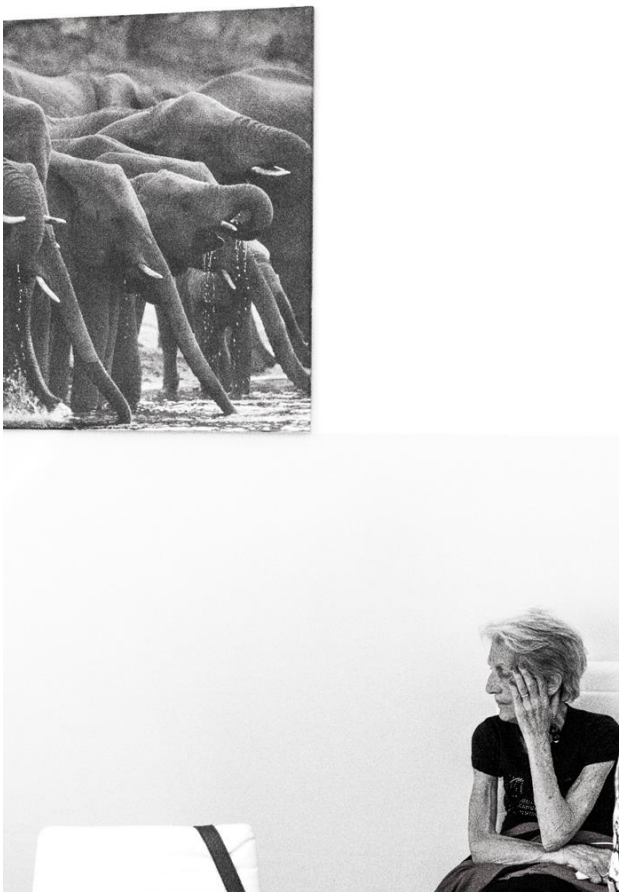
The social understanding of mental health crisis in dementia

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Thesis submitted to the University of Nottingham for the degree of PhD in the School of Medicine

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Dementia: A day in the file. 80x60cm

The performer. *A poem by Alessandro Bosco*

'Every day the same, you wake up and get ready for what life expects you to be.

Better be ready, as life drags you to unexpected experiences: Laugh, smile and deep fear perhaps. Life leaves you with no other choice but to live it.

The performer is there with you every day, and when you do not feel ready to be on stage, you count on him to play the part.

How difficult life is! People all around you seem friendly… lots of words, smiles and laughs, yet you feel the emptiness in their talks. I need you, I need the performer to play the part when I am not able to. He is always there, he wears the mask, reassures me and the show is finally on.

This is life I am told. No matter how difficult it can get, the performer is there for you, the lights are on and the audience is there, yet I am not there, my mind is blank.

People seem to notice, I blush, they laugh, and you are not there. Why do they laugh?

The performer is not there, the mask is left aside, I am exposed, my mind freezes.

You are not there, yet the show goes on, the lights are on and the audience is there. My mind is blank.

Every day the same, I wake up and get ready for what life expects me to be, no matter what laughs I face, I am the performer'.

Abstract

Introduction: Dementia is a neurodegenerative and psychosocial condition, affecting cognition and leading to experiences of crisis that can prove destabilising for the person with dementia and their family carers. In the UK, the Prime Minister's Challenge on Dementia 2020 calls for post diagnosis secondary support for crisis care as key to reduce hospital admissions, care burden and maintain the person with dementia in a familiar environment. Although at community level, crises are managed through multidisciplinary teams, the provision of these teams is not consistent across the care sector, as different teams may have different structure and provide different therapeutic options for resolution of crisis. Research on the experience of crisis care is still limited. For this reason, the study aims to explore (i) the experience of managing crises in dyads, people with dementia and their carers, and (ii) the way the person with dementia is actively involved by teams managing crisis in dementia when delivering professional support. Owing to the variety of experiences and triggers that crises may entail, crises were operationalised in more general terms and according to mechanisms underlying the behavioural process. A Crisis was defined as 'a process in which a stressor(s) causes an imbalance that requires immediate decision to reach a crisis resolution. In the presence of an unresolved crisis, the cycle continues.

Methods: The study employed a two-phase process for knowledge acquisition and generation. The first phase comprised four systematic reviews around the social dimension of dementia: 1) How dementia has been conceived of through history and the power held by the person with dementia to change societal views around the condition, 2) the role of the carer in promoting a positive care environment and ways in which decisional power in the person with dementia is fostered, 3) the key factors determining the degree of involvement of the people with dementia in their own care, and 4) how the members of the dyad construct their own experience of crisis in dementia. These first lines of inquiry informed the interview topics for the empirical phase of the study exploring the experiences of crisis and decisional power. Longitudinal qualitative interviews were held with dyads living in the community, to explore how they coped with episodes of crises and their overall experience of receiving care from multidisciplinary teams managing crisis in dementia. Two co-researchers with lived experience of dementia were trained in qualitative interviews

and helped deliver the dyadic interviews. Dyadic interviews were first analysed through thematic analysis and then data were further analysed through narrative inquiry to create a storyline across cases. Focus groups were held with staff members of teams managing crisis in dementia and family carers to explore how co-production, defined here as active participation, could be promoted in the delivery of care. Framework analysis was used for focus group interviews. For all interviews, a codebook was created to facilitate data coding. Two raters coded 10% of interviews and inter-rater reliability was measured through Cohen's Kappa (*k*). Disagreement was resolved through consensus.

