 45-53.
- ONS. (2014). Changes in the Older Resident Care Home Population between 2001 and 2011. Retrieved from <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/changesintheolderresidentcarehomepopulationbetween2001and2011/2014-08-01>
- Paintings in Hospitals. (n.d. [online]). Retrieved August 3, 2020, from <https://www.paintingsinhospitals.org.uk/artworks-for-health-and-social-care>
- Pajaczkowska, C. (2012). Empathy by design: The Cultural Value Project, *Arts & Humanities Research Council*. Retrieved from https://www.academia.edu/30027495/Empathy_By_Design_final_report
- Park, A. (2016). Carved panels using braille 2016 [Image]. Retrieved August 9, 2020, from <http://www.carvings-with-stories.co.uk/2016/05/20/southmead-panel-please-touch-2016/>

- Partridge, E. (2019). *Art therapy with older adults: Connected and empowered*. London and Philadelphia: Jessica Kingsley Publishers
- Peters, C., Shelton, J.A., & Thomas, J.B. (2011). Self-concept and the fashion behavior of women over 50, *Journal of Fashion Marketing and Management*, 15(3), 291-305.
- Perry, M., & Medina, C. (2011). Embodiment and performance in pedagogy research: Investigating the possibility of the body in the curriculum experience. *Journal of Curriculum Theory*, 27(3), 62-75.
- Phillipson, L., & Hammond, A. (2018). More than talking: A scoping review of innovative approaches to qualitative research involving people with dementia. *International Journal of Qualitative Methods*, 17(1), 1-13.
- Pink, S. (2009). *Doing Sensory Ethnography*, London: SAGE Publications.
- Pink, S. (2015). *Doing Sensory Ethnography* (2nd Ed.), London: SAGE Publications.
- Pink, S. (2011). 'Multimodality, multisensoriality and ethnographic knowing: Social semiotics and the phenomenology of perception' *Qualitative Research* 11(1), 261 – 276.
- Pink, S., & Leder Mackley, K. (2012). Video and a sense of the invisible: Approaching domestic energy consumption through the sensory home, *Sociological Research Online*, 17(1). <https://doi.org/10.5153/sro.2583>
- Pink, S., & Morgan, (2013). Short-term ethnography: Intense routes to knowing. *Symbolic Interaction*, 36(3), 351-361.
- Pitts-Taylor, V. (2015). A feminist carnal sociology? Embodiment in sociology, feminism and naturalized philosophy. *Qualitative Sociology*, 38, 19-25. doi: 10.1007/s11133-014-9298-4.

Point of Care Foundation. (n.d.). Experience based co-design toolkit. Retrieved from <https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/>

Pratt, M., & Rafaeli, A. (1997). Organizational dress as a symbol of multilayered social identities. *The Academy of Management Journal*, 40(4), 862-898.

Priest, F. (n.d.). The tiled corridor, Frances Priest, Tonic Arts, Edinburgh and Lothians Health Foundation. Photograph by Shannon Tofts [Image]. Retrieved August 9, 2020, from <http://www.francespriest.co.uk/work/projects/the-tiled-corridor.html>

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., Adelaja, B., Hu, B., King, D., Rehill, A., & Salimkumar, D. (2014). *Dementia UK: Update* Second Edition report. Retrieved from https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf?fileID=2323

Reavey, P., & Prosser, J. (2012). Visual research in psychology. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbooks in psychology®. APA handbook of research methods in psychology, Vol. 2. Research designs: Quantitative, qualitative, neuropsychological, and biological* (p. 185–207). American Psychological Association.

Richardson, L. (2000). Writing: A method of inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed) (pp. 923–943). Thousand Oaks: Sage.

Rivett, E. (2017). Research involving people with dementia: A literature review. *Working with Older People*, 21(2), 107-114

- Robertson, L., Nevay, S., Jones, H., Moncurl, W., & Lim, C. (2020). Birds of a feather sew together: A mixed methods approach to measuring the impact of textile and e-textile crafting upon wellbeing using Warwick-Edinburgh Mental Wellbeing Scale. In K. Christer, C. Craig, P. Chamberlain (Eds.), *Proceedings of the 6th International Conference on Design4Health* (pp. 561-570). Amsterdam: Lab4Living Sheffield Hallam University
- Robson, C. (2011). *Real World Research* (3rd ed). Chichester: John Wiley & Sons.
- Schweitzer, P., Bruce, E., & Gibson, F. (2008). *Remembering Yesterday, Caring Today: Reminiscence in Dementia Care: A Guide to Good Practice*. London: Jessica Kingsley Publishers.
- Shapiro, J. (2012). Whither (whether) medical humanities? The future of humanities and arts in medical education. *Journal for Learning through the Arts*, 8(1) 1–24.
- Sheppard, C., McArthur, C., & Hitzig, S. (2016). A systematic review of Montessori-based activities for persons with dementia, *Journal of the American Medical Directors Association*, 17(2), 117-122.
- Shercliff, E., & Holroyd Twigger, A. (2020). Stitching Together: Participatory textile making as an emerging methodological approach to research, *Journal of Arts & Communities*, 10(1-2), 5-18.
- Sims, J., Browning, C., Lundgren-Lindquist, B., & Kendig, H. (2011). Urinary incontinence in a community sample of older adults: prevalence and impact on quality of life, *Disability and Rehabilitation*, 33(15-16), 1389-1398
- Skinner, J. (2012). *The interview: An ethnographic approach*. Oxford: Bloomsbury.
- Smart, A. & Harrison, E. (2017). The under-representation of minority ethnic groups in UK medical research. *Ethnicity & Health*, 22(1), 65-82

- Smith, A. J. (2015). *Qualitative Psychology: A practical guide to research methods*. (3rd ed.) London: Sage.
- Smith, A. J., Flower, P., & Larkin, M (2009). Interpretative Phenomenological Analysis: Theory, Method and Research, *Qualitative Research in Psychology*, 6(4), 346-347.
- Smith, S.K. & Mountain, G.A. (2012). New forms of information and communication technology (ICT) and the potential to facilitate social and leisure activity for people living with dementia, *International Journal of Computers in Healthcare*, 1(4), 332-45.
- Souyave, J., Treadaway, C., Fennell, J., & Walters, A. (2019). Designing folding interventions for positive moments. In K. Niedderer, G. Ludden, R. Cain, C. Wölfel (Eds.), *Proceedings of the International MinD Conference: Designing with and for people with dementia*. (pp.59-68). Dresden: Technische Universität Dresden
- Stacpoole, M., Hockley, J., Thompsell, A., Simard, J., & Volicer, L. (2017). Implementing the namaste care program for residents with advanced dementia: Exploring the perceptions of families and staff in UK care homes. *Annals of Palliative Medicine*, 6(4), 327-339.
- Stephan, B., & Brayne, C. (2010). Prevalence and projections of dementia. In M. Downs & B. Bowers (Eds.), *Excellence in dementia care: Research into practice* (pp.9-35). Berkshire: Open University Press
- Stephens, A., Cheston, R., & Gleeson, K. (2013). An exploration into the relationships people with dementia have with physical objects: An ethnographic study. *Dementia-international journal of social research and practice*, 12 (6), 697-712

- Stokes, G. (2008). *And still the music plays: Stories of people with dementia*. London: Hawker Publications Ltd
- Sutton, B. (2011). Playful cards, serious talk: A qualitative research technique to elicit women's embodied experiences. *Qualitative Research*, 11(2), 177-196.
- Sweetman, P. (2001). Shop-window dummies? Fashion, the body, and emergent socialities. In J. Entwistle & E. Wilson (Eds.), *Body dressing* (pp. 59-77). Oxford: Berg.
- Swinnen, A., & de Medeiros, K. (2018). "Play" and people living with dementia: A humanities-based inquiry of Timeslips and the Alzheimer's poetry project. *The Gerontologist*, 58(2), 261–26.
- Tanner, D. (2012). Co-research with older people with dementia: Experience and reflections. *Journal of Mental Health*, 21(3), 296-306.
- Taylor, J.S., DeMers, S.M., Vig, E.K., & Borson, S. (2012). The disappearing subject: Exclusion of people with cognitive impairment and dementia from geriatrics research. *Journal of American Geriatrics Society*, 60(3), 413-419
- Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. In C. Willig, W. Stainton Rogers (Eds.), *The Sage handbook of qualitative research in psychology* (2nd ed.) (pp.17-37). London: Sage.
- The CCRI Impact Blog. (2019, June 13). Lab4Living awarded £4m by Research England. Retrieved from <https://blogs.shu.ac.uk/c3riimpact/lab4living-awarded-4-million-research-england/>
- The Dementia Centre at Stirling University. (2011, September 1). Tearing clothes. Retrieved from <https://dementia.stir.ac.uk/tearing-clothes>

- The Woolmark Company. (2019). Freedom to move with NAGNATA [Image]. Retrieved from <https://www.woolmark.com/news/activewear/freedom-to-move/>
- Thomson, L. J. M., & Chatterjee, H. J. (2016). Well-being with objects: Evaluating a museum object-handling intervention for older adults in health care settings. *Journal of Applied Gerontology*, 35(3), 349–362.
- Timin, G., & Rysenbry, N. (2010). *Design for Dementia*. Retrieved August 3, 2020, from <https://www.rca.ac.uk/research-innovation/research-centres/helen-hamlyn-centre/research-projects/2010-pr>
- Topo, P., & Iltanen-Tähkävuori, S. (2010). Scripting patienthood with patient clothing. *Social Science & Medicine*, 70(11), 1682-1689.
- Townsend, K., Sadkowska, A. & Sissons, J. (2017). Emotional fit: developing a new fashion methodology with older women. *Clothing Cultures*, 4(3), 235-253.
- Treadaway, C. (2018). LAUGH improves wellbeing, happiness and quality of life of people living with advanced dementia, *Research Features*, 122, ISSN 2399-1534
- Treadaway, C., Fennell, J., Taylor, A. (2020). Compassionate Design: a methodology for advanced dementia, In K. Christer, C. Craig, P. Chamberlain (Eds.), *Proceedings of the 6th International Conference on Design4Health* (pp.667-673). Amsterdam: Lab4Living Sheffield Hallam University
- Treadaway, C., Fennell, J., Taylor, A., Kenning, G. (2018). Designing for playfulness through compassion: Design for advanced dementia. In K. Christer, C. Craig, D. Wolstenholme (Eds.), *Proceedings of the 5th*

- International Conference on Design4Health* (pp. 275-285). Sheffield: Lab4Living Sheffield Hallam University.
- Treadaway, C., & Kenning, G. (2016). Sensor e-Textiles: person centered co-design for people with late stage dementia. *Working with Older People*, 20(2). <https://doi.org/10.1108/WWOP-09-2015-0022>.
- Treadaway, C., & Kenning, G. (2018). Designing for dementia: Iterative grief and transitional objects. *Design Issues*, 34(1), 42-53.
- Tseelon, E. (2012). How successful is communication through clothing? Thoughts and evidence on an unexamined paradigm. In: A. M. Gonzalez, & L. Bovone (Eds.), *Identities through fashion. A multidisciplinary approach* (pp.109-138). Oxford: Berg Publishers.
- Tsen Chang, M. (n.d.). MAOMAO [Image]. Retrieved August 9, 2020, from <https://www.arts.ac.uk/colleges/london-college-of-fashion/people/mao-tsen-chang>
- Twigg, J. (2000). Carework as a form of bodywork. *Ageing and Society*, 20(4), 389-411.
- Twigg, J. (2001). *Bathing - the body and community care: The body and community care*. ProQuest Ebook Central <https://ebookcentral.proquest.com>
- Twigg, J. (2003). The body and bathing: Help with personal care at home, In C. Faircloth (Ed.), *Aging bodies: images and everyday experience* (pp. 143-171), Oxford: Altmira Press
- Twigg, J. (2010). Clothing and Dementia: A Neglected Dimension? *Journal of Aging Studies*, 24 (4) 223–30.
- Twigg, J. (2013). *Fashion and Age: Clothing, the Body and Later Life*. London: Bloomsbury.

- Twigg, J. (2015). Dress and age: The intersection of life and work. *International Journal of Ageing and Later Life*, 10(1), 55-67.
- Twigg, J. (2019). Why clothes matter: The role of dress in everyday lives of older people. In S. Katz (Ed.) *Ageing in Everyday Life: Materialities and Embodiments*. Bristol, UK: Policy Press.
- Twigg, J., & Buse, C. (2013). Clothing, Dementia and the Embodiment of Identity. *Special issue of Dementia*, 12(3), 326-36.
- University of Bradford. (2005). *Dementia Care Mapping*. Bradford, UK: University of Bradford.
- Uran, S. & Gersak, J. (2018). Smart clothing to increase safety of people with dementia. *IOP Conference Series: Materials Science and Engineering*. 460. <https://doi.org/10.1088/1757-899X/460/1/012047>.
- Van Steenwinkel, I., Van Audenhove, C., Heylighen, A. (2014). Mary's little worlds. changing person-space relationships when living with dementia. *Qualitative Health Research*, 24(8), 1023–1032.
- Vidal, F. (2009). Brainhood, anthropological figure of modernity. *History of the Human Sciences*, 22(1), 5-36.
- Wallace, J., Thieme, A., Wood, G., Schofield, G., & Olivier, P. (2012). Enabling self, intimacy and a sense of home in dementia: an enquiry into design in a hospital setting. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12)* (pp. 2629–2638), New York: Association for Computing Machinery.
- Wallace, J., Wright, P., McCarthy, J., Green, D., Thomas, J., & Olivier, P. (2013). A design-led inquiry into personhood in dementia. *Proceedings of the SIGCHI*

