Emotion-focused care for patients with dementia:

defining distress and responsive care from hospital staff

Stephanie Petty BSc ClinPsyD

Thesis submitted to the University of Nottingham
for the degree of Doctor of Philosophy

October 2019

With acknowledgement of supervisors Prof. A Griffiths; Prof. T Dening and Dr. D Coleston-Shields and supervision of the systematic literature review from Dr. K Harvey.

Abstract

Hospital care for patients with dementia needs to improve because of concern for patient wellbeing and hospital resources. When patients are distressed, care is particularly challenging. This thesis sets out definitions of emotional distress and emotion-focused care for hospital patients with dementia. Drawing directly upon the contributions of patients and ward staff, the thesis proposes solutions for improving care for patients in real-life hospital settings.

This thesis presents four studies.

Study 1 aimed to find out how emotional distress experienced by people with dementia has been described. The study is a mixed-method systematic literature review. Personal accounts of what emotional distress is and what causes it were sought and analysed using corpus-based and ethnographic methods. This provided a comprehensive and original description of emotional distress for people with dementia from the largest number of viewpoints to date. The findings established that complex and varied emotions are well described for people with dementia, which gives an alternative viewpoint to the care of people with dementia to the use of diagnostic labels to understand and respond to mood. Recommendations were made for this understanding to inform the design of holistic healthcare.

Study 2 is presented in two parts. The aims were to describe how the emotional distress of hospital patients with dementia is noticed, understood and responded to by hospital staff, in order to develop an understanding of emotion-focused care that could be achieved within routine hospital practice. Interviews were conducted with a full UK hospital ward team providing dementia care (n=47), using freelisting methodology, which gives quantitative and qualitative findings. The study produced a description of distress as it existed within hospital practice and produced a menu of ways that staff across the hospital could act to deliver emotion-focused care. The results showed that hospital staff had a shared understanding and shared approach to emotional distress that had not been described in literature before. Hospital staff emphasised existing resources, including existing personal and professional caregiving experiences of staff members; this is important because the findings could have immediate impact on current practice.

Study 3 aimed to explore the specific barriers and facilitators to hospital staff caring for the emotional wellbeing of patients with dementia, in order to make recommendations

for practice that were sensitive to hospital priorities and existing resources. Semi-structured interviews were conducted with hospital nursing staff (n=12) from a hospital site different from that in Study 2, which provided long-term care placements for patients with complex care needs. Thematic analysis was used to describe the conditions under which delivering emotion-focused care was more or less possible. Findings recommended gathering concise, personal patient information, sharing multidisciplinary and personal skills and investing in an ethos of being with the patient in their experience; changes that could be effectively implemented without incurring additional costs. Studies 2 and 3 suggested that under-recognised resources already exist within routine hospital care to improve the emotional wellbeing of patients with dementia.

Study 4 aimed to present the requests for care made personally by hospital patients with dementia when they are emotionally distressed, to give the perspective of patients with dementia that is mostly missing from care planning in hospitals. The study is an analysis of written advance care planning documents that were retrieved from real world hospital practice. Descriptive phenomenology was used to describe the essential components of the care requests. The results showed that requests were personalised and varied with the type and extent of distress felt, and could not be easily simplified into a description of care that would meet the needs of all patients; however, personalised care was requested succinctly by patients with dementia using advance care planning documents, suggesting their value in making this knowledge available within routine hospital practice.

The thesis contributes to practice by recommending solutions for improving the care of patients with dementia that suit real world hospital practice, as described by the key stakeholders of frontline hospital staff and patients with dementia personally. Collectively, the findings of this thesis showed that the emotions of people with dementia were individually variable, extreme and understandable, changing in meaningful ways as a reaction to circumstances. Knowing the patient, being with the patient and sharing existing expertise amongst peers were priorities for hospital staff; use of under-recognised resources within routine hospital care were described as achievable mechanisms for promoting emotion-focused care.

This thesis contributes to the research literature by presenting original, empirically supported perspectives that promote the emotional wellbeing of people with dementia.

Acknowledgements

This thesis would not have been possible without the honesty and commitment of healthcare professionals who took their time to share their practice. Firstly, I would like to thank all hospital staff for their continued contributions over the course of the thesis. Second, I would like to thank The Retreat York for their generous funding of the PhD studentship, which is in line with their commitment to provide innovative and compassionate patient care. I hope this body of work helps with that endeavour. The Retreat is an independent and charitable mental healthcare provider based in York, UK. I want to thank each of my research supervisors, Prof. Amanda Griffiths, Prof. Tom Dening and Dr. Dons Coleston-Shields; collectively they provided all of the essential conditions for me to thrive. Individually, they challenged me in important ways. Their wisdom, their kindness and their exacting standards will be the things that I will properly miss and the things that I will take with me beyond this PhD. Finally, I would like to thank my husband for being my other half and for always being there; he knows how important this has been to me and he made it equally important in our lives.

Table of contents

Abstract 1

Acknowledgements 3

Table of contents 4

List of tables 14

Chapter 2 Systematic literature review 14

Chapter 3 Freelisting interview study - Part 1 14

Chapter 4 Freelisting interview study - Part 2 14

Chapter 5 Semi-structured interview study 15

Chapter 6 Analysis of advance care planning documents 15

List of figures 16

Thesis structure 16

Chapter 2 Systematic literature review 16

Publications, conference proceedings and awards 17

Journal publications 17

Additional publications 17

Conference proceedings 18

Awards 19

Glossary 17

Preface 21

Thesis structure 22

Chapter 1. Introduction. 23

1.1 Chapter overview 23

1.2 Research aims of the thesis 24

1.3 Background to the research 25

1.3.1 Dementia 25

1.3.2 Defining emotion and emotional distress 26

1.3.3 Emotional distress and dementia 29

1.3.4 Hospital care and patients with dementia 30

1.3.5 The culture of hospitals 32

1.3.6 Emotional distress in hospital 33

1.3.7 Person-centred care 35

1.3.8 Emotion-focused care 37

1.4 Patient and Public Involvement 38

1.5 Philosophy of science 44

1.6 Chapter summary and introduction to studies 51

Chapter 2. Study 1. Systematic literature review of personal accounts of emotional distress: corpus-based analysis and meta-ethnography. 53

2.1 Chapter overview 53

2.2 Aim 54

2.3 Methods 55

2.3.1 Search method 55

2.3.2 Screening 56

2.3.3 Rationale for quality appraisal 62
2.3.4 Quality appraisal 63
2.3.5 Data extraction 67
2.3.6 Data synthesis 67
2.3.7 Corpus-based analysis 68
2.3.8 Meta-ethnography 72
2.4 Results 74
2.4.1 Overview of studies 74
2.4.2 Study quality 75
2.4.3 Descriptions of distress 76
2.4.4 Explanations for distress 81
2.5 Discussion 86
2.5.1 A brief consideration of language 86
2.5.2 Interpretation of findings 87
2.5.3 Updated search 89
2.5.4 Implications for practice 91
2.5.5 Implications for research 92
2.6 Critique 93
2.7 Impact statement 95
2.8 Chapter summary 96

Chapter 3. Study 2. Part 1. A freelisting interview study with ward staff. Meeting the emotional needs of hospital patients with dementia. 98

3.1 Chapter overview 98

3.2 Aims 99

3.3 Methods 100

3.3.1 Freelisting and cultural consensus analysis 100

3.3.2 Pilot 101

3.3.3 Participants 102

3.3.4 Ethical considerations 103

3.3.5 Data collection 104

3.3.6 Data analysis 105

3.4 Results 108

3.4.1 Participant characteristics 108

3.4.2 Responses to freelisting questions 110

3.5 Discussion 118

3.5.1 Interpretation of findings 118

3.5.2 Implications for practice 120

3.5.3 Implications for research 121

3.6 Critique 122

3.7 Impact statement 124

3.8 Chapter summary 127

Chapter 4. Study 2. Part 2. A freelisting interview study with ward staff. Personal and professional experience and the provision of person-centred care.....129

4.1 Chapter overview.....130

4.2 Aims.....130

4.3 Methods.....131

4.3.1 Participants.....131

4.3.2 Data collection.....131

4.3.3 Data analysis.....132

4.3.4 Cultural consensus analysis.....132

4.4 Results.....134

4.4.1 Participant overview.....134

4.4.2 Comparing approaches to dementia care: personal experiences of caregiving.....135

4.4.3 Comparing approaches to dementia care: professional experiences of caregiving.....142

4.5 Discussion.....147

4.5.1 Interpretation of findings.....147

4.5.2 Implications for practice.....149

4.5.3 Implications for research.....150

4.6 Critique.....151

4.7 Impact statement.....152

4.8 Chapter summary.....152

5. Chapter 5. Study 3. A semi-structured interview study with hospital staff. Facilitators and barriers to providing emotion-focused care for patients with dementia when in hospital. 154

5.1 Chapter overview 155

5.2 Aims 155

5.3 Methods 156

5.3.1 Participants 156

5.3.2 Data collection 156

5.3.3 Data analysis 157

5.3.4 Thematic analysis 159

5.3.5 Alternative analysis methods 160

5.3.6 Ethical considerations 161

5.4 Results 161

5.4.1 Participants 161

5.4.2 Facilitators of emotion-focused care 162

5.5 Discussion 170

5.5.1 Interpretation of findings 170

5.5.2 Implications for practice 174

5.6 Critique 175

5.7 Impact statement 177

5.8 Chapter summary 177

6. Chapter 6. Study 4. An analysis of advance care planning documents using descriptive phenomenology. Emotion-focused care requested by hospital patients with dementia.....179

6.1 Chapter overview.....180

6.1.1 Introduction to Advance Care Planning.....180

6.2 Aims.....183

6.3 Methods.....183

6.3.1 Setting and participants.....183

6.3.2 Advance Care Planning tools.....184

6.3.3 Data collection.....184

6.3.4 Ethical considerations.....185

6.3.5 Data analysis.....186

6.3.6 Descriptive phenomenology.....186

6.4 Results.....191

6.4.1 Overview of ACP documents.....191

6.4.2 Overview of care requests.....191

6.4.3 Summary statement of care requests.....193

6.5 Discussion.....193

6.5.1 Interpretation of findings.....193

6.5.2 Implications for practice.....194

6.5.3 Implications for research.....195

6.6 Critique.....196

6.7 Impact statement.....199

6.8 Chapter summary....199

Chapter 7. Conclusions....201

7.1 Overview....201

7.2 Executive summary of main findings....202

7.3 Research aims achieved....204

7.4 Impact....211

7.5 Critique and future improvements....217

7.5.1 Changing the hospital system....217

7.5.2 The views of people with dementia....220

7.5.3 Happiness....224

Chapter 8. Personal reflection....227

8.1 Overview....227

8.2 Reflexivity....228

8.3 Thanks....234

References....235

Appendices....258

Appendix 1. Involvement. Brief information sheet shared with patients and the public accessing services provided by the Alzheimer's Society York in the preliminary design of the thesis (April 2016)....258

Appendix 2. Involvement. Updated information sheet shared with patients and the public accessing services provided by the Alzheimer's Society York (June 2017).....260

Appendix 3. Systematic review: A display of the key concepts within each study to help determine the relationships between studies. 262

Appendix 4. Systematic review. The main features of all 121 included studies with their assigned quality ratings. 267

Appendix 5. Systematic review. Explanations for distress: full concept descriptions. 288

Appendix 6. Freelisting. Participant information sheet.....295

Appendix 7. Freelisting. Interview schedule 299

Appendix 8. Freelisting. A brief excerpt from the code book of all unique list items generated from the freelisting interviews.....301

Appendix 9. Freelisting. Scree curve plots showing the number of listed items with the highest salience for each of the four freelisting tasks.....302

Appendix 10. Freelisting. Summary of findings sheet 304

Appendix 11. Semi-structured interviews. Participant information sheet.....307

Appendix 12. Semi-structured interviews. Interview guide.....310

Appendix 13. Semi-structured interviews. Example interview transcript 312

Appendix 14. Semi-structured interviews. Example excerpts of three iterations of the coding scheme used for thematic analysis of interview data 316

Appendix 15. Semi-structured interviews. Consolidated Criteria for Reporting Qualitative Research (COREQ) 321

Appendix 16. Semi-structured interviews. Summary of findings sheet.....323

Appendix 17. Document analysis. Standards for Reporting Qualitative Research (SRQR). 326

List of tables

Chapter 2 Systematic literature review

Table 2-1. Search strategies used for all electronic databases……..57

Table 2-2. Assessment form: inclusion checklist for full text appraisal.……61

Table 2-3. Mixed studies quality appraisal checklist.……..65

Table 2-4. Excerpt from the extraction table used to collate descriptions or explanations of emotional distress from all studies……..68

Table 2-5. Keywords in the descriptions of distress corpus (1. self-reported and 2. other-reported distress descriptions) ranked in order of keyword strength.……..78

Table 2-6. Strong collocates of the keywords 'fear', 'loneliness' and 'distress' that have an MI score of >3. Grammatical collocates such as 'of', 'with' and 'the' were omitted……..79

Table 2-7. Concordance lines showing example descriptions of distress using the words 'fear', 'lonely/loneliness' and 'distress' in context……80

Table 2-8. Descriptions of six concepts: explanations for distress from 121 studies.……82

Table 2-9. Summary of all explanations for distress……..85

Chapter 3 Freelisting interview study - Part 1

Table 3-1. Participant demographics……..109

Table 3-2. Salience information for the top list items for interview question (1); How to notice emotional distress……111

Table 3-3. Salience information for the top list items for interview question (2); Causes of emotional distress……113

Table 3-4. Salience information for the top list items for interview question (3); Responses to emotional distress……..115

Table 3-5. Salience information for the top list items for interview question (4); Responses to emotional distress that seem to work……..117

Chapter 4 Freelisting interview study - Part 2

Tables 4-1a to 4-1d. Top six list items with the greatest difference in salience between hospital staff with and without personal experience of dementia caregiving for each of four interview questions

Table 4-1a. Interview question: how to notice emotional distress……..137

Table 4-1b. Interview question: causes of emotional distress……..138

Table 4-1c. Interview question: responses to emotional distress……139

Table 4-1d. Interview question: responses to emotional distress that seem to work… ……..…….140

Tables 4-2a to 4-2d. Top six list items with the greatest difference in salience between hospital staff with more years of professional experience and fewer years of working experience for each of four interview questions.

Table 4-2a. Interview question: how to notice emotional distress……..143

Table 4-2b. Interview question: causes of emotional distress……..144

Table 4-2c. Interview question: responses to emotional distress……145

Table 4-2d. Interview question: responses to emotional distress that seem to work……..

……..…146

Chapter 5 Semi-structured interview study

Table 5-1. Coding scheme for thematic analysis of interviews with hospital nurses and nursing assistants (n=12) showing facilitators of emotion-focused care for patients with dementia……..163

Table 5-2. Illustrative quotes of themes from interviews with hospital nurses and nursing assistants (n=12) describing facilitators of emotion-focused care for patients with dementia……..169

Table 5-3. Recommended staff actions to improve the delivery of emotion-focused care for patients with dementia; results from interviews with hospital nurses and nursing assistants……..172

Table 5-4. Summary of recommended practice to promote the emotional wellbeing of patients with dementia reported in previous research……..173

Chapter 6 Analysis of advance care planning documents

Table 6-1. Steps of the descriptive phenomenology analysis method……..188

Table 6-2. Examples of steps 1-3 of the descriptive phenomenology analysis method applied to advance care planning documents for patients with dementia: document excerpts with accompanying significant statements and assigned meanings……189

Table 6-3. Themes of care requested by hospital patients with dementia within advance care planning documents……..192

List of figures

Thesis structure

Figure 0-1. Thesis structure……..22

Chapter 2 Systematic literature review

Figure 2-1. Flowchart illustrating the inclusion and exclusion of literature……..62

Publications, conference proceedings and awards

Journal publications

Petty, S., Dening, T., Griffiths, A., & Coleston, D. (2016). Where is the happiness in dementia? International Psychogeriatrics. 28(10), 1752-1753. doi:10.1017/S1041610216000879

Petty, S., Dening, T., Coleston, D.M., & Griffiths, A. (2018a). Dementia: beyond disorders of mood. Aging & Mental Health, 23(5), 525-528. doi:10.1080/13607863.2018.1430742

Petty, S., Dening, T., Griffiths, A., & Coleston, D. M. (2018b). Meeting the emotional needs of hospital patients with dementia: a freelisting study with ward staff. The Gerontologist. doi: 10.1093/geront/gny151

Petty, S., Harvey, K., Griffiths, A., Coleston, D.M., & Dening, T. (2018c). Emotional distress with dementia: a systematic review using corpus-based analysis and meta-ethnography. International Journal of Geriatric Psychiatry, 33(5), 679-687. doi:10.1002/gps.4870

Petty, S., Dening, T., Griffiths, A., & Coleston, D. M. (2019). Importance of personal and professional experience for hospital staff in person-centred dementia care: a cross-sectional qualitative interview study using freelisting within a UK hospital ward. BMJ Open. doi.org/10.1136/bmjopen-2018-025655

Petty, S., Coleston, D. M., Dening, T., & Griffiths, A. (2020). Emotion-focused care requested by hospital patients with dementia via advance care planning. British Journal of Neuroscience Nursing, 16(1), 2-6.

Additional publications

Tom Dening and colleagues. 16th August 2018. A cup of tea. Dementia Day-to-Day blog post. https://idea.nottingham.ac.uk/blogs/posts/cup-tea

Petty, S. (under review). Nursing standard. Opinion. Insights into hospital ward life: a researcher's reflections.

Conference proceedings

Dening, T. Where is the happiness in dementia? INTERDEM Annual meeting at Alzheimer Europe, Copenhagen. 31st October 2016. Oral presentation.

Petty, S. Where is the emotion in dementia? Institute of Mental Health and The Retreat Research Conference, 12th December 2016. Oral presentation.

Petty, S., Harvey, K., Griffiths, A., Coleston, D. M., & Dening, T. Personal accounts of distress and dementia: a systematic review with corpus-based analysis and meta-ethnography. Alzheimer Europe, Berlin. 2-4 October 2017. Poster presentation.

Petty, S. Where is the emotion in dementia? An exploration of emotionally responsive care in hospitals. The Sue Watson Postgraduate Presentation Prize, School Of Medicine, University of Nottingham. 30th November 2017. Oral presentation.

Petty, S., Dening, T., Griffiths, A., & Coleston, D. M. Addressing the emotional needs of individuals with dementia when in hospital. Alzheimer Europe, Barcelona. 29-31 October 2018. Poster presentation.

Petty, S. (2018). Two minutes of impact: Emotional wellbeing in hospital. Medicine and Health Sciences Faculty Research Forum, University of Nottingham, 27th June 2018, Oral presentation.

Petty, S. (2018). Addressing the emotional needs of individuals with dementia when in hospital. Institute of Mental Health Annual Research Day, University of Nottingham, 22nd May 2018. Oral presentation.

Awards

The University of Nottingham Doctoral Programmes Committee and Division of Psychiatry and Applied Psychology each awarded grants for attendance at the 27th Alzheimer Europe Conference in Berlin, October 2017.

Glossary

ACP	Advance care planning
BPSD	Behavioural and psychological symptoms of dementia
BNC	British National Corpus
COREQ	Consolidated criteria for reporting qualitative research
DCM	Dementia care mapping
JCR	Journal citation reports
MeSH	Medical subject headings
MI	Mutual information scores used within corpus-based analysis methods
PPI	Patient and public involvement
PRS	Positive response schedule
SRQR	Standards for reporting qualitative research

Preface

Improved care for hospital patients with dementia is a priority from many different perspectives; more specifically, there is need for person-centred care and finding achievable ways to deliver this. In part, this is because of the high demand for hospital care and the associated costs; and in part because of the negative outcomes for patients with dementia when their care is poorly tailored. As one important component of person-centred care, healthcare professionals are asked to care for the emotional needs of patients with dementia, but there is insufficient direction from research or practice guidelines of how to do so. When emotionally distressed, patients can be more difficult to care for. Emotional distress has been understood mostly as a symptom of the diseases causing dementia, rather than an understandable, human reaction to circumstances, and the dominant approaches within healthcare have followed this understanding, for example, by the excessive use of pharmacological treatment. Personal perspectives of emotion-focused care are particularly lacking. No study has yet defined emotion or emotional distress for people with dementia, systematically explored the causes of emotional distress or sought the most appropriate responses from caregivers. These questions have not been asked directly for hospital settings, as one of the most challenging settings for care delivery. This is the important context for the four studies of this thesis.

Thesis structure

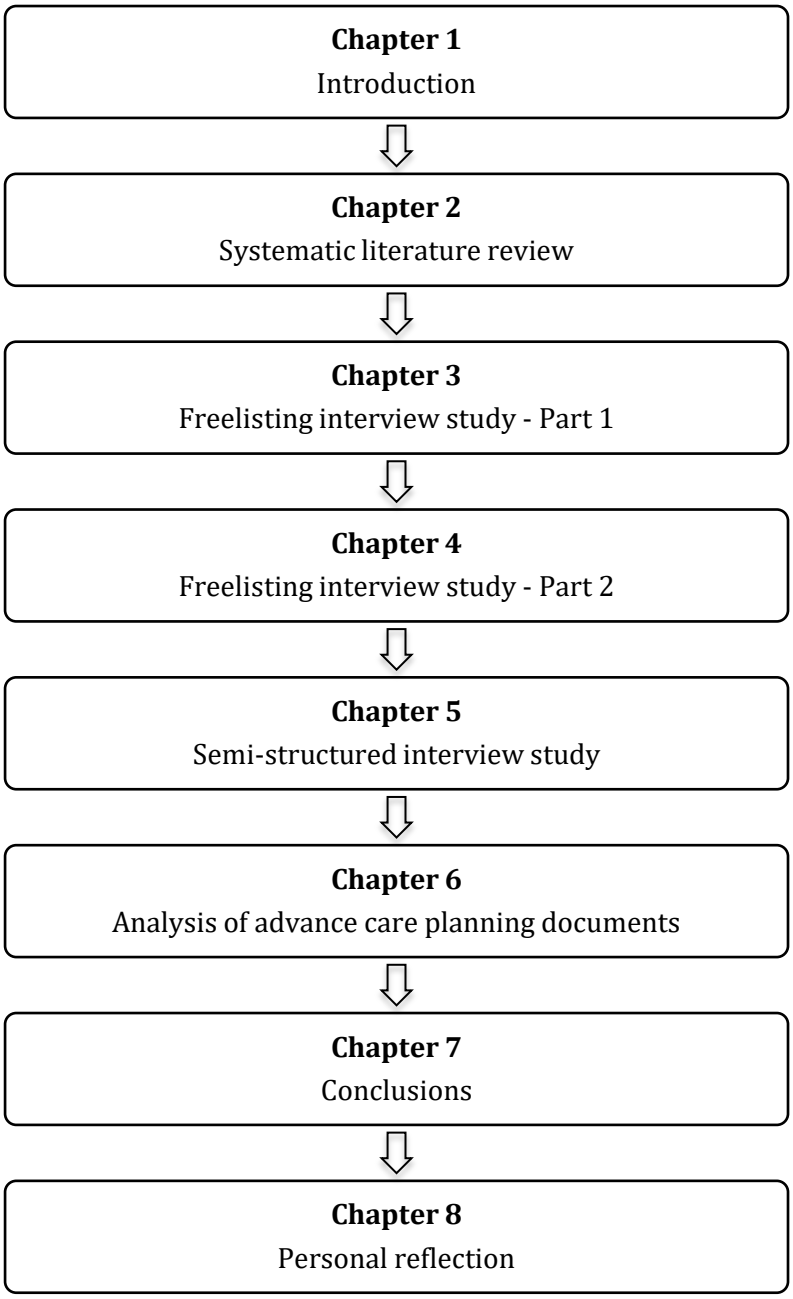
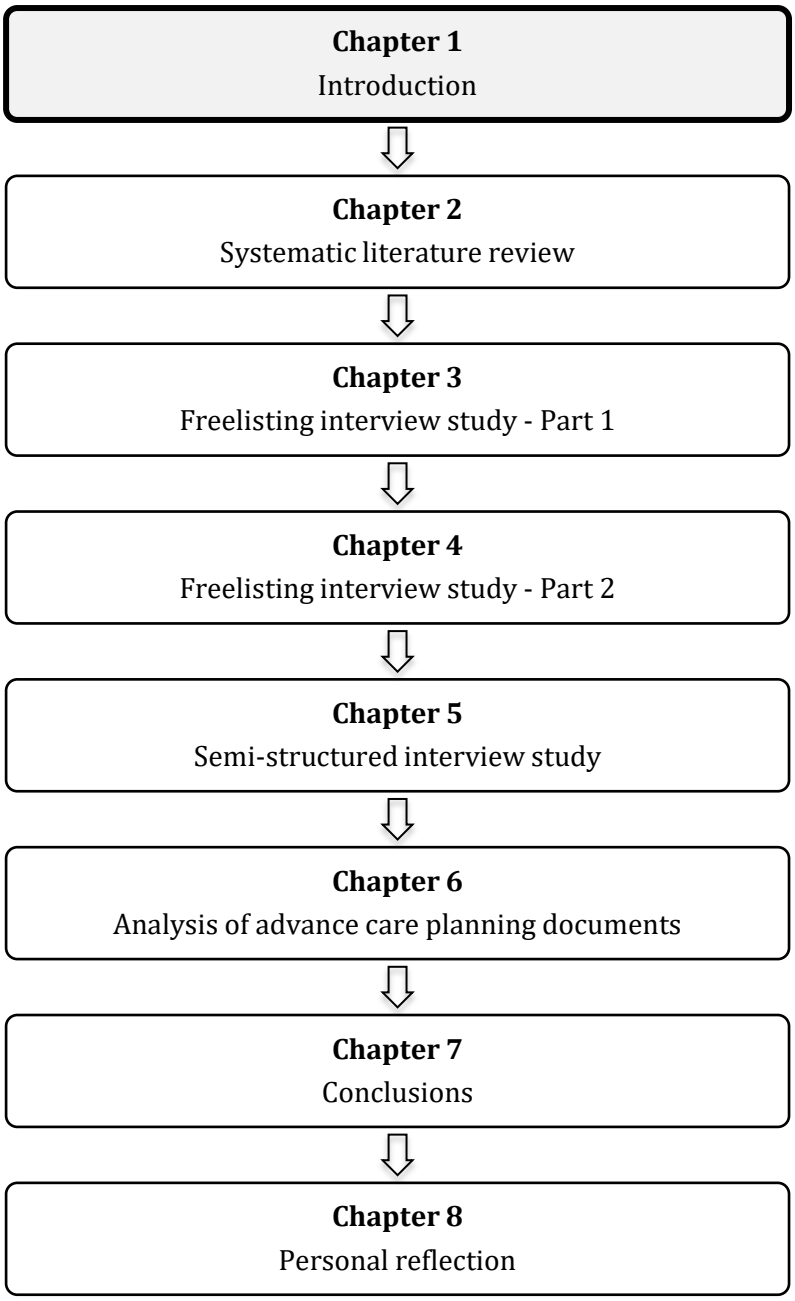


Figure 0-1. Thesis structure.

Chapter 1. Introduction.



1.1 Chapter overview

This chapter introduces the research area, firstly by stating the aims of the thesis and then by presenting the important research literature that preceded the four studies of the thesis. Dementia, emotion and the hospital context are each introduced, to give the

context for the subsequent research into the emotional distress of people with dementia and how hospital care can incorporate emotionally responsive care.

Within this introductory chapter, two subsections then introduce principles that underpin the research: patient and public involvement (PPI) and philosophical assumptions. The need for the research to influence the real world is discussed; PPI here means that a research priority was the involvement of people with dementia, and the involvement of hospital staff who are responsible for providing their care. Assumptions that underpin how 'emotional distress' can be understood, given its inconsistent meanings across research literature and clinical practice, are then discussed. This serves to explain the influences underlying the conduct of research throughout the thesis.

This chapter provides the rationale for selecting the different research methods of the thesis.

1.2 Research aims of the thesis

The body of work in this thesis aims to:

- make a useful contribution to day-to-day healthcare within contexts that pose high challenge for people with dementia and healthcare providers: the hospital setting; (Research aim 1)
- find helpful solutions for improving person-centred hospital care using existing knowledge and resources; (Research aim 2)
- reach a representative description of 'what emotional distress is', as experienced by people with dementia; (Research aim 3)
- present the personal requests for emotion-focused hospital care made by patients with dementia; (Research aim 4)

- reach a representative description of how the emotional distress of patients with dementia is understood by multidisciplinary hospital staff; (Research aim 5)
- reach a representative description of how the emotional distress of patients with dementia is responded to by multidisciplinary hospital staff; (Research aim 6)
- explore the barriers and facilitators to delivering person-centred and emotion-focused care in hospitals; (Research aim 7)
- contribute an argument to the research literature that the emotional needs of patients with dementia are important and an important component of person-centred care; (Research aim 8)
- use research methods that are interesting and that best answer the research questions of this thesis, underpinned by ethnography; (Research aim 9).

1.3 Background to the research

1.3.1 Dementia

Dementia is experienced by many people and its impact is considerable. 7.7 million people each year will receive a diagnosis of dementia; in total there are currently estimated to be 47.5 million people with dementia across the world, a number that is rapidly rising (World Health Organization, 2016). Dementia is a condition of progressive and irreversible deterioration in the nerve cells of the brain (Lezak, Howieson, Loring, & Fischer, 2004). These changes cause impairments in more than one area of functioning, often called global impairment, meaning there can be deterioration in a person's memory, attention, language, understanding of incoming visual information, and in other abilities. The causes of the many different diseases underlying dementia are not fully understood. Dementia has a personal and variable trajectory (van der Steen *et al.*,

2013). In an overview of the prevalence and description of dementia and its multiple impacts upon an individual, their social environment and society, the World Health Organization (World Health Organization, 2016) referred to dementia as 'overwhelming'.

The majority of people with a diagnosis of dementia have complex care needs (Royal College of Psychiatrists, 2005) and will express their needs in ways that have been labelled as behavioural and emotional symptoms of dementia, such as showing agitation or apathy (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012; van der Linde *et al.*, 2016). And yet, the personal experiences of people with dementia have been underrepresented in research and policy, meaning that the priorities of the care for patients with dementia have not been appropriate or individualised (Alzheimer's Society, 2014; Dewing & Dijk, 2016; Patterson *et al.*, 2011).

This thesis presents the perspective of people with dementia in an attempt to improve the relevance of the research. See Research aims 3, 4 and 9, in section 1.2.

1.3.2 Defining emotion and emotional distress

What is emotion?

For this thesis, 'emotion' is understood as a person's transient, internal and subjective experience that has some marker of intensity or urgency, with arousal in the body and accompanying thoughts (LeDoux, 1998; Martin & Carlson, 2019). Emotion tells us something about a person's wellbeing and signals a need for action. Lists of emotions most commonly feature anger, fear, happiness and sadness.

Other authors have commented that emotional experiences can be discussed in the research literature without a preceding definition; for example, research into 'loneliness' is extensive, but there is no consistent definition of loneliness, which is

suggested to be due to difficulty defining the subjective experience, or an assumption that we understand what it means to be lonely (Murphy, 2006). This observation was made regarding the experiences of older people receiving nursing home care. I extend this observation to the experience of emotion for people with dementia.

Within the past 25 years, the emotional experiences of people with dementia have started to be discussed by clinicians and researchers. Notable examples of psychological theories that have been applied to understand the commonplace experience of emotions for people with dementia include attachment theory to understand human relationships (Miesen, 1993) and psychoanalytic theory to understand changes to a person's sense of self with dementia (Davenhill, 2007; Evans, 2008; Malloy, 2009). However, this literature has not been routinely integrated into healthcare. In 1996, Magai, Cohen, Gomberg, Malatesta and Culver (1996) noted the lack of systematic research into the emotions of people with dementia, stated that the field of dementia research was 'ripe' for this research and spoke of a need to inform dementia care with the person's emotional needs (Magai *et al.*, 1996). Over 20 years later, the under-acknowledgement of the emotional experiences of people with dementia has continued. Indeed, there continues to be an 'overemphasis on physical care and a failure to see these patients as individuals with feelings, beliefs, and values' (Johansson & Grimby, 2013, p. 445).

What is emotional distress?

Here I have defined 'emotional distress' as an expression of negative emotion, with some marker of intensity or urgency (LeDoux, 1998; Martin & Carlson, 2019). This was to exclude emotional experiences that could be considered negative but not necessarily distressing, such as boredom or displeasure.

The use of a clear definition in this thesis was different from how 'distress' has been used to label a comprehensive and indiscriminate range of experiences for people with dementia to date.

In some research, 'distress' has not been defined (Morandi *et al.*, 2015). Alternatively, distress has been assumed to motivate a person's behaviour without further definition, such as when authors describe a 'distress reaction', or use 'distress' interchangeably with 'challenging behaviour' or 'unmet needs' (Elliot, Williams, & Meyer, 2014; Jones & Mitchell, 2015). Distress has been considered to be a direct symptom of dementia, in the same way that aggression or repetitive vocalisations have been understood to be symptoms of the disease (Elliot *et al.*, 2014; World Health Organization, 2016). Most frequently, distress has been used as an umbrella term, which can incorporate physical discomfort or pain (Crowther, Brennan, & Bennett, 2018; De Roo *et al.*, 2015; Elliot *et al.*, 2014; Fujii, Butler, Hirazakura, & Sasaki, 2014; Jones & Mitchell, 2015; Morandi *et al.*, 2015; National Institute for Health and Care Excellence, 2006, 2010; Regnard, Mathews, Gibson, & Clarke, 2003).

A clear but inclusive definition of emotional distress was employed in this thesis to capture diverse expressions of distress. It acknowledged existing definitions of emotional distress used across a wide range of health conditions (Pilkonis *et al.*, 2011; Regnard *et al.*, 2003; Wilson, Arnold, Schneider, Li, & Bennett, 2007).

This thesis builds upon the assumption that overlooking the emotional needs of people with dementia can have notable, negative implications for the healthcare that they receive (Bartlett, Windemuth-Wolfson, Oliver, & Dening, 2017); see Research aims 3-8, in section 1.2.

1.3.3 Emotional distress and dementia

As part of the early scoping of the research context for this thesis, I wrote an editorial to express concern that 'disorders' such as agitation, anxiety and depression defined by psychiatric diagnostic criteria, do not well serve individuals with dementia, despite being the most used and most influential ways of understanding emotion for people with dementia. I stated that when considering the clinical care of any person, clinicians should tread cautiously and not presume that the current, predominant descriptions of mood disorders are true. Understanding the emotional experience for the person with dementia could be considered an area of 'spurious certainty' (Petticrew & Roberts, 2006), whereby there has been an assumption that a more robust understanding exists than is actually the case. The most common approach to understanding emotion for people with dementia is with imprecise descriptions of behaviour (Forester & Vahia, 2019). This is unfortunate because it can overlook the richness and complexity of the internal world of people with dementia.

As with the under-acknowledgement of the prevalence of and importance of emotional distress for people with dementia, until this thesis, there had been no overview of the causes of emotional distress for people with dementia in the research literature. In turn, there had been few considered recommendations for supporting the emotional needs of people with dementia. Quality care for people with dementia is indicated by an approach that is personalised, and meets holistic needs (Department of Health, 2015; National Institute for Health and Care Excellence, 2006, 2010; Royal College of Psychiatrists, 2017). As one component of person-centred hospital care, healthcare professionals are required to understand and respond to the emotional distress of patients with dementia (Institute of Medicine, 2001).

This thesis sought to reach a representative description of 'what emotional distress is', as experienced by people with dementia. See Research aim 3, in section 1.2.

1.3.4 Hospital care and patients with dementia

Prevalence estimates suggest that patients with dementia can occupy over a third of hospital beds in the UK (Boaden, 2016). Patients with dementia are particularly vulnerable when admitted to hospital. There are overlapping realities of physical illness, confusion, a frightening physical environment, being in receipt of unsuitable treatment and a prolonged stay (Dewing & Dijk, 2016; Digby & Bloomer, 2014; Hermann, Muck, & Nehen, 2015; National Institute for Health and Care Excellence, 2018; Reilly & Houghton, 2019). These experiences of hospitals for patients with dementia have been recognised internationally.

The experience of hospital is markedly different and more detrimental for patients with dementia than for older adults without dementia. In an investigation of health outcomes for patients with dementia admitted for acute care in a London hospital, prevalent reasons for unplanned admissions were pneumonia and urinary tract infections (Sampson, Blanchard, Jones, Tookman, & King, 2009). These findings were also reported from a general hospital in Maryland, USA (Lyketsos, Sheppard, & Rabins, 2000). People with dementia admitted to hospital present with greater physical ill health than older adults without dementia and have significantly increased mortality (Sampson *et al.*, 2009); however, despite increased ill health, people with dementia have been shown to receive fewer medical interventions, such as end-of-life care (Boyd *et al.*, 2019; Sampson, Gould, Lee, & Blanchard, 2006). 'Reduced physiological and cognitive reserve' can increase the vulnerability of patients with dementia to adverse effects of medical interventions, such as over sedation, worsened cognitive impairment, over diagnosis and an accumulation of medication side effects George, Long, & Vincent, 2013, p. 357).

Patients rely upon multiple and changeable professional carers to maintain their wellbeing (Bradshaw, Goldberg, Schneider, & Harwood, 2013; Dewing & Dijk, 2016;

Harwood, 2012). The hospital system presumes that patients can express their needs and comply with treatment (Heath, Sturdy, & Wilcock, 2010), which is not necessarily true for patients with dementia. They rely upon hospital staff to maintain their wellbeing, and yet hospital staff infrequently understand their needs (Boaden, 2016; Dewing & Dijk, 2016; Samra *et al.*, 2015). Staff have reported insufficient training, knowledge and skills when caring for patients with dementia (Dewing & Dijk, 2016; Griffiths, Knight, Harwood, & Gladman, 2014).

The reduced ability of patients with dementia to communicate their needs and influence their care can interact with rapid movement through care services within a hospital setting and contribute to their needs going unmet (George *et al.*, 2013; Griffiths *et al.*, 2014). There are serious implications of poor treatment compliance and wastage of care efforts when the patient's needs are not known (Ocloo & Matthews, 2016).

The physical environment of hospitals for patients with dementia has been described by researchers, clinicians and government bodies as confusing and hostile, turbulent, impersonal, frightening, overwhelming, and with noise, busyness, clutter, crowding and layouts that contribute to an unsuitable environment (Boaden, 2016; Brooke & Semlyen, 2017; Cowdell, 2010; Goldberg, Whittamore, Pollock, Harwood, & Gladman, 2014; Heath *et al.*, 2010; Hermann *et al.*, 2015; Lyketsos *et al.*, 2000; Reilly & Houghton, 2019; Samra *et al.*, 2015). Digby and Bloomer (2014) interviewed patients with dementia in a hospital in Australia about their experience of the environmental design; patients reported feeling lost, having limited privacy and being affected by peers calling out. UK hospital staff have explained that aggressive behaviour of patients with dementia can be in response to the hospital environment specifically (Griffiths *et al.*, 2014).

An opinion article by a consultant geriatrician in the UK described the patient's experience of hospital as 'uncomprehending, threatened, scared in provocative, busy, crowded, noisy environments' (Harwood, 2012, p. 36) and said that patients who then

respond with aggression or withdrawal are often reprimanded or offered medication (Harwood, 2012).

Therefore, there are frequently negative outcomes for patients with dementia in hospital when their care is poorly tailored (Digby, Lee, & Williams, 2016; National Institute for Health and Care Excellence, 2018). This is the context within which the care provided for hospital patients with dementia is described as an international priority (World Health Organization, 2017).

The scale and the complexity of meeting the needs of patients with dementia (Boaden, 2016; National Institute for Health and Care Excellence, 2018) means that research is welcomed into how care can be improved in achievable ways. Research must address the hospital context specifically. Recommendations for doing things differently must also recognise current hospital priorities, which are to demonstrate quality medical care and manage risk, and be sensitive to resource constraints (Brooke & Ojo, 2017; Handley, Bunn, & Goodman, 2017).

These prior recommendations informed the aims of this thesis; see Research aims 1 and 2, in section 1.2.

1.3.5 The culture of hospitals

Ethnography is an attempt to provide a rich description of what it might be like to be somebody else, within their culture. In this thesis I consider what it might be like to be a patient with dementia in hospital.

Ethnography has established that hospitals retain their own social space (Finkler, Hunter, & Iedema, 2008; Foucault, 2003). The unique cultures of hospitals are in part influenced by the complexity of patient presentations, the workplace demands and the prioritised rituals around medical care. Because of their very purpose, hospitals

represent some degree of difference from the norm, or 'deviance', which is in some ways similar to prisons or asylums (Foucault, 2003; Street & Coleman, 2012). Finkler, Hunter and Iedema (Finkler *et al.*, 2008) stated that the public has a limited and unrealistic view of what it is like inside a hospital because of the confidential delivery of care and the ever progressive nature of medical practices.

The experience of entering hospital for any patient has been described as somewhat taking away that person's identity (Foster & Anderson, 1978). Timeliness, safety, or whether a patient's behaviour is considered to be 'good' or 'right' can determine the interactions between staff and patients (Fry, 2012; Street & Coleman, 2012). Therefore, the care of any patient needs to be understood in the context of the hospital culture they enter (Hessler *et al.*, 2017).

In a review of hospital care for patients with dementia, Dewing and Dijk (2016) criticised the over-emphasis on theoretical recommendations and asked what care is achievable specifically in this context. These are the reasons why the design of this thesis focuses on collecting data directly from routine practice in hospital settings, both NHS and private hospitals. See Research aim 9, in section 1.2.

1.3.6 Emotional distress in hospital

The hospital environment and hospital care, discussed in section 1.3.4, provide conditions to cause emotional distress for patients with dementia, whereby emotional distress is defined as an expression of negative emotion, with some marker of intensity or urgency.

In a preliminary search of the research literature, descriptive accounts of patients with dementia showing emotional distress in hospital were found (Boaden, 2016; Clissett, Porock, Harwood, & Gladman, 2013; Cowdell, 2010; Dewing & Dijk, 2016; Innes, Kelly,

Scerri, & Abela, 2016; Scerri, Innes, & Scerri, 2015). For example, Cowdell (2010) interviewed individuals with dementia in a hospital in the UK; some individuals reported horrible or terrible feelings and said that hospital staff did not care about their needs. Together, this literature suggests that emotional distress is experienced, but is infrequently understood or addressed. Therefore, few authors have explicitly recognised that hospital admission is both physically and emotionally demanding for patients with dementia (Clissett *et al.*, 2013; Dewing & Dijk, 2016; Scerri *et al.*, 2015).

Within the third national audit of dementia care in hospitals, The Royal College of Psychiatrists in the UK (Royal College of Psychiatrists, 2017) reported that times of emotional distress, the causes of distress and the possible responses of hospital staff to distress are not well documented. This same conclusion was highlighted in a proposed theory of effective dementia care for hospitals (Handley *et al.*, 2017). Hence, meeting the emotional needs of patients with dementia is supposedly not a routine aspect of hospital care. This is important because times of patient upset, including patients showing aggressive behaviour or anxiety, cause the greatest challenge to hospital staff (Boaden, 2016; Hessler *et al.*, 2017; National Institute for Health and Care Excellence, 2018; Sampson *et al.*, 2014).

The cost of emotional distress is an important consideration. Psychological distress can have detrimental effects across a wide range of health conditions (Barry *et al.*, 2019). The Royal College of Psychiatrists (Royal College of Psychiatrists, 2017) reported that overlooking times of emotional distress for patients with dementia specifically could have negative implications for the patient's prognosis, cause further challenge to hospital staff and increase the use of antipsychotic medication, resulting in increased healthcare costs. Other costs can be associated with reduced treatment compliance and low staff morale (Annear & Lucas, 2018; Cerejeira *et al.*, 2012; Kaminishi, Sutherland, Youngblood, Capistrano, & Tseng, 2019). The latest qualitative evidence synthesis, by

Reilly and Houghton (2019), showed that the hospital environment exacerbates behaviours of concern, suggesting an unhelpful relationship between hospital stay and patient wellbeing.

The available guidance from the UK's National Institute for Health and Care Excellence (National Institute for Health and Care Excellence, 2018) recommends that hospital staff understand and respond to emotional distress. Importantly though, the guidance does not yet detail how this can be achieved (National Institute for Health and Care Excellence, 2018; Scerri, Innes, & Scerri, 2017).

This thesis presents a description of how the emotional distress of patients with dementia can be understood and responded to by multidisciplinary hospital staff, with further exploration of the barriers and facilitators to delivering emotion-focused care in hospitals specifically. See Research aims 5-7, in section 1.2.

1.3.7 Person-centred care

Person-centred care is considered best practice for people with dementia. Person-centred care is defined as care that meets the holistic needs of the patient as a person, who shares the same value and humanness as any other person (Brooker & Surr, 2006; Kitwood, 1997).

As one component of person-centred hospital care, healthcare professionals are required to understand the emotional distress of patients with dementia and respond appropriately (Institute of Medicine, 2001; National Institute for Health and Care Excellence, 2018; Royal College of Psychiatrists, 2017).

Hospital care for patients with dementia has been criticised for being task-orientated and falling short of person-centred care (Brooke & Ojo, 2017; Digby *et al.*, 2016; Reilly & Houghton, 2019), and yet, a personal perspective can tailor care to address what

matters most for the patient and can therefore improve health outcomes, including physical and emotional wellbeing (Ocloo & Matthews, 2016; Worthington, Rooney, & Hannan, 2013). Personalised care planning is important because of the known inadequacies of care for patients with dementia, which include emotional neglect (World Health Organization, 2011).

In multiple hospital settings, basic physical needs have been shown to take priority over psychological needs (Goldberg *et al.*, 2014; Griffiths *et al.*, 2014). These experiences have been reported by patients with dementia, who have described their needs being surpassed by the 'patterns' of the ward (Cowdell, 2010). Relationships can lack warmth and fail to provide comfort, instead emphasising tasks and superficial rapport (Clissett *et al.*, 2013; Digby *et al.*, 2016; Goldberg *et al.*, 2014). Some authors have described interactions as uncaring (Borbasi, Jones, Lockwood, & Emden, 2006). Multidisciplinary hospital staff and family members in a UK hospital have described how recordable aspects of care determined the priorities of the unit, meaning that personalised care, such as offering a patient a cup of tea or seeking the views of family members, was not prioritised (Walker & Dewar, 2001). Close proximity to hospital staff has been shown to be more important to hospital patients than the physical environment (Brooke & Semlyen, 2017; Dewing & Dijk, 2016; Digby & Bloomer, 2014). Similarly, being treated as an individual and a person has been shown to be more important to hospital patients than the physical environment (Reilly & Houghton, 2019).

Research shows that in hospitals, the quality of dementia care delivered by healthcare staff is variable (Brooke & Ojo, 2017; Digby *et al.*, 2016; Goldberg *et al.*, 2014; Moyle, Borbasi, Wallis, Olorenshaw, & Gracia, 2010; Reilly & Houghton, 2019). Hospital staff have reported largely negative attitudes towards being able to deliver high quality care for patients with dementia (Boaden, 2016; Dewing & Dijk, 2016; Samra *et al.*, 2015).

Dementia care can be personalised in hospitals by having family members present (Reilly & Houghton, 2019; Scerri *et al.*, 2015; Worthington *et al.*, 2013) and the involvement of family is recognised as one of the most positive aspects of hospital care as described by multidisciplinary hospital staff and family members (Scerri *et al.*, 2015); however, this is limited by the physical and emotional demands on family members (Dewing & Dijk, 2016; Herron, Funk, & Spencer, 2019; Reilly & Houghton, 2019). Additionally, some hospital priorities of managing risk and delivering medical care fall within professional roles only (Brooke & Ojo, 2017). Therefore, while families can helpfully contribute to hospital care, multidisciplinary hospital staff are required to deliver person-centred care (National Institute for Health and Care Excellence, 2018).

Successful interventions to enhance person-centred care designed so far have been shown to be time- and resource-intensive and with variable outcomes (Surr, Smith, Crossland, & Robins, 2016).

An outstanding question remains as to how person-centred care, and emotion-focused care as an essential component of this, can be achieved consistently by hospital staff (Brooke & Ojo, 2017; Dewing & Dijk, 2016; Scerri *et al.*, 2017). This is why this thesis sought helpful solutions for improving care delivery, and specifically person-centred care delivery, within hospitals. See Research aims 1 and 2, in section 1.2.

1.3.8 Emotion-focused care

'Emotion-focused care' is a term introduced in this thesis. It is defined here as: care that is orientated towards the person's emotional wellbeing. Times of emotional distress provide opportunity to consider emotion-focused care, but I suggest that all interactions with a person with dementia can, to some degree, be emotion-focused. This includes promoting positive emotions as well as responding at times of emotional distress.

Emotion-focused care is an important component of integrated care, meaning that patients receive the care that they need (Boaden, 2016; Mental Health Foundation, 2013; National Institute for Health and Care Excellence, 2018) and physical and mental health needs are not treated in isolation (Royal College of Nursing, 2014).

It is not known how widely-recommended emotion-focused approaches (Brooker & Surr, 2006; Feil, 1993; Kitwood, 1997) translate into hospital care (Dewar & Nolan, 2013; Edvardsson, Sandman, & Rasmussen, 2011; Scerri *et al.*, 2015). The experience reported by those within hospital dementia care is that emotional distress is often missed, confused with physical illness, regarded as a symptom of disease or ignored (Crowther *et al.*, 2018; Dewing & Dijk, 2016).

In a review of all dementia care training interventions for hospital staff, Scerri *et al.* (2017) found an absence of emotion-orientated training and reported that the wellbeing and emotions of patients were not evaluated as an outcome in any study. Ideas of how appropriate emotion-focused care can be achieved in the hospital setting are only beginning to emerge (Clissett *et al.*, 2013; Edvardsson *et al.*, 2011; Handley *et al.*, 2017; Schneider, Scales, Bailey, & Lloyd, 2010). This thesis was designed to make contributions to the research literature on the subject of hospital staff noticing and responding appropriately to the emotional needs of patients with dementia. See Research aims 1-9, in section 1.2.

1.4 Patient and Public Involvement

Context for involvement

Involvement of patients and members of the public in the design and conduct of research, often called Patient and Public Involvement (PPI), is promoted for a number of different reasons. One reason is that for practice to be considered moral or ethical, it is said that those affected by research should be involved in setting the agenda (Bagley *et*

al., 2016). The important stance of PPI is that research is conducted 'with' stakeholders and not 'to', 'about' or 'for' them (INVOLVE, 2018). A second, linked assumption as to why PPI is important is that involvement leads to research outputs that are more relevant to day-to-day healthcare and will therefore have better translation into clinical practice (Crocker, Boylan, Bostock, & Locock, 2017; Domecq *et al.*, 2014). This is discussed further in the introductory chapter of this thesis in section 1.5 Philosophy of Science. Furthermore, research that is relevant to the different stakeholders should have higher face validity, meaning that the research has common sense appeal, making it more likely that individuals and organisations will participate (Evans *et al.*, 2014). The research findings should then relate more closely to the real world because of higher quality sampling and should deliver more impact.

Consistent with the research literature, the values guiding PPI in the Institute of Mental Health, University of Nottingham, include having humility to recognise that others contribute things that might have been missed, accountability to those who will benefit from the research, and equality.

For these reasons, PPI is increasingly required as part of research activity. International guidance has been written to improve the reporting of public involvement in research (Staniszewska *et al.*, 2017), which says, 'the PPI evidence base is like an ice-berg, only partly visible within the literature, with much information hidden, either not reported or poorly reported' (Staniszewska, Brett, Mockford, & Barber, 2011, p. 397). As an example of the increasing demand for PPI, The BMJ, a high impact, international, peer reviewed medical journal, requires a 'participant involvement' statement to be incorporated in the methods section of all submitted articles. The BMJ's guidance for authors actively encourages patient and public involvement in clinical research and co-production.

Informed by these assumptions and requirements, PPI was an integral part of the planning and conduct of this thesis.

Context for the involvement of people with dementia

Involving people with dementia in research has been said to be especially important because of documented experiences of them losing their voice and value (Lloyd, Gatherer, & Kalsy, 2006). Froggatt (1988) suggested that the experience of dementia remains largely unknown because of the very nature of the disease. And yet, an understanding of the personal experiences of dementia is what is needed to improve understanding (Weiner, Perry, & Magnusson, 1988). Swaffer (2014) wrote an editorial for the journal Dementia about the perpetuation of stigma around dementia and stated that research is predominantly about people with dementia, without reflecting their views. Swaffer stated that when the subjective experiences of dementia are not captured, the broad view of dementia is a misconception, which isolates people and perpetuates negative labelling.

However, the recruitment and involvement of people with dementia in research is recognised to be challenging, in part this is due to difficulties establishing capacity to consent (Garand, Lingler, Conner, & Dew, 2009; Swaffer, 2014); research tends to seek people with mild dementia who are able to give informed consent to participate (Pesonen, Remes, & Isola, 2011). People with dementia who do participate in research may also form a particularly homogenous group through choosing to take part (Garand *et al.*, 2009). This implies that researchers need to be more creative in their inclusion of people with dementia.

When directly asked about their priorities for research, people with dementia have said that effective care and implementing research findings about effective care into practice

are more important than research into prevention or diagnosis (Kelly *et al.*, 2015); more specifically, two of the top five research priorities stated were: effective non-pharmacological interventions for managing challenging behaviour, and, the best way to care for people with dementia in a hospital setting. This is the James Lind Alliance list of priorities (Cowan & Oliver, 2013).

Research priorities

This thesis builds upon previous involvement of people with dementia and is designed in line with their research priorities. The aim of both the systematic review (Chapter 2) and the analysis of advance care planning documents (Chapter 6) was to capture personal accounts from people with dementia, about their emotions and the care that could support their emotional wellbeing, hence non-pharmacological interventions. The systematic review sought personal accounts from people with dementia, therefore addressing the underrepresentation of individuals with dementia in the wider research culture. The document analysis collated collaborative care plans that are little used in healthcare and research. Both studies present the views of people with more advanced dementia, which are notably limited in the existing research literature (Jansson, Norberg, Sandman, Athlin, & Asplund, 1993; Kolanowski, Litaker, Catalano, Higgins, & Heineken, 2002; Lee, Algase, & McConnell, 2013; Magai *et al.*, 1996; Tappen & Williams, 1998).

The emphasis of the freelisting and semi-structured interview studies with hospital staff (Chapters 3-5) was upon achievable care that would translate into everyday practice. Staff were asked for solutions from their routine working and the methodologies were designed to be compatible with the hospital environment.

Involvement in design

Patients and the public were involved directly in the design of this research in the following ways.

As part of the preliminary design of the scope of the thesis, a brief overview of the proposed research questions was shared with the service manager for the Alzheimer's Society across Ripon, Harrogate, York and Selby. This resulted in an invitation to meet service users and share information about the proposed research (see Appendix 1). The information sheet was circulated by the service manager with a request for members to share their thoughts.

I then attended a 'Reading and Reminiscing' group facilitated by the Alzheimer's Society for people with dementia and their carers to introduce the research. Feedback given in person by the group members included one carer saying, 'In answer to Question 2 [Do health professionals understand and notice emotions in their interactions with individuals with dementia? For example, when in hospital?], no, not at all,' (Member of the public PPI.1). A second carer said, 'We didn't get any emotional support whatsoever, when he received his diagnosis, nothing at all. I don't think either of us understand it,' (Member of the public PPI.2). Furthermore, personal communication was received via email from one group member, stating, 'I have read your research overview and thought about it from a personal/family perspective and in relation to the people I work with affected by dementia. Causes of distress and reactions to distress seem to depend very much on the individual, their personality, home and family situation and relationships and lifestyle and routine. I could tell you what I observed to be causes of distress for my father at home and in healthcare settings and how he responded to the distress,' (Member of the public PPI.3). Informal comments shared in person were that the research questions were valuable and relevant and general support was given. Group

members also recommended reading of possible interest, including an anticipated publication by the Alzheimer's Society on hospital care.

Third, following completion of the systematic literature review (Chapter 2), an updated overview of the thesis was shared with the Alzheimer's Society in York (see Appendix 2). The overview included an invitation for members to share their thoughts.

Fourth, hospital staff were involved in the design of the freelisting study within a pilot, as discussed in Chapter 3. Comments included, 'Really good questions. No changes to make. These are the main things in dementia, I personally think so. The answers are easy to provide because they are bread and butter in our role,' (Member of hospital staff from the pilot discussed in Chapter 3, PPI.4), and 'I have no concerns with taking part. I can understand everything that will happen and why. It doesn't leave you with any questions,' (Member of hospital staff PPI.5). Following the pilot and in response to PPI, details of the method were refined, such as choosing to ask questions aloud, rather than collecting written lists.

In line with the recommendations of each journal, outputs from this thesis have included a patient involvement statement.

PPI in this thesis was thus achieved in various practical ways, which is as recommended (Domecq *et al.*, 2014). The benefits of involvement for the participant were anticipated to include making a contribution that was valued and that shaped research with real world impact. It was thought to be beneficial to the research outputs by steering the research questions towards those with relevance for people with dementia and healthcare professionals and steering methods that were sensible and feasible for routine hospital care. Patients and hospital staff were considered to be experts by experience.

Limitations of involvement are discussed in Chapter 7, section 7.5 Critique and future improvements.

1.5 Philosophy of science

In this section, assumptions that underpin the conduct of the research are introduced. Firstly, positivist, realist and constructivist approaches are considered. This is because emotional distress is without an explicit or consistent definition in both clinical practice and the research literature. This means that before asking research questions specifically about the application to a clinical setting, it is important to consider what assumptions are being made about what distress is. The chapter recognises the variety of standpoints from which this question could be approached. Then, evidence-based practice is discussed, alongside the philosophies of ethnography and phenomenology.

The research question

A positivist approach

A positivist approach assumes that 'distress' exists in an objective and static form, that can be defined and measured. From this stance, the systematic review presented in Chapter 2 partly offers a definition of distress. The use of corpus-based analysis gave quantitative values as to how prominent, hence how valid, different descriptions were within the full data set. The data set was an attempt at collecting all possible definitions. Errors in how accurately distress was defined were considered, for example, by using inter-rater reliability calculations and using real text quotations to exemplify conclusions drawn (Sandelowski & Barroso, 2006). If distress existed in an objective form for people with dementia, experienced in the same way for everybody, it could be said that the review attempted to reveal it. This might reflect an assumption frequently

held by research students that the aim of research is to reach impressive, novel findings that did not exist before (Chalmers *et al.*, 2014; Tanggaard & Wegener, 2016).

A realist approach

An alternative standpoint is a realist philosophy of science, where that question asked is not 'what is distress?', but 'how has distress been described in certain circumstances, and why?' As an example, in this thesis a question of interest would be, why might individuals themselves describe distress differently from observers? In the inclusion criteria for the systematic review (Chapter 2), a range of dementia diagnoses, dementia severities, living environments and countries were sampled. Self-report, other-report, observation and accumulated theoretical understanding were also included. However, in line with a realist approach, there could be more hypothesising as to why different descriptions of distress existed, or greater recognition that distress might hold different meanings for different people at different times. Individuals who wrote an article or book about their personal experience might have had reason to do so at that time, or the means to do so. It could have been further considered why individuals with dementia collectively described emotional distress as being mainly caused by feeling worthless, criticised and negatively labelled, whereas others reported the main cause of distress for them as being a change to their sense of self. In this respect, the systematic review was approached largely from a positivist perspective in the attempt to reach a consistent definition of distress. The loss of individual variability of experiences through the process of reaching research conclusions is discussed in the limitations section of Chapter 2, section 2.6.

A constructivist approach

A third viewpoint, looking at the research question through a constructivist lens, would posit that 'distress' does not exist in any set way. Rather, distress will have multiple and varying definitions or 'created realities' at any one time (Stringer, 1996, p. 41). As such, the unique contexts within which emotional distress exists would mean that any one account of distress would not generalise to other contexts (Appleton & King, 2002), hence reaching a simple summary of what distress is and what care responses would be appropriate would be immediately dated and limited in reach. Ultimately, distress would need to be defined by the person experiencing it (Regnard *et al.*, 2003) and any cause of distress would have meaning that is personal to them (Evans & Garner, 2004). It was therefore important to acknowledge that the findings of the systematic review (see Chapter 2) suggested that only frequent accounts of emotional distress were valid; this was discussed because different accounts of emotional distress to those summarised existed and could be considered to be equally true. If a constructivist approach was adopted, the study would conclude by saying that the definition of distress as written here would be likely to change and be redefined by different people, making it difficult to inform the design of patient care (Appleton & King, 2002). For this reason, the conclusions of the thesis are cautious as not to presume that any 'one size fits all' definition of distress or care response would be suitable.

In summary, the conclusions of the thesis emphasise the individual nature of distress and the need for a personally-tailored response from caregivers. This reflects the findings of all four studies. This is most aligned with a constructivist approach.

The link between research and practice

The value of research, or evidence, in clinical practice has been thoroughly discussed. The first tenet of this discussion is the assertion that it is important to generate helpful research questions initially, so that research comes from clinical practice. The second tenet of the discussion is how research evidence then returns to practice through having the findings recognised and incorporated into the real world. These two lines of reasoning are discussed in turn and applied to this thesis.

Research from practice

It has been well-stated that valuable research is firmly embedded within real world practice and that research and practice are reciprocal so that valuable questions and valuable outputs are shared (Green, Ottoson, Garcia, & Hiatt, 2009). This is the 'knowledge creation' aspect of the Knowledge to Action Framework (Graham *et al.*, 2006), which is one framework that attempts to guide researchers in their linking of research evidence and practice. Stokes (1997) described this as 'use-inspired' research.