Results: Findings from the systematic review on the historical construction of dementia pointed to the association of dementia with ageing, to confusing statements about capacity both in older people and in people with dementia, and the consequent assumption that people in old age acquire dementia and lose capacity. The systematic reviews on agency and on the dyadic construction of dementia added to our knowledge of how, in dementia care, the concept of capacity is often conceived of as either present or absent, with no appreciation of degrees of ability. This could lead people with dementia to have their views only partially considered because they appear to be less able to make decisions. The review on personhood and dignity further highlighted the role of 'others', the carer and health professionals, in determining the degree of decisional power exerted by the person with dementia. Problems in the promotion of decisional power were reported during the dyadic interviews. A total of 16 dyadic interviews were conducted with five dyads on mental health crisis. What was found was that the experience of crisis made the member of the dyad feel disoriented about how to best manage the episode, the carer often retained responsibility to make decisions with very few options and little information at hand. This not only increased the perceived level of responsibility of the carer, with possible added care burden, but it also decreased the decisional power exerted by the person with dementia who was regarded as unable to make decisions with respect to managing the crisis episode. Decisional power was often withheld by professionals who had limited knowledge and or experience of the condition. This tended to divest the person with dementia of their right to practise agency. When adequate information was not provided around the role of the teams and best timing to call for help for crisis, there was the consequent risk to delay the call for professional help.

With respected to the interviews around co-production, three focus groups were run with a total of 22 staff members and two focus groups with a total of three family carers. Staff reported that strategies which were deployed included caring for the carer, talking to the person with dementia on a one to one basis if the carer tended to over decide for the person they cared for, and promoting proxy decision making when necessary. Carers reported that acknowledging what the person can and cannot do is key to promoting co-production. If this is not made in accordance with the level of capacity of the person, there is the risk of disempowerment and having their views not adequately considered.

Conclusion: Analysis of mental health crises in dementia was approached from multiple perspectives, using primary and secondary data. With co-production as an aim, these results have implications for service organisation and delivery. People with dementia and their carers need to be fully informed about the overall experience of crises and about the professional support to which they are entitled before a crisis occurs. Staff members need to increase awareness of the 'grey areas' of mental capacity in dementia. Strategies and mechanisms for actively involving people with dementia and carers in health care planning need greater attention and development.

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Disclaimer

The views expressed are those of the authors and not necessarily those of the NHS, the ESRC or the University of Nottingham.

Declaration

No part of this thesis has been submitted in support of an application for another academic degree or qualification neither at the University of Nottingham nor any other academic institutions.

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Glossary

Advance Care Planning: Conversation held between people about future adjustments needed to support the person when the condition progresses to such an extent that decision making is compromised.

Care Quality Commission: A public entity of the Department of Health and Social Care of the United Kingdom, regulating and monitoring performance of health and social care services in England and Wales.

Dyad: Consisting of two parts. Couples can be regarded as dyads.

Mental capacity: Individuals who are able to understand, retain and weight information and make a decision based on this information.

Mental health crisis: An episode in which a stressor(s) creates an imbalance in the person that requires an immediate coping strategy to manage the situation.

Multidisciplinary team: Health care professionals from different backgrounds (e.g. psychiatry, general medicine, pharmacy, occupational therapy, nursing), working as a team and providing specialist services to their clients.

Narrative Inquiry: The study of human experiences to understand the way individuals make meaning in their life through narratives.

NICE The National Institute for Health and Care Excellence is a non-departmental public body of the Department of Health in the UK. It provides guidelines on the use of health technology, best clinical practice, health promotion and guidance for users of care services.

Personhood: The status of being a person entitled to rights, privileges and responsibilities.

Process behaviour synthesis: This is a term used in the systematic review on dyadic construction of dementia (chapter 6), to describe the synthesis of findings from existing literature around the behavioural mechanisms that a couple uses to allocate responsibilities in decision making in dementia care.

SCIE: The Social Care Institute for Excellence is an accredited consultancy acting for the social care and health sectors with the aim to improve the performance of health and social are professionals through training.

Social constructivism: Sociological theory explaining human development as socially situated, within which knowledge is explained as generated by interacting human beings (socially constructed).