- Conference on Human Factors in Computing Systems* (pp. 2617-2626),
New York : Association for Computing Machinery
- Ward, R., & Campbell, S. (2013a). Mixing methods to explore appearance in dementia care. *Dementia*, 12(3), 337–347.
- Ward, R., & Campbell, S. (2013b). An ethics journey: Ethical governance of social research with vulnerable adults and the implications for practice. In L. Green & M. Carey (Eds.), *Practical social work ethics: Complex dilemmas within applied social care* (pp. 151-167). London: Routledge
- Ward, R., Campbell, S., & Keady, J. (2014). "Once I had money in my pocket, I was every colour under the sun": Using 'Appearance Biographies' to explore the meanings of appearance for people with dementia. *Journal of Aging Studies* 30, 64-72.
- Ward, R., Campbell, S., & Keady, J. (2016). 'Gonna make yer gorgeous': Everyday transformation, resistance and belonging in the care-based hair salon. *Dementia*, 15(3), 395–413
- Ward, G., Holliday, N., Fielden, S., & Williams, S. (2012). Fall detectors: A review of the literature, *Journal of Assistive Technologies*, 6(3), 202-215.
- Ward, R., Vass, A. A., Aggarwal, N., Garfield, C., & Cybyk, B. (2008). A different story: Exploring patterns of communication in residential dementia care. *Ageing and Society*, 28(5), 629-651.
- WHO. (2018, February 5). *Ageing and health*. Retrieved August 3, 2020, from <https://www.who.int/news-room/fact-sheets/detail/ageing-and-health>
- Wilkinson, C., & Wilkinson, S. (2019). Childhood disability and clothing: (Un)dressing debates. In N. von Benzon & C. Wilkinson (Eds.), *Intersectionality and Difference in Childhood and Youth*. Global

- Perspectives. Routledge. Retrieved from
<http://researchonline.ljmu.ac.uk/id/eprint/12375/>
- Windle, G., Joling, K., Howson-Griffiths, T., Woods, B., Hedd Jones, C, M. van de Ven, P., Newman, A., & Parkinson, C. (2018). The impact of a visual arts program on quality of life, communication, and well-being of people living with dementia: A mixed-methods longitudinal investigation, *International Psychogeriatrics*, 30(3), 409 – 423
- Windle, G., Algar-Skaife, K., Caulfield, M., Pickering-Jones, L., Killick, J., Zeilig, H., & Tischler, V. (2020). Enhancing communication between dementia care staff and their residents: An arts-inspired intervention, *Aging & Mental Health*, 24(8), 1306-1315.
- Winnicott, D. W. (1953). Transitional objects and transitional phenomena; A study of the first not-me possession. *The International Journal of Psychoanalysis* 34, 89–97.
- Woodward, S. (2007). *Why women wear what they wear*. Oxford: Berg Publishers.
- Woodward, S. (2015). Object interviews, material imaginings and “unsettling” methods: Interdisciplinary approaches to understanding materials and material culture. *Qualitative research*, 16(4), 359-374
- Woodward, S., & Greasley, A. (2015). Personal collections as material assemblages: A comparison of wardrobes and music collections. *Journal of consumer culture*, 17(3), 659-676
- Woodward, S. (2020). *Material methods: Researching and thinking with things*. London: Sage
- World Economic Forum. (2017, September 21). *This is one of the biggest global health challenges of the 21st Century*. Retrieved from

<https://www.weforum.org/agenda/2017/09/dementia-trillion-dollar-global-crisis/>

- Yardley, L. (2000). Dilemmas in Qualitative Health Research, *Journal of Psychology & Health* 15(2), 215-228.
- Young, R., Camic, M, P., & Tischler, V. (2016). The impact of community-based arts and health interventions on cognition in people with dementia: a systematic literature review, *Aging & Mental Health*, 20(4), 337-351
- Zeilig, H. (2013). Dementia as a cultural metaphor. *The Gerontologist* 54(2), 258-267.
- Zeilig, H., & Almila, A-M. (2018). 'It's play really isn't it?' Dress, creativity, old age. In D. Amigoni, G. McMullan (Eds.), *Creativity in later life: Beyond late style*. London: Routledge.
- Zeilig, H., Tischler, V., van der Byl Williams, M., West, J., & Strohmaier, S. (2019). Co-creativity and agency: A case study analysis of a co-creative arts group for people with dementia, *Journal of Aging Studies*, 49, 16-24.
- Zeilig, H., West, J., & van der Byl Williams, M. (2018). Co-creativity: Possibilities for using the arts with people with a dementia, *Quality in Ageing and Older Adults*, 19(2),135-145.

APPENDICES

APPENDIX A Visual reflexive journal

The visual reflexive diary contains mixed media reflections in response to my experiences over the course of this project. The full journal can be accessed here:

https://issuu.com/rebecka.fleetwood-smith/docs/reflexive_journal_rebecka_fleetwood-smith_august

APPENDIX B Writing conventions

The following terms and conventions have been followed:

- I have used first person e.g. “I”, “we” and “me”. The use of the first person highlights my approach to research whereby I co-created the research with participants. This is discussed in detail see **Chapter 3, Method**.
- I have used the American Psychological Association style of referencing throughout the thesis. Where there are three authors these are cited and when there are four or more authors ‘et al.’ has been used. Authors are presented in alphabetically in the text and reference list.
- Numbers from one to nine are written in full, with numbers 10 and above written in numerical form.
- Direct quotes that are more than 30 words have been indented within the text. Shorter quotes are embedded in the text with double quotation marks.

- My reflexive notes are included throughout the thesis and are written in *italics*.
- I refer to the 'PhD supervisory team' i.e. Prof Victoria Tischler and Dr Deirdre Robson.
- I have used the terms 'people living with dementia' / 'people with dementia' throughout.
- I have used the term 'residents' to refer to people living in care homes, and people with dementia living in care homes.
- I have used the term 'care home staff' to refer to people working in care homes i.e. managers, care-workers, activities co-ordinators. Where appropriate I have outlined a person's role e.g. when discussing specific findings.

APPENDIX C Glossary of key terms

This glossary was written for the purpose of this thesis and defines key terms used.

Activity coordinators: develop and plan activities, outings and events. They may work in various settings including care homes.

Affect: is a concept used in psychology to describe the experience of feelings or emotions when interacting with stimuli.

Arts-based research methods: invite people to engage with creative practice e.g. sketch an image (Kara, 2015).

Care home staff: this may include care-workers, nurses, team managers, team leaders, activity coordinators, and occupational therapists.

Care-workers: this includes people whose job involves supporting for and caring for people e.g. in a care home.

Corporeal: refers to the physical body.

Creative practitioners: this may include practicing artists and designers working in a health or social care setting

Creative research methods: can be used to describe methods that draw upon both arts-based research methods and design-led research methods (Kara, 2015).

Dementia: is an umbrella term used to describe particular degenerative cognitive impairments, there are many types of dementia including, but not limited to, vascular dementia, Alzheimer's disease and dementia with Lewy bodies.

Design-led research methods: typically focus on the design of objects to explore people's interactions and responses (Kara, 2015).

Embodiment: the term refers to emphasizing the role that the body plays in shaping the mind. The body is both a representation of the self and creates the self.

Embodied selfhood: separates the notion that the body is secondary to cognition and embraces the notion that a person is his or her body, its gestures, movements and habits (Kontos 2005). In recent years there has been an increase of efforts to enhance understanding of dementia by acknowledging both the mind and the body in relation to dementia care.

Focussed ethnography: is a form of short-term ethnography that involves intensive periods of data collection, it is often used in settings (e.g. healthcare settings) in which traditional long-term ethnography could prove problematic.

Informal caregivers: are caregivers who provide unpaid support and care for loved ones e.g. a family member or friend.

Holistic: from a philosophical perspective, means that the parts of something are intimately connected and understood only by reference to the whole. With regards to a person, holistic care would encompass both psychological and social factors, rather than just medical symptoms.

Little-c creativity: or everyday creativity is defined as engagement with creative practice that is meaningful to everyday life (Beghetto & Kaufman, 2007)

Nominated consultee: where no personal consultee is available, a person who has no connection with the project and who is willing to be consulted about the participation of a person who lacks capacity in an approved research project may be nominated e.g. paid healthcare professional.

Personal consultee: someone who is engaged in caring for an incapacitated person and is interested in the welfare of the person and is prepared to be consulted regarding the individual e.g. family member or friend.

Selfhood: is defined as the quality that constitutes one's individuality and one's state of having identity; it is what makes each person unique. The terms 'selfhood' and 'personhood' are often used interchangeably.

Sensorial: relates to the senses and sensation. The term 'senses' in this study refers to the traditional Western view; touch, sight, sound, smell, taste.

Sensory Ethnography: is a form of ethnography, which focusses on the embodied experience, the nonverbal, and the intangible and tacit meanings (Pink 2009) of the phenomenon being explored.

Sensory qualities: are qualities that characterise what it is like to sense or perceive things, for example the feel of an item of clothing.

Tacit knowledge: knowledge is said to be tacit when it cannot be explicitly explained (Polanyi 1966). It is considered as knowing through the body, for example; knowing to wrap someone in a blanket when they are cold.

Team manager: is used within this thesis to refer to the most senior member of staff on the floor of the care home. Team managers were responsible for managing all care-workers on their floor of the care home.

Team leader: team leaders support the team manager (see above) in managing care-workers.

Textile sample: is typically a piece of cloth or fabric designed to represent a larger whole or created as a trial piece to test ideas.

Textiles: refer to a type of cloth, material or fabric.

Visual reflexive journal: this contains various forms of text, sketching, mark making, painting and textiles (such as embroidery) as a series of reflective responses to the research. The visual journal does not include any identifiable information or imagery of participants.

Wearer: refers to a person having clothing on the body.

Wellbeing: is subjective, broadly it refers to the presence of positive emotions and moods, the absence of negative emotions, satisfaction with life, fulfilment and positive functioning.

APPENDIX D Ethical considerations

These ethical considerations were extracted from the Research Protocol Version 2, 29.11.2018. IRAS Project ID: 242104.

There are a number of ethical concerns to be taken into consideration for this research including: voluntary participation, privacy, confidentiality and consent. These will be carefully considered throughout the research process. This research will be guided by the Mental Capacity Act (2005) in order to ensure the research is ethically grounded. RFS has completed relevant training on the Mental Capacity Act (2005), Valid Informed Consent Training, 18th April 2018, Informed Consent for Adults Lacking Capacity, 24th May 2018, Introduction to Good Clinical Practice eLearning course, 24th May 2018, and has an up to date Disclosure and Barring System (DBS) Form which she will carry with her at all times during the research process.

The following ethical concerns have been considered:

- **Consent issues.** People living with dementia. Due to their dementia some people may find it difficult to understand the study, or be able to express their views unequivocally, in order to give fully informed consent. Every effort will be taken to involve the person with dementia in the consent process. According to the Mental Capacity Act (2005), capacity is defined as a person's ability to understand the information about the research, retain the information to consider if they wish to take part, weigh up the consequences and communicate their decision. To support this guidance has been sought from DEEP guidelines (The Dementia Engagement and Empowerment Project). Thus, the study will be explained verbally with the use of written and visual information. Where a participant lacks capacity, assent from a nominated or personal consultee will be sought. Participants who lack capacity will be given an accessible Participant Information and Consent Booklet. The decision to include people with dementia who lack capacity will be made in close collaboration with RFS, the CI, the care home manager and the personal or nominated consultee, considering the person with dementia's past wishes and views, and their current situation. The advice provided by the British Psychological Society (2008) 'Conducting Research with People not having the Capacity to Consent to

their Participation' and the Mental Capacity Act (2005) will be used to guide this process. The CI, is experienced in recruiting people living with dementia from a range of care settings. Consent will be an ongoing process, RFS will communicate with key stake holders (care services manager, personal/nominated consultees, and the research team) at regular two weekly intervals. If a participant with dementia loses capacity, the decision to include the participant will be made between RFS, the CI, the care home manager and the personal or nominated consultee, considering the person with dementia's past wishes and views, and their current situation. If the decision is made to continue including the participant in the study, assent will be sought from the personal or nominated consultee. If a participant regains capacity, as guided by the Mental Capacity Act 2005, Informed Consent will be sought by RFS. Where a person with dementia is thought by any of the key stake holders to be too unwell or vulnerable, they will be excluded from the study. Key stake holders will be asked to contact RFS or the CI should they have questions, concerns or thoughts about the person's participation in the research.

- **Participant distress** - general issues. RFS will be available for telephone and face to face discussions if concerns arise. It will be stressed that all participants are free to withdraw from the research at any time. All aspects of the research will be carried out sensitively by RFS, and will be guided by the CI who is experienced in carrying out research with people with dementia and their caregivers. The research team have worked

closely with the Study Site to ensure that the appropriate procedures are in place. The Distress Protocol will guide RFS should any participants become distressed. Contact information for appropriate support organizations will be signposted to care home staff, consultees, relatives, friends and volunteer facilitators, in the case that further help, or support is needed. The following actions will be taken, once RFS has followed the Distress Protocol:

- RFS will report the event to the CI and Co-Investigator.
- RFS will record the event/s via a fieldwork diary, complete with date, time and description of the occurrence.

- **Participant distress - observations and interviews.** Observations and interviews for both parties may be distressing. The research will focus on the content of the

study, however it is possible that a person may become distressed. If a participant becomes distressed RFS will offer empathy and listening, and participants will be asked whether they would like to stop taking part. Should any participant indicate that they are experiencing high levels of stress or shows signs of distress (i.e. uncontrolled crying, shaking etc.) during the observations and interviews the following steps, as per the Distress Protocol), will be taken:

1. The observation/interview will cease immediately, and the audio recording will be stopped.
2. RFS will ask the participant if they would like to share their feelings or whether they wanted to discuss anything that may have been concerning them. RFS will be sensitive to the fact the participant may need time alone and will therefore respond to the situation as appropriate
3. RFS will offer the participant a drink of water, if appropriate.
4. RFS will ask the participant how he / she is feeling. Dependent on the cause of the distress,
5. RFS will explore the participants' support network and offer to supply contact details of relevant organisations, if necessary.
6. If the participant wishes to continue the observation/interview, the observation/interview will resume. If not, RFS will make sure that the participant is stable and ensure that it is appropriate to leave.

• **Invasion of privacy - observations in the care home.** Observations in the care home are an intrusion into the privacy of the care home situation and careful consideration of consent / assent will be required for this. RFS will only carry out observations with participants who have consented to take part in the research or where assent has been received. Observations will be carried spaces of the care home where only consented participants are present i.e. 'do not disturb' signs will be used to ensure confidentiality.

RFS has been volunteering in the care home/ study site and has built a rapport with residents, care home staff and residents' family and friends.