Research that is designed in this way challenges the presumption that the best evidence for practice comes from tightly controlled evaluations of specific conditions (Green, 2001), such as targeting a simplified participant sample by employing extensive exclusion criteria. It is argued that the knowledge gained from such designs may not be inherently valuable, especially given how much research evidence is accumulating; it is important to be aware that not all research can be used in practice because there is an inevitable filtering and loss 'in the pipeline', whereby only some research will be reviewed, considered high quality, given favourable weighting and made available to a wide audience (Green *et al.*, 2009). 'This practice often makes such research of dubious relevance to many public health practitioners who would be expected to adopt and

implement the guidelines' (Green *et al.*, 2009, p. 156). This is especially true if researchers move away from local contexts. A blog by Greenhalgh (Greenhalgh, 2016) for the Centre for Evidence-Based Medicine, University of Oxford, discussed the 'mountains' of evidence that does not translate into clinical practice. Greenhalgh recognised that this is in part because of the complexity of humans, despite attempts to describe or map them, and because the person-to-person relationships that are fundamental to caregiving are not well accounted for in research.

'The experience of looking at a map, however detailed, is nothing like the experience of walking through a landscape. Similarly, the 'map' of medical science, however evidence-based, is nothing like the 'territory' of human suffering. The discourse of evidence-based clinical practice is focused on the 'map'' (Greenhalgh, 2016).

Following this reasoning, research that addresses hospital care for patients with dementia must ask questions about how things are in the real world hospital setting and ask how things can be improved in ways that will be achievable in the local setting, which is reliant on the people receiving or delivering the care. Needs-led research benefits from interactions between researchers, applied researchers and users of research, including clinicians (Bauer, Damschroder, Hagedorn, Smith, & Kilbourne, 2015; Chalmers *et al.*, 2014). For this thesis, this was addressed by seeking the personal perspectives of patients with dementia and full hospital ward staff teams, as well as collecting research data directly from hospital wards. Section 1.4 outlined PPI more fully. In these ways, stakeholders from real world clinical practice influenced the design of the research.

Ethnography and phenomenology

Two theoretical underpinnings were consistent in the data analysis methods chosen. These were ethnography and phenomenology. Both theories allowed the researcher to place people with a diagnosis of dementia and hospital staff working in dementia care at the focus of study. They differ in the following ways.

Ethnography emphasises the viewpoints of the people within a culture as being important when designing research questions (Schlechty & Noblit, 1982). The approach requires the assumption that individuals exist within cultures and are influenced by them. Ethnography is discussed throughout the thesis as underpinning the systematic literature review presented in Chapter 2 and the interview study with hospital staff presented in Chapter 5 (Noblit & Hare, 1988; Weller & Romney, 1988).

Phenomenology is described in the method section of the advanced care planning study presented in Chapter 6; here the research question concerned the personal experiences of distress of people with dementia and the accompanying requests for hospital care. Phenomenology is a well-used method in healthcare because of the importance of understanding a patient's individual experiences, as in person-centred care, and as compatible with the philosophy of caring professions (Beck, 1994; Edward & Welch, 2011).

Ethnography and phenomenology are compatible in that they both assume that the researcher needs to be close to the people closely involved in the phenomena of interest, and that people will construct their own reality; however, phenomenology places more emphasis on the experiences of each individual (Atkinson, Coffey, Delamont, Lofland, & Lofland, 2001; Polit & Beck, 2014).

Research for practice

The ‘Semmelweis barrier’ has been used to label the poor uptake of research evidence into clinical practice (Doherty, 2005). The term was borrowed from the observation of the slow implementation of hand washing into practice despite its clear, evidenced benefits, though this was an example where robust evidence existed for the proposed change to practice.

The study of ‘implementation science’ is extensive: it is referred to variably as the translation, transfer, diffusion, dissemination, brokering, utilisation, integration or implementation of knowledge into routine healthcare (Eccles & Mittman, 2006; Green *et al.*, 2009). In an earlier blogpost on the same topic of evidence-based medicine, Greenhalgh (2015) stated that the same rigour and assistance available to guide researchers through research design do not apply to translating findings into practice. There is a vast array of theoretical guidance of how to implement new knowledge into routine healthcare (Nilsen, 2015), but a criticism of these frameworks is that they are abstract and difficult to implement. The use of the Knowledge to Action Framework (Graham *et al.*, 2006), for example, has been variable, ‘with varying degrees of completeness and theory fidelity’ (Field, Booth, Ilott, & Gerrish, 2014, p. 177). Lost money, effort and patient benefit have all been discussed as considerable concerns when research findings do not translate into healthcare (Morris, Wooding, & Grant, 2011).

Morris *et al.* (2011) attempted to better understand the time delay between achieving research findings and translating these findings into practice; they reported, ‘There is a clear trend in the literature to seek a single answer to a single question’ (p. 518).

In this thesis, the impact of the research is discussed in the separate chapters for each study and summarised for the full thesis in section 7.4. Traditional attempts to improve impact were implemented (Grol & Grimshaw, 2003); for example, this included using a wide range of formats to disseminate findings, such as poster and oral conference

presentations, newsletters and a range of journal publications that targeted clinicians and policymakers.

1.6 Chapter summary and introduction to studies

Chapter summary

This chapter has introduced the research aims, background literature and key assumptions that underpin the four studies of this thesis. The chapter presented the arguments for the importance of understanding one aspect of person-centred care for hospital patients with dementia: emotion-focused care. In brief, the reasons included the need to underpin research and healthcare design with personal perspectives, international pressure to deliver person-centred care for patients with dementia, difficulties relating to hospital priorities and resources in particular, and the costs to patients and to healthcare providers when patients are not well understood and their care is not tailored to their needs. Therefore, the subsequent studies of this thesis set out to better understand the emotional wellbeing of patients with dementia and define ways in which hospital care staff can act to promote it.

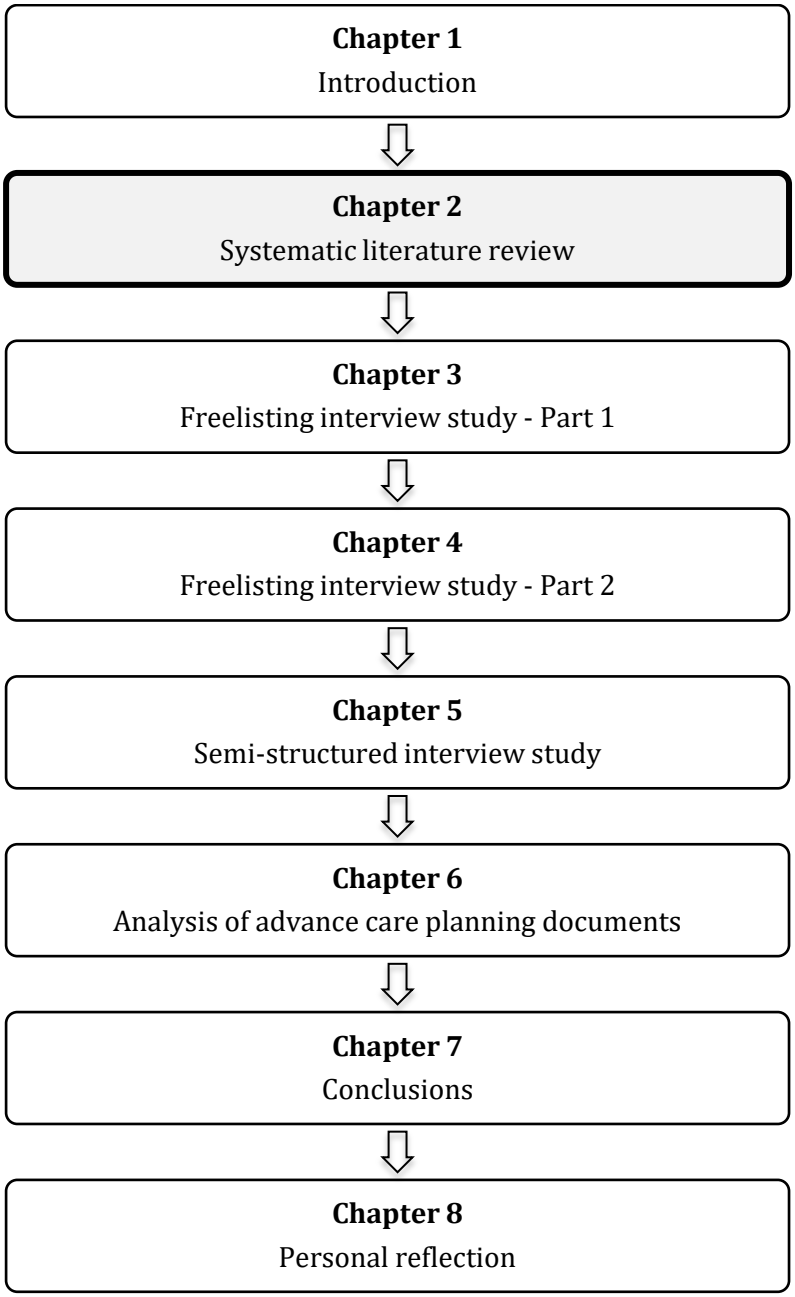
As defined in this introductory chapter, emotion is a person's transient, internal and subjective experience that has some marker of intensity or urgency, which tells us something about a person's wellbeing and signals a need for action. Emotional distress is an expression of negative emotion, with some marker of intensity or urgency.

Introduction to the studies of the thesis

This thesis attempts to seek the views of patients with dementia and hospital care staff to develop a multi-angle exploration of what emotion-focused care looks like and how it might be improved within hospital care. It does so in the following ways:

- Study 1: a systematic review presents all available descriptions of emotional distress and explanations for emotional distress experienced by individuals with dementia. See Chapter 2.
- Study 2: exploratory qualitative interviews using ethnographic freelisting provide a concise description of achievable emotion-focused care for patients with dementia from a full, multidisciplinary hospital ward staff team (see Chapter 3); and
- variations in approaches to dementia care between staff subgroups are detailed. See Chapter 4.
- Study 3: semi-structured interviews explore the facilitators and barriers to hospital staff being able to care for the emotional wellbeing of patients with dementia. See Chapter 5.
- Study 4: an analysis of written advance care planning documents completed by patients with dementia gives a concise description of personal care requests by hospital patients with dementia when emotionally distressed. See Chapter 6.

Chapter 2. Study 1. Systematic literature review of personal accounts of emotional distress: corpus-based analysis and meta-ethnography.



2.1 Chapter overview

This chapter presents a systematic search and review of literature on the descriptions of emotional distress experienced by people with dementia. The previous chapter gave the

rationale for this review, by describing how dementia is otherwise understood in research literature and in healthcare, with an underrepresentation of the personal experiences of people with dementia. The review provides evidence from the largest number of viewpoints to date of what emotional distress is, as well as the causes of emotional distress for people with dementia. This follows research aims 3, 4 and 9 of the thesis (see section 1.2). Defining the concept of emotional distress from the personal perspective of people with dementia was considered to be the essential beginning of the thesis.

The review is mixed-methods and employs corpus-based and meta-ethnographic methods to analyse the retrieved descriptions of distress and explanations for distress (see the methods section, 2.3). The methodological quality of the literature is reviewed to inform the conclusions and to give comment on the particular strengths and omissions in the research literature in this area.

Three journal publications from the work presented in this chapter were achieved, and these were: a review article, an editorial and a letter. These challenged the leading ways of understanding the emotional wellbeing of people with dementia in the research literature by stating that emotions are personal, meaningful and widely variable, and that happiness is mostly missing from the lexicon. The work of this chapter featured in four conference proceedings, in the UK and Germany.

2.2 Aim

To locate and summarise all available written descriptions of emotional distress and explanations for emotional distress experienced by people with dementia, articulated personally and by others.

2.3 Methods

2.3.1 Search method

A systematic, mixed studies review was conducted. Literature was included whereby primary subjects were: human, diagnosed with dementia of any severity or diagnostic type and were of any age; any study design could be used, published in the English language, with no date restriction prior to 31 January 2016; literature provided an original description or explanation of the emotional distress of people with dementia from any viewpoint.

In addition to available self-reported accounts of distress, information from family, friends, professional caregivers and researchers was included, hence original descriptions or explanations were not limited to primary data; novel descriptions or explanations of emotional distress by authors were included, such as accumulated understanding from clinical experience or original theory development.

Seven stages for completing the review (Petticrew & Roberts, 2006) were as follows: 1. the research question was defined; 2. advance criteria were agreed for the inclusion of relevant literature; 3. a search strategy was developed, which informed a systematic search of all available literature; 4. retrieved literature was screened for inclusion; 5. the included literature was appraised for quality; 6. data were extracted from the included literature; 7. descriptions and explanations within the included literature were analysed.

Twelve electronic databases were searched for conventional academic and commercial publications and grey literature (see Table 2-1). The reference lists of retrieved articles were then hand-searched. Search terms were derived from the two essential elements of the research question and included: 1) 'dementia' or 'Alzheimer's' and 2) synonyms of emotion, informed by Medical Subject Headings (MeSH), subject headings or thesaurus terms for each database and keywords, using truncation and wildcards to accommodate

different word endings and spellings. The approach to database searching was sensitive, meaning a wide net was cast, given the range of cross-disciplines and study designs, and the low positive prediction value of the search terms. Search terms did not include descriptions of behaviours or intervention approaches; this was an attempt to minimise the amount of irrelevant literature retrieved.

2.3.2 Screening

Duplicate literature was first removed electronically using EndNote bibliography software, and, second, by manual searching.

Screening was led by an inclusion checklist: subjects were human, of any age; primary subjects had a dementia of any severity or diagnostic type; the title of the literature suggested that the personal experiences of people with dementia could be included; in the English language; any methodology including clinician and caregiver perspectives. This excluded literature concerned with: the caregiver's own experiences, a biomedical perspective such as genetic research, neuropsychological performance, prevalence or correlates of symptoms or diagnoses, profiling or description of diagnoses, evaluation of interventions and the validation of existing measurement scales. Where there was uncertainty over the suitability for inclusion, the title was retained in an attempt to include all relevant literature.

Table 2-1. Search strategies used for all 12 electronic databases.

Database	Search strategy	Results
ASSIA	*ab(dement* or Alzheimer*) AND ab(emoti* or distress* or affect or affective or feeling* or depress* or anxi* or angry or anger or *shame* or fear* or well*being or sad* or agitat* or happy or happiness or apath* or grief or jealous* or desire or hopeless* or lonel*)*	1 608
BNI	*ab(dement* or Alzheimer*) AND ab(emoti* or distress* or affect or affective or feeling* or depress* or anxi* or angry or anger or *shame* or fear* or well*being or sad* or agitat* or happy or happiness or apath* or grief or jealous* or desire or hopeless* or lonel*)*	844
Cochrane Library	*'dement* OR Alzheimer* in Record Title in Cochrane Reviews'*	152
CINAHL	*AB (dement* or Alzheimer*) AND AB (emoti* or distress* or affect or affective or feeling* or depress* or anxi* or angry or anger or *shame* or fear* or well*being or sad* or agitat* or happy or happiness or apath* or grief or jealous* or desire or hopeless* or lonel*)*	5 054
HMIC	*HMIC 1 AND 2* *1 HMIC (dement* OR alzheimer*).ab* *2 HMIC (emoti* OR distress* OR affect OR affective OR feeling* OR depress* OR anxi* OR angry OR anger OR shame* OR ashame* OR fear* OR well*being OR sad* OR agitat* OR happy OR happiness OR apath* OR grief OR jealous* OR desire OR hopeless* OR lonel*).ab*	522
IBSS	*ab(dement* OR Alzheimer*) AND ab(emoti* OR distress* OR affect OR affective OR feeling* OR depress* OR anxi* OR angry OR anger OR ashame* or shame* OR fear* OR well*being OR sad* OR agitat* OR happy OR happiness OR apath* OR grief OR jealous* OR desire OR hopeless* OR lonel*)*	275
Medline	*((dement* or Alzheimer*) and (emoti* or distress* or affect or affective or feeling* or depress* or anxi* or angry or anger or *shame* or fear* or well*being or sad* or agitat* or happy or happiness or apath* or grief or jealous* or desire or hopeless* or lonel*)).ab* *Limit (english language and humans)*	15 358
PQDT Global	*ab(Dement* OR Alzheimer*) AND ab(emoti* OR distress* OR affect OR affective OR feeling* OR depress* OR anxi* OR angry OR anger OR *shame* OR fear* OR well*being OR sad* OR agitat* OR happy OR happiness OR apath* OR grief OR jealous**	2 433

	OR desire OR hopeless OR lonel*)* *Limit Language : English*	
PsycINFO	*((dement* or Alzheimer*) and (emoti* or distress* or affect or affective or feeling* or depress* or anxi* or angry or anger or *shame* or fear* or well*being or sad* or agitat* or happy or happiness or apath* or grief or jealous* or desire or hopeless* or lonel*)).ab* *Limit (english language and humans)*	15 156
Scopus	*(ABS (dement* OR alzheimer*) AND ABS (emoti* OR distress* OR affect OR affective OR feeling* OR depress* OR anxi* OR angry OR anger OR *shame* OR fear* OR well*being OR sad* OR agitat* OR happy OR happiness OR apath* OR grief OR jealous* OR desire OR hopeless* OR lonel*)) AND SUBJAREA (mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci) AND (LIMIT-TO (LANGUAGE , "English"))*	19 316
The Campbell Library	*dement* OR Alzheimer* in Title*	1
Web of Science	*TITLE: (dement* OR alzheimer*) AND TITLE: (emoti* OR distress* OR affect OR affective OR feeling* OR depress* OR anxi* OR angry OR anger OR *shame* OR fear* OR well*being OR sad* OR agitat* OR happy OR happiness OR apath* OR grief OR jealous* OR desire OR hopeless* OR lonel*) Refined by: LANGUAGES: (ENGLISH) Timespan: All years.*	4 179

Two raters, including me personally and one supervisor of the thesis, independently screened a sample of titles (1%), which was informed by a power analysis calculation using the Kappa statistic. The following parameter values were assumed: the proportions of articles chosen for inclusion by the first rater and the second rater were to be 0.05 or 5% of all titles, true agreement between raters given by kappa=0.8, 80% power and a 5% significance level for a one-sided test. This was to test the null hypothesis of kappa=0.6 against the one-sided alternative hypothesis, kappa>0.6, to demonstrate that agreement between the two raters was substantial or better than substantial.

456 articles were screened by two raters.

There was disagreement over 8% (n= 36) of jointly reviewed titles. Taking into account chance agreement using Cohen's k, there was 'fair' agreement between the two raters' judgements (κ = .34); however, using a formula for kappa to correct for 'prevalence' due to there being a truly unequal number of studies to be excluded and included (Byrt, Bishop, & Carlin, 1993), with more titles to be excluded than retained, agreement was suggested to be higher (κ = .84). The main reasons for disagreement were the inclusion of literature from a biological or neurological perspective by the first rater in an attempt to retain all relevant literature.

A consensus was reached on all jointly reviewed titles through discussion and in consultation with the second and third supervisors of this thesis.

I screened all remaining titles; uncertainty over the inclusion of a subset of titles was resolved through group discussion with the three supervisors of this thesis. A total of 1204 titles were retained for abstract review.

Two raters, including me personally, screened 5% of abstracts (n= 60). Additional inclusion criteria were used: the abstract suggested that the literature offered an original description or explanation of the emotional distress of people with dementia; though describing or explaining emotional distress need not have been an explicit aim. Fictional reports of dementia such as book or film reviews were omitted, as were reviews of literature. Literature reviews were read in full to locate missed primary literature.

There was disagreement over 18% (n= 11) of jointly reviewed abstracts. Taking into account chance agreement using Cohen's k, there was 'poor' agreement between the two raters' judgements (κ = .13). The main reason for disagreement was one rater opting to retain possibly relevant articles, such as when the caregiver experience was dominant. Where there was disagreement over the suitability for inclusion, the abstract was retained.

A consensus was reached on all jointly reviewed titles through discussion and in consultation with the second and third supervisors of this thesis. A total of 12 of the jointly screened abstracts were included following discussion.

I personally screened all remaining abstracts. A total of 194 abstracts were retained for full text review.

Two raters, including me personally, screened 10% of full texts for inclusion using an extended inclusion checklist (see Table 2-2). Assumed, surmised or unexplained descriptions of distress were excluded, such as 'distress' being mentioned as occurring without further description or explanation, with 'distress' as the rationale for an intervention. Where only an abstract was available, the first author of the literature was contacted in an attempt to acquire any full text. This resulted in one further text being screened. No abstract-only or poster-only texts were included because of their limited contribution of concepts and due to the limited information available to quality review.

Reading of full texts generated 22 additional studies relevant to the research question. I screened all remaining full texts.

Table 2-2. Assessment form: inclusion checklist for full text appraisal.

	Checklist item	
Availability	*Any subject/s were human, with dementia*	[ ]
	English language full text was available	[ ]
	Full text/sufficient detail was available to contribute to the research question (not abstract-only or poster-only)	[ ]
	The full text could be retrieved (available to access in print or electronic holdings)	[ ]
Relevance to the research question	*Offered an original description or explanation of emotional experiences of people with dementia*	[ ]
	Original data (quantitative or qualitative) or original theoretical contribution beyond the reporting of standardised outcome measures	[ ]
	Beyond an assumed, surmised or unexplained contribution	[ ]
Dates	*No start date – January 2016*	

A flowchart illustrating the inclusion and exclusion of literature through the systematic search is presented in Figure 2-1. A total of 64 898 retrieved titles including duplicates contained 121 studies for inclusion.

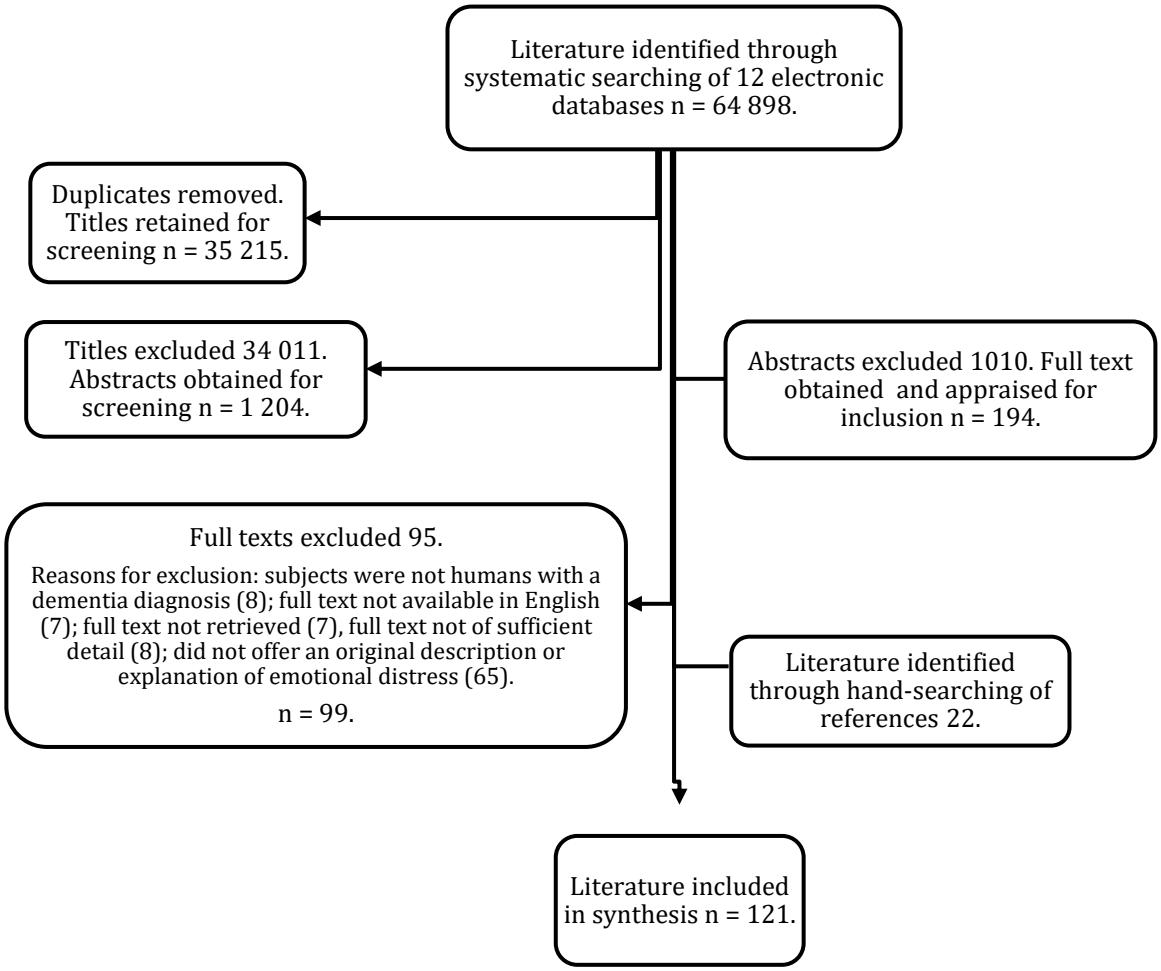


Figure 2-1. Flowchart illustrating the inclusion and exclusion of literature.

2.3.3 Rationale for quality appraisal

When reviewing complex evidence with heterogeneous study designs, the risk of location biases must be minimised, of which publication bias is most often critiqued. Approximately half of qualitative studies seem to reach publication, with unpublished studies being of poorer methodological quality and having less clear conclusions than published studies (Petticrew *et al.*, 2008). Published studies may therefore differ systematically from non-published studies. However, methods for showing publication bias used in quantitative studies, such as funnel plots, the fail-safe N calculation or the trim and fill method (Clarke & Stewart, 1994; Egger, Smith, Schneider, & Minder, 1997; Petticrew & Roberts, 2006) cannot be applied to qualitative or mixed design studies.

Additional potential biases for qualitative literature include studies published in the English-language and studies with briefer word-counts being more accessible, as well as those studies indexed in electronic databases or supported by well-cited studies being more accessible (Petticrew & Roberts, 2006). Literature that could be relevant to a systematic review therefore can become 'hidden' or 'lost' (Liebesny, 1960; Petticrew & Roberts, 2006). To minimise the risk of such location biases, the search strategy was designed to retrieve grey literature and all retrieved literature was subject to a thorough appraisal of quality (Egger *et al.*, 1997; Petticrew & Roberts, 2006). In this way, detail was given of the methodological rigour of the studies so the trustworthiness of the findings could be discussed in this review. The quality appraisal also contributed directly to the conclusions of the review by allowing comment to be made on the particular strengths or omissions in the research literature.

2.3.4 Quality appraisal

A systematic approach to quality appraisal was employed, which allowed the appraisal of any study design. A quality appraisal checklist was produced for this review, by collating all items that could apply from existing tools. The quality appraisal checklist incorporated items from the Critical Appraisal Skills Programme (Critical Appraisal Skills Programme, 2013), the Quality Assessment Tool for Studies with Diverse Designs (Sirriyeh, Lawton, Gardner, & Armitage, 2012), the Methodology checklist: qualitative studies (National Institute for Health and Care Excellence, 2009), The Evaluative Tool for Quantitative- and Qualitative- Research Studies (Long, Godfrey, Randall, Brettle, & Grant, 2002), a checklist for critiquing quantitative reports (Taylor, Kermode, & Roberts, 2006), criteria for assessing the validity of qualitative research (Popay, Rogers, & Williams, 1998), guidance from the methods of meta-ethnography (Noblit & Hare, 1988)

and adaptations of these tools (Campbell *et al.*, 2003; Hawker, Payne, Kerr, Hardey, & Powell, 2002). This was an attempt to conduct a thorough appraisal of all study designs.

Each of the 35 checklist items and their original citations are presented in Table 2-3. Raw scores of 0-70 were applied to each study and then summarised to one of seven quality categories (for example, 0-10 became the first category and 11-21 became the second, and so on) to improve the reliability and validity of ratings. Two reviewers, including me personally, independently quality appraised 5% of the full texts to improve reliability. I appraised all remaining studies. All literature with the lowest quality ratings was retained and used to supplement the findings of studies appraised to be of higher quality, as has been applied in other studies (Attree, 2004; Dixon-Woods *et al.*, 2006; Jamal *et al.*, 2013; Noblit & Hare, 1988). This decision was made with recognition that there was no agreed or systematically tested quality appraisal tool for mixed methods literature (Pluye, Gagnon, Griffiths, & Johnson-Lafleur, 2009) and in an attempt to retain all important contributions to answering the research question.

Table 2-3. Mixed studies quality appraisal checklist.

0 = criteria predominantly unmet; 1 = criteria partly met; 2 = criteria predominantly met

1	**Theoretical underpinning** The theoretical underpinnings are made explicit[a, b] (underpinnings might include theoretical questions, unanswered findings or observation)[c]
2	**Aims** The aims of the literature are made clear[b, d] The aims are relevant to a real life social setting[e] The scope and limits of the study are stated[c]
3	**Method** The method (quantitative/qualitative/mixed) is appropriate to address the aims[b, d]
4	**Design** The design (descriptive or experimental, sample, data collection methods) is appropriate to address the aims[b, d] The rationale for the choice of data collection tool(s) is presented[a, b] The reliability and validity of the data collection tool(s) is mentioned[a]
5	**Sample** The choice of sample is discussed in line with the type of knowledge sought[d] The sample is representative of the target group/is of a reasonable size/rationale given[a, b] Inclusion and exclusion criteria for the sample is presented[f]
6	**Data collection** The setting for data collection is described clearly[a] and justified[d] It is made clear how data were collected (*e.g.* focus group with topic guide)[b, d] The form of data is clear (*e.g.* tape recordings, video material, notes)[b, d] There is sufficient breadth of perspective (professional, service, user, carer) to address the aims[b, f] The 'depth' of data collection and 'width' of data collection (across time, settings and events) are appropriate to address the aims[b, f]
7	**Bias** The relationship between the author and sample is adequately considered (i.e. potential bias)[b, d]

8 **Ethics**
Ethical issues have been considered and addressed (i.e. issues of informed consent or confidentiality, approval sought from an ethics committee)[b, d]

9 **Data analysis**
The method of analysis is appropriate to address the aims[a]
The data analysis is sufficiently rigorous to address the study aims[b, d]
The data analysis is sufficiently described to allow reproduction[f]
The data presented are appropriate given the original sample; contradictory data are taken into account[b, d]
Sufficient data are presented to support the findings[b, d]
Confounding variables are controlled for or discussed[f]

10 **Findings**
The findings are clearly stated[b, d]
There is adequate discussion of the evidence for and against the findings, including contradictions[b, d, e]
Strengths and limitations are critically discussed[a], including the credibility of the findings (*e.g.* triangulation, validity or reliability checks)[b, d]
The findings are discussed in relation to the aims[b, d]
Conclusions are justified[f]

11 **Contribution**
The literature makes a valuable contribution, conceptual richness[b, d, g]
Contributions to existing knowledge or understanding are discussed[b, d]
Detail is given as to how the literature can be used; implications for policy or practice are given[b, f]
Generalisability: sufficient detail is given to allow comparison with other populations[f]
Generalisability: sufficient detail is given to allow comparison with other contexts[h]

12 **Overall summary**
Congruence[b, i]

Total score out of 70

[a] Sirriyeh *et al.* 2012; [b] NICE, 2009; [c] Taylor *et al.* 2006; [d] CASP, 2013; [e] Popay, Rogers and Williams, 1998; [f] Long *et al.* 2002; [g] Noblit & Hare, 1988; [h] Hawker *et al.* 2002; [i] Campbell *et al.* 2003.

2.3.5 Data extraction

Each included study was read in full to locate concepts, which were descriptions or explanations of emotional distress. The extracted concepts formed the raw data for the synthesis. A 'concept' was an attempt to reach the simplest description of the whole account, while preserving the original meaning (Noblit & Hare, 1988). The original wording was preserved where possible whilst attempting to be succinct due to the breadth of literature and number of studies included (Toye *et al.*, 2014). A concept could range in length from single words to a number of paragraphs (Graneheim & Jansson, 2006). An extraction table was used alongside continuous referencing back to the original papers to extract concepts; an excerpt from the extraction table is shown in Table 2-4.

2.3.6 Data synthesis

Two methods of analysis were employed in an attempt to best represent the data produced by the search: descriptions of distress formed a single concept, consisting of single words and short phrases; the method of analysis employed was corpus-based analysis. In contrast, the explanations for distress formed multiple concept categories, dispersed within lengthier accounts; meta-ethnography was employed. The mixed-methods approach of quantitative analysis alongside qualitative analysis to interpret and make sense of language use in its context offered an overarching synthesis. This was otherwise missing from the research literature.

Table 2-4. Excerpt from the extraction table used to collate descriptions or explanations of emotional distress from all studies.

Study	Description or explanation of emotional distress
McGee *et al.* (2013)	Threat to the sacred self… 'I am scared to death it is going to come to a place where I am going to be dependent on somebody, and I am a very independent person. I have always been independent.'
Sinason (1992)	Maybe the loneliness then was not to do with physically being alone, it was an inner feeing of isolation and loss that he carried about inside himself even if he was in company… I said it was very painful that he was losing his memory. 'Yes. It makes me feel so lonely… Do you know, sometimes I forget my wife's name.' He cried. 'Sometimes I forget what she did, what her job was…' '… He suddenly cried and briskly wiped his eyes.' 'I am frightened. But then I also like being on my own… I have been thinking about killing myself. Before I lose all my brain… My – son – my son. The first one. I've forgotten his name.' He cried loudly.
Bahro *et al.* (1995)	Particularly on awakening, his confusion as to why he was in a hospital bed led to severe anxiety. A clock on his wall became, at times, a marker of his 'minutes left on earth'.

2.3.7 Corpus-based analysis

Descriptions of distress

Corpus-based analysis is a commonly used approach for analysing large samples of written text, or 'corpora' (Baker, 2010), first by applying quantitative methods to uncover patterns in language use, and second by using qualitative methods to interpret the patterns. The method has been used in a range of health contexts, including psychiatric contexts (Harvey, 2012).

In principle, corpus analysis is descriptive, offering an objective overview of the language that has been used in a particular setting, to 'allow the data to speak entirely for itself' (Partington, 2008, p. 98). It is considered to be factual, driven by the data more than by intuition, and largely quantitative (Partington, 2008; Widdowson, 2000). In choosing the method, this objectivity was thought to be important because an objective

overview of the emotional distress experienced by people with dementia was missing from the research literature.

Corpus-based methodology allows analysis of data beyond what could be achieved by hand-searching or reading by eye, by using computer analysis. The analysis overcomes the time constraints of manual searching of large data sets, as well as overcoming possible error and unreliability of analysing data by eye (McEnery & Hardie, 2012). Text that can be read and analysed by machine allows for the searching and sorting of data, increased accuracy and reduced bias, and the detection of patterns that would be unlikely to be perceived otherwise, those that could be 'non-obvious' (McEnery, Xiao, & Tono, 2006; Partington, 2008).

The use of samples of text, compiled into a specialised corpus, is where corpus-based linguistics differs from traditional discourse analysis; in the latter, whole texts are retained to understand what language use is showing: language in 'use' (Brown & Yule, 1983). Texts that are greater in length than a sentence are typically required. Corpus-based tools can be used for discourse analysis, but with a specific focus. In corpus-based linguistics, the interest is with the words themselves (McEnery *et al.*, 2006), with all of the words, which are to be considered 'exhaustively rather than selectively' (Hardt-Mautner, 1995, p. 23). Specific examples are then selected purposefully from the analysis. This was relevant for this thesis given the short accounts of distress that were available within the literature, which were dispersed widely within different written accounts.

A corpus can be compiled to investigate a particular variety of language that has been used by certain people in a particular context, such as how adolescents talk about depression to health professionals (Harvey, 2012). Here, a specialised corpus was compiled from texts that were determined by the search strategy (Baker, 2010; McEnery *et al.*, 2006) because this collection of texts did not otherwise exist. The

formation of the corpus was consistent with guidelines for assembling texts for a particular purpose, to form a representative selection (Koester, 2010; McEnery *et al.*, 2006). The descriptions of distress that formed the corpus were considered to be authentic, were produced by a range of individuals across a range of contexts and formed a sample that was considered to be representative of the available published literature because of the systematic search strategy applied. The specialised corpus consisted of 25 163 words, which is considered to be an acceptable size (Biber, 1993; Koester, 2010). This featured all extracted study data from the 121 studies.

Corpus-based analysis was used to produce an objective and original description of emotional distress for people with dementia as described by themselves and others. The analysis reduced the a priori bias of researchers, since keywords and salient patterns of distress descriptions were generated computationally (Baker, 2010; Harvey & Koteyko, 2012; McEnery & Hardie, 2012; McEnery *et al.*, 2006; Partington, 2008). WordSmith Tools (Scott, 2017a, 2017b) was used to perform the analysis because it has been widely supported as a corpus analysis package (Baker, 2006; McEnery & Hardie, 2012).

Keywords, collocation and concordance analyses were carried out, as discussed next.

Keywords

Keywords were single words that occurred in the 'distress corpus' compiled here more frequently than would be expected in general language use. Hence keyword analysis was used to show salient language that defined the descriptions of distress. The 'keyness' of words was calculated by comparing the frequency of all words in the distress corpus with their occurrence in a reference corpus that represented general language use, using log-likelihood and likelihood ratio tests. Keywords were the most

frequent single words used to describe distress when general language use was taken into account.

The keywords displayed in the results section (see section 2.4) each had a p-value of $p<0.000001$, showing minimal likelihood of the keywords being selected in error. Of these, any word that expressed an emotional experience was considered for the keywords list, comprised of nouns, adjectives and verbs.

The British National Corpus (BNC) (Baker, 2010; Partington, 2008) was used as the reference corpus, in part due to its compatibility with WordSmith Tools, the software used for analysis, and in part due to its status as a reference corpus within the research literature. The BNC is considered to be large (consisting of 100 million words) (Baker, 2010) and representative of a broad collection of both written and spoken texts in British English (Burnard, 2009).

Self-reported descriptions and other-reported descriptions of distress were then each compared with the reference corpus separately to reveal differences in language use between the groups. The self-reported distress corpus was composed of direct quotes from people with dementia as well as summaries of their viewpoint by original study authors. Other-report data included descriptions of distress experienced by people with dementia as observed by family, professional care staff, clinicians and academic writers.

Collocation analysis

Analysis of collocation provided further information of how distress was described, by showing the words that occurred next to the keywords. Analysis of collocation assesses the strength of the relationship between two words when they occur as neighbours, and determines whether the relationship is statistically significant. The list of all collocates was sorted by 'mutual information' (MI) scores, which takes into account words that

frequently occur together generally, such as high frequency grammar words, and only presents words that occurred at a higher frequency with the keyword than would be expected in general language use (Scott, 2017a). Therefore, instead of showing high frequency collocates such as 'of' or 'being', words such as 'imminent' or 'tomorrow' were shown. MI is a measure of statistical significance, which compares the observed frequency of two words occurring together with the expected frequency of the two words occurring together by chance. A higher MI score shows a stronger relationship between two words; a MI score of >3 indicates a strong relationship, which is useful to interpret further (Harvey *et al.*, 2008; Hunston, 2002).

Concordance lines

Finally, concordance lines show excerpts of original text where the keywords remain in their contexts (Baker, 2010; Biber, 1993; McEnery & Hardie, 2012). Considering concordance lines can help to explain the frequencies and patterning of certain words within the corpus.

2.3.8 Meta-ethnography

Explanations for distress

Meta-ethnography was used to provide a usable summary of explanations for emotional distress. Meta-ethnography has been recognised as the most widely used and rigorous method for synthesising qualitative literature (Britten *et al.*, 2002; Campbell *et al.*, 2011; Campbell *et al.*, 2003; Pound *et al.*, 2005; Toye *et al.*, 2014), as well as being recognised as an important method for synthesising evidence to inform policy in the fields of nursing and healthcare (France *et al.*, 2014; Noblit & Hare, 1988). It offers a technique for systematically finding and mapping out ideas that exist within different literature,

then comparing how these ideas translate into each other or mutually contradict. Meta-ethnography was considered to be appropriate for this research question because it is immediately concerned with the experiences of the individuals involved in the phenomenon of interest: the everyday, lived experiences of people with dementia. A meta-ethnography synthesis therefore provides an alternative to other review methods by offering more than narrative description, or an aggregation of findings, by building a collective and original summary.

Explanations for distress were extracted from the full texts and presented beneath six main concept categories. This organisation was in part due to the large number of studies and in part as a way of presenting the information to best answer the research question, as has been done in previous meta-ethnographies (Atkins *et al.*, 2008; Forbes & Griffiths, 2002; Pound *et al.*, 2005; Taylor, 1982; Toye *et al.*, 2014). The emerging list of concepts was identified by me personally and agreed in continuous discussion with all supervisors to refine the wording of the concepts. One supervisor independently reviewed the extracted data for 10% of studies to refine the concept categories. Studies could contribute data to multiple categories if they offered multiple explanations for distress.

A concept grid, illustrating which concepts were represented within each study (see Appendix 3) allowed decisions to be made about the relationships between the studies and therefore the most appropriate type of analysis. 'Reciprocal translation' was chosen because the studies presented similar explanations that could be related to each other (Noblit & Hare, 1988).

The studies were ordered by their quality rating; in this way, consideration was given to the order in which studies were synthesised and how ideas were built upon each other in the analysis (Noblit & Hare, 1988; Petticrew & Roberts, 2006). The concepts from the first study (with the highest assigned quality rating) were compared with the concepts

from the second study; then the concepts from the first and second study are compared with the concepts from the third study, and so on. In this way, all studies within each category were 'translated' into each other using constant comparison. Essentially similar explanations were related to each other to reach a coherent summary (Noblit & Hare, 1988; Strike & Posner, 1983).

2.4 Results

2.4.1 Overview of studies

121 studies met the inclusion criteria. The full study list can be found in Appendix 4, where the mean features of each study and the assigned quality ratings are also presented. The self-reported accounts of 906 individuals with dementia were represented, and the accounts of 399 family members, 135 professional caregivers and 44 academic writers or researchers. The number of individuals with dementia represented indirectly by these viewpoints collectively was unquantifiable, but easily over 1000. A range of dementia diagnoses were included, though for the majority of studies, 'dementia' was used without further elaboration. When stated, 44 studies represented people with a diagnosis of Alzheimer's disease, 13 with vascular dementia, 10 with mixed dementia diagnoses, four with multi-infarct dementia, two with frontal or fronto-temporal dementia, two with dementia with Lewy bodies, two with Parkinson's dementia, and one study representing people with each of subcortical dementia, Korsakoff's dementia, Pick's disease, Creutzfeldt-Jakob disease and AIDS dementia. In 18 studies (15%), authors described moderate or moderate-to-severe dementia presentations, with all other studies representing presentations described as probable, mild or without a description of severity. A range of living environments for people with dementia were featured: when stated, 34 studies presented the experiences of people living within the community, alone, with family, in a shared house or retirement

complex, 16 studies featured people residing within a nursing home, 11 within residential care or supported accommodation, five within an inpatient psychiatric unit, four within a day care service, three within a hospital setting and one within a hospice. Studies were conducted in 14 countries, with the majority conducted in the UK (34%), the USA (29%) and Sweden (12%). Studies were published between 1984 and 2016. Although all studies contained explanations for emotional distress for people with dementia, only 18 (15%) stated this as an explicit study aim.

Therefore, the majority of the literature concerned the experiences of people with an unspecified dementia or Alzheimer's disease, of mild-to-moderate or unspecified severity, residing within the community. Personal accounts from people with dementia were greater in number than any other stakeholder. The experiences presented represented a range of cultural perspectives, though these were mainly within the UK, USA and Sweden.

2.4.2 Study quality

The quality ratings were close to forming a normal distribution, suggesting that ratings were applied independently to each study, that the quality ratings were random across the studies and that a sufficiently large number of studies were appraised. An equal number of studies received high as low quality ratings. Higher quality studies represented a range of viewpoints, a range of dementia diagnoses and were conducted in a range of countries. Higher rated studies also featured all explanations for distress concepts. The same broad-ranging study features applied to lower quality studies. However, it was noted that the majority of studies that represented moderate-to-severe dementia presentations (94%, n=17) were rated as higher in quality, suggesting that this may be a specialist research area. The most frequent reason for lower quality ratings was the omission of methodological processes that would have improved the

reliability and validity of findings, such as controlling for or discussing confounding variables or discussing the representativeness of the sample.

2.4.3 Descriptions of distress

The most frequently occurring descriptions of distress in the self-report and the other-report corpora are displayed as keywords in Table 2-5. Only descriptions of distress are presented, with words such as 'dementia', 'I', 'her' and 'participants' omitted in order to best answer the research question (McEnery *et al.*, 2006).

For the self-reported descriptions of distress, feeling fearful was the predominant experience, accounting for five of the 12 most frequent descriptions. The log-likelihood ratios displayed in the keyness column of Table 2-5 show how frequent keywords were; a log ratio of 1 shows that a keyword was twice as frequent than in the reference corpus, a log ratio of 2 shows that a keyword was four times as frequent, 3 was eight times as frequent, and so on (Scott, 2017a). 'Fear', 'worried' and 'frightened' each had a log-likelihood ratio of greater than five, meaning they were more than 32 times more likely to occur in the self-report distress corpus than in general language.

Taking the self-reported and other-reported descriptions of distress together, loneliness was the second most frequent description of distress, after descriptions of fear.

When comparing the self-reported and other-reported descriptions of distress, self-reported descriptions included 'worried', 'frightened' and 'panic' in contrast to 'anxious' or 'anxiety'. Similarly, people with dementia themselves used 'tears' rather than 'crying'. 'Distress' was used frequently by both groups, but more so within the other-report corpus. Therefore, when others described the distress of people with dementia, they tended to use summarised and surmised terms, such as 'anxiety', 'distress', 'depression' and 'agitation'. Within the self-report corpus, the distress descriptions were more

varied; distress keywords were dispersed, with fewer high frequency words, as shown in the frequency column of Table 2-5, despite both corpora being of equal word-count.

The higher log ratio values in the other-reported descriptions also show the higher occurrence of a more limited selection of words. 'Anxiety' and 'distress' were 128 times more likely to occur in the other-report distress corpus than in general language. This reflected the variety of distress words used in the self-reported accounts, compared with repetition of the same words in the other-report accounts.

Both groups captured extreme emotional experiences, such as 'panic', 'despair' and 'terror' within the most frequent descriptions.

Collocates, or neighbouring words to the keywords from all distress descriptions showed markers of intensity and the individual nature of the emotional experience. Collocates are displayed in Table 2-6. Examples are 'imminent', 'extreme', 'frequently' and 'idiosyncratic', which collocated with 'fear', 'loneliness' and 'distress'. The high number of significant collocates also demonstrated the breadth of descriptions, especially for 'fear'.

A selection of concordance lines for 'fear', 'loneliness' and 'distress' are presented in Table 2-7. They provide examples of the original context of the keywords. In the examples, 'fear' occurred most frequently with a qualifier of intensity (also shown in the analysis of collocation) or with a secondary emotional label to expand the description. For example, 'alarming', 'extreme' and 'terrible' were used, as were 'terror', 'anguish' and 'existential'. Therefore, descriptions of distress were rich and evocative. Explanations for feeling fearful, such as fear of appearing to be a fool, fearing tomorrow or fearing being with strangers are presented in the results of the meta-ethnography analysis to follow.

Table 2-5. Keywords in the descriptions of distress corpus (1. self-reported and 2. other-reported distress descriptions) ranked in order of keyword strength.

	1. Self-reported distress descriptions				
	Word	Frequency	RC Frequency	Keyness	
				Log-likelihood	Log ratio
1	Fear	37	9845	193	5.17
2	Worried	19	4362	101	5.24
3	Frightened	16	2503	97	5.78
4	Lost	27	18770	87	3.65
5	Frightening	10	991	70	6.46
6	Lonely	11	1637	68	5.87
7	Panic	11	2000	63	5.58
8	Angry	13	3980	62	4.83
9	Loneliness	8	575	61	6.92
10	Sad	12	3304	60	4.98
11	Tears	12	3935	56	4.73
12	Distress	9	1446	54	5.76
	2. Other-reported distress descriptions				
1	Anxiety	52	2609	414	7.20
2	Distress	30	1446	242	7.25
3	Fear	44	8945	230	5.18
4	Loneliness	19	575	170	7.93
5	Anger	26	3660	155	5.71
6	Anxious	23	2984	140	5.83
7	Depression	18	2247	111	5.88
8	Distressed	13	607	105	7.30
9	Crying	15	1849	93	5.90
10	Despair	13	1419	84	6.08
11	Terror	13	1445	83	6.05
12	Agitated	9	374	75	7.47

Table 2-6. Strong collocates of the keywords 'fear', 'loneliness' and 'distress' (which appeared in the keywords list for both self- and other-report distress descriptions) that have an MI score of >3. Grammatical collocates such as 'of', 'with' and 'the' were omitted.

	Self- and other-reported distress descriptions
Fear	tomorrow, generated, imminent, dreams, relating, conscious, starting, placed, unknown, remembering, dread, underlying, extreme, isolation, agitation, failure, unconscious, alienation, dying, seen, fearful, terror, happen, uncertainty, losing, becoming, end, particularly, great, memories, real, alone, deep, associated, sadness, words, dependency, mind, some, loneliness, burden, anxiety, control, left, might, Alzheimer's, distress, experienced, participants, being, feelings, fears, going, something, anger, become, death, self, family, disease, experience, loss, feeling, things, very, others, home
Loneliness	occur, extreme, frequently, isolation, uncertainty, experience, feelings, found, even, depression, participants, fear, loss, sense
Distress	idiosyncratic, withheld, worked, signs, particular, number, frustration, shock, diagnosis, experienced, anger, fear, felt, feelings, anxiety, dementia, know

Table 2-7. Concordance lines showing example descriptions of distress using the words 'fear', 'lonely/loneliness' and 'distress' in context.

	Self-reported	Other-reported
Fear	*Diagnosis includes a huge injection of **fear**… Some **fear** runs deep into your inner being… **fear** of what will happen tomorrow… a deep existential **fear** that is starting to creep into my heart and my mind… I **fear** being alone with a stranger who I don't know, maybe won't like… I've got this terrible **fear** of someone taking my pills off me*	*She realizes that with alarming **fear**, she doesn't know why she is standing in front of her stove… the sense of isolation contributed to feelings of **fear** and terror, which were sometimes extreme… mental, emotional and existential anguish that living and the **fear** and anticipation of death created… her eyes betrayed another emotion: **fear**. I realized that she was terrified… It was a real **fear** that she would abandon him.*
Lonely/Loneliness	*it is quiet and **lonely**, but the silence, I have never liked… I do feel very **lonely**, and when you go out… I never tell her I'm **lonely**…. If I feel **lonely**, it's at night when I miss my wife… painfully **lonely**… I'm so **lonely** here… the sense of **loneliness** can be so overpowering… feelings of **loneliness** and social isolation… feelings of guilt and **loneliness** overwhelmed me*	*isolation and **loneliness**… intensified feelings of **loneliness**… holding deep within herself the **loneliness** and the loss of the world she had known… the fear of **loneliness** can be the fear of being left alone… it is clear that **loneliness** can be a distressing experience… extreme **loneliness**… carers frequently mentioned an association between **loneliness** and memory loss*
Distress	*even worse when what you can remember causes additional **distress**! … frustration or **distress** felt… symptoms of psychological **distress**, for example, outbursts of anger, panic attacks… clearly experienced **distress***	*signs of **distress** are idiosyncratic… with expressions of **distress** centered on feelings of uncertainty… obvious signs of shock and **distress**… her scream tells of her **distress**… wailing loudly in a voice full of **distress**… expression of deep **distress**… that caused her particular **distress***

2.4.4 Explanations for distress

Six broad explanations for distress are presented with example quotes in Table 2-8. These are: a change to the person's sense of self, a negative social position, the loss of meaningful relationships, anticipating the future, the physical environment and distressing sensory experiences. Sub-concepts are shown in italics. More detailed descriptions of each concept, supplemented with all study excerpts, are given in Appendix 5. A summary of the explanations for emotional distress is presented in Table 2-9. The six explanations for distress are discussed in turn below.

Self: 'The whole disease is about insecurity and poor self-esteem' (Olsson, Lampic, Skovdahl, & Engström, 2013, p. 797). The concept 'self' represented distress being caused by change to the person's sense of self, which included a loss of self and individuals describing what they can't do. This was the most frequent explanation offered for distress across this literature, offered within 65 studies. The self was described as lost, empty and akin to an object or alien, being between different worlds and struggling to find meaning. A loss of self also included a loss of capabilities, professional and family roles, activity and active participation and meaningful routine. Words such as 'drifting', 'void', 'absence', 'estrangement', 'strangeness' and 'disconnect' were used. A person's self was described as being threatened or attacked or stolen or murdered. A lost sense of self also included individuals no longer feeling special; they felt vulnerable and they questioned their reason for existence. For some, the self became defined by damage and disability, which included forgetting, difficulties with conversation and struggling to think clearly.

Table 2-8. Descriptions of six concepts: explanations for distress from 121 studies. Study IDs are displayed with full details of each study in Appendix 4.

Concept	Featured in (study ID):	Concept examples
Self	1, 2, 4, 5, 7, 9, 10, 13, 14, 15, 17, 19, 21, 23, 26, 27, 28, 29, 30, 32, 34, 37, 39, 40, 43, 44, 45, 47, 48, 50, 55, 57, 58, 61, 63, 66, 68, 70, 71, 74, 76, 80, 82, 83, 84, 86, 92, 93, 94, 95, 96, 98, 99, 100, 101, 102, 105, 106, 107, 108, 111, 112, 117, 119, 121 (65 studies)	'The whole disease is about insecurity and poor self-esteem' (84), 'a nearly complete dismantling of the self I once knew' (44), 'I was used to having a home' (82), 'I who could move mountains!' (71), 'helplessness to control this insidious thief who was little by little taking away my most valued possession, my mind' (30), 'loss of the self, fear of dying twice' (106), 'First of all, you are nobody' (48).
Social position	1, 2, 3, 4, 7, 8, 13, 14, 17, 18, 21, 22, 23, 26, 29, 30, 36, 39, 40, 41, 43, 45, 50, 51, 52, 53, 55, 58, 64, 66, 67, 71, 78, 79, 81, 83, 85, 86, 87, 88, 89, 90, 93, 94, 95, 98, 100, 101, 102, 104, 106, 115, 116, 118, 120 (55 studies)	'feeling excluded by others and society' (39), 'I feel that I'm not much use to anybody' (22), 'like a little girl admitting she had been naughty and had done something wrong' (39), 'I'm a lot of rubbish now' (23), 'All my enjoyment they took it away from me… everything I try or want to do' (89), 'feared becoming a nuisance or burden' (21).
Relational needs	1, 4, 5, 8, 11, 13, 14, 15, 23, 27, 29, 30, 31, 36, 37, 39, 40, 42, 44, 45, 46, 47, 49, 52, 56, 60, 62, 64, 65, 68, 69, 70, 72, 73, 75, 76, 78, 79, 81, 93, 94, 97, 100, 104, 105, 106, 107, 108, 110, 115, 119, 121 (52 studies)	'I've no one here at all' (23), 'feeling lonely despite being surrounded by lots of people' (45), 'abandonment or betrayed' (31), 'a terrified, disorganized, and uncontained infant' (29), 'compounded by memory loss and not recalling visits from family and friends' (5).
Future	5, 6, 7, 8, 12, 13, 17, 18, 20, 21, 24, 26, 27, 29, 30, 32, 34, 39, 40, 42, 44, 48, 49, 51, 52, 54, 55, 57, 61, 66, 68, 70, 74, 77, 82, 84, 86, 87, 89, 92, 100, 101, 102, 106, 116, 118, 120, 121 (48 studies)	'disclosure of the diagnosis' (77), 'feeling unreal, I think I was just in a vacuum' (48), 'you have Alzheimer's' (120), 'nightmares about the future' (48), 'I thought that was the end of my life' (89), 'downward spiral of hopelessness' (17), 'fear of losing control of the mind' (39), 'foreboding of what's in front of me' (42), 'frightened that my mind had 'snapped' (40), 'the anticipation of death' (6).
Physical environment	5, 8, 12, 14, 15, 19, 23, 29, 30, 33, 34, 35, 39, 47, 50, 54, 59, 67, 87, 91, 100, 106, 113, 119 (24 studies)	'too many stimuli in the ward' (14), 'everything around them was moving too fast' (50), 'confused by their environment' (47), 'totally overwhelmed by new or complex environmental demands' (119), 'she was constantly looking around nervously as people moved towards or around her' (8).
Perception	1, 8, 16, 17, 25, 30, 38, 40, 41, 43, 47, 54, 76, 100, 103, 109, 114, 119, 121 (19 studies)	're-experiencing from childhood' (8), 'unhappiness in personality' (43), 'hallucinations' (17), 'all the adrenaline rush, perspiration, rapid breathing, and heart pounding of a real situation' (30), 'the floor suddenly heaved and swayed' (40).

Social position: the second most frequent reason for distress was an individual being viewed by themselves or others as worthless or useless. Individuals felt embarrassed or ashamed about dementia and the associated symptoms; they spoke of stigma being attached to a dementia diagnosis and anticipated negative judgment from others, such as criticism or laughing. Negative judgments that individuals feared included being mad, stupid, childish, a liar or being dangerous. Individuals expressed the need to keep the dementia diagnosis from others, through isolation or being hypervigilant as not to give themselves away. Individuals also felt excluded by others and society by not being consulted, informed or understood. Being confined by rules and being told what to do (including not being able to leave environments and not being able to drive) was distressing, as was being physically confined by restraints.

Loss of relationships: distress was described as being caused by being alone and away from meaningful others, who included family, formal caregivers, friends and neighbours and religious comfort. Aloneness was described as absolute and permanent. Being forgotten, abandoned or betrayed were described. Physical aloneness, such as having infrequent contact with family, being surrounded by strangers or experiencing the loss of family through death caused distress. In addition, a sense of aloneness was described due to cognitive difficulties, which caused some people to interpret that they were without relationships. For example, some people could not recall information about loved ones and carried an inner feeling of isolation, or could not remember interactions with others. Furthermore, being dependent on others was described as distressing. Also, the onset of dementia was described as being threatening due to a fear of returning to the early experiences of being an infant: needing others who might not be available.

Future: explanations for distress included receiving a diagnosis of dementia, anticipation of an unknown and dreaded future with dementia and looking towards the end of life. The process of receiving a diagnosis of dementia was described as cause for

distress for the person with dementia, including immediate shock. A lengthy process of diagnosis and not knowing was distressing. Beyond diagnosis, some individuals felt hopeless, some anticipated the loss of their future as a whole. More specifically, distress was caused by people anticipating losing control of their mind, including becoming lost, losing things and losing control over their life. Distress was explained by individuals looking towards and anticipating death.

Physical environment: misunderstanding the environment, being affronted by the behaviour of others within a care setting, sounds and the movement of other people could be over-stimulating and was described as too fast or too loud. Some people described fear of getting lost, of theft or coming to harm in their environments.

Perception: the final theme described perceptual experiences of two different causes, re-experiencing of previous distress and distressing perceptions. Remembered and re-experienced distress from earlier times in a person's life caused distress, such as past violence. The circumstances were perceived as existing in the present, which was explained by people having less bearing on their current reality as well as aspects of the current situation mirroring their past experiences. Hallucinations or frightening perceptions were also described, such as perceiving animals or perceiving the room to be swaying.

Table 2-9. Summary of all explanations for distress.

Key concepts	Sub-concepts	Concept description
Self	Loss of self Can't	Distress was caused by changes to an individual's stable sense of knowing themselves; this included being defined by difficulties, feeling alien, fragmented and under attack.
Social position	Judgment Exclusion and control Burden	Being positioned as worthless, criticised and negatively labelled caused distress. Equally, being controlled by the actions of others or physical constraints caused distress. Individuals feared burdening others.
Relational needs	Alone Cognitive difficulties Dependence	Having relational needs that were unmet caused distress, which included the actual absence of relationships as well as individuals interpreting that relations were absent or would be absent when needed. Hence, individuals could not receive comfort from others when needed.
Future	Diagnosis The future Death	Individuals assigned meaning to their dementia diagnosis that caused distress; they anticipated the loss of their cognitive and physical abilities, their future as a whole and fearfully anticipated death.
Physical environment		Distress was caused when the external world seemed confusing due to things being too fast, loud or bright, as well as living in strange environments such as care settings.
Perception		Distress was caused by being cued in to a time and place from the past, which caused re-living of events. Distress was caused by unusual perceptual experiences, including hallucinations.

2.5 Discussion

2.5.1 A brief consideration of language

This chapter presents a systematic review of the available descriptions of emotional distress for people with dementia. This is prefaced on the understanding that language is a valuable representation of distress as it is experienced. Language is the primary means of communicating thoughts and feelings to others, regarded since the fourth century to be a means of 'expression' above all else (Bloom, 1995; Taylor, 1985). This social function of language has been said to make it possible for individuals to exist within relationships (Bloom, 1995). Writers such as Balota and Schwanenflugel (Schwanenflugel, 2013) argued that even a single word is with context and can be particularly revealing of a person's experience. Words also convey differing meanings depending on the other words that they are used alongside, which is especially true for abstract words such as those used to convey emotion (Hoffman, Lambon Ralph, & Rogers, 2013; Shallice & Cooper, 2013); this is because of 'semantic diversity', that is, the number of different contexts that a word can appear within. The findings of this study depend upon this understanding, that words offer a valuable representation of a person's experience.

In this study, the words used to express the emotional distress of people with dementia were thought to reveal a wealth of personal meanings, when represented as single words, collocates and concordance lines. Demonstrated here, emotions had a vast array of qualifiers, synonyms and collocates. The results showed that self-reported accounts of emotional distress, in particular, were varied.

2.5.2 Interpretation of findings

The results suggest that feeling fearful is the most prominent experience of emotional distress described by people with dementia, followed by feeling lonely. Fear was qualified as 'imminent', 'extreme', 'real' and 'deep' as well as being used synonymously with 'dread', 'terror' and 'anxiety'. The findings are consistent with what is otherwise known of the experience of anxiety for people with dementia, which is that anxiety is common (Alzheimer's Society, 2014; Evans & Garner, 2004; Seignourel, Kunik, Snow, Wilson, & Stanley, 2008). Seignourel *et al.* (2008) reviewed how anxiety has been defined for people with dementia; they concluded that there was too little research and that often the caregiver's view was unquestioned and predominant. Therefore, the study presented in this chapter expanded upon what was known of the experience of anxiety in dementia by offering a more comprehensive description than what was otherwise available (Seignourel *et al.*, 2008).