List of Abbreviations

ACP Advance Care Planning

ADI Alzheimer's Disease International

AQUEDUCT Achieving Quality and Effectiveness in Dementia care Using Crisis Teams

CI Chief Investigator

CMHN Community Mental Health nurse

CQC Care Quality Commission

ESRC Economic Social Research Council

GCP Good Clinical Practice

IBSS International Bibliography of Social Sciences

ICD-10 International Statistical Classification of Diseases and Related Health Problems 10th - Revision

LPA Lasting Power of Attorney

MCA Mental Capacity Act

MHA Mental Health Act

NHS National Health Service

NIHR National Institute of Health Research

OT Occupational Therapy

PI Principal Investigator

PICO Population, Intervention, Comparison, Outcomes

PPI Patient and Public Involvement

PRISMA Preferred Reporting Items for Systematic Reviews and Meta-Analyses

R&I Research and Innovation

REC Research Ethics Committee

SM Service Manager

TMCD Teams Managing Crisis in Dementia

UNECE United Nations Economic Commission for Europe

WHO World Health Organisation

List of Publications

PhD-related publications

Bosco, A., Schneider, J., Coleston-Shields DM., & Orrell M. Co-producing care for mental health crises: The experience of family carers and staff members of dementia crisis teams. *Sage Open* (Under review).

Bosco, A., Schneider, J., Coleston-Shields DM., & Orrell M. Narrative inquiry on case studies of crisis in dementia. *Quality in Ageing and Older Adults* (Under review).

Bosco, A., Schneider, J., Coleston-Shields, D. M., Higgs, P., & Orrell, M. (2019). The social construction of dementia: Systematic review and metacognitive model of enculturation. *Maturitas, 120,* 12-22.

Bosco, A., Schneider, J., Coleston-Shields, D. M., & Orrell, M. (2019). Dementia care model: Promoting personhood through co-production. *Archives of gerontology and geriatrics, 81,* 59-73.

Bosco, A., Schneider, J., Coleston-Shields, D. M., Jawahar, K., Higgs, P., & Orrell, M. (2018). Agency in dementia care: systematic review and meta-ethnography. *International Psychogeriatrics,* 1-16.

Bosco, A., Schneider, J., Coleston-Shields, D. M., Sousa, L., & Orrell, M. (2018). Dyadic construction of dementia: meta-ethnography and behaviour-process synthesis. *Aging & mental health,* 1-9.

Non PhD-related publications

Di Lorito, C., Bosco, A., Pollock, K., Harwood, R., das Nair, R., Logan, P.,…& Van Der Wardt, V. Validation of the 'PHYT in dementia', a theoretical model promoting physical activity in people with dementia. (In process of submission).

Strydom, A., Bosco, A., Vickerstaff, V., Hunter, R., & Hassiotis, A. Clinical and cost effectiveness of staff training in the delivery of positive behaviour support (PBS) for adults with intellectual disabilities, autism spectrum disorder and challenging behaviour. *BMC Psychiatry* (Under review).

Bosco, A., Jones, K., Blossom, S., Orrell, M., & Oliveira, D. People's opinions about changing their lifestyle for dementia risk reduction: Qualitative content analysis of a national UK survey. *PloS one* (in process of submission).

Di Lorito, C., Bosco, A., Booth, V., Goldberg, S., Harwood, R.H., van der Wardt, V. Adherence to exercise and physical activity interventions in older people with mild cognitive impairment and dementia: A systematic review. *Preventive Medicine* (Under review).

Bosco, A., Paulauskaite, L., Hall, I., Crabtree, J., Soni, S., Biswas, A., ... & Crawford, M. J. (2019). Process evaluation of a randomised controlled trial of PBS-based staff training for challenging behaviour in adults with intellectual disability. *PloS one*, *14*(8), e0221507.

Oliveira, D., Bosco, A., & di Lorito, C. (2019). Is poor health literacy a risk factor for dementia in older adults? Systematic literature review of prospective cohort studies. *Maturitas, 124,* 8-14.

Bosco, A., Schneider, J., & Broome, E. (2019). The social value of the arts for care home residents in England: A Social Return on Investment (SROI) analysis of the Imagine Arts programme. *Maturitas, 124,* 15-24.

Hassiotis, A., Poppe, M., Strydom, A., Vickerstaff, V., Hall, I., Crabtree, J., ... & Biswas, A. (2018). Positive behaviour support training for staff for treating challenging behaviour in people with intellectual disabilities: a cluster RCT. *Health Technology Assessment, 22*(15), 1-110.

Di Lorito, C., Bosco, A., Birt, L., & Hassiotis, A. (2018). Co-research with adults with intellectual disability: A systematic review. *Journal of Applied Research in Intellectual Disabilities, 31*(5), 669-686.

Kouimtsidis, C., Bosco, A., Scior, K., Baio, G., Hunter, R., Pezzoni, V., ... & Hassiotis, A. (2017). A feasibility randomised controlled trial of extended brief intervention for alcohol misuse in adults with mild to moderate intellectual disabilities living in the community; The EBI-LD study. *Trials, 18*(1), 216.