• **Invasion of privacy – video-recording in the care home.** Video-recording in the care home is an intrusion into the privacy of the care home situation and careful

consideration of consent/ assent will be required for this. Following discussion with the care home manager RFS will set up the video camera in an agreed private room (for example, activities room) in which the Object Handling Session will take place. Recordings will only take place at the start of the Object Handling Session and will be terminated at the end of the Session. Discussion will also take place with the Study Site regarding practical issues such as, interruptions to ensure videotaping always has the consent/assent of all involved (e.g. signage may be used and stuck on the door to the room to ensure that it is clear videotaping is taking place). Participants will be informed prior to, during and at the end of videotaping.

• **Participant distress – video-recording.** Participants may become distressed by the video process. Because of the design of the study the person with dementia will always be with a staff caregiver and if possible their consultee/relative/friend during videotaping. Care home staff and consultees/relative/friends will be asked to monitor for any signs of distress in themselves and the person they are supporting, and to stop taking part in the Object Handling Session if this occurs. RFS will explain what the camera is recording and why. She will tell participants when recording commences and when it finishes. Should any participant indicate that they are experiencing high levels of stress or shows signs of distress (i.e. uncontrollable crying, shaking etc.) the following steps, outlined by the Distress Protocol), will be taken:

1. RFS will immediately stop the video-recording of the session.
2. The Session will cease immediately, and the video-recording will be stopped and ask participants to take a break, whilst she assists any distressed participants.
3. RFS will ask the participant if they would like to share their feelings or whether they wanted to discuss anything that may have been concerning them. RFS will be sensitive to the fact the participant may need time alone and will therefore respond to the situation as appropriate
4. RFS will offer the participant a drink of water, if appropriate.
5. RFS will ask the participant how he / she is feeling. Dependent on the cause of the distress, she will ask the participant whether they would like her to contact a person of their choice.

6. If the participant is happy to resume being part of the Object Handling Session and being video-recorded during the session, RFS will continue the recording. If they are not happy to resume being recorded, RFS will ensure the participant is stable and will assist the participant in leaving the room and help them return to either their room, or their preferred space in the care home.

7. RFS will ask if the rest of the group, once taking a break, are happy to continue with the Object Handling Session, if so recording will commence. If not, the Session will end.

- **Anonymity – video-recording.** The video-recordings will be viewed by the research team for the purpose of data analysis. The recordings will be stored securely on a password protected portable hard drive that will be stored in a locked filing cabinet at the University of West London. The recordings will be deleted from the recorder as soon as the recordings have been transferred to the computer and hard-drive.

- **Anonymity - visual journal.** RFS will use a visual journal to document text-based and visual reflections. These will not include any images of participants, or any identifiable information about participants.

- **Detection of inappropriate behaviours or abuse.** Whilst spending time in the care home RFS could detect inappropriate behaviours or instances of abuse. In this instance, RFS will follow the Abuse Protocol.

- **Diagnosis of dementia.** RFSs will rely on the opinion of the care home manager regarding the dementia status of residents (Aragon et al., 2002; Sixsmith & Gibson, 2007) and will not view medical records. The care home manager will make a judgment based on their knowledge of each resident. The research will not ask participants to discuss their, the resident's or their loved ones diagnosis of dementia.

APPENDIX E Ethical approval

NHS
Health Research Authority
London - Camden & Kings Cross Research Ethics Committee
NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Telephone: 0207 104 8018

07 January 2019

Prof Victoria Tischler
Professor of Arts and Health
University of West London
University of West London
College of Nursing, Midwifery and Healthcare
W5 5RF

Dear Prof Tischler

Study title: Exploring the sensorial and embodied experience of clothing in people living with dementia
REC reference number: 18/LO/1707
SSA reference number: 18/LO/2247
Protocol number: 21348584
IRAS project ID: 242104

The REC gave a favourable ethical opinion to this study on 29 November 2018.

Following site-specific assessment by the Committee, I am pleased to confirm the extension of the favourable opinion to the new site(s) and investigator(s) listed below:

Research site	Principal Investigator / Local Collaborator
NAME OMITTED	Prof Victoria Tischler

The favourable opinion is subject to management permission or approval being obtained from the host organisation prior to the start of the study at the site concerned.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

18/LO/1707	Please quote this number on all correspondence
-------------------	---

Yours sincerely
pp

18/LO/1707

Page 2 of 2



Jane Harker
REC Assistant

Email: nrescommittee.london-camdenandkingscross@nhs.net

Copy to: Prof Heather Loveday



College of Nursing, Midwifery and
Healthcare
Research Ethics Panel
Paragon House
Boston Manor Road
Brentford TW8 9GA
Tel: +44 (0)20 8209 4110/4145
email: cnmh.ethics@uwl.ac.uk

Rebecka Fleetwood Smith

Date 19 June 2018

Dear Rebecka

Re: Application for Ethical Approval No CREP 00465

Thank you for sending in your application for approval. The Panel has considered this and conditionally approved the research without major amendment with the requirement that NHSRES and if appropriate HRA approval is granted. The IRAS system will require the study to be signed by the University as sponsor and you should select Professor Anthony Woodman (DVC) to act as signatory. I suggest that you alert Professor Woodman when you intend to submit the application by emailing him and copying in Jackie Halvey.

Please send a copy of the NHSRES approval letter to the CNMH CREP once received. Please note that the research cannot commence until these approvals have been granted. If the research does not progress, or if you make any changes to your research proposal or methodology, can you please inform the Committee; changes may entail the need for additional review by NHSRES. It is your responsibility, as the principal investigator, to submit a report on the progress/completion of the research twelve months from the date of this letter, or on completion of the research, whichever is the sooner.

Font

The Panel wish you well with your research and look forward to receiving your report.

Yours sincerely

A handwritten signature in black ink, appearing to read 'H Loveday'.

Professor Heather Loveday
Director of Research
Chair, CNMH Research Ethics Panel

IRAS Project ID: 242104



Research Volunteers Needed

Exploring the significance of clothing to
people living with dementia



Do you work with people with dementia?

Are you interested in taking part in research?

We would like your assistance in learning about the significance of clothing to people with dementia, and would like to find out more your experiences.

If you are interested in taking part in the research, or would like more information, please contact Rebecka Fleetwood-Smith:

Email: Rebecka.Fleetwood-Smith@uwl.ac.uk

Telephone: [REDACTED]

Recruitment Advert. Care Home Staff. STUDY 1. Version 1 [01.05.2018]

APPENDIX G CYCLE 1 Participant information sheet (Care home staff)

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University

Participant Information Sheet

Exploring the significance of clothing to people living with dementia



Invitation

We would like to invite you to take part in our research study. The research is being conducted by the University of West London. Before you decide whether you would like to take part, Rebecka Fleetwood-Smith (PhD student) will explain the research to you using this sheet, this should take about ten minutes. If you have any questions please ask.

Why are we carrying out this study?

This study explores the significance of clothing to people with dementia, who live in a care home. There is research to suggest that the design of the care setting can affect a person's ability to live well, for example; decor, furniture, plates, and cutlery, can impact upon the ability to live well. Research from the social sciences has also established the close link between clothing and the person wearing the clothing. Clothing can affect mood and feelings, it can affect behaviour and it affects how others respond to the wearer. There is currently little research into the significance of clothing to people with dementia. This research will contribute to this area and will explore ways in which to enhance the care of people living with dementia.

1
Participant Information Sheet. Care Home Staff. STUDY 1. Version 2 [29.11.2018]

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University

Why have I been invited to take part?

You are a member of staff in a care home and work with people with dementia.

What will happen to me if I take part in the research?

Rebecka will visit the care home 1-2 days per week, over approximately 6 months. Whilst there Rebecka may ask to spend time with you and talk to you about your clothing and residents' clothing. Rebecka will ask if you are happy for her to spend time with you as part of the research at each visit. She may ask to interview you and record your answers using an audio recording device. During her visits she may also take notes. You may choose not to take part that day and can choose to stop taking part in the research at any point. All observations and interviews will take place in quiet spaces in the care home. Rebecka may ask you to take part in between 4-6 interviews across the 6-month period.

Do I have to take part?

No, your participation is voluntary. It is entirely up to you to decide whether or not to take part. If you decide to take part you are free to stop taking part at any time, without giving a reason.

Can I stop taking part in the study?

Yes, you do not have to take part in this study. You can stop taking part at any time and you do not need to give a reason why.

If you stop taking part, you may withdraw any data already collected if you wish, if you tell the research team before [REDACTED] at which time your anonymised data will have been analysed.

Do I get paid for taking part?


No, your participation is voluntary and there is no payment.

Are there any risks to taking part?

No, there are no foreseen risks in participating in the study. A possible disadvantage is that you will give up your time when taking part.

2
Participant Information Sheet. Care Home Staff. STUDY 1. Version 2 [29.11.2018]

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University

Will my taking part in this study be kept confidential?

Yes, your identity and all the information about your participation will be kept confidential. We will change your name to a pseudonym in all documents. Audio-recordings will be deleted from the audio-recording device as soon as the audio data has been transferred on to the University of West London computer. Audio data and transcriptions will be stored on a secure computer at the University of West London and will be password protected, they will also be stored on a portable backup hard-drive which will be stored in a locked filing cabinet at the University of West London. Paper documents will be stored in a locked filing cabinet at the University of West London. The anonymised data and consent forms will be stored for 5 years, but items such as your contact details will be deleted as soon as they are no longer needed. Pseudonyms will be used to label the data.

The PhD student will be responsible for the personal data collected during this study.

Who is organising and funding the research?

This study is funded by a PhD Studentship (2017-2020) which is sponsored by the University of West London.

What will happen to the results of this study?

The results of this study will form a PhD thesis and may be published in journals or presented at conferences and public engagement events, but participants will not be identifiable.

When we have finished the work


If you would like me to share findings, I can email or post you a leaflet, you can let me know which you would like me to do. I will also invite you to an event where I will talk about the work. It is up to you whether you would like to come or not.

Who has reviewed this study?

This study was reviewed and given favourable opinion by the Research Ethics Committee NRES Reference number: 18/LO/1707. This study has been reviewed and given favourable opinion by the University of West London's Nursing, Midwifery and Healthcare Ethics Committee on 19th June 2018.

3
Participant Information Sheet. Care Home Staff. STUDY 1. Version 2 [29.11.2018]

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University

What if there is a problem?

Please contact Rebecka Fleetwood-Smith or Victoria Tischler who will do their best to help you. If you wish to complain formally, you can do this by contacting the Research and Enterprise Operations at University of West London:


Research and Enterprise Operations
University of West London
St. Mary's Road
London
W5 5AF
Email: research@uwl.ac.uk
Telephone: 020 8231 2255

What happens next?


If you agree to take part in the study Rebecka will provide you with an Informed Consent Form that you will be asked to read through, date and sign.

Research Team Contact Details:

PhD Student: Rebecka Fleetwood-Smith
Email: Rebecka.Fleetwood-Smith@uwl.ac.uk
Address: University of West London, The Graduate School, Saint Mary's Road, Ealing, London, W5 5RF
Telephone: [REDACTED]



Chief Investigator: Professor Victoria Tischler
Email: Victoria.Tischler@uwl.ac.uk
Address: University of West London, The Graduate School, Saint Mary's Road, Ealing, London, W5 5RF
Telephone: 02082094208




Thank you for taking the time to read this information sheet.

4
Participant Information Sheet. Care Home Staff. STUDY 1. Version 2 [29.11.2018]

APPENDIX H CYCLE 1 and CYCLE 2 Consent form

Care home staff and creative practitioners

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University

CONSENT FORM

Study Title: Exploring the significance of clothing to people with dementia

We are asking if you would like to take part in a research project to explore the significance of clothing to people living with dementia. Before you agree to take part in the study we ask that you read the Participant Information Sheet Version 2 [29.11.2018].


Please mark each box below with your initials if you agree. If you have any queries regarding signing this Consent Form please contact Rebecka Fleetwood-Smith.

1. I confirm that I have read the information sheet version 2 [29.11.2018] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my care or legal rights being affected. ☐
3. I understand that audio data and notes will be collected during the study, and that these will be accessed by the research team only. ☐
4. I understand that my name and personal details will not be shared in the study, and all of my information will be stored securely. ☐
5. I understand that the results of this study will form part of a PhD thesis, and may be published in journals or presented at conferences and public engagement events. ☐
6. I agree to take part in the above study. ☐

1

Participant Consent Form. Care Home Staff. STUDY 1. Version 1 [01.05.2018]

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University


To be complete by participant
Name of Participant: _____


Participant Signature: _____ **Date:** _____

To be complete by researcher
Name of Person Receiving Consent: _____

Signature of Person Receiving Consent: _____ **Date:** _____

Research Team Contact Details

 PhD Student: Rebecka Fleetwood-Smith
Email: Rebecka.Fleetwood-Smith@uwl.ac.uk
Address: University of West London, The Graduate School, Saint Mary's Road, Ealing, London, W5 5RF
Telephone: [REDACTED]

 Chief Investigator: Professor Victoria Tischler
Email: Victoria.Tischler@uwl.ac.uk
Address: University of West London, Saint Mary's Road, London W5 5RF
Telephone: 02082094208

2

Participant Consent Form. Care Home Staff. STUDY 1. Version 1 [01.05.2018]

IRAS Project ID: 242104



Exploring the significance of clothing to people with dementia



Participant Information Sheet

Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018]

1

IRAS Project ID: 242104



I would like your assistance in learning about the significance of clothing to people with dementia.



I would like to work with you to explore the significance of clothing to you.

I would like to talk to you about your clothing and to learn about how your clothing makes you feel.

Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018] 3

IRAS Project ID: 242104



Hello, my name is Rebecka Fleetwood-Smith



I am a PhD student at the University of West London.

I am researching the significance of clothing to the lives of people with dementia.

Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018]

2

IRAS Project ID: 242104



I would like to visit you approximately 4-6 times over approximately 6 months.

During a visit I will ask if it is ok to spend some time with you. I may ask to sit with you and talk to you. I may also ask if you would like to discuss your clothing that day.

If you do not want to take part or want to stop taking part please tell me at any time.

Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018]

4

I would like to record our conversations and also take notes whilst spending time with you.