In this study, distress was explained predominantly by people losing hold of themselves and their social world, the prospect of losing their future, freedom and control, and needing to turn to others for emotional care; hence dementia raised all fundamental, human anxieties (Yalom, 1980). The cognitive symptoms of dementia contributed to emotional distress when a person perceived themselves to be failing, being without value, being blamed as 'mad' or 'stupid' and when cognitive difficulties inhibited meaningful relationships with others. This understanding is consistent with theoretical perspectives of the psychosocial needs of people with dementia, which are discussed briefly next (Davenhill, 2008; Evans & Garner, 2004; Kasl-Godley & Gatz, 2000).

Psychodynamic theory offers an understanding of the distress caused when the cognitive changes caused by dementia contribute to a loss of the self (Sadavoy, 1991), or 'de-selfing' (Lieberman & Tobin, 1983), which underpins these findings. The self, or ego, was theorised by Jung (1967) to be a whole and constant representation of who a

person is: how we see ourselves, along with what meaning and emotions we attach to this. In support of the study findings, Kitwood and Bredin (1992) introduced personal worth or self-esteem as one of four main apprehensions for people with dementia.

The findings are also supported by identity theories (Calhoun, 1994; Holland, Lachicotte, Skinner, & Cain, 1998). These theories state that a person defines themselves through a process of sense-making, or 'self-making', with other people (Urrieta, 2007). The viewpoints presented in this review described the social world of people with dementia as stigmatising. People with dementia described a transition from a valued identity, to one that was devalued and shameful (Schwartz & Merten, 1968). The dominating socially held view of dementia as negative and as existing within the person (World Health Organization, 2016) likely contributes to this distressing experience. The findings here showed 'self-stigma' (Corrigan, Kerr, & Knudsen, 2005); that is, people with dementia anticipated negative evaluation and social exclusion from others and held negative views about themselves.

The social experience of dementia has been written about by Kitwood and Bredin (1992) and Sabat and Harré (1992). These authors introduced the concept of 'social positioning' to describe people with dementia as being disadvantaged in society: 'story lines that paint the sufferer as inadequate, confused, helpless… the fencing off of the sufferer so that no adequate self can be constructed' (Sabat & Harré, 1992, p. 460). Garand *et al.* (2009) wrote about the use of diagnostic labels for dementia. They stated that diagnostic labels by their nature reduce a group of individuals to being homogenous. In an interview study concerned with the social world of people with dementia, Langdon, Eagle and Warner (2007) asked 12 people with early-stage dementia how others had reacted to them since receiving a diagnosis of dementia. The main themes of the interview transcripts included social exclusion and 'feeling left out of the social loop' (p. 998). These findings are consistent with Burgener and Berger (2008)

who asked people with dementia directly about their experiences of stigma using the Stigma Impact Scale and Stigma Experience Scale.

Finally, the study findings showed that the need for others at times of distress was considerable. This is in keeping with fundamental principles of psychotherapy, whereby people turn to other people for comfort and understanding at heightened times of need (Lazarus, 1980).

2.5.3 Updated search

Due to the time elapsed between the completion of the systematic review and the completion of the full thesis, a repeated search of literature was performed to identify any additional descriptions of emotional distress and explanations for emotional distress that did not emerge from the first analysis. This was an attempt to retrieve literature that could offer a valuable contribution to the discussion of findings and not an attempt to repeat the literature search or analysis in full.

The database that returned the highest number of titles was selected for the updated search: this was Scopus (see Table 2-1). The same search strategy as presented in Table 2-1 was used. Literature was retrieved from between 1 February 2016 and 31 August 2019.

The screening criteria described in section 2.3.2 revealed eight full texts that would meet the inclusion criteria for the synthesis: Aldridge, Fisher and Laidlaw (2019); Crowther, Brennan and Bennett (2018); Goyal, Engedal and Eriksen (2019); Karger (2018); Rapaport *et al.* (2018); van Gennip, Pasman, Oosterveld-Vlug, Willems and Onwuteaka-Philipsen (2016); van Vliet *et al.* (2017); and Wyatt and Liggett (2019).

Collectively, 42 personal accounts of distress (Aldridge *et al.,* 2019; van Gennip *et al.*, 2016; van Vliet *et al.*, 2017; Wyatt & Liggett, 2019), 44 accounts given by family

members (Karger, 2018; van Vliet *et al.*, 2017; Wyatt & Liggett, 2019) and 90 professional caregiver accounts (Goyal *et al.*, 2019; Karger, 2018; Rapaport *et al.*, 2018) could be added to the corpus from these additional texts. The studies were located in the UK, The Netherlands and Germany.

The descriptions of distress within these studies were consistent with the results presented in section 2.4.3; they contained descriptions of fear and loneliness, which were the most frequent descriptions of distress in the corpus-based analysis, as well as descriptions of shame, grief and anger. Extreme emotions were indicated by qualifiers such as 'very', 'really' and 'existential'.

The explanations for distress described within these studies were consistent with the results presented in section 2.4.4. Reasons for emotional distress described in these additional texts included: change to a person's sense of self due to being defined by difficulties with the progression of dementia (Aldridge *et al.*, 2019; van Gennip *et al.*, 2016; van Vliet *et al.*, 2017; Wyatt & Liggett, 2019); seeing oneself as being less valuable than other people or viewing oneself as burdening others (Aldridge *et al.*, 2019; Goyal *et al.*, 2019; van Gennip *et al.*, 2016; Wyatt & Liggett, 2019); aloneness (Aldridge *et al.*, 2019; Goyal *et al.*, 2019; Karger, 2018; Rapaport *et al.*, 2018); anticipating the loss of abilities and a feared future (Aldridge *et al.*, 2019; Goyal *et al.*, 2019; van Vliet *et al.*, 2017); and perceiving the physical environment to be unsuitable (Rapaport *et al.*, 2018). These fall beneath five of the six themes that summarised all explanations for distress as presented in Table 2-9; distressing perceptions were not discussed further in these additional texts.

In addition to consolidating the main study findings, these studies provide a valuable contribution to the conclusions of this chapter. Observable behaviours, such as increased activity or restlessness, or people with dementia seeking closeness to caregivers, were said to communicate emotion or emotional needs for people with

dementia (Crowther *et al.*, 2018; Rapaport *et al*., 2018); consequently, close observation of each person, paired with an understanding of each person and their life history, were said to be necessary in order to understand emotions because of individual variability in the communication of emotions (Crowther *et al*., 2018; Karger, 2018; Rapaport *et al*., 2018).

2.5.4 Implications for practice

These findings evidenced the experience of emotional distress for people with dementia, first by showing that emotional distress exists and can be articulated personally, and second, by presenting a dataset that moves beyond surmised or reduced notions of emotional distress as being the symptom of a disease or a diagnosable mood disorder. These findings are relevant to clinicians as they attempt to improve the limited understanding of personal experiences of dementia and individual care needs which, in turn, can influence care planning. In particular, the findings of this study show that people with dementia have expressed that being consulted and receiving a timely diagnosis could reduce their emotional distress. More generally, the results indicated that feeling valued by other people, being able to depend upon others for emotional support, being able to anticipate a hopeful future and maintaining purpose and a continuous sense of self could reduce emotional distress for people with dementia.

Dening, Jones and Sampson (2012b) examined how people with dementia defined their preferences for their end-of-life care. The descriptions given were different from the terms used by family caregivers and different from terms that are well-used in healthcare literature, such as dignity and respect; the following quote was given from a person with dementia: '… look after me with care… don't treat me like a vegetable… like a mad person' (p. 413). The same finding, of people with dementia speaking clearly of their personal experiences, is presented in this study.

2.5.5 Implications for research

This review demonstrated that research into the emotional experiences of people with dementia could adopt more robust methodology, notably to enhance the reliability and validity of findings, by discussing confounding variables and the representativeness of the participant sample. Researchers could learn from the research into moderate-to-severe dementia presentations to increase confidence in representing this population more widely. Furthermore, future research should continue to explore solutions for conducting mixed studies reviews; the selection of literature in this review was made difficult by variability in methods, terminology and article structures adopted in the social sciences (Forbes & Griffiths, 2002; Hawker *et al.*, 2002; Noyes, Popay, Pearson, & Hannes, 2008; Petticrew & Roberts, 2006); searching of mixed studies is known to be time and resource intensive (Dixon-Woods *et al.*, 2006; Greenhalgh & Peacock, 2005; Hawker *et al.*, 2002; Shaw *et al.*, 2004).

Since this study was completed, research published in an influential medical journal, JAMDA, presented evidence that the experiences of patients with dementia and their communication is not well described by terms such as agitation or aggression, and that rating scales that measure these constructs are equally unhelpful (Volicer & Galik, 2018). This is in keeping with the editorial that I wrote for Aging & Mental Health, which argued that labels such as 'agitation' are unhelpful umbrella terms, which don't help healthcare professionals to understand the needs of patients with dementia.

2.6 Critique

Strengths

The best represented populations in this review were people with a diagnosis of Alzheimer's disease, with a mild severity of dementia, and people residing within the community in the UK, USA and Sweden. This reflects the profile of dementia among the populations of those three countries (Winblad *et al.*, 2016). The sensitive search strategy also allowed some representation of a range of dementia severities, dementia diagnoses, countries and living environments, which strengthened the generalisability of the findings. The inclusion of quantitative and qualitative studies in this mixed-methods review was also considered to be a strength; principally, the search strategy allowed for a more comprehensive answer to the research question than from an otherwise reduced study selection (Bryman, 2012). The study number was meaningful or large in size for both corpus-based and meta-ethnography analyses (Atkins *et al.*, 2008; Biber, 1993; Koester, 2010; Toye *et al.*, 2014). The application of corpus-based analysis to understand the language used to articulate emotional distress was original and introduced an objective analysis.

Limitations

The following limitations are acknowledged. The included texts might have missed some of the variability in how individuals have articulated distress. Notable examples might be social media such as diaries, blogs and social networking (Kaplan & Haenlein, 2010), the use of multimedia (Lee, 2008) and accounts that have not been captured in media, which were outside of the scope of this review. Additionally, eight non-English language reports were excluded during the search; the reference corpus used was essentially concerned with British English (Baker, 2010) though the data in this study were not

solely British English, with some authors being from the USA or Europe. Therefore, a particular format of academic writing and a particular language register was represented in this study and might have omitted other descriptions and explanations of emotional distress (Hunston, 2002). Furthermore, a critique of any synthesis is that the findings contain some level of interpretation of the original data, moving away from the original distress experience (Byrne, 2002; Sandelowski & Barroso, 2006). This need for caution holds true for both analysis methods adopted in this study. Corpus-based linguistics attempts to reveal what is typical or frequent in the sample of language (McEnery & Hardie, 2012; Stubbs, 2001) and does not reveal unique or individual examples of language use. Therefore, individuals expressing their distress using imagery or metaphor, for example, might not have been prioritised because of using different turns of phrase (McEnery *et al.*, 2006; Widdowson, 2000). The synthesis stage in meta-ethnography has received similar criticism (Atkins *et al.*, 2008), that the resulting explanations for distress are removed from the original experience. The criticism of interpretation also applies directly to the notion of distress: ultimately, distress is defined by the individual (Regnard *et al.*, 2003), and any cause of distress will have personal meaning (Evans & Garner, 2004). Therefore, the findings could suggest that only frequent or representative accounts of written distress were valid. Another potential criticism of this study is the inclusion of other-reports alongside self-reported accounts; however I thought these were important to include because such accounts help to give a voice to people with more advanced dementia who may not be able to verbalise their experiences well.

In line with these criticisms, I made efforts to optimise the validity of the study findings. Efforts included quality appraisal, the use of second reviewers where feasible, peer review by a supervisor where feasible, a transparent process with a documentation trail, adherence to recommended methodology (Baker, 2006; Petticrew & Roberts, 2006;

Toye *et al.*, 2014) and the use of real text quotations to exemplify conclusions drawn (Sandelowski & Barroso, 2006). Thorough reading of full texts also offered some assurance that the conclusions drawn reflected the original context of the texts (Flowerdew, 2008).

2.7 Impact statement

In addition to the publications and conference proceedings listed at the beginning of the thesis, impact of the study was demonstrated in the following ways.

A summary of this study features on the 'National Elf Service' website as a blog post by Hilary Shepherd; this followed publication in the International Journal of Geriatric Psychiatry, where the article was noticed. The National Elf Service website provides accessible summaries to clinicians without the time or skill to remain up-to-date with the latest evidence: 'No bias. No misinformation. No spin.' It was designed as an evidence-based healthcare website with the aim of making 'evidence-based research more accessible and usable for busy health and social care professionals'. https://www.nationalelfservice.net/mental-health/dementia/emotional-distress-in-dementia-qualitative-systematic-review/

Feedback from a reviewer for the International Journal of Geriatric Psychiatry also suggested the value of this study. They said: 'This is an interesting study which is innovative in its combination of corpus linguistics and meta-ethnography and provides fresh insight into emotional distress and dementia.'

A summary of the study findings featured in The Retreat Newsletter, sent to a mailing list of Quaker Friends. The Retreat is an independent and charitable mental healthcare provider based in York, UK. Three people emailed me with thanks and personal reflections, which included a person with dementia, the wife of a person with dementia

and the Chair of the Board of Trustee Directors for The Retreat and York Quakers Clerk. One comment received was, 'It must be a very difficult task to try to analyse the distress of dementia sufferers, as everyone is so different. I knew that my husband, who suffered from Alzheimer's, was aware of his own deterioration and felt discouraged and depressed by his situation. Being a cheerful, active practical person in normal life, he continued to be as active as possible for as long as possible, showing a great deal of courage. I hope that your research will help to increase understanding and promote better care of this condition,' (Member of the public PPI.4).

The published systematic review was circulated to the full mailing list of the Faculty of the Psychology of Older People within the British Psychological Society, which is the representative body for psychology in the UK, and is responsible for promoting excellence and ethical practice.

An article was also published by the Division of Clinical Psychology, Faculty of the Psychology of Older People, The Bulletin, in October 2017; this is a quarterly publication for a division of the British Psychological Society. The audience of The Bulletin is practicing clinicians who are able to apply what they read directly to the delivery of care of people with dementia. The article details were as follows:

Petty, S. (October, 2017). Where is the emotion in dementia? FPOP Bulletin, No. 140, 25-26.

2.8 Chapter summary

This systematic review reported the descriptions of emotional distress from over 1000 people with dementia. This study first employed computer-assisted corpus-based analysis to offer an objective overview of how distress has been described. The analysis then introduced a summary of the leading causes of emotional distress using meta-

ethnography. It demonstrated that people with dementia have expressed their experiences of emotional distress using rich, varied and personal language. Explanations for emotional distress incorporated a change to the person's sense of self, a negative social position and the loss of meaningful relationships. (See the results and discussion sections, 2.4 and 2.5).

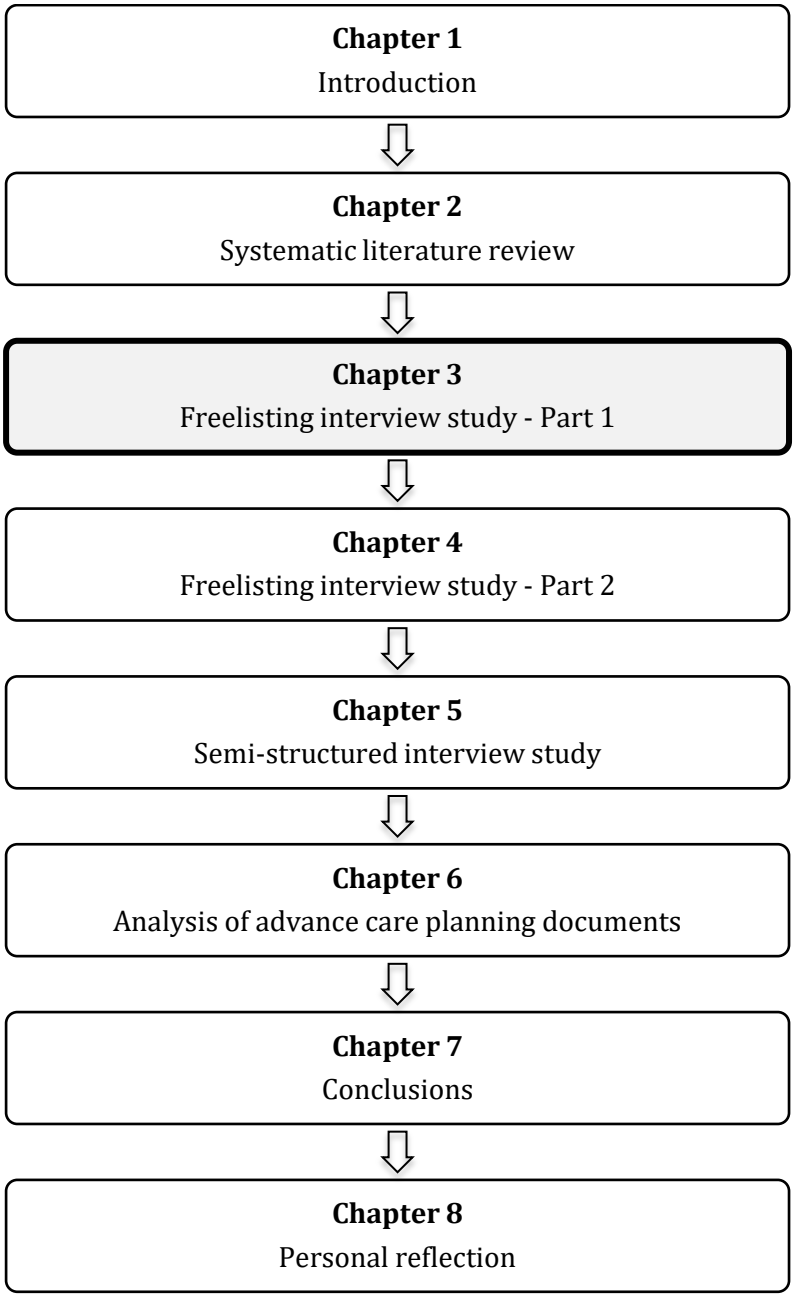
The review of quantitative and qualitative studies, the sensitive search strategy and the number of studies reviewed were considered to be strengths of this study; however, presenting only the most representative accounts of distress across written materials was the main limitation (see the critique section, 2.6).

Section 2.7 describes academic impact as well as the uptake of the study by a healthcare professionals' blog and personal reflections from a person with dementia, the wife of somebody with dementia and a charity Director.

This chapter responds to the current context of dementia within healthcare as described in the opening chapter, Chapter 1, of ill-defined, confused understandings of distress and predominant use of diagnostic labels. The findings of this chapter offer a conceptual starting point from which to explore how emotional distress is understood within a healthcare setting, and what healthcare staff can do to provide appropriate care responses. This study suggests that people with dementia would require care that reflects the variability of their personal experiences and their accompanying emotions. As discussed in the introduction to this thesis, this has not yet been researched.

In the next stage of this thesis, presented in the following four chapters, empirical research was located within two hospital settings, which collectively learned the views of hospital ward staff and patients with dementia about how emotional distress is understood within routine hospital practice and the ways in which staff across the hospital system can act to meet the needs of patients with dementia.

Chapter 3. Study 2. Part 1. A freelisting interview study with ward staff. Meeting the emotional needs of hospital patients with dementia.



3.1 Chapter overview

This chapter presents an interview study conducted with a hospital ward staff team, where 47 staff members comprised the full ward. Staff from a range of professional

backgrounds who contributed to the care of patients with dementia were asked to describe how they notice, understand and respond to the emotional distress of patients with dementia within their routine hospital practice. The aims are presented in section 3.2; in brief, this study was designed to provide a concise description of how emotion-focused care can be achieved in hospitals, from the perspective of multidisciplinary hospital staff. It follows research aims 1, 2, 3, 5, 6 and 9 of the full thesis (see section 1.2) by defining emotional distress, collecting data from routine hospital practice and exploring the care actions of multidisciplinary hospital staff.

Ethnographic freelisting was the chosen interview method to give quantitative and qualitative findings, to summarise how the staff team agree in their approach and how they respond as a whole. The method included a pilot study with hospital nursing staff to ensure the relevance and appropriateness of the questions being asked (section 3.3).

Three publications are listed, including a journal publication of the research study, an opinion article and a blog post. Three conference proceedings are also listed, from the UK and Spain.

3.2 Aims

The research question for this study was: how are moments of emotional distress received in interactions between individuals with dementia and hospital care staff? More specifically, how do staff notice, understand and respond to the emotional distress of patients with dementia, and which responses are the most effective? The study aimed to identify good practice as reported by hospital staff, from an emic viewpoint, meaning the viewpoint from within the culture of the hospital ward.

3.3 Methods

Exploratory qualitative interviews were conducted with multidisciplinary hospital staff using freelisting methodology.

3.3.1 Freelisting and cultural consensus analysis

Freelisting is an ethnographic interviewing technique used to capture the viewpoints of the people inside a culture, to allow the members to determine what is important and relevant. Participants are asked to provide a list that describes a particular domain, such as describe 'a person who is depressed' (Barg *et al.*, 2006) or describe 'how to facilitate person-centredness' (Edvardsson, Varrailhon, & Edvardsson, 2014). Here, the domain to be defined was 'the emotional distress of patients with dementia', by hospital care staff. An advantage of this interview method is that freelisting is less influenced by the assumptions of researchers (Weller & Romney, 1988); participants are presumed to use the language and concepts that are relevant and meaningful to them. Another advantage is that freelisting offers a systematic way to generate focused, qualitative data that captures all of the relevant content.

Freelisting is recommended when a domain is not yet known (Weller & Romney, 1988); I consider the emotional distress of patients with dementia to be an unknown domain as this has been poorly described to date (Petty *et al.*, 2018a) and to my knowledge, emotional distress within a hospital setting has not yet been understood, including what is known from the perspectives of hospital staff involved in patient interactions. Freelisting studies have shown that participants are able to generate highly varied descriptions of emotion, which come together to form a single, coherent domain (Barg *et al.*, 2006; Schrauf & Sanchez, 2008) or multiple domains (Martinez Tyson, Castaneda, Porter, Quiroz, & Carrion, 2011), across different contexts.

Cultural consensus analysis is a means to examine the data from freelisting interviews, to determine whether the responses given by people in a group share an underlying

cultural definition, and the extent to which there is shared cultural knowledge (Romney, Weller, & Batchelder, 1986). This is important when aiming to reach a representative description given by a particular group of people as here, of how the emotional distress of patients with dementia is understood by multidisciplinary hospital staff (Research aim 5).

3.3.2 Pilot

It was estimated that 10% of the full sample would equal no more than six participants, based on preliminary discussions with a hospital ward manager about the staffing duty roster. Therefore, three nursing assistants, one consultant psychiatrist, one domestic assistant and one registered mental health nurse participated in a pilot of the interview method. These staff members were sampled from a separate hospital ward and did not participate in the main study (see section 3.3.3).

Both spoken and written methods of asking for lists were trialled, guided by previous freelisting studies (Barg *et al.*, 2006; Douma, Steverink, Hutter, & Meijering, 2017; Edvardsson *et al.*, 2014; Martinez Tyson *et al.*, 2011; Schrauf & Sanchez, 2008), with three participants being asked to give their responses aloud within an audio-recorded interview and three participants being asked to read the questions and write their responses down. Both formats generated an equal number of list items on average, approximately eight items for each question. One participant stated that they preferred to give a spoken list. It was noted that when participants gave written lists they made less conversation throughout and were less likely to explain or expand on their responses. They also made less informal conversation outside of the interview questions, thought to be due to the amount of silence and the role of the researcher seemingly being to observe them.

Participants understood the freelisting task without further explanation; they gave lists when asked to do so; they often qualified their lists by saying 'first' and finished by saying 'that's all I can think of right now', hence it seemed that participants prioritised their responses in terms of their perceived importance, suggesting face validity of the task. No participant asked for clarification over what was meant by 'emotional distress'. Participants spontaneously stated that the questions were relevant and important to their roles in providing dementia care.

In response to the observations of conducting the pilot study and the feedback from participants, a spoken list format was chosen. It was expected to produce more detailed responses from participants, with more explanation of their responses than written lists; the spoken format was also thought to replicate the exchanges between care staff within a hospital setting more closely than a written task, thus capturing real world descriptions of emotional distress and care.

3.3.3 Participants

Staff members were recruited from one ward within a teaching hospital in the UK; the ward was described as an elderly medicine ward, providing care for older people including older people admitted to the hospital with confusion or suspected dementia. The hospital was a member of Dementia Action Alliance, which connects over 150 national organisations in the UK, including hospitals, Royal Colleges and Government bodies, who show a commitment to improving dementia care in England. The hospital was also signed up to John's Campaign: a national campaign to confirm a commitment to improving the experience of patients with dementia and their families when in hospital (Alzheimer's Society, 2016). This setting was chosen in an attempt to produce findings that would generalise to other hospital settings, and in recognition that there is no

single recommended design of hospital services for patients with dementia in Europe (Hermann *et al.*, 2015).

Study information was made available to all staff by the ward manager. Participants were informed of times when the researcher was available.

A total of 47 hospital staff members constituted the whole ward staff team over a three-month period, as determined by the staffing duty roster; this included bank and temporary staff members, administrative and cleaning staff working on the ward and all shifts including night shifts. There were no exclusion criteria because all participants contributed to patient care within their professional role. The whole ward was sampled in recognition of the skills of the whole hospital workforce (Ashton & Manthorpe, 2017; Boaden, 2016; Innes *et al.*, 2016).

The number of participants was determined by the analysis method and a calculation proposed by Weller (2007), which sets a conservative sample size at 20-30 participants to reach agreement of a single domain. The number was also in line with previous studies (Barg *et al.*, 2006; Martinez Tyson *et al.*, 2011; Schrauf & Sanchez, 2008). The full ward sample of 47 was achieved because of staff interest and commitment in taking part.

All participants read an information sheet (see Appendix 6), volunteered to take part and provided written consent.

3.3.4 Ethical considerations

Ethical approval was granted by the Health Research Authority (18/HRA/0221), the relevant NHS Foundation Trust (195538Y NP) and the University of Nottingham (FMHS 143-1709).

The study was designed in line with The University of Nottingham's Code of Research Conduct and Research Ethics. There were no anticipated disadvantages or risks to participants of taking part in the study; the questions were not intended to be difficult to answer, but participants were reminded that they did not have to answer any question and could end the interview or leave at any time without having to give a reason. Participation was voluntary and without a financial incentive. The interview took place within the participants' workplace so their usual means of receiving support was available. All participants had capacity to consent to taking part and were asked to read an information sheet and complete a written consent form prior to participation.

To protect participant anonymity, personal information obtained from the study was considered confidential and not disclosed to third parties. The interview data were transcribed in a confidential room; the transcribed interview data were made anonymous before being used for analysis, write up and the dissemination of findings. Participants consented to the data collected in the study being shared with other researchers and being used in academic research provided that their anonymity was protected.

There were no anticipated risks to me as the researcher, a clinical psychologist experienced in discussing sensitive topics.

3.3.5 Data collection

I collected spoken lists within individual, face-to-face interviews, each lasting approximately 15 minutes. Hospital staff were asked to keep in mind their working with patients with dementia and list as many items as they could to describe: (1) how they notice when somebody is emotionally distressed; (2) what they think causes them to be emotionally distressed; (3) all the ways they respond when somebody is emotionally

distressed; (4) of the ways to respond, all the things that seem to work. Participants were first asked how they notice emotional distress to access the immediate language available within their workplace. See Appendix 7 for the interview schedule. Staff were not prompted to create longer lists or to review their list and no time limit was imposed. When staff indicated that they had completed the list, the next question was asked. When all interview questions had been asked, the researcher asked staff to provide demographic information, including whether they had personal experiences of dementia (such as having a family member or friend with the diagnosis), their job title, duration working on the ward, duration working with people with dementia in other places, any training or education received in working with people with dementia, gender (male, female, other, prefer not to say), age range (under 25 years, 25 to 34 years, 35 to 44 years, 45 to 54 years, 55 years and above, prefer not to say) and ethnic origin (White, Asian or Asian British, mixed ethnic group, Black/African/Caribbean, other ethnic group, prefer not to say). Interviews were audio-recorded and I wrote down each participant's list as it was spoken to account for any difficulties caused by lost sound on the audio-recording. I also took field notes so that the findings could be understood in the context of the hospital environment.

I had no prior relationship with any participant. It was important to declare that I was a clinical psychologist, experienced in working with people across the age range with mental health diagnoses, and their support networks.

3.3.6 Data analysis

Each interview was transcribed in full. List items were taken from each transcript and each unique listed item was given a three-letter code. A code book was used to document each code, its description and all verbatim words and phrases that contributed to that code (see Appendix 8). In creating the code book, the aim was to

retain all unique list items. I did not attempt to group items by theme. Therefore, as many unique terms were retained as possible in case participants used different words to express different things. This process was iterative and required reference back to the original recordings and transcripts to ensure that the meaning of each participant was retained.

To improve the reliability of coding, together with supervisors, I considered the use of multiple reviewers. Published examples did not provide enough detail to ascertain how many reviewers were involved in each stage of the analysis, though authors said 'we examined freelists to identify and group terms with similar meaning' (Barg *et al.*, 2006) or 'we coded and standardized responses'. I emailed Professor Barg and Professor Schrauf with a request for further information; both of whom replied. Their recommendations for using multiple reviewers were followed; in adherence with author recommendations, the code book for each question was reviewed in full by me personally and all supervisors and was edited through group discussion; a sample (10%) of transcripts was coded independently by two reviewers. In this way, decisions were made about whether list items were unique, or could be considered synonyms that describe the same list item; for example, the code 'TAL' was used for the unique list item 'talking', which was used to code 'talking', 'sharing conversation' and 'chatting' as essentially similar. There was disagreement over 11% of list items (n=16 of 145), meaning the reviewers did not select the same code from the code book on these occasions. The reviewers chose from between 67 and 104 codes for each list item depending on the question.

It was not appropriate to use Cohen's kappa as a measure of agreement due to the assumption that raters were selecting from a small number of possible categories. If simplified and the two reviewers were said to agree or disagree in their coding only,

Cohen's kappa showed agreement at κ = .15, slight agreement. Four codes were changed following discussion.

Repetitions within the same list were not coded because staff frequently recapped aloud when giving spoken lists.

The codes for list items became the dataset for analysis. Each list was written in ASCII computer language and analysed with ANTHROPAC software (Borgatti, 1996).

The ANTHROPAC freelist procedure was used to calculate: the total number of times each item was listed (frequency), the average position in a list when listed (average rank) and the salience of each item, Smith's saliency score. Salience is a measure of how important an item is and is calculated using both the frequency and rank of an item; an item with higher salience will have been mentioned more frequently and earlier in lists. Salience scores were plotted as a scree curve; breaks in the curve showed the difference between items that were culturally shared and those that represented individual responses (see Appendix 9). Only items with higher salience and items mentioned by at least 20% of respondents were displayed in the results table for each question, as these criteria served to mark the boundary of the cultural definition (Barg *et al.*, 2006).

Using ANTHROPAC software, recode and consensus procedures were used to organise the data into a matrix, with rows representing staff members and columns representing list items (a participant-by-item matrix); cells contained a 1 if an item was listed and a 0 if it was not. Factor analytic methods then used a participant-by-participant correlation matrix, with staff members represented as rows and columns, to indicate agreement between staff members. The analysis used participants as the variables in factor analysis.

Cultural consensus, and the coherence of the cultural domain, is shown by a single-factor solution and stronger agreement between staff is shown by a higher ratio

between the first and second factor. A large first eigenvalue relative to the second eigenvalue, with a ratio greater than 3:1, shows that a single domain exists (Handwerker & Borgatti, 1998).

Knowledge scores represent each staff member's awareness of a domain by showing the level of agreement of each staff member with the cultural consensus, or each staff member's loadings on the first factor, where the maximum value is 1.0.

Cultural consensus is a means to examine whether the responses given by people in a group share an underlying cultural definition, and the extent to which there is shared cultural knowledge (Romney *et al.*, 1986). Cultural consensus analysis was used here to determine whether a single description was reached that was agreed by all hospital staff for each interview question, hence whether the responses of the hospital ward staff team showed a cultural consensus about emotional distress and the possible ways to respond.

The analysis was repeated separately for each of the four interview questions.

3.4 Results

3.4.1 Participant characteristics

Participant demographic data are shown in Table 3-1. The majority of hospital staff were female (70%) and White British (75%). The professions with the highest representation were nursing assistants (43%) and nurses (26%). The sample featured all professions and demographics expected in a UK hospital setting (Dewar & Nolan, 2013; Griffiths *et al.*, 2014). The mean length of time working on the ward was six years (SD 7.4, range 1 week to 28 years). The mean length of time working with people with dementia was 11 years (SD 9.4, range 3 months to 37 years).

Table 3-1. Participant demographics.

	N = 47
Female	33
Age	
less than 25 years	7
25-34 years	8
35-44 years	9
45-54 years	13
55 and more	10
Ethnic origin	
White British	35
Indian	5
Pakistani	2
White background other than British, Irish or Irish	2
Other	3
Professional role	
Nursing assistant	20
Nurse or student nurse	12
Occupational therapist, physiotherapist or therapy assistant	4
Doctor	3
Manager or deputy manager	3
Domestic assistant/cleaner	2
Volunteer	2
Ward clerk	1
With personal experience of dementia	18
Years working with people with dementia	
0-5 years	18
6-10 years	10
11-15 years	5
16-20 years	6
20+ years	8
Training in dementia care	
No formal training	6
Mandatory training and online courses	12
Classroom teaching	26
Qualification in dementia care	3

3.4.2 Responses to freelisting questions

For each of the four interview questions, the most salient list items, their frequency and average list position are given in Tables 3-2 to 3-5.

Collectively, multidisciplinary hospital staff produced a single, shared description of how to notice, understand and respond to the emotional distress of patients with dementia. This reflects a comprehensive and shared understanding of how to address the emotional needs of patients with dementia when in hospital.

Question (1) How to notice emotional distress

A total of 67 unique descriptions of distress were listed. The mean list length was 8.3 items (SD 3.4). One coherent, bounded cultural domain was represented: the first and second eigenvalues were 29.4 and 1.5 respectively, with a ratio far greater than 3:1 (Handwerker & Borgatti, 1998). The average knowledge score was 0.8 (SD 0.1), indicating a high level of agreement for each staff member with the cultural consensus. The most salient items for 'how to notice emotional distress' (with Smith's saliency score shown in brackets) were: agitation (0.418), crying (0.350), mobilising more (0.238), restlessness (0.235), facial expression (0.215), body language (0.209), aggression (0.170), being withdrawn (0.169), disorientation or confusion (0.169), anger (0.155), verbal aggression (0.154) and calling out or shouting out (0.150). 'Agitation' was listed by 53% of participants and on average was given third in a list. Agitation was the list item with the highest saliency score, showing the high prevalence of its use. 'Crying' was listed by 51% participants and tended to be ranked lower. Whilst 'being withdrawn' was listed by the next highest number of participants, 36%, it tended to be ranked below sixth, suggesting that being withdrawn was a less immediate way of noticing distress. See Table 3-2 for the 12 most salient items listed.

Table 3-2. Salience information for the top list items for interview question (1); How to notice emotional distress.

List item	Description of list item	Frequency	Listed by (%)	Average rank	Salience
Agitation	The words 'agitation' or 'agitated' were used; verbal or physical agitation was described.	25	53	2.9	0.418
Crying	Descriptions included crying, tears and weeping.	24	51	3.6	0.350
Mobilising more	Descriptions were of more movement, including wandering, pacing, running, standing to move and getting out of bed.	16	34	4.3	0.238
Restless	Being unsettled was described; descriptions included fiddling, fidgeting, fussing with items, tearing items, pulling at clothing or equipment, being flustered or unable to settle.	14	30	3.3	0.235
Facial expression	A person's face or facial expression shows distress. This includes descriptions of anxiety, strain, upset, anger or pain showing on their face, or a change in expression.	13	28	2.8	0.215
Body language	Body language or posture was listed; descriptions included waving, pointing or moving hands or putting hands to their head.	12	26	2.7	0.209
Aggression	The terms 'aggression' or 'aggressive' were used without further description.	14	30	4.7	0.170
Withdrawn	Being withdrawn, quiet, disengaged or subdued were described. Individuals were described as being distressed within themselves.	17	36	6.4	0.169
Disorientated or confused	Confusion or disorientation were listed; included a person not understanding where s/he is, not understanding what s/he is doing or having poor attention.	15	32	6.0	0.169
Anger	'Anger' or 'angry' were listed, sometimes with explanations for the anger.	10	21	3.3	0.155

Verbal aggression	Verbal aggression was listed or descriptions of swearing, bad language or arguing were given.	11	23	4.3	0.154
Raised volume	Staff described an increase in the volume of speech. Descriptions included shouting, calling out or crying out.	14	30	5.4	0.150

Question (2) Causes of emotional distress

A total of 97 unique causes for emotional distress were listed. The mean list length was 8.3 items (SD 4.2). One coherent, bounded cultural domain was represented: the first and second eigenvalues were 33.1 and 0.7 respectively. The average knowledge score was 0.8 (SD 0.1). The most salient items for 'causes of emotional distress' were: the hospital environment (0.355), not knowing what is happening (0.313), being away from loved ones (0.288), not knowing where they are (0.268), pain (0.150), wanting to go home (0.143), confusion (0.136) and strangers (0.124). Although 'being away from loved ones' was listed by the highest number of participants, 52%, on average it was listed fifth, whilst the hospital environment was listed third on average and was the most salient item. See Table 3-3 for the eight most salient items listed.

Table 3-3. Salience information for the top list items for interview question (2); Causes of emotional distress.

List item	Description of list item	Frequency	Listed by (%)	Average rank	Salience
The hospital environment	Descriptions of the environment included descriptions of an unfamiliar, new or foreign setting or the hospital setting explicitly; this included descriptions of an intrusive environment and descriptions of hospital bays and beds.	20	43	3.1	0.355
Not knowing what is happening	Meant a person not understanding why s/he is in hospital; descriptions included asking why s/he is in hospital, denying the need for hospital and not knowing the duration of hospital stay.	20	43	3.4	0.313
Being away from loved ones	Included descriptions of wanting to see family or friends, looking for them and thinking about them, not being with them, awaiting or not receiving visitors and not knowing where family are. Specific family members, such as 'mum' or 'husband', were mentioned. Descriptions also included feeling left or abandoned by family.	24	52	5.1	0.288
Not knowing where s/he is	Disorientation to place included descriptions of a person not knowing where s/he is, asking where s/he is and not knowing that s/he is in hospital.	17	37	3.3	0.268
Pain	Pain was listed.	11	24	4.7	0.150
Wanting to go home	Staff described a person missing home, wanting to go home and asking to go home.	11	24	4.3	0.143
Confusion	'Confused' or 'confusion' were listed as single words without further description.	9	20	3.6	0.136
Strangers	Strangers, unfamiliar or unknown people, unfamiliar faces and voices and individuals not knowing who is around them were described.	9	20	4.7	0.124

Question (3) Responses to emotional distress

A total of 104 unique responses to distress were listed. The mean list length was 10.7 items (SD 5.6). One coherent, bounded cultural domain was represented: the first and second eigenvalues were 31.9 and 0.8 respectively. The average knowledge score was 0.8 (SD 0.1). The most salient items for 'all the ways to respond to emotional distress' were: reassurance (0.357), talking (0.306), sitting with or being with (0.260), distraction (0.255), comfort (0.247), asking the person about their needs (0.191), a cup of tea (0.167), empathising (0.167), identifying the cause (0.166), knowing the person (0.148), listening (0.140), touch (0.137) and offering space or a different environment (0.133). The highest total of list items was given in response to this question; this question also produced the highest number of culturally shared items as shown by the scree curve plot and over 13 items being listed by more than 20% of participants. See Table 3-4 for the 13 most salient items listed.

Table 3-4. Salience information for the top list items for interview question (3); Responses to emotional distress.

List item	Description of list item	Frequency	Listed by (%)	Average rank	Salience
Reassurance	Giving reassurance was listed, such as 'reassure them', without further description. It was used to mean telling a person verbally that things would be OK.	20	43	2.5	0.357
Talking	Talking; sharing conversation and stories; talking whilst walking.	21	45	4.8	0.306
Sitting with, being with	Included descriptions of being with the person in their distress and offering company.	20	43	5.9	0.260
Distraction	Distraction was sometimes described as providing distraction from the person's thoughts or mood; changing topic; distracting for a short time.	20	43	6.2	0.255
Comfort	The word 'comfort' was used. Descriptions of giving comfort also included descriptions of being calming or nurturing in manner.	16	34	3.9	0.247
Ask them	Responding by asking the person; this included asking what the matter is or why s/he is distressed; asking what s/he would like.	15	32	6.2	0.191
Cup of tea	A cup of tea or cup of tea with biscuits was listed. Described as a comfort and described as allowing time together.	18	38	8.8	0.167
Empathising	Trying to understand; empathising. Descriptions included tuning in to what is troubling them, getting into their mind-set or universe; telling them they understand.	12	26	5.0	0.167
Identify the cause	Responding by identifying the cause or reason for distress, identifying the problem or the need; included descriptions of fathoming, working out or getting to the grounds of the distress; not assuming.	11	23	5.6	0.166
Knowing the person	Staff described having to know or get to know the person; included each person being different/unique and	10	21	6.0	0.148

	different responses working for different people.				
Listen	Listening was listed. Also included telling the person they are listening.	12	26	5.8	0.140
Touch	Descriptions of touch included holding a person's hand or touching their shoulder, arm or knee; offering a hug; allowing them to rest their head.	11	23	6.7	0.137
Space	Staff listed offering a different or preferred environment, room or space. This included using the café away from the ward.	14	30	8.3	0.133

Question (4) Responses to emotional distress that seem to work

A total of 70 unique items were listed. The mean list length was 5.6 items (SD 2.1). One coherent, bounded cultural domain was represented: the first and second eigenvalues were 32.2 and 0.8 respectively. The average knowledge score was 0.9 (SD 0.1). The most salient items for 'ways to respond that seem to work' were: knowing the person (0.299), talking (0.283), sitting with or being with (0.269), trying all of the responses listed (0.258), reassurance (0.176) and a cup of tea (0.126). 'Trying all of the responses listed' was ranked highest when listed, first or second on average, but was listed by fewer participants than other list items, 28%, suggesting that a subset of staff feel well-resourced in responding to emotional distress. Most participants, 43%, said that talking to the person worked at times of distress. Knowing each person as an individual was the most salient item for this question. See Table 3-5 for the six most salient items listed.

Table 3-5. Salience information for the top list items for interview question (4); Responses to emotional distress that seem to work.

List item	Description of list item	Frequency	Listed by (%)	Average rank	Salience
Knowing the person	Staff described having to know or get to know the person; included each person being different/unique; being person centred; being patient-led; different responses working for different people.	19	40	3.1	0.299
Talking	Talking; included sharing conversation, chatting, communicating.	20	43	3.2	0.283
Sitting with, being with	Sitting with, being with, engaging with. Included descriptions of giving attention and being a person without uniform or equipment.	19	40	3.9	0.269
All of them	'Anything', 'everything' or 'all of them' were listed; sometimes any in combination.	13	28	1.9	0.258
Reassurance	Giving reassurance generally was listed, including reassurance not to worry or that problems would be resolved.	12	26	2.9	0.176
Cup of tea	A cup of tea or cup of tea with biscuits was listed.	11	23	4.6	0.126

Questions (3) and (4) Comparison of responses and responses that seem to work

Hospital staff listed significantly fewer items on average for responses that seem to work than they did for all responses that they try ($t(46)= 7.54$, $p< .001$). Despite listing fewer items, staff showed slightly more agreement with each other for responses that seem to work, as shown by higher knowledge scores ($t(92)= 2.27$, $p= .026$) and showed the same high levels of agreement over the most salient items as shown by the ratio between the eigenvalues for the first and second factor and the spread of salience scores shown in Tables 3-4 and 3-5. This suggests a confident consensus over responses to emotional distress that seem to work.

3.5 Discussion

3.5.1 Interpretation of findings

This study provides an illustration of how an entire hospital ward staff team understands the emotional needs of patients with dementia as part of routine practice in a UK hospital setting. Consensus analysis of four questions showed that a shared cultural domain underlay the descriptions given by individual hospital staff members, with a high degree of consensus. The descriptions of emotional distress and care responses given by hospital staff were ordered by priority, with items of the highest salience reported. This provides an operational definition of compassionate hospital care. This study responds to the requirement for hospital staff to provide integrated care and emotion-focused care (Boaden, 2016; Mental Health Foundation, 2013; National Institute for Health and Care Excellence, 2018).

The main ways of noticing emotional distress listed closely match what have been labelled as the behavioural and psychological symptoms of dementia (BPSD) (Cerejeira *et al.*, 2012). These include: agitation or restlessness, increased mobilising, low mood, aggression, irritability and aberrant vocalisations. Importantly, though, this study challenges these symptom labels in the following ways: firstly, the symptom labels were listed as ways that emotional distress is communicated, thus offering some understanding of their meaning; second, the causes thought to underlie these behaviours were described in equal detail and with equal confidence as the behavioural descriptions, which gives more information about what helpful interventions or responses might look like; third, over 50 additional descriptions of the ways to notice emotional distress were provided beyond the twelve most-used descriptions, meaning that there is a broader lexicon available to describe a person's emotional distress than this shorthand. For example, increased mobilising was more fully described here as getting out of bed, wanting to leave the ward and looking for or searching for somebody.

The behaviour described was semiotic, or meaning-driven, because a person was upset about being in an unfamiliar place, without knowing what was happening to them. The listed descriptions of distress in this study were understood as usual reactions to circumstance, rather than the symptoms of a disease. Table 3-3 gives examples of what could cause emotional distress for any person, regardless of diagnosis. The findings restate that the range of behaviours shown by people with dementia are heterogeneous because they reflect personal and widely variable experiences (Cerejeira *et al.*, 2012; Stokes, 2017).

The leading causes of emotional distress were described by hospital staff as the unfamiliar hospital environment and the patient not understanding what is happening. Supportive of these findings, the physical hospital environment is the focus of international intervention (National Institute for Health and Care Excellence, 2018; Waller, Masterson, & Evans, 2017; World Health Organization, 2017). The need to improve a patient's understanding of their placement in hospital also replicates findings from other studies (Digby, Moss, & Bloomer, 2012; Edvardsson & Nordvall, 2008). However, hospital staff did not describe responding to emotional distress by addressing the physical environment or increasing orientation to time and place. Addressing these factors could, therefore, prove helpful in the prevention of emotional distress, rather than the response to it.

From the numerous possible responses to emotional distress, the responses thought to work described person-centred and validating care, which is widely recommended for people with dementia (Brooker & Surr, 2006; Feil, 1993; Kitwood, 1997); this included staff having to know each person as an individual, talking, being with the patient as a person, offering reassurance that problems can be resolved and offering a cup of tea. What staff did to try to help the persons in distress, in one way or another, involved engaging with the person as a human being in need. When distress was felt for the

reasons described in Table 3-3, the person was helped by having someone notice them, understand them and be humane with them. Beyond the diagnosis of dementia, treating the patient with dementia as a person was key. Consistent with what staff prioritised in this study, accounts of hospital care from patients with dementia and their families have established that relationships with care staff are of greater importance to them than the physical environment (Cowdell, 2010; Digby & Bloomer, 2014; Edvardsson & Nordvall, 2008). Staff in this study showed strong agreement over these effective responses to emotional distress (Barg *et al.*, 2006; Schrauf & Sanchez, 2008).

3.5.2 Implications for practice

Firstly, commonly used labels such as agitation and aggression should be understood as meaningful behaviour of patients with dementia that conveys an emotional reaction to the circumstance of being in hospital, and not simply the symptoms of a disease.

Second, it is of note that the skills to respond to emotional distress described in the literature to date have been variable in all settings (Clissett *et al.*, 2013; Edvardsson *et al.*, 2011; Griffiths *et al.*, 2014; Nolan, 2006; Scerri *et al.*, 2015). Training interventions designed for hospital staff have demonstrated that translating person-centred care into practice is challenging to achieve and is resource-intensive (Innes *et al.*, 2016; Surr *et al.*, 2016). Here, staff produced a menu of possible ways to notice, understand and respond to the emotional distress of patients with dementia. The personal connection that was prioritised at times of emotional distress could suggest a skillset that is quick to draw upon and that is transferable to a range of care situations. The results are the prioritised interventions of hospital staff who are responsible for providing care in moments of the highest challenge (Boaden, 2016; Hessler *et al.*, 2017; National Institute for Health and Care Excellence, 2018) thus showing the value of recommending these aspects of care provision.

Staff demonstrated relevant knowledge and experience; the emphasis of both clinical practice and research going forward should, therefore, be the implementation of this knowledge into care delivery. Importantly, any change to practice must suit the hospital environment and complement what hospital staff are asked to do within their routine working: this study was situated in a ward providing medical care for older adults with a wide range of needs, thus existing ward priorities included delivering high quality medical care and managing risk (Brooke & Ojo, 2017; Handley *et al.,* 2017). I recommend that the findings are applied to clinical practice given the potential benefits to patient wellbeing and staff wellbeing, the reduced use of antipsychotic medication and reduced healthcare costs if patients were to have improved emotional wellbeing (Cerejeira *et al.*, 2012; Royal College of Psychiatrists, 2017).

Third, a comprehensive understanding was shared by the whole staff team; this has implications for person-centred care being delivered more consistently, beyond what volunteer or liaison services can achieve (Dewing & Dijk, 2016; Griffiths *et al.*, 2014; Handley *et al.*, 2017). This also recognises the valued input of cleaning staff, amongst other professional groups (Ashton & Manthorpe, 2017).

Finally, the findings support further development in addressing the physical environment (Digby *et al.*, 2012; Waller *et al.*, 2017) and campaigns (Boaden, 2016) and research (Kelley, Godfrey, & Young, 2019) to increase the presence of family members in hospital as preventions for emotional distress, as these were described as the leading causes of emotional distress for patients with dementia when in hospital.

3.5.3 Implications for research

Future research would benefit from supplementing staff report with other outcomes of interest, including observations of care (Innes *et al.*, 2016) and patient-report (Hung *et al.*, 2017). This study poses questions as to whether emotion-focused care is

consistently delivered and asks what the multiple impacts on the system might be were it to be delivered. For example, these might include changes in staff attitude and confidence, use of medication, length of stay, incidence of falls, patient aggression and family member wellbeing (Scerri *et al.*, 2017); research has shown that training programmes for multidisciplinary staff in a community care setting that prioritise knowing the person with dementia can achieve these benefits (Alonzo, Mitchell, & Knupp, 2015). This research would contribute to the limited evidence that is currently available to recommend emotion-focused approaches to care in hospital (National Institute for Health and Care Excellence, 2018).

3.6 Critique

Strengths

Firstly, this study provided details of achievable person-centred, and more specifically, emotion-focused care for hospital patients with dementia, which recognised the existing knowledge of hospital staff; such research had been called for (Brooke & Ojo, 2017; Dewing & Dijk, 2016). Importantly, the findings offered are solutions from practice that suggest ways to respond to distress of patients with dementia when it has been noticed, not previously known (Crowther *et al.*, 2018). The study responds to prior criticism of an overemphasis on theoretical models of person-centred care for patients with dementia when in hospital (Dewing & Dijk, 2016). The suggestions made could inform the design of interventions for the hospital setting to improve patient wellbeing.

Second, the sample featured all professions and demographics expected in a UK hospital setting (Dewar & Nolan, 2013; Griffiths *et al.*, 2014). A major strength of the sampling was the multi-profession perspective, with greater representation of different professions than in previous studies (Griffiths *et al.*, 2014; Innes *et al.*, 2016). The

sample was larger than in other studies with UK hospital staff (Crowther *et al.*, 2018) and the participation of the full ward did not introduce the sampling biases that have limited other studies (Crowther *et al.*, 2018).

Third, freelisting was a novel method to explore the realities of everyday practice in a hospital setting and is praised for being simple, inexpensive and an efficient way to gather meaningful information (Fleisher & Harrington, 1998). Future research situated in similarly fast-moving settings might benefit from using the method.

The analysis was challenging, and required interview data to be presented in ASCII language, with file types and a file naming system that were compatible with the ANTHROPAC software. The software then required a DOS operating system. The three available software manuals were written for those familiar with these processes, and therefore needed to be supplemented with additional instruction and IT support. Therefore, the skills learnt for the analysis were thought to strengthen the impact of the thesis.

Limitations

An important consideration when applying the findings to future care design is whether the descriptions of care given are equivalent to care that is routinely delivered. For example, interviews with hospital staff (Crowther *et al.*, 2018) have provided examples of barriers to recognising and caring for emotional distress in patients with dementia, such as the busy hospital environment. Additionally, there is likely to be variability in the care delivered at any one time, given what is prioritised on the ward, busyness, fatigue and demands on staff, including aggression and the emotional toll of being with distress and illness (Ashton & Manthorpe, 2017; Goldberg *et al.*, 2014; Griffiths *et al.*, 2014; Handley *et al.*, 2017; Moyle *et al.*, 2010). In a previous study, hospital staff

described providing person-centred interactions with patients, but these were not supported by observation (Innes *et al.*, 2016). In this study, both the spontaneous listing task completed within a working shift and the strong agreement shown between staff, suggested that staff do have reliable knowledge; however, the care described was not observed. Additionally, I explored ways to respond to distress once it is manifest, therefore, additional questions would need asking prior to recommending interventions, which would pertain to the prevention of distress. Finally, the findings would benefit from replication beyond a single hospital site, as different staff teams might contribute to a more comprehensive set of responses and might appraise effectiveness differently; this study has limited generalisability due to the homogeneous nature of the sample, and the findings reflect aspects of the English culture that might not translate well to other countries, such as the value of a 'cup of tea'.

3.7 Impact statement

This study was designed to deliver impact in the following ways. For the patient, the study provides research evidence that their experiences cannot be easily reduced to labels of symptoms or challenging behaviour; instead, these communicate emotional distress, have known causes and can receive personalised interventions. The findings also offer a list of actions for hospital staff that are person-centred, attentive and validating, which offers alternatives to medical interventions such as prescribing antipsychotic medication. For hospital staff, the strong peer agreement over the most effective responses to emotional distress provides a succinct menu of interventions. This research recognises the existing skillset of hospital staff. If recognised in future best practice guidance, the promotion of achievable skills developed from practice could improve staff confidence and wellbeing, though this would need to be evidenced with further research. For the hospital system, the findings could guide investment in

developments in the hospital environment and staff team that will have the most impact for patients with dementia according to hospital staff, including training of the entire staff team with the expertise of multidisciplinary staff; currently, emotion-focused care is not explicitly taught and is variable across settings. For academic knowledge, the methodology was novel and succeeded in gaining succinct data from a representative sample. This could be replicated in other less accessible settings, such as prisons.

Impact was demonstrated by the immediate effects of involving a working hospital ward in discussions of ways to achieve emotion-focused care for patients with dementia, and through dissemination of the findings via participant feedback, journal publication, a blog post and conference attendance.

Participation of the full ward suggested that there was an appreciable level of interest from the staff and support from management. My field notes read: 'On day two, it seemed as though my presence on the ward, as well as participation in the study, was enjoyed! The research seemed to be a point of interest and some fun. Two student nurses were deciding who could go first, and seemed excited. A nursing assistant thanked me for inviting them to take part. Taking part had gained a positive reputation; I heard people in the corridor saying, 'shall I go next?' I had to ask somebody to wait until next week.'

In a different way, the study seemed to have immediate impact by modelling an opportunity for reflective practice, and the value of all professions within a hospital ward. Excerpts of the field notes read, 'After the study, somebody wanted to chat about their upcoming interview to be a nursing assistant, pleased to be talking about what they bring to the role … The Consultant Physician was 'very happy to take part' and asked to take a Participant Information sheet away 'because I'd be interested in finding this when it is published'.

After the study, eight staff members who took part requested a summary of the research findings (see Appendix 10). One staff member replied to the results summary emailed to them by saying 'Many thanks- this is really helpful. Would you mind if I circulated it to colleagues?'

The study was published in The Gerontologist. The journal's impact factor is 4.078, and the journal is ranked 3 out of 36 journals in Gerontology by Journal Citation Reports, which marks the quality and importance of this study in this area. Reviewer 1 of the peer-review process said: 'This is an important study that focuses on understanding and appreciating the subjective experience of people with dementia, especially their distress and the outward expressions thereof, when they are in hospital and what can be done by hospital staff to be helpful to such people. I think that this sort of qualitative approach is especially important and contributes a great deal to our understanding and development of good practice.'

As noted at the beginning of the thesis, a blog post on Dementia Day-to-Day reached a different audience from journal publication, because it is freely available on websites hosted by the University of Nottingham and Improving Dementia Education and Awareness, IDEA. The post received a comment from a professional caregiver who reflected on the changes they will make in their future practice.

Finally, a reflective article was written for Nursing Standard on how it felt to be a researcher in a hospital ward, where parallels were drawn with what it might be like to be a patient. Nursing Standard is produced by RCNi, a subsidiary of the Royal College of Nursing, which aims to provide nurses and associated health professionals with the latest developments impacting their practice. Daily news updates increase the dissemination of the content to its audience. Nursing Standard states it is the UK's best-selling nursing journal. This increased the likelihood of the study influencing the real world practice of nursing staff.

3.8 Chapter summary

In this chapter, a hospital ward staff team were interviewed to describe existing ways of noticing, understanding and responding to patients with dementia when they showed emotional distress. This study was designed following the arguments set out in Chapter 1, which were that people with dementia are vulnerable when in hospital, with serious risks to their physical and emotional wellbeing, and, hospital staff are expected to understand and respond to their emotions despite little guidance about how this could be achieved. A simple and focussed interview method was chosen, which achieved a large participant sample and full multidisciplinary representation. Results showed that the staff team had a shared approach, and this gave a menu of possible actions for delivering emotion-focused care. The most effective ways to respond to emotional distress were said to require knowing the person, talking with and being with the person. The findings emphasised existing resources within the staff team (see results, section 3.4, and discussion, section 3.5). The findings suggested that labels used to describe behaviour do not convey the personal and widely variable experiences of the patient, or the ways to help the patient feel better.

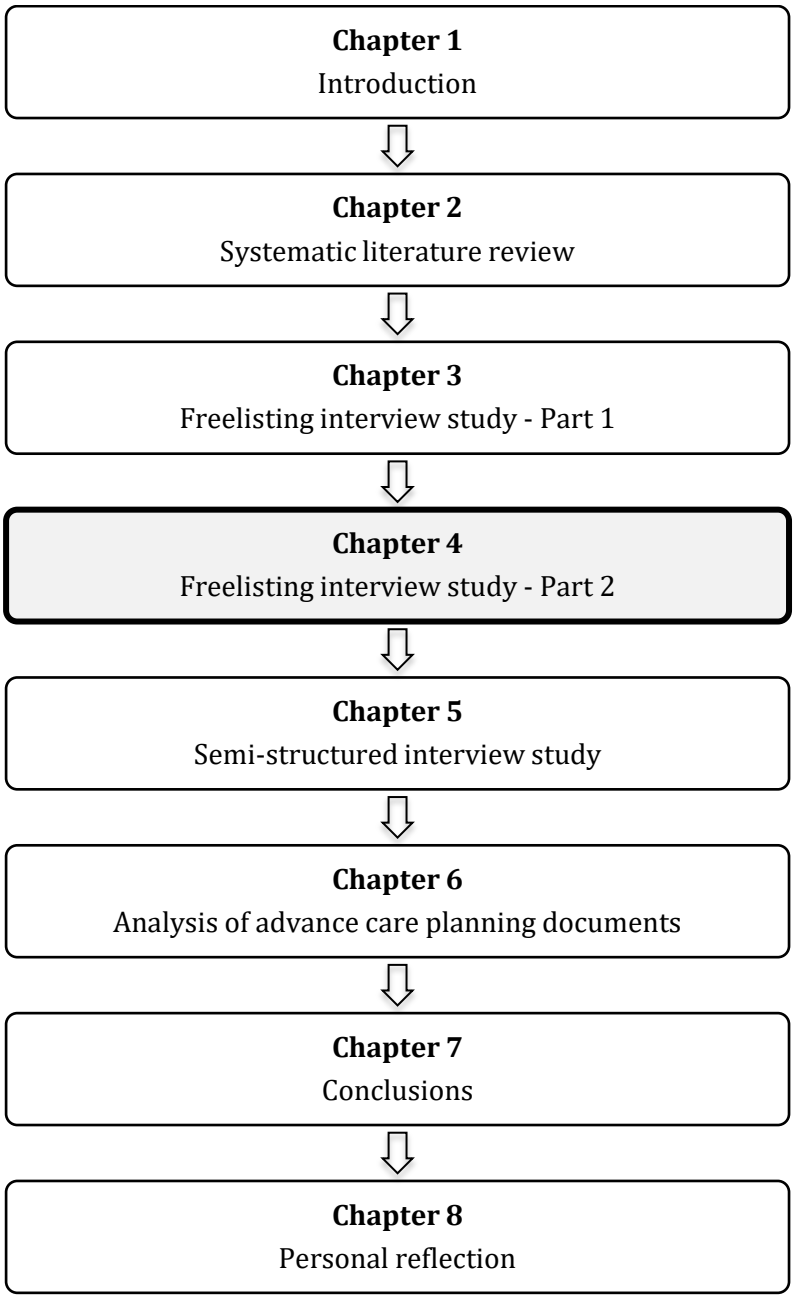
This is the first study of this thesis to conclude that person-centred care is recommended as the most appropriate response to emotional distress for hospital patients with dementia. The important components described first here were: knowing each patient as a person, being with them and talking with them.

The chapter then presented a critique of the work (3.6) and a discussion of impact (3.7). The main strengths were the participant sample and the emphasis on finding solutions fit for everyday practice. Immediate and anticipated impacts included providing improved understanding and more varied language to describe patient behaviour,

enabling reflective practice for the staff who took part and giving value to the expertise of multidisciplinary staff.

Further analysis of this interview data is presented in Chapter 4 in an exploration of how different staff members approach patient care differently.

Chapter 4. Study 2. Part 2. A freelisting interview study with ward staff. Personal and professional experience and the provision of person-centred care.