Authors' contributions

Alessandro Bosco (AB) has actively contributed to all phases of study planning, development, analysis, writing and editing of the thesis. In regard to the preliminary phase of the study, AB designed the reviews methodology (i.e. the search strategy, drafted a codebook for co-rating data, conducted the quality appraisal of studies, analysed data, wrote and edited each manuscript and he was responsible for submission of reviews to peer-review journals. In regard to the empirical phase of the study, AB was responsible for obtaining ethical approval from HRA, REC and R&D, deliver site initiation visits at each of the dementia crisis services identified, he was responsible for liaising with research sites during and after recruitment of participants, and for participants' recruitment. He recruited and trained co-researchers with lived experience of dementia in delivering qualitative interviews with vulnerable individuals, and in analysing qualitative data. AB further planned and develop the interview topic guides for both dyadic interviews and focus groups, and he undertook all interviews with participants. AB was also responsible for the dissemination of findings through publications and conferences, and presentation at PPI meetings in the school of medicine (university of Nottingham).

Martin Orrell (MO) and Justine Schneider (JS) acted as primary and secondary supervisors for the PhD and supervised the whole process of review design for the systematic reviews, and the empirical phases of the main project, and edited the manuscripts. Donna Maria Coleston-Shields (DMCS) acted as advisor for the study and checked the accuracy of the methodology for the interviews with participants.

Statement of contribution

During my PhD studies, I was required to attend MSc credit bearing courses (total of 200 credits) and by attending an MSC credit bearing course in foundations in qualitative methods at the University of Nottingham I became familiar with key readings on epistemology and research designs (Bryman, 2008; Denzin & Lincoln, 2011; Lincoln, Lynham, & Guba, 2011) which proved key in providing me with the necessary knowledge on how to contain contradictions in logic (Nasi, 1979) and the potential risk for example, that a specific epistemology (i.e. social constructivism) could be accompanied by an incorrect use of research methods for data collection (e.g. a positivistic method such as quantitative questionnaires).

During my studies, I was required to consider the resources I had at hand, in terms of financials, time and workforce to deliver the qualitative interviews with participants within the allocated timeframe. In this respect, I made sure that within the 3 years of funding available, I applied for and received ethics from the relevant bodies, I recruited and trained the co-researchers with lived experience of dementia for the delivery of the interviews, I explored research capacity with dementia crisis teams operating in Nottinghamshire, I recruited participants through dementia crisis teams, and I delivered the interviews. As part of the studies, I analysed data, I disseminated findings through peer-reviewed journals and through attending international conferences.

Furthermore, I could optimise the time I was allocated to be able to spend three months in secondment at the Mental Health & Policy Unit at the World Health Organisation in Geneva.

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Thank you

Alessandro

Memorandum on the published work

Paper in Thesis (N)	**Title**	**Status on publication**	**Journal or (Target Journal)**	**Chapter and Page in Thesis** (N)
I	The social construction of dementia: A systematic review and metacognitive model of enculturation.	Published in 2018	Maturitas	Chapter 2 (p.39)
II	Agency in dementia care: Systematic review and meta-ethnography	Published in 2019	International Psychogeriatrics	Chapter 3 (p.72)
III	Dementia care model: Promoting personhood through co-production	Published in 2018	Archives of gerontology and geriatrics	Chapter 4 (p.102)
IV	Dyadic construction of dementia: Meta-ethnography and behaviour process synthesis	Published in 2019	Aging & Mental Health	Chapter 5 (p.151)
V	How couples accessing crisis teams choose to cope: Narrative inquiry on case studies of crisis in dementia	Submitted in August 2019 (Under review)	Quality in Ageing and Older Adults	Chapter 6 (p.177)
VI	Co-producing care for mental health crisis in dementia: The experience of carers and staff of dementia crisis teams	Submission in progress	(Sage Open)	Chapter 7 (p.202)

Chapter 1. Introduction on dementia and mental health crisis

1.1 Incidence and prevalence of dementia

An estimated 46.8 million individuals worldwide were living with dementia in 2015. Projections indicate that the prevalence of dementia is expected to rise to 74.7 million in 2030 and 131.5 million in 2050 (ADI, 2015; WHO, 2015). Population ageing is responsible for these increases (WHO, 2012). However, owing to the fact that prevalence is a function of incidence and survival rates of dementia, a change in either of these indicators may lead to a drop in the age-specific prevalence (Prince et al., 2016). A fall in age-specific incidence is deemed possible, for example, due to changes in public health exposure to risk factors for dementia (i.e. cardiovascular conditions) (Prince et al., 2016). Estimated global costs for dementia have increased exponentially from 2010 ($604 billion) to 2015 ($818 billion) of 35.4% (ADI, 2015), with informal care representing the majority of costs associated to dementia (1.09% of the global GDP, 0.65% of GDP when costs associated with informal care are not considered) (ADI, 2015). Costs associated with informal care may be exacerbated in the presence of critical situations requiring immediate resolution but with a great dispersion of energy for the carer (e.g. managing a crisis in dementia may lead the carer to increased levels of care burden) who may require health and social care support.