I won't share the audio recordings with anyone other than the research team.

I will stop audio recording and taking notes at any time if you would like to stop.

Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018] 5



If you want to stop or take a break

You can stop taking part at any point during the research. You can ask me to stop recording or you can stop talking whenever you want.

Taking part is voluntary.

Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018]

This is the research team. These are the only people who will be able to listen to the audio recordings or read the notes taken.



Rebecca Fleetwood-Smith

University of West London

Email: Rebecca.Fleetwood-Smith@uwl.ac.uk

Telephone: [REDACTED]



Professor Victoria Tischler

University of West London

Email: Victoria.Tischler@uwl.ac.uk

Telephone: 02082094208



Dr Deirdre Robson

University of West London

Email: Deirdre.Robson2@uwl.ac.uk

Telephone: 02082312667

Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018] 6

I would like to make sure that you are happy to take part in this research. I want to be sure that you understand what is involved.

You don't have to agree to talk to me.

You may want to talk to friends or relatives about the research to help you decide if you would like to take part.

Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018]

If you do decide to take part, I would like to record you telling me your decision to take part.

You can do this by signing a 'Consent Form'



Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018]

9

The audio recordings and notes will be stored securely.



Any written information will be stored in a locked filing cabinet at the University of West London.

All audio recordings will be stored on a password protected computer. As soon as they are put on the computer they will be deleted from the audio recorder.

No one other than the research team will be able to access them.

Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018]

11

You can change your mind...

You can decide not to talk to me, even after agreeing to take part.

You do not have to tell me why you do not want to take part.

Confidentiality

The audio recordings and notes will not have your name on.

I will not tell anyone your name or where you live.

Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018]

10

When we have finished the work

I would like to tell you about what we have found out.

I will either visit you or send you a leaflet in the post. You can decide which you would like me to do.

I will invite you to an event where I will talk about the work. It is up to you whether you would like to come or not.

Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018]

12

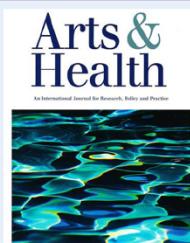
Telling other people about the work

I would like to tell people about what we have learned as part of the work.

This will include:

- Presenting at conferences, meetings or events.
- Writing articles for specialist journals.
- My PhD thesis.

I will not use your name or tell people where you live.



Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018] 13

Looking ahead

It is possible that during the research things might change for you. It may become harder for you to decide on your own whether you would like to continue to take part in the research.

It may be a good idea to name someone who can help you make a decision about taking part in the research or to make a decision on your behalf.
If this were the case, we would like to go through the information with them and ask them to sign on your behalf, if it is something they think you still want to be involved with.

Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018]14



My Contact Details

Rebecka Fleetwood-Smith

Telephone: [REDACTED]

Email: Rebecka.Fleetwood-Smith@uwl.ac.uk

Address: University of West London,
The Graduate School,
Saint Mary's Road
London,
W5 5RF

Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018]

15

Questions?

If you have any questions, or encounter a problem, please contact myself or Victoria Tischler.

If you wish to make a formal complaint about the work please contact:

Research and Enterprise Operations

Address: University of West London

St. Mary's Road, London, W5 5AF

Email: research@uwl.ac.uk

Telephone: 020 8231 2255

Thank you for taking the time to read this booklet.

Participant Information Person with dementia with capacity. STUDY 1. Version 2 [29.11.2018]

16

APPENDIX J

CYCLE 1 Consent form (People with dementia)

IRAS Project ID: 242104



Your agreement to take part in the research: "Exploring the significance of clothing to people with dementia"



This booklet contains my agreement(s) for taking part in the research: "Exploring the significance of clothing to people with dementia"

Consent Form. Person with dementia with capacity. STUDY 1. Version 1 [01.05.2018]

IRAS Project ID: 242104



I can confirm that I have had the chance to ask any questions that I have.

I confirm that I have been able to ask any questions that I have (write your initials in the box)

Consent Form. Person with dementia with capacity. STUDY 1. Version 1 [01.05.2018]

IRAS Project ID: 242104



Exploring the significance of clothing to people with dementia



Participant Information

I can confirm that I have had the chance to read and look at the Participant Information for this study. This Participant Information was Version 2 [29.11.2018]

I can confirm that I have read and discussed the Participant Information. (write your initials in the box)

Consent Form. Person with dementia with capacity. STUDY 1. Version 1 [01.05.2018]

IRAS Project ID: 242104



I understand that taking part in this research is voluntary and I can stop taking part at any time without giving a reason.

I confirm that I understand that I can stop taking part at any time without giving a reason (write your initials in the box)

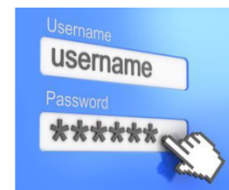
Consent Form. Person with dementia with capacity. STUDY 1. Version 1 [01.05.2018]



I agree to have my voice recorded when I take part in an interview and understand that notes may be taken as part of the research.

I confirm that I agree to the audio-recording and note taking (write your initials in the box)

Consent Form. Person with dementia with capacity. STUDY 1. Version 1 [01.05.2018]



I understand that the audio-recordings and notes made as part of the research will be stored securely at the University of West London. No one other than the research team will be able to access them.

I confirm that I agree that recordings and notes will be stored securely (write your initials in the box)

Consent Form. Person with dementia with capacity. STUDY 1. Version 1 [01.05.2018]



I agree to quotes being used, from things I tell you during the research, in specialist journals and in presentations. I understand that I cannot be identified and that my name will not be used.

I confirm that I agree for quotes to be used, and understand that my name will be changed (write your initials in the box)

Consent Form. Person with dementia with capacity. STUDY 1. Version 1 [01.05.2018]

I agree to take part in this research

This is my name:

Name:.....

Signature:.....

Date:.....

Consent Form. Person with dementia with capacity. STUDY 1. Version 1 [01.05.2018]

This is Rebecka
Fleetwood Smith's
signature - who
received this consent



Name:.....

Signed:.....

Date:.....

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University

[Insert Date]

Dear [Insert Name],

I am writing to you to tell you about a study titled: 'Exploring the significance of clothing to people living with dementia'. The purpose of this research is to work with people with dementia in order to understand the significance of clothing in their lives. The research is being conducted as part of my PhD studies at the University of West London. I am contacting you as you have been identified as a person who is able to act as a nominated consultee for [insert name of person with dementia].

You are being asked to act as a nominated consultee as you are unconnected with the research study and you know [insert name of person with dementia] in a professional capacity. As a nominated consultee we are asking if you can help [insert name of person with dementia] to make a decision about whether they would like to take part in the research study. Please take the time to read the information booklet included with this letter to learn more about the research study, and in order to decide whether you think that [insert name of person with dementia] would have wanted to consent to take part in the research when they had the capacity to make this informed decision.


If you are interested in [insert name of person with dementia] taking part in the research or would like to talk to me directly please contact me on [insert phone number] or via email: Rebecca.Fleetwood-Smith@uwol.ac.uk. Thank you for your time and consideration.

Yours sincerely,
Rebecca Fleetwood-Smith (PhD Student)
The Graduate School,
University of West London,
Saint Mary's Road,
Ealing,
London
W5 5RF

Cover Letter, Nominated Consultee, STUDY 1, Version 2 [30.11.2018]


1

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University

Nominated Consultee Information Sheet

Exploring the significance of clothing to people living with dementia



Introduction


[Insert name of person with dementia] is being invited to take part in a research project. We feel that they, may at times, be unable to decide for himself/herself whether to participate in this research. To help decide if s/he should join the study, we would like to ask your opinion as a consultee, as to whether or not they would want to be involved. We ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any decisions that they may have made in advance about participating in research. These should take precedence.

If you decide that they would have no objection to taking part, we will ask you to read and sign the nominated consultee declaration on the last page of this information leaflet. We will then give you a copy to keep. We will then contact [insert name of person with dementia] and explain the research to them. We will use the same information that we have given to you. We will keep you fully informed during the study so you can let us know if you have any concerns or think that they should be withdrawn.

If you are unsure about taking on the role of nominated consultee you may seek independent advice. We understand if you do not want to take on this responsibility.

Nominated Consultee Information Sheet and Declaration Form, STUDY 1, Version 2 [30.11.2018]

2

 UNIVERSITY OF WEST LONDON
The Career University

Invitation

We would like to invite [insert name of person with dementia] to take part in our research study. The research is being conducted by the University of West London. Before you decide whether you would like them to take part, Rebecka will explain the research to you using this sheet. If you have any questions please ask. This should take about ten minutes.

Why are we carrying out this research?


This research explores the significance of clothing to people with dementia, living in a care home. There is research to suggest that the design of the care setting can effect a persons' ability to live well; for example, decor, furniture, plates and cutlery can impact upon the ability to live well. Research from the social sciences has established the close link between clothing and the wearer. Clothing can affect mood and feelings, it can affect behaviour and it affects how others respond to the wearer. We want to explore the potential use of clothing in the care setting, and the significance of clothing to people living with dementia.

Why have they been invited to take part?

They have been invited to take part in this study as they are living in a care setting and are living with dementia.

Nominated Consultee Information Sheet and Declaration Form, STUDY 1, Version 2 [30.11.2018]

3

 UNIVERSITY OF WEST LONDON
The Career University

What will happen to them if they take part?

Rebecka would like to invite [insert name of person with dementia] to take part in a series of observations and interviews.

Over a period of approximately 6 months Rebecka will visit [insert name of person with dementia] at the care home. During her visit she may spend time observing and/or talking to them about their clothing. These visits will take place in public spaces of the care home. Rebecka may spend between 30 minutes – 2 hours with them during a visit.

They may be asked to take part in between 4-6 interviews that will last no longer 30 minutes. During the interviews Rebecka may ask to record their answers using an audio recording device, she may also take notes. She will ask for their agreement before carrying out any research.

Do they have to take part?

No. We are asking you whether you are happy for [insert name of person with dementia] to be approached to take part in this study.

You should only agree for them to be approached if you think that they would not have refused to take part. If you decide that they would have no objection to taking part we will ask you to read and sign the nominated consultee declaration on the last page of this information leaflet. If you decide that they would not wish to take part, it will not affect the standard of care that they receive in any way. You do not have to give a reason for not wanting them to take part.

Can they stop taking part?

Yes. They do not have to take part in this research. They can stop taking part at any time and they do not need to give a reason why. Please let us know if you have any concerns or you think that they should be withdrawn from the research. Withdrawal will not affect their care or legal rights.

If they stop taking part, no more data will be collected, and you may withdraw any data already collected if you wish, as long as you tell the research team before [redacted] at which time their anonymised data will have been analysed.

Nominated Consultee Information Sheet and Declaration Form, STUDY 1, Version 2 [30.11.2018]

4

Do participants get paid to take part?

No, participation is voluntary.

Are there any risks to taking part?

No, there are no foreseen risks in participating in the study. The main disadvantage is that they will give up their time to take part.

Are there any benefits to taking part?

Some participants may enjoy discussing the research topic. Similar research has reported the participants can find the process enjoyable.

Will their taking part be kept confidential?

Yes. Their identity and all the information about their participation will be kept confidential. We will change their name to a pseudonym in all documents. Audio-recordings will be deleted from the audio-recording device as soon as the audio data has been transferred on to the University of West London computer. Audio data and transcriptions will be stored on a secure computer at the University of West London and will be password protected, they will also be stored on a portable backup hard-drive which will be stored in a locked filing cabinet at the University of West London. Paper documents will be stored in a locked filing cabinet at the University of West London. The anonymised data and consent forms will be stored for 5 years, but items such as, contact details, will be deleted as soon as they are no longer needed. Pseudonyms will be used to label the data. The PhD student will be responsible for the personal data collected during this study.

Who is organising and funding this research?

This study is funded by a University of West London PhD Studentship (2017-2020) which is sponsored by the University of West London.

What will happen to the results of this study?

The results of this study will form a PhD thesis and may be published in journals or presented at conferences and public engagement events. Rebecka would like to share the findings with you and [insert name of person with dementia]. She will either visit you both at the care home or send you a leaflet in the post. You can decide which you would like her to do.

She will also invite both of you to an event where she will talk about the work. It is up to you both whether you would like to come or not.

Who has reviewed this study?

This study was reviewed and approved by the Research Ethics Committee NRES
Reference number: 18/LO/1707. This study has been reviewed and given favourable opinion by the University of West London's Ethics Committee on the 19th June 2018.

What if there is a problem?

Please contact Rebecka Fleetwood-Smith or Victoria Tischler who will do their best to help you. If you wish to complain formally, you can do this through by contacting the Research and Enterprise Operations at University of West London:

Research and Enterprise Operations,
University of West London,
St. Mary's Road,
London,
W5 5AF

Email: research@uwl.ac.uk

Telephone: 020 8231 2255.

What happens next?

If you decide that [insert name of person with dementia] would have no objection to taking part you will be asked to read and sign the nominated consultee declaration on the last page of this document. Rebecka will then provide them with an information Booklet and ask if they would like to take part in the study, they may choose not to take part.

Research Team Contact Details



PhD Student: Rebecka Fleetwood-Smith
Email: Rebecka.Fleetwood-Smith@uwl.ac.uk
Address: University of West London, The Graduate School, Saint Mary's Road, Ealing, London, W5 5RF
Telephone: [REDACTED]



Chief Investigator: Professor Victoria Tischler
Email: Victoria.Tischler@uwl.ac.uk
Address: University of West London, Saint Mary's Road, Ealing, London, W5 5RF
Telephone: 02082094208

Thank you for taking the time to read this information.

CONSULTEE DECLARATION FORM

Study Title: Exploring the significance of clothing to people living with dementia

	Please Initial
I can confirm that I have read and understood the consultee information sheet version 2 [30.11.2018] and I have had the opportunity to ask questions about the study and understand what is involved.	
In my opinion s/he would have no objection to taking part in the study.	
In my opinion they would be happy to take part in observations and interviews as part of the research.	
In my opinion s/he would have no objection to being audio-recorded as part of the study.	
I understand that I can request s/he is withdrawn from the research at any time, without giving any reason and without his/her care being affected.	
I understand that the data collected during the study will be looked at and analysed by the research team.	