4.1 Chapter overview

This chapter presents a second analysis of data collected in the freelisting interview study introduced in Chapter 3. This analysis sought variations in how different subgroups within a hospital ward staff team approach dementia care; specifically, how care differed when staff members have personal experiences of caregiving for somebody with dementia or with the amount of professional caregiving experience that staff have. The aim, given in section 4.2, was to recognise existing skills of hospital staff and to recommend ways of improving patient care in achievable ways within the constraints of existing resources. This follows the rationale for the thesis given in the introductory chapter, Chapter 1, and thesis aims 1 and 2 (section 1.2): patient upset poses a particular challenge to hospital staff, and priorities of the hospital culture can make it especially difficult to work in person-centred ways.

The initial stages of data collection as described in Chapter 3 are summarised in brief in this chapter before the new research question and analysis methods are introduced (see section 4.3). The descriptions of care emphasised by staff members with differing care experiences were compared.

The study findings were published in an open access journal.

4.2 Aims

To detail how hospital staff with differing personal and professional caregiving experiences approach the care of patients with dementia when they show emotional distress, in order to inform practical recommendations to improve person-centred practice.

4.3 Methods

This study presents the analysis of intracultural variations in the approaches to dementia care across different subgroups within a hospital ward staff team. Specifically, I investigated whether staff with either personal experience of caregiving for a person with dementia or more years of professional experience than their peers approached care differently.

4.3.1 Participants

Participants were as described in Chapter 3, section 3.3.3. In brief, 47 hospital staff members constituted a whole ward staff team, working within an elderly medicine ward, within a teaching hospital in the UK. All ward staff who interacted with patients within their working role were invited to participate, and this was an attempt to recognise whole system working (Innes *et al.*, 2016).

4.3.2 Data collection

Data collection is described more fully in Chapter 3, section 3.3.5. Face-to-face, individual, freelisting interviews were conducted with all staff members in the hospital ward team. In each interview, staff were asked to keep in mind their working with patients with dementia and list as many items as they could to describe: (1) how they notice when a patient is emotionally distressed; (2) what they think causes patients to be emotionally distressed; (3) all the ways they respond when a patient is emotionally distressed; (4) of the ways to respond, all the things that seem to work.

4.3.3 Data analysis

Analysis methods for the comparison of the different staff subgroups are described here. These build upon the methods described in Chapter 3, section 3.3.6, which analysed the list data of the hospital ward as a whole.

Overview of staff subgroups

Cultural consensus analysis (Weller & Romney, 1988) was used to determine how different subgroups of staff described their approaches to care. Two sets of subgroups were created as follows.

Personal caregiving experience: the list data of staff members who reported personal experience of dementia caregiving, such as having a family member or friend with the diagnosis (n=18), were compared with the list data of staff without personal caregiving experience (n=29); this formed datasets for two staff subgroups.

Professional caregiving experience: the list data of staff members who had worked in a professional role with people with dementia for more than 15 years (n=15), were compared with the list data of staff who had worked with people with dementia for less than 5 years (n=18). This formed data sets for two further staff subgroups. The year boundaries chosen were a means of comparing staff with relatively more and fewer years of professional experience based on the demographic data in this study.

4.3.4 Cultural consensus analysis

ANTHROPAC analysis software (Borgatti, 1996) was used in the following ways, with close reference to example studies (Barg *et al.*, 2006; Schrauf & Sanchez, 2008). Firstly, recode and consensus procedures were used to apply factor analytic methods to

determine whether each staff subgroup reached a shared domain description in response to each of the four interview questions. As described in more detail in Chapter 3, section 3.3.6, consensus is shown by a single-factor solution, where the eigenvalues of the first factor and second factor formed a ratio of greater than 3:1. Chapter 3 presents the analysis of the list data for the full ward staff team as a whole; the analysis presented in this chapter was performed for each of four different staff subgroups.

Second, each staff member's agreement with the consensus description of the subgroup was given by a knowledge score; this was each staff member's loading on the first factor, with a maximum loading of 1.0. This analysis showed whether different staff subgroups formed a consensus in their approach to care and how much each individual staff member agreed with the consensus.

Salience of list items

For each staff subgroup, the freelist procedure was used to calculate the listed items that were highest in salience for each of the four interview questions. As described in Chapter 3, section 3.3.6, ANTHROPAC applies Smith's salience index (Smith, 1993) to measure how important an item is; an item with higher salience will have been mentioned more frequently and earlier in lists by people within the subgroup.

Group comparisons

Two group comparisons were made, between: (1) staff members with personal experience of dementia caregiving compared with those without, and (2) staff members with more years of professional caregiving experience compared with those with fewer years of experience.

For each comparison, the salience scores of items produced by one staff subgroup were subtracted from the salience scores of items produced by the second staff subgroup. This gave a list of difference scores ranging from positive values (items with higher salience for the first staff subgroup) to negative values (items with higher salience for the second staff subgroup). The list items at each end of the continuum show the emphasis of one group relative to the other (Schrauf & Sanchez, 2004). Qualitative differences in the items listed were then considered.

In addition, the mean number of items listed for each question was compared for staff with and without personal caregiving experience, and staff with more and fewer years of professional experience, using independent sample t-tests.

Finally, mean knowledge scores of each staff subgroup were compared with the mean knowledge score for the whole staff team for all four interview questions using paired sample t-tests; this shows the amount of agreement over the approach to care between members within a subgroup as compared with the full hospital ward.

I performed all analysis.

4.4 Results

4.4.1 Participant overview

Demographics of the full participant sample were as described in Chapter 3, section 3.4.1.

Demographic differences between staff subgroups were: both volunteers and three of four physiotherapists or therapy assistants had personal experience of caregiving; all other professions and genders were proportionately represented. The majority of staff without personal caregiver experience were aged 45-55 years; the majority of staff with

personal caregiver experience were aged 55 years or over. There were no differences of note in the representation of different professions or genders in the staff subgroups with more or fewer years of professional caregiving experience, however, all staff with more years of professional experience were aged 35 years or over and, collectively, were relatively older than staff with fewer years of professional experience, as might be expected.

4.4.2 Comparing approaches to dementia care: personal experiences of caregiving

Shared domain descriptions

Both staff subgroups, with and without personal experiences of caregiving, produced a single, consensus domain description in response to each of the four interview questions. Both subgroups listed an equal number of items for all four questions: no comparison of mean number of items between staff subgroups for the four questions reached statistical significance. Therefore, neither group was more or less able to describe their approach to responding to the emotional needs of patients with dementia; however, meaningful differences were revealed in the amount of agreement between staff and in the different items listed.

Staff agreement

Knowledge scores showed that staff with personal experience of dementia caregiving showed less agreement with each other as a subgroup than they did with the whole staff team in their responses to all four interview questions, as shown by lower mean knowledge scores: ways to notice emotional distress ($t(63)= 4.21$, $p< .001$); causes of emotional distress ($t(62)= 4.16$, $p< .001$); responses to emotional distress ($t(63)= 2.41$, $p= .019$); responses to emotional distress that seem to work ($t(63)= 2.96$, $p= .004$). In contrast, staff without personal experience of dementia caregiving did not differ

significantly in their level of agreement with each other when compared with the whole staff team. Therefore, personal experience was influential when forming a consensus approach. This means that ward staff with personal experience of dementia caregiving showed more variety in how they notice, understand and respond to the emotional distress of patients with dementia.

Comparison of list items

Tables 4-1a to 4-1d show the list items with the greatest difference in salience between staff with personal caregiving experience as compared with staff without, for all four interview questions.

Tables 4-1a to 4-1d. Top six list items with the greatest difference in salience between hospital staff with and without personal experience of dementia caregiving for each of four interview questions.

Table 4-1a. Interview question: how to notice emotional distress.

Higher salience items for staff members with personal experience of dementia		Higher salience items for staff members without personal experience of dementia	
List item	Difference in salience	List item	Difference in salience
The person will tell you: Patients are able to say that they are distressed, such as describing an emotion.	0.221	*Withdrawn*: Included being quiet, disengaged or subdued; patients were described as being distressed within themselves.	0.107
Body language or posture: Including descriptions of a patient waving, pointing or putting hands to their head.	0.197	*Asking for family or friends*: Included asking where family are, whether family are safe, whether family know where they themselves are.	0.105
Face or facial expression.	0.160	*Easily visible*: Distress was visible and seen by looking at somebody; or distress is obvious; 'it's not hard to tell'.	0.104
Seeking, searching, looking for someone or something: Didn't always describe what was being searched for.	0.118	*Anxious or frightened*.	0.103
Behaviour or actions: Sometimes described as a change for the person.	0.093	*Repeated questions*: Included patients not feeling reassured.	0.101
Knowing the person: To be able to notice distress; the patient not being their usual self, something being different.	0.082	*Wanting to leave*: Included attempting to leave; asking to go out or for doors to be unlocked, trying exit doors, banging doors, absconsion, calling for a taxi, asking about the train station.	0.081

Table 4-1b. Interview question: causes of emotional distress.

Higher salience items for staff members with personal experience of dementia		Higher salience items for staff members without personal experience of dementia	
List item	Difference in salience	List item	Difference in salience
Not knowing where they are: Disorientation, asking where they are and not knowing that they are in hospital.	0.176	*Overemphasis on reality or contradicted*: Included descriptions of others not understanding a person's reality and insisting on orientating them to present time and place, questioning them or not giving an answer that a patient expects to hear.	0.122
Strangers: Unfamiliar or unknown people, unfamiliar faces and voices and patients not knowing who is around them.	0.145	*Wanting to go home*: Missing home, asking to go home.	0.112
Hunger or thirst.	0.134	*Being away from loved ones*: Wanting to see family or friends, looking for them, not being with them, awaiting or not receiving visitors and not knowing where family are. Specific family members, such as 'mum' or 'husband', were mentioned. Descriptions also included feeling left or abandoned by family.	0.085
Expression difficulties: Patients being unable to express what they want to say or not being understood by others; included being unable to verbally express pain or emotions.	0.124	*Frightened, scared or fearful*.	0.077
The hospital environment: An unfamiliar, new or foreign setting; this included descriptions of an intrusive environment and descriptions of hospital bays and beds.	0.109	*Infection*.	0.063
Upset by staff: Included descriptions of the attitude, skills and manner of staff and the way people were spoken to causing distress; included staff being impatient and not understanding how to talk to somebody.	0.102	*Rumination, remembering the past*: Included patients replaying past scenarios, experiencing flashbacks of earlier life.	0.060

Table 4-1c. Interview question: responses to emotional distress.

Higher salience items for staff members with personal experience of dementia		Higher salience items for staff members without personal experience of dementia	
List item	Difference in salience	List item	Difference in salience
Empathise: Trying to understand, tuning in to what is troubling them, getting into their mind-set or universe; telling them they understand.	0.164	*It depends on the level of distress*.	0.134
Distraction: Sometimes distracting from the person's thoughts or mood; changing topic; distracting for a short time.	0.136	*Activities*: A range of games and puzzles were listed, including jigsaws, draughts, bingo, skittles crosswords and word puzzles, flower arranging and building.	0.109
Listening: Included telling the patient they are listening.	0.103	*Contact with family*: Enabling contact with family included speaking with family on the phone, allowing family to visit at flexible times or stay longer.	0.093
Sometimes can't help: Staff said they sometimes couldn't help or couldn't fully understand; not every time; included stating that they don't know the patient well.	0.100	*Reassurance*: Giving reassurance generally was listed without further description.	0.092
Mirroring: Mirroring the person, their actions or volume; described building off each other.	0.097	*It depends on the circumstances*.	0.063
Talking: Sharing conversation and stories; included talking whilst walking.	0.096	*Comfort*: Included descriptions of being calming or nurturing.	0.058

Table 4-1d. Interview question: responses to emotional distress that seem to work.

Higher salience items for staff members with personal experience of dementia		Higher salience items for staff members without personal experience of dementia	
List item	Difference in salience	List item	Difference in salience
Sometimes can't help: Staff said they sometimes couldn't help, sometimes nothing works or a response doesn't work; responses that work are never guaranteed.	0.110	*Reassurance*: Giving reassurance generally was listed, including reassurance not to worry or that problems would be resolved.	0.174
Empathise: Trying to understand, putting self in their place; telling them they understand.	0.101	*It depends on the level of distress*.	0.082
Knowing the person: Staff described having to know or get to know the person; included each person being different/unique; being person-centred; being patient-led; different responses working for different people.	0.088	*Contact with family*: Enabling contact with family included speaking with family on the phone, allowing family to visit at flexible times.	0.076
Comfort: Included descriptions of calming somebody, being nurturing or giving emotional contact.	0.077	*Allowing space*: To pace or let their anger out.	0.073
Change the member of staff: Included changing to a more familiar staff member or changing to a male or female staff member.	0.072	*Listen*: Included telling and showing the patient they are listening.	0.062
Consult colleagues: Included consulting with and learning from multidisciplinary colleagues.	0.067	*All/any responses*: Anything, everything or all of them was listed.	0.058

Staff with personal experience of dementia caregiving demonstrated a greater expectation that the patient would communicate their distress verbally or nonverbally through their facial expression or their body language. They emphasised that the staff member needs to know the patient as a person to be able to notice their emotional distress and their ways of communicating. In their responses to emotional distress, this staff subgroup was more likely to report that they empathise, talk to, listen to and mirror the patient. They were more likely to say that sometimes it is not possible to understand fully or respond helpfully. This suggests an approach to care that is responsive to each individual and is personalised. This subgroup also placed stronger weighting on the hospital being a cause of distress, including being with strangers, being in an unfamiliar environment and feeling upset by the manner of hospital staff.

In contrast, ward staff without personal experience of dementia caregiving placed more emphasis on the role of a patient's family in maintaining their wellbeing: they recognised that a patient might ask for their family when distressed and recognised that causes of distress included being away from loved ones and wanting to go home. This subgroup also stated they would be more likely to respond to emotional distress by contacting a patient's family for a telephone call or visit. They showed more caution in how to respond to emotional distress: they were more likely to state that their response would depend on the level of distress or would depend on the circumstances and they were more likely to say that a wide range of responses to distress work at different times.

The approach described by all staff was reassuring and comforting.

4.4.3 Comparing approaches to dementia care: professional experiences of caregiving

Shared domain descriptions

Both staff subgroups produced a single, shared domain description for each question; however, staff members with more years of professional experience listed significantly more items for ways to respond to emotional distress (mean 13.13, SD 4.94) than did staff with fewer years of professional experience (mean 8.33, SD 4.14), ($t(31)= -3.04$, $p= .005$), suggesting an accumulation of possible ways to respond to patients. They did not list significantly more responses that they deemed to work, as asked by the fourth question; this might suggest shared agreement between all staff of a limited number of effective responses.

Comparison of list items

Tables 4-2a to 4-2d show the list items with the greatest difference in salience between staff with more and fewer years of professional caregiving experience for all four interview questions.

Tables 4-2a to 4-2d. Top six list items with the greatest difference in salience between hospital staff with more years of professional experience and fewer years of working experience for each of four interview questions.

Table 4-2a. Interview question: how to notice emotional distress.

Higher salience items for staff members with more years of professional experience		Higher salience items for staff members with fewer years of professional experience	
List item	Difference in salience	List item	Difference in salience
Crying: Descriptions include crying, tears and weeping.	0.400	*The person will tell you*: Patients are able to say that they are distressed, such as describing an emotion.	0.168
Agitation: The words 'agitation' or 'agitated' are used; verbal or physical agitation is described.	0.384	*Body language or posture*: Including descriptions of a patient waving, pointing or putting hands to their head.	0.159
Unsettled, fidgety, not relaxed, fiddling: Being unsettled was described; descriptions include fiddling, fidgeting, fussing with items, tearing items, pulling at clothing or equipment, being flustered or unable to settle.	0.320	*Face or facial expression*.	0.130
Aggression: The terms 'aggression' or 'aggressive' were used without further description.	0.250	*Easily visible*: Distress was visible and seen by looking at somebody; or distress is obvious; 'it's not hard to tell'.	0.111
Descriptions included.			
Anxious or frightened.	0.207	*It is different patient to patient*: state distress is shown differently by different people; can include distress depending on the person's life experiences.	0.105
Knowing the person: To be able to notice distress; the patient not being their usual self, something being different.	0.142	*Behaviour or actions*: Sometimes described as a change for the person.	0.097

Table 4-2b. Interview question: causes of emotional distress.

Higher salience items for staff members with more years of professional experience		Higher salience items for staff members with fewer years of professional experience	
List item	Difference in salience	List item	Difference in salience
The hospital environment: An unfamiliar, new or foreign setting; this included descriptions of an intrusive environment and descriptions of hospital bays and beds.	0.242	*Lots of different things*: staff said there are lots of/a variety/a myriad of things that cause distress; the causes can change; the reasons for distress need to be worked out or analysed.	0.151
Infection.	0.153	*Being confused.*	0.117
Frustration.	0.143	*Strangers*: Unfamiliar or unknown people, unfamiliar faces and voices and patients not knowing who is around them.	0.113
Delirium.	0.129	*Being too hot or too cold.*	0.098
Missing belongings and objects: being without familiar things such as a teddy bear and sleeping in a different bed.	0.129	*Hunger or thirst*.	0.096
Not knowing where they are: Disorientation, asking where they are and not knowing that they are in hospital.	0.112	*Memory problems:* forgetfulness, forgetting having their questions answered, forgetting reassurance, being unable to recall their date of birth or items on a cognitive screening tool.	0.091

Table 4-2c. Interview question: responses to emotional distress.

Higher salience items for staff members with more years of professional experience		Higher salience items for staff members with fewer years of professional experience	
List item	Difference in salience	List item	Difference in salience
Space: staff listed offering a different or preferred environment, room or space. This included using the café away from the ward.	0.221	*Comfort:* Included descriptions of being calming or nurturing.	0.167
Reassurance: listed without further description.	0.144	*Ask the person:* asking what the matter is or why they are distressed, asking what they would like.	0.093
Empathise: Trying to understand, tuning in to what is troubling them, getting into their mind-set or universe; telling them they understand.	0.137	*Talking*: Sharing conversation and stories; included talking whilst walking.	0.091
A cup of tea.	0.130	*Leave them:* included allowing space for the patient to let off steam or wind down, being hands off, allowing them liberty, not stopping somebody from wandering, staff keeping their distance for the safety of colleagues or patients.	0.091
Touch: included holding a person's hand or offering a hug.	0.127	*Mirroring*: Mirroring the person, their actions or volume; described building off each other.	0.069
Body language: listed without further explanation, meaning staff used their body language in their response.	0.123	*Identify the cause or reason for distress*: identifying the problem or the need; fathoming, working out or getting to the grounds of the distress.	0.057

Table 4-2d. Interview question: responses to emotional distress that seem to work.

Higher salience items for staff members with more years of professional experience		Higher salience items for staff members with fewer years of professional experience	
List item	Difference in salience	List item	Difference in salience
Space: offering a different or preferred environment, room or space. This included quiet and still spaces.	0.280	*Knowing the person*: Staff described having to know or get to know the person; included each person being different/unique; being person-centred; being patient-led; different responses working for different people.	0.271
Touch: descriptions of touch included holding a person's hand or offering a hug.	0.133	*It depends on the circumstances.*	0.174
It depends on the level of distress.	0.126	*Listen*: Included telling and showing the patient they are listening.	0.148
Sitting with, being with, engaging with. Included descriptions of giving attention and being a person without uniform or equipment.	0.099	*Change the member of staff*: Included changing to a more familiar staff member or changing to a male or female staff member.	0.117
All/any responses: Anything, everything or all of them was listed.	0.076	*Talking*: sharing conversation, chatting, communicating.	0.114
Activities.	0.067	*Sometimes can't help*: Staff said they sometimes couldn't help, sometimes nothing works or a response doesn't work; responses that work are never guaranteed.	0.093

Personalised care was more prevalent across responses to all questions for the staff subgroup with fewer years of professional experience. These staff were more likely to say that they noticed distress through easily visible cues, such as from a patient's face, or through their body language. They expected patients to voice their distress. They were more likely to say that they needed to know the patient as a person and that they would listen to the patient. In contrast, staff with more years of professional experience were more likely to use surmised terms when describing emotional distress; they listed agitation, aggression and anxiety, which might suggest a shorthand developed over time.

4.5 Discussion

4.5.1 Interpretation of findings

Hospital care for patients with dementia requires improvement and would benefit from clear recommendations that apply to routine practice (Brooke & Ojo, 2017; Dewing & Dijk, 2016; World Health Organization, 2017). This study explored how existing resources of personal and professional caregiving experiences could differentiate between the reported approaches of hospital staff when patients show emotional distress. The results show that different staff subgroups emphasised varying features of person-centred care.

Staff members with personal experience of dementia caregiving prioritised knowing the person, achieving reciprocal communication and showing an understanding of the patient's perspective. The second staff subgroup comparison revealed complementary findings, whereby ward staff that were newer to a professional care role were more likely to notice each patient as a person and notice their individual communication. These findings make two notable contributions to the research literature. Firstly, the approach described by these two staff subgroups, staff members with personal

experience of dementia caregiving and staff members newer to professional caregiving, mirrors person-centred care (Brooker & Surr, 2006; Kitwood, 1997) and exemplifies the most positive aspects of hospital care described in the research literature by multidisciplinary hospital staff and family members (Scerri *et al.*, 2015); that is, to share a human connection, with a 'human touch' (Scerri *et al.* 2015, p. 4). The findings provide an example from practice of how hospital staff describe recommended approaches to care as their routine practice, such as that described by the VIPS framework (Brooker, 2007) and compassionate care (Dewar & Nolan, 2013). The emphasis on being with and connecting with a patient at times of suffering has been long-embedded in the ambitions of the caring profession since the time of Florence Nightingale, but has been underrepresented in the delivery of care for patients with dementia (Davenhill, 2008). The findings from the present study suggest that this approach to care can be enhanced by novice and personal perspectives of caregiving. These staff said they communicated with the patient, hence they involve patients in their care; such involvement is required as a fundamental standard of person-centred care and is particularly lacking for patients with dementia when in hospital (George *et al.*, 2013).

In previous research (Griffiths *et al.*, 2014), hospital staff have expressed having more confidence in their working when they have personal experience of dementia caregiving. The current study suggests that personal experience of dementia caregiving contributes knowledge, confidence and a positive attitude to professional working, as described elsewhere (Griffiths *et al.*, 2014; Tropea, LoGiudice, Liew, Roberts, & Brand, 2017).

I also speculate as to whether career longevity promotes knowledge, but fosters a 'professional' approach to dementia care whereby technical expertise and shorthand are valued for the purposes of documentation and risk management (Digby *et al.*, 2016). This shorthand is consistent with expert thinking that has been refined over time, as

compared with staff newer to the profession who make decisions more slowly and are influenced by more information (Shanteau, 1992), such as that relating to each individual patient. Traditional training in dementia care has prioritised medical care (Brooke & Ojo, 2017), which reflects the approach prioritised here by longer-standing staff; in this study, staff with more years of professional experience tended to describe behaviour as agitation or aggression and were more likely to list medical causes of emotional distress such as infection or delirium, which suggests an approach that overlooks the complexity of a person beyond diagnostic criteria. In a review of dementia care, Digby *et al.* (2016) concluded that 'efficiency has been misinterpreted to exclude empathetic care' (p. 1168). This interpretation does not dismiss the dedication of staff who sustain a career in working with patients with dementia, as was shown in the compassionate responses of all ward staff in this study. Instead I aim to recognise the variations in approaches within a team.

4.5.2 Implications for practice

I recommend that the personal caregiving experiences and the novice curiosity of hospital staff delivering dementia care are considered to be two areas of expertise within staff teams. For example, the approaches described in this study could contribute valuable content to staff training interventions; training in the format of learning with colleagues and embedding learning in routine practice has been reported to be more effective in improving personalised dementia care than formal training interventions, which are not always suitable in their content and are not available to all staff (Griffiths *et al.*, 2014; Surr *et al.*, 2016). The current findings support future investment in models of training whereby colleagues who have differing expertise learn with and from each other. Flexible training formats (Surr *et al.*, 2016), which emphasise collaborative learning and the sharing of existing expertise, are recommended.

The person-centred approach described could also be given merit by hospital management and clinical leaders. Hospital staff have expressed beliefs of having little authority or permission to influence routine patient care (Brooke & Ojo, 2017), though their contributions to service development and delivery can be particularly valuable in the delivery of person-centred dementia care (Brooke & Ojo, 2017; Griffiths *et al.*, 2014). Hospital staff providing dementia care have asked that their existing knowledge and skills be recognised (Brooke & Ojo, 2017). This study shows the potential value of developing a hospital culture of staff learning together and sharing approaches that work.

Possible benefits to sharing expertise amongst multiple professions include building a reliable skillset that is more resistant to staff turnover and is valuable when family members are not consistently available.

4.5.3 Implications for research

These findings require follow-up in three ways: first, with replication beyond a single UK hospital ward; second, with further exploration of how patient, staff and the hospital system variables interact to complicate the delivery of person-centred care; third, with evaluative studies of how personal experience and professional curiosity can be prioritised in practice. These are discussed further in Chapter 3, section 3.6. Future research would benefit from measuring staff knowledge, attitudes and training in dementia care as possible confounding variables in the delivery of person-centred care, alongside measures of personal and professional caregiving experiences. It may also be that different professional groups describe different approaches, which could be researched.

4.6 Critique

Strengths

Primarily, I sought to discover the existing expertise within routine hospital care using the ethnographic freelisting method. This is important given the manifold barriers to hospital staff implementing best practice dementia care, such as having limited time (Brooke & Ojo, 2017; Samra *et al.*, 2015; Surr *et al.*, 2016; Tropea *et al.*, 2017). The study built upon prior research recommendations to minimise future investments in interventions that rely on theoretical models of care only and have not been tested in a clinical setting; this is to increase the real world impact of the research (Dewing & Dijk, 2016). The findings offer some discussion as to how person-centred approaches could be enhanced, and how patients with dementia could be involved in their care by staff members who describe being skills in facilitating this (National Institute for Health and Care Excellence, 2018; Ocloo & Matthews, 2016). The sample was representative of a UK hospital ward staff team that included different professions.

Limitations

As discussed in Chapter 3, section 3.6, the approach described by ward staff does not necessarily equate to care delivered for all patients at all times. Whilst the results have detailed the knowledge of staff, it was beyond the design of this study to directly observe their behaviour. The generalisability of the findings is limited by the setting being a single hospital ward in the UK. The findings require more robust testing and replication.

4.7 Impact statement

The study was published in BMJ Open as open access; further information of the benefits of open access is presented in section 7.4 Impact. The impact factor of BMJ Open at the time of publication was 2.413.

Comments received via peer review of the study suggested the findings might have a positive effect in the wider world. Of note, Anthony Scerri reviewed the study: his research into quality hospital care for patients with dementia is cited throughout this thesis (Scerri *et al.*, 2015; Scerri *et al.*, 2017) meaning his critique was gratefully received. Scerri said: 'This qualitative study sought to show how personal and professional caregiving experiences of hospital staff influence their person-centred care practices. The study is well conceived with a robust sample of different health care professionals working in one site. The discussion/conclusions drawn are logical and derived from the findings.'

Final comments following peer review from Iain Wilkinson were: 'I would happily accept this for publication. For me it explores an under explored area that will have implications for the make up of teams across the UK.'

4.8 Chapter summary

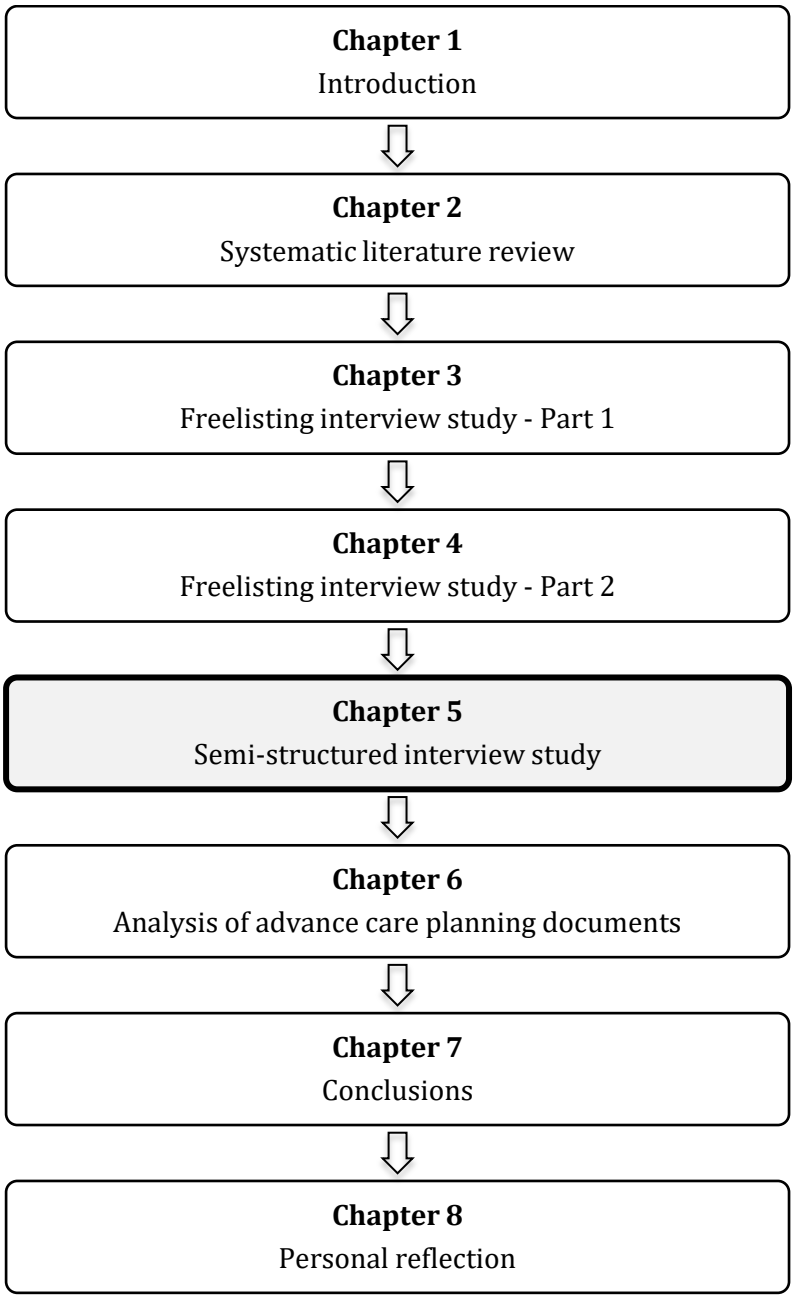
This chapter presents a second analysis of data from the freelisting interview study with hospital staff introduced in Chapter 3. It is the second study of the thesis to conclude that person-centred care is recommended as the most appropriate response to emotional distress for hospital patients with dementia; it adds that this approach can be enhanced by valuing existing characteristics within a hospital staff team, including newness to caregiving and personal perspectives of caregiving. These staff subgroups were more likely to say that they notice each patient as a person and share a human

connection (see Results, section 4.4 and Discussion, section 4.5). A recommendation for practice is for hospital staff teams to share existing expertise amongst each other. The attempt to find practical solutions suited to the constraints of hospital care was the main strength of the study (see the critique offered in section 4.6).

Open access publication and comments received via peer review are discussed within an impact statement for the chapter (section 4.7).

The next chapter builds on these findings and presents a semi-structured interview study that sought to understand the conditions under which delivering emotion-focused care in a hospital setting is more or less likely when taking into account hospital priorities and resource constraints; as in Chapters 3 and 4, this explicitly seeks solutions for improving care delivery for patients with dementia within hospitals.

5. Chapter 5. Study 3. A semi-structured interview study with hospital staff. Facilitators and barriers to providing emotion-focused care for patients with dementia when in hospital.



5.1 Chapter overview

This chapter presents an interview study consisting of 12 semi-structured interviews with hospital nursing staff, employing a qualitative design. The hospital sample is different from that in Chapters 3 and 4; in this study, participants were recruited from two long-stay hospital wards providing care for patients with dementia admitted because of behaviour found to be challenging, and the sample consisted of nurses and nursing assistants only. This was in keeping with the main study aim, which was to explore the facilitators and barriers to staff delivering emotion-focused care within hospitals: findings were derived from a setting familiar with patient distress and were descriptions of routine practice from frontline hospital staff. This meets research aims 1, 2, 7 and 9 of the thesis (see section 1.2).

This chapter also introduces ways of promoting the emotional wellbeing of patients with dementia more generally, in addition to considering responses of healthcare staff at times of patient emotional distress.

Interviews were analysed thematically to give a representative overview of how staff said they could achieve emotion-focused care (see methods section 5.3).

5.2 Aims

The aim of this study was to use the expertise of frontline hospital staff to recommend ways of caring for the emotional wellbeing of patients with dementia within existing resources by asking about known facilitators and barriers.

5.3 Methods

5.3.1 Participants

The setting of this study was two wards within a hospital in the UK offering long-term placements for patients diagnosed with dementia and mental and physical health comorbidities, admitted because of behaviour found to be challenging. Mean patient age was 75 years (SD 7.98); mean duration of stay was 2.43 years (SD 2.06) for 27 beds. A multidisciplinary staff team supported nursing staff and included a consultant psychiatrist, clinical psychologist and occupational therapist. Physiotherapy, dietetics and social work involvement required referral. The setting was chosen in an attempt to find solutions where care delivery was complex (National Institute for Health and Care Excellence, 2018) to ensure that any recommendations were fit for real world practice.

Participants were employed as Registered General or Mental Health Nurses or nursing assistants for a minimum of three months. Participants were recruited using non-random convenience and volunteer sampling. 12 participants were recruited in an attempt to reach stable interview responses (Guest, Bunce, & Johnson, 2006); according to Guest *et al.* (2006), the main themes emerging from interviews with a homogenous sample of participants, who are from a shared culture with shared cultural knowledge, can be found in the range of 6 to 12 interviews.

5.3.2 Data collection

A qualitative study was undertaken using thematic analysis (Braun & Clarke, 2006), which comprised semi-structured interviews for data collection, multiple coders of interview data and independent audit for the data analysis before consensus was reached on the factors that facilitate hospital staff meeting the emotional needs of patients with dementia.

Written study information was made available to nursing staff via the ward manager within ward meetings and via email (see Appendix 11). Interviews were conducted by me personally in a confidential room on each of the wards. A semi-structured interview guide was used (see Appendix 12): participants were asked to describe their role and the hospital context, their own and colleagues' practice, and the facilitators and barriers to emotion-focused care provision. Participants were then asked if anything important was missing from the questions or their responses. Thus, staff were asked for an overview of the care system and the actions of staff across the hospital. Participants were then asked to complete a written demographics questionnaire. Interviews lasted 9-24 minutes (mean duration 15 minutes), were audio-recorded and transcribed in full by me personally.

5.3.3 Data analysis

I undertook thematic analysis of the interview transcripts following an established six-step protocol (Braun & Clarke, 2006). The stages of the analysis were:

1. Familiarisation with the data through repeated listening to the interviews, during transcription and repeated reading of the transcripts for data analysis. An example transcript is shown in Appendix 13.

2. An inductive approach meant details in the text that explicitly answered the research question were given a code. No themes for coding were identified in advance. Colour and text annotations were used within standard computer software to mark coded text. Text could be retained beneath more than one code to retain the full meaning of participants.

3. A coding scheme was drafted by me personally and developed in consultation with all supervisors over three iterations; this was to introduce different perspectives into the

analysis and code responses to the research question in as many ways as possible. Each iteration of the coding scheme was based on all 12 transcripts. Three iterations of the coding scheme are shown in Appendix 14. Codes were grouped together into possible themes to organise the data set. A theme was a summary of something important that repeated across the dataset in answering the research question. Any discrepancies in the coding of transcripts were resolved through discussion with all supervisors and documented in the refinement of the coding scheme.

4. An independent auditor with relevant experience examined the code framework and code descriptions. The auditor was a clinical psychologist with research experience. Three transcripts were coded independently by the auditor and by me personally to improve the reliability and validity of results; recommendations made by the auditor were minor and were followed. Audit thus offered a check of whether the interpretation of the data was overly biased by the researchers' own perceptions. For the multiple-rater coding of transcripts, the percentage agreement was 65% for a total of 154 quotes, meaning both reviewers selected the same code from a possible 31 codes on these occasions. Cohen's kappa was used as a measure of agreement; the calculation makes an assumption that reviewers were selecting from a small number of categories and that the categories were mutually exclusive. Therefore, if the reviewers agreed to include the same quote and assign any code, meaning a quote was retained for the results, Cohen's kappa showed agreement at $\kappa = .70$, which is 'substantial agreement'. The following revisions were made from the auditor's recommendations: the descriptions of three codes were edited and a further description was added to explain how uncoded text was used. Firstly, the description of '1bivP Promoting happiness' was refined to make clear that staff actions were using humour and emphasising the happy side of things; second, '1bvR Remembering the patient' was edited so staff actions were not confused with a more general definition of person-centred care; third, it was made clear that 'sitting

with', 'being with' and 'listening' to the patient were part of '1biE Entering into the patient's experience'. The explanation added to the beginning of the coding scheme stated that definitions given of emotion-focused or person-centred care would be used to describe the context of the findings, along with descriptions of the hospital, but would not be coded as staff actions.

Data saturation was deemed to be achieved when the final two interviews did not generate new codes.

5. Themes were named, informed by discussion with all supervisors and in response to feedback from the auditor.

6. Interview quotes were presented throughout the description of findings to exemplify the conclusions drawn.

In using this method, the data collected was distilled through an iterative process to reach a concise answer to the research question.

The consolidated criteria for reporting qualitative research (COREQ) were used for transparency (Tong, Sainsbury, & Craig, 2007), shown in Appendix 15.

5.3.4 Thematic analysis

Thematic analysis (Braun & Clarke, 2006) aims to find something, all things, important in a dataset, even if they occur infrequently, so that all relevant features are noted and coded. Coded features are then grouped into themes and sub-themes, and the research seeks to find an overarching map of the disparate or overlapping themes. The map tells the story of the data (Braun & Clarke, 2006).

5.3.5 Alternative analysis methods

Different qualitative research methods were considered, and thematic analysis was selected as the most appropriate analysis method for answering the research question. Given the absence of prior literature to inform more focussed questions or a structured topic guide, I did not adopt framework analysis (Ritchie, Lewis, Nicholls, & Ormston, 2013). Practical restraints of the small sample and single research site meant I did not intend to develop a generalisable theory of care delivery, for which grounded theory could have been suitable (Walker & Myrick, 2006). I did not intend to explore the meaning of care delivery to participants by seeking rich detail from the lived experiences of staff, as methods such as interpretative phenomenological analysis could facilitate (Smith, Flowers, & Larkin, 2009). Other methods that were briefly considered and discarded would have offered an analysis of the structure and meaning of language being used by healthcare staff, using discourse analysis (Burman & Parker, 1993), or observation of the language used within healthcare interactions between staff or patients, using conversation analysis (Hutchby & Wooffitt, 1998). These questions were not the focus of this study. Finally, I did not intend for healthcare staff to tell the story of their care delivery (Murray, 2003). The question asked was of an overview of the care system. Thematic analysis was selected because it emphasises the semantic content of interviews, or that which is explicitly said by participants. It is independent of epistemology, thus providing a transparent way to describe the responses of healthcare staff without favouring theoretical assumptions. It was selected to give a preliminary and robust overview of how hospital staff described ways of achieving emotion-focused care.

5.3.6 Ethical considerations

The study was approved by the hospital's directors and the University of Nottingham (Division of Psychiatry and Applied Psychology Research Ethics Sub-Committee, 0242). Participation was voluntary and written informed consent obtained. All data were anonymised at the point of interviews being transcribed and forming the data for the analysis.

All participants had capacity to consent to taking part; staff only participated if they read the participant information, chose to participate, signed the consent form and contacted the researcher. A gatekeeper, the hospital's Clinical Records Manager, was required for access to potential participants to minimise staff feeling obliged to participate; potential participants were not approached personally, but invited to take part collectively with their colleagues. There were no anticipated disadvantages to participants of taking part in the study. None of the questions were intended to be difficult to answer, but participants were informed that they did not have to answer any questions and could end the interview at any time without giving a reason and were directed to support should they find the discussion upsetting. There were no anticipated disadvantages to me as the researcher. For this analysis, it was important to declare that I am female and was employed as a Clinical Psychologist and PhD researcher at the time of data collection and analysis. I did not work as a colleague to any participant.

5.4 Results

5.4.1 Participants

Eight of 12 participants were nursing assistants; four were registered nurses, one with senior status. This was of approximately 50 potential participants. Most were female (n=7), White British (n=10) and mostly aged 25-44 (n=8). Mean length of time working

with people with dementia was 11 years (SD 10.8, range 1-40). Three staff members chose not to participate after reading the study information.

5.4.2 Facilitators of emotion-focused care

Three themes emerged, shown with accompanying subthemes in Table 5-1. Illustrative quotations are given in Table 5-2. Descriptions of the hospital environment are given throughout to describe the conditions that make different staff actions more or less possible.

Table 5-1. Coding scheme for thematic analysis of interviews with hospital nurses and nursing assistants (n=12) showing facilitators and barriers to emotion-focused care for patients with dementia.

Theme	Subtheme
1 Interpersonal factors	
Personalising care	Accessing information
	Investigating reasons for emotions
	Tailoring responses
Care interactions	Empathising
	Being patient-led
	Using nonverbal communication
	Promoting happiness
	Maintaining the care interaction
2 Service design	
Prioritising emotion-focused care	Having shared motivators
	Modelling and leadership
	Going over and above the task culture
Staff team composition	Team working
	Multidisciplinary working
	Making use of the variety of staff characteristics
Therapeutic resources	Increasing the involvement of family in care
	Increasing the use of therapeutic activities
	Increasing community involvement
3 The hospital context for emotion-focused care	
The hospital environment	Enhancing patient belonging
	Accessing outside spaces and providing freedom of movement

Theme 1: Interpersonal factors

Personalising care

Staff said that they made use of the following resources prior to approaching a care interaction with a patient: personal patient information, knowledge of dementia and emotions, and understanding of what had worked or not worked before in the hospital setting.

Staff said they needed to know the patient as a person to meet their emotional needs, including how each patient expressed their emotions. They needed access to information provided by the patient, their families and health professionals and to know that useful information existed and how it was stored. At the point of patient admission, relevant information was often not readily available or presented concisely.

Staff said they asked patients about their emotional needs; they viewed this as ideal. Information could be from personal books prepared prior to admission, which can help staff to be less reliant on patients' verbal abilities. Staff accessed information generated by previous care teams and information from family members, about sources of enjoyment and comfort.

By knowing the patient personally, staff with the most experience of working with people with dementia said they could anticipate the likely reasons for different emotions, which prevented high levels of distress and rapid changes in emotion for patients; half of the staff said it was difficult to calm somebody when their level of emotional distress was high, such that the patient becomes distraught and distracted by their upset. Tailored responses could include adapting communication by preparing visual aids. Staff said there was no consistent way to relieve upset for all patients.

Care interactions

Within interactions with patients, staff could modify their actions to pause and notice patient emotions, allow the patient to experience their thoughts and feelings without trying to change them, offer touch, share positive emotions and hold the patient in mind when away from them.

Staff described feeling emotions themselves to identify with patient experiences. They chose to be with and talk with patients, and imagine the patient's perspective. Some staff said they entered into being confused and attempted to understand visual misperceptions and hallucinations.

Some staff said it was important not to offer superficial reassurance and tell patients that everything was OK when it wasn't. Staff chose words carefully to explain their actions, to let the patient know that somebody was there to look after them and that they were in a safe place. In one example given, a staff member said they would not repeatedly return a patient's bags to their room when the patient kept bringing them to the hospital entrance, showing that they were unhappy and wanting to leave hospital.

Though some said it was difficult to understand patient needs, they said they could nonetheless gauge when different responses were more or less helpful by reading nonverbal cues. This was important as patients often have reduced verbal language. Staff themselves used nonverbal communication to portray patience and understanding, offer touch and sit close at hand, to help when patients misunderstand verbal language.

Staff said they sometimes used humour and emphasised the happy side of things. They found sharing positive emotions to be rewarding.

Staff described the effort required to recall personal information when with the patient, and to keep the patient 'in mind' when away from them before returning to the patient,

sometimes after a number of minutes, sometimes to try a different approach. This was especially important when patients withdrew from expressing themselves. Many said the impact of keeping patients in mind carried a cost of feeling upset and disappointed in their role.

Theme 2: Service design

Prioritising emotion-focused care

Emotion-focused care was facilitated by shared motivators of duty, respect and honouring patients' human rights, and by an organisational ethos of leaders giving permission to promote emotional wellbeing alongside other prioritised tasks.

Staff said that valuing the person as a human being, the same as before the illness, with the same interpersonal needs for comfort as any other person, was the reason for getting to know the person, and treating them and their belongings with care. Many said that hospital leaders needed to encourage and model emotion-focused behaviours and judge them to be positive; an example given was of senior staff members spending time with patients.

Staff said it was difficult to identify specific actions that were emotion-focused when they were commonplace, such as being flexible with timings of care interventions, communicating throughout interventions and spending time with the patient following interventions. When additional time was needed, staff would make an effort to find small increments of time, even a few minutes. They said they persisted in making this effort in the context of having insufficient time to spend with patients. Staff said they worked with, rather than against, routine care tasks, such as providing food and

completing documentation, because such tasks were important and provided daily structure.

Staff team composition

Team working, contributions from multidisciplinary professions and personal caregiving experience were reported as existing team resources.

Team working, through attending meetings, attending supervision and observing colleagues to learn from them had the purpose of sharing approaches to care that worked. This was thought particularly valuable because times of increased patient need were difficult to predict and team working did not depend upon staffing numbers. However, staff agreed that emotion-focused care was facilitated by a service designed with sufficient and consistent staffing. Not all staff understood the service design and said having adequate staffing to support patients emotionally was good luck or a blessing.

Multi-disciplinary working supported the complexity of patient presentations, which included physical ill health and end of life care.

Staff said patients benefited from having choice of staff gender. They described benefits of having team members with more personal experience of dementia-caregiving, which they said often taught them how to provide emotion-focused care that was missing from formal training. Different staff members built relationships with patients in different ways, which was said to be a further benefit of team variability.

Therapeutic resources

Involving family and friends in care was said to be important, as was using therapeutic activities and community connections. Staff said they invited family to participate in hospital events or made telephone contact so patients could speak with family members. Staff asked for pictures and memories of family.

Recommended activities included reminiscence (for happiness, competence and inclusion), music, sensory resources (with spaces where sounds and scents could be adapted), dolls and animals, which could promote positive emotions or offer distraction from emotional distress. Visiting community events and being visited by external agencies were examples of community involvement.

Theme 3: The hospital context

Staff reported that hospital could be perceived as intense, overstimulating, busy, undignified and regimented. Patients could feel fear, sadness or anger. Staff described their attempts to reduce negative impacts of hospital by being present in the environment and including patients in conversation, to enhance belonging.

Staff said that patients benefitted from an environment that was familiar and provided associations with their life, having access to outside spaces and spaces that offered low stimulation. The restrictions of a hospital environment, such as locked doors, were said to make this difficult.

Table 5-2. Illustrative quotes of themes from interviews with hospital nurses and nursing assistants (n=12) describing facilitators of emotion-focused care for patients with dementia.

Theme 1 Interpersonal factors
Personalising care
'speaking just to the actual person, because they'll be able to tell you something, even if it is only a tiny little thing, that tiny little thing could make their life a lot easier' (P12)
'what I try and do is try and understand who they once were, try and find out who they are now and blend that together' (P7)
The care interaction
'I suppose you, you're almost feeling it with them, it's kind of empathy… I think you almost have to enter into what that person's feeling to be able to support them' (P1)
'I think the thing about positive emotions is that you make a connection, a really strong connection with people, and it's really lovely (…) and it feels like you've reached the person that's inside, that's really valuable' (P1)
Theme 2 Service design
Prioritising emotion-focused care
'I think having it engrained in the day-to-day running, making it be ok to just sit with somebody and talk to somebody and hold their hand and give them that reassuring comfort' (P2)
Staff team composition
'also work colleagues you know, watching how colleagues, whether they're nurses, nursing assistants, therapists, psychologists, psychiatrists, just watching how they interact and learning what works' (P7)
'if I can't do it personally, get somebody else, do you know if someone else isn't busy, just say 'can you just go and spend five minutes with them' (P12)
Increasing the use of resources
'get the family involved… if you need to ring her daughter you know the family can help' (P4)
Theme 3 The hospital context
The hospital environment
'exchanges between staff and patients can normalise a situation, cause more of a homely environment rather than an institutional one' (P6)

5.5 Discussion

5.5.1 Interpretation of findings

This study presents the ways that hospital staff say they can meet the emotional needs of patients with dementia, by way of addressing an outstanding and high priority healthcare concern. This study adds to the literature that attempts to promote the emotional wellbeing of patients with dementia, draws on hospital nursing staff's existing expertise and provides suggestions suited to the hospital setting.

Table 5-3 summarises the recommended actions for staff across a hospital setting to meet patient emotional needs.

The findings expand upon what has only been mentioned in brief in the literature previously; in studies from the UK and Sweden, actions to promote patient emotional wellbeing have been described indirectly, alongside other care priorities (Crowther *et al.*, 2018; Edvardsson *et al.*, 2011; Handley *et al.*, 2017; Schneider *et al.*, 2010). Table 5-4 shows recommendations of good practice made in previous research studies that aimed to improve the emotional wellbeing of patients with dementia. Previous studies have used a range of methods and participant samples, including interview, participant observation, and document analysis designs, with hospital staff members, non-hospital healthcare staff (including GP and social work professions) and people with dementia as participants. This suggests there is agreement that emotion-focused care described here falls beneath a broader umbrella of best practice, of person-centred care. The actions described in this study can be recognised within descriptions of person-centred hospital care (Clissett *et al.*, 2013; Edvardsson *et al.*, 2014). Thus, the work has significance beyond the UK.

Building on research that has sought to identify good practice in emotion-focused care specifically, as discussed in Chapters 3 and 4 of this thesis, this study sought the facilitators and barriers that underpin how this practice can be achieved.

Perhaps the most significant finding of this study is the list of suggested solutions for hospital staff attending to the emotional wellbeing of patients with dementia, shown in Table 5-3; these provide an alternative perspective to the known hopelessness and barriers to delivering tailored hospital dementia care (Crowther *et al.*, 2018; Dewing & Dijk, 2016; Digby *et al.*, 2016; Scerri *et al.*, 2017; Surr *et al.*, 2016) and add to the limited descriptions of what person-centred dementia care looks like in practice. The suggestions for practice could inform hospital policy that reflects a person-centred ethos; qualitative research into personal perspectives of healthcare has been lacking in hospitals and therefore has been slow to inform policy (Godfrey, 2015).

Not previously recognised in the literature, staff said they allow patients to experience their thoughts and feelings without dismissing them, they keep patients in mind when away from them and they make use of the variability in staff-patient relationships. These actions require a shift from the usual hospital care priorities, whereby hospital staff often have little time to think beyond their to-do list, which can depersonalise patient care (Digby *et al.*, 2016); however, they are not recognised by the hospital system as it is currently designed. The actions are not easily measureable and require personal effort that takes an emotional toll, as described in this study. I suggest that the findings reveal what has been done by hospital staff for a long time, but not before described in research.

Table 5-3. Recommended staff actions to improve the delivery of emotion-focused care for patients with dementia; results from interviews with hospital nurses and nursing assistants.

Optimise existing resources
-access existing documents containing personal information provided by the patient and file notes; what is usual; how would emotional distress show?
-create documents through conversation with patients and family and choose a concise presentation format
-pause to share the patient's experience
-reassure the patient of their safety and staff intention to provide care
-match non-verbal communication with verbal communication
-document what works and does not work for each patient
-promote values of respectful, humane care through staff recruitment, modelling and appraisal
-use small increments of time and routine tasks to be with patients
-share happiness
-share expertise within the team; share tasks to use team member strengths
-encourage family involvement
-use sensory, relational and reminiscence activities, such as animal or doll resources
Invest in:
-therapeutic activities, including community connections
-outside spaces and low-stimulus spaces
-consistency of staffing

Table 5-4. Summary of recommended practice to promote the emotional wellbeing of patients with dementia reported in previous research.

Recommended care practice	Previous research
Interpersonal factors	
accessing information from the patient, their family or care professionals about the patient's usual self and their ways of communicating	Crowther *et al.*, 2018; Handley *et al.*, 2017
investigating reasons for patient emotion, with the intention of reducing distressed behaviour	Handley *et al.*, 2017
tailoring staff actions towards patients by learning what works	Handley *et al.*, 2017
entering the patient's experience largely through being with the patient	Crowther *et al.*, 2018; Handley *et al.*, 2017
communicating nonverbally to offer comfort using manner and touch	Schneider *et al.*, 2010
promoting positive emotions through positive comments, sharing smiling and laughing and coming together for daily activities	Edvardsson *et al.*, 2011
Service design	
sharing principles of dignity, respect and pride in care delivery	Crowther *et al.*, 2018
leaders modelling a culture of caring for emotional wellbeing around routine care tasks	Crowther *et al.*, 2018; Edvardsson *et al.*, 2011; Handley *et al.*, 2017
staffing the team sufficiently	Crowther *et al.*, 2018
working as a multidisciplinary team	Crowther *et al.*, 2018; Handley *et al.*, 2017
valuing experiential learning	Handley *et al.*, 2017
involving families in care	Crowther *et al.*, 2018
using therapeutic and community activities	Finnema, Dröes, Ribbe, & Van Tilburg, 2000
The hospital context	
reducing negative impacts of the hospital environment	Edvardsson *et al.*, 2011

When compared with what is known of patient priorities when in hospital (Chapter 6 in this thesis; Cowdell, 2010), staff in this study more clearly described elements of service design, such as team configuration and team working, but otherwise described the same priorities as patients.

The themes reflect a simplified version of an existing work system model of clinical practice (Carayon & Smith, 2000), which suggests that the findings are thorough and could have valuable applications; the model includes details about patient needs, the care task, knowledge, skills and experience of staff members, team performance, staffing, workload and managerial support within the work environment, the resources, culture and priorities of the organisation and the physical environment. These were all described in this study as being important considerations for improving patient care.

5.5.2 Implications for practice

Findings suggest that there is value in making use of readily available information, flexible use of existing team resources and a philosophy from leaders to 'be with' the patient for routine tasks. All of these require minimal outlay and could improve hospital care for patients with dementia (Brooke & Ojo, 2017; Houghton, Murphy, Brooker, & Casey, 2016). Concise formats such as advance care planning documents can collate personal information (see Chapter 6) and can be shared through computerised systems (Griffiths *et al.*, 2014). Expertise of staff members can be shared through experiential learning (Griffiths *et al.*, 2014; Handley *et al.*, 2017); in this study, hospital staff demonstrated relevant knowledge and experience, as they have in previous studies (Ashton & Manthorpe, 2017). Sharing of positive emotions with patients is little discussed in hospital dementia care and could improve patient and staff satisfaction, and partly manage the toll on staff of sharing patient distress (Brooke & Ojo, 2017; Crowther

et al., 2018; Griffiths *et al.*, 2014). The notion of healthcare staff needing permission from leadership to act in ways that will best meet patients' needs is recognised in other healthcare settings (Crosbie *et al.*, 2019); the latest qualitative evidence synthesis, by Reilly and Houghton (2019), agrees that hospital managers must promote a multidisciplinary and person-centred ethos to improve the experience of patients with dementia. The findings also repeat previous recommendations for family members to have greater presence in hospitals (Boaden, 2016; Digby *et al.*, 2016).

In summary, the recommendations made in this study are consistent with a body of research literature that promotes person-centred care for patients with dementia. The findings here more clearly describe the ways that hospital staff can care for the emotional wellbeing of patients with dementia within existing hospital resources. The emphasis of clinical practice and research going forward should be to evaluate the cost and gain of these recommendations being implemented into practice.

5.6 Critique

Strengths

Multiple coders of the interview data and the use of independent audit strengthened the analysis and attempted to improve the reliability and validity of the findings. For these same reasons, the findings were embedded within an understanding of hospital practice, such as the existing hospital priorities, staffing restraints, recognition of what the hospital environment is like for patients with dementia and demands placed on hospital staff, suggesting their applicability to real world practice (Dewing & Dijk, 2016). The findings are presented as recommended actions for hospital staff because it is known that intending to provide person-centred care is not sufficient (Crowther *et al.*, 2018; Innes *et al.*, 2016; Surr *et al.*, 2016) and further theory about person-centred hospital

care has been criticised (Dewing & Dijk, 2016). The interview design gave participants an opportunity to reflect on their practice, and through participation they could have gained new insights into their working to improve future patient care and staff wellbeing.

Limitations

A small participant sample from long-stay wards within a single hospital limits the generalisability of findings, including how the findings might suit acute hospital settings, and need replication with a larger sample from across different hospital sites. Ward priorities and available resources in this setting are likely to differ from acute wards. Interviews were also of shorter mean duration than similar studies (Crowther *et al.*, 2018) suggesting further research would helpfully supplement these findings.

Secondly, participants volunteered to take part in the interviews, therefore, bias might have been introduced from a non-representative sample, meaning the findings could represent a limited viewpoint. Bias could also have been introduced by the researchers performing the analysis as the results were not shared with members of hospital staff to verify, and so the conclusions might have moved away from the personal accounts of staff.

Finally, the descriptions of emotion-focused practice given here need to be evaluated against objective outcomes, including patient wellbeing and medication use (Handley *et al.*, 2017), before they are used to inform any changes made to hospital practice.

5.7 Impact statement

The main way that this study sought to have a positive impact on the real world was through presenting ways of using existing team resources to improve hospital care for patients with dementia.

After the study, four staff members who took part requested a summary of the research findings (see Appendix 16). This suggests immediate impact of engaging healthcare professionals in a research study that requires reflective practice. A similar outcome is discussed for Study 2, see section 3.7. For further discussion of impact, see section 7.4.

The study was written for consideration by a peer reviewed journal, publishing research that aims to improve healthcare for older people. The journal was selected because of its standing within gerontology and its potential to disseminate the study findings to a wide academic readership.

5.8 Chapter summary

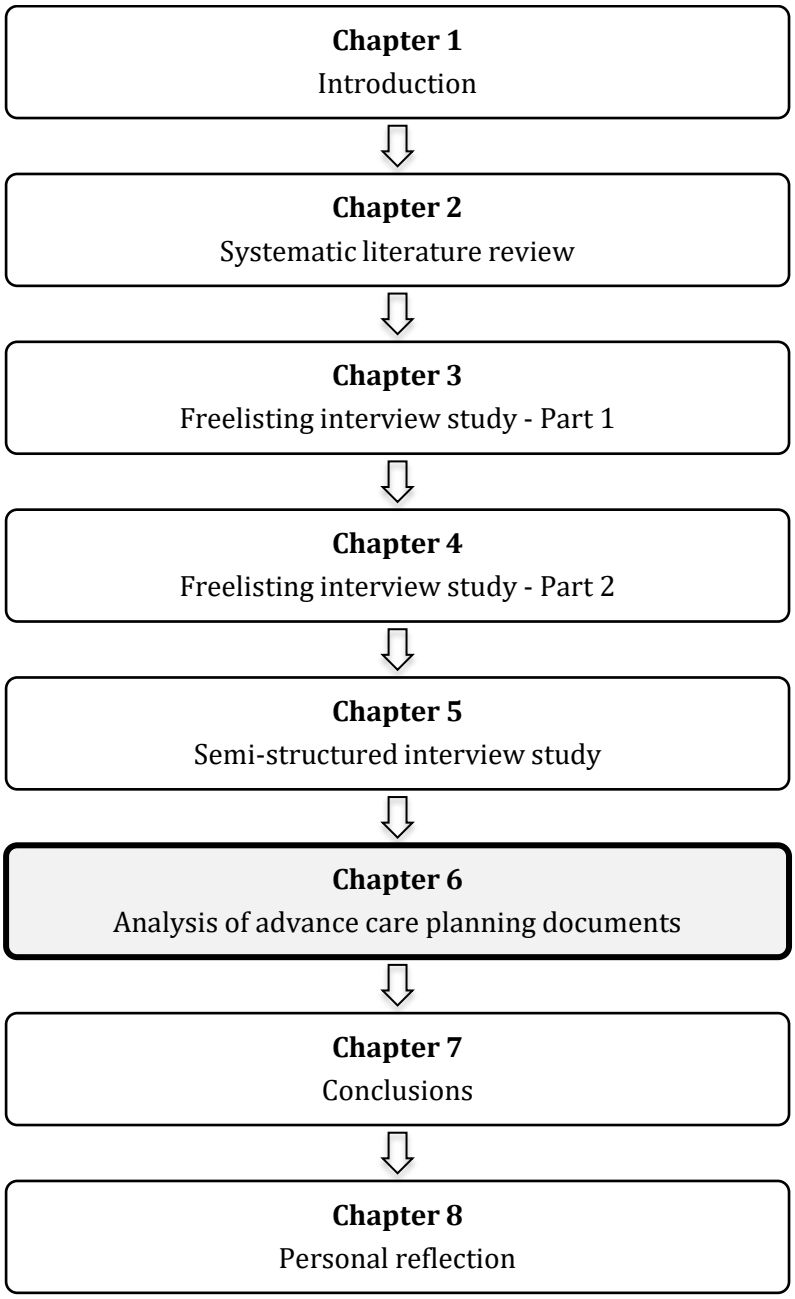
This is the penultimate study of the thesis. Its builds on previous chapters that asked staff to describe patient distress and describe possible care responses, to explore the conditions under which delivering emotion-focused care is more or less possible. The findings give a description of actions that can be performed by staff within their day to day practice within a hospital ward to improve the emotional wellbeing of patients with dementia. Results showed that staff were able to describe resources they could use flexibly, which existed within the ward team and did not incur additional costs. The resources included gathering and presenting personal information about patients concisely, sharing multidisciplinary and personal skills through experiential learning and sharing an ethos of 'being with' patients. Research has already shown that these are recognised within good, person-centred practice; here they were identified as ways to

promote the emotional wellbeing of hospital patients with dementia (see results 5.4 and discussion sections 5.5).