Dementia is a neurodegenerative syndrome with chronic manifestation of symptoms and characterised by a progressive course leading to a deterioration of cognition that is beyond the cognitive decline found in normal aging (NICE, 2018). Multiple mental functions may be affected by dementia, with deficits predominantly found in cognition (e.g. memory, thinking and orientation, language), and mental health (e.g.

changes in personality, neuropsychological symptoms) (NICE, 2018). The ability of the person to understand the situation, to engage in abstract thought, to learn new tasks and make judgements of an event are also compromised. In the late stages of the condition, the individual experiences a lack of independence in initiating social action and in expressing preferences (NICE, 2018). The most common forms of dementia are: Alzheimer's disease (nearly 60% of new cases in the UK), vascular cognitive impairment (17% of new dementia cases), dementia with Lewy Bodies (10-15% of new cases), frontotemporal dementia (in around 2% of new cases), and mixed dementia, in which more than one dementia form is present (National Institute on Aging, 2017).

Dementia has negative consequences for the quality of life of the individual and can be associated with behavioural psychological symptoms of dementia (BPSD) such as expansive symptoms (e.g. aggression, irritability, night-time disturbances), psychotic symptoms (e.g. delusions), and affective symptoms (e.g. anxiety and depression) (Hessler et al., 2018). Looking after a person with dementia is highly associated with care burden and decreased quality of life in family carers as well (ADI, 2015). Such associations may be exacerbated by the attempt of the carer to maintain a balance in their relationship with the person with dementia, yet failing to do so, because of the difficult environment brought by dementia, they are more likely to experience emotional distress (Molyneaux, Butchard, Simpson, & Murray, 2011). Hence, the wellbeing of the person with dementia and that of their family carers, and the quality of their mutual relationships, are dependent on the degree of severity of the condition (Molyneaux, Butchard, Simpson, & Murray, 2011). The quality of the relationship they had before the diagnosis was made, may mediate the quality of the care process and the perceived care burden (Molyneaux, Butchard, Simpson, & Murray, 2011).

1.2 Degrees of impairment

The International Classification of Diseases (ICD-10) (1990) reports three different degrees of impairment of dementia: mild, moderate, and severe (National Institute on Aging, 2017; WHO, 1992), each denoting a negative impact on the overall experience of dementia that is commensurate to the progression of the condition. Each degree of impairment requires different degrees of care responsibility for those providing care.

In mild impairment, dementia is often difficult to diagnose because of the gradual onset of symptoms, which include becoming unable to recognise familiar places, difficulty keeping the track of time and being increasingly forgetful of events (National Institute on Aging, 2017). The main characteristic is the difficulty in learning new material, these are best described in problems with registering, storing and recalling events or situations (National Institute on Aging, 2017). The symptoms are not so severe as to prevent the person to live independently, although some degree of support may be necessary. In mild impairment, the carer may still be able to support the person with dementia through promoting a certain degree of autonomy in their decision making, and if a diagnosis is made during this mild phase, the dyad may have time to adapt their relationship to the changes posed by dementia (Keady & Nolan, 2003).

In moderate impairment, the symptomatology becomes more debilitating, and a diagnosis of dementia becomes clearer. A variety of symptoms may affect the individual and these most commonly include: being forgetful of familiar names and places, being lost at home, experiencing problems with communication, requiring support for personal care and experiencing behaviour changes (e.g. wandering, aggressive behaviours) which may be accompanied by altered states of personality

(National Institute on Aging, 2017). Symptoms are more severe than in mild dementia, and they may affect independent living (National Institute on Aging, 2017). This may prove challenging for both the carers and the person with dementia and their relationship may be strained by the difficulties experienced in the everyday care, especially if no external professional support is provided. During this phase, the mental capacity of the person with dementia fluctuates and this may lead the carer to feeling disoriented, anxious and overwhelmed by the responsibility of making immediate life decisions with very few options available to them (National Institute on Aging, 2017).

In severe impairment, the person becomes inactive and unable to retain information. The person relies on others for important daily life care (National Institute on Aging, 2017). The symptoms experienced in the middle stage of the condition become serious and mental, cognitive and physical ailments become more evident. The agency of the person becomes altered to such an extent that the carer becomes the proxy for all care decisions (National Institute on Aging, 2017). This phase may represent a period requiring the transfer of the person to a nursing home, and although this may lessen carer's burden, the physical detachment may also lead to early mourning and consequent emotional strains, especially if the decision was exclusively made by the carer (Lord, Livingston, Robertson, & Cooper, 2016).

1.3 The social construction of dementia

Whereas such classification of dementia represents a widely used system for the detection of the condition, it is important to note that for some members of the community (either scientific or general public) it may not represent a just way of targeting effective treatment options and promote recovery in the patients (Timimi, 2014). Some evidence gathered around the effectiveness of diagnostic tools for

psychiatric conditions points at these as promoting factors for stigma and for imposing Western beliefs around mental health disorders in populations with different cultural backgrounds (WHO, 2010). There are alternative interpretations challenging the medical model of dementia which lay on the conceptualisation of dementia as a highly subjective experience, whose progressive symptoms are mediated by the quality of the social environment the person lives in (Cheston & Bender, 1999).