To be completed by consultee

Name of Nominated Consultee:

Signature:

Date:

Relationship to Participant:

Participant's Name:

To be completed by researcher

Nominated Consultee Assent Received by:

Signature:

Date:

When completed: 1 (original) to be kept in care record, 1 for consultee; 1 for researcher site file.

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University

Participant Information Sheet

Exploring the significance of clothing to people living with dementia



Invitation


We would like to invite you to take part in our research study. The research is being conducted by the University of West London. Before you decide whether you would like to take part, Rebecca will explain the research to you using this sheet, this should take about ten minutes. If you have any questions, please ask.

Why are we carrying out this study?

This study explores the significance of clothing to people with dementia, living in a care home. There is research to suggest that the design of the care setting can affect a person's ability to live well, for example; decor, furniture, plates, and cutlery, can impact upon the ability to live well. Research from the social sciences has established the close link between clothing and the person wearing the clothing. Clothing can affect mood and feelings, it can affect behaviour and it can affect how others respond to the wearer. There is currently little research into the experience of clothing to people living with dementia. This research will contribute to this area and will explore ways in which to enhance the care of people living with dementia.

Participant Information Sheet. Creative Practitioner. STUDY 1. Version 2
[29.11.2018] 1

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University

Why have I been invited to take part?

You are a practicing artist or designer working with people living with dementia.

What will happen to me if I take part in the research?

You will be invited to take part in a meeting called a Focus Group. During the Focus Group you will be asked to discuss themes that have arisen during the first stage of the research. You will be asked to draw on your experience of working with people living with dementia and your own creative practice.

The Focus Group will last no longer than two hours, there will be up to 6 people taking part. The Focus Group will be audio-recorded to capture responses.

If you do not wish to take part in the Focus Group but are interested in contributing to the research, we can arrange a telephone interview, or for Rebecca to visit you for an interview.

Do I have to take part?

No, your participation is voluntary. It is entirely up to you to decide whether or not to take part. If you decide to take part you are free to stop taking part at any time, without giving a reason.

Can I stop taking part in the study?

Yes, you do not have to take part in this study. You can stop taking part at any time and you do not need to give a reason why.

If you stop taking part, you may withdraw any data already collected if you wish, if you tell the research team before [REDACTED] at which time your anonymised data will have been analysed.

Do I get paid for taking part?


No, your participation is voluntary. If you incur travel costs that you would not normally incur we will reimburse you.

Are there any risks to taking part?

No, there are no foreseen risks in participating in the study. The main disadvantage is that you will give up your time when taking part.

Participant Information Sheet. Creative Practitioner. STUDY 1. Version 2
[29.11.2018] 2

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University

Will my taking part in this study be kept confidential?

Yes, your identity and all of the information about your participation will be kept confidential. We will change your name in all future documents. Audio-recordings will be deleted from the audio-recording device as soon as the audio data has been transferred on to the University of West London computer. Audio data and transcriptions will be stored on a secure computer at the University of West London and will be password protected, they will also be stored on a portable backup hard-drive which will be stored in a locked filing cabinet at the University of West London. Paper documents will be stored in a locked filing cabinet at the University of West London. The anonymised data and consent forms will be stored for 5 years, but items such as your contact details will be deleted as soon as they are no longer needed. Pseudonyms will be used to label the data.

The PhD student will be responsible for the personal data collected during this study.

Who is organising and funding the research?

This study is funded by a University of West London PhD Studentship (2017-2020) which is sponsored by the University of West London.

What will happen to the results of this study?

The results of this study will form a PhD thesis and may be published in journals or presented at conferences and public engagement events, but there will be no way of knowing who has taken part.

When we have finished the work


I would like to tell you about what we have found out. I can email or post you a leaflet, you can let me know which you would like me to do. I will invite you to an event where I will talk about the work. It is up to you whether you would like to come or not.

Who has reviewed this study?

This study was reviewed and approved by the Research Ethics Committee NRES Reference number: 18/LO/1707. This study has been reviewed and given favourable opinion by the University of West London's Ethics Committee on the 19th June 2018.

Participant Information Sheet. Creative Practitioner. STUDY 1. Version 2
[29.11.2018] 3

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University

What if there is a problem?


Please contact Rebecca Fleetwood-Smith or Victoria Tischler who will do their best to help you. If you wish to complain formally, you can do this by contacting the Research and Enterprise Operations at University of West London:

Research and Enterprise Operations
University of West London
St. Mary's Road
London
W5 5AF
Email: research@uwl.ac.uk
Telephone: 020 8231 2255


What happens next?

If you agree to take part in the study, Rebecca will provide you with an Informed Consent Form that you will be asked to read through, date and sign.

Research Team Contact Details:



PhD Student: Rebecca Fleetwood-Smith
Email: Rebecca.Fleetwood-Smith@uwl.ac.uk
Address: University of West London, The Graduate School, Saint Mary's Road, Ealing, London, W5 5RF
Telephone: [REDACTED]



Chief Investigator: Professor Victoria Tischler
Email: Victoria.Tischler@uwl.ac.uk
Address: University of West London, Saint Mary's Road, Ealing, London, W5 5RF
Telephone: 02082094208

Thank you for taking the time to read about our study.

Participant Information Sheet. Creative Practitioner. STUDY 1. Version 2
[29.11.2018] 4

IRAS Project ID: 242104



Exploring the significance of clothing to people with dementia



Participant Information and Consent Booklet

Participant Information. Person with dementia without capacity. STUDY 1. Version 1 [01.05.2018]

1

IRAS Project ID: 242104



Hello, my name is Rebecca Fleetwood-Smith



I am a PhD student at the University of West London.

I am researching the significance of clothing to the lives of people with dementia.

Participant Information Person with dementia without capacity. STUDY 1. Version 1 [01.05.2018]

2

IRAS Project ID: 242104



What am I asking you?

I would like to spend time with you and talk to you about your clothing.



Participant Information Person with dementia without capacity. STUDY 1. Version 1 [01.05.2018]

3

IRAS Project ID: 242104



What will happen if I take part?

I would like spend time with you and carry out interviews with you to talk about your clothing.

I would like to visit you 4-6 times to talk to you.

If you do not want to take part, or want to stop taking part, you can at any time.

We will go at your pace, you can stop talking at any time.

Participant Information Person with dementia without capacity. STUDY 1. Version 1 [01.05.2018]

4

Audio-recording you

If it is ok with you, I would like to audio-record the interviews and take notes.



I will stop audio-recording at any time if you would like to stop.

I won't share the audio-recording with anyone other than the research team.

What happens after you have spoken to me?

I will look at what you have told me.

I will look at what other people have told me.

I will use what you have told me to help people understand your thoughts and feelings about your clothing.



What happens if I don't want to take part?

You can stop taking part at any time.

You can ask me to stop recording or you can stop talking whenever you want.

Taking part is voluntary.

This is the research team:

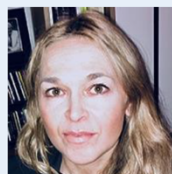


Rebecca Fleetwood-Smith

University of West London

Email: Rebecca.Fleetwood-Smith@uwl.ac.uk

Telephone: [REDACTED]

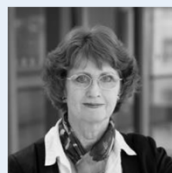


Professor Victoria Tischler

University of West London

Email: Victoria.Tischler@uwl.ac.uk

Telephone: 02082094208



Dr Deirdre Robson

University of West London

Email: Deirdre.Robson2@uwl.ac.uk

Telephone: 02082312667

Please tick in the box to answer either YES or No to the questions:

Are you happy for me to visit you and talk to you about your clothing?

YES	NO
<input type="checkbox"/>	<input type="checkbox"/>

Are you happy for me to audio-record our interviews and make notes?

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

Would you like to take part?

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

Name:.....

would like to take part in the research

Signed:.....

Date:.....

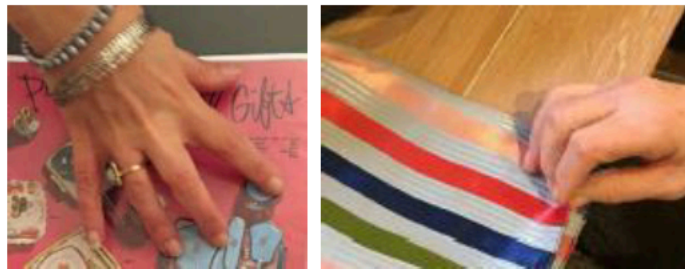
This accessible participant information booklet was used with people with dementia who were unable to give informed consent.

IRAS Project ID: 242104



Research Volunteers Needed

Exploring the significance of clothing to
people living with dementia



Do you work with people with dementia?

Are you interested in taking part in research?

We would like your assistance in learning about the significance of clothing to people living with dementia and would like to invite you to take part in an Object Handling Session. During the Session, you will be asked to look at and discuss different items of clothing and materials.

If you are interested in taking part in the research, or would like more information, please contact Rebecka Fleetwood-Smith:

Email: Rebecka.Fleetwood-Smith@uwl.ac.uk

Telephone: [REDACTED]

Recruitment Advert. Care Home Staff. STUDY 2. Version 1 [01.05.2018]

APPENDIX O CYCLE 3 Participant information sheet (People with dementia)

IRAS Project ID: 242104



Exploring the significance of clothing to people with dementia



Participant Information Sheet

Participant Information Person with dementia with capacity. STUDY 2. Version 2 [29.11.2018]

1

IRAS Project ID: 242104



I would like your assistance in learning about the significance of clothing to people living with dementia.



I would like to work with you to explore the significance of clothing to you.

I would like to talk to you about different items of clothing and textiles and discuss how you feel about them.

Participant Information Person with dementia with capacity. STUDY 2. Version 2 [29.11.2018]

3

IRAS Project ID: 242104



Hello, my name is Rebecka Fleetwood-Smith



I am a PhD student at the University of West London.

I am researching the significance of clothing to the lives of people with dementia.

Participant Information Person with dementia with capacity. STUDY 2. Version 2 [29.11.2018]

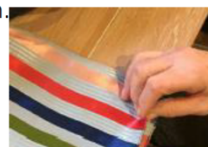
2

IRAS Project ID: 242104



I would like you to join 3 Object Handling Sessions. Each session will last for no more than 1 hour. Approximately 8 people will take part. Each session will take place in a room in the care home.

During the session myself and a volunteer will pass around different items of clothing and textiles and ask you to handle and discuss them.



If you do not want to take part, or want to stop taking part, you can at any time.

Participant Information Person with dementia with capacity. STUDY 2. Version 2 [29.11.2018]

4

I would like to video-record the Object Handling Sessions.

I will tell you when the video-recording will start.

I will tell you when the video recording is stopped.



I will stop video-recording at any time if you would like to stop.

I won't share the video-recording with anyone other than the research team.

This is the research team. These are the only people who will be able to watch the video-recordings.



Rebecka Fleetwood-Smith

University of West London

Email: Rebecka.Fleetwood-Smith@uwl.ac.uk

Telephone: [REDACTED]

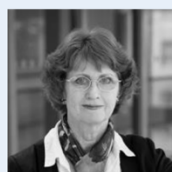


Professor Victoria Tischler

University of West London

Email: Victoria.Tischler@uwl.ac.uk

Telephone: 02082094208



Dr Deirdre Robson

University of West London

Email: Deirdre.Robson2@uwl.ac.uk

Telephone: 02082312667



If you want to stop or take a break

You can stop taking part at any point during the research. You can ask me to stop recording or you can stop talking whenever you want.

Taking part is voluntary.

I would like to make sure that you are happy to take part in this research. I want to be sure that you understand what is involved.

You don't have to agree to take part in the sessions.

You may want to talk to friends or relatives about the research to help you decide if you would like to take part.

If you do decide to take part, I would like to record you telling me your decision to take part.

You can do this by signing a 'Consent Form'



The video-recordings will be stored securely.



Any written information will be stored in a locked filing cabinet at the University of West London.

All video-recordings will be stored on a password protected computer.

No one other than the research team will be able to access them.

As soon as they are put on the computer they will be deleted from the video-recorder.

You can change your mind...

You can decide not to take part in the sessions, even after agreeing to take part.

You do not have to tell me why you do not want to take part.

Confidentiality

The video-recordings will not have your name on. I will not tell anyone your name or where you live.

Using images from the video-recordings...

When we have finished the work, we may ask to use images taken from the video-recordings to help explain the research.

If that is the case, I will visit you and show you the images and ask for your permission.

You can choose whether you are happy for us to use all, some, or none of the images.

The images will be edited to protect your identity.

When we have finished the work

I would like to tell you about what we have found out.

I will either visit you or send you a leaflet in the post. You can decide which you would like me to do.

I will invite you to an event where I will talk about the work. It is up to you whether you would like to come or not.

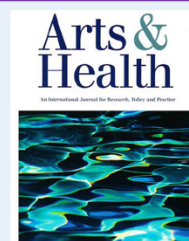
Telling other people about the work

I would like to tell people about what we have learned as part of the work.

This will include:

- Presenting the work at conferences, meetings or events.
- Writing articles for specialist journals.
- My PhD thesis.

I will not use your name or tell people where you live.



Looking ahead

It is possible that during the research things might change for you. It may become harder for you to decide on your own whether you would like to continue to take part in the research.

It may be a good idea to name someone who you would like to help you make a decision about taking part in the research, or to make a decision on your behalf.

If this were the case, we would like to go through the information with them and ask them to sign on your behalf, if it is something they think you still want to be involved with.



My Contact Details

Rebecka Fleetwood-Smith

Telephone: [REDACTED]

Email: Rebecka.Fleetwood-Smith@uwl.ac.uk

Address: University of West London,
The Graduate School,
Saint Mary's Road
London,
W5 5RF

Questions?

If you have any questions, or encounter a problem, please contact myself or Victoria Tischler.

If you wish to make a formal complaint about the work please contact:

Research and Enterprise Operations

Address: University of West London

St. Mary's Road, London, W5 5AF

Email: research@uwl.ac.uk

Telephone: 020 8231 2255

**Thank you for taking the time to read this
booklet.**

APPENDIX P

CYCLE 3 Consent form (People with dementia)

IRAS Project ID: 242104



Your agreement to take part in the research: "Exploring the significance of clothing to people living with dementia"



This booklet contains my agreement(s) for taking part in the research: "Exploring the significance of clothing to people living with dementia"

Consent Form. Person with dementia with capacity. STUDY 2. Version 1 [01.05.2018]

IRAS Project ID: 242104



I have had the chance to ask questions about the research.