Multiple coders of the data and independent audit were thought to strengthen the analysis; however, limitations of the small sample size and single UK hospital ward were discussed within a critique of the study (section 5.6).

The remaining question for this thesis was to understand what patients themselves request for their care in hospital when emotionally distressed. This is presented in the final study in Chapter 6.

6. Chapter 6. Study 4. An analysis of advance care planning documents using descriptive phenomenology. Emotion-focused care requested by hospital patients with dementia.



6.1 Chapter overview

To complement the findings from the earlier chapters of this thesis, which defined emotional distress for people with dementia generally and then more specifically within a hospital setting, then explored ways to promote the emotional wellbeing of patients with dementia from the perspective of healthcare professionals, this chapter explores ways to promote patient emotional wellbeing as described personally by patients with dementia. The aim was to reach a concise description of personal care requests by hospital patients with dementia in advance of feeling emotionally distressed, so hospital care can be personalised (see section 6.2). This aligns with research aims 1, 3, 4 and 9 of the full thesis (see section 1.2). This chapter presents a qualitative analysis of written advance care planning documents made by 21 patients and their caregivers, within which patients made requests for the care they receive when in hospital. Descriptive phenomenology was used to analyse the care requests, staying true to the experiences described, with little interpretation from the researcher (see section 6.3). Results (see section 6.4) and discussion sections (see section 6.5) are presented, which are then followed by a critique of the work (see section 6.6) and a statement of impact (see section 6.7).

6.1.1 Introduction to Advance Care Planning

This study reviews the requests of hospital patients with dementia made within advance care planning documents, for the essential descriptions of care they require when they are emotionally distressed.

'You are entitled to be involved so far as is practical in making decisions about your own care'; this is the wording of the Patient's Charter (Department of Health, 1991), which

has been embedded in guidance for delivering high quality and personalised healthcare in the UK since 1991.

Advance care planning (ACP) is a process of reaching a shared understanding of a patient's needs, with the patient, their family and healthcare providers, and creating a written statement of care (Piers *et al.*, 2018; World Health Organization, 2011). The document produced is a statement formed of a patient's needs, values and preferences. The statement is not legally binding; in this way it differs from other formal outcomes of care planning, such as advance decisions to refuse treatment or the appointment of Lasting Powers of Attorney, as used in the UK.

There are inconsistencies in what is meant by the term 'advance care planning' across healthcare. For example, international policy written by the World Health Organization (World Health Organization, 2011) does not change terminology when describing care planning for a patient deemed to have capacity and a patient deemed not to have capacity to make decisions around their care; however, NHS Improving Quality (2014) makes a distinction and states that 'advance' care planning requires a patient to have capacity to express their needs, when capacity is expected to be lost in the future due to the progression of illness. When a person is deemed not to have capacity, care planning adheres to the same standards, whereby the patient makes their own decisions where possible, facilitated by others who know the person well and can communicate most effectively with the patient (Department of Health, 2007; NHS Improving Quality, 2014; World Health Organization, 2011).

For all care planning, conversations should occur flexibly and over time and in recognition of fluctuating capacity (Piers *et al.*, 2018). Therefore, distinguishing capacitous care planning from that which captures a person's perspective in flexible ways is likely to be inconsistent in practice. In this study, it was made clear that the care

planning statements retrieved and analysed were not legally binding and that the capacity of patients to plan their care was not formally assessed.

'For patients and families facing advanced illness, the medical interventions and quality of life that lie ahead are largely determined through a series of conversations they have with their physicians and other health care providers,' (Larson & Tobin, 2000, p. 1573).

ACP can help healthcare professionals to achieve person-centred care, whereby the patient expresses what is most relevant to them across physical, social, emotional and spiritual aspects of wellbeing (NHS Improving Quality, 2014; Schwartz *et al.*, 2003). Thus care planning enables care to be designed beyond the medical framework and the planning of medical procedures (Schwartz *et al.*, 2003). In the UK and USA, ACP often occurs on admission to hospital (National Institute for Health and Care Excellence, 2016; NHS Improving Quality, 2014); it therefore offers a means of designing hospital care in line with best practice in a systematic way: the National Institute for Health and Care Excellence (2016) recommends that the needs and wishes of the person with dementia be recorded at care transition points, such as when entering hospital.

Health care professionals are advised to plan care in line with a full understanding of the person, and this includes their emotional wellbeing (Piers *et al.*, 2018); however, ACP tools are mostly used to document decision-making around crisis medical care (Dening, Greenish, Jones, Mandal, & Sampson, 2012a; Detering, Hancock, Reade, & Silvester, 2010; Dixon, Karagiannidou, & Knapp, 2018; Royal College of Physicians, 2009; Triplett & Black, 2008) and research shows that patients with dementia are infrequently involved in ACP (Dening *et al.*, 2012a; Pecanac, Wyman, Kind, & Voils, 2018). In hospital, the perspectives of multidisciplinary staff suggest that emotional distress is a routine aspect of UK hospital care, as evidenced in this thesis. Existing research has not directly

asked what people with dementia require when emotionally distressed in hospital. Therefore, ACP has potential beyond its current use.

Where the care preferences of people with dementia have been explored using open-ended questions in other healthcare settings, their priorities have been around care that addresses their emotions (Dening *et al.*, 2012b). Family members of patients with advanced dementia within UK nursing homes have also prioritised emotional support through ACP (Brazil *et al.*, 2017). Similarly, emotion-focused care has been shown to be a priority for patients diagnosed with other life-limiting illnesses (Schwartz *et al.*, 2003).

6.2 Aims

This chapter reports an exploratory study of the content of ACP documents used routinely within a UK hospital that ask patients with dementia how they would like to be treated should the feel emotionally distressed. The analysis of care requests intends to inform the future design of appropriate hospital care for patients with dementia, which includes consideration of their emotional wellbeing.

6.3 Methods

6.3.1 Setting and participants

All available ACP documents used routinely within a hospital in the UK were retrieved for this study. ACP documents were completed collaboratively by patients and their personal and professional caregivers upon admission to hospital. Patients were admitted for a long-term hospital placement because of behaviour described as challenging. Patients were aged over 55 with a diagnosis of dementia, of any type and severity.

6.3.2 Advance Care Planning tools

ACP tools vary in their content and design, ranging from asking multiple-choice questions, asking patients to select statements such as, 'I wish to be cared for with kindness and cheerfulness, and not sadness' in the Five Wishes document (Aging with Dignity, 2011), to having a small number of open questions with a wide scope, such as, 'what are your preferences and priorities for your future care?' in the Preferred Priorities for Care document (National End of Life Care Programme, 2011). 'This is me' is another well-used tool, developed in partnership by the Alzheimer's Society and the Royal College of Nursing to enable person-centred care planning, which asks the person to state, 'what makes me feel better if I am anxious or upset' (Alzheimer's Society, 2017).

6.3.3 Data collection

The ACP document used in this study was created in 2010 by the hospital that was selected as the research setting; it was created in consultation with service users. It comprised 18 entries beneath the following subheadings: family, friends and carers; arrangements for people or pets in their care; home, plans and finances; how the patient wishes to be treated day-to-day; and named advocates. The written responses to one item were collated for this study: '*How I wish to be treated: if I become upset and distressed and am unable to say what I need please refer to the following: …*'

All available ACP documents used routinely within the hospital were retrieved by me personally between September and November 2018. This study makes use of existing data from a document that was offered routinely to all patients at the point of admission and was used to plan individualised care. Within the hospital's routine practice, the capacity of patients to inform their care through care planning was not formally assessed; care planning was flexible in recognition of fluctuating capacity (Piers *et al.*,

2018). Patients were supported to express their views by caregivers who were able to communicate effectively with them (NHS Improving Quality, 2014; Piers *et al.*, 2018; World Health Organization, 2011), including family members, professionals from previous care services or advocates. Caregivers are said to be able to respond to the patient's emotions and their non-verbal communication and involve them in conversation when the patient may not otherwise be able to express their needs (Piers *et al.*, 2018).

As all available documents were retrieved, data saturation was assumed.

6.3.4 Ethical considerations

The study was approved by the hospital's directors and following review by the University of Nottingham (Division of Psychiatry and Applied Psychology, Research Ethics Sub-Committee, 0238). Only anonymous data were accessed and were stored securely under the data protection policy of the University of Nottingham. I had no contact with any research participant.

This study features secondary analysis of an anonymised dataset. The study was designed with input from the organisation's Research Governance Lead and the Caldicott Guardian; it was agreed that only anonymised data would be accessed for the study and only documents completed prior to 25.5.18 (and a significant change to General Data Protection Regulations) would be used. A gatekeeper was required to access the study data.

6.3.5 Data analysis

Descriptive phenomenology was used in this study to analyse the data from the retrieved documents and reach a concise description of the care requested by patients with dementia collectively. The method enables researchers to reach a summary of all that is essential from across different descriptive accounts (Colaizzi, 1978).

6.3.6 Descriptive phenomenology

Descriptive phenomenology is concerned with how a phenomenon is experienced by the people involved, so the researcher does not interpret the data (Beck, 1994). This method was chosen as a means of retaining the personal accounts of patients with dementia. Descriptive phenomenology is used when there is little existing research and when personal accounts are limited; it was chosen in this study because of the hard-to-reach accounts of patients with dementia and the minimal existing research into their care preferences when in hospital, where the method is valuable (Martins, 2008; Polit & Beck, 2014).

The method is used to reveal the 'essence' or 'essential structure' of any phenomenon under investigation, sifting away everything that is not essential in order to reach an adequate description whilst staying close to the data, not needing to add to or take from what is being described. The method describes the experience as told, without inferring causes. As an example, Martins (2008) used descriptive phenomenology to understand the experiences of homeless people with concurrent ill health. In line with this philosophy, the patient does not need to understand why or how they require a response from healthcare staff, nor does the researcher; they just provide a description of their requests.

The analysis is unlike other qualitative analysis methods such as thematic analysis (Braun & Clarke, 2006), for which the aim is to describe all of the content of a dataset, grouping what is described into themes and sub-themes. In descriptive phenomenology, the aim is to reach themes that are common across *all* accounts and not those only representing the accounts of some participants.

Steps of the analysis outlined by Colaizzi (1978) were followed closely, see Table 6-1.

To improve the trustworthiness of the analysis, all stages were detailed in an audit trail, including documentation of significant statements and assigned meanings as a coding tree. Examples of the method with data excerpts are shown in Table 6-2. All stages of the analysis and the full dataset were viewed by me personally and all supervisors in an attempt to reduce the influence of personal opinions. In addition, three staff members working in the hospital reviewed the exhaustive and essential descriptions to further reduce researcher bias in the analysis.

For this analysis, it was important to declare that I am female and was employed as a Clinical Psychologist and PhD researcher at the time of data collection and analysis.

Table 6-1. Steps of the descriptive phenomenology analysis method.

Step	Step description
1	All original documents were read multiple times to understand the care requests individually and collectively.
2	Significant statements of direct relevance to the research question were extracted; most data could be extracted in full given the brevity of most requests.
3	Significant statements were assigned meaning as a means of moving to a representative description of all statements; for example, 'leave me alone for a while' was described as 'seeking aloneness', 'the request will change' and 'a first person account'. Table 6-2 shows an excerpt of data, the assigned significant statements and assigned meanings.
4	Assigned meanings were clustered into themes based on their similarity and occurrence across all documents.
5	An exhaustive description was written from the full descriptions of each theme; this was an overview of all themes considered together, with particular attention paid to what was fundamental about all care requests.
6	The exhaustive description was condensed to a statement that captured the essential aspects of the care requests.
7	All documents were read in full and used to verify whether patients' experiences were captured by the concise statement.

Table 6-2. Examples of steps 1-3 of the descriptive phenomenology analysis method applied to advance care planning documents for patients with dementia: document excerpts with accompanying significant statements and assigned meanings.

Patient	Data from ACP document	Significant statement	Assigned meaning
P05	Make sure I am comfortable and my care needs are met.	make sure I am comfortable	physical comfort
		make sure my care needs are met	practical support for basic care
	Use PRN medication if I am very agitated or distressed.	use PRN medication	medication
		qualifier: if I am very agitated or distressed	requests depend on intensity of distress
	Quiet low stimulus area.	quiet low stimulus area	physical hospital environment: quiet, low stimulus
	Soft music.	soft music	relaxing activity: music
			{ first person account
			{ multiple requests made
P11	Leave me alone for a while	leave me alone	aloneness
		qualifier: for a while	the request will change
			{ first person account

P13	[named person a] offer hot water to wash.	offer hot water to wash	practical support for basic care
	Put radio on.	put radio on	activity: radio
		named person	different requests for different people
	[named person b] give space.	give space	aloneness
		named person	different requests for different people
	[named person c] cup of tea/cake.	cup of tea/cake	tea/cake
		named person	different requests for different people
			{ multiple requests made

The Standards for Reporting Qualitative Research (SRQR) were used for transparency, shown in Appendix 17.

6.4 Results

6.4.1 Overview of ACP documents

A total of 21 ACP documents were retrieved, from a possible 44 patients admitted with a dementia diagnosis between 2010 and 2018 (47%); not all patients completed the document. The earliest document was from 2012. Patients were mostly male (male n=13; female n =8), with a mean age of 75 years (SD 7.98). All patients had an ICD-10 diagnosis of dementia but the subtype was inconsistently documented. The mean duration of placement was 2.43 years (SD 2.06). Most documents were written in the first person (67%, n=14), the others in combined first and third person (n=3), third person (n=2) or without pronouns (n=2).

6.4.2 Overview of care requests

85 significant statements were extracted from the care requests in line with step 2 of the analysis, and were given 66 assigned meanings as per step 3. The assigned meanings were grouped beneath three themes: holistic care requests, personalisation and distress as changeable (see Table 6-3). As per the methodology, a theme refers to a description or observation of the dataset as a whole; the first theme captures the content of care requests and the further two themes qualify the ways in which care requests were made. A concise summary of all care requests is then presented.

Table 6-3. Themes of care requested by hospital patients with dementia within advance care planning documents.

Themes and theme descriptions
Holistic care requests Requests were for care of the whole person and their holistic needs, which included: basic care interventions such as being offered food, being supported to access the toilet or with washing; being physically comfortable or warm; medical interventions including monitoring of blood glucose levels, possible constipation or infection, assessing for pain and administering medication; communication, such as explaining what is happening and offering reassurance, using a calm and caring manner, 'listen to me and allow me to express my feelings' (P15); being treated with dignity, respect, kindness and gentleness, asking to be seen as a person; to be with, hear the voice of or talk about family members or significant others, including advocacy or hospital staff; for somebody to make sure that family members were being looked after; touch, including holding hands; relaxation, being peaceful, listening to soft music, having a bath or going for a walk; activities, including distraction with beauty activities or listening to the radio, a cup of tea or coffee; aloneness or space; a different physical environment, which included low stimulation, minimal noise or crowding.
Personalisation This theme describes the detailed nature of care requests, which made care personal to each patient. For example, one patient requested a cup of coffee with two sugars and one biscuit only when calming down from feeling agitated (P12); a second patient gave a phrase for staff to use as their preferred way of being spoken to. Patients asked for different responses from different named people. Patients also asked for personalised care explicitly by saying 'please see me and not my behaviour' (P14). No single request was made by a majority of patients.
Distress as changeable Care requests varied with the type and intensity of emotional distress, and there was right timing for different responses. In half of the documents (52%), patients added qualifiers as to when different responses were appropriate, such as for when they were upset, agitated, aggressive, frightened, scared or depressed, very agitated or when calming down. Eighteen documents (86%) had more than one request listed; the number of requests ranged from one to nine (mean 3.76, SD 2.36), for example:

'Relaxation techniques. I like my own space. Going for a walk. When upset I would rather not be left alone' (P01). When one request was made, this was to be treated with respect or understood as a person (P10) and P16).

6.4.3 Summary statement of care requests

The care requests made by patients with dementia for when they experience emotional distress in hospital did not form a simplified description of care that would meet the needs of all patients. There was no typical request made to hospital staff. Patients made multiple requests for others to respond to them, which varied with the type and extent of emotional distress that they felt. Personalised care, for physical health, social and spiritual needs, were concisely described for each patient using ACP documents, meaning that the detail of how their emotional wellbeing could be improved within hospital was easily accessible.

6.5 Discussion

6.5.1 Interpretation of findings

Personalised care

Results are consistent with research showing the comprehensive and personal accounts of emotional distress from people with dementia. The findings complement the reports of multi-profession staff within UK hospitals discussed in Chapter 3 who have recognised that the causes of emotional distress for patients with dementia are numerous and the most effective ways to respond depend upon knowing each patient personally. The ACP requests in this study replicate the findings of Dening *et al.* (2012b) who explored preferences for end-of-life care of people with dementia in a community setting and they showed that the main preference was for personalised care; they

presented the following quote: '… look after me with care… don't treat me like a vegetable… like a mad person' (p.413). Therefore, the findings show that the extensive literature into person-centred care for people with dementia (Brooker & Surr, 2006; Kitwood, 1997; Scerri *et al.*, 2017) is consistent with what was requested personally by patients with dementia as part of their hospital care in this study.

Advance Care Planning

Requests for emotion-focused care were made succinctly by patients with dementia via ACP documents and yet this detail is missing from existing research literature and healthcare guidelines (National Institute for Health and Care Excellence, 2018; Royal College of Psychiatrists, 2017). This is important because hospital staff have reported having limited time and training to communicate with patients with dementia (Dening *et al.*, 2012a; Pecanac *et al.*, 2018), with difficulty understanding their emotional needs in particular (Annear & Lucas, 2018), which can result in sub-optimal care (Digby *et al.*, 2016). Knowledge of patients as individual people must therefore be documented so that it is accessible to the hospital staff team (Pecanac *et al.*, 2018; Piers *et al.*, 2018); this ensures that hospital staff share responsibility in delivering tailored care. This study suggests the value of ACP in making this knowledge of personalised care available to staff in a structured way within routine hospital practice.

6.5.2 Implications for practice

The results illustrated that holistic and humane care is required from hospital staff. The findings from this local setting agree with previous research (Houghton *et al.*, 2016) in suggesting that hospital patients with dementia cannot be prescribed a 'one size fits all'

care intervention, and this applies to the care they require when emotionally distressed. ACP provided a structured process for documenting person-centred care for each patient in a way that is compatible with hospital systems (Piers *et al.*, 2018; van der Steen *et al.*, 2014) and could be integrated into routine practice (Houghton *et al.*, 2016; Piers *et al.*, 2018).

Existing recommendations from research suggest that training for healthcare staff in the purposes and legal standing of ACP could promote its more consistent use (Beck, McIlfatrick, Hasson, & Leavey, 2017; van der Steen *et al.*, 2014). I add a further recommendation that training in ACP should emphasise holistic care planning, using these tools as a means of collecting and sharing personalised care requests. I also recommend a revision to ACP documents to ask what could sustain emotional wellbeing, as well as asking for responses to emotional distress, to provide further opportunities for emotion-focused care. Questions that ask about patient preferences at times of emotional upset are not included in all ACP documents.

6.5.3 Implications for research

Finding ways to communicate with patients with dementia is particularly important because of the known difficulties with involving patients directly in their care because of communication difficulties and acute illness (George *et al.*, 2013; National Institute for Health and Care Excellence, 2018). It is possible that the descriptions given here could generalise to individuals who have not been able to describe their preferences, and could be important for the training of staff teams, but this requires confirmation through replication with a larger sample. The findings also require replication beyond a single hospital.

For the findings of this study, it is of particular concern that it was not possible to describe whether the written care preferences were those of patients or caregivers. Valuable future research would address this concern; it is anticipated that this research would require an intervention design, whereby hospital staff are trained in the use of ACP documents and they assess each patient's capacity to describe their own care preferences at the point of completing ACP documents. This would provide the necessary criteria for a further analysis of ACP documents whereby care preferences are personally described by patients with dementia.

Future research into the impact of ACP in a hospital setting should also measure patient wellbeing, quality of care, medication use and duration of hospital stay as outcomes (Annear & Lucas, 2018; Cerejeira *et al.*, 2012; Houghton *et al.*, 2016). Currently, there is too little evaluative research into the use of ACP with patients with dementia (Dixon *et al.*, 2018), meaning the benefits or implications of using ACP more cannot be described; however, studies of older people in hospital have shown that ACP can increase patient satisfaction with care and reduce emotional distress for families (Detering *et al.*, 2010). Similar benefits might apply to patients with dementia, though this must be a question asked within future research.

6.6 Critique

Strengths

ACP has been mostly used in hospitals to inform crisis medical care and has often omitted the patient's perspective; this study contributes the patient's perspective on their care needs and shows patients with mild-to-severe dementia being involved in care planning (NHS Improving Quality, 2014). Commenting on the use of Advance Directives in the USA, Triplett and Black (2008) said, 'Surprisingly, little is known about

the wishes that people actually express in such documents,' (p. 584). The national guideline written by the Royal College of Physicians (2009) recognises that patients want to express their care preferences in their own words.

In this study, data were retrieved from routine practice and therefore captured real world care planning. ACP provided a way to share information in a structured way, which was recommended by Reilly and Houghton (2019) in the most recent qualitative evidence synthesis of how patients experience acute care settings. ACP also offered a way to involve families in hospital dementia care (Kelley *et al.*, 2019; Reilly & Houghton, 2019).

The number of completed documents was consistent with prevalence estimates of ACP across a range of care settings, within and outside of the UK (Dixon *et al.*, 2018; Triplett & Black, 2008). The setting was thought to be a further strength, with most current research into ACP located in the USA and in care homes (Dixon *et al.*, 2018; van der Steen *et al.*, 2014).

Finally, descriptive phenomenology was employed as the analysis method best able to answer the research question for this study because it offered a clear and rigorous method of qualitative analysis, which stayed close to the personal accounts of patients with dementia (Colaizzi, 1978). Care was taken to detail all stages of the method transparently, as some stages are omitted from other published examples, notably stages 5 and 6 where an exhaustive description and dense statement are frequently not presented.

Limitations

It was not possible to quantify the extent to which patients had determined the content of their ACP documents, which capture collaborative care planning; this is important because patients and caregivers have been shown to differ in their preferences for end

of life care (Dening *et al.*, 2012b). Despite most of the documents being written in the first person, it was not possible to know the extent to which patients contributed to the plans or whether these were written on their behalf by family members or staff members. This limits the conclusions of this study as to whether personal care preferences were described.

The sample was limited to one care setting, was small in size and featured more males, meaning the generalisability of the findings is limited. Richness of the data analysed was also limited when compared with interview studies (Polit & Beck, 2014). For example, in line with a phenomenological approach that gives invitations for rich personal accounts, Martins (2008) asked 'tell me a story about…'. This differed from the more structured question asked in the ACP document analysed here; however, written formats are compatible with the analysis method (Morrow, Rodriguez, & King, 2015). The brevity of the accounts allowed the researchers to stay close to the data as intended, as evidenced by the low ratio of significant statements to assigned meanings.

Because of retrospective data collection, it was not possible for patients to review the analysis.

Finally and perhaps most importantly, interpretation of how the care requested by patients translates into care delivered was beyond the scope of this study. The findings require replication and further research is needed into how care requests can be delivered in practice.

6.7 Impact statement

The main impact of this study was intended to be the recommendation of using ACP as a structured process for improving person-centred care for patients with dementia that could be integrated into routine practice within hospital systems.

The study was written for consideration by a peer reviewed journal, publishing research with relevance to clinical practice. The journal was selected because of its readership of healthcare professionals providing palliative care and in an attempt to share the findings of this study with the right audience.

For more discussion of impact, see section 7.4.

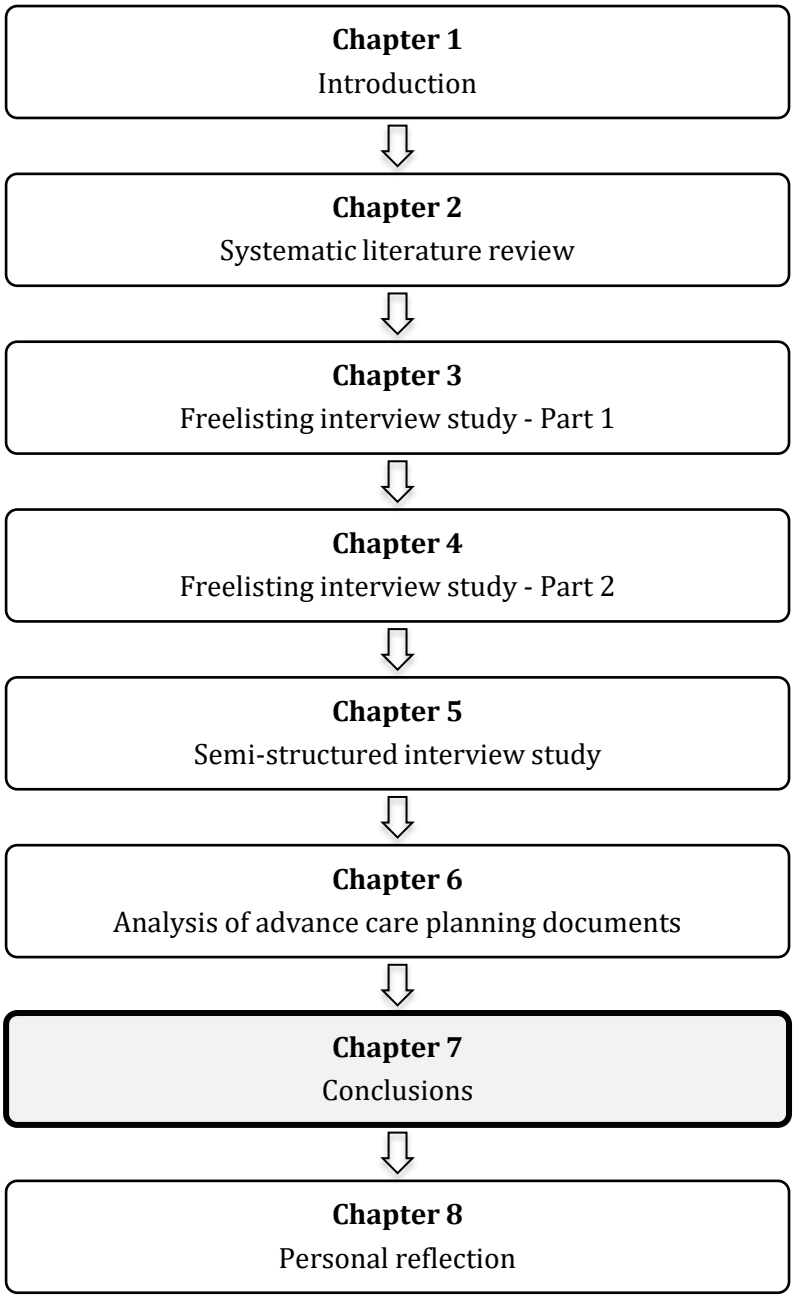
6.8 Chapter summary

In the final study of this thesis, hospital patients with dementia communicated their care preferences for when they are emotionally distressed using written ACP documents. A concise summary of their care requests was presented using descriptive phenomenology, which was of person-centred and holistic care. The perspective of patients presented here expands the research literature beyond a care home setting into the more challenging care setting of hospitals. It also describes important aspects of hospital care beyond the design of the physical environment. An important finding was that ACP can provide a structured intervention to help inform person-centred care, which is suitable for the hospital setting because of its existing use. Furthermore, findings showed the changeable and personal nature of emotional distress and the variable responses required by hospital nursing staff; this finding is in keeping with the findings presented throughout this thesis, of the viewpoint of hospital staff. Recommendations were made for increased use of ACP in hospitals as a practical way to inform hospital care with patient preferences for person-centred care.

The main impact of this study was planned to be achieved via publication in a journal with an extensive readership of different professional disciplines contributing to the field of palliative care.

This is the conclusion of the empirical work of this thesis.

Chapter 7. Conclusions.



7.1 Overview

This chapter presents the conclusions of the thesis, firstly with an executive summary of the main findings (see section 7.2), followed by an overview of how each of the research aims introduced in section 1.2 have been achieved (see section 7.3). Two subsections

then introduce a discussion of how the work has influenced academia and the real world with a summary of impact (see section 7.4), and a critique of the work, with consideration of future improvements (see section 7.5).

7.2 Executive summary of main findings

> *'the threatened disappearance of any self is not directly linked to the progress of the disease. Rather, it is related to the behaviour of those who are regularly involved in the social life of the sufferer...'* (Sabat & Harré, 1992, p. 459).

The context of this thesis was the routine care received by patients with dementia when they are in hospital, which had been identified by the World Health Organization as a priority for improvement within international healthcare (World Health Organization, 2017). When care is poorly tailored, there can be serious implications for the patient's wellbeing, as well as increased demand on staff and other hospital resources. The work of this thesis primarily aimed to improve the understanding within research and healthcare fields of achievable ways to improve person-centred care in hospitals for patients with dementia; more specifically, ways to improve patient emotional wellbeing.

The thesis presents research evidence of what emotional distress is (see Chapters 2 and 3), how distress is shown by patients with dementia and noticed by healthcare staff (see Chapters 3 and 4), the causes of distress within a hospital setting (see Chapters 3, 4 and 5), and achievable ways that hospital staff can act to improve the emotional wellbeing of patients with dementia (see Chapters 3-6). These findings were informed by people with dementia and multi-disciplinary hospital ward staff.

The main conclusions are as follows: the emotions of people with dementia are personally variable, understandable, can be extreme and they change in meaningful ways, as a human reaction to circumstances. In turn, there is no suitable 'one size fits all'

way that caregivers can respond to the emotions of patients with dementia. Instead, it is important to draw upon achievable ways to personalise care.

Findings showed the most important ways that hospital staff can respond to the emotional distress of their patients with dementia include: knowing each patient as an individual, respecting the holistic needs that the patient has as a human being (of which, physical health needs and a peaceful environment are important considerations), noticing and responding to them, talking with and being with them and listening to what they request for their hospital care. Chapters 2-6 of this thesis contain more detailed recommendations for practice; these included, improved use of readily available information and concise formats such as advance care planning documents to present personalised care preferences, flexible use of existing team resources through team working, sharing of existing staff expertise through collaborative and experiential learning to deliver person-centred care more consistently, a philosophy from leaders to 'be with' the patient for routine tasks and sharing of positive emotions between staff and patients.

Recommendations made were described by frontline hospital staff directly, and included a menu of possible ways for staff to notice, understand and respond to the emotional distress of patients, which were quick to draw upon and were transferable across a range of care situations. The recommendations were also informed by the personal requests for care made by patients with dementia and their families. For these reasons, the recommendations made were considered to be relevant to routine hospital care and were believed to offer achievable ways to promote emotion-focused care within hospitals. The findings provide alternatives to the dominant approaches within healthcare, for example, the excessive use of pharmacological treatment.

In summary, this thesis contributes to healthcare practice in one main way: it recommends solutions for improving person-centred care for patients with dementia by

improving their emotional wellbeing, which suit real world hospital practice, as described by the key stakeholders of patients with dementia and the multi-disciplinary ward staff team.

The conclusion of each aim of the thesis is discussed below (section 7.3). This is followed by a summary of the impact of the thesis in the real world (section 7.4) and a critique of the body of work with discussion of future improvements (section 7.5).

7.3 Research aims achieved

All nine research aims of the thesis were achieved. Each aim is discussed in turn below.

- Research aim 1: *to make a useful contribution to day-to-day healthcare within contexts that pose high challenge for people with dementia and healthcare providers: the hospital setting.*

Three empirical studies were located within hospital settings, which collectively learned the views of hospital ward staff and patients with dementia. Study 2, the first interview study with ward staff (see Chapters 3 and 4), provided a definition of the emotional distress of patients, as it existed within routine hospital practice. The study then produced a menu of ways that staff across the hospital ward could act to deliver emotion-focused care. This is important because the findings could be relevant for current practice in hospitals. The fit-for-purpose study design for the hospital setting was shown in the participant sample, which included the full ward staff team; freelisting was a novel method to explore the realities of everyday practice in a hospital setting and is praised for being a simple and an efficient way of gathering meaningful information.

Study 3, the second interview study with ward staff (see Chapter 5), explored the conditions within which delivering emotion-focused care is more or less possible, because of hospital priorities and resource constraints. This study was designed with

the purpose of making more detailed recommendations for the hospital setting. As in the first interview study, findings recommended ways that staff across the hospital system can act, within existing resources, by knowing the patient, being with the patient and sharing existing expertise amongst peers.

These studies suggested that under-recognised resources exist within routine hospital care, which is a valuable conclusion of this thesis, to inform research and healthcare.

There were immediate impacts of involving a working hospital ward in research and in reflective practice, which were additional ways in which this thesis achieved Research aim 1 in making a useful contribution to hospital care, as will be discussed in section 7.4.

Study 4 (see Chapter 6) then presented the requests made by patients with dementia for how they would like to be cared for when in hospital, made using advance care planning documents. The documents were retrieved retrospectively from real world practice; these requests should be highly valued because of their direct relevance to personalising hospital care.

- Research aim 2: *to find helpful solutions for improving person-centred hospital care using existing knowledge and resources.*

The two interview studies (Studies 2 and 3), using freelisting and semi-structured interview designs, directly sought existing knowledge of hospital ward staff. The questions asked for achievable ways of improving patient care within existing resources: in Study 2, presented in Chapters 3 and 4, ward staff were asked, '*In your work with people with dementia, can you list all the ways you respond when they are emotionally distressed… Of these, can you list the things that seem to work?*'; in Study 3, presented in Chapter 5, ward staff were asked, '*Could you tell me about some of the things that make it possible to care for the person's emotional needs day to day… can you*

tell me about some times when it has not been possible… could anything help you and your colleagues do it more often?' Recommended ways of providing emotion-focused care were produced from a shared understanding amongst the staff team and their use of existing resources. The main facilitators of improving emotion-focused care required support from management, a shared ethos, experiential learning and smart use of information, which did not require increased staffing. Both Studies 2 and 3 were designed to be sensitive to hospital priorities and resource constraints. Therefore, these two studies valued the expertise of hospital staff, through the selection of methods and in the study conclusions.

- Research aim 3: *to reach a representative description of 'what emotional distress is', as experienced by people with dementia.*

Three studies of the thesis defined emotional distress, from the perspectives of people with dementia, their families and professional caregivers. Chapter 2 presents a systematic review of how emotional distress experienced by people with dementia had been described in literature. It provided evidence from the largest number of viewpoints to date of what emotional distress is for people with dementia, in response to Research aim 3.

To reach a context-specific definition of emotional distress, Study 2 (Chapters 3 and 4) presented the definition of emotional distress from the perspective of the main caregivers of patients with dementia when in hospital; ward staff were asked '*How do you notice when somebody is emotionally distressed, so, all of the ways it shows?*' within a freelisting interview study.

Study 4, presented in Chapter 6 also sought the views of people with dementia, in reviewing what they need from hospital staff when emotionally distressed, using an

analysis of advance care planning documents. Patients with dementia asked that hospital staff cared for them as a whole person and their holistic needs, with different priorities dependent on the person and their experience of distress, which changed over time.

Findings collectively established that complex and varied emotions are well described for people with dementia; they are expressed using rich, varied and personal language. Hospital staff had a shared understanding that behaviours such as agitation or restlessness were ways that emotional distress is communicated, and they noticed emotional distress from over 60 other descriptions. The conclusion of Research aim 3 therefore is with a definition of emotional distress that moves beyond surmised or reduced descriptions of behaviour or symptom labels. I recommended that these conclusions inform successive work into how holistic healthcare is designed for patients with dementia.

- Research aim 4: *to present the personal requests for emotion-focused hospital care made by patients with dementia.*

The systematic literature review presented in Chapter 2 set the foundations for the empirical research, in concluding that people with dementia experience rich, personal and varying emotions. Building from this understanding, Chapter 6 presents the personal requests for emotion-focused hospital care made by patients with dementia, in response to Research aim 4. This was an analysis of written advance care planning documents using descriptive phenomenology. The results provided a description of the essential components of what patients with dementia ask of hospital staff when they are distressed, so that hospital care can be personalised. Existing research had suggested that such documents had been little used to inform routine hospital care and had often omitted the views of patients with dementia. Findings showed that hospital patients

with dementia were able to make requests for their care with support from family and professional caregivers.

Chapter 6 presents the conclusion that patients with dementia cannot be prescribed a 'one size fits all' care intervention. Care planning documents provided a way to design person-centred care, which, in this study, included physical health care, communication, connection or aloneness, a different environment and peacefulness.

- Research aim 5: *to reach a representative description of how the emotional distress of patients with dementia is understood by multidisciplinary hospital staff.*

Study 2, presented in Chapters 3 and 4, was designed to respond directly to Research aim 5: in an interview study, hospital staff were asked to describe how they notice and make sense of the emotional distress of patients with dementia using freelisting methodology. Cultural consensus analysis was used because it provides a way to examine whether the responses given by a group of participants, ward staff, share an underlying cultural definition, and to what extent their given definition is shared. Results from quantitative and qualitative analysis methods gave the most-used descriptions of emotional distress and the best-understood reasons for emotional distress as shared by a ward staff team. Staff showed understanding beyond 'behavioural and psychological symptom' labels; they shared an understanding that behaviour was meaning-driven because a person was upset about being in an unfamiliar place without knowing what was happening to them, which was a usual reaction to circumstance that could cause emotional distress for any person. They used a broader lexicon to describe distress than prevalent terms such as 'agitation' or 'depression', which was consistent with the evidence of the widely variable language used by people with dementia personally to describe their distress, as concluded in Chapter 2.

- Research aim 6: *to reach a representative description of how the emotional distress of patients with dementia is responded to by multidisciplinary hospital staff.*

The study presented in Chapters 3 and 4 was designed to respond directly to Research aim 6; in an interview study, hospital staff were asked to describe how they respond to the emotional distress of patients with dementia, and then, which responses seemed to work, using freelisting methodology. The findings gave a menu of possible actions for delivering emotion-focused care, which staff agreed were the most effective. The responses thought to work described person-centred and validating care and included staff having to know each person as an individual, talking with the patient, being with the patient as a person, offering reassurance that problems can be resolved and offering a cup of tea.

The analysis presented in Chapter 4 provided further description of how the emotional distress of patients with dementia is responded to differently by multidisciplinary hospital staff with personal experiences of caregiving for somebody with dementia and differing amounts of professional caregiving experience. A recommendation for practice was for hospital staff teams to share existing expertise amongst each other.

- Research aim 7: *to explore the barriers and facilitators to delivering person-centred and emotion-focused care in hospitals.*

Chapter 5 presents Study 3, which was designed to respond directly to Research aim 7; a semi-structured interview study asked hospital nursing staff about the barriers and facilitators to delivering person-centred and emotion-focused care for patients with dementia. Staff were asked to describe times when it had been possible to care for the emotional needs of patients with dementia and the things they thought made it possible; they were also asked to describe times when it had not been possible, and what they

thought the barriers were. The findings gave recommendations for ways that staff across the hospital system can act, including gathering concise patient information, sharing multidisciplinary and personal skills and investing in an ethos of being with the patient in their experience, which did not incur additional costs. The recommendations were described by frontline hospital staff who routinely worked in a setting familiar with patient distress.

- Research aim 8: *to contribute an argument to the research literature that the emotional needs of patients with dementia are important and an important component of person-centred care.*

All four studies of the thesis, presented in Chapters 2-6, were designed to meet Research aim 8, as is reflected in their objectives, methods and conclusions. This thesis introduced an alternative definition of emotional distress for people with dementia, as personal, variable and an understandable, human reaction to circumstances, in contrast to a predominant understanding of emotions being the symptom of disease. This was the first definition of emotion and emotional distress for people with dementia in the research literature.

- Research aim 9: *to use research methods that are interesting and that best answer the research questions of this thesis, underpinned by ethnography.*

The following research methods were introduced in this thesis. Ethnography is defined in Chapter 1, section 1.5 Philosophy of science. In brief, it is a theoretical underpinning of research that emphasises the viewpoints of the people within a culture as being important.

Corpus-based analysis and meta-ethnography are then defined in Chapter 2, section 2.3, as methods of analysing literature returned from the systematic review of how emotional distress has been described. Corpus-based analysis was used to uncover patterns in the large sample of written text retrieved by the search; it was chosen to provide an objective overview of the language being used, to give an original description of emotional distress as described by people with dementia. Meta-ethnography was chosen because it is chiefly concerned with the experiences of the individuals involved in the phenomenon of interest: the everyday, lived experiences of people with dementia. Freelisting is introduced in Chapter 3, section 3.3, as an ethnographic interviewing technique used to capture the viewpoints of staff members within a hospital culture. Descriptive phenomenology is introduced in Chapter 6, section 6.3, and was chosen as a means of retaining the personal accounts of patients with dementia, being principally concerned with how a phenomenon is experienced by the people involved.

Methods were carefully chosen to best suit each study objective, and the methods of systematic literature review, interview and document analysis. Rationale is given throughout the thesis for the decisions made. All four studies sought the perspectives of the key stakeholders in this research, of patients with dementia and the multi-disciplinary ward staff team providing their hospital care. The conclusions of the thesis emphasise the individual nature of distress and the need for a personally-tailored response from caregivers. The methods are most aligned with a constructivist approach, as discussed in Chapter 1, section 1.5 Philosophy of science.

7.4 Impact

Research impact refers to the effect that research has on the wider world: how things change or benefit from the research activity and the findings. Routes to achieving impact include involving key stakeholders (see 1.4 Patient and Public Involvement) and

disseminating research findings in meaningful ways. An impact statement is given for each chapter of the thesis to provide an overview of how each study was designed to contribute something of value to healthcare and give any evidence for impact achieved. Impact is discussed in relation to the anticipated benefits for patients, care staff, the hospital system and academic knowledge, though it is recognised that there are no simple ways to quantify how impact has been achieved. Of these, academic impact is discussed with the most certainty, covering the dissemination of research findings through conference presentations, newsletter publications for different interest groups and peer-reviewed journal publications, as well as feedback from academic peers. Academic impact is discussed first. Ways in which the research may have benefitted non-academic audiences are then discussed.

Academic impact

The potential reach of the journal publications from this thesis is broad. One measure of this reach is the 'impact factor' of each journal, which is the number of times an average article published in the journal has been cited in an academic publication in the previous two years. It offers a simple estimate of the dissemination and awareness of the research results and is one of the most used measures of research impact (Banzi *et al*. 2011). Of the five journal publications achieved through the body of work within this thesis, impact factors ranged from 2.261 to 4.078. This suggests that the work is being represented within the top 20% of influential journals according to the Journal Citation Reports (JCR) database. It also shows that the work meets the highest academic standards and is thought to be a priority for the journals' readers.

Criticism of impact factors alone is that they are valuable to publishers and library catalogues and they guide authors in choosing outlets for their work, but the mark of quality does not necessarily reflect the value of the work to wider society; however,

dissemination through high impact factor journals can lead to unanticipated impacts. A publication of the systematic review (see Chapter 2) in the International Journal of Geriatric Psychiatry was read and re-written as a blog post by the National Elf; this provides evidence that the article reached an interested audience, which then generated further possible impact with healthcare practitioners.

Beyond the single impact factor calculation, rank tables use additional information to order journals in a subject area; information such as the immediacy index and citing half-life are used to rank journals, which are the number of times an article is cited in the year it is published, and whether citations from a journal are from later issues (as would be expected for a journal producing cutting-edge findings) or from older editions (for theoretical papers). As an example, in the published work from this thesis, The Gerontologist has an impact factor of 4.078 and a rank of 3 out of 36 journals in the field of Gerontology as reported by the JCR database, published annually as part of the Science Citation Index by ISI; this suggests that the journal has a strong reputation for being relevant to the study of older people. As a further example, a respected peer in the field of dementia research learned of the work of this thesis through its journal publications and contacted me via email to commend the work into the emotional wellbeing of patients with dementia and direct me towards a bursary for conference attendance.

The work of the thesis was also shared with a wider audience than subscription-only journals might reach, via open access publication. Importantly, the ease of access to journal articles has been said to reflect impact. Open access articles, which are available online on the day of publication and are accessible without membership or fees, are shown to reach different readers than would be reached from subscription-only publications. Open access publications show up in electronic searches and they give the same advantage to everybody trying to access research. Students, patients, healthcare

professionals and members of the public are recognised as groups who benefit from open access. An additional contribution of open access publication is the open peer review that the journals offer; this affords the opportunity for further dialogue with academic peers, which can promote the sharing of ideas and improve the quality of research. In publishing with a range of journals with varying access policies, it is hoped that the potential readership of the body of work produced by this thesis is widened.

The reach of the work can also be considered by looking at whether publications are being shared or cited immediately in other research; metrics reported by the journals of the published papers from this thesis show the work as being cited six times by other authors; Google Scholar shows 11 citations. BMJ Open also provides metrics for the number of 'tweets' an article has received, and shows that the study presented in Chapter 4 is in the top 25% of research represented by these metrics, having been shared by six members of the public, five scientists and two healthcare practitioners.

In addition, outputs of the thesis were presented at Alzheimer Europe on three occasions, in Copenhagen, Berlin and Barcelona (see Chapters 2, 3 and 4). Alzheimer Europe is one of the most important events in the dementia research field. The audience of the conference is mixed, including other researchers, but also people living with dementia, carers, voluntary organisations, policy makers and service providers. A major strength of this particular conference is its involvement of people living with dementia, who contribute to deciding which papers are accepted for presentation, which provided a valuable opportunity for disseminating findings directly to society.

A final marker of academic impact is the opinion of respected academic peers. The impact section of Chapter 3 (section 3.7) shows email contact with published authors from the US that state the work is valuable and the chosen method is sound. Similarly, the feedback from journal reviewers suggests the merit of the work; feedback from reviewers for the International Journal of Geriatric Psychiatry (see section 2.7), The

Gerontologist (see section 3.7) and BMJ Open (see section 4.7) said the findings of the thesis collectively are important, provide fresh insight into emotional distress and dementia and appreciate the subjective experience of people with dementia, will have implications for the make-up of teams across the UK, contribute a great deal to our understanding and development of good practice and use interesting and innovative methods.

Wider impact

Beyond academia, it is more difficult to quantify impact. That is, 'it is not clear how the impact of research on other areas of society should be measured – unlike the impact which research has on itself' (Bornmann, 2014, p. 896).

In an attempt to achieve impact beyond academia, members of society were consulted throughout the design and conduct of the thesis, as described in section 1.4 Patient and Public Involvement. In brief, the research aims were aligned with what people with dementia had personally set as their priorities for research; members of the Alzheimer's Society contributed directly to the design of the thesis at two time points and the four empirical studies collected the personal accounts of people with advanced dementia and frontline hospital staff involved day-to-day dementia care.

In addition, the work was shared with a range of audiences in the following four ways:

Contact with research participants. Study summaries were shared with all research participants who agreed to be contacted at the close of each study, as described further in Chapters 3, 4 and 5. Responses from participants who learned of the research findings through newsletter publications or email showed thanks and said the research was of value to them and their colleagues.

Professional and organisational mailers. As discussed in Chapter 2, the findings of the systematic review were shared via an organisational newsletter (The Retreat Newsletter), a professional body (The Bulletin, Division of Clinical Psychology) and via the mailing list of a professional special interest group (the Faculty of the Psychology of Older People within the British Psychological Society). Personal reflections and thanks were received from three people, including a person with dementia, the wife of somebody with dementia and the Chair of The Retreat. Similarly, as discussed in Chapter 3, a reflective article was written for Nursing Standard on how it felt to be a researcher in a hospital ward. Nursing Standard is a professional newsletter produced by RCNi to provide nurses and associated health professionals with the latest developments impacting their practice.

Third, work from this thesis has been published in five different peer-reviewed journals. Collectively, the journals have international readership of multidisciplinary healthcare professionals and students, including psychiatrists, psychologists and nurses, across topic areas of biological, psychological and social aspects of aging.

Finally, effort was made to present the findings of the thesis in an easily accessible format to a wide audience via blogging. Supervisor, Prof. T Dening wrote a blog post on Dementia Day-to-Day to share a finding from the freelisting interview study (see Chapters 3 and 4), title 'A cup of tea'. Dementia Day-to-Day explores how people from all walks of life experience aging and wellbeing. The post received a comment from a professional carer who reflected on the changes they will make in their future practice. Though not planned, further evidence of demonstrated impact through blogging was the uptake of the systematic review (see Chapter 2) in a blog post by Hilary Shepherd on the 'National Elf Service' website. The website provides accessible summaries to clinicians who might not have the time or skill to remain up-to-date with the latest research evidence.

In summary, the design and dissemination of findings from throughout the thesis benefited from interaction with stakeholders within and outside of academia. Attention was paid to using a variety of ways to reach people, including personal contact, newsletter, blog posting, open access journal publication and demonstrating the highest possible academic standard through journal impact factors and journal rank; this was in an attempt to reach a broad audience who could benefit from the research.

7.5 Critique and future improvements

The work of this thesis is critiqued here with discussion of three main considerations: changing hospital practice, conducting meaningful research with people with dementia and the choice to emphasise distress or happiness. A discussion of the hospital system and the known barriers between research findings being reported and their implementation into practice is important in ensuring that the findings of this thesis are not overstated. The involvement of people with dementia in this thesis is then discussed; collaboration in the design of the research and the design of two studies that sought the views of people with dementia directly are appraised, while the analysis of written literature only is discussed as a limitation, with suggestions given for future research. Finally, the merits of researching both negative emotions and positive emotions are discussed.

7.5.1 Changing the hospital system

This thesis was designed to produce findings that were of value to real world hospital practice (see section 7.3 Research aims achieved); however, the three empirical studies of the thesis (Chapters 3-6) each concluded with caution that the person-centred practice described and recommended from the study findings needed to be objectively

evaluated before any changes to practice could be made. This was because care requested by patients might not match the care resources available in hospitals, and because care described by hospital staff might represent what is thought to be optimal but not consistently delivered. There are also likely to be numerous implications across the hospital system if any aspect of practice changes, which have not been thoroughly anticipated in the scope of this thesis. As discussed in Chapter 1, section 1.3.5, hospitals are said to maintain complex and interdependent rituals around their highest priorities of patient care and safety. The knowledge of good practice introduced in this thesis was previously missing from the research literature, and in this respect, the thesis makes a valuable contribution, however, the reach of these findings is not to be overstated.

Here, some of the barriers between research findings being reported and their implementation into practice over time are discussed (Field *et al.*, 2014). This is discussed further in Chapter 1, section 1.5 Philosophy of science.

The 'action cycle' of the Knowledge to Action Framework (Graham *et al.*, 2006) suggests ways for the findings of this thesis to be expanded into practice. The first two criteria of the action cycle have been met in part, in addressing the relevance of the knowledge to the local context, the hospital ward, and in assessing barriers to knowledge use (see section 7.3 Research aims achieved). Importantly though, it is acknowledged that culture varies from hospital to hospital, with differences in beliefs, values and traditions (van der Geest & Finkler, 2004). Variability also exists within a hospital, across staff teams and wards (Street & Coleman, 2012) and hospitals are constantly changing (Finkler *et al.*, 2008). Therefore, the generalisability of the findings from the three empirical studies of this thesis, each based within a single UK hospital setting, is limited. Before the recommendations of any of the studies could be implemented more widely, future research would need to consider how the findings generalise to different hospital settings and there would need to be robust assessment of the costs and implications of

changing current practice. The Knowledge to Action Framework would suggest that this exploration is followed by the design of tailored interventions for practice, monitoring of their use and evaluation of both immediate and sustained outcomes.

Observational methods would provide a valuable addition to this research area, in observing how different approaches to care are effective in promoting patient emotional wellbeing. Dementia Care Mapping (DCM) is one such method, and has been recommended for the evaluation of different care approaches (Innes *et al.*, 2016). DCM is a validated observational tool used to measure patient wellbeing, including patient distress and interactions with caregivers; however, alone, DCM may not offer a detailed-enough evaluation of emotion-focused care. As one additional suggestion, the Positive Response Schedule (PRS) could be a useful instrument for recording the wellbeing of patients with dementia (Perrin, 1997); it was developed as a supplement to DCM, as a way to look more closely at behaviour and be more sensitive to the emotions of people with dementia. It has been said to be more suitable for people with severe dementia than DCM, who might not be able to describe their wellbeing. PRS has been used to evaluate the effects of the varying communication styles of care assistants when interacting with care home residents with dementia (Stanyon, Thomas, Gordon, & Griffiths, 2019), suggesting its value in this field.

Future research should also include cost- and benefit- analyses of making any changes to existing hospital systems, including evaluations of patient mental and physical wellbeing as outcomes, as well as the costs of treatment and hospital stay (Annear & Lucas, 2018; Cerejeira *et al.*, 2012; Kaminishi *et al.*, 2019; Royal College of Psychiatrists, 2017). As rationale for this recommendation, in a review of dementia care training interventions for hospital staff, Scerri *et al.* (2017) found that the wellbeing and emotions of patients were not evaluated as an outcome in any study.

In summary, the conclusions and recommendations of this thesis must be interpreted with an appreciation of the significant difficulties of changing real world practice. Both the culture and priorities of hospitals in particular, and the study of implementation science, provide valuable insights into these difficulties.

7.5.2 The views of people with dementia

It has been suggested that the experience of dementia remains largely unknown to those without the condition because of the very nature of the disease (Froggatt, 1988; Weiner *et al.*, 1988); therefore, personal accounts from people with dementia are needed to inform research and healthcare. As one example of this reasoning, Barnett (2000) suggested that people with dementia can be more strongly connected to their emotions and immediate perceptions because they might be without words or memories, meaning we cannot presume what is most important to them. We can, however, attune ourselves to the person's emotions and ways of communicating these.

Research concerned with the care of patients with dementia needs to find ways to include their perspective. Within healthcare, Bartlett (2014) has suggested that the medical view of dementia can somewhat contribute to the exclusion of people with dementia. Similarly, Greenhalgh (2016) has written about professional 'vices' that might describe the ways of working in health systems, whereby some health professionals might assume that their knowledge is worth more than that of others because of their status and standing, including the views of patients. The 'vice' of practising 'the way it is done' could also be said to be true of the design of research.

These were some of the reasons for seeking the views of people with dementia in this thesis. The involvement of people with dementia was demonstrated in the following ways: people with dementia and their carers were involved in the preliminary design of the thesis and in an interim evaluation of the findings (see Chapter 1, section 1.4 Patient

and Public Involvement); both the systematic review (see Chapter 2) and the analysis of advance care planning documents (see Chapter 6) sought personal accounts from people with dementia, their descriptions of their emotions and their requests for their care, in line with Research aims 3 and 4. This follows recommended good practice of the values of involvement to include groups of people in research who might not have been involved before (INVOLVE, 2018).

Ways in which the involvement of people with dementia was limited and suggestions of ways to conduct future research are discussed next.

Some of the recognised limitations of patient and public involvement (Crocker *et al.*, 2017; Domecq *et al.*, 2014; Evans *et al.*, 2014) were evident in this thesis. For example, contributions from people with dementia did not feature across all levels of the research equally; whilst there was 'consultation' and 'involvement' in the design of the aims and methodology, 'collaboration' was not achieved; patients and the public did not feature as active partners, they did not collect or analyse data.

In addition, it cannot be assumed that the views of the participants in this thesis were representative of all people with dementia more widely (Domecq *et al.*, 2014), despite the comprehensive sampling methods of both the systematic review (see Chapter 2) and advance care planning document analysis (see Chapter 6).

For the studies of the thesis that captured the personal perspectives of people with dementia (see Chapters 2 and 6), only secondary data analysis was conducted. The rationale is discussed in more detail within each chapter, but in brief was to systematically reach descriptions of distress from the largest number of viewpoints possible, as a way to evidence a way of talking about personal experiences that was different from the dominant medical narrative, and to analyse all available advance care planning documents, which are not often used. These may have missed the variability in how people with dementia have expressed their distress and their care needs - accounts

that have not been captured in literature - as discussed within the study limitations. The analysis of advance care planning documents sought achievable, real world practice, hence the documents were retrieved retrospectively, but the richness of data collected was limited to short written entries and it was not clear to what extent these represented patient views only, as opposed to caregiver views. It was beyond the scope of this thesis to conduct successive studies that would improve the representation of people with dementia and their descriptions of their emotions and needs.

Suggestions for future research include interview studies with hospital patients with dementia to enquire about their subjective experiences of hospital and their requests for hospital care, using methods similar to those of Digby *et al.* (2012). Techniques that have been recommended for interview studies with people with dementia have included building rapport over time and with practice, using conversation rather than questions to elicit views and listening for metaphors and stories (Sutton & Cheston, 1997).

In future improvements, it would also be important to find ways to avoid assumptions that a group of people pooled for the purposes of study are homogenous, with uniform needs. This is discussed in Chapter 1, section 1.5 Philosophy of science. Amongst others, Bartlett (2014) has presented evidence that having dementia does not make people alike. Obtaining the view of somebody with dementia should not attempt to reduce the vast range of personal experiences by implying 'somebody with dementia' will have a typical experience that is representative of others' (Davenhill, 2007; Garand *et al.*, 2009; Sinason, 1992). Collectively, patients with dementia can have difficulty communicating their needs (George *et al.*, 2013; Griffiths *et al.*, 2014) and receive poorer care (Boyd *et al.*, 2019; Ocloo & Matthews, 2016; Sampson *et al.*, 2006), but this will not be a uniform experience. In an attempt to improve the care of people with a diagnosis of dementia, the studies of this thesis might have inadvertently suggested that people with dementia can be considered alike. Hospital staff report that they infrequently understand the

needs of patients with dementia (Boaden, 2016; Dewing & Dijk, 2016; Samra *et al.*, 2015) and report having insufficient training, knowledge and skills when caring for patients with dementia (Dewing & Dijk, 2016; Griffiths *et al.*, 2014); it can therefore be tempting to give simple suggestions in an attempt to be helpful. This need for caution is discussed throughout the thesis; for example, the findings presented in Chapters 2, 3 and 6 do not support this view. When people with dementia described their emotional distress or described their requests for care when feeling distressed, the descriptions were widely varying; they were different for each person and changed as the person's emotions changed. Similarly, distress was explained by widely varying influences that included fundamental, human anxieties of the person losing their sense of self, their social world, the prospect of losing their future, freedom and control, and needing to turn to others for emotional care. Hospital staff agreed that distress could be communicated in varied ways, with a high number of possible causes for emotional distress. Therefore, where summaries of emotional distress and possible responses were presented in this thesis, this occurred consistently with the caution that personal experiences were widely variable. Recognised limitations discussed in 1.5 Philosophy of Science and the critique of each chapter include the possible over-simplification of distress.

It must also be acknowledged that viewpoints additional to those presented in this thesis are essential to understanding the emotional experiences of people with dementia and how these can be most suitably responded to or enhanced; namely, the viewpoints of family members and unpaid caregivers. The systematic review presented in Chapter 2 sought information from family and friends of people with dementia, as well as self-reported accounts of distress and information from professional caregivers and researchers. This was an attempt to reach a comprehensive overview of how the emotional distress of people with dementia has been described and understood to date. As described in the research aims of the thesis, see section 1.2, the further three studies

of the thesis were located within a hospital setting and collectively learned the views of hospital ward staff within routine hospital practice. This omitted the viewpoints of family and friends. Future research would benefit from asking the questions of this thesis to unpaid caregivers, who are of central importance to caring for people with dementia (National Institute for Health and Care Excellence, 2018).

7.5.3 Happiness

This thesis was more concerned with emotions of distress than with emotions of happiness. This was aligned with the research and best practice literature reviewed in Chapter 1, which revealed the more urgent need for improved care at times of increased challenge to care staff, when patients with dementia are distressed (Boaden, 2016; Hessler *et al.*, 2017; National Institute for Health and Care Excellence, 2018; Sampson *et al.*, 2014). Chapters 3 and 4 present studies that asked explicitly about emotional distress. On reflection of this focus, the article 'Where is the happiness in dementia?' was written and published by International Psychogeriatrics. This said, in completing the comprehensive literature search, it became apparent that a surprisingly small proportion of the literature on the emotional experience of people with dementia was concerned with positive emotions. Of the approximately 40,000 titles retrieved, the largest number of titles retrieved from any single database solely using positive emotion terms was 156, which was 1.7% of all titles at most. This showed a marked asymmetry in the research literature towards negative emotions. The findings might suggest something about what is going on inside the heads of people with dementia – that there is an absence of happiness – or else something about what is going on inside the heads of those researching dementia – a disinterest in happiness; this might reflect a negative lens through which dementia is viewed in society. Prevailing intervention models, such as Living Well with Dementia and Person-Centered Care (Banerjee, 2010; Kitwood,

1997) would suggest that the experience of dementia does not comprise an emotional experience that is 99% distressing. Therefore, there could be an important omission of positive experience in the research literature that could helpfully contribute to alternative views to those of burden, risk, and mortality.