It follows that when the care environment is not nurturing, and people with dementia have little or no autonomy for decision making, they may feel objectified, and experience negative consequences in their overall wellbeing and in their relationship with carers (Kitwood & Bredin, 1992). As family carers provide the daily care, they have a fundamental role in sustaining identity and in promoting independence in the person with dementia (Kitwood, 1995). This further leads the way to the forming of a shared understanding of dementia within the dyad, the person living with the condition and their family carer. This social constructionist view of dementia asserts that the dyad constructs their everyday life experiences and its members each negotiates understanding of the situation, from the everyday life events to acute experiences of problem behaviours.

People with dementia experience critical situations that may be triggered by care burden, underlying physical disability (e.g. immobility, falls), cognitive problems (e.g. memory), mental and behavioural problems (e.g. agitation, depression) associated with the condition (Backhouse, Camino, & Mioshi, 2018; Toot et al., 2013; Gaugler, Kane, & Newcomer, 2007; Knapp et al., 2007; Banerjee et al., 2003). Although behavioural problems (e.g. symptoms of anxiety) tend to be considered manifestations (or consequences) of an underlying triggering factor (e.g. either

physical, mental or cognitive), the behaviour itself may be the cause of ulterior negative experiences in the individual. In addition, the experience of crisis does not necessarily have a behavioural outlet, as it may also be expressed internally (e.g. the person being silent for hours, social isolation) (Backhouse, Camino, & Mioshi, 2018; Goldsmith, 1996).

The way the environment is experienced by the person with dementia may also lead the person to feelings of distress, and this may have negative consequences for their mental wellbeing (Toot et al., 2013). As such, when the person's ability to respond to environmental cues is not adequate to the circumstances, the person may feel disorientated, agitated and experience problem behaviours which in some cases can be aggressive towards the carer (O'Conner et al. 2007; Bond and Corner, 2001). These are situations/triggers that may be responsible for the experience of mental health crises in people with dementia and their carers. The experience of crises may be different for the carer and the person with dementia, as they may hold different meanings around specific life events. However, their overall experience of the event is based on how the dyad socially constructs the situation (i.e. through social interaction).

The impact that dementia has on the whole social system of the individual makes it a social concept, not just a medical one. From this perspective, health care services should focus on the preservation of identity and personhood in both the person with dementia and their carers (Bond and Corner, 2001).

The primary objective of the Person Centred Care (PCC) framework is to uphold the sense of personhood and wellbeing of the individual as dementia progresses (Brooker & Surr, 2005), through positive interaction during the delivery of care,

which includes the enactment of genuine feelings of social contacts, affection, emotions and acceptance. These in turn help the person with dementia to attain a sense of self-respect and pleasure towards life and daily activities (Bradford Dementia Group, 1997).

In contrast to the medical paradigm, whereby the person with the condition risks being labelled with stigmatising designations (e.g. 'demented'), the term personhood has been adopted by the social and health care sectors, along with emphasising the need for preserving dignity and showing respect towards people living with dementia and their carers. In Kitwood's work (1997), personhood is often defined in terms of interconnection and interdependence:

'… a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust.' (Kitwood, 1997)

This definition highlights the need for social relationships, a need that positions the wellbeing of the person with dementia as dependent upon the quality of care received through caregiving (Higgs & Gilleard, 2016). Inadequate care could potentially lead to depersonalisation in the recipient of care. Such negative consequence, defined as 'malignant social psychology' can result from the interplay between negative social interaction and neurological symptoms of dementia (Kitwood, 1997; Kelly, 2007).

Establishing good social interactions is not the only variable promoting personhood, as people with dementia need to be given opportunities to collaborate with local communities and health services and have their human rights of safety and autonomy acknowledged throughout the delivery of care (NICE, 2017). This requires a new

approach of collaboration which is grounded in co-production, defined as promoting active involvement of people with dementia in research, health and social care policy and community life.

1.4 The policy context on dementia crisis care

Owing to the economic and societal pressure posed by dementia on the health and social care sector, countries set guidelines on best practice to complement existing policies around dementia care. From a UK perspective, statutory guidance has informed the current legislation on dementia care, from the time of diagnosis, management of symptoms, advanced care, to palliative care (Care Act 2014; Mental Capacity Act 2005; Health and Social Care Act 2008). In this respect, the Prime Minister's Challenge on Dementia 2020 set strategies at governmental level to promote key changes, with a focus on improving diagnostic screening, providing equal access to services, offering NHS practitioners with dementia training which is commensurate to their role and ensuring that people with dementia are offered meaningful support (Department of Health and Social Care, 2015). The Care Act 2014 further grants carers with the legal rights for support (DoH, 2014).