I confirm that I have asked any questions that I have about the research (write your initials the box)

Consent Form. Person with dementia with capacity. STUDY 2. Version 1 [01.05.2018]

3

IRAS Project ID: 242104



Exploring the significance of clothing to people with dementia



Participant Information

I can confirm that I have had the chance to read and look at the Participant Information for this study. This Participant Information was Version X and dated

I can confirm that I have read and discussed the Participant Information. (write your initials the box)

IRAS Project ID: 242104



I understand that taking part in this research is voluntary and I can stop taking part at any time without giving a reason.

I confirm that I understand that I can stop taking part at any time without giving a reason (write your initials the box)

Consent Form. Person with dementia with capacity. STUDY 2. Version 1 [01.05.2018]

4



I agree to being video-recorded whilst I am taking part in the Object Handling Sessions.

I confirm that I agree to be video-recorded when I am taking part in the Object Handling Sessions
(write your initials the box)

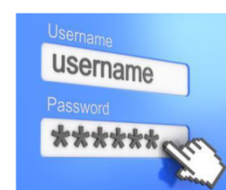
Consent Form. Person with dementia with capacity. STUDY 2. Version 1 [01.05.2018]5

If the research team want to use images from the video-recording to help explain the research, then they need to ask for my permission.

I agree to you contacting me again for this purpose.

I confirm that I agree to this
(write your initials the box)

Consent Form. Person with dementia with capacity. STUDY 2. Version 1 [01.05.2018]



I understand that the video-recordings will be stored securely at the University of West London. No one other than the research team will be able to access them.

I confirm that I agree that the video-recordings will be stored securely (write your initials in the box)

Consent Form. Person with dementia with capacity. STUDY 2. Version 1 [01.05.2018] 6



I agree to quotes being used, from things I tell you during the research, in specialist journals and in presentations. I understand that I cannot be identified and that my name will not be used.

I confirm that I agree for quotes to be used, and understand that my name will be changed (write your initials in the box)

Consent Form. Person with dementia with capacity. STUDY 2. Version 1 [01.05.2018] 8

I agree to take part in this research

This is my name and signature:

Name:.....

Signed:.....

Date:.....

This is Rebecka's
signature who
received this consent



Name:.....

Signed:.....

Date:.....

APPENDIX Q Consultee information and declaration form

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University

[Insert Date]

Dear [Insert Name],

I am writing to you to tell you about a study titled: 'Exploring the significance of clothing to people living with dementia'. The purpose of this research is to work with people with dementia in order to understand the significance of clothing in their lives. The research is being conducted as part of my PhD studies at the University of West London. I am contacting you as you have been identified as a person who is able to act as a nominated consultee for [Insert name of person with dementia].

You are being asked to act as a nominated consultee as you are unconnected with the research study and you know [Insert name of person with dementia] in a professional capacity. As a nominated consultee we are asking if you can help [Insert name of person with dementia] to make a decision about whether they would like to take part in the research study. Please take the time to read the information booklet included with this letter to learn more about the research study, and in order to decide whether you think that [Insert name of person with dementia] would have wanted to consent to take part in the research when they had the capacity to make this informed decision.

If you are interested in [Insert name of person with dementia] taking part in the research or would like to talk to me directly please contact me on [insert phone number] or via email: Rebecca.Fleetwood-Smith@uwl.ac.uk. Thank you for your time and consideration.


Yours sincerely,

Rebecca Fleetwood-Smith (PhD Student)
The Graduate School,
University of West London,
Saint Mary's Road,
Ealing,
London
W5 SRF

Cover Letter, Nominated Consultee, STUDY 2, Version 2 [30.11.2018]


1

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University

Consultee Information Sheet

Exploring the significance of clothing to people living with dementia



Introduction

[Insert name of person with dementia] is being invited to take part in a research project. We feel that they, may at times, be unable to decide for himself/herself whether to participate in this research. To help decide if s/he should join the study, we would like to ask your opinion as to whether or not they would want to be involved. We ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any decisions that they may have made in advance about participating in research. These should take precedence.


If you decide that they would have no objection to taking part, we will ask you to read and sign the nominated consultee declaration on the last page of this information leaflet. We will then give you a copy to keep. We will then contact [Insert name of person with dementia] and explain the research to them. We will use the same information that we have given to you. We will keep you fully informed during the study so that you can let us know if you have any concerns or think that they should be withdrawn.

If you are unsure about taking the role of nominated consultee you may seek independent advice. We will understand if you do not want to take on this responsibility.

Nominated Consultee Information Sheet and Declaration Form, STUDY 2, Version 2 [30.11.2018]

2

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University

Invitation

We would like to invite [Insert name of person with dementia] to take part in our research study. The research is being conducted by the University of West London. Before you decide whether you would like them to take part, Rebecca will explain the research to you using this sheet. If you have any questions please ask. This should take about ten minutes.

Why are we carrying out this research?

This research explores the significance of clothing to people with dementia, living in a care home. There is research to suggest that the design of the care setting can effect a persons' ability to live well; for example, decor, furniture, plates and cutlery can impact upon the ability to live well. Research from the social sciences has established the close link between clothing and the wearer. Clothing can affect mood and feelings, it can affect behaviour and it affects how others respond to the wearer. We want to explore the potential use of clothing in the care setting, and the significance of clothing to people living with dementia.


Why have they been invited to take part?

They have been invited to take part in this study as they are living in a care setting and are living with dementia.

Nominated Consultee Information Sheet and Declaration Form, STUDY 2, Version 2 [30.11.2018]

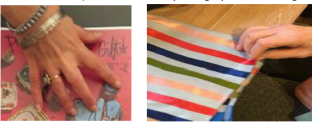
3

IRAS Project ID: 242104

 UNIVERSITY OF WEST LONDON
The Career University

What will happen to them if they take part?

Rebecca would like to invite [Insert name of person with dementia] to take part in up to 3 Object Handling Sessions. The sessions will involve handling and discussing items of; clothing, textile swatches, accessories and photographs of clothing.



The research team would like to video-record the sessions to help capture any discussions and responses that occur. Each session will last for approximately an hour and will take place in a private room in the care home (i.e. the activities room). Up to 8 people will take part in the session. Participants will include other care home residents, a staff caregiver and relative/friend's of participants with dementia. The session will be led by Rebecca and a volunteer.

Before taking part on the day, they will be asked if they wish to take part in the session. If they do not wish to take part that day, or they do not wish to take part at all in the research, they can let Rebecca know at any time and do not need to say why they do not wish to take part.

Do they have to take part?

No. We are asking you whether you are happy for [Insert name of person with dementia] to be approached to take part in this study. You should only agree if you think that they would not have refused to take part. If you decide that they would have no objection to taking part, we will ask you to read and sign the consultee declaration on the last page of this information leaflet.

If you agree for them to take part, but for any reason they do not wish to join the session when we approach them, we will not continue with the study.

Nominated Consultee Information Sheet and Declaration Form, STUDY 2, Version 2 [30.11.2018]

4

If you decide that they would not wish to take part, it will not affect the standard of care they receive in any way. You do not have to give a reason for not wanting them to take part.

Can they stop taking part in the research?

Yes. They do not have to take part in this research. They can stop taking part at any time and they do not need to give a reason why. Please let us know if you have any concerns or you think that they should be withdrawn from the research. Withdrawal will not affect their care or legal rights.

If they stop taking part, no more data will be collected, and you may withdraw any data already collected if you wish, as long as you tell the research team before [redacted] at which time their data will have been analysed.

Do participants get paid for taking part?

No, participation is voluntary.

Are there any risks to taking part?

No, there are no foreseen risks in participating in the study. The main disadvantage is that they will give up their time to take part.

Are there any benefits to taking part in this research?

Some participants may enjoy discussing the research topic. Similar research has reported the participants can find the process enjoyable.

Will their taking part in this study be kept confidential?

Yes. Their identity and all the information about their participation will be kept confidential. We will change their name in all future documents.

Video-recordings will be stored securely on a secure server and will be password protected, they will also be stored on a portable backup hard-drive which will be stored in a

locked filing cabinet at the University of West London. As soon as the video-recordings are on the computer and portable hard-drive, they will be deleted from the video-recorder.

Paper documents will be stored in a locked filing cabinet at the University of West London. All data will be destroyed after 5 years.

The video-recordings of the Object Handling Sessions will be kept confidential and will only be viewed by the research team for analysis. At the end of the research Rebecka may ask if she can use some still images from the video footage in the dissemination of the research. If this is the case Rebecka will provide you with a Nominated Consultee Image Reproduction Form. She will show you the images that she would like to use and ask you to give your permission to use the images. You do not need to give permission for Rebecka to use the images and this will not affect [Insert name of person with dementia's] participation in the research.

Who is organising and funding the research?

This study is funded by a University of West London PhD Studentship (2017-2020) which is sponsored by the University of West London.

What will happen to the results of this study?

The results of this study will form a PhD thesis and may be published in journals or presented at conferences and public engagement events.

Rebecka would like to share the findings with you and [Insert name of person with dementia] . She will either visit you both at the care home or send you a leaflet in the post. You can decide which you would like her to do. She will also invite both of you to an event where she will talk about the work. It is up to you both whether you would like to come or not. If you have given your permission using the Nominated Consultee Image Reproduction Form, their image(s) may be used in the dissemination of the research. You will have selected the image(s) used. The images will be edited by Rebecka to protect their identity. If you do not give your permission no images of [Insert name of person with dementia] will be used and there will be no way of knowing who has taken part.

Who has reviewed this study?

This study was reviewed and approved by the Research Ethics Committee NRES xxx, Reference number: xxxx. This study has been reviewed and given favourable opinion by the University of West London's Ethics Committee on June 19th 2018.

What if there is a problem?

Please contact Rebecka Fleetwood-Smith or Victoria Tischler who will do their best to help you. If you wish to complain formally, you can do this by contacting the Research and Enterprise Operations at University of West London:

Research and Enterprise Operations
University of West London
St.Mary's Road
London
W5 5AF

Email: research@uwl.ac.uk
Telephone: 020 8231 2255.

What happens next?

If you decide that [Insert name of person with dementia] would have no objection to taking part you will be asked to read and sign the nominate consultee declaration on the last page of this document.

Rebecka will then provide [Insert name of person with dementia] with an Information Booklet and ask if they would like to take part in the study, they may choose not to take part.

Can I take part in the study?

Yes. If you are interested in taking part in the Object Handling Sessions, please contact Rebecka, who can provide you with further details.

Research Team Contact Details



PhD Student: Rebecka Fleetwood-Smith

Email: Rebecka.Fleetwood-Smith@uwl.ac.uk
Address: University of West London, The Graduate School, Saint Mary's Road, Ealing, London, W5 5RF
Telephone: [redacted]



Chief Investigator: Professor Victoria Tischler

Email: Victoria.Tischler@uwl.ac.uk
Address: University of West London, Saint Mary's Road, Ealing, London, W5 5RF
Telephone: 02082094208

Thank you for taking the time to read this information.

CONSULTEE DECLARATION FORM

Study Title: Exploring the significance of clothing to people living with dementia

	Please Initial
I can confirm that I have read and understood the consultee information sheet <i>insert date (xxxx)</i> and I have had the opportunity to ask questions about the study and understand what is involved.	
In my opinion s/he would have no objection to taking part in the study.	
In my opinion they would be happy to take part in up to 3 Object Handling Sessions.	
In my opinion s/he would have no objection to being video-recorded as part of the study.	
I understand that I can request s/he is withdrawn from the research at any time, without giving any reason and without his/her care being affected.	
I understand that the data collected during the study will be looked at and analysed by the research team only.	
I agree for Rebecka to contact me, if the research team wish to use still images of <i>[insert name of person with dementia]</i> to help explain the research. I understand that they need my permission before any images can be used.	

To be completed by consultee

Name of Nominated Consultee:

Signature:

Date:

Relationship to Participant:

Participant's Name:

To be completed by researcher

Nominated Consultee Assent Received by:

Signature:

Date:

When completed: 1 (original) to be kept in care record, 1 for consultee; 1 for researcher site file.

APPENDIX R Abuse protocol

This Abuse protocol was extracted from the Research Protocol Version 2, 29.11.2018. IRAS Project ID: 242104.

Should a case(s) of physical, emotional, sexual, financial, discriminatory, institutional abuse or neglect be disclosed at any stage of the research:

1. RFS will directly acknowledge the disclosure and will give the participant the opportunity to talk about the disclosure should he/she wish to do so. However, RFS will not press for information nor ask the participant to describe the disclosure. It is paramount that the participant controls the information he/she wishes to share without prompting.
2. If RFS considers the participant to be in immediate danger, she will contact the Care Services Manager, [name omitted], at the care home immediately. If they are unavailable she will immediately contact the Head of Nursing at the care home.
3. If RFS considers the participant not to be in immediate danger, but still at risk, she will contact the Care Services Manager [name omitted].

Should a case(s) of physical, emotional, sexual, financial, discriminatory, institutional abuse or neglect be observed by RFS during observations or when reviewing the video-recordings:

1. RFS will contact the chief investigator immediately
2. RFS will document the incident including the date and time of the incident, as well as the type of abuse that has been observed
3. RFS will contact [name omitted] Care Services Manager at the care home, to report the incident.
4. RFS will preserve any evidence – i.e. will not destroy or disturb any articles that could be used as evidence

Actions:

- RFS will report the event to the Chief Investigator immediately to debrief.
- RFS will record the event/s via a fieldwork diary, complete with date, time and description of what took place.

APPENDIX S Distress protocol

This Distress protocol was extracted from the Research Protocol Version 2, 29.11.2018. IRAS Project ID: 242104.

The safety and well-being of those involved in the research are paramount. Patience and empathy of the researcher is required.