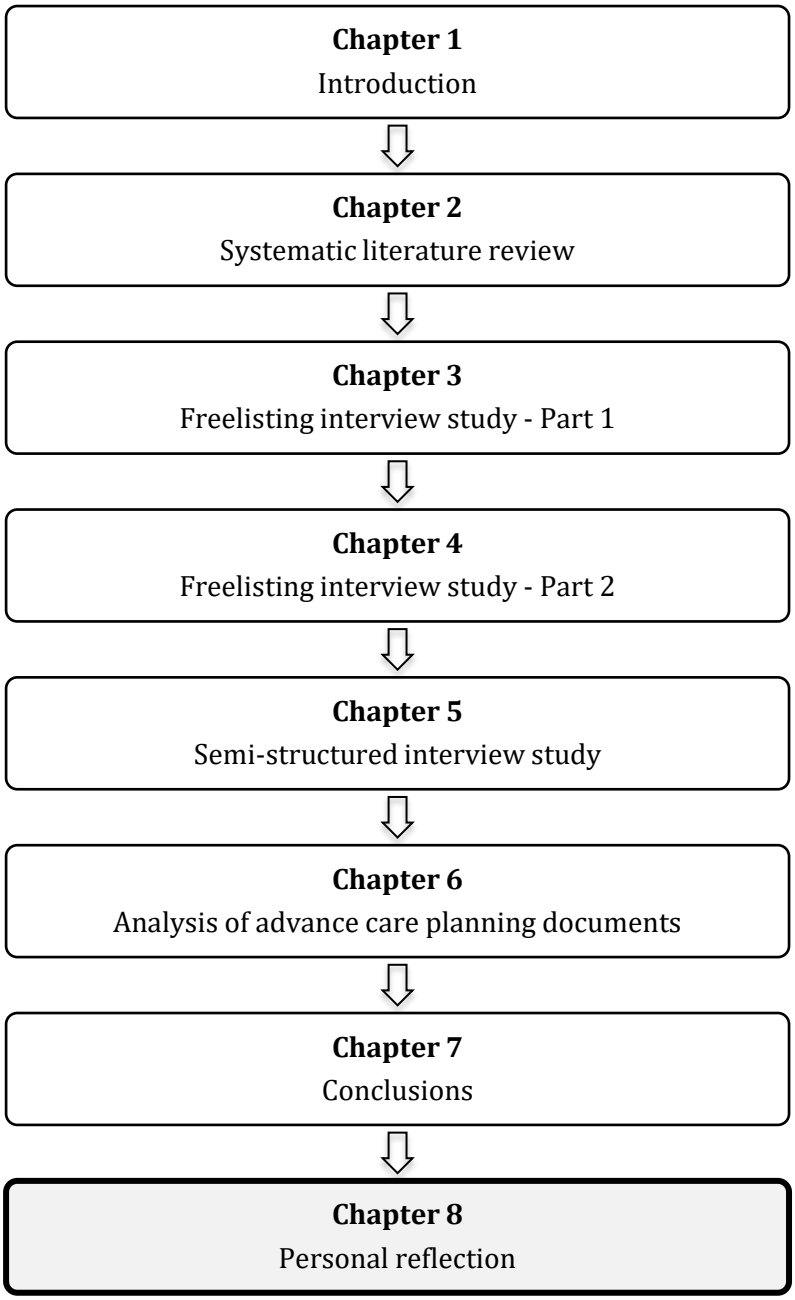
In an attempt to address patient wellbeing more fully, Chapter 5 presents a study that asked more broadly about patient emotional wellbeing, including the promotion of positive emotional experiences within hospital care. Findings suggested that ways to promote happiness for patients with dementia when in hospital included using information prepared prior to admission, such as from personal books or from families or previous care services, to learn of sources of enjoyment and comfort, sharing humour and emphasising the happy side of things to share positive emotions, working as a team to allow different interpersonal relationships to develop between staff members and patients, staff members being present in the environment and including patients to enhance belonging, reminiscing with patients to promote competence and inclusion and accessing dolls and animals as therapeutic resources.

These could be important contributions to the promotion of emotional wellbeing and balance to emotional distress, which can take a toll on healthcare professionals and researchers in their pursuit of improving patient care (Dartington, 2007; Yalom, 1980). For example, research has suggested that healthcare staff can choose to avoid topics that might cause upset, such as when discussing care preferences when care planning (Livingston *et al.*, 2012). A recommendation was made in Chapter 6 to revise ACP documents to ask what could sustain patient emotional wellbeing.

Importantly in this thesis, there was an aspiration for balance between fostering positive emotions and offering emotional comfort at times of distress, both as components of emotional wellbeing. Too great an emphasis on positive emotions has been discussed as being a defensive process of simplifying the care needs of patients,

who ask less of caregiving staff if they 'appear to be happy' (Bartlett *et al.*, 2017; Müller-Hergl, 2009). Too great an emphasis on emotional distress has been associated with burden; Matthews and Sunderland (2019) discuss the emotional labour sometimes endured by healthcare staff when the personal stories of people with dementia cause shock or stir negative emotions for them personally. This has particular relevance for this thesis. The studies and their conclusions were not intended to increase the burden on healthcare staff, rather, to speak about things that were part of their routine work that have been under-recognised in literature regarding the design of services. In Chapter 5, when asked about barriers to caring for the emotional needs of patients with dementia, ward staff spoke of the sadness, difficulty and weight on them of keeping individual patients in mind. Staff also spoke of motivators of doing the right thing in sharing the patient's experience with them. In this thesis, across studies, staff drew upon resources to make sense of and share difficult aspects of this work. Chapters 3 and 4 discuss this more fully; staff talked with and spent time with patients, they shared positive experiences; they also worked as a team and required support from management. This is, as Matthews and Sunderland (2019) describe, the promising process of using personal patient stories to positively influence healthcare.

Chapter 8. Personal reflection.



8.1 Overview

This final chapter presents my personal reflections on undertaking a PhD, which was alongside my employment as a clinical psychologist working within mental healthcare. The chapter introduces reflexivity, discusses personal biases and complementary roles

of being a clinician and being a researcher (section 8.2). Some of the reflections shared may be of interest to clinicians and their prospective research. The final remarks give thanks to Prof. A Griffiths, Prof. T Dening and Dr. D Coleston-Shields (section 8.3).

8.2 Reflexivity

When conducting research, especially qualitative research as in this thesis, it is necessary for the researcher to recognise how they as a person might influence the research design and how they might shape the findings (Lincoln, Lynham, & Guba, 2011; Noble & Smith, 2015). This is referred to as reflexivity; it means honest and continuous self-awareness. The sharing of this awareness in the dissemination of research seeks to reduce biases that can otherwise be introduced into the research conclusions by the researcher's own views, and seeks to improve the trustworthiness of the researcher's claims. This section offers a brief overview of relevant aspects of my identity, in the hope of improving the transparency of the findings presented in this thesis. Possible biases are made explicit.

Personal biases

As discussed in the Philosophy of Science section (Chapter 1, section 1.5), this thesis prioritised research that is firmly embedded within real world practice: the commonplace experiences of people with dementia entering hospital, and the routine care they receive. This was the motivation for the thesis, rather than this being devised along the way, because of my having practiced as a clinician within healthcare for older people for five years. During this period of clinical practice, I had already developed an interest in this area.

I hold a Doctorate in Clinical Psychology (ClinPsyD), building on a degree in Psychology (BSc Hons). Working within the NHS and for private providers had given me experience of multi-disciplinary healthcare, the impact of care systems on the mental health of a wide range of people from across the age range, and, most importantly, the reliance in healthcare on policies and research evidence to justify any spend of time or money. It was my experience that within dementia care, the drivers for improving the subjective wellbeing of the patient, their mental healthcare, were underdeveloped because the research literature was underdeveloped. I was aware of this in my role as a clinical psychologist when the resources available to older people, such as art therapists and access to psychological therapy, were not the same as for younger people, or people without dementia. In an attempt to request increased resources, it was very difficult to draw upon an evidence base or predict valuable outcomes to justify the investments. This became more apparent to me throughout the course of this thesis as the organisation within which I was employed responded dramatically to the Government's Five Year Forward View strategy (Ham & Murray, 2015), which emphasised the prevention of mental health problems and more decision making powers being given to GPs. Arguments for what mattered most to older patients with complex needs, including dementia, could not be formed quickly enough or with enough evidence and the services that I worked into began to close. Older adult hospital wards closed and the wards for younger patients stayed open. An implication of these changes for me personally was that I was at risk of being made redundant, not likely from my role as a clinical psychologist, but from working within dementia care.

Having solid evidence to draw upon that identified the emotional needs of people with dementia, with an emphasis on finding solutions from real world practice, was needs-led research because it appeared that there was little existing comprehension from managers and other healthcare colleagues about the emotional wellbeing of people with dementia.

Another personal experience over the course of the thesis that will have influenced my approach to the research is that my grandma - one of the most important people in my life - developed dementia, and it was not a sad process of her losing herself. The things that mattered most to her were with her until she died. Our experience as a family was probably similar to many other families; and I think my grandma was entitled to her identity and to her emotions.

For these personal reasons, I continuously critiqued my approach to the work in this thesis as it was taking place and I tried to be aware of introducing bias or imbalance into the work.

One possible bias might be that I think it is valuable to enter into the world of the person with dementia, how they are feeling, what would help them to feel better. For example, in the analysis of interview data presented in Chapter 5, I hoped that comments such as 'You can't imagine what the experience is like for the person with dementia, but you can at least try to imagine what it's like' would represent the full data set and be represented in the conclusions.

As another example of a personal bias, I had experience of working with staff teams who cared for patients with dementia. In this research, when I didn't know the staff, I thought I knew of some of their experiences because of working with previous colleagues in other settings. I believed the care that hospital staff delivered was vast and varied, but could be excellent and often went undocumented and under-recognised. In this research, I wanted the staff to demonstrate competence in recognising the emotional needs of people with dementia. A risk of this bias is to be dismissive of the full extent of the care system - that is, of staff struggling and having a very difficult job to improve physical health, with basic needs of being clean, warm and fed, of there being too few hospital beds, high staff turnover, changing incentives and too little time… and try to find quick fixes that unfairly present the positives.

The following were examples of in-built mechanisms to reduce these personal biases: supervision and the collective thinking of four researchers; the invited expertise in linguistic analysis offered by Dr. Kevin Harvey; reference to external guidelines and published examples of analysis protocols; quantitative and qualitative analysis methods including computer software and methodological design that used multiple reviewers and independent audit.

Some of the reflections resulting from the constant meaning-making conversations with the research supervisors are captured in two publications: Nursing Standard accepted a reflective article on how it felt to be a researcher in the hustle and bustle of a hospital ward, where parallels were drawn with what it might be like to be a patient. International Psychogeriatrics published a letter written to reason with academic peers about whether the happiness of people with dementia is interesting to researchers, discussed more fully in section 7.5.

Researcher and clinician identities

Here I share thoughts on how my identity as a researcher developed over the course of this thesis, and the influences on my clinical practice.

At the beginning of the thesis, the first stumbling blocks seemed to be the skill in asking a research question that was too big to be able to imagine the answer, and that would take three years of full time study to comprehend. In practice, I had conducted research studies that were small in ambition and asked questions about the local service, to directly change practice. In contrast, this thesis began with an intense and extremely vast systematic search of literature in an attempt to define the concept of emotional distress, which is not where I expected to begin. I then moved the research into the hospital setting, asking ward staff about their approaches to care, and finished with the

requests for hospital care made by patients with dementia. This is not the course I anticipated at the beginning of the thesis because I had started with plans that were far too ambitious in scope and I anticipated simpler findings, which I think came from an underappreciation of robust research design. I had expected to develop an outcome measure so that intervention studies could be evaluated against the impact on the emotional wellbeing of patients with dementia. The research is nowhere near being ready for that even now (see section 7.5).

For me, the difference between clinical practice and research has partly come to be the scale of thinking, whereby research requires a much greater degree of abstraction and conceptual thinking. And partly, I think the difference is of quality, whereby many drivers in clinical practice are of things that can be easily quantified, or done quickly or in high number - which is a huge shame in my opinion. Doing research has been like an essential pause to think clearly about what questions should be asked, and how they can be properly answered - not quickly and not within the realm of what is already known. The positivist approach to research discussed in section 1.5 is aligned with these influences within healthcare; decisions made in this thesis were to adopt a constructivist approach.

The skills I have learnt of being a researcher are more and more apparent in my clinical work. A downside is that I can feel less satisfied by how people reach conclusions across services about what is going well or not well. Often basic concepts such as framing a question first and then considering the information that would be needed to answer the question are missing. In a simple way, there is a lack of thoroughness, probably because of time pressures and because of how variable clinical work can be. It was helpful for me to read literature along the way about 'virtue ethics', which gave me an understanding of what transferable skills I had been learning. Virtue ethics describes there being a trust in morally responsible people who will thereby act in an appropriate, informed and

compassionate way whilst adhering to rules and standards (Israel & Hay, 2006). In research, this would mean that research carried out to an acceptable standard would rely upon the researcher and take into account their training and experience, supervision, their judgments and intentions. This can be a helpful way to view the variability within clinical practice. Intellectual virtues within the researcher, or clinician, might include questioning, carefulness, flexibility, open-mindedness and creativity. Rigidity is then considered to be a vice (Amaya & Ho, 2013). In a survival guide for doctoral training, Tanggaard and Wegener (2016) describe a process of 'becoming somebody', living as a researcher, embedded in a social practice or culture of research; and this is an 'antidote' to knowledge acquisition or research outputs per se. The virtues can overlap both research practice and clinical practice, which otherwise at times seem like very different worlds.

In addition to research skill positively influencing clinical practice, I have often reflected on how the reverse is also true; that is, 'what can I bring to research as a clinician?' 'Insider status' is discussed in the research literature as a way in which a researcher can access participants and build trust more easily (Kerstetter, 2012). I had to be clear that participation was informed and voluntary; this seemed to be the case because some participants chose not to participate, three in total (study presented in Chapter 5). One important benefit of being a clinician in this thesis was the relative ease of navigating data collection – of being with multidisciplinary colleagues, of frequenting hospital corridors. I am sure that for some parts of the research, my professional title allowed me access more quickly than would have been the case for an unknown researcher, or one without practitioner status. I also think my clinical title meant that hospital staff replied to my emails, participated in a pilot study (see Chapter 3) and supported the recruitment of participants, because they seemingly understood how I might conduct myself. Clinical skills, such as interviewing people in different circumstances and being comfortable with the unpredictable things that might arise, were valuable. My clinician

title seemed to offer some face validity to the data being collected and what might be done with the findings. In other shoes, on a different day, I could have been a research participant as they were, being interviewed about my professional role. I had seen first-hand the things that staff were telling me about, meaning I could probably more easily understand the material.

As a final reflection, it has been my experience that research and clinical practice are not always complementary. For me, they each have different priorities and require different skills. The integration of the two roles over this thesis has been difficult but important. It is my belief that the research designed and the outputs achieved benefited from the starting point of me being embedded within healthcare as a practitioner. As a clinician, I feel more rounded and robust because of my acquired research skills.

8.3 Thanks

This is the briefest section of the thesis but to me the most important. I feel incredibly grateful, and unique, to have been supported so thoroughly and in so many different ways by my three supervisors, Prof. Amanda Griffiths, Prof. Tom Dening and Dr. Dons Coleston-Shields. Their collective strengths means I could probably learn from them forever. I feel equally grateful and equally sad that the work of this thesis has come to its end.

References

Aging with Dignity. (2011). *Five wishes*. Tallahassee, FL: Aging with Dignity.

Aldridge, H., Fisher, P., & Laidlaw, K. (2019). Experiences of shame for people with dementia: an Interpretative Phenomenological Analysis. *Dementia, 18*(5), 1896-1911.

Alonzo, T. M., Mitchell, K. M., & Knupp, C. E. (2015). Comfort care for people with dementia: the Beatitudes campus model. In M. L. Malone, E. A. Capezuti, & R. M. Palmer (Eds.), *Geriatrics Models of Care* (pp. 299-302). Switzerland: Springer International Publishing.

Alzheimer's Society. (2014). Dementia 2014: Opportunity for change. Retrieved from https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_2014_opportunity_for_change.pdf

Alzheimer's Society. (2016). *Fix dementia care NHS and care homes*. London: Alzheimer's Society.

Alzheimer's Society. (2017). This is me. Retrieved from https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/this_is_me.pdf

Amaya, A., & Ho, H. L. (2013). *Law, virtue and justice*. Oxford: Bloomsbury Publishing.

Annear, M. J., & Lucas, P. (2018). Dementia in a regional hospital setting: contextual challenges and barriers to effective care. *International Journal of Ageing and Later Life*, 1-29.

Appleton, J. V., & King, L. (2002). Journeying from the philosophical contemplation of constructivism to the methodological pragmatics of health services research. *Journal of Advanced Nursing, 40*(6), 641-648.

Ashton, C., & Manthorpe, J. (2017). The views of domestic staff and porters when supporting patients with dementia in the acute hospital: An exploratory qualitative study. *Dementia & Neuropsychologia, 0*(0), 1-18.

Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., & Volmink, J. (2008). Conducting a meta-ethnography of qualitative literature: lessons learnt. *BMC Medical Research Methodology, 8*(1), 21-30.

Atkinson, P., Coffey, A., Delamont, S., Lofland, J., & Lofland, L. (2001). *Handbook of ethnography*. London: Sage.

Attree, P. (2004). Growing up in disadvantage: a systematic review of the qualitative evidence. *Child: Care, Health and Development, 30*(6), 679-689.

Bagley, H. J., Short, H., Harman, N. L., Hickey, H. R., Gamble, C. L., Woolfall, K., . . . Williamson, P. R. (2016). A patient and public involvement (PPI) toolkit for meaningful and flexible involvement in clinical trials–a work in progress. *Research involvement and engagement, 2*(1), 15-28.

Baker, P. (2006). *Using corpora in discourse analysis*. London: Bloomsbury Academic.

Baker, P. (2010). *Sociolinguistics and corpus linguistics*. Edinburgh: Edinburgh University Press.

Banerjee, S. (2010). Living well with dementia: development of the national dementia strategy for England. *International Journal of Geriatric Psychiatry, 25*(9), 917-922.

Banzi, R., Moja, L., Pistotti, V., Facchini, A., & Liberati, A. (2011). Conceptual frameworks and empirical approaches used to assess the impact of health research: an overview of reviews. *Health Research Policy and Systems, 9*(1), 26.

Barg, F. K., Huss-Ashmore, R., Wittink, M. N., Murray, G. F., Bogner, H. R., & Gallo, J. J. (2006). A mixed-methods approach to understanding loneliness and depression in older adults. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 61*(6), S329-S339.

Barnett, E. (2000). *Including the Person with Dementia in Designing and Delivering Care: I Need to be Me!* London: Jessica Kingsley Publishers.

Barry, V., Stout, M. E., Lynch, M. E., Mattis, S., Tran, D. Q., Antun, A., . . . Kempton, C. L. (2019). The effect of psychological distress on health outcomes: a systematic review and meta-analysis of prospective studies. *Journal of Health Psychology*. doi:10.1177/1359105319842931

Bartlett, R. (2014). Citizenship in action: the lived experiences of citizens with dementia who campaign for social change. *Disability and Society, 29*(8), 1291-1304.

Bartlett, R., Windemuth-Wolfson, L., Oliver, K., & Dening, T. (2017). Suffering with dementia: the other side of "living well''. *International Psychogeriatrics, 29*(2), 177-179.

Bauer, M. S., Damschroder, L., Hagedorn, H., Smith, J., & Kilbourne, A. M. (2015). An introduction to implementation science for the non-specialist. *BMC Psychology, 3*(1), 32-43.

Beck, C. T. (1994). Phenomenology: its use in nursing research. *International Journal of Nursing Studies, 31*(6), 499–510.

Beck, E. R., McIlfatrick, S., Hasson, F., & Leavey, G. (2017). Health care professionals' perspectives of advance care planning for people with dementia living in long-

term care settings: a narrative review of the literature. *Dementia, 16*(4), 486-512.

Biber, D. (1993). Representativeness in corpus design. *Literary and linguistic computing, 8*(4), 243-257.

Bloom, L. (1995). *The transition from infancy to language: acquiring the power of expression*. Cambridge: Cambridge University Press.

Boaden, A. (2016). Fix dementia care: hospitals. Retrieved from https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID¼2907

Borbasi, S., Jones, J., Lockwood, C., & Emden, C. (2006). Health professionals' perspectives of providing care to people with dementia in the acute setting: toward better practice. *Geriatric Nursing, 27*(5), 300-308.

Borgatti, S. P. (1996). ANTHROPAC 4.0. Natick, MA: Analytic Technologies.

Bornmann, L. (2014). Do altmetrics point to the broader impact of research? an overview of benefits and disadvantages of altmetrics. *Journal of Informetrics, 8*(4), 895-903.

Boyd, M., Frey, R., Balmer, D., Robinson, J., McLeod, H., Foster, S., . . . Gott, M. (2019). End of life care for long-term care residents with dementia, chronic illness and cancer: prospective staff survey. *BMC Geriatrics, 19*(1), 137-145.

Bradshaw, L. E., Goldberg, S. E., Schneider, J. M., & Harwood, R. H. (2013). Carers for older people with co-morbid cognitive impairment in general hospital: characteristics and psychological well-being. *International Journal of Geriatric Psychiatry, 28*, 681-690.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Brazil, K., Carter, G., Cardwell, C., Clarke, M., Hudson, P., Froggatt, K., . . . Kernohan, G. (2017). Effectiveness of advance care planning with family carers in dementia nursing homes: a paired cluster randomized controlled trial. *Palliative Medicine, 32*(3), 603-612.

Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta ethnography to synthesise qualitative research: a worked example. *Journal of Health Services Research and Policy, 7*(4), 209-215.

Brooke, J., & Ojo, O. (2017). Elements of a sustainable, competent, and empathetic workforce to support patients with dementia during an acute hospital stay: a comprehensive literature review. *The International Journal of Health Planning and Management, 33*(1), e10-e25.

Brooke, J., & Semlyen, J. (2017). Exploring the impact of dementia-friendly ward environments on the provision of care: a qualitative thematic analysis. *Dementia, 0*(0), 1-16.

Brooker, D. (2007). *Person-centred dementia care: making sevices better*. London: Jessica Kingsley Publishers.

Brooker, D. J., & Surr, C. (2006). Dementia Care Mapping (DCM): initial validation of DCM 8 in UK field trials. *International Journal of Geriatric Psychiatry, 21*(11), 1018-1025.

Brown, G., & Yule, G. (1983). *Discourse analysis*. Cambridge: Cambridge University Press.

Bryman, A. (2012). *Social Research Methods* (4th ed.). New York: Oxford University Press.

Burgener, S., & Berger, B. (2008). Measuring perceived stigma in persons with progressive neurological disease: Alzheimer's dementia and Parkinson's disease. *Dementia, 7*, 31–53.

Burman, E., & Parker, I. (1993). *Discourse analytic research: repertoires and readings of texts in action*. London: Routledge.

Burnard, L. (2009). About the British National Corpus. Retrieved from http://www.natcorp.ox.ac.uk/corpus/index.xml

Byrne, D. (2002). *Interpreting quantitative data*. London: Sage.

Byrt, T., Bishop, J., & Carlin, J. B. (1993). Bias, prevalence and kappa. *Journal of Clinical Epidemiology, 46*(5), 423-429.

Calhoun, C. J. (1994). *Social theory and the politics of identity*. Oxford: Blackwell Publishers.

Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R., . . . Donovan, J. (2011). Evaluating meta ethnography: systematic analysis and synthesis of qualitative research. *Health Technology Assessment, 15*(43), i-165.

Campbell, R., Pound, P., Pope, C., Britten, N., Pill, R., Morgan, M., & Donovan, J. (2003). Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science and Medicine, 56*(4), 671-684.

Carayon, P., & Smith, M. J. (2000). Work organization and ergonomics. *Applied Ergonomics, 31*(6), 649-662.

Cerejeira, J., Lagarto, L., & Mukaetova-Ladinska, E. (2012). Behavioral and psychological symptoms of dementia. *Frontiers in Neurology, 3*, 73-93.

Chalmers, I., Bracken, M. B., Djulbegovic, B., Garattini, S., Grant, J., Gülmezoglu, A. M., Howells, D. W., Ioannidis, J. P. A., & Oliver, S. (2014). How to increase value and reduce waste when research priorities are set. *The Lancet, 383*(9912), 156-165.

Clarke, M. J., & Stewart, L. A. (1994). Obtaining data from randomised controlled trials: how much do we need for reliable and informative meta-analyses? *British Medical Journal, 309*(6960), 1007-1010.

Clissett, P., Porock, D., Harwood, R. H., & Gladman, J. R. (2013). The challenges of achieving person-centred care in acute hospitals: a qualitative study of people with dementia and their families. *International Journal of Nursing Studies, 50*(11), 1495-1503.

Colaizzi, P. F. (1978). Psychological research as the phenomenologist views it. In R. S. Valle & M. King (Eds.), *Existential phenomenological alternatives for psychology* (pp. 48-71). New York: Plenum.

Corrigan, P., Kerr, A., & Knudsen, L. (2005). The stigma of mental illness: explanatory models and methods for change. *Applied & Preventive Psychology, 11*(3), 179-190.

Cowan, K., & Oliver, S. (2013). *The James Lind Alliance guidebook*. Southampton, UK: National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre.

Cowdell, F. (2010). The care of older people with dementia in acute hospitals. *International Journal of Older People Nursing, 5*(2), 83-92.

Critical Appraisal Skills Programme. (2013). 10 Questions to Help You Make Sense of Qualitative Research. Retrieved from http://www.casp-uk.net/checklists

Crocker, J. C., Boylan, A. M., Bostock, J., & Locock, L. (2017). Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: a UK-based qualitative interview study. *Health Expectations, 20*(3), 519-528.

Crosbie, B., Ferguson, M., Wong, G., Walker, D. M., Vanhegan, S., & Dening, T. (2019). Giving permission to care for people with dementia in residential homes: learning from a realist synthesis of hearing-related communication. *BMC Medicine, 17*(1), 54-69.

Crowther, G. J. E., Brennan, C. A., & Bennett, M. I. (2018). The barriers and facilitators for recognising distress in people with severe dementia on general hospital wards. *Age and Ageing, 47*(3), 458-465.

Dartington, A. (2007). *Where angels fear to tread. Idealism, despondency, and inhibition in thought in hospital nursing*. London: Karnac.

Davenhill, R. (2007). *Looking into later life: a psychoanalytic approach to depression and dementia in old age*. London: Karnac Books.

Davenhill, R. (2008). Psychoanalysis and old age. In B. Woods & L. Clare (Eds.), *Handbook of the clinical psychology of ageing*. New York: John Wiley & Sons Ltd.

De Roo, M. L., Albers, G., Deliens, L., De Vet, H. C., Francke, A. L., Van Den Noortgate, N., & Van den Block, L. (2015). Physical and psychological distress are related to dying peacefully in residents with dementia in long-term care facilities. *Journal of Pain and Symptom Management, 50*(1), 1-8.

Dening, K. H., Greenish, W., Jones, L., Mandal, U., & Sampson, E. L. (2012a). Barriers to providing end of life care for people with dementia: a whole-system qualitative study. *BMJ Supportive and Palliative Care, 2*(2), 103-107.

Dening, K. H., Jones, L., & Sampson, E. L. (2012b). Preferences for end of life care: a nominal group study of people with dementia and their family carers. *Palliative Medicine, 27*(5), 409-417.

Department of Health. (1991). *The patient's charter*. London: HMSO.

Department of Health. (2007). *Mental Capacity Act 2005: code of practice*. London: HMSO.

Department of Health. (2015). *Prime Minister's challenge on dementia 2020*. London, England: Cabinet Office, Prime Minister's Office.

Detering, K. M., Hancock, A. D., Reade, M. C., & Silvester, W. (2010). The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ, 340*(c1345).

Dewar, B., & Nolan, M. (2013). Caring about caring: developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies, 50*(9), 1247-1258.

Dewing, J., & Dijk, S. (2016). What is the current state of care for older people with dementia in general hospitals? A literature review. *Dementia, 15*(1), 106-124.

Digby, R., & Bloomer, M. J. (2014). People with dementia and the hospital environment: the view of patients and family carers. *International Journal of Older People Nursing, 9*(1), 34-43.

Digby, R., Lee, S., & Williams, A. (2016). The experience of people with dementia and nurses in hospital: an integrative review. *Journal of Clinical Nursing, 26*(9-10), 1152-1171.

Digby, R., Moss, C., & Bloomer, M. (2012). Transferring from an acute hospital and settling into a subacute facility: the experience of patients with dementia. *International Journal of Older People Nursing, 7*(1), 57-64.

Dixon-Woods, M., Bonas, S., Booth, A., Jones, D. R., Miller, T., Sutton, A. J., Shaw, R. L., Smith, J. A., & Young, B. (2006). How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative Research, 6*(1), 27-44.

Dixon, J., Karagiannidou, M., & Knapp, M. (2018). The effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their carers: a systematic review and critical discussion. *Journal of Pain and Symptom Management, 55*(1), 132-150.

Doherty, S. (2005). History of evidence-based medicine. Oranges, chloride of lime and leeches: barriers to teaching old dogs new tricks. *Emergency Medicine Australasia, 17*(4), 314-321.

Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., . . . Murad, M. H. (2014). Patient engagement in research: a systematic review. *BMC health services research, 14*(1), 89-97.

Douma, L., Steverink, N., Hutter, I., & Meijering, L. (2017). Exploring subjective well-being in older age by using participant-generated word clouds. *The Gerontologist, 57*(2), 229-239.

Eccles, M. P., & Mittman, B. S. (2006). Welcome to implementation science. *Implementation Science, 1*, 1-3.

Edvardsson, D., & Nordvall, K. (2008). Lost in the present but confident of the past: experiences of being in a psycho-geriatric unit as narrated by persons with dementia. *Journal of Clinical Nursing, 17*(4), 491-498.

Edvardsson, D., Sandman, P. O., & Rasmussen, B. (2011). Forecasting the ward climate: a study from a dementia care unit. *Journal of Clinical Nursing, 21*(7), 1114-1136.

Edvardsson, D., Varrailhon, P., & Edvardsson, K. (2014). Promoting person-centeredness in long-term care: an exploratory study. *Journal of Gerontological Nursing, 40*(4), 46-53.

Edward, K. L., & Welch, T. (2011). The extension of Colaizzi's method of phenomenological enquiry. *Contemporary Nurse, 39*(2), 163-171.

Egger, M., Smith, G. D., Schneider, M., & Minder, C. (1997). Bias in meta-analysis detected by a simple, graphical test. *British Medical Journal, 315*(7109), 629-634.

Elliot, V., Williams, A., & Meyer, J. (2014). Supporting staff to care for people with dementia who experience distress reactions. *Nursing Older People, 26*(7), 22-26.

Evans, D., Coad, J., Cottrell, K., Dalrymple, J., Davies, R., Donald, C., Laterza, V., Long, A., Longley, A., Moule, P., Pollard, K., Powell, J., Puddicombe, A R., Rice, C., & Sayers, R. (2014). Public involvement in research: assessing impact through a realist

evaluation. *Health Services and Delivery Research, 2*(36), 1-158. doi:10.3310/hsdr02360

Evans, S. (2008). 'Beyond forgetfulness': How psychoanalytic ideas can help us to understand the experience of patients with dementia. *Psychoanalytic Psychotherapy, 22*(3), 155-176.

Evans, S., & Garner, J. (2004). *Talking over the years: a handbook of dynamic psychotherapy with older adults*. Hove: Bruner Routledge.

Feil, N. (1993). *The validation breakthrough: simple techniques for communicating with people with "Alzheimer's-type dementia"*. Baltimore, MD, US: Health Professions Press.

Field, B., Booth, A., Ilott, I., & Gerrish, K. (2014). Using the Knowledge to Action Framework in practice: a citation analysis and systematic review. *Implementation Science, 9*(1), 172-185.

Finkler, K., Hunter, C., & Iedema, R. (2008). What is going on? Ethnography in hospital spaces. *Journal of Contemporary Ethnography, 37*(2), 246-250.

Finnema, E., Dröes, R. M., Ribbe, M., & Van Tilburg, W. (2000). The effects of emotion-oriented approaches in the care for persons suffering from dementia: a review of the literature. *International journal of geriatric psychiatry, 15*(2), 141-161.

Fleisher, M. S., & Harrington, J. A. (1998). Freelisting: management at a women's federal prison camp. In V. C. De Munck & E. J. Sobo (Eds.), *Using methods in the field: a practical introduction and casebook* (pp. 69-83). Walnut Creek, CA: Alta Mira Press.

Flowerdew, L. (2008). Corpora and context in professional writing. In V. K. Bhatia, J. Flowerdew, & R. H. Jones (Eds.), *Advances in discourse studies* (pp. 115-131). London: Routledge.

Forbes, A., & Griffiths, P. (2002). Methodological strategies for the identification and synthesis of 'evidence'to support decision-making in relation to complex healthcare systems and practices. *Nursing Inquiry, 9*(3), 141-155.

Forester, B. P., & Vahia, I. (2019). Behavioral and psychological symptoms: an emerging crisis of the Alzheimer dementia epidemic. *JAMA network open, 2*(3), e190790-e190790.

Foster, G. M., & Anderson, B. G. (1978). *Medical anthropology*. New York: John Wiley & Sons.

Foucault, M. (2003). *The birth of the clinic. An archaeology of medical perception*. London: Routledge.

France, E. F., Ring, N., Thomas, R., Noyes, J., Maxwell, M., & Jepson, R. (2014). A methodological systematic review of what's wrong with meta-ethnography reporting. *BMC Medical Research Methodology, 14*(1), 119-134.

Froggatt, A. (1988). Self-awareness in early dementia. In B. Gearing, M. Johnson, & T. Heller (Eds.), *Mental health problems in old age: a reader* (pp. 131-136). Chichester: John Wiley & Sons.

Fry, M. (2012). An ethnography: understanding emergency nursing practice belief systems. *International Emergency Nursing, 20*(3), 120-125.

Fujii, M., Butler, J. P., Hirazakura, A., & Sasaki, H. (2014). Mini-Emotional State Examination for dementia patients. *Geriatrics & Gerontology International, 14*(2), 508-513.

Garand, L., Lingler, J. H., Conner, K. O., & Dew, M. A. (2009). Diagnostic labels, stigma, and participation in research related to dementia and mild cognitive impairment. *Research in Gerontological Nursing, 2*(2), 112-121.

George, J., Long, S., & Vincent, C. (2013). How can we keep patients with dementia safe in our acute hospitals? A review of challenges and solutions. *Journal of the Royal Society of Medicine, 106*(9), 355-361.

Godfrey, M. (2015). Qualitative research in age and ageing: enhancing understanding of ageing, health and illness. *Age and Ageing, 44*, 726–727.

Goldberg, S. E., Whittamore, K. H., Pollock, K., Harwood, R. H., & Gladman, J. R. (2014). Caring for cognitively impaired older patients in the general hospital: a qualitative analysis of similarities and differences between a specialist Medical and Mental Health Unit and standard care wards. *International Journal of Nursing Studies, 51*(10), 1332-1343.

Goyal, A. R., Engedal, K., & Eriksen, S. (2019). Clinicians' experiences of anxiety in patients with dementia. *Dementia, 18*(1), 80-93.

Graham, I., Logan, J., Harrison, M., Strauss, S., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: time for a map? *The Journal of Continuing Education in the Health Professions, 26*, 13-24.

Graneheim, U. H., & Jansson, L. (2006). The meaning of living with dementia and disturbing behaviour as narrated by three persons admitted to a residential home. *Journal of Clinical Nursing, 15*(11), 1397-1403.

Green, L. W. (2001). From research to "best practices" in other settings and populations. *American Journal of Health Behavior, 25*, 165-178.

Green, L. W., Ottoson, J. M., Garcia, C., & Hiatt, R. A. (2009). Diffusion theory and knowledge dissemination, utilization, and integration in public health. *Annual Review of Public Health, 30*, 151–174.

Greenhalgh, T. (2015). Knowledge to action: there is no tooth fairy [Blog post]. Retrieved from http://www.cebm.net/knowledge-to-action-there-is-no-tooth-fairy/

Greenhalgh, T. (2016). Virtues and vices in evidence based clinical practice [Blog post]. Retrieved from http://www.cebm.net/5395-2/

Greenhalgh, T., & Peacock, R. (2005). Effectiveness and efficiency of search methods in systematic reviews of complex evidence: audit of primary sources. *BMJ, 331*(7524), 1064-1065.

Griffiths, A., Knight, A., Harwood, R., & Gladman, J. R. (2014). Preparation to care for confused older patients in general hospitals: a study of UK health professionals. *Age and Ageing, 43*(4), 521-527.

Grol, R., & Grimshaw, J. (2003). From best evidence to best practice: effective implementation of change in patients' care. *The Lancet, 362*(9391), 1225-1230.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59-82.

Ham, C., & Murray, R. (2015). *Implementing the NHS five year forward view: aligning policies with the plan*. London: King's Fund.

Handley, M., Bunn, F., & Goodman, C. (2017). Dementia-friendly interventions to improve the care of people living with dementia admitted to hospitals: a realist review. *BMJ Open, 7*(7), e015257.

Handwerker, W. P., & Borgatti, S. P. (1998). Reasoning with numbers. In H. R. Bernard (Ed.), *Handbook of methods in cultural anthropology* (pp. 549-591). Walnut Creek, CA: AltaMira Press.

Hardt-Mautner, G. (1995). *Only connect. Critical discourse analysis and corpus linguistics. UCREL Technical Paper 6*. Lancaster, UK: Lancaster University.

Harvey, K. (2012). Disclosures of depression: using corpus linguistics methods to examine young people's online health concerns. *International journal of corpus linguistics, 17*(3), 349-379.

Harvey, K., Churchill, D., Crawford, P., Brown, B., Mullany, L., Macfarlane, A., & McPherson, A. (2008). Health communication and adolescents: what do their emails tell us? *Family Practice, 25*(4), 304-311.

Harvey, K., & Koteyko, N. (2012). *Exploring health communication: language in action*. Oxon: Routledge.

Harwood, R. H. (2012). Dementia for the hospital physician. *Clinical Medicine, 12*(1), 35-39.

Hawker, S., Payne, S., Kerr, C., Hardey, M., & Powell, J. (2002). Appraising the evidence: reviewing disparate data systematically. *Qualitative Health Research, 12*(9), 1284-1299.

Heath, H., Sturdy, D., & Wilcock, G. (2010). *Improving quality of care for people with dementia in general hospitals*. Harrow, England: Royal College of Nursing.

Hermann, D. M., Muck, S., & Nehen, H. G. (2015). Supporting dementia patients in hospital environments: health-related risks, needs and dedicated structures for patient care. *European Journal of Neurology, 22*(2), 239-245.

Herron, R. V., Funk, L. M., & Spencer, D. (2019). Responding the "wrong way": the emotion work of caring for a family member with dementia. *The Gerontologist*. doi:10.1093/geront/gnz047

Hessler, J. B., Schäufele, M., Hendlmeier, I., Junge, M. N., Leonhardt, S., Weber, J., & Bickel, H. (2017). Behavioural and psychological symptoms in general hospital patients with dementia, distress for nursing staff and complications in care: results of the General Hospital Study. *Epidemiology and Psychiatric Sciences, 27*(3), 278-287.

Hoffman, P., Lambon Ralph, M. A., & Rogers, T. T. (2013). Semantic diversity: a measure of semantic ambiguity based on variability in the contextual usage of words. *Behavior Research Methods, 45*, 718–730.

Holland, D., Lachicotte, W., Skinner, D., & Cain, C. (1998). Identity and agency in cultural worlds. Cambridge: Harvard University Press.

Houghton, C., Murphy, K., Brooker, D., & Casey, D. (2016). Healthcare staffs' experiences and perceptions of caring for people with dementia in the acute setting: qualitative evidence synthesis. *International Journal of Nursing Studies, 61*(1), 104-116.

Hung, L., Phinney, A., Chaudhury, H., Rodney, P., Tabamo, J., & Bohl, D. (2017). "Little things matter!" Exploring the perspectives of patients with dementia about the hospital environment. *International Journal of Older People Nursing, 12*(3), e12153.

Hunston, S. (2002). *Corpora in applied linguistics*. Cambridge: Cambridge University Press.

Hutchby, I., & Wooffitt, R. (1998). *Conversation analysis: principles, practices and applications*. Oxford: Polity Press.

Innes, A., Kelly, F., Scerri, C., & Abela, S. (2016). Living with dementia in hospital wards: a comparative study of staff perceptions of practice and observed patient experience. *International Journal of Older People Nursing, 11*(2), 94-106.

Institute of Medicine. (2001). *Crossing the quality chasm: a new health system for the 21st century*. Washington DC: National Academy Press.

INVOLVE. (2018). What is public involvement in research? Retrieved from http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/

Israel, M., & Hay, I. (2006). *Research ethics for social scientists*. London: Sage.

Jamal, F., Fletcher, A., Harden, A., Wells, H., Thomas, J., & Bonell, C. (2013). The school environment and student health: a systematic review and meta-ethnography of qualitative research. *BMC Public Health, 13*(1), 798-808.

Jansson, L., Norberg, A., Sandman, P.-O., Athlin, E., & Asplund, K. (1993). Interpreting facial expressions in patients in the terminal stage of the Alzheimer disease. *OMEGA-Journal of Death and Dying, 26*(4), 309-324.

Johansson, Å. K., & Grimby, A. (2013). Grief among demented elderly individuals: a pilot study. *American Journal of Hospice and Palliative Medicine, 30*(5), 445-449.

Jones, S., & Mitchell, G. (2015). Assessment of pain and alleviation of distress for people living with a dementia. *Mental Health Practice, 18*(10), 32-36.

Jung, C. (1967). *Two essays on analytical psychology (Vol. 7)*. Princeton New Jersey: Princeton University Press.

Kaminishi, K., Sutherland, E., Youngblood, E., Capistrano, J., & Tseng, L. (2019). Challenging behaviors on inpatient medical units: integrated, non-pharmacological approach for patients with dementia. *The American Journal of Geriatric Psychiatry, 27*(3), S131-133.

Kaplan, A. M., & Haenlein, M. (2010). Users of the world, unite! The challenges and opportunities of Social Media. *Business Horizons, 53*(1), 59-68.

Karger, C. R. (2018). Emotional experience in patients with advanced Alzheimer's disease from the perspective of families, professional caregivers, physicians, and scientists. *Aging and Mental Health, 22*(3), 316-322.

Kasl-Godley, J., & Gatz, M. (2000). Psychosocial interventions for individuals with dementia: an integration of theory, therapy, and a clinical understanding of dementia. *Clinical Psychology Review, 20*(6), 755-782.

Kelley, R., Godfrey, M., & Young, J. (2019). The impacts of family involvement on general hospital care experiences for people living with dementia: an ethnographic

study. *International Journal of Nursing Studies*. doi:10.1016/j.ijnurstu.2019.04.004

Kelly, S., Lafortune, L., Hart, N., Cowan, K., Fenton, M., & Brayne, C. (2015). Dementia priority setting partnership with the James Lind Alliance: using patient and public involvement and the evidence base to inform the research agenda. *Age and Ageing, 44*(6), 985-993.

Kerstetter, K. (2012). Insider, outsider, or somewhere in between: the impact of researchers' identities on the community-based research process. *Journal of Rural Social Sciences, 27*, 99 –117.

Kitwood, T. (1997). The experience of dementia. *Aging & Mental Health, 1*(1), 13-22.

Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: personhood and well-being. *Ageing and Society, 12*(3), 269-287.

Koester, A. (2010). Building small specialised corpora. In A. O'Keeffe & M. McCarthy (Eds.), *The Routledge handbook of corpus linguistics* (pp. 66-70). Abingdon: Routledge.

Kolanowski, A. M., Litaker, M. S., Catalano, P. A., Higgins, P. A., & Heineken, J. (2002). Emotional well-being in a person with dementia. *Western Journal of Nursing Research, 24*(1), 28-48.

Langdon, S. A., Eagle, A., & Warner, J. (2007). Making sense of dementia in the social world: a qualitative study. *Social Science and Medicine, 64*(4), 989-1000.

Larson, D. G., & Tobin, D. R. (2000). End-of-life conversations: evolving practice and theory. *JAMA, 284*(12), 1573-1578.

Lazarus, L. W. (1980). Self psychology and psychotherapy with the elderly: theory and practice. *Journal of Geriatric Psychiatry, 13*, 69-88.

LeDoux, J. (1998). The Emotional Brain. London: Weidenfeld and Nicolson.

Lee, D. Y. (2008). Corpora and discourse analysis. In V. Bhatia, J. Flowerdew, & R. H. Jones (Eds.), *Advances in discourse studies* (pp. 86-99). Abingdon, Oxon Routledge.

Lee, K. H., Algase, D. L., & McConnell, E. S. (2013). Daytime observed emotional expressions of people with dementia. *Nursing Research, 62*(4), 218-225.

Lezak, M. D., Howieson, D. B., Loring, D. W., & Fischer, J. S. (2004). *Neuropsychological assessment*. New York: Oxford University Press.

Lieberman, M. A., & Tobin, S. S. (1983). *The experience of old age: stress, coping, and survival*. New York: Basic Books.

Liebesny, F. (1960). *Lost information: unpublished conference papers*. Paper presented at the Proceedings of the International Conference on Scientific Information.

Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research (4th ed)* (pp. 97-128). Thousand Oaks, CA: Sage.

Livingston, G., Pitfield, C., Morris, J., Manela, M., Lewis-Holmes, E., & Jacobs, H. (2012). Care at the end of life for people with dementia living in a care home: a qualitative study of staff experience and attitudes. *International Journal of Geriatric Psychiatry, 27*(6), 643–650.

Lloyd, V., Gatherer, A., & Kalsy, S. (2006). Conducting qualitative interview research with people with expressive language difficulties. *Qualitative Health Research, 16*(10), 1386-1404.

Long, A. F., Godfrey, M., Randall, T., Brettle, A. J., & Grant, M. J. (2002). *Developing evidence based social care policy and practice. Part 3: feasibility of undertaking systematic reviews in social care*. Leeds: Nuffield Institute for Health.

Lyketsos, C. G., Sheppard, J.-M. E., & Rabins, P. V. (2000). Dementia in elderly persons in a general hospital. *American Journal of Psychiatry, 157*(5), 704-707.

Magai, C., Cohen, C., Gomberg, D., Malatesta, C., & Culver, C. (1996). Emotional expression during mid- to late-stage dementia. *International Psychogeriatrics, 8*(3), 383-395.

Malloy, L. (2009). Thinking about dementia–a psychodynamic understanding of links between early infantile experience and dementia. *Psychoanalytic Psychotherapy, 23*(2), 109-120.

Martin, G. N., & Carlson, N. R. (2019). Psychology (6th ed.). Harlow: Pearson Education Limited.

Martinez Tyson, D. D., Castaneda, H., Porter, M., Quiroz, M., & Carrion, I. (2011). More similar than different? Exploring cultural models of depression among Latino immigrants in Florida. *Depression Research and Treatment, 2011*, 564396.

Martins, D. C. (2008). Experiences of homeless people in the health care delivery system: a descriptive phenomenological study. *Public Health Nursing, 25*(5), 420-430.

Matthews, N., & Sunderland, N. (2019). Listening with feeling: emotional labour and digital storytelling in dementia care education. In B. Avieson, F. Giles, & S. Joseph (Eds.), *Still here: memoirs of trauma, illness and loss* (pp. 115-128). London: Routledge, Taylor and Francis Group.

McEnery, T., & Hardie, A. (2012). *Corpus linguistics: method, theory and practice*. Cambridge: Cambridge University Press.

McEnery, T., Xiao, R., & Tono, Y. (2006). *Corpus-based language studies: an advanced resource book*. London: Routledge.

Mental Health Foundation. (2013). *Crossing boundaries. Improving integrated care for people with mental health problems*. London: Mental Health Foundation.

Miesen, B. M. L. (1993). Alzheimer's disease, the phenomenon of parent fixation and Bowlby's attachment theory. *International Journal of Geriatric Psychiatry, 8*(2), 147-153.

Morandi, A., Lucchi, E., Turco, R., Morghen, S., Guerini, F., Santi, R., Gentile, S., Meagher, D., Voyer, P., Fick, D., Schmitt, E. M., Inouye, S. K., Trabucchi, M., & Bellelli, G. (2015). Delirium superimposed on dementia: A quantitative and qualitative evaluation of patient experience. *Journal of Psychosomatic Research, 79*(4), 281-287.

Morris, Z. S., Wooding, S., & Grant, J. (2011). The answer is 17 years, what is the question: understanding time lags in translational research. *Journal of the Royal Society of Medicine, 104*(12), 510-520.

Morrow, R., Rodriguez, A., & King, N. (2015). Colaizzi's descriptive phenomenological method. *The Psychologist, 28*(8), 643-644.

Moyle, W., Borbasi, S., Wallis, M., Olorenshaw, R., & Gracia, N. (2010). Acute care management of older people with dementia: a qualitative perspective. *Journal of Clinical Nursing, 20*(3-4), 420-428.

Müller-Hergl, C. (2009). Accept people as they are. *Journal of Dementia Care, 17*(3), 15.

Murphy, F. (2006). Loneliness: a challenge for nurses caring for older people. *Nursing Older People, 18*(5), 22-25.

Murray, M. (2003). Narrative psychology and narrative analysis. In P. M. Camic, L. E. Rhodes, & L. Yardley (Eds.), *Qualitative Research in Psychology* (pp. 95-112). Washington, DC: American Psychological Association.

National End of Life Care Programme. (2011). *Preferred priorities for care*. Leicester: National Health Service.

National Institute for Health and Care Excellence. (2006). Supporting people with dementia and their carers in health and social care [CG42]. London: National Institute for Clinical Excellence and Social Care Institute for Excellence.

National Institute for Health and Care Excellence. (2009). The guidelines manual [PMG6]. London: National Institute for Health and Care Excellence.

National Institute for Health and Care Excellence. (2010). Dementia: support in health and social care [QS1]: National Institute for Health and Care Excellence.

National Institute for Health and Care Excellence. (2016). Transition between inpatient mental health settings and community or care home settings. NICE Guideline [NG53]. London: National Institute for Health and Care Excellence.

National Institute for Health and Care Excellence. (2018). Dementia. Assessment, management and support for people living with dementia and their carers. NICE Guideline [NG97]. London: National Institute for Health and Care Excellence.

NHS Improving Quality. (2014). *Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff*. London: NHS Improving Quality.

Nilsen, P. (2015). Making sense of implementation theories, models and frameworks. *Implementation Science, 10*(1), 53-65.

Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence-Based Nursing, 18*(2), 34-35.

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies* (Vol. 11). Newbury Park: Sage Publications, Inc.

Nolan, L. (2006). Caring connections with older persons with dementia in an acute hospital setting – a hermeneutic interpretation of the staff nurse's experience. *International Journal of Older People Nursing, 1*, 208-215.

Noyes, J., Popay, J., Pearson, A., & Hannes, K. (2008). Qualitative research and Cochrane reviews. *Cochrane handbook for systematic reviews of interventions*, 571-591.

Ocloo, J., & Matthews, R. (2016). From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Quality & Safety, 25*, 626-632.

Olsson, A., Lampic, C., Skovdahl, K., & Engström, M. (2013). Persons with early-stage dementia reflect on being outdoors: a repeated interview study. *Aging & Mental Health, 17*(7), 793-800.

Partington, A. (2008). The armchair and the machine: corpus-assisted discourse research. In C. T. Torsello, K. Ackerley, & E. Castello (Eds.), *Corpora for university language teachers* (pp. 95-118). Bern: Die Deutshe Bibliothek.

Patterson, M., Nolan, M., Rick, J., Brown, J., Adams, R., & Musson, G. (2011). From metrics to meaning: culture change and quality of acute hospital care for older people. *Report for National Intsitue for Health Research Service Delivery and Oranisation programme*, 1-9.

Pecanac, K. E., Wyman, M., Kind, A. J., & Voils, C. I. (2018). Treatment decision making involving patients with dementia in acute care: a scoping review. *Patient Education and Counseling, 101*(11), 1884-1891.

Perrin, T. (1997). The Positive Response Schedule for severe dementia. *Aging & Mental Health, 1*, 184-191.

Pesonen, H. M., Remes, A. M., & Isola, A. (2011). Ethical aspects of researching subjective experiences in early-stage dementia. *Nursing Ethics, 18*(5), 651-661.

Petticrew, M., Egan, M., Thomson, H., Hamilton, V., Kunkler, R., & Roberts, H. (2008). Publication bias in qualitative research: what becomes of qualitative research presented at conferences? *Journal of Epidemiology and Community Health, 62*(6), 552-554.

Petticrew, M., & Roberts, H. (2006). *Systematic reviews in social sciences: a practical guide*. Oxford: Blackwell Publishing.

Piers, R., Albers, G., Gilissen, J., De Lepeleire, J., Steyaert, J., Van Mechelen, W., . . . Van den Block, L. (2018). Advance care planning in dementia: recommendations for healthcare professionals. *BMC Palliative Care, 17*(1), 88-104.

Pilkonis, P. A., Choi, S. W., Reise, S. P., Stover, A. M., Riley, W. T., Cella, D., & Group, P. C. (2011). Item banks for measuring emotional distress from the Patient-Reported Outcomes Measurement Information System (PROMIS®): depression, anxiety, and anger. *Assessment, 18*(3), 263-283.

Pluye, P., Gagnon, M.-P., Griffiths, F., & Johnson-Lafleur, J. (2009). A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in mixed studies reviews. *International Journal of Nursing Studies, 46*(4), 529-546.

Polit, D. F., & Beck, C. T. (2014). *Essentials of nursing research*. Philadelphia: Wolters Kluwer/Lippincott/Williams & Wilkins Health.

Popay, J., Rogers, A., & Williams, G. (1998). Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative Health Research, 8*, 341-351.

Pound, P., Britten, N., Morgan, M., Yardley, L., Pope, C., Daker-White, G., & Campbell, R. (2005). Resisting medicines: a synthesis of qualitative studies of medicine taking. *Social Science and Medicine, 61*(1), 133-155.

Quality, N. I. (2014). *Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff*. London: NHS Improving Quality.

Rapaport, P., Livingston, G., Hamilton, O., Turner, R., Stringer, A., Robertson, S., & Cooper, C. (2018). How do care home staff understand, manage and respond to agitation in people with dementia? A qualitative study. *BMJ Open, 8*(6), e022260.

Regnard, C., Mathews, D., Gibson, L., & Clarke, C. (2003). Difficulties in identifying distress and its causes in people with severe communication problems. *International Journal of Palliative Nursing, 9*(4), 173-176.

Reilly, J. C., & Houghton, C. (2019). The experiences and perceptions of care in acute settings for patients living with dementia: a qualitative evidence synthesis. *International Journal of Nursing Studies*. doi:10.1016/j.ijnurstu.2019.04.018

Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (2013). *Qualitative research practice: a guide for social science students and researchers*. California: Sage.

Romney, A. K., Weller, S. C., & Batchelder, W. H. (1986). Culture as consensus: a theory of culture and informant accuracy. *American Anthropologist, 88*(2), 313-338.

Royal College of Nursing. (2014). Defining nursing. Retrieved from https://www.rcn.org.uk/professional-development/publications/pub-004768

Royal College of Physicians. (2009). *Concise guidance to good practice: a series of evidence based guidelines for clinical management: Number 12 Advance Care Planning National Guidelines*. London: Royal College of Physicians.

Royal College of Psychiatrists. (2005). *Who cares wins*. London: Royal College of Psychiatrists.

Royal College of Psychiatrists. (2017). *National audit of dementia care in general hospitals 2016-17: third round audit report*. London: Royal College of Psychiatrists.

Sabat, S., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society, 12*, 443–461.

Sadavoy, J. (1991). Psychodynamic perspectives on Alzheimer's disease and related dementias. *American Journal of Alzheimer's Care and Related Disorders & Research, 6*(3), 12-20.

Sampson, E. L., Blanchard, M. R., Jones, L., Tookman, A., & King, M. (2009). Dementia in the acute hospital: prospective cohort study of prevalence and mortality. *The British Journal of Psychiatry, 195*(1), 61-66.

Sampson, E. L., Gould, V., Lee, D., & Blanchard, M. R. (2006). Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age and Ageing, 35*(2), 187-189.

Sampson, E. L., White, N., Leurent, B., Scott, S., Lord, K., Round, J., & Jones, L. (2014). Behavioural and psychiatric symptoms in people with dementia admitted to the acute hospital: prospective cohort study. *British Journal of Psychiatry, 205*(3), 189-196.

Samra, R., Griffiths, A., Cox, T., Conroy, S., Gordon, A., & Gladman, J. (2015). Medical students' and doctors' attitudes toward older patients and their care in hospital settings: a conceptualisation. *Age and Ageing, 44*(5), 776-783.

Sandelowski, M., & Barroso, J. (2006). *Handbook for synthesizing qualitative research*. New York: Springer Publishing Company.

Scerri, A., Innes, A., & Scerri, C. (2015). Discovering what works well: exploring quality dementia care in hospital wards using an appreciative inquiry approach. *Journal of Clinical Nursing, 24*(13-14), 1916-1925.

Scerri, A., Innes, A., & Scerri, C. (2017). Dementia training programmes for staff working in general hospital settings: a systematic review of the literature. *Aging & Mental Health, 21*(8), 783-796.

Schlechty, P., & Noblit, G. (1982). Some uses of sociological theory in educational evaluation. In R. Corwin (Ed.), *Policy research*. Greenwich, CT: JAI Press.

Schneider, J., Scales, J., Bailey, J., & Lloyd, J. (2010). *Challenging care: the role and experience of health care assistants in dementia wards*. Southampton: Queen's Printer and Controller of HMSO.

Schrauf, R. W., & Sanchez, J. (2004). The preponderance of negative emotion words in the emotion lexicon: a cross-generational and cross-linguistic study. *Journal of Multilingual and Multicultural Development, 25*(2-3), 266-284.

Schrauf, R. W., & Sanchez, J. (2008). Using freelisting to identify, assess, and characterize age differences in shared cultural domains. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 63*(6), S385-S393.

Schwanenflugel, P. J. (2013). *The psychology of word meanings*. London: Psychology Press.

Schwartz, C., Lennes, I., Hammes, B., Lapham, C., Bottner, W., & Ma, Y. (2003). Honing an advance care planning intervention using qualitative analysis: the Living Well interview. *Journal of Palliative Medicine, 6*(4), 593-603.

Schwartz, G., & Merten, G. S. (1968). Social identity and expressive symbols: the meaning of an initiation ritual. *American Anthropologist, 70*(6), 1117-1131.

Scott, M. (2017a). Introduction to WordSmith Tools. Version: 7.0. Retrieved from http://lexically.net/downloads/version7/HTML/index.html?getting_started.htm

Scott, M. (2017b). WordSmith Tools 7.0: Windows software for finding word patterns. Retrieved from http://www.lexically.net/wordsmith/downloads/

Seignourel, P. J., Kunik, M. E., Snow, L., Wilson, N., & Stanley, M. (2008). Anxiety in dementia: a critical review. *Clinical Psychology Review, 28*(7), 1071-1082.

Shallice, T., & Cooper, R. P. (2013). Is there a semantic system for abstract words? *Frontiers in Human Neuroscience, 7*(175), 1-10.

Shanteau, J. (1992). Competence in experts: the role of task characteristics. *Organizational Behavior and Human Decision Processes, 53*, 252-266.

Shaw, R. L., Booth, A., Sutton, A. J., Miller, T., Smith, J. A., Young, B., Jones, D. R., & Dixon-Woods, M. (2004). Finding qualitative research: an evaluation of search strategies. *BMC Medical Research Methodology, 4*(1), 5-9.

Sinason, V. (1992). The man who was losing his brain. In V. Sinason (Ed.), *Mental handicap and the human condition* (pp. 87-110). London: Free Association Books.

Sirriyeh, R., Lawton, R., Gardner, P., & Armitage, G. (2012). Reviewing studies with diverse designs: the development and evaluation of a new tool. *Journal of Evaluation in Clinical Practice, 18*(4), 746-752.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: theory, method and research*. California: Sage.

Smith, J. J. (1993). Using Anthropac 3.5 and a spreadsheet to compute a free list salience index. *Cultural Anthropology Methods Newsletter, 5*(3), 1-3.

Staniszewska, S., Brett, J., Mockford, C., & Barber, R. (2011). The GRIPP checklist: strengthening the quality of patient and public involvement reporting in research. *International Journal of Technology Assessment in Health Care, 27*(4), 391-399.

Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., . . . Tysall, C. (2017). GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *Research involvement and engagement, 3*(1), 1-7.

Stanyon, M., Thomas, S., Gordon, A., & Griffiths, A. (2019). Effects of care assistant communication style on communicative behaviours of residents with dementia: a systematic multiple case study. *Scandinavian Journal of Caring Sciences, 33*(1), 207-214.

Stokes, D. E. (1997). *Pasteur's quadrant: basic science and technological innovation*. Washington, DC: Brookings Institution Press.

Stokes, G. (2017). *Challenging behaviour in dementia: a person-centred approach*. London: Taylor & Francis Ltd.

Street, A., & Coleman, S. (2012). Introduction: real and imagined spaces. *Space and Culture, 15*(1), 4-17.

Strike, K., & Posner, G. (1983). Types of synthesis and their criteria. In S. Ward & L. Reed (Eds.), *Knowledge structure and use*. Philadelphia: Temple University Press.

Stringer, E. T. (1996). *Action research: a handbook for practitioners*. California: Sage Publications Inc.

Stubbs, M. (2001). Texts, corpora, and problems of interpretation: a response to Widdowson. *Applied linguistics, 22*(2), 149-172.

Surr, C. A., Smith, S. J., Crossland, J., & Robins, J. (2016). Impact of a person-centred dementia care training programme on hospital staff attitudes, role efficacy and perceptions of caring for people with dementia: a repeated measures study. *International Journal of Nursing Studies, 53*, 144-151.

Sutton, L. J., & Cheston, R. (1997). Rewriting the story of dementia: a narrative approach to psychotherapy with people with dementia. In M. Marshall (Ed.), *State of the art in dementia care* (pp. pp. 159–163). London: Centre for Policy on Ageing.

Swaffer, K. (2014). Dementia: stigma, language, and dementia-friendly. *Dementia, 13*(6), 709-716.

Tanggaard, L., & Wegener, C. (2016). *A survival kit for doctoral students and their supervisors: traveling the landscape of research*. London: Sage Publications.

Tappen, R. M., & Williams, C. (1998). Attribution of emotion in advanced Alzheimer's disease: family and caregiver perspectives. *American Journal of Alzheimer's Disease and Other Dementias, 13*(5), 257-264.

Taylor, B., Kermode, S., & Roberts, K. (2006). *Research in nursing and health care: evidence for practice* (3rd ed.). South Melbourne: Thomson.

Taylor, C. (1982). Interpretation and the sciences of man. In E. Bredo & W. Feinberg (Eds.), *Knowledge and values in social and educational research*. Philadelphia: Temple University Press.

Taylor, C. (1985). *Philosophical papers: human agency and language (Vol. 1)*. Cambridge: Cambridge University Press.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349-357.

Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, E., & Barker, K. (2014). Meta-ethnography 25 years on: challenges and insights for synthesising a large number of qualitative studies. *BMC Medical Research Methodology, 14*(1), 80-93.

Triplett, P., & Black, B. S. (2008). Content of advance directives for individuals with advanced dementia. *Journal of Ageing and Mental Health, 20*(5), 583-596.