Although current legislation places people with dementia at the forefront of care, they still experience decreased opportunity for co-producing care. This has been a cause of concern for people with dementia who continue to report lack of dignity in the care they receive, both in acute settings (Royal College of Psychiatrists, 2011) and in community services (Care Quality Commission, 2014). This has also negative implications for the wellbeing of carers providing intensive care.

What seems to further impact on the quality of care delivered, is the lack of dementia-specific training for the health and social care workforce. (Galvin et al.,

2010). However, despite policies target pre-qualifying courses on dementia within health care programs, and professional regulatory bodies (PRBs) require a certain degree of proficiency in delivering specialty care to people with cognitive impairment, dementia is not included among the requirements for accreditation for health and social care professions (Surr, Baillie, Waugh & Brown, 2017). In addition, there is still the need to bridge the gap between the theory and the practice in dementia care (Banerjee et al., 2017). A knowledge gap remains around the provision of multidisciplinary care for people with dementia, and on the direct experience for people with dementia and their carers who receive this type of input.

This type of specialty care is delivered by teams working in secondary community services and who assess and manage the mental and physical symptoms in older people with complex needs, as it is the case in people with dementia experiencing mental health crises (Johri, Beland, & Bergman, 2003; Mounier-Jack, Mayhew, & Mays, 2017).

In the UK, three main elements indicate high quality in multidisciplinary care: effective communication between professionals, effective collaboration between specialist and primary care staff, building trusting relationship between professionals and patient through continuity of care (Shaw, Rosen, & Rumbold, 2011). However, in general the care provided for the management of crises is still fragmented and poorly designed collaboration across services negatively impacts on the experience of care in all the agents involved: people with dementia, carers and staff members of multidisciplinary services (European Commission, 2015; De La Maisonneuve & Martins, 2013). Although there is knowledge about the type of crises experienced by people with dementia and the carers (van der Linde, Dening, Matthews, & Brayne, 2014), research output on the way the experience of crisis is managed within the care

dyad is scant. In this research project I set out the basis for an investigation of the experience of multidisciplinary teams managing crises for people with dementia and their carers, how mental health crises are negotiated within the care dyad, and how and to what extent people with dementia are granted opportunity to co-produce care. The aims and objectives of the study are reported in the methods section.

1.5 Methods

This is a qualitative study exploring the experience of managing crisis in dementia and how to promote co-production in care, intended as the active participation and decisional power of people with dementia in the planning and delivery of care for crisis.

With respect to the term 'crisis', because of the variety of experiences associated with this type of experience, no consensus exists on its meaning (MacNeil et al., 2013). Examples, however, exist around the behaviours associated with crisis episodes such as agitation/aggression, delusions, wandering, dysphoria, and resistance to care (Backhouse, Camino, & Mioshi, 2018). For this reason, I opted for an operational definition that could explain the behavioural mechanism underlying the manifestation of the crisis. As further explained in the relevant chapter on dyadic coping with crisis (Chapter six) I used the definition by MacNeil et al. (2013) according to whom, the crisis entails a process where a stressor(s) causes an imbalance within the dyad that requires an immediate decision to reach a desired outcome, the crisis resolution. The cycle continues, until the crisis is not resolved.

1.5.1 Aims and objectives

In regard to the primary objective, the study aims firstly to explore the meaning making process of mental health crisis for people with dementia and their carers

'dyads' and secondly to explore their subjective experience of the caring process during crisis (i.e. coping mechanisms, quality of care received by teams managing crisis in dementia).