Any participant with dementia who does not have capacity and shows distress at any point during the research process will be withdrawn immediately from the study and will not be re-enrolled. Should any participant indicate they are experiencing high levels of stress or shows signs of distress (i.e. uncontrolled crying, shaking etc.) during the observations and interviews the following procedure will be taken:

1. The observation/interview will cease immediately, and the audio recording will be stopped.
2. RFS will ask the participant if they would like to share their feelings or whether they wanted to discuss anything that may have been concerning them. RFS will be sensitive to the fact the participant may need time alone and will therefore respond to the situation as appropriate
3. RFS will offer the participant a drink of water, if appropriate.
4. RFS will ask the participant whether they would like RFS to contact a person of their choice.
5. RFS will ask the participant how they are feeling. Dependent on the cause of the distress, RFS will explore the participants' support network and offer to supply contact details of relevant organisations, if necessary. If the participant wishes to continue the observation/interview, the interview will resume. If not, RFS will make sure that the participant is stable and ensure that it is appropriate to leave.

Should any participant indicate that they are experiencing high levels of stress or shows signs of distress (i.e. uncontrolled crying, shaking etc.) during the Object Handling Sessions the following steps will be taken:

1. RFS will immediately stop the video-recording of the session.

2. The Session will cease immediately, and the video-recording will be stopped.
3. RFS will ask the participant if they would like to share their feelings or whether they wanted to discuss anything that may have been concerning them. RFS will be sensitive to the fact the participant may need time alone and will therefore respond to the situation as appropriate
4. RFS will offer the participant a drink of water, if appropriate.
5. RFS will ask the participant whether they would like RFS to contact a person of their choice.
6. RFS will ask the participant how he / she is feeling. Dependent on the cause of the distress, RFS will ask the participant whether they would like RFS to contact a person of their choice.
7. If the participant is happy to resume being part of the Object Handling Session and being video-recorded during the session, RFS will continue the recording. If they are not happy to resume being recorded, RFS will ensure the participant is stable and will assist the participant in leaving the room and help them return to either their room, or their preferred space in the care home.

Actions:

Where a participant living with dementia remains distressed RFS will talk with [name omitted] (Care Services Manager) or if they are unavailable she will talk with the Head of Nursing at the care home.

- RFS will report the event to the Chief Investigator and Co-Investigator.
- RFS will record the event/s via a fieldwork diary, complete with date, time and description of the occurrence.
- RFS will routinely debrief with the supervisory team, this will be an important aspect of the research given the sensitive nature of working with people with dementia.

APPENDIX T Participant sample identification

This has been extracted from the Research Protocol Version 2, 29.11.2018. IRAS Project ID: 242104. The sample identification procedure will follow the same steps for each recruitment.

People living with dementia. The care services manager will be given the Study Protocol and will ask RFS any questions that they may have regarding participation in the study. RFS will be invited by the care services manager to attend a meeting at the study site at which she will discuss the research. During the meeting she will explain the inclusion and exclusion criteria and managers will be asked to use that information to identify potential participants. The research team will rely on the opinion of the care home managers regarding the dementia status of residents and will not view medical records. The care home managers will make a judgment based on their authority and personal knowledge of each resident. Following the managers meeting, managers will identify potential participants and will support RFS in inviting them to an initial contact meeting at which she will present the research to potential participants living with dementia. During the meeting RFS will present and discuss the research with participants. RFS will leave information packs for potential participants to read through. The packs contain a cover letter and a participant information sheet.

Care Home Staff. RFS will attend staff meetings in order to present the research and discuss staff member's possible participation. RFS will also provide a participant recruitment poster to be posted on staff notice boards at the study site, this will contain brief information about STUDY 1 and STUDY 2. RFS will leave information packs for potential participants to read through. The packs contain a cover letter and a participant information sheet.

Creative Practitioners. RFS will meet with creative practitioners at the care home in order to present the research and discuss their possible participation in the research. RFS will leave information packs for potential participants to read through. The packs contain a cover letter and a participant information sheet. RFS will also use her arts and health network to email a recruitment blurb, this will contain brief

information about the Focus Group. Potential participants will be invited to contact RFS should they be interested in taking part in the research.

Relative/friend of participant living with dementia. Personal Consultees will have been given the Consultee Information Sheet, containing RFS's contact details. The Consultee Information Sheet will detail that personal consultees can take part in the research (STUDY 2A and STUDY 2B) and can contact RFS if they are interested in participating. OR, the care home managers will assist in identifying potential relatives/friends of participants living with dementia who may be interested in taking part in the research. RFS will send an information pack that will include a cover letter and a participant information sheet.

I met with the participant and had a lengthy discussion with her about the research. She was very interested and asked lots of questions about taking part. I gave her the information to read through and said that she could talk through the sheet with friends or family if she wished to.

I re-visited her the following day and talked through the project with her. We began filling in the consent form, on nearing completion she told me that she did not want to sign the form and that she would need to talk to her solicitor. I explained the purpose of the signature, but she was clear and said that she did not want to sign the form until she had received advice. I asked if I could come back and talk to her after she had spoken to someone about participating - she said that would be fine.

I re-visited the participant the following week. We talked through the research again. I talked through the participant information sheet with her and we went through the consent form. She asked questions about how long the research would take and how many times she would have to take part – I explained the process to her, and she completed the consent form.

We re-visited consent at the start of each research encounter and prior to starting she confirmed that she was happy to take part. On a couple of occasions, she talked of us being in 'lessons' during these instances I reiterated the purpose of the research to ensure that she wanted to continue participating. We used the same room for each of the three research encounters and during each I placed the audio recording device on a small table next to her chair – this helped to support understanding.

Hi, I would like to talk to you about your clothing today. Before we start please can I have your permission to record this interview? The interview will be transcribed and any information which could identify you such as your name will be removed, the recording of the interview will then be erased. The questions I ask may seem to have an obvious answer, however, please answer them as fully as you can, there are no right or wrong answers. If it is okay with you, I will start by asking you some questions about yourself as it is useful to know about who you are, when we explore your answers - (to be gathered at first research encounter only).

Baseline demographic information:

- Gender
- Date of birth
- Ethnicity

Firstly, would you please be able to tell me about your clothing today?

- Please can you describe your clothing today?
- What does your clothing feel like?
- What do you think about your clothing?
- How do you feel about your clothing?
- What do you like most about your clothing today?
- What do you dislike most about your clothing today?
- Do you have any other thoughts about your clothing today?
- Are there any other things you would like to discuss about your clothing?

Thank you very much for your help with this research that is all I wanted to ask you about, are there any other things you would like to ask me or discuss?

APPENDIX W CYCLE 1 Prompts: Care home staff

Hi, I would like to talk to you about people living with dementia and their clothing, I would also like to ask you a little about your clothing. Before we start please can I have your permission to record this interview? The interview will be transcribed and any information which could identify you such as your name, or a resident's name, will be removed, the recording of the interview will then be erased. The questions I ask may seem to have an obvious answer, however, please answer them as fully as you can, there are no right or wrong answers. If it is okay with you, I will start by asking you some questions about yourself as it is useful to know about who you are, when we explore your answers - (to be gathered at first interview only).

Baseline demographic information:

- Gender
- Date of birth
- Ethnicity
- Brief description of job role

Firstly, I would like to talk to you about your clothing.

- Firstly, would you please be able to tell me about your clothing today?
- Can you describe the ... i.e. material, colour, pattern of your top/clothing/trousers/skirt etc?
- What do you like most about your clothing today?
- What do you dislike most about your clothing today?
- How do you feel in your clothing today?

Thank you, now, I would like to talk to you about residents' clothing.

- Would you please be able to tell me about your experience of clothing in the care home?
- What are your thoughts in regards to residents' and their clothing?
- Can you talk about residents' likes/dislikes with regards to their clothing?
- Could you please talk about any behaviours that you have noticed with regards to residents' and their clothing?

- Can you please describe any conversations or interactions that you have had with residents' about their clothing?
- Can you explain your thoughts on the clothing that residents' wear?
- Can you please talk about your thoughts generally on clothing in the care home?
- Are there any other things you would like to discuss?

Participant thanked and debriefed. Thank you very much for your help with this research that is all I wanted to ask you about, are there any other things you would like to ask me or discuss?

APPENDIX X CYCLE 2 Focus group discussion guide

This focus group guide was extracted from the Research Protocol Version 2, 29.11.2018. IRAS Project ID: 242104.

Facilitator's welcome, introduction and instructions to participants

Welcome and thank you for volunteering to take part in this focus group. I realize that you are very busy people and I really appreciate your time. This focus group discussion is designed to assess your thoughts and feelings surrounding the significance of clothing in the lives of people with dementia. We are particularly interested in the 'in the moment' and multisensory experiences of people living with dementia. During this focus group I will present a number of themes, that arose from a series of observations and interviews that took place in a care home. I will ask you questions about how you think these themes may be represented as an object, material or image. The focus group discussion will last no longer than an hour and a half. I would like to audio record this discussion so that I can remember what we talked.

Is it ok to tape our discussion? (If yes, turn on the audio recorder)

Anonymity and Confidentiality

Although this focus group is being audio recorded, I would like to assure you that the

discussion we have will be anonymised. The audio files will be kept on a University of West London computer and deleted from the audio-recording device. The audio recordings will be transcribed as quickly as possible, and the transcripts will remove any identifiable information. I and the other focus group members would appreciate it if you refrain from discussing any comments made outside of this focus group. If there are any topics that you do not want to contribute to, you do not have to do so.

- During this discussion it is important that only one person speaks at a time. There may be a temptation to jump in but please wait for other people to finish talking.
- There are no right or wrong answers and you do not have to agree with others
- Please try to contribute throughout the discussion. Your opinion counts.
- Does anyone have any questions?

Introduction

- Introductions – go around the circle and introduce themselves and say a little bit about their work / practice.
- Introductory question I am now going to read to you to you one of our findings from Study 1. The finding is also on the power-point.
- I would like to give you a couple of minutes to think about what you think and feel about the finding.
- We are now going to explore the theme and discuss ways in which it could be represented using objects, materials or images. There are no right or wrong answers.

Guiding questions

- What are your initial thoughts or feelings about the theme?
- How do you think this theme could be represented?
- Can you name a material, object or image that you can think of that may represent this theme?
- Why do think this object / material / object may be represent this theme?
- Could you please describe that further...
- Could you please explain your choice...
- Is there anything else that you can think that may be useful?

Conclusion

Thank you for participating. Your opinions are a valuable component of this research study. We hope that you have found this discussion interesting, and once again we remind you that everything discussed in this group should be kept within this group and not discussed outside of it. I would like to remind you that any comments featuring in the write up of this research will be kept anonymous, and I will send you a copy of a summary detailing what we have found at the end of the study so that you are kept up to date with the progression of the project. If you have any questions I will be staying until everyone has left, or if you want to contact me via telephone or email, I can give you my details so that you can do this. Once again thank you very much for your time.

APPENDIX Y Designing textiles for the 'playful' object handling session

I explored the use of different knit techniques and the use of various yarns and embellishment methods to create the samples for the session. I designed samples on the machine using quick sketches as references. The following images show experimentations with different yarn combinations and one of the samples 'in progress'.



APPENDIX ZCYCLE 3 Risk assessment - video recording



London School of Film, Media and Design, University of West London Risk Assessment Approved
Approved 04/10/2019 16:03 By: Timothy Bowerman

Author: Rebecca Fleetwood-Smith

London School of Film Media and Design - Risk Assessment for Studios and Equipment. This form needs to be completed thoroughly and completely.

1. Describe the Activity

Risk Assessment Title: Research activity for the study 'Exploring the significance of clothing to people with dementia'

Date: 21/10/2019

Supervisors Name: Professor Victoria Tishler

Description: This research activity (i.e. object handling sessions) forms the third phase of my PhD research. I will facilitate up to 6 object handling sessions in a care home, equating to 1 per week (over a 6 week period). The object handling sessions will explore verbal and nonverbal responses to different items of clothing and textiles. The sessions will be approximately 1 hour long and involve working with up to 8 people. The objects used in the sessions will consist of items such as, clothing, textiles and images. Filming the sessions will enable me to capture nonverbal interactions and enable continuous observation in order to analyse modalities e.g. verbal, visual, and touch.

Before taking part in the sessions participants will be given detailed information about the research, the object handling sessions and what taking part involves. If a participant wishes to take part they will be asked to complete an informed consent form. Where a participant is not able to give informed consent I will work with an identified person (personal or nominated consultee) and go through the consultee assent process. The consent and consultee assent forms will ask those taking part to agree to be filmed for the purposes of the research.

Footage of the sessions will not be used out of the research. Stills from the footage may be used, however these will be edited so that participants are not able to be identified. Participants will be asked to complete an image reproduction form if stills of the footage are to be used.

All aspects of this research, including the research methods and the use of film, have received ethical approval from the College of Nursing, Midwifery and Healthcare Ethics Committee (CREP 00465) and NHS Research Ethics Committee (18/LO/1707).

Note, I carried out the first phase of my research at the care home (i.e. the research site) and have volunteered at the research site so am familiar with staff and residents.