Tropea, J., LoGiudice, D., Liew, D., Roberts, C., & Brand, C. (2017). Caring for people with dementia in hospital: findings from a survey to identify barriers and facilitators to implementing best practice dementia care. *International Psychogeriatrics, 29*(3), 467-474.

Urrieta, L. (2007). Identity production in figured worlds: how some Mexican Americans become Chicana/o activist educators. *The Urban Review, 39*(2), 117-144.

van der Geest, S., & Finkler, K. (2004). Hospital ethnography: introduction. *Social Science and Medicine, 59*(10), 1995-2001.

van der Linde, R. M., Dening, T., Stephan, B. C., Prina, A. M., Evans, E., & Brayne, C. (2016). Longitudinal course of behavioural and psychological symptoms of dementia: systematic review. *British Journal of Psychiatry, 209*(5), 366-377.

van der Steen, J. T., Radbruch, L., Hertogh, C. M., de Boer, M. J., Hughes, J. C., & Larkin, P. (2013). White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendation from the European Association for Palliative Care. *Palliative Medicine, 28*, 197-209.

van der Steen, J. T., van Soest-Poortvliet, M. C., Hallie-Heierman, M., Onwuteaka-Philipsen, B. D., Deliens, L., de Boer, M. E., . . . de Vet, H. C. (2014). Factors associated with initiation of advance care planning in dementia: a systematic review. *Journal of Alzheimer's Disease, 40*(3), 743-757.

van Gennip, I. E., Pasman, H. R. W., Oosterveld-Vlug, M. G., Willems, D. L., & Onwuteaka-Philipsen, B. D. (2016). How dementia affects personal dignity: a qualitative study on the perspective of individuals with mild to moderate dementia. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences, 71*(3), 491-501.

van Vliet, D., Persoon, A., Bakker, C., Koopmans, R., De Vugt, M., Bielderman, A., & Gerritsen, D. L. (2017). Feeling useful and engaged in daily life: exploring the experiences of people with young-onset dementia. *International Psychogeriatrics, 29*(11), 1889-1898.

Volicer, L., & Galik, E. (2018). Agitation and aggression are 2 different syndromes in persons with dementia. *Journal of the American Medical Directors Association, 19*(12), 1035-1038.

Walker, D., & Myrick, F. (2006). Grounded theory: an exploration of process and procedure. *Qualitative Health Research, 16*(4), 547-559.

Walker, E., & Dewar, B. J. (2001). How do we facilitate carers' involvement in decision making? *Journal of Advanced Nursing, 34*(3), 329-337.

Waller, S., Masterson, A., & Evans, S. C. (2017). The development of environmental assessment tools to support the creation of dementia friendly care environments: innovative practice. *Dementia, 16*(2), 226-232.

Weiner, B., Perry, R. P., & Magnusson, J. (1988). An attributional analysis of reactions to stigmas. *Journal of Personality and Social Psychology, 55*, 738–748.

Weller, S. C. (2007). Cultural consensus theory: applications and frequently asked questions. *Field Methods, 19*(4), 339-368.

Weller, S. C., & Romney, A. K. (1988). *Systematic data collection* (Vol. 10). Newbury Park, California: Sage Publications.

Widdowson, H. G. (2000). On the limitations of linguistics applied. *Applied linguistics, 21*(1), 3-25.

Wilson, R. S., Arnold, S. E., Schneider, J. A., Li, Y., & Bennett, D. A. (2007). Chronic distress, age-related neuropathology, and late-life dementia. *Psychosomatic Medicine, 69*(1), 47-53.

Winblad, B., Amouyel, P., Andrieu, S., Ballard, C., Brayne, C., Brodaty, H., . . . Feldman, H. (2016). Defeating Alzheimer's disease and other dementias: a priority for European science and society. *The Lancet Neurology, 15*(5), 455-532.

World Health Organization. (2011). *Palliative care for older people: best practices*. Copenhagen: World Health Organization.

World Health Organization. (2016). Dementia: factsheet. Retrieved from http://www.who.int/mediacentre/factsheets/fs362/en/

World Health Organization. (2017). *Global action plan on the public health response to dementia 2017–2025*. Geneva, Switzerland: World Health Organization.

Worthington, A., Rooney, P., & Hannan, R. (2013). *The triangle of care. Carers included: a guide to best practice in mental health care in England. (2nd ed.)*. London: Carers Trust.

Wyatt, M., & Liggett, S. (2019). The potential of painting: unlocking disenfranchised grief for people living with dementia. *Illness Crisis and Loss, 27*(1), 51-67.

Yalom, I. D. (1980). *Existential psychotherapy*. New York: Basic Books.

Appendices

Appendix 1. Involvement. Brief information sheet shared with patients and the public accessing services provided by the Alzheimer's Society York in the preliminary design of the thesis (April 2016)

Invitation to share your thoughts

Thank you for taking time to look over these early ideas for research. I hope you will share your opinions. I would value hearing the views of individuals with personal experience of dementia, whether people have received the diagnosis themselves, or know people who have.

I am at the beginning of a research project with the Institute of Mental Health, Nottingham, as a part-time PhD. I am trying to find the most helpful questions to ask. This will be something I work on for at least 6 years, so hope to contribute to the research literature in helpful ways. I also work as a Clinical Psychologist at The Retreat, York and will therefore bring my clinical experience to the research, and likewise, take what I learn from research back to practice.

Brief overview of research interests (as it stands)

1. What are the emotional experiences of individuals with dementia – what is emotional distress?

2. Do health professionals understand and notice emotions in their interactions with individuals with dementia? For example, when in hospital.

3. How can we be better at providing emotional support when needed? In the moment, how can health professionals respond?

   What is already known: The experiences of somebody with dementia are often talked about as symptoms, such as agitation and apathy. In this way, we have limited ways of talking about and understanding somebody's own experiences, particularly when feeling frightened, upset or angry. We need to find ways of working other than using medication to relieve distress. There is little guidance for how people can offer comfort at times of distress.

How to share your thoughts

Are these questions helpful? Who should I ask and how?



You can jot your ideas down – anything is welcome! Write something on a post-it or something longer. Pass this to me **Stephanie** or **Penny** at the Alzheimer's Society.



Send me an email: **spetty@theretreatyork.org.uk**

Many thanks in advance for your thoughts.

Dr Stephanie Petty, Clinical Psychologist

Appendix 2. Involvement. Updated information sheet shared with patients and the public accessing services provided by the Alzheimer's Society York (June 2017)

Invitation to share your thoughts

Thank you for taking time to look over this brief overview of a research study. I hope you will share your opinions. I would value hearing the views of individuals with personal experience of dementia, whether people have received the diagnosis themselves or know people who have.

I am a third of the way through a research project with the Institute of Mental Health, Nottingham, as a part-time PhD. I am trying to find the most helpful questions to ask and hope to contribute to the research literature in helpful ways. I also work as a Clinical Psychologist at The Retreat, York and will therefore bring my clinical experience to the research, and likewise, take what I learn from research back to practice.

Brief overview of the proposed research

My research question is: how can hospital care staff notice, understand and meet the emotional needs of individuals with dementia?

We know that hospitals can be unusual places for people to be and people with dementia can be particularly vulnerable when in hospital. This is because of their physical health, because of how suitable the environment is and because they might not be able to express their needs or comply with treatment. However, few researchers have wondered whether people with dementia are emotionally upset sometimes when in hospital. Individuals with dementia rely upon hospital staff to maintain their wellbeing. To our knowledge, there has been no research into what hospital staff notice and think, and all the ways they attempt to meet the emotional needs of somebody who has dementia. We know that good practice happens in hospitals, but the skills demonstrated by hospital staff vary widely, and this is not often captured or shared.

I am interested in what hospital staff who work with people with dementia say about: whether it is possible to notice times of emotional distress for people with dementia, what staff think are the causes for people being distressed, and what staff are able to do. Hospital staff from a range of professions will be asked to take part in short interviews lasting 15 minutes to answer these questions.

How to share your thoughts

Are these questions helpful? Is there anything that I am missing?



Anything is welcome! Talk to me in person or write something down and pass this to me **Stephanie** or **your Dementia Support Worker** at the Alzheimer's Society.



Send me an email: **spetty@theretreatyork.org.uk**

Many thanks in advance for your time.

Dr Stephanie Petty, Clinical Psychologist

Appendix 3. Systematic review: A display of the key concepts within each study to help determine the relationships between studies.

	Self	Social position	Loss of relationships	Future	Physical environment	Perception
Abraham, R. (2005).	x	x	x			x
Aggarwal, N., *et al.* (2003).	x	x		x		
Ahonen-Eerikainen, H., *et al.* (2007).		x	x			
Aminzadeh, F., *et al.* (2007).	x	x				
Aminzadeh, F., *et al.* (2013).	x		x	x	x	
Anderson, D. (2011).				x		
Bahro, M., Silber, E., & Sunderland, T. (1995).	x	x		x		
Barnett, E. (2000).		x	x	x	x	x
Bartlett, R. (2007).	x					
Bartlett, R. (2014).	x					
Baruch, J., *et al.* (2004).			x			
Beart, K. (2008).				x	x	
Bender, M. P., & R. Cheston (1997).	x	x	x	x		
Bergland, Å., Johansen, H., & Sellevold, G. S. (2015).	x	x	x		x	
Bourbonnais, A., & Ducharme, F. (2010).	x		x		x	
Bryden, C. (2005).	x	x		x		x
Burton, C. & Crossley, M. (2003).						x
Cahill, S. M., *et al.* (2008).		x		x		
Cedervall, Y., Torres, S., & Åberg, A. C. (2015).	x				x	
Clare, L. (2002).				x		
Clare, L. (2003).	x	x		x		
Clare, L., Goater, T., & Woods, B. (2006).		x				
Clare, L., *et al.* (2008).	x	x	x		x	
Cohen, D., Kennedy, G., & Eisdorfer, C. (1984).				x		

Costello, J. (1996).						x
Couch, J. B. (1997).	x	x	x	x		
Dahlberg, K. & Svanstrom, R. (2004).	x		x	x		
Dalby, P., Sperlinger, D. L., & Boddington, S. (2012).	x					
Davenhill, R. (2007).	x	x	x	x	x	
Davis, R. (1989).	x	x	x	x	x	x
De Vries, K. & McChrystal, J. (2010).			x			
Dickinson, R. (2004).	x			x		
Dietch, J. T., Hewett, L. J., & Jones, S. (1989).					x	
Doka, K. (2010).	x			x	x	
Edvardsson, D. & Nordvall, K. (2008).					x	
Edvardsson, D., Sandman, P. O., & Rasmussen, B. (2012).		x	x			
Evans, S. (2008).	x		x			
Feil, N. (1993).						x
Frazer, S. M., Oyebode, J. R., & Cleary, A. (2012).	x	x	x	x	x	
Friel-Mcgowin, D. F. (1993).	x	x	x	x		x
Genoe, R. (2013).		x				x
Gilmour, J. A. & Huntington, A. D. (2005).	x	x				x
Godwin, B. & Poland, F. (2015).	x		x	x		
Graboys, T. B. (2012).	x	x	x			
Graneheim, U. H., & Jansson, L. (2006).					x	
Gruetzner, H., Ellor, J. W., Back, N. (2012).			x			
Hausman, C. (1992).	x		x		x	x
Hedman, R., *et al.* (2013).	x			x		
Heggestad, A. K. T., Nortvedt, P., & Sletteboe, A. (2013).			x			
Holst, G. & Hallberg, I. R. (2003).	x	x	x		x	
Husband, H. J. (1999).		x		x		

Husband, H. J. (2000).		x	x	x		
Hynninen, N., Saarnio, R., Isola, A. (2015).		x				
James, I. A. (1999a).				x	x	x
James, I. A. (1999b).	x	x		x		
Johansson, Å. K. & Grimby, A. (2013).			x			
Jones, S. N. (1995).	x			x		
Jones, G. M. M. (2004).	x	x				
Jordan *et al.* (2012).					x	
Judkins, W. & Roberto, K. A. (2001).			x			
Kelly, A. (2008).	x			x		
Kitwood, T. & Bredin, K. (1992).			x			
LaBarge, E. & Trtanj, F. (1995).	x					
LaBarge, E., Von Dras, D., & Wingbermuehle, C. (1998).		x	x			
Lewis, M. M. & Trzinski, A. L. (2006).			x			
Lipinska, D. (2010).	x	x		x		
Lloyd, B. T. & Stirling, C. (2015).		x			x	
Loboprabhu, S., Molinari, V., & Vomax, J. (2007).	x			x		
Magai, C., *et al.* (1996).			x			
Malloy, L. (2009).	x	x		x		
Mazaheri, M., *et al.* (2013).	x	x				
McGee, J. S., *et al.* (2013).			x			
Miesen, B. M. L. (1993).			x			
Miesen, B. M. L. (1997).	x			x		
Miesen, B. M. L. (1998).	x		x			x
Miesen, B.M.L. (1999).	x		x			x
Mormont, E., de Fays, K., & Jamart, J. (2012).				x		
Morton, I. (2007).		x	x			

Moyle, W., *et al.* (2011).		x	x			
Newborg, M. (2006).	x					
Ng, A. V. (2009).		x	x			
O'Connor, M., *et al.* (2013).	x			x		
Öhman, A., Josephsson, S., & Nygård, L. (2008).	x	x		x		
Olsson, A., *et al.* (2013).	x			x		
Orulv, L. (2014).		x				
Ostwald, S. K., Duggleby, W., & Hepburn, K. W. (2002).	x	x		x		
Peach, E., & Duff, G. (1993).		x		x	x	
Phillips, J. M. (2000).		x				
Pratt, R., & Wilkinson, H. (2001).		x		x		
Pratt, R., & Wilkinson, H. (2003).		x		x		
Preston, L., Marshall, A., & Bucks, R. S. (2007).					x	
Reese, R. (2005).	x			x		
Rentz, C., Krikorian, R., & Keys, M. (2005).	x	x	x			
Ronch, J. L. (1996).	x	x	x			
Sabat, S. R. (2008).	x	x				
Sabat, S. R. (2011).	x					
Sinason V. (1992).			x			
Snyder, L., *et al.* (1995).	x	x				
Solomon, D. (1988).	x					
Solomon, K., & Szwabo, P. (1992).	x	x	x	x	x	x
Steeman, E., *et al.* (2007).	x	x		x		
Steeman, E. (2013).	x	x		x		
Stevenson, A., Thomson, J., & Roth, H. (2010).						x
Svanström, R., & Sundler, A. J. (2015).		x	x			
Tappen, R. M. & Williams, C. (1998).	x		x			

Taylor, R. (2007).	x	x	x	x	x		
Temple-Jones, J. E. (2012).	x		x				
Terry, P. (2010).	x		x				
van Achterberg, M. E., Rohrbaugh, R. M., & Southwick, S. M. (2001).							x
Waddell, M. (2000).			x				
Walker, D. A. (2004).	x						
Wallace, D. (2011).	x						
Wang, J.-J., Feldt, K., & Cheng, W. Y. (2012).					x		
Wang, J. J., *et al.* (2014).							x
Ward-Griffin, C., Bol, N., & Oudshoorn, A. (2006).		x	x				
Watkins, R., *et al.* (2006).		x		x			
Wawrziczny, E., *et al.* (2015).	x						
Weaks, D., Wilkinson, H., & McLeod, J. (2015).		x		x			
Weiner, M. F. (1991).	x		x		x	x	
Werezak, L., & Stewart, N., (2002).		x		x			
Zingmark, K., Norberg, A., & Sandman, P-O. (1993).	x		x	x			x

Appendix 4. Systematic review. The main features of all 121 included studies with their assigned quality ratings.

Study ID	Source paper	Country	Viewpoint/participants	Setting and description of dementia	Method	Quality rating
1	Abraham, R. (2005).	USA.	Clinician report: 1 art therapist.		Including three case reports.	3
2	Aggarwal, N., *et al.* (2003).	UK.	Self-report: 27.	Residential setting or day-care. Dementia.	Individual interviews, case note review, observation and filming.	4
3	Ahonen-Eerikainen, H., *et al.* (2007).	Canada.	Academic. 6 individuals with dementia (6 female, age range 77-90).	Dementia.	Group observation.	4
4	Aminzadeh, F., *et al.* (2007).	Canada.	Self-report: 30 (20 female). Family members: 30: 7 spouse, 20 child, 3 other family	Alzheimer's disease and/or vascular dementia.	Tape recording of the disclosure meeting, individual interviews, focus group interviews, field observations.	6
5	Aminzadeh, F., *et al.* (2013).	Canada.	Self-report: 16 Family members: 16	Residential care facility.	Individual interviews.	6
6	Anderson, D. (2011).	UK.	Clinician report: 1.	Dementia, mild.	Reflections on group analysis.	4
7	Bahro, M., Silber, E., & Sunderland, T. (1995).	USA.	Clinician report: 7 (4 female, mean age 71, range 61-80).	Inpatient geriatric psychiatry section.	Case studies.	4
8	Barnett, E. (2000).	UK.	Self-report: 22.	Day hospital (11), inpatient unit (6), day hospital and inpatient unit (5). Dementia.	Individual interviews.	4

9	Bartlett, R. (2007).	UK.	Academic. Individual with dementia, age 84.	Specialist dementia care nursing home. Alzheimer's disease. 1.	Case report.	5
10	Bartlett, R. (2014).	UK.	Self-report: 16 (5 female, mean age 64, range 53-74).	Dementia.	Individual interviews, focus group, written, audio and photographic diary.	5
11	Baruch, J., *et al*. (2004).	UK.	Academic.	Sheltered accommodation. 1. Dementia.	Case report.	4
12	Beart, K. (2008).	UK.	Self-report: 10. Family members: 10	Dementia.	Joint interview with carer.	3
13	Bender, M. P., & R. Cheston (1997).	UK.	Academic.	Dementia.		3
14	Bergland, Å., Johansen, H., & Sellevold, G. S. (2015).	Norway.	Nursing home staff: 3 registered nurses, 8 state enrolled nurses, 4 nursing assistants, 8 nursing students, 1 other.	Nursing home. Dementia.	Focus group interviews, reflection groups.	5
15	Bourbonnais, A., & Ducharme, F. (2010).	Canada.	Self-report: 7 (4 female, mean age 81 years). Family members: 7 (5 spouses, 2 children). Formal carers: 7 (5 nurses, 2 nursing assistants, 1 nurse Aids).	Nursing home. Dementia, moderate to severe	Observation, individual interviews with family and formal carers.	7
16	Bryden, C. (2005).	Australia.	Self-report: 1 female. Age 46.	Fronto-temporal dementia, moderate.		5
17	Burton, C. & Crossley, M. (2003).	Canada.	Family members: 27 (21 female). Individuals with dementia: 27 (13	Mild to severe dementia. Living at home with family member	Written logbook, ratings of cognitive and functional	4

			female, mean age 78 years).	(16), long term care (11).	impairment.	
18	Cahill, S. M., *et al*. (2008).	Ireland.	Self-report: 13 (part of a larger sample without dementia). Family members: 13	Alzheimer's disease (8), mixed dementia (5), vascular dementia (1).	Individual interviews, semi-structured questionnaire.	5
19	Cedervall, Y., Torres, S., & Åberg, A. C. (2015).	Sweden.	Self-report: 14 (8 female, mean age 70, range 59-79).	Living in the community. Probable Alzheimer's disease, mild.	Individual interviews.	6
20	Clare, L. (2002).	UK.	Self-report: 12 (3 female, mean age 71 years, range 57-83). Family members: 12 spouses.	Living at home with a partner. Probable Alzheimer's disease, mild.	Individual interviews.	6
21	Clare, L. (2003).	UK.	Self-report: 12 (3 female, mean age 71, range 57-83 years).	Living with a partner or caregiver. Alzheimer's disease, minimal severity.	Individual interviews.	6
22	Clare, L., Goater, T., & Woods, B. (2006).	UK.	Self-report: 22 (10 female, mean age 74, range 57 to 87 years).	Living alone or with family. Alzheimer's disease (20), mixed (2), early stage.	Individual interviews.	6
23	Clare, L., *et al.* (2008).	UK.	Self-report: 81 (69 female, mean age 83, range 59-96). Academic	Residential care homes. Moderate to severe dementia.	Unstructured conversations, field notes, record consultation.	6
24	Cohen, D., Kennedy, G., & Eisdorfer, C. (1984).	USA.	Academic.	Alzheimer's disease and related disorders.		2
25	Costello, J. (1996).	UK.	Care staff: 1.	Hospital. Dementia. 1.	Case report.	1
26	Couch, J. B. (1997).	USA.	Clinician report: 1. Individuals with dementia: 71 (62	Dementia.	Reflections from art therapy.	2

			female).			
27	Dahlberg, K. & Svanstrom, R. (2004).	Sweden.	Self-report: 5 (2 women, age range 73-80). Family members: 5 spouses.	Living in the community. Dementia.	Individual interviews, spouse-completed diaries.	5
28	Dalby, P., Sperlinger, D. L., & Boddington, S. (2012).	UK.	Self-report: 6 (5 female, age range 70-94).	Living at home (4), warden-assisted accommodation (1), care home (1). Alzheimer's disease (3), vascular dementia (3) or mixed dementia.	Individual interviews.	6
29	Davenhill, R. (2007).	UK.	Academic. Self-report: 1 female. Alzheimer's disease. Age 58.	Dementia.	Including personal account and interpretation of art.	3
30	Davis, R. (1989).	USA.	Self-report: 1	Alzheimer's disease.	Personal account and account of spouse.	4
31	De Vries, K. & McChrystal, J. (2010).	UK.	Hospice staff: 11 nurses, 6 health care assistants, 3 doctors, 2 social workers. Family members: 5.	Hospice. Variant Creutzfeldt-Jakob disease.	Individual interviews, focus group interviews, note review.	5
32	Dickinson, R. (2004).	USA.	Nursing home staff: 1 nurse. Individual with dementia: 1 (1 female).	Living at home. Alzheimer's disease.	Personal account.	1
33	Dietch, J. T., Hewett, L. J., & Jones, S. (1989).	USA.	Clinician report: 2.	Alzheimer's disease.	Case reports.	2
34	Doka, K. (2010).	USA.	Academic.	Dementia.		2
35	Edvardsson, D. & Nordvall, K. (2008).	Sweden.	Self-report: 6 (5 female, mean age 75 years, range 70-83).	Psycho-geriatric unit. Dementia, mild to severe.	Individual interviews.	6

36	Edvardsson, D., Sandman, P. O., & Rasmussen, B. (2012).	Sweden.	Academic.		Participant observation.	6
37	Evans, S. (2008).	UK.	Academic.	Dementia.		5
38	Feil, N. (1993).	USA.	Academic.	Dementia.		3
39	Frazer, S. M., Oyebode, J. R., & Cleary, A. (2012).	UK.	Self-report: 8 (8 female, mean age 83, range 75-95).	Living alone. Alzheimer's disease and/or mixed vascular dementia, mild to severe cognitive impairment.	Individual interviews.	5
40	Friel-Mcgowin, D. F. (1993).	USA.	Self-report: 1	Alzheimer's disease and multi-infarct dementia.	Personal account.	4
41	Genoe, R. (2013).		Self-report: 4: (2 female, age 59-82). Academic.	Living in the community. Early stage dementia. Multi infarct and Alzheimer's disease, Alzheimer's disease.	Individual interviews, participant observation, Photovoice.	5
42	Gilmour, J. A. & Huntington, A. D. (2005).	New Zealand.	Self-report: 9 (4 female, age range 56–79 years).	Living at home. Alzheimer's disease, multiinfarct or frontal lobe dementia.	Individual interviews.	5
43	Godwin, B. & Poland, F. (2015).	UK.	Self-report: 10 (8 female, age range 69-97- not all reported). Family members: 10 Residential care staff: 10	Residential or nursing homes (3). Vascular dementia (2), Parkinson's dementia (1), Korsakoff's dementia (1), Lewy-Body dementia (1), dementia (5), moderate to advanced.	Individual interviews with observations of non-verbal behaviour.	5
44	Graboys, T. B. (2012).	USA.	Self-report: 1	Parkinson's disease and Lewy body dementia.	Personal account.	3
45	Graneheim, U. H., &	Sweden.	Self-report: 3 (1 female, mean age 75,	Residential home. Vascular	Individual interviews.	6

	Jansson, L. (2006).		range 73-79).	dementia 2, Alzheimer's disease 1, mild to moderate.		
46	Gruetzner, H., Ellor, J. W., Back, N. (2012).	USA.	Family members: 16 (5 spouses, 11 children). Long term care staff: 6 (physician, psychiatrist, psychologist, social worker, nurse, nurse practitioner).	Nursing home. Alzheimer's disease (10), circulatory dementia (2), unclear (4). Details of full sample not given.	Focus group interviews.	4
47	Hausman, C. (1992).	USA.	Academic.	Dementia.		4
48	Hedman, R., *et al.* (2013).	Sweden.	Self-report: 12 (5 female, age range 60-80 years)	Living alone or with spouse. Alzheimer's disease, mild to moderate.	Individual interview.	6
49	Heggestad, A. K. T., Nortvedt, P., & Sletteboe, A. (2013).	Norway.	Self-report: 26 (age range 73-99)	Two nursing homes (special care unit for people with dementia, general unit). Dementia, mild to severe.	Participant observation, individual interviews.	6
50	Holst, G. & Hallberg, I. R. (2003).	Sweden.	Self-report: 11.	Living with family or living alone. Dementia, moderate.	Individual interviews.	5
51	Husband, H. J. (1999).	UK.	Clinician report: 1.	Living alone. Alzheimer's disease (2), probable Alzheimer's disease (1).	Case report.	3
52	Husband, H. J. (2000).	UK.	Self-report: 23 (14 female, mean age 69, range 61–78).	Dementia, early.	Interview.	2
53	Hynninen, N., Saarnio, R.,	Finland.	Self-report: 7 (4 women).	Hospital surgical wards (4). Alzheimer's disease, mild to	Individual interviews, joint	6

	Isola, A. (2015).		Family members: 5 (4 spouses , 1 child). Individuals with dementia: 5 (5 female, mean age 81, range 74-85).	moderate.	interviews.	
54	James, I. A. (1999a).	UK.	Academic.	Dementia.	Case report.	4
55	James, I. A. (1999b).	UK.	Academic.	Dementia.		3
56	Johansson, Å. K. & Grimby, A. (2013).	Sweden.	Nursing home staff: 1 nurse. Individuals with dementia: 17 (12 female, age range 74-90).	Nursing home. Dementia.	Observation.	3
57	Jones, S. N. (1995).	USA.	Academic.	Dementia.		4
58	Jones, G. M. M. (2004).	UK.	Academic.	In part residential/long-term care.		4
59	Jordan *et al.* (2012).	UK	Academic. Individuals with dementia: 79 (57 female, mean age 82).	NHS continuing care unit (1), private elderly mentally infirm (EMI) nursing homes (3). Alzheimer's disease (42), vascular dementia (23), mixed (9), dementia with Lewy bodies (3), severe.	Observation (PAINAD and DisDAT tools), note review, relative view, physical examinations and medical opinion.	7
60	Judkins, W. & Roberto, K. A. (2001).	USA.	Day centre staff: nurses, van drivers, the program director, and activities personnel. Academic. Individuals with dementia: 2 (2 female).	Day center. Alzheimer's disease, mid-stage.	Participant observation, interviews.	3
61	Kelly, A. (2008).	Australia.	Academic.	AIDS dementia.	Participant observation, interviews, informant (person with dementia and significant	3

					and extended others) drawings.	
62	Kitwood, T. & Bredin, K. (1992).	UK.	Academic.	Dementia.		4
63	LaBarge, E. & Trtanj, F. (1995).	USA.	Self-report: 10 (4 female, age range 54-83).	Dementia, mild to moderate.	Notes from a support group.	4
64	LaBarge, E., Von Dras, D., & Wingbermuehle, C. (1998).	USA.	Academic. Individuals with dementia: 11 (4 female, mean age 69, range 55-82).	Living in the community (9) or in a nursing home (2). Probable Alzheimer's disease, mild to moderate.	Video-taped support group.	5
65	Lewis, M. M. & Trzinski, A. L. (2006).	USA.	Academic.	Nursing home. Dementia, early stages.	Intervention with case report.	3
66	Lipinska, D. (2010).	USA and UK.	Clinician report: 1.		Clinician viewpoint.	2
67	Lloyd, B. T. & Stirling, C. (2015).	Australia.	Self-report: 7 (3 female, age 48-85 years).	Living alone. Mild to moderate dementia.	Individual interviews.	4
68	Loboprabhu, S., Molinari, V., & Vomax, J. (2007).	USA.	Academic.	Dementia.		3
69	Magai, C., *et al.* (1996).	USA.	Academic. Individuals with dementia: 82 (63 female, me an age 84 years, SD 6.8).	Nursing home. Alzheimer's disease, mid to late range impairment.	Observation during a family visit.	3
70	Malloy, L. (2009).	UK.	Academic.	Dementia.		7
71	Mazaheri, M., *et al.* (2013).	Sweden. Participants lived in Iran.	Self-report: 15 (6 female, age range 60-87 years).	Living alone or with family. Alzheimer's disease or vascular dementia, moderate.	Individual interviews.	5

72	McGee, J. S., *et al.* (2013).	USA.	Self-report: 28 (16 female, mean age 78).	Alzheimer's disease, mild.	Individual interviews.	6
73	Miesen, B. M. L. (1993).	Netherlands.	Academic. Individuals with dementia: 40 (27 female, age range 64-90).	Nursing home. Dementia.	Experiment.	6
74	Miesen, B. M. L. (1997).	Netherlands.	Academic.	Dementia.		2
75	Miesen, B. M. L. (1998).	Netherlands.	Academic.	Dementia.	Including case studies.	5
76	Miesen, B.M.L. (1999).	Netherlands.	Academic.	Dementia.	Including case studies.	4
77	Mormont, E., de Fays, K., & Jamart, J. (2012).	Belgium.	Self-report: 107 Caregiver: 107 (64 spouses, 31 children, 12 other).	Alzheimer's disease.	Interview: structured questionnaire.	5
78	Morton, I. (2007).	UK.	Dementia care team manager report	Mixed Alzheimer's and vascular dementia.		1
79	Moyle, W., *et al.* (2011).	Australia.	Self-report: 70 (49 female, age 66–97 years). Family members: 73.	Community or long term care. Dementia, probable or early stage.	Individual interviews.	5
80	Newborg, M. (2006).	Unknown.	Academic.	Alzheimer's disease.	Creative account.	2
81	Ng, A. V. (2009).	UK.	Academic.	Hospital.	Observation.	3
82	O'Connor, M., *et al.* (2013).	Australia.	Self-report: 23 (13 female, age <65-90+). Residential care staff: 16 nurses, 4 personal carers, 1 manager, 4 allied health professionals.	Aged care facility/nursing home. Mild dementia.	Individual interviews.	4

83	Öhman, A., Josephsson, S., & Nygård, L. (2008).	Sweden.	Self-report: 6 (3 female, mean age 73 years, range 65-80).	Living at home. Alzheimer's disease, mild to moderate.	Individual interviews.	5
84	Olsson, A., *et al.* (2013).	Sweden.	Self-report: 11 (5 female, mean age 68, range 52-81).	Living alone. Alzheimer's disease, early stage.	Individual interviews.	6
85	Orulv, L. (2014).	Sweden.	Academic.	Dementia.		4
86	Ostwald, S. K., Duggleby, W., & Hepburn, K. W. (2002).	USA.	Self-report: 56 (26 female, mean age 77.6, range 47-97.	Living in the community. Dementia with behavioural problems as perceived by caregivers.	Individual interviews.	5
87	Peach, E., & Duff, G. (1993).	New Zealand.	Self-report: 13 (12 female, age range 61-82).	Living alone (4), living with family (7), retirement complex (1), rest home (1). Alzheimer's disease, multi-infarct dementia or unspecified dementia.	Notes from a support group.	4
88	Phillips, J. M. (2000).	USA.	Self-report: 1 (female, age 50)	Early onset Alzheimer's disease.	Personal account.	3
89	Pratt, R., & Wilkinson, H. (2001).	UK.	Self-report: 24 (13 female, mean age , range 44-78 years)	Living with a partner or family (21) or living alone (3). Alzheimer's disease (10), frontal lobe dementia (1), multi infarct dementia (2), vascular dementia (1), Pick's disease (1), Parkinson's disease (1), unknown (8), early stage.	Interviews.	6
90	Pratt, R., & Wilkinson, H. (2003).	UK.	Self-report: 24 (13 female, age range 44-78).	Living with a spouse (15), living with family (6), living alone (3).	Interviews.	5

91	Preston, L., Marshall, A., & Bucks, R. S. (2007).	UK.	Self-report: 12 (5 female, mean age 71, range 58-81).	Living at home with spouse (9), living alone (2), living in supported accommodation (1). Alzheimer's disease (9), vascular dementia (3), mild.	Interviews.	6
92	Reese, R. (2005).	USA.	Medical center staff: 1 nursing assistant.	Dementia unit at a medical center. Dementia.	Case report.	1
93	Rentz, C., Krikorian, R., & Keys, M. (2005).	USA.	Academic.	Dementia.		3
94	Ronch, J. L. (1996).	USA.	Academic.	Dementia.	Case report.	1
95	Sabat, S. R. (2008).	USA.	Academic.	Dementia.		3
96	Sabat, S. R. (2011).	USA.	Academic.	Dementia.		3
97	Sinason V. (1992).	UK.	Academic.	Dementia.	Case vignette.	2
98	Snyder, L., *et al.* (1995).	USA.	Self-report: 15 (6 female, mean age of 76 years).	Alzheimer's disease or a related disorder, earlier stages.	Verbal evaluations of an intervention.	2
99	Solomon, D. (1988).	USA.	Academic.	Dementia.	Including case example.	3
100	Solomon, K., & Szwabo, P. (1992).	USA.	Academic.	Dementia.		3
101	Steeman, E., *et al.* (2007).	Belgium.	Self-report: 20 (16 female, mean age 78, age range 69–91 years). Family members: 19 (13 children, 5 spouses, 1 niece).	Living a home. Alzheimer's disease (12), Subcortical atrophy (6), mixed dementia (1), vascular dementia (1), probable, questionable or mild.	Interviews, individual and joint.	6

102	Steeman, E. (2013).	Belgium.	Self-report: 20 (16 female, mean age 78, age range 69–91 years). Family members: 19 (13 children, 5 spouses, 1 niece).	Living a home. Alzheimer's disease (12), Subcortical atrophy (6), mixed dementia (1), vascular dementia (1), probable, questionable or mild.	Interviews, individual and joint.	6
103	Stevenson, A., Thomson, J., & Roth, H. (2010).	UK.	Staff / Academic Psychology graduate, development worker, anatomist, psychology student.	Care home. Dementia.	Case report, informal observations.	2
104	Svanström, R., & Sundler, A. J. (2015).	Sweden.	Self-report: 6 (mean age 84, range 80-90).	Living alone. Dementia.	Individual interviews.	6
105	Tappen, R. M. & Williams, C. (1998).	USA.	Residential care staff: 19 (7 registered and practical nurses, 7 nursing assistants, 3 activity technicians, 1 social worker, and 1 rehabilitation specialist). Family members: 20 (7 spouses, 13 children). Individuals with dementia, mean age 85 (nursing home residents) and 81 (day center clients).	Nursing home residents or living at home and attending day center. Alzheimer's disease, probable, middle and late stages.	Individual interviews.	5
106	Taylor, R. (2007).	USA.	Self-report: 1.	Alzheimer's disease.	Collection of essays.	4
107	Temple-Jones, J. E. (2012).	Canada.	Chaplain.	Nursing home. Dementia.	Case report.	2
108	Terry, P. (2010).	UK.	Academic.	Dementia.		2
109	van Achterberg, M. E., Rohrbaugh, R. M., &	USA.	Academic.	Alzheimer's disease (2), multi-	Case reports.	2

	Southwick, S. M. (2001).			infarct dementia (1).		
110	Waddell, M. (2000).	UK.	Academic.	Dementia.	Case vignette.	3
111	Walker, D. A. (2004).	UK.	Clinician report: 1	Living with spouse. Alzheimer's disease.	Case report.	3
112	Wallace, D. (2011).	UK.	Self-report: 1	Vascular dementia.	Personal account.	3
113	Wang, J.-J., Feldt, K., & Cheng, W. Y. (2012).	Taiwan.	Family members: 12. Individuals with dementia: 12 (8 female, age range 74-92).	Alzheimer's disease, moderate.	Individual interviews.	4
114	Wang, J. J., *et al.* (2014).	China.	Family members: 20 (13 female, spouse 5, children 15). Individuals with dementia: 20 (16 female, mean age 79 years, range 69-92).	Alzheimer's disease	Individual interviews.	4
115	Ward-Griffin, C., Bol, N., & Oudshoorn, A. (2006).	Canada.	Self-report: 10 (10 female, mean age 88, range 75-98).	Living in the community. Dementia, mild to moderate.	Individual interviews, joint interviews with daughter or granddaughter and field note data.	7
116	Watkins, R., *et al.* (2006).	UK.	Self-report: 10 (3 female, mean age 69, range 59-81).	Living at home. Alzheimer's disease (8), dementia (2).	Group psychotherapy transcripts, 10 sessions.	3
117	Wawrziczny, E., *et al.* (2015).	France.	Self-report: 16 married couples (mean age of individual with dementia, 57 years).	Living at home with spouse. Probable Alzheimer's disease.	Couple interviews.	6
118	Weaks, D., Wilkinson, H., & McLeod, J. (2015).	UK.	Self-report: 5 (3 female, mean age 74, range 68-79). Academic	Alzheimer's disease, early.	Sequential interviews, participant observation, contact with family members.	5
119	Weiner, M. F. (1991).	USA.	Academic.	Dementia.	Including case examples.	3

120	Werezak, L., & Stewart, N., (2002).	Canada.	Self-report: 6 (3 female, age range 61-79).	Living at home with spouse. Dementia.	Individual interview.	5
121	Zingmark, K., Norberg, A., & Sandman, P-O. (1993).	Sweden.	Ward staff: 1 ward sister. Individuals with dementia: 6.	Shared house, Alzheimer's disease, moderate or severe.	Participant, non-participant observation.	3

References

1. **Abraham, R.** (2005). When words have lost their meaning: Alzheimer's patients communicate through art, Westport, CT, US, Praeger Publishers/Greenwood Publishing Group.
2. **Aggarwal, N., *et al.*** (2003). People with dementia and their relatives: Personal experiences of Alzheimer's and of the provision of care. Journal of Psychiatric and Mental Health Nursing, 10, 187-197.
3. **Ahonen-Eerikainen, H., Rippin, K., Sibille, N., Koch, R. and Dalby, D.M.** (2007). "Not bad for an 85-year-old!"--The qualitative analysis of the role of music, therapeutic benefits and group therapeutic factors of the St. Joseph's Alzheimer's Adult Day Program Music Therapy Group. Canadian Journal of Music Therapy, 13, 37-62.
4. **Aminzadeh, F., Byszewski, A., Molnar, F.J. and Eisner, M.** (2007). Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. Aging and Mental Health, 11, 281-290.
5. **Aminzadeh, F., Molnar, F.J., Dalziel, W.B. and Garcia, L.J.** (2013). An exploration of adjustment needs and efforts of persons with dementia after relocation to a residential care facility. Journal of Housing for the Elderly, 27, 221-240.
6. **Anderson, D.** (2011). Group analysis and dementia: Reflections on conducting an analytic space. Group Analysis, 44, 385-394.
7. **Bahro, M., Silber, E. and Sunderland, T.** (1995). How do patients with Alzheimer's disease cope with their illness? A clinical experience report. Journal of the American Geriatrics Society, 43, 41-46.
8. **Barnett, E.** (2000). Including the Person with Dementia in Designing and Delivering Care: I Need to be Me!, London, Jessica Kingsley Publishers.
9. **Bartlett, R.** (2007). 'You can get in alright but you can't get out': Social exclusion and men with dementia in nursing homes: Insights from a single case study. Quality in Ageing, 8, 16-26.
10. **Bartlett, R.** (2014). Citizenship in action: the lived experiences of citizens with dementia who campaign for social change. Disability and Society, 29, 1291-1304.
11. **Baruch, J., Downs, M., Baldwin, C. and Bruce, E.** (2004). A case study in the use of technology to reassure and support a person with dementia. Dementia: The International Journal of Social Research and Practice, 3, 372-377.

12. **Beart, K.** (2008). Care for the person with dementia, 3: psychological and emotional effects. British Journal of Neuroscience Nursing, 4, 66-73.
13. **Bender, M.P. and Cheston, R.** (1997). Inhabitants of a lost kingdom: A model of the subjective experiences of dementia. Ageing and Society, 17, 513-532.
14. **Bergland, Å., Johansen, H. and Sellevold, G.S.** (2015). A qualitative study of professional caregivers' perceptions of processes contributing to mealtime agitation in persons with dementia in nursing home wards and strategies to attain calmness. Nursing Open, 2, 119-129.
15. **Bourbonnais, A. and Ducharme, F.** (2010). The meanings of screams in older people living with dementia in a nursing home. International Psychogeriatrics, 22, 1172-1184.
16. **Bryden, C.** (2005). Dancing with dementia: My story of living positively with dementia, London, Jessica Kingsley Publishers.
17. **Burton, C. and Crossley, M.** (2003). Examining the utility of the Saskatchewan mood inventory for individuals with memory loss. Canadian Journal on Aging, 22, 297-309.
18. **Cahill, S.M., Gibb, M., Bruce, I., Headon, M. and Drury, M.** (2008). 'I was worried coming in because I don't really know why it was arranged': The subjective experience of new patients and their primary caregivers attending a memory clinic. Dementia, 7, 175-189.
19. **Cedervall, Y., Torres, S. and Åberg, A.C.** (2015). Maintaining well-being and selfhood through physical activity: experiences of people with mild Alzheimer's disease. Aging & Mental Health, 19, 679-688.
20. **Clare, L.** (2002). We'll fight it as long as we can: Coping with the onset of Alzheimer's disease. Aging and Mental Health, 6, 139-148.
21. **Clare, L.** (2003). Managing threats to self: Awareness in early stage Alzheimer's disease. Social Science and Medicine, 57, 1017-1029.
22. **Clare, L., Goater, T. and Woods, B.** (2006). Illness representations in early-stage dementia: A preliminary investigation. International Journal of Geriatric Psychiatry, 21, 761-767.
23. **Clare, L., Rowlands, J., Bruce, E., Surr, C. and Downs, M.** (2008). The experience of living with dementia in residential care: An interpretive phenomenological analysis. The Gerontologist, 48, 711-720.
24. **Cohen, D., Kennedy, G. and Eisdorfer, C.** (1984). Phases of change in the patient with Alzheimer's dementia: A conceptual dimension for defining health care management. Journal of the American Geriatrics Society, 32, 11-15.
25. **Costello, J.** (1996). Hiding in the depths of distress. Journal of Dementia Care, 4, 24-25.
26. **Couch, J.B.** (1997). Behind the veil: mandala drawings by dementia patients. Art Therapy: Journal of the American Art Therapy Association, 14, 187-193.
27. **Dahlberg, K. and Svanstrom, R.** (2004). Living with dementia yields a heteronomous and lost existence. Western Journal of Nursing Research, 26, 671-687.
28. **Dalby, P., Sperlinger, D.J. and Boddington, S.** (2012). The lived experience of spirituality and dementia in older people living with mild to moderate dementia. Dementia, 11, 75-94.
29. **Davenhill, R.** (2007). Looking into later life: A psychoanalytic approach to depression and dementia in old age, London, Karnac Books.
30. **Davis, R. and Davis, B.** (1989). My journey into Alzheimer's disease, Chicago, Tyndale House Publishers.

31. **De Vries, K. and Mcchrystal, J.** (2010). Using attachment theory to improve the care of people with dementia. International Journal of Work Organisation and Emotion, 3, 287-301.
32. **Dickinson, R.** (2004). Taking a stand against fear. Nursing, 34, 43.
33. **Dietch, J.T., Hewett, L.J. and Jones, S.** (1989). Adverse effects of reality orientation. Journal of the American Geriatrics Society, 37, 974-976.
34. **Doka, K.** (2010). Grief, multiple loss and dementia. Bereavement Care, 29, 15-20.
35. **Edvardsson, D. and Nordvall, K.** (2008). Lost in the present but confident of the past: experiences of being in a psycho-geriatric unit as narrated by persons with dementia. Journal of Clinical Nursing, 17, 491-498.
36. **Edvardsson, D., Sandman, P.O. and Rasmussen, B.** (2012). Forecasting the ward climate: A study from a dementia care unit. Journal of Clinical Nursing, 21, 1114-1136.
37. **Evans, S.** (2008). 'Beyond forgetfulness': How psychoanalytic ideas can help us to understand the experience of patients with dementia. Psychoanalytic Psychotherapy, 22, 155-176.
38. **Feil, N.** (1993). The Validation breakthrough: Simple techniques for communicating with people with "Alzheimer's-type dementia.", Baltimore, MD, US, Health Professions Press.
39. **Frazer, S.M., Oyebode, J.R. and Cleary, A.** (2012). How older women who live alone with dementia make sense of their experiences: An interpretative phenomenological analysis. Dementia, 11, 677-693.
40. **Friel-Mcgowin, D.** (1993). Living in the labyrinth: A personal journey through the maze of Alzheimer's, San Francisco, Elder.
41. **Genoe, M.R.** (2013). “There is life after diagnosis”: Dementia, leisure, and meaning-focused coping. Recreation and Society in Africa, Asia and Latin America, 4, 329.
42. **Gilmour, J.A. and Huntington, A.D.** (2005). Finding the balance: Living with memory loss. International Journal of Nursing Practice, 11, 118-124.
43. **Godwin, B. and Poland, F.** (2015). Bedlam or bliss? Recognising the emotional self-experience of people with moderate to advanced dementia in residential and nursing care. Quality in Ageing and Older Adults, 16, 235-248.
44. **Graboys, T.B.** (2012). Finding hope in the midst of despair: My decade with Parkinson's disease and Lewy body dementia. Movement Disorders, 27, 1358-1359.
45. **Graneheim, U.H. and Jansson, L.** (2006). The meaning of living with dementia and disturbing behaviour as narrated by three persons admitted to a residential home. Journal of Clinical Nursing, 15, 1397-1403.
46. **Gruetzner, H., Ellor, J.W. and Back, N.** (2012). Identifiable Grief Responses in Persons With Alzheimer's Disease. Journal of Social Work in End-of-Life and Palliative Care, 8, 151-164.
47. **Hausman, C.** (1992). Dynamic psychotherapy with elderly demented patients. In*:* Jones, G. M. M. & Miesen, B. M. L. (Eds.) Care-giving in dementia: research and applications. London: Routledge.
48. **Hedman, R., Hansebo, G., Ternestedt, B.-M., Hellstrom, I. and Norberg, A.** (2013). How people with Alzheimer's disease express their sense of self: Analysis using Rom Harre's theory of selfhood. Dementia: The International Journal of Social Research and Practice, 12, 713-733.

49. **Heggestad, A.K.T., Nortvedt, P. and Sletteboe, A.** (2013). 'Like a prison without bars': Dementia and experiences of dignity. Nursing Ethics, 20, 881-892.
50. **Holst, G. and Hallberg, I.R.** (2003). Exploring the meaning of everyday life, for those suffering from dementia. American Journal of Alzheimer's Disease and other Dementias, 18, 359-365.
51. **Husband, H.J.** (1999). The psychological consequences of learning a diagnosis of dementia: Three case examples. Aging & Mental Health, 3, 179-183.
52. **Husband, H.J.** (2000). Diagnostic disclosure in dementia: an opportunity for intervention? International Journal of Geriatric Psychiatry, 15, 544-547.
53. **Hynninen, N., Saarnio, R. and Isola, A.** (2015). Treatment of older people with dementia in surgical wards from the viewpoints of the patients and close relatives. Journal of Clinical Nursing, 24, 3691–3699.
54. **James, I.A.** (1999). A cognitive conceptualization of distress in people with dementia. Clinical Psychology Forum, 21-25.
55. **James, I.A.** (1999). Using a cognitive rationale to conceptualize anxiety in people with dementia. Behavioural and Cognitive Psychotherapy, 27, 345-351.
56. **Johansson, Å.K. and Grimby, A.** (2013). Grief Among Demented Elderly Individuals: A Pilot Study. American Journal of Hospice and Palliative Medicine, 30, 445-449.
57. **Jones, G.M.M.** (2004). The loss of meaningful attachment in dementia and behavioural behaviour stage-specific Implications. In*:* Jones, G. M. M. & Miesen, B. M. L. (Eds.) Care-Giving in Dementia: Research and Applications. Hove: Brunner-Routledge.
58. **Jones, S.N.** (1995). An Interpersonal Approach to Psychotherapy With Older Persons With Dementia. Professional Psychology: Research and Practice, 26, 602-607.
59. **Jordan, A., Regnard, C., O'brien, J.T. and Hughes, J.C.** (2012). Pain and distress in advanced dementia: choosing the right tools for the job. Palliative Medicine, 26, 873-878.
60. **Judkins, W. and Roberto, K.A.** (2001). Abandonment fears of persons with Alzheimer's disease attending adult day care. American Journal of Alzheimer's Disease and other Dementias, 16, 247-250.
61. **Kelly, A.** (2008). Living loss: An exploration of the internal space of liminality. Mortality, 13, 335-350.
62. **Kitwood, T. and Bredin, K.** (1992). Towards a theory of dementia care: personhood and well-being. Ageing and Society, 12, 269-287.
63. **Labarge, E. and Trtanj, F.** (1995). A support group for people in the early stages of dementia of the Alzheimer type. Journal of Applied Gerontology, 14, 289-301.
64. **Labarge, E., Von Dras, D. and Wingbermuehle, C.** (1998). An analysis of themes and feelings from a support group for people with Alzheimer's disease. Psychotherapy, 35, 537-544.
65. **Lewis, M.M. and Trzinski, A.L.** (2006). Counseling older adults with dementia who are dealing with death: Innovative interventions for practitioners. Death Studies, 30, 777-787.
66. **Lipinska, D.** (2010). Why counsel people with dementia? Healthcare Counselling & Psychotherapy Journal, 10, 4-7.
67. **Lloyd, B.T. and Stirling, C.** (2015). The will to mobility: life-space satisfaction and distress in people with dementia who live alone. Ageing & Society, 35, 1801-1820.

68. **Loboprabhu, S., Molinari, V. and Lomax, J.** (2007). The transitional object in dementia: Clinical implications. International Journal of Applied Psychoanalytic Studies, 4, 144-169.
69. **Magai, C., Cohen, C., Gomberg, D., Malatesta, C. and Culver, C.** (1996). Emotional expression during mid- to late-stage dementia. International Psychogeriatrics, 8, 383-395.
70. **Malloy, L.** (2009). Thinking about dementia - A psychodynamic understanding of links between early infantile experience and dementia. Psychoanalytic Psychotherapy, 23, 109-120.
71. **Mazaheri, M., *et al.*** (2013). Experiences of living with dementia: Qualitative content analysis of semi-structured interviews. Journal of Clinical Nursing, 22, 3032-3041.
72. **Mcgee, J.S., Myers, D.R., Carlson, H., Funai, A.P. and Barclay, P.A.** (2013). Spirituality, faith, and mild Alzheimer's disease. Research in the Social Scientific Study of Religion, 24, 221-257.
73. **Miesen, B.M.L.** (1993). Alzheimer's disease, the phenomenon of parent fixation and Bowlby's attachment theory. International Journal of Geriatric Psychiatry, 8, 147-153.
74. **Miesen, B.M.L.** (1997). Awareness in dementia patients and family grieving: a practical perspective. In: Miesen, B. M. L. & Jones, G. M. M. (Eds.) Care-Giving in Dementia: Research and Applications. London: Routledge.
75. **Miesen, B.M.L.** (1998). Attachment behavior in dementia: Parent Orientation and Parent Fixation (POPFiD) theory. The Course Of Life, Vol. 7: Completing the journey, 197-229.
76. **Miesen, B.M.L.** (1999). Dementia in Close-up. Understanding and Caring for People with Dementia. London/New York: Routledge.
77. **Mormont, E., De Fays, K. and Jamart, J.** (2012). Experiences of the patients and their caregivers regarding the disclosure of the diagnosis of Alzheimer's disease: A Belgian retrospective survey. Acta Neurologica Belgica, 112, 249-254.
78. **Morton, I.** (2007). Psychoanalysis and dementia: understanding disturbance and distress. Journal of Dementia Care, 15, 18-20.
79. **Moyle, W., Kellett, U., Ballantyne, A. and Gracia, N.** (2011). Dementia and loneliness: An Australian perspective. Journal of Clinical Nursing, 20, 1445-1453.
80. **Newborg, M.** (2006). A lonely journey. Geriatric Nursing, 27, 26-27.
81. **Ng, A.V.** (2009). Making sense of dementia using infant observation techniques: A psychoanalytic perspective on a neuropathological disease. Infant Observation, 12, 83-105.
82. **O'connor, M., Tan, H., O'connor, D. and Workman, B.** (2013). Is the frequent death of residents in aged care facilities a significant cause of grief for residents with mild dementia? Progress in Palliative Care, 21, 7-12.
83. **Öhman, A., Josephsson, S. and Nygård, L.** (2008). Awareness through interaction in everyday occupations: Experiences of people with Alzheimer's disease. Scandinavian Journal of Occupational Therapy, 15, 43-51.
84. **Olsson, A., Lampic, C., Skovdahl, K. and Engström, M.** (2013). Persons with early-stage dementia reflect on being outdoors: A repeated interview study. Aging and Mental Health, 17, 793-800.

85. **Orulv, L.** (2014). The subjectivity of disorientation: Moral stakes and concerns. In*:* Hydén, L. C., Lindemann, H. & Brockmeier, J. (Eds.) *Beyond loss: Dementia, identity, personhood*. Oxford: Oxford University Press.
86. **Ostwald, S.K., Duggleby, W. and Hepburn, K.W.** (2002). The stress of dementia: View from the inside. American Journal of Alzheimer's Disease and other Dementias, 17, 303-312.
87. **Peach, E. and Duff, G.** (1993). Mutual support groups: a response to the early and often forgotten stage of dementia. Practice, 6, 147-157.
88. **Phillips, J.M.** (2000). A personal view of living with earlyonset Alzheimer's. Perspectives- A Newsletter for Individuals with Alzheimer's Disease, 6, 1-3.
89. **Pratt, R. and Wilkinson, H.** (2001). Tell Me the Truth: The Effect of Being Told the Diagnosis of Dementia from the Perspective of the Person with Dementia. London: The Mental Health Foundation.
90. **Pratt, R. and Wilkinson, H.** (2003). A psychosocial model of understanding the experience of receiving a diagnosis of dementia. Dementia, 2, 181-199.
91. **Preston, L., Marshall, A. and Bucks, R.S.** (2007). Investigating the ways that older people cope with dementia: a qualitative study. Aging & Mental Health, 11, 131-143.
92. **Reese, R.** (2005). The long trip home. Nursing, 35, 46-47.
93. **Rentz, C., Krikorian, R. and Keys, M.** (2005). Grief and mourning from the perspective of the person with a dementing illness: Beginning the dialogue. Omega: Journal of Death and Dying, 50, 165-179.
94. **Ronch, J.L.** (1996). Mourning and grief in late life Alzheimer's dementia: Revisiting the vanishing self. American Journal of Alzheimer's Disease and other Dementias, 11, 25-28.
95. **Sabat, S.R.** (2008). Positioning and conflict involving a person with dementia: A case study. In*:* Moghaddam, F. M., Harré, R. & Lee, N. (Eds.) Global conflict resolution through positioning analysis. New York, NY, US: Springer.
96. **Sabat, S.R.** (2011). Maintaining the self in dementia. In: Hughes, J., Lloyd-Williams, M. & Sachs, G. (Eds.) Supportive Care for the Person with Dementia. UK: Oxford University Press.
97. **Sinason, V.** (1992). The man who was losing his brain. In: Sinason, V. (Ed.) Mental handicap and the human condition. London: Free Association Books.
98. **Snyder, L., Quayhagen, M.P., Shepherd, S. and Bower, D.** (1995). Supportive seminar groups: an intervention for early stage dementia patients. Gerontologist, 35, 691-695.
99. **Solomon, D.** (1988). Look what happens to a person: The loss of autonomy in Alzheimer's disease and the impact on the client and the social worker. Alzheimer's Disease And Related Disorders: Psychosocial Issues For The Patient, Family, Staff, and Community, 29-36.
100. **Solomon, K. and Szwabo, P.** (1992). Psychotherapy for patients with dementia. Memory Function And Aging-Related Disorders, 295-319.
101. **Steeman, E.** (2013). Managing identity in early-stage dementia: maintaining a sense of being valued. Ageing & Society, 33, 216-242.
102. **Steeman, E., Godderis, J., Grypdonck, M., De Bal, N. and De Casterle, B.D.** (2007). Living with dementia from the perspective of older people: Is it a positive story? Aging & Mental Health, 11, 119-130.
103. **Stevenson, A., Thomson, J. and Roth, H.** (2010). Dolls: handle with care. Journal of Dementia Care, 18, 16-17.

104. **Svanström, R. and Sundler, A.J.** (2015). Gradually losing one's foothold – A fragmented existence when living alone with dementia. Dementia, 14, 145-163.
105. **Tappen, R.M. and Williams, C.** (1998). Attribution of emotion in advanced Alzheimer's disease: Family and caregiver perspectives. American Journal of Alzheimer's Disease, 13, 257-264.
106. **Taylor, R.** (2007). Alzheimer's from the inside out, Baltimore, MD, US, Health Professions Press.
107. **Temple-Jones, J.E.** (2012). "I Want to Find my Life Again": Dementia and Grief. The Journal of Pastoral Care & Counseling, 66.
108. **Terry, P.** (2010). Dementia: a psychodynamic perspective. Healthcare Counselling & Psychotherapy Journal, 10, 12-15.
109. **Van Achterberg, M.E., Rohrbaugh, R.M. and Southwick, S.M.** (2001). Emergence of PTSD in trauma survivors with dementia. Journal of Clinical Psychiatry, 62, 206-207.
110. **Waddell, M.** (2000). Only connect: Developmental issues from early to late life. Psychoanalytic Psychotherapy, 14, 239-252.
111. **Walker, D.A.** (2004). Cognitive behavioural therapy for depression in a person with Alzheimer's dementia. Behavioural and Cognitive Psychotherapy, 32, 495-500.
112. **Wallace, D.** (2011). The view of the person with dementia. In*:* Hughes, J. C., Lloyd-Williams, M. & Sachs, G. A. (Eds.) Supportive Care for the Person with Dementia. Oxford: Oxford University Press.
113. **Wang, J.J., Feldt, K. and Cheng, W.Y.** (2012). Characteristics and underlying meaning of hoarding behavior in elders with Alzheimer's dementia: Caregivers' perspective. Journal of Nursing Research, 20, 189-196.
114. **Wang, J.-J., Cheng, W.-Y., Lai, P.-R. and Pai, M.-C.** (2014). Delusions and underlying needs in older adults with Alzheimer's disease: influence of earlier life experiences and the current environment. Journal of Gerontological Nursing, 40, 38-47.
115. **Ward-Griffin, C., Bol, N. and Oudshoorn, A.** (2006). Perspectives of women with dementia receiving care from their adult daughters. Canadian Journal of Nursing Research, 38, 120-146.
116. **Watkins, R., Cheston, R., Jones, K. and Gilliard, J.** (2006). 'Coming out' with Alzheimer's disease: Changes in awareness during a psychotherapy group for people with dementia. Aging and Mental Health, 10, 166-176.
117. **Wawrziczny, E., Pasquier, F., Ducharme, F., Kergoat, M.J. and Antoine, P.** (2015). From 'needing to know' to 'needing not to know more': An interpretative phenomenological analysis of couples' experiences with early-onset Alzheimer's disease. Scandinavian Journal of Caring Sciences, 30, 695-703.
118. **Weaks, D., Wilkinson, H. and Mcleod, J.** (2015). Daring to tell: The importance of telling others about a diagnosis of dementia. Ageing and Society, 35, 765-784.
119. **Weiner, M.F.** (1991). Dementia as a psychodynamic process. In: Weiner, M. F. (Ed.) The dementias: Diagnosis and management. Arlington, VA, US: American Psychiatric Association.
120. **Werezak, L. and Stewart, N.** (2002). Learning to live with early dementia. The Canadian journal of nursing research= Revue canadienne de recherche en sciences infirmieres, 34, 67-85.

121. **Zingmark, K., Norberg, A. and Sandman, P.-O.** (1993). Experience of at-homeness and homesickness in patients with Alzheimer's disease. American Journal of Alzheimer's Disease and Other Dementias, 8, 10-16.

Appendix 5. Systematic review. Explanations for distress: full concept descriptions.

Self

'The whole disease is about insecurity and poor self-esteem' (84, p. 797). The concept 'self' represents distress being caused by change to the person's sense of self: Loss of self and individuals describing what they Can't do. This was the most frequent explanation offered for distress across this literature, offered within 65 studies. Within this concept, the most frequently mentioned cause for distress was the self being lost, as was discussed by 39 studies. Not being able to do things any more was the second most frequent explanation for distress regarding change to the self, described in 27 studies.

Loss of self A 'loss of self' was spoken of explicitly and was further defined as having decreased self-value (48, 7, 98), a loss of sense of identity, (4, 100, 44, 99, 26, 107, 94), or change or discontinuity in the self (28, 29, 44), for example, 'a nearly complete dismantling of the self I once knew' (44, p. 1359). This included a tangible loss of meaningful routines and places that contributed to the person's identity (5, 105, 63, 82, 92): 'I mean, my home was my home and there I'd do my own washing and ironing and, you know, those sorts of things' (5, p. 228); 'I was used to having a home' (82, p. 10); 'without people and things [that provide need and purpose], life becomes a prison of searching endlessly and aimlessly for them' (58, p. 262). Loss of self was also described as being caused by a loss of meaningful aspects of identity, roles and capabilities (39, 71, 10, 106, 1, 95, 100, 34): 'I who could move mountains!' (71, p. 11). No longer being somebody who helped others (101, 102, 71, 7), feeling removed from being a mother or nurturer (39), a husband, father, and grandfather (44), no longer holding meaningful professional identity (105, 39, 63, 30, 29, 34) and loss of activity and active participation (71, 44) were all given as explanations for distress. The loss of self also meant losing a connection with past relationships that defined the self (68, 107, 108) or future relationships that would define the self (93, 44).