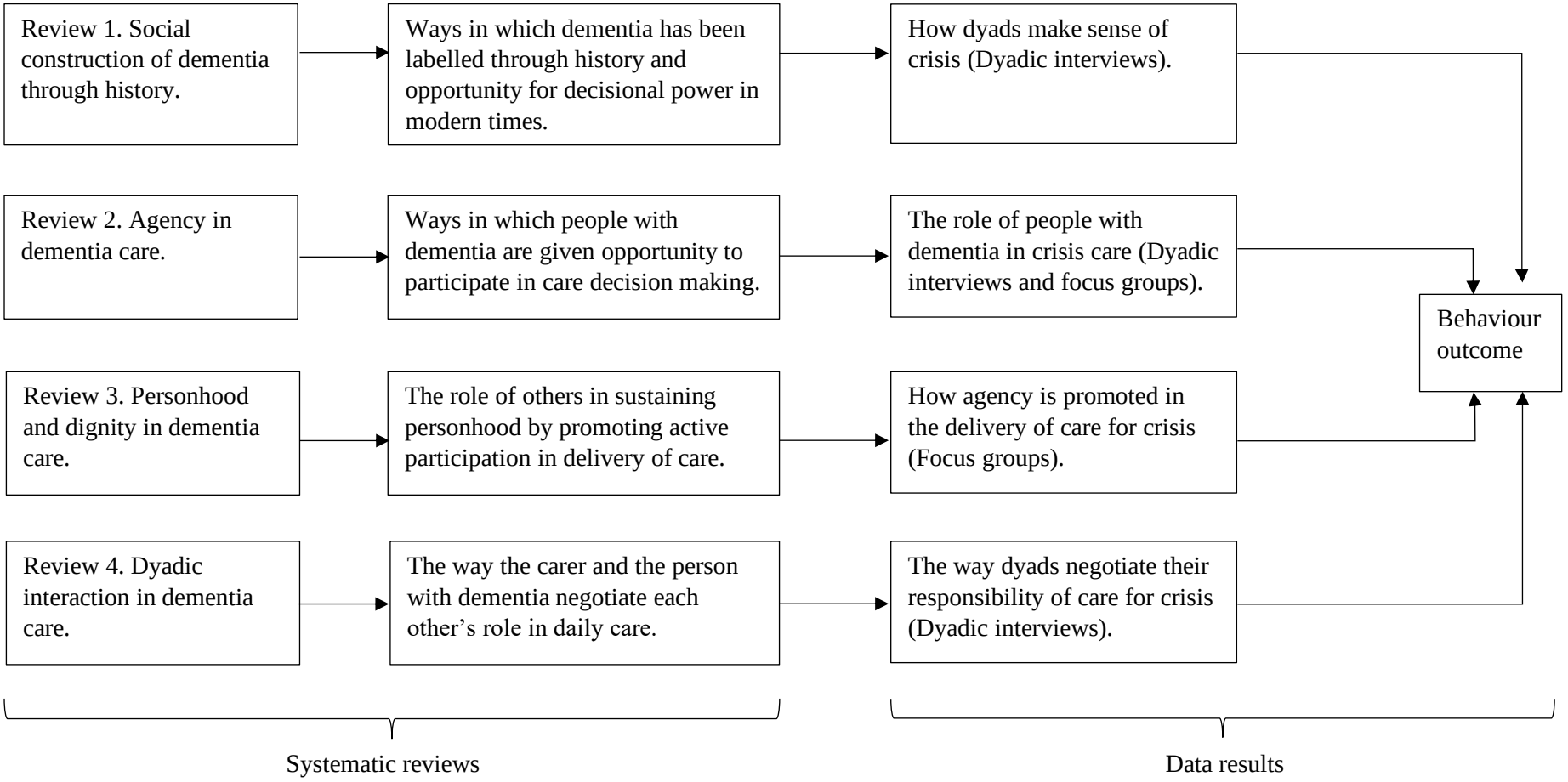
In regard to the secondary objective, the study further aims to explore the process of co-production; how it is undertaken in planning and delivering crisis services.

1.5.2 Two phases: knowledge appraisal and knowledge generation

The thesis has been structured into two main phases: a preliminary phase representing the groundwork and including four systematic reviews; and an empirical phase representing the process of generation of new knowledge and consisting in qualitative interviews with participants with dementia, their family carers and staff of dementia crisis teams (Figure 1.1 for a graphic description of how the reviews informed the empirical phase of the study).

As I was interested in the social understanding of dementia crisis, I undertook systematic reviews that could further my understanding of how the condition has been socially constructed in terms of autonomy, from a broader societal level (macro level) to a narrower dyadic level of construction (micro level). For this reason, four systematic reviews and a discussion paper were conducted as groundwork for the research project. I grounded the definition of macro (intended as the most expansive system the person is enmeshed in such as the society at large), meso (intended as intermediate system such as the organisations the person engages in, such as health care systems) and micro levels of analysis (intended as the most immediate system for the person, such as the family) from the ecological model by Bronfenbrenner (1979). I shall explain each review in detail in their relevant chapter of the thesis.

Figure 1.1. Graphic representation of how the theoretical phase links with the empirical phase of the study.



The first systematic review (chapter 2) aimed to explore, at macro level, how the meaning of dementia has been constructed through history and the power of people with dementia in asserting their views of the condition at the societal level. I was particularly interested in the extent to which discourses on dementia in the media influence the way the condition is perceived of at the societal level, and how in contemporary times, the person with dementia can assert their own autonomy, through social media, and influence development of new discourses on dementia.

The second systematic review (chapter 3), on agency in dementia care, aimed to deeper the analysis, at meso level, of how individuals exert autonomy when required to make decisions for their care, as the condition progresses, and the role of others (e.g. carers) in promoting or limiting their decisional power.

The third systematic review (chapter 4) aimed to explore, at meso level, the existing literature on personhood and dignity and to explore how the care environment has a key role in creating opportunity for decision making as the cognitive impairment advances in dementia and comprised:

1) A scoping review of health care policy documents (with international and national relevance) on how the concept of personhood and dignity were addressed in relation to dementia care.
2) A systematic review and meta-ethnography of qualitative studies looking at how personhood was sustained by carers and or health professionals.

This third review further aimed to create an integrated model to care to give equal positioning to the person with dementia through co-production. This would place the person with dementia as an active member who contributes with the carer in designing their own care rather than acting as passive recipient. The model gave a

contextual dimension to the phenomena investigated and informed the areas of qualitative investigation for the main project.

The fourth review