2. People at Risk

Primary Risk Assessment holder: Rebecca Fleetwood-Smith

Contact Information:

Name	Group	Role	Contact Number
Care home resident research participants	Public	Care home resident research participants	N/A
Care home staff research participants	Staff	Care home staff research participants	N/A

	however cables and wires will not be used.		of prevention should be carefully measured and limited. Risks reduction measures should be implemented within a defined period. Where the moderate risk is associated with extremely harmful consequences, further assessment may be necessary to establish more precisely the likelihood of harm as a basis for determining the need for improved control measures.	and tripod will be positioned in the corner of the room to ensure that care home staff and care home residents do not need to move around the camera when entering or walking around the room. I will ensure that care home staff and care home residents are away of the equipment and make sure that walkways are clear.	Imposes no additional cost burden. Monitoring is required to ensure that the controls are maintained
21/10/2019	Access & egress Obstructions to walkways, doors, exit routes	Public Staff Students	Potential Outcome: Minor Likelihood of Incident: Possible Moderate Risk Efforts should be made to reduce the risk, but the costs of prevention should be carefully measured and limited. Risks reduction measures should be implemented within a defined period. Where the moderate risk is associated with extremely harmful consequences, further assessment may be necessary to establish more precisely the likelihood of harm as a basis for determining the need for improved control measures.	Keep all equipment away from access routes. Make sure all care home staff, and care home residents are aware of exit points and not to block them. Allow for at least 1 metre width access routes past your working area.	Tolerable Risk No additional controls are required. Consideration may be given to a more cost-effective solution or improvement that imposes no additional cost burden. Monitoring is required to ensure that the controls are maintained
21/10/2019	Manual handling, awkward lifting, moving furniture and adapting the room for the research activity. Well-being of student		Potential Outcome: Minor Likelihood of Incident: Possible Moderate Risk Efforts should be made to reduce the risk, but the costs of prevention should be carefully measured and limited. Risks reduction measures should be	I will ensure that I will move all seating carefully and not lift items that are heavy. If items are heavy and require moving I will seek help from the appropriate member of staff at the care home (e.g. porter) who can support with moving furniture and tables.	Tolerable Risk No additional controls are required. Consideration may be given to a more cost-effective solution or improvement that imposes no additional cost burden. Monitoring is required to ensure that the controls are maintained

Page 3/9

			implemented within a defined period. Where the moderate risk is associated with extremely harmful consequences, further assessment may be necessary to establish more precisely the likelihood of harm as a basis for determining the need for improved control measures.		
21/10/2019	Participant distress – video-recording. Participants may become distressed by the video process.	Public Staff Students	Potential Outcome: Minor Likelihood of Incident: Possible Moderate Risk Efforts should be made to reduce the risk, but the costs of prevention should be carefully measured and limited. Risks reduction measures should be implemented within a defined period. Where the moderate risk is associated with extremely harmful consequences, further assessment may be necessary to establish more precisely the likelihood of harm as a basis for determining the need for improved control measures.	Because of the design of the activity the care home resident will always be with a staff caregiver and if possible their consultee/relative/friend during videotaping. Care home staff and consultees/relative/friends will be asked to monitor for any signs of distress in themselves and the person they are supporting, and to stop taking part in the Object Handling Session if this occurs. I will explain what the camera is recording and why. I will tell participants when recording commences and when it finishes. Should any participant indicate that they are experiencing high levels of stress or shows signs of distress (i.e. uncontrolled crying, shaking etc.) the following steps, outlined by the Distress Protocol, will be taken: 1. I will immediately stop the video-recording of the session. 2. The Session will cease immediately, and the video-recording will be stopped and ask participants to take a break, whilst I assist any distressed participants. 3. I will ask the participant if they would	Tolerable Risk No additional controls are required. Consideration may be given to a more cost-effective solution or improvement that imposes no additional cost burden. Monitoring is required to ensure that the controls are maintained

Page 4/9

				like to share their feelings or whether they want to discuss anything that may have been concerning them. I will be sensitive to the fact the participant may need time alone and will therefore respond to the situation as appropriate. 4. I will offer the participant a drink of water, if appropriate. 5. I will ask the participant how he / she is feeling. Dependent on the cause of the distress, I will ask the participant whether they would like her to contact a person of their choice. 6. If the participant is happy to resume being part of the Object Handling Session and being video-recorded during the session, I will continue the recording. If they are not happy to resume being recorded, I will ensure the participant is stable and will assist the participant in leaving the room and help them return to either their room, or their preferred space in the care home. 7. I will ask if the rest of the group, once taking a break, are happy to continue with the Object Handling Session, if so recording will commence. If not, the Session will end.	
21/10/2019	Invasion of privacy in the care home. Video-recording in the care home is an intrusion into the privacy of the care home situation and careful consideration of consent/assent will be required for this.	Public Staff Students	Potential Outcome: Minor Likelihood of Incident: Possible Moderate Risk Efforts should be made to reduce the risk, but the costs of prevention should be carefully measured and limited. Risks reduction measures should be implemented within a defined period. Where the moderate	Following discussion with the care home manager I will set up the video camera in an agreed private room (for example, activities room) in which the Object Handling Session will take place. Recordings will only take place at the start of the Object Handling Session and will be terminated at the end of the Session. Discussion will	Tolerable Risk No additional controls are required. Consideration may be given to a more cost-effective solution or improvement that imposes no additional cost burden. Monitoring is required to ensure that the controls are maintained

Page 5/9

			risk is associated with extremely harmful consequences, further assessment may be necessary to establish more precisely the likelihood of harm as a basis for determining the need for improved control measures.	also take place with the care home regarding practical issues such as, interruptions to ensure videotaping always has the consent/assent of all involved (e.g. signage may be used and stuck on the door to the room to ensure that it is clear videotaping is taking place). Participants will be informed prior to, during and at the end of video recording.	
21/10/2019	Ethical considerations - filming activities with care home residents and care home staff	Public Staff Students	Potential Outcome: Minor Likelihood of Incident: Possible Moderate Risk Efforts should be made to reduce the risk, but the costs of prevention should be carefully measured and limited. Risks reduction measures should be implemented within a defined period. Where the moderate risk is associated with extremely harmful consequences, further assessment may be necessary to establish more precisely the likelihood of harm as a basis for determining the need for improved control measures.	This research has received ethical approval from the College of Nursing, Midwifery and Healthcare (CREP 00465) and the NHS Research Ethics Committee (18/LO/1707). Consent from each participant, or where appropriate consultee assent, will be received before filming commences. Participants will only be filmed during the research activity (i.e. object handling session) as soon as the activity has finished filming will finish.	Tolerable Risk No additional controls are required. Consideration may be given to a more cost-effective solution or improvement that imposes no additional cost burden. Monitoring is required to ensure that the controls are maintained
21/10/2019	Research participant anonymity – video-recording.	Public Staff	Potential Outcome: Minor Likelihood of Incident: Unlikely Moderate Risk Efforts should be made to reduce the risk, but the costs of prevention should be carefully measured and limited. Risks reduction measures should be implemented within a defined period. Where the moderate risk is associated with	The video-recordings will be viewed by the research team for the purpose of data analysis. The recordings will be stored securely on a password protected portable hard drive that will be stored in a locked filing cabinet at the University of West London. The recordings will be deleted from the recorder as soon as the recordings have been transferred to the	Tolerable Risk No additional controls are required. Consideration may be given to a more cost-effective solution or improvement that imposes no additional cost burden. Monitoring is required to ensure that the controls are maintained

Page 6/9

			extremely harmful consequences, further assessment may be necessary to establish more precisely the likelihood of harm as a basis for determining the need for improved control measures.	computer and hard-drive.	
21/10/2019	Water & proximity of water (drinks) to equipment Well-being of all present	Public Staff Students	Potential Outcome: Minimal Likelihood of Incident: Possible Moderate Risk Efforts should be made to reduce the risk, but the costs of prevention should be carefully measured and limited. Risks reduction measures should be implemented within a defined period. Where the moderate risk is associated with extremely harmful consequences, further assessment may be necessary to establish more precisely the likelihood of harm as a basis for determining the need for improved control measures.	Drinks will not be placed near equipment. There will be a table away from the equipment where people can place their drinks.	Tolerable Risk No additional controls are required. Consideration may be given to a more cost-effective solution or improvement that imposes no additional cost burden. Monitoring is required to ensure that the controls are maintained
	Lighting equipment, stands, cables, power supplies Using, protection and placement of equipment	Public Staff Students	Potential Outcome: Minimal Likelihood of Incident: Possible Moderate Risk Efforts should be made to reduce the risk, but the costs of prevention should be carefully measured and limited. Risks reduction measures should be implemented within a defined period. Where the moderate risk is associated with extremely harmful consequences, further assessment may be necessary to establish more	Complete induction training with UWL technical staff on the correct use of equipment. Make sure all stands are weighted and placed in a secure location. Make sure there is adequate access passed the equipment. Make sure all leads and wires are taped or covered.	Tolerable Risk No additional controls are required. Consideration may be given to a more cost-effective solution or improvement that imposes no additional cost burden. Monitoring is required to ensure that the controls are maintained

			precisely the likelihood of harm as a basis for determining the need for improved control measures.		
	Fatigue Well-being of all present.	Public Staff Students	Potential Outcome: Minimal Likelihood of Incident: Possible Moderate Risk Efforts should be made to reduce the risk, but the costs of prevention should be carefully measured and limited. Risks reduction measures should be implemented within a defined period. Where the moderate risk is associated with extremely harmful consequences, further assessment may be necessary to establish more precisely the likelihood of harm as a basis for determining the need for improved control measures.	All research participants will take part in filming for a maximum of 1 hour (care home staff and care home residents) in order to avoid fatigue. Where someone taking part becomes tired and wants to stop taking part they will be supported to leave the session.	Tolerable Risk No additional controls are required. Consideration may be given to a more cost-effective solution or improvement that imposes no additional cost burden. Monitoring is required to ensure that the controls are maintained
21/10/2019	Fire prevention & fire evacuation procedures For all present, members of the public, etc.	Public Staff Students	Potential Outcome: Minimal Likelihood of Incident: Possible Moderate Risk Efforts should be made to reduce the risk, but the costs of prevention should be carefully measured and limited. Risks reduction measures should be implemented within a defined period. Where the moderate risk is associated with extremely harmful consequences, further assessment may be necessary to establish more precisely the likelihood of harm as a basis for determining the need for improved control measures.	I will be supported by a member of care home staff throughout the session who in the case of a fire will adhere to the care home's procedures. I will ensure no equipment is in the way of the doorway to ensure clear access in and out of the room.	Tolerable Risk No additional controls are required. Consideration may be given to a more cost-effective solution or improvement that imposes no additional cost burden. Monitoring is required to ensure that the controls are maintained

Reflexive notes 14: Preparing for video recording

Transporting the equipment from the university to the care home was difficult, although lightweight, the equipment was difficult to carry, and I realised that I would need to securely store the camcorder tripod at the study site. It would not have been possible to transport all of the equipment and materials needed on a weekly basis as I travelled using public transport. If I had not carried the trial session out, I would not have realised that this was quite so difficult to manage.

The trial session involved 'setting-up' the room in the care home in which the sessions were held i.e. rearranging furniture, positioning the camcorder and tripod and filming my own interactions with a series of objects, images, and materials. The trial session enabled me to examine; the optimum position for the camcorder/tripod and furniture in the space.

This session supported me in feeling confident in setting-up the space on the day. I had previously not worked with camcorders and so this could have been a very daunting prospect. I was very fortunate that staff were very supportive and understood that I needed to do this in preparation for the research. This I think was down to the relationships that I developed over the course of CYCLE 1.

DISSEMINATION ACTIVITIES

Publications

Fleetwood-Smith, R. (upcoming, commissioned). Clothing, textiles and little-c creativity. In P. Crawford & P. Kadetz (Eds.), *Palgrave Encyclopaedia of Health Humanities*.

Fleetwood-Smith, R., Tischler, V., & Robson, D. (in preparation). Reflecting upon the use of sensory, creative research methods when working with people with dementia. *Arts and Health*.

Fleetwood-Smith, R. (2020). Fashion and textiles. In P. Crawford (Ed.), *The Routledge Companion to the Health Humanities* (pp. 262-267). Routledge: London

Fleetwood-Smith, R., Tischler, V., & Robson, D. (2018). Clothing and Dementia. The embodied and sensory experience. In K. Christer, C. Craig, & D. Wolstenholme (Eds.), *Proceedings of the 5th International Conference on Design4Health* (pp.174-183). Sheffield: Lab4Living Sheffield Hallam University.

Fleetwood-Smith, R., Hefferon, K., & Mair, C. (2019). "It's like it's me": Exploring clothing attachment during wear. *International Journal of Fashion Studies*, 6(1), 41-62.

Conference Presentations

Fleetwood-Smith R., Tischler, V., & Robson, D. (2019). Exploring clothing and textiles in the lives of people with dementia. Poster presented at the British Society of Gerontology Annual Conference, 10th-12th July 2019, Liverpool, UK.

Fleetwood-Smith R., Tischler, V., & Robson, D. (2019). Exploring the use of sensory research methods with people with dementia. Poster presented at 'Creative methods in applied research', British Psychological Society Seminar Series, 8th July 2019, University of West England, UK.

Fleetwood-Smith R., Tischler, V., & Robson, D. (2019). Exploring the role of clothing and textiles to people with dementia. Poster presented at the Annual Alzheimer's Society Conference, 22nd May 2019, The Oval, London, UK.

Fleetwood-Smith R., Tischler, V., & Robson, D. (2018). Clothing and Dementia. The sensory experience. Presented at the Design4Health Conference, 4th-6th September 2018, Sheffield Hallam University, UK.

Fleetwood-Smith R., Tischler, V., & Robson, D. (2018). Clothing and Dementia. The embodied and sensory experience. Poster presented at the Early Career Researchers in Ageing Pre-Conference Event – The Annual Gerontology Conference, 4th July 2018, University of Manchester, UK.

Fleetwood-Smith R., Tischler, V., & Robson, D. (2018). Exploring the embodied and sensorial experience of clothing in the lives of people with dementia. Presented at the Empowered Bodies Postgraduate Conference, 26th June 2018, University of York, UK.

University Conference Presentations

Fleetwood-Smith R., Tischler, V., & Robson, D. (2020). "It's like each individuals' soul is on the table" Using thematic cards as tools for elicitation. Presented at the Annual Doctoral Conference, 17th June 2020, University of West London, UK. Awarded runner-up prize for best paper.

Fleetwood-Smith R., Tischler, V., & Robson, D. (2019). Exploring the role of clothing and textiles to people living with dementia. Poster presented at the Annual Doctoral Conference, 29th May 2019, University of West London, UK. Awarded prize for best poster.

Fleetwood-Smith R., Tischler, V., & Robson, D. (2018). Exploring the significance of clothing to people living with dementia. Presented at the Annual Doctoral Conference, 23rd May 2018, University of West London, UK. Awarded runner-up prize for best paper.

Public Engagement Events

The Imagination Café @ UWL, Dementia Action Week, 22nd May 2019, University of West London, London, UK

The Imagination Café, 23rd April 2018, Menier Gallery, London, UK

Stimulating all the senses: Art, food, music and dementia, 20th November 2017, Being Human Festival, University of West London, London UK

Further Dissemination Activities

I am working with the study site to create a booklet to share the project's findings.