The self was described as being 'threatened' or 'attacked' or stolen or murdered (50, 39, 37, 7, 1, 29, 61, 34, 13, 99, 26); 'helplessness to control this insidious thief who was little by little taking away my most valued possession, my mind' (30, p. 91); 'loss of the self, fear of dying twice' (106, p.)68; 'That's not me, not the real Molly. So I go around looking for Molly, but she's nowhere to be found' (94, p. 26).

In 13 studies, distress was explained by the individual feeling lost and empty and akin to an object or alien (15, 23, 21, 45, 27, 50, 17, 76, 1, 121, 13, 80, 34). These explanations included individuals being between different worlds and struggling to find meaning, hence having little connection to the past, present or future. There was a lack of order or sense described. Words such as 'drifting', 'void', 'absence', 'estrangement', 'strangeness' and 'disconnect' were used.

For some, the self became defined by difficulty: 'First of all, you are nobody' (48, p. 720). A preoccupation with 'damage and disability' increased with the progression of dementia (47, 57, 30, 40, 29, 28). Absolute descriptions were applied to the self, such as having nothing left (1), being incapable (111, 26), real helplessness and powerlessness (117, 56, 100 29, 119 28). Individuals no longer felt special; they felt vulnerable and

reduced to being 'like others' (1, 100, 29, 26). Distress was caused by individuals asking 'why me?' (28, 30, 70, 74) and reaching an existential or spiritual challenge (28, 57, 30).

I can't The position of 'not being able to do things' (84, 86, 121, 32) was described in 27 studies. When examples were provided, these included no longer being able to drive a car (84), exhaustion (84, 117, 74), most frequently, forgetting (117, 9, 83, 50, 30, 47, 1, 93, 66), not being able to recognize things including objects and family members (14, 105), difficulties with conversation (14, 105, 47, 1, 29), taking longer (50), impairment to hearing and vision (43, 1, 29), not being able to care for the self (2, 111), not being able to think clearly or find solutions (30, 96, 100, 29, 80, 66), disorientation (40, 80) and being unable to control the body (44). One study likened the experienced to 'that first day of school' (80, p. 26). Exhaustion and stress contributed to individuals making mistakes, further mistakes, catastrophes (19, 50).

While distress was explained by the loss of abilities in and of themselves, further explanation offered was the loss of abilities without resources to remedy the situation (47), referring to an individual's inability to maintain a coherent and positive view of themselves when experiencing difficulties (47, 106, 100, 119, 74). Change to abilities resulted in low confidence, low self-esteem or insecurity (84, 19, 111).

Social position

Judgment One of the most frequent reasons for distress within this theme was the individual being viewed by themselves or others as worthless or useless (23, 22, 4, 101, 102, 3, 7, 40, 100, 116, 55) and not being wanted or valued by other people (22, 101, 102, 71, 55); 'I feel that I'm not much use to anybody' (22, p. 764), 'taken down a peg' (29, p. 290). This included a loss of value relating to working or employment roles (23, 71). In eight studies, people stated that having dementia and the associated symptoms was something to feel embarrassed about or ashamed of (22, 4, 18, 86, 41, 7, 40, 1). In particular, a reason offered included stigma being attached to a dementia diagnosis and anticipated judgment from others (4, 118, 39, 7). Individuals feared having done something wrong and felt accused (4), they expected criticism and hurtful behaviour from others (64, 120), including gossiping or laughing (51, 120, 52): 'Now, what did I do wrong to be put under such a spell' (4, p. 286) was one remark, which referred to the negative views they perceived from their social environment. Individuals thought that others viewed them or might view them to be dangerous (4, 39), doolally, mad or a fool, stupid, childish or a liar (118, 83, 39, 64, 18, 86, 41, 3, 40, 116, 51, 55, 52); 'like a little girl admitting she had been naughty and had done something wrong' (39, p. 685). Distress was caused by not being acknowledged as a person (50) and being patronised or overprotected (101, 102, 64, 52). Individuals evaluated themselves, such as being a fool (51), or 'It's all a lot of rubbish, and I'm a lot of rubbish now' (23, p. 716). In one example, an individual devalued themselves to the point of stating, 'I should be executed' (7, p. 44).

Embarrassment and concern of being negatively evaluated was described at times when individuals could not remember something, including a name or something to do, if they might make a mistake, might struggle to communicate, could not do 'simple things' such

as reading the newspaper or lost bladder control (39, 64, 18, 86, 41, 3, 106, 1, 51). On one occasion, 'my brain's private betrayal' was described as becoming 'publically observable' (29, p. 288).

Individuals expressed the need to keep the dementia diagnosis from others (4, 118, 40), to be isolated from others (4, 50, 64, 106) and to be 'on guard' and hypervigilant as not to 'give the self away' (51). Individuals felt to blame for cognitive difficulties (79, 7).

Exclusion and control A second social explanation for distress was 'feeling excluded by others and society' (39, p. 690): 'I feel to be an outsider' (23, p. 715). Individuals described not feeling like a person, 'no longer a participant in the world' (23, 104), feeling disregarded (102), invisible (39), 'I sit here like a parcel' (104, p. 8), not existing anymore (98). Explanations offered included isolation and loneliness because of not being spoken to (23, 104, 36, 50, 58), not being consulted, informed or understood by others (23, 36, 50, 39, 71, 17, 51, 93, 52): 'not having a voice' (52, p. 546). One example of being misunderstood was of being 'silent mourners', whereby others did not acknowledge the grief being felt (93, p. 171). In a care setting, distress was caused by exclusion, whereby individuals felt that 'tasks or procedures' meant staff and patients shared different spaces and that patients came second (36 p. 4, 29). A sense of persecution was described twice (81, 78). Being physically excluded was also described: in a care setting, an individual was prevented from entering a room and was escorted away (36).

Being confined was distressing, described as others adhering to rules, not being allowed to go out, having a nanny, being told what to do, being thwarted (23, 45, 89, 101, 102, 71, 43, 2, 67, 30, 29, 26, 94), by both professional staff and family members. Being physically confined was distressing, by restraints (53, 36) or by physical restrictions in the environment (71). Being given slippers to wear was described as 'a deeply sinister move to keep her from going home' (8, p. 84). Being unable to drive was described as distressing in five studies (89, 101, 2, 67, 98), 'All my enjoyment they took it away from me… everything I try or want to do' (89, p. 22). 'I don't mind dying but I don't want to be… coddled here' (23, p. 717); 'it is a hell of a life' (45, p. 1400), 'the lack of life', (23, p. 717). Being confined restricted relationships with family (89). Individuals were distressed by anticipating being confined within a care setting (39).

A specific example of social control was given whereby diagnosis was withheld from the individual, when the individual could not make sense of the changes they were experiencing (89, 90).

Being socially excluded, or devalued, was also described as the poor care available to individuals, due to funding and training not being of a high enough standard (13).

Burden Aside from experiencing or expecting negative judgment because of changes in behaviour due to dementia, fearing being a burden to others because of dementia was given as an explanation for distress (115, 21, 22, 101, 102, 39, 120, 87, 95, 51, 52). The impact of the dementia on others - misery and devastation (88) - and the need for others to then receive their own support was discussed (106, 95, 66), as was the potential for loss of love between individuals because of the support they required, given through obligation or commitment (106). Individuals were concerned at burdening their

children (115, 101, 102, 71) and spouse (22, 120, 87). They were concerned about money that would be needed to provide their future care (101, 102). It was stated that individuals therefore suppressed their own wishes, needs and emotions (115, 22) and did more for themselves (39). One explanation for distress offered was that being 'dependent on others' generosity' was different from the sense of being otherwise 'decent' and 'morally responsible' (85).

Loss of relationships

Within this concept, distress was described predominantly as being caused by being lonely, alone, by yourself, away from meaningful others (115, 23, 104, 45, 27, 79, 11, 1, 29); meaningful others included formal caregivers (15, 36, 14, 1), family (69, 23, 73, 8, 5, 27, 105, 39,79, 31, 46, 119, 93, 56, 52, 107, 94), friends and neighbours (5, 27, 44), and religious comfort (30). Individuals experienced an absence of meaningful relationships in their lives, an absence of connection with meaningful others and an absence of feeling needed (8) and rewarded (39) by relationships. The loss of relationships was qualified by descriptors of being all the time (115), a permanent separation (73), having nobody at all in the world (23, 104), never to be found again and a blackness of spirit (30) a violent shattering of the internal world, completely abandoned (29), ceasing to exist in the minds of family (81), alone so much, utterly alone (75, 76).

Beyond being alone, further explanations of distress offered included being forgotten, deserted, abandoned, left behind and betrayed (5, 81, 29, 39. 75, 76, 31, 1, 121, 110), like an 'orphan child' (30). Individuals felt deserted by family, friends and neighbours, professional staff and religious faith. On one occasion being 'deserted' was at the time of admission to respite care (31), once when a therapist suddenly went on leave (1).

Physical aloneness was described as causing distress and included the moment of parting from family (69) and professional staff (14, 1), envy at staff or family spending time with others (14), not seeing family due to them making infrequent contact (23, 27, 8, 79, 39), not hearing or seeing anybody else (104), family being out of sight (27, 1, 31), or a person being unreachable, not reacting or inaccessible (75, 76). The loss of family through death was the most frequently discussed physical separation from others (8, 39, 75, 76, 46, 119, 93, 56, 65, 107, 94), with the loss of a husband being mentioned the most (8, 39, 46, 107). Other descriptions of physical aloneness included the presence of strangers (94), strange, new and unfamiliar environments and being away from home (105, 31, 81, 60), night time (79, 30) and waking up alone (121) and a dwindled circle of friends, 'leprosy syndrome' (44, p. 1359). Strangers were said not to know or understand the individual (106). The complexity of navigating beyond the home- 'like going on a voyage to another country' (5, p. 229), mobility, speech and hearing difficulties (79) contributed to individuals being physically alone.

However, as well as physical aloneness, a 'sense of' aloneness was described to cause distress: the worst sense of aloneness was described because of needing assurance that others would stand by them through upcoming battles (40, 30), through contact with professionals (13) and in death (29). On study described distress as being caused by

others not being understanding or sensitive (64). The absence and expected future absence of emotional support caused distress (40), which included fearing the loss of others in the future due to illness (119). This was despite being physically surrounded by others (45, 62, 121).

Cognitive difficulties were sometimes given as reason for seeming to be without relationships, including difficulties with memory, communication and understanding. Memory: 'eroded' connections with others (73), not recalling visits (5, 79), not making new impressions of interactions with others (75, 76) and being without comforting memories including religious verses and prayer (30) were explanations given. One explanation of sensed aloneness offered was of interpreting that others had died or that social networks had been lost (100). Another explanation offered was of an inner feeling of isolation, loss carried about, because of losing memories of family members, forgetting their names (97). Understanding: not being able to make sense of the current situation included being unable to resolve a bereavement (73), being unable to understand who had died, an 'unknown death' (46, 65), trying to find home and not understanding the temporary nature of a day centre (60), questioning whether a husband ever loved them because of his prolonged absence (107). Not understanding the loss of a person was substituted for the loss of an object in one example, a 'metaphone' or a metaphorical substitution, whereby the individual became distressed about their belongings (46). Communication: being unable to contribute to conversation and express feelings (79) contributed to sensed aloneness, causing distress.

Dependence Being dependent on others (106) and no longer in control was interpreted as 'having nothing left' (15), falling into a black hole (29), helplessness (47), blind trust upon a caregiver (68), the self being threatened (72). Physical dependency and being without words to communicate were described (8, 70, 78, 108). The onset of dementia was described as threatening due to a fear of re-entering or returning to the early environment of an infant (37, 29, 110, 70), a child with an absent mother or a caregiver unable to understand the individual's emotions, and being without the cognitive abilities to find comfort (68): 'a terrified, disorganized, and uncontained infant' (29, p. 233). Distress was caused by needing others who might not be available; this could be felt in 'all or nothing' terms such that the carer seems absolutely absent (29, 110, 70, 108).

Future

Diagnosis Receiving a diagnosis in itself (48, 5, 89, 118, 77, 120, 68, 29, 70, 24) and the process of receiving a diagnosis of dementia (118, 5, 18, 17, 40, 106, 68) were both described as causes for distress for the individual with dementia, discussed in 15 studies. An immediate response was described at the point of diagnosis, which included feeling shock, feeling unreal, in a vacuum and in suspense (48, 5, 89). At this time, individuals described not knowing what to do and not being able to function or understand the information being given (48, 118, 89). Disbelief was expressed (48, 12). The 'label' of Alzheimer's Disease in particular was mentioned in three studies as

causing distress (5, 17, 106), once likened to 'a curse' (17) and once likened to 'purgatory' (106).

In addition to having received a dementia diagnosis, the process of receiving the diagnosis was described as distressing; in particular, a lengthy process of diagnosis (118) and the duration of not knowing (17, 106) were distressing, as well as particulars of what was said (118, 5), attendance at a memory clinic and the testing procedures (17, 40, 68): 'I was wondering what the hell are they going to do with me' (18, p. 181).

The future Expectations of the future generally caused distress. Most frequently, distress was explained by individuals contemplating a future that was both unknown and dreaded, as featured in 23 studies. For some, the diagnosis of dementia was interpreted as confirmation of a 'dreadful', 'obliterating' future (29, p. 309-310). 'Nightmares about the future' (48, p 721). Hopelessness was mentioned in five studies (27, 17, 100, 26, 92). Individuals anticipated general losses in their future or the loss of their future as a whole (5, 89, 17, 34): 'I thought that was the end of my life' (89, p. 15), 'life is over' (27, p.), 'it felt as if my life had been thrown away! … hanging onto a high cliff, above a lurking black hole' (17, p. 98-105). In three studies, fearful anticipation of the future was influenced by witnessing the experiences of dementia for others (20, 89, 83) and in one study influenced by the information provided about dementia in multiple outlets (20).

Secondary to the anticipation of an unknown and dreaded future, distress was caused by anticipating 'losing control of the mind' (39, p. 685), described within 13 studies. Descriptions used for losing control of the mind included 'going 'gaga', 'mad', 'barmy' or 'vegetable', (21, p. 1023, 40, 51, 52), 'a loony is somebody you put in… an asylum' (42, p. 120, 51). Individuals feared difficulties with their memory in the future (21), specifically not knowing where they are (84, 89) and losing things (101, 102). Also, anticipation of not understanding changes within themselves (89), losing reason (39) and losing control over their life (101, 102, 39) were distressing to some. 'I think the whole class of problems that Alzheimer's disease belongs to are the most frightening name you could find in the language' (42, p. 120). Other anticipated losses due to dementia included anticipating a wheelchair or loss of physical capabilities (48, 44), anticipating living indefinitely in a care facility (2) and forgetting loved ones (6).

Death Within 11 studies, distress was explained by individuals looking towards and anticipating death, a nightmare, interpreted as 'a fear of approaching death' (8, p. 89). The waiting for a known death was specifically described (61, 74). In three examples offered, distress was influenced by observing the death of somebody else (5, 82), knowing the prognosis for Alzheimer's Disease (86) or an awareness of time passing because of a clock on the wall (7). One individual spoke of 'longing to go home to God. 'There I can rest' (121, p. 13).

Physical environment

Distress was explained by individuals misunderstanding their environment and situations they found themselves in (59, 15, 47, 106, 100, 119, 12, 33). This included not

understanding or being affronted by the behaviour of others within a care setting (59, 23, 8, 5, 35, 14). Activities, sounds and the movement and talking of other people could be over-stimulating (23, 14, 30, 100). It also included feeling trapped within their own home due to being unable to travel to other places (106). Not understanding the external world as a whole, whereby 'everything' seemed 'cognitive' and 'fast' (15, 50, 67, 119), poorly lit (67, 30) or too loud (100) caused distress. Individuals felt suspicious (47) and feared what might happen to them, including getting lost (19, 39, 67, 54, 87). Some individuals feared theft (23, 113) or being intruded upon or hit by others (8, 35) within an inpatient setting. 'Dis-ease' was described and a sense of feeling frightened without a known reason but an overall sense of things being wrong (5, p. 226, 29, 34).

Perception

Remembered and re-experienced distress from earlier times in an individual's life was described in 11 studies; examples from the past were violence that was experienced in childhood (8), unresolved loss (43, 47, 76, 38), unexpressed emotions (38, 1, 100), family disputes (114), extra-marital affairs (114), burglary or assault (114, 54), being dismissed from work (76), financial worries (76) or a life-threatening experience described as trauma (109). The circumstances were perceived 'as still existing in the moment' (114, p. 42). The re-experiencing was explained by impaired cognitive abilities (43) and 'los[ing] bearing on present reality' (76, p. 122). It was also explained by vulnerabilities to unhappiness or depression (43, 41) or anxiety (47, 100) due to the individuals' personality. Additionally, re-living was explained by aspects of the current situation mirroring past experiences, such as being dependent on care by others, being physically restricted or being away from safety (8, 54, 76, 25).

Eight studies gave hallucinations or frightening perception as the explanation for distress for the individual with dementia. Hallucinations were described of 'being pursued by malevolent aggressors' (43, p. 243), being shot in the chest (16), 'a tiger with bared fangs, waking into sleep, never ending land' (30) and screaming (121). Twice, hallucinations were mentioned without further description (17, 100). At the time of hallucinating, one individual described 'all the adrenaline rush, perspiration, rapid breathing, and heart pounding of a real situation' (30). One author described 'false perception' of children or airplanes, 'to organise an otherwise incomprehensible environment' (119, p. 44-45). One individual described their perceptual experience as distressing: 'the floor suddenly heaved and swayed… the ground swirled' (40).

Appendix 6. Freelisting. Participant information sheet



Participant Information Sheet

(Final version 1.0: 21.07.2017)

IRAS Project ID: 195538

Title of Study: Dementia and emotional distress in hospital: skilled interactions by hospital care staff.

Name of Researcher(s): Dr Stephanie Petty. Supervisors: Prof Tom Dening; Prof Amanda Griffiths; Dr Donna Maria Coleston.

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

The research question is: how can hospital care staff notice, understand and meet the emotional needs of individuals with dementia?

Hospitals can be strange and challenging places for people to be, because of their systems, workplace demands and the complexity of problems that patients have. We know that people with dementia are particularly vulnerable when in hospital because of their physical health, because of how suitable the environment is and because they might not be able to express their needs or comply with treatment. Individuals with dementia rely upon hospital staff to maintain their wellbeing.

Until recently, times when individuals with dementia feel emotional distress have been poorly understood and have featured in very little research. Few researchers have wondered whether people with dementia are emotionally upset sometimes when in hospital. To our knowledge, there has been no research into what hospital staff notice and think, and all the ways they attempt to meet the emotional needs of somebody who has dementia. We know that good practice happens in hospitals, but this is not often captured or shared. The skills demonstrated by hospital staff vary widely and we don't know what helps and what doesn't.

The purpose of the study is to learn more about what hospital staff who work with people with dementia say about: whether it is possible to notice times of emotional distress for people with dementia, what staff think are the causes for people being distressed, and what staff are able to do. We hope to use the findings to inform future dementia care.

Why have I been invited?

You have been invited to take part because you work alongside people with dementia in your current professional role and you contribute to the ward culture. A range of staff who work at York Hospital will be invited to participate in the study. This includes a range of different healthcare and non-healthcare professionals who might be able to give helpful answers to the study questions. We are inviting 40-60 participants like you to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your working role at York Hospital.

What will happen to me if I take part?

One of the researchers (Stephanie) will come to your workplace at York Hospital and meet with you at a time that suits you. This can be during your working hours, most likely at quieter times of the day. You will meet together for 15 minutes and you will be asked four questions about your working with people with dementia, as well as some brief information about your working role. The researcher will write down your answers and will also make a recording of the interview using an audio recorder like a Dictaphone. The recording will not capture your name and after the interview the recording will be transcribed into written notes and made anonymous. You will not need to meet with the researcher again. The things you say will be analysed together with what other hospital staff say about working with individuals with dementia when in hospital.

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you can change your mind and withdraw at any time before or during the interview without giving a reason.

Expenses and payments

Participants will not be paid to participate in the study. The researcher will meet with you at your workplace so hopefully you already have transport.

What are the possible disadvantages and risks of taking part?

There are no anticipated disadvantages or risks of taking part in this study. None of the questions are intended to be difficult to answer, but they might cause you think about some difficult or emotive aspects of your job role, or your personal experiences. The researcher is a Clinical Psychologist and is experienced in discussing sensitive topics. Remember that you do not have to answer any questions that you do not wish to and you can end the interview or leave at any time and without having to give a reason. The interview will take place within your workplace so your usual means of receiving support will be available. The ward manager is aware of this research study taking place.

What are the possible benefits of taking part?

We cannot promise the study will help you directly but the information we get from your participation might help us to better understand the day-to-day experiences of people with dementia when in hospital. What you and your colleagues say might contribute to others understanding what the best care for people with dementia when in hospital might look like. This means asking you and your colleagues what your views are, which you might enjoy. We hope to reach an understanding of dementia care that is relevant for hospital wards and we intend to inform future good practice for this patient group.

What happens when the research study stops?

After the one-off interview, the study is complete and you do not need to be contacted again unless you would like to receive a summary of the findings or information about similar studies. You can provide your contact details on the consent form if you would like to be contacted again.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the FMHS Research Ethics Committee Administrator, c/o The University of Nottingham, Faculty PVC Office, B Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk. Please quote FMHS REC ref no: 143-1709.

Will my taking part in the study be kept confidential?

All information that is collected from you during the course of the research will be kept strictly confidential, will be password protected when saved electronically and will be stored in a secure office if a paper record. If your interview data is used in any write up of the study it will not include any personal information that could identify you. The only record of your name (and address if you choose to give this) will be on the consent form that you complete.

Your information will be kept securely for seven years according to the University of Nottingham's Code of Research Conduct and Research Ethics. After this time the data will be disposed of securely. During this time precautions will be taken by all those involved to maintain your confidentiality.

This anonymized interview data may be looked at by authorised persons from the University of Nottingham who are organising the research. The data may also be looked at by authorised people to check that the study is being carried out correctly or to analyse the data for future projects. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty. We will follow ethical and legal practice and all information about you will be handled in confidence.

Although what you say in the interview is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason and without your working role at York Hospital being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?

This study will be part of Stephanie Petty's PhD research project and therefore some of the study findings will be written up as part of this publication. The findings may also be published in academic journals, blogs or presented at academic conferences. A summary of the findings will be made available to you if you request this. Remember that you will not be identified in any report or publication.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded as part of a PhD by The Retreat, York.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, if this is required, or by the R&D department to protect your interests. This study has been reviewed and given favourable opinion by York Hospital R&D.

Further information and contact details

Researcher: Dr Stehphanie Petty Email: msxsp9@nottingham.ac.uk

Chief Investigator: Professor Tom Dening Email: tom.dening@nottingham.ac.uk

Division of Psychiatry and Applied Psychology, Institute of Mental Health, University of Nottingham, Triumph Road, Nottingham, NG7 2TU. Phone: 0115 7484230.

Appendix 7. Freelisting. Interview schedule

All participants will be read the following introductory statement:

Thank you for agreeing to take part in this short interview. As the information sheet explained, I want to ask you about some of your experiences of working with people who have dementia. I wanted to meet with you because I think you have a viewpoint that other people don't have, and only you can explain what it is like working in this setting. There aren't any right answers, or any that I know of, which is why I am excited to ask you. I am going to ask you for four different lists.

I will be listening and trying to jot down what you say. But because I would rather pay attention to you, I would like to make an audio-recording of this interview so that I don't miss what you say, and have a back-up. When I write up the interview I will take out any information that could identify you, such as your name. Can I have your permission to record this interview?

All participants will be asked to respond to the following statements:

In your work with people with dementia, can you come up with a list for:

- *How you notice when somebody is emotionally distressed? So, all of the ways it shows?*

In your work with people with dementia, can you list:

- *What you think causes them to be emotionally distressed?*

In your work with people with dementia, can you list:

- *All the ways you respond when they are emotionally distressed? What do you try?*

- *Of these, can you list the things that seem to work?*

A bit about you

If it is okay with you, just before we finish I will ask you some brief questions about yourself.

- *Do you have personal experiences of dementia, such as people you know personally or in your family?*
- *May I ask your job title?*

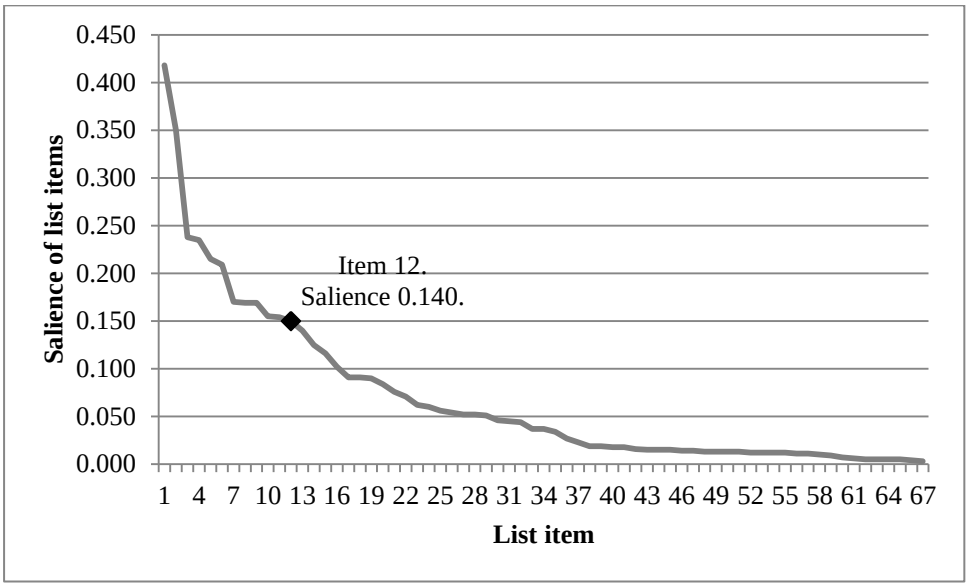
- *Roughly, how many years have you worked here?*
- *Have you worked with people with dementia in other places?*
- *Can you tell me about any training or education you have received in working with people with dementia?*
- *Was it any good?*
- *If you are happy to, can you tick an answer to these three questions*

Appendix 8. Freelisting. A brief excerpt from the code book of all unique list items generated from the freelisting interviews

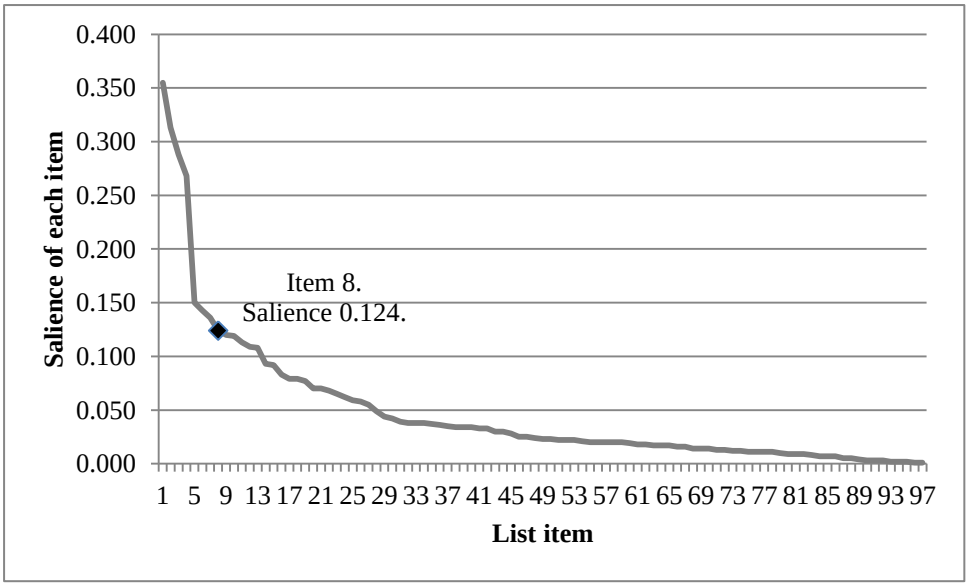
Code	Code explanation	Code content	Code summary
REA	Reassurance	'reassure', 'reassurance', 'reassure everything is fine'	Giving reassurance generally was listed without further description.
SIT	Sitting with, being with	'sit down', 'keep company', 'little bit of time', 'be with them in their distress'	Sitting with or being with included descriptions of being with the person in their distress and offering company.
TAL	Talking	'talk it through', 'talk to them about it', 'conversation, stories, chat', 'talk whilst walking'	Talking; included sharing conversation and stories; included talking whilst walking.

Appendix 9. Freelisting. Scree curve plots showing the number of listed items with the highest salience for each of the four freelisting tasks.

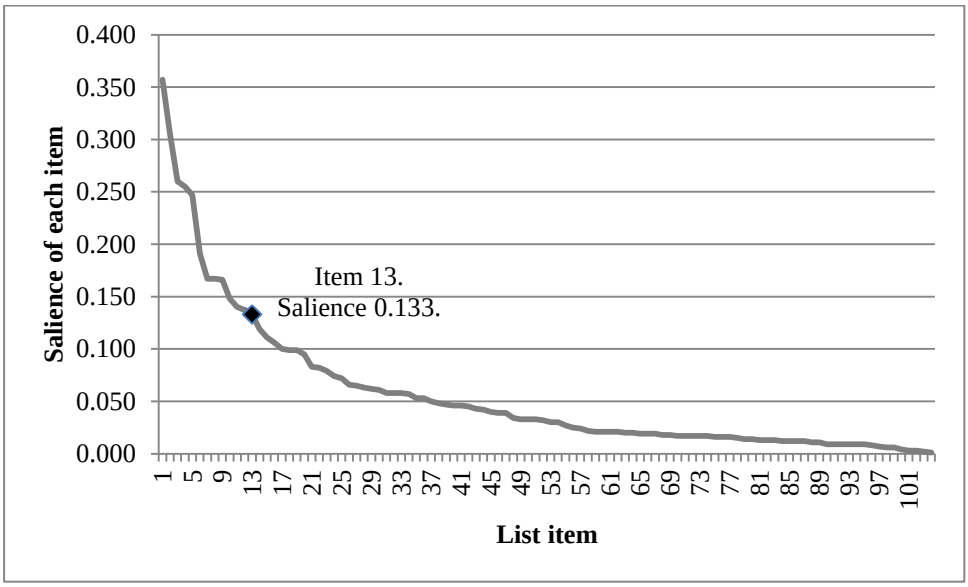
Interview question (1) how to notice emotional distress



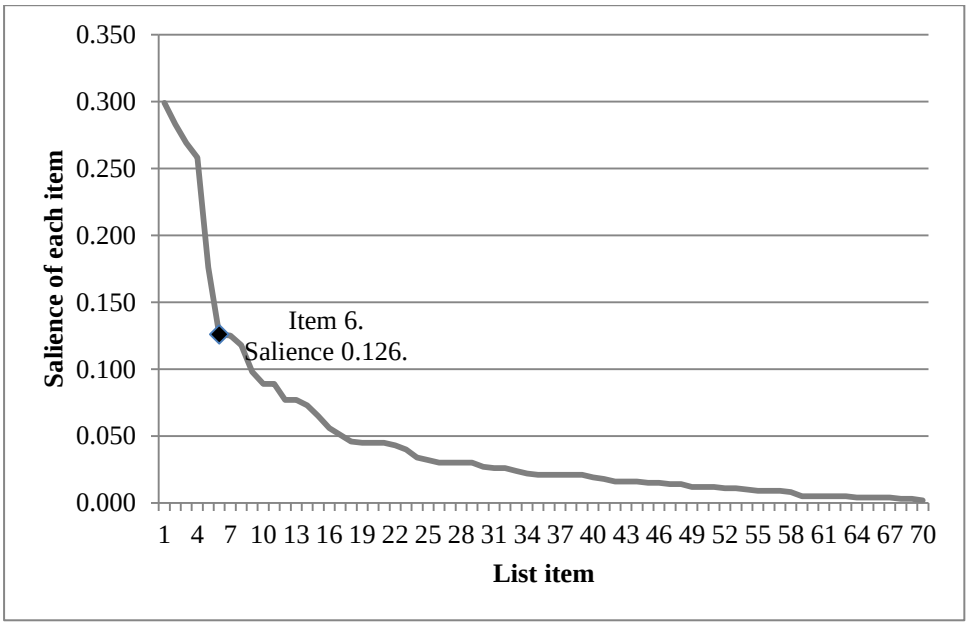
Interview question (2) causes of emotional distress



Interview question (3) responses to emotional distress



Interview question (4) responses to emotional distress that seem to work



Appendix 10. Freelisting. Summary of findings sheet

Summary of findings: Dementia and emotional distress in hospital

Dr Stephanie Petty

For all staff members,

I want to say a huge thank you to all of you who chose to take part in this research study. Now the study is completed, this letter offers a brief summary of the findings.

Brief overview of the study

You may remember that I asked you to tell me about your work with people with dementia and list all of the ways: (1) you notice when somebody is emotionally distressed, (2) what you think causes them to be emotionally distressed, (3) the ways you respond when they are emotionally distressed, and (4) the ways you respond that seem to work. 47 people from Ward […] took part, from all professional groups.

Why is this research important?

Individuals with dementia are particularly vulnerable when in hospital. We know that there can be serious risks to their physical health and to their emotional wellbeing, and hospital staff are expected to understand and respond to emotional distress. However, in the research literature and in professional guidelines, there is little detail about how this can be achieved.

What happened after the study?

Each interview was transcribed into written notes and any personal information about you was taken out. Then the lists of words from all staff members were analysed together. The analysis worked out which answers were given most often and which were mentioned early in a list. It looked at how much agreement there was between staff members.

The results

The commonest responses to the four questions were as follows:

(1) How to notice emotional distress

Agitation
Crying (including weeping or tears)
Moving around more (including wandering, pacing and getting out of bed)
Restlessness
Facial expression
Body language
Aggression
Being withdrawn

(2) The main causes of emotional distress

The unfamiliar hospital environment

Not knowing what is happening (such as not understanding being in hospital)

Being away from loved ones

Pain

Wanting to go home

(3) Possible ways to respond to emotional distress

Reassurance

Talking with

Sitting with or being with

Distraction

Comfort (such as being calming or nurturing)

Asking the person about their needs

A cup of tea

Empathising

(4) Ways to respond to emotional distress that seem to work

Having to know the person

Talking with

Sitting with or being with the person

Reassurance

A cup of tea

Conclusions

- As a whole team, you described person-centred care. This was a skillset that you drew upon in a wide range of situations.
- A major strength of the study was the involvement of all the multi-professional staff on the ward. It therefore values everyone's contributions equally.
- There seem to be some things that work best and these are worth concentrating on.
- The findings provide the detail of achievable practice because they are solutions that have developed from routine practice.

What happens next?

We made recommendations for clinical practice:

- Future training should recognise the existing knowledge and experience of hospital staff. The focus should be on translating this knowledge into everyday practice.
- All professions are equally able to provide emotion-focused care.
- These findings provide brief summaries of care that could be used when hospital staff document a patient's emotional needs.

We also made recommendations for future research:

- Future research should look at whether it is possible to consistently deliver the care that was described; some barriers might include busyness or this work taking an emotional toll. Research should make use of observation studies and should listen to the views of patients.
- The findings support research into the physical hospital environment and campaigns that increase the presence of family in hospitals.

We plan to publish the findings in a research journal.

I will keep in touch with […] and make sure that I forward any publications of the research to her at Ward […] for your interest.

Please get in touch if you want to share any thoughts about the study or the findings.

Thank you again for all of your time.

With the best of wishes,

Stephanie



Dr Stephanie Petty

Clinical Psychologist

spetty@theretreatyork.org.uk

Acknowledgments: Prof Amanda Griffiths, Prof Tom Dening, Dr Donna Maria Coleston-Shields. Division of Psychiatry & Applied Psychology, School of Medicine, University of Nottingham.

The study was approved by the Health Research Authority (18/HRA/0221), the NHS Foundation Trust (RGS 17067) and the University of Nottingham, Faculty of Medicine & Health Sciences Research Ethics Committee (FMHS 143-1709). IRAS Project ID: 195538.

Appendix 11. Semi-structured interviews. Participant information sheet



University of Nottingham
UK | CHINA | MALAYSIA

School of Medicine
University of Nottingham
Medical School
Nottingham
NG7 2UH

PARTICIPANT INFORMATION

STUDENT RESEARCH PROJECT ETHICS REVIEW
Division of Psychiatry & Applied Psychology

Project Title: Descriptions of emotion-focused care for patients with dementia when in hospital

Researcher/Student: Dr. Stephanie Petty (stephanie.petty@nottingham.ac.uk)

Supervisor(s)/Chief Investigator: Prof. Tom Dening (tom.dening@nottingham.ac.uk), with Prof. Amanda Griffiths (amanda.griffiths@nottingham.ac.uk) and Dr. Dons Coleston-Shields (donna.coleston-shields@nottingham.ac.uk)

Ethics Reference Number: 0242

We would like to invite you to take part in a research study about the care provided for people with dementia. Before you begin, we would like you to understand why the research is being done and what it involves for you.

What is the purpose of this study?
We want to ask hospital staff who deliver care for patients with dementia about the facilitators and barriers to providing emotion-focussed care. This is because we know that there is currently little guidance for how hospital staff can understand and respond to the emotional distress of patients with dementia.

Why have I been invited?
You have been invited to take part because you work alongside people with dementia in your current professional role. All nurses and support workers from two hospital units have been invited to take part. We hope to have a total of 12 participants.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You may change your mind about being involved, or decline to answer a particular question. You are free to withdraw at any point before or during the interview without giving a reason. There will be no negative consequences for you if you choose not to take part. The researcher will be acting in this role rather than as a fellow member of staff

What will I be asked to do?

If you choose to take part, the researcher, Stephanie, will meet with you within working hours for about 20 minutes and ask you some questions about your working with people with dementia: for example, about your views about how to provide care that meets a person's emotional needs. Stephanie will make a recording of the interview using an audio recorder like a Dictaphone. The recording will not capture your name and after the interview, the recording will be transcribed into written notes and made anonymous so that you cannot be identified. The things you say will be analysed together with what other staff say about working with people with dementia. After your interview, the study is complete and we don't need to contact you again.

Will the research be of any personal benefit to me?

We cannot promise the study will help you directly, but the information we get from your participation might help us learn more about the care provided for people with dementia in hospital. What you and your colleagues say might contribute to our understanding about what the best care for people with dementia looks like.

Are there any possible disadvantages or risks in taking part?

There are no anticipated disadvantages of taking part in this study. None of the questions are intended to be difficult to answer, but they might cause you to think about aspects of your job role; the interview questions might cause you to recall past experiences that may have been upsetting or challenging for you. You do not have to answer any questions that you do not wish to and you can end the interview at any time and without giving a reason. The interview will take place in your workplace and the unit manager is aware that this study is taking place. In the unlikely event that you find anything you discuss about your work upsetting, you should always access the support and advice available to you from a range of sources including your unit manager, your line manager, your supervisor, your colleagues, and BUPA Employee Assistance (0800 269 616).

What will happen to the information I provide?

The only personal data being collected from you is your name (and your email address if you choose to give this), which will be on the consent form that you complete. This will be stored in a secure office. You may give personal data during your interview that could identify you or others, but you are not asked to do so. The audio recording of the interview will be saved on a password-protected computer.

When a written transcript of the interview is made by the researcher, all personal data will be taken out so that you cannot be identified. If your interview data is used in any write up of the study it will not include anything that could identify you. We would like to be able to quote what you say in our report or a publication. We will make sure that your anonymity is protected. But if you do not wish us to do so, please tell us.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

This study will be part of Stephanie Petty's PhD research project and therefore some of the study findings will be written up as part of this publication. The findings may also be published in academic journals, blogs or presented at academic conferences. You will receive a summary of the study findings if you choose to, which can be

emailed to you or delivered to the staff office of your unit as a paper copy.
Remember that you will not be identified in any report or publication.

We will follow ethical and legal practice and all information will be handled in confidence.
Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx.

At the end of the project, all raw data will be kept securely by the University under the terms of its data protection policy after which it will be disposed of securely. The data will not be kept elsewhere.

If you have any questions or concerns, please don't hesitate to ask. We can be contacted before and after your participation at the email addresses above.

What if there is a problem?
If you have any queries or complaints, please contact the student's supervisor in the first instance. If this does not resolve your query, please write to the Administrator to the Division of Psychiatry & Applied Psychology's Research Ethics Sub-Committee adrian.pantry1@nottingam.ac.uk who will pass your query to the Chair of the Committee.

Appendix 12. Semi-structured interviews. Interview guide

1. Just to start off with: in a couple of sentences, what does your job involve on a daily basis?

2. Can you describe what you think it is like for somebody with dementia to be in hospital?

3. Can you describe some times when it has been possible for you to care for the emotional needs of the person with dementia?

4. What do you think made this possible?

5. Can you tell me about some times when it has not been possible to care for the emotional needs of the person?

6. What do you think the barriers were?

7. From your experience, could you tell me about some of the things that make it possible to care for the person's emotional needs day to day; which might be tricks or strategies that you've found that help, or things that other people do?

8. Could anything help you and your colleagues do it more often?

9. Do you think there's anything important that we haven't talked about?

If it is okay with you, just before we finish I would like to ask you some brief questions about yourself using this form. We need to gather this sort of information when we are doing research studies, and summarise it anonymously.

Job title:

Number of years working with people with dementia:

Gender

□Male

□Female

□Other

□Prefer not to say

Age

□under 25 years

□25 to 34 years

□35 to 44 years

□45 to 54 years

□55 years and above

□Prefer not to say

Ethnic origin

White

□British

□Irish

□Irish traveller

□Any other white background

Asian or Asian British

□Indian

□Pakistani

□Bangladeshi

□Chinese

Any other Asian background

Mixed ethnic group

□White and Black Caribbean

□White and Black African

□White and Asian

□Any other mixed background

Black/African/Caribbean

□Caribbean

□African

□Any other Black background

Other Ethnic Group

□Arab

□Any other Ethnic Group

□Prefer not to say

Appendix 13. Semi-structured interviews. Example interview transcript

Just to start off with: in a couple of sentences, what does your job involve on a daily basis?

Erm looking after people with complex needs erm part of those complex needs are dementia with a lot of people my job involves planning care giving medication supporting junior members of staff implementing care evaluating it and record keeping report writing and a day to day reporting of what's happened during that day handovers for the following shift

Can you describe what you think it's like for somebody with dementia to be in hospital?

I think it'd be really really confusing for somebody to be in hospital with dementia I think that they're probably trying to make sense of where they are who they're with what's going on all around them the sounds the sights and I think it must be very difficult to recognise people and if they do to recognise what role they're in erm I think that they probably do have some kind of recognition some kind of recognition of familiar faces who they see day in and day out and their voices I think that they probably can pick up when a person is being very kind and gentle towards them they can recognise the emotion rather than the person I think but I think it must be so difficult for them to be even in their own home it's difficult with dementia

Can you describe some times when it has been possible for you to care for the emotional needs of the person with dementia?

When it has been?

Yeah

Does that have to be at work?

Within your working role yeah when has it been possible?

Erm well I've been involved with all the ladies that have dementia erm I think that it's it has been possible for me I started off in a support worker role when I was waiting for my pin to come back so I was involved more in the care side than the nursing role and I don't think there's enough time really you properly need that time really ideally where you can sit with them and just hold their hand talk to them and sooth them somehow but I have been involved in the care on a daily basis

What are some of the things that do make it possible?

Erm good staffing levels if you've got enough staff on erm it's been probably more possible over the last couple of weeks when we've had less patients it's been more possible to spend more quality time with those people it's been less busy erm I think the erm routine the general routine is is around getting a job there is more time here than there has been in other places I have worked actually so yeah if you have got lots of time and good staffing levels those are the main things

What else…

And equipment the right kind of equipment and the kind of having their history knowing what they like what they don't like and remembering that and trying to tailor activities towards and their care towards that towards erm to them as an individual

What did you mean by equipment?

Well erm equipment maybe such as sensory stuff erm computer sometimes we play things you know we play music that they might like on the computer or erm the CD player personally I would have used if I'd been more on the activities side I'd have used the little [sensory] room a bit more it doesn't get a lot of use but I like all the sensory stuff it's very soothing erm the scent thing you know with the oil diffuser with nice smells and just having that time to sit look at books or yeah because of course they won't do it by themselves will they'll just [personal anecdote]

How do you think that links in with their emotional wellbeing?

I think that their emotional wellbeing would benefit from that you know you can tell even when people have got dementia you can tell when they are content and satisfied and well cared for and happy can't you

Can you tell me about some times when it has not been possible to care for the person's emotional needs?

Not particularly in this establishment I think that people do try and time constraints short staffing people going off sick using agency staff when they don't know them very well don't know what they like what they don't like erm I can tell you about somewhere else that I have worked without naming any names where their emotional needs were not really met at all and erm it was all just a case of keeping people washed and cleaned and fed and that was the whole focus even though I know that things are in place that say we have to meet emotional needs but I don't think those targets are always met maybe on paper but I don't think it always happens everywhere

What do you think some of the barriers are?

Erm private private care homes seem to always be struggling there's a shortage of nursing there's a shortage of care staff erm again they're using bank nurses and carers who don't really they might never have been there before so and they're probably just trying to get their head around what they're doing and their role and erm meeting their needs and the unit's needs the legal needs what was the question again sorry?

What some of the barriers are?

To meeting their emotional needs?

Yeah

Yeah I think that I think the staff here are well trained but they either they are not well trained or they are not taking it on board in some places and I think the problem is that sometimes you see people and don't because they are not expressing something it doesn't mean that they haven't got a need and I think the barriers are it might be that person's personality you know

they might be they might not be focusing on the other person's emotional needs so they might be short-staffed they might be under pressure they might be erm just be focussing on the people who are who are able to voice what they need and who are like maybe on here that might be people who are being very loud might take all of the attention and you've got to manage a situation and there might be somebody who is sitting quietly with dementia who's who's not really getting much attention because they don't complain so much

You mentioned training and training being good here, where does that training come from, how do you learn?

I think that generally people in my experience people have had a lot of training here in various aspects of the job but you know maybe there are gaps in the emotional side of it yeah

What training do you think people have had?

Well I'm trying to remember because I have spent a long time around people with dementia erm so so maybe a lot of it has come from experience rather than training but I think that I can't I can remember [staff member] doing trying to do some training around dementia but actually I can't remember any training specifically for dementia here apart from the workbook that we did erm and maybe I think they maybe need someone to come in and talk to them about how it might feel when I did my training they actually made us wear a pad and fed us trifle and it was horrendous but and there was glass in mine a piece of glass in it but even just I can imagine when I when I am with a patient I kind of like I can imagine what they're going through but I don't think everybody can and it's different personality types and I don't think everybody is I can almost feel it what they're feeling but I don't think that applies to everyone I think their attention is it's not their fault it's just the different types of personality but yeah maybe they could do with some training I don't know

Is there anything else that you think makes it possible to care for the person's emotional needs day to day; so any strategies anything that you find helps is there anything that your colleagues do?

Erm I think to really try and get to know that person their background their erm family history erm their particularly their likes dislikes erm and I think that to give them time to give them time to just to be with them if they can't you know even if you don't understand them it's and they don't understand you it's nice that if you can just sit and maybe hold their hand or just sit next to them for a bit and erm helping just to know that someone's there with them who cares about them and then try to involve the family if the family want to be involved erm it depends it depends how they've who they have been in their life as to the kind of things that might make them happy once they have got dementia [personal anecdote] but I think it's nice to put music on not too much if they've liked it before put music on do the sensory stuff erm nice things to eat just anything you know just just to stimulate all of the senses

Do you think anything would help you and your colleagues do it more often?

Erm having the time to do it I think that nurses are not encouraged to do that side of things and I have in fact been criticised in one place I worked because I was working as a staff nurse but I spent a lot of time with patients it was actually on psychiatric intensive care and I was spending time doing pottery art work erm playing games with people and outside playing basketball with people who very easily got upset and attacked each other or staff or broke

property and I was asked to not behave like a support worker so which I think is really sad because I came into nursing because I liked to be with patients but you do find that as a nurse your shift is filled up and the care the support workers can't always see that you know they sometimes say well the nurse is not doing anything but just to get the drug round done all the signatures done the notes done there's there's it pretty much takes you through the shift and I always make time to sit and talk or as I'm going past I will say are you alright have a little chat but I think it would be really nice if we if we were all of us doing more activities and I think people like [staff name] you know I think she does a great job I think the activities on here have been amazing you know they do all the little the cakes and cheese and wine and different cultures and well it's great it is.

Is there anything else that you think could help you or your colleagues do it more often?

Erm just when the unit was full maybe like an extra member of staff but yeah

Is there anything that you think is important that I haven't asked or that you wanted to say?

No I don't think so no

[Length: 16:52]

Appendix 14. Semi-structured interviews. Example excerpts of three iterations of the coding scheme used for thematic analysis of interview data

Coding scheme (v1) 04.01.2019

	A	B
1	***Coding scheme (v1) 04/01/2019***	
2	Activities	
3	Adaptating communication	
4	Animals	
5	As respectful	
6	Blame/misattribution	
7	Change in presentation	
8	Child-like	
9	Comfort	
10	Communication	
11	Community	
12	Community events	
13	Conversation with person: asking	
14	Conversation with person: valuing conversation	
15	Different emotions	
16	Different person to person	
17	Different staff relationships	
18	Documentation	
19	Doing everything possible	
20	Dolls	
21	Empathy	
22	Extent of distress	
23	Family input	
24	Fluctuating emotions	
25	Food/drink	
26	Giving space	
27	Having insight	
28	Having the time	
29	Holistic/comprehensive care	
30	Hospital as a barrier	
31	Hospital as a facilitator: environment	

Coding scheme (v2) 25.01.2019

Coding scheme (v2) 25/01/2019			
Codes grouped	Code	Code description	*Code quote*
FACILITATORS	*50 codes*	*Codes in this section are staff descriptions of facilitors to meeting patients' emotional needs*	
INTERPERSONAL FACTORS			
Coming to know patients as a person	Knowing the person	Knowing the patient as a person facilitated staff meeting the emotional needs of patients with dementia	*"often trying to offer some protection to the person that feels so scared that feels lost trying to understand you know a person-centred view really knowing that patient" (P9)*
	Noticing emotion	Knowing the person meant that the emotions communicated by patients could be better understood by staff because of knowing what was usual for a patient and staff being able to tailor communication to the patient	*"generally if they are not you know participating in their usual behaviour so it's it kind of depends on the client and how well we know the client I think that's quite important" (P6)*
	Understanding the reasons for emotions	Knowing the patient as a person meant that the likely reasons for different emotions could be anticipated	*"once you get to know that person you know when they're up or down" (P4)*
	Adaptating communication	Knowing the patient as a person allowed staff to adapt their communication to individual needs; e.g. using gestures or pictures as visual aids	*"if somebody is hard of hearing you could use a whiteboard and write things down that's what we use to use with one of ours erm or you can use pictures or items you know like hand gestures you know like for a cup of tea or do you want something to eat there are various ways of getting around things" (P12)*
	To tailor responses	Aappropriate responses to emotional distress could be appropriately tailored because of having learned important details about the patient's life	*"I think with dementia you've just got to look at how someone's presenting and know like think about the history and their life story and know kind of who the person is" (P2)*
	As respectful	Knowing the person was described as being respectful	*"you've gotta just respect them and get to know them really" (P4)*
	To promote happiness	Knowing the person was a means to promote happiness though understanding patient history and preferences	*"it depends how they've who they have been in their life as to the kind of things that might make them happy once they have got dementia" (P11)*
	Remembering	Knowing the person required staff to remember the personal information of patients	*"I think the important thing in acknowledging people's emotions is remembering who they are and who they've always been and I think that can get lost a little bit" (P1)*

	Investigating	Knowing the person required staff to investigate reasons for their emotions and seeing beyond presenting behaviour	*way… there was obviously something really wrong but it's it's looking it's trying to see past the aggression erm it's trying to work out" (P2)*
Tailoring care	Tailoring, with trial and error	Tailoring care to the patient by gauging when different responses are more or less helpful and by trying one response and then changing the response	*"it's a case of adapting and trying to find out things erm well through trial and error I suppose… trying to work out has this thing happened before are there certain triggers that would upset a person" (P3)*
The care interaction	Relationship	Building a relationship between the patient and staff member	*"the value of building up strong relationships is that people do seem to have some recognition of people and I think that [hospital as disconcerting and scary] eases eases that a little bit" (P1)*
	Empathy	Noticing the emotions of the patient, trying to understand the emotions and feeling the emotions with the patient in order to identify with their experience	*"I suppose you you're almost feeling it with them it's kind of empathy" (P1)*
	One-to-one time	Staff said that they were required to be with, sit with and talk with the patient, one-to-one	*"working one-to-one with somebody you actually get a real experience erm of how it feels to be that person" (P1)*
	Return to the patient	Staff held the patient in mind and they continued to return to check how the patient was	*"I always try and make a point of going back and sitting with them speaking to them and seeing how they are" (P12)*
	Comfort	The relationship with staff was said to provide comfort, reassurance and familiarity	*"sometimes just contact just listening has been sufficient without PRN medication just some comfort" (P9)*
	Reassurance	Reassurance described as talking to the patient to let them know that somebody is there to look after them, to explain staff actions or to tell the patient that they are in a safe place	*"all you can do is reinforce that she is in a safe place and that she is being looked after" (P7)*

Coding scheme (v3) 05.02.2019

Coding scheme 05/02/2019			
Codes grouped	Code	Code description	*Code quote*
1. INTERPERSONAL FACTORS			
1a. Personalising care			
Access to information	Knowing the person	Knowing the patient as a person facilitated staff meeting the emotional needs of patients with dementia	*"often trying to offer some protection to the person that feels so scared that feels lost trying to understand you know a person-centred view really knowing that patient" (P9)*
	Relationship	Building a relationship between the patient and staff member	*"the value of building up strong relationships is that people do seem to have some recognition of people and I think that [hospital as disconcerting and scary] eases eases that a little bit" (P1)*
	Noticing emotion	Knowing the person meant that the emotions communicated by patients could be better understood by staff because of knowing what was usual for a patient and staff being able to tailor communication to the patient	*"generally if they are not you know participating in their usual behaviour so it's it kind of depends on the client and how well we know the client I think that's quite important" (P6)*
	Understanding the reasons for emotions	Knowing the patient as a person meant that the likely reasons for different emotions could be anticipated	*"once you get to know that person you know when they're up or down" (P4)*
	Different person to person	Effective care responses were said to be different for each patient, requiring staff to know the patient as a person	*"everyone's different so they all communicate and show their emotions in different ways so you can't just say right this is a great way cause it might work for one person but it won't work for another" (P12)*
	Information from notes	Written information about a patient's history included file notes and information generated from previous care teams, information brought by the patient such as personal books, and information generated by the current staff team in the format of care plans	*"reading through lots and lots of notes" (P9)*
	Lack of information	A recognised barrier to care delivery was a lack of information about the patient, such as at the point of admission	*"in some respects there are times when it's a bit hit and miss especially if we don't have a great deal of information about them and obviously the more information we have the easier it can be" (P3)*

	Information from families	Family members providing information of patient interests, sources of enjoyment and comfort, and dislikes	*"Usually if they have families or if they have long term friends … I usually try to go off what they say calms them cause they they're usually the ones that obviously know them best" (P5)*
	Extent of distress	Staff said it was difficult to meet the patient's emotional needs when their level of distress became too high; the patient was distraught or distracted by their upset	*"it would just depend on what kind of emotion he was going through at that time because if he was really really tearful you could kind of support him you know you could rub his back and stuff and tell him his wife was coming to see him but on other occasions you just kind of had to erm take a little bit of a step back and let himself get out of it" (P5)*
	Different emotions	Staff said it was difficult to meet the patient's emotional needs when they experienced different strong emotions	*"[patient's name] is very complicated and can be up and down" (P4)*
	Fluctuating emotions	Staff said it was difficult to meet the patient's emotional needs when their emotions changed rapidly	
	Change in presentation	Staff said that the nature of dementia as a progressive illness meant that the presentation of patients changed	*"I know it sounds awful but dementia can change a person a lot and change their preferences" (P5)*
Investigating	Investigating	Knowing the person required staff to investigate reasons for their emotions and seeing beyond presenting behaviour	*"try and understand why they might be acting in a certain way… there was obviously something really wrong but it's it's looking it's trying to see past the aggression erm it's trying to work out" (P2)*
	Blame/misattribution	The behaviour of patients could be misunderstood as the patient 'playing up'	*"sometimes people can't see that the behaviours are due to a diagnosis erm and some people might say oh but they're playing up when actually they are just trying to express something" (P2)*

Appendix 15. Semi-structured interviews. Consolidated Criteria for Reporting Qualitative Research (COREQ)

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	159
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	163
Occupation	3	What was their occupation at the time of the study?	163
Gender	4	Was the researcher male or female?	163
Experience and training	5	What experience or training did the researcher have?	163
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	163
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	307
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	160
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	162
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	158
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	159
Sample size	12	How many participants were in the study?	164
Non-participation	13	How many people refused to participate or dropped out? Reasons?	164
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	159
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	159
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	164
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	310
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	159
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	159
Field notes	20	Were field notes made during and/or after the inter view or focus group?	159
Duration	21	What was the duration of the inter views or focus group?	159
Data saturation	22	Was data saturation discussed?	161
Transcripts returned	23	Were transcripts returned to participants for comment and/or	178

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	159
Description of the coding tree	25	Did authors provide a description of the coding tree?	316
Derivation of themes	26	Were themes identified in advance or derived from the data?	160
Software	27	What software, if applicable, was used to manage the data?	161
Participant checking	28	Did participants provide feedback on the findings?	178
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	171
Data and findings consistent	30	Was there consistency between the data presented and the findings?	171
Clarity of major themes	31	Were major themes clearly presented in the findings?	165
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	166

Appendix 16. Semi-structured interviews. Summary of findings sheet

Summary of findings: Dementia and emotional distress in hospital

Dr Stephanie Petty

Dear [xxx],

Thank you once again for taking part in this research study. Here is a brief summary of my findings.

Brief overview of the study

You may remember that I asked you to tell me about your work with people with dementia and describe: (1) your role in the hospital, (2) times when it has been possible for you to care for the emotional needs of the person with dementia, (3) times when it has not been possible, or barriers, and (4) anything that could help you and your colleagues care for emotional needs more often.

Why is this research important?

Individuals with dementia are particularly vulnerable in hospital. We know that there can be serious risks to their physical health and to their emotional wellbeing, and hospital staff are expected to understand and respond to emotional distress. However, in the research literature and in professional guidelines, there is not much detail about how to achieve this.

What happened after I talked with you?

Each interview was transcribed into written notes and any personal information about you was taken out. All of the things you said that make it possible, or make it difficult, to care for the emotional needs of a person with dementia were pulled together with responses from all the other participants. The analysis looked at common themes to give a summary that reflected what you and your colleagues told me.

The results

You told me that what helps you care for the emotional needs of a person with dementia were:

Maximise existing resources
-accessing existing documents containing personal information provided by the patient and file notes (to show what is usual and how emotional distress might be displayed)
-creating documents from conversations with patients and family in a concise format
-pausing to share the patient's experience

-reassuring patients of their safety and your intention to care for them

-matching non-verbal communication with verbal communication

-documenting what works and does not work for each patient

-promoting values of respectful, humane care by recruiting the right staff, modelling good practice and rewarding it

-using small pockets of time and clever design of routine tasks to be with patients as much as possible

-sharing happiness

-sharing expertise within the team and sharing tasks to use team member strengths

-encouraging family involvement

-using sensory, relational and reminiscence activities, such as animal or doll resources

Invest in:
-therapeutic activities, including community connections
-outside spaces and low-stimulus spaces
-staff retention

Conclusions

- As a staff team, you described person-centred care. You described resources that you and your colleagues already have that you draw upon to care for the emotional wellbeing of people with dementia.
- The study drew upon the skills and knowledge that you already have, as frontline staff. It therefore gives answers that apply to everyday practice.
- There seem to be some things that work best and these are worth concentrating on.
- Things that you mentioned that weren't discussed in previous research include how important it is not to tell patients that everything is OK when it isn't, to keep patients in mind even when away from them, and to make use of different staff members having different patient relationships: a benefit of having staff with various skills and abilities.
- The findings provide achievable solutions because they are solutions that have developed from routine practice.

What happens next?

We have made recommendations for clinical practice and for future research:

- Future training should recognise the existing knowledge and experience of hospital staff. The focus should be on translating this knowledge into everyday practice.
- These findings give a list of actions that can be used immediately.
- Future research should look at what difference these actions make, such as how they affect staff wellbeing and patient wellbeing.
- We plan to publish the findings in a research journal.

Thank you again for your time. With best wishes,

Stephanie

Dr Stephanie Petty, Clinical Psychologist. spetty@theretreatyork.org.uk

Acknowledgments: Prof Amanda Griffiths, Prof Tom Dening, Dr Donna Maria Coleston-Shields, University of Nottingham. The study was approved by the hospital's directors and the University of Nottingham (Division of Psychiatry and Applied Psychology Research Ethics Committee, 0242).

Appendix 17. Document analysis. Standards for Reporting Qualitative Research (SRQR)

No	Topic	Item	Page & Line #
	Title and abstract		
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	181
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2
	Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	182
S4	Purpose or research question	Purpose of the study and specific objectives or questions	185
	Methods		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale[b]	188
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	189
S7	Context	Setting/site and salient contextual factors; rationale[b]	186
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale[b]	186
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	187
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale[b]	186
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	186
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	186
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	186
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale [b]	188
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale[b]	189
	Results/findings		
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	194
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	194

	Discussion		
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field	195
S19	Limitations	Trustworthiness and limitations of findings	198
	Other		
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	198
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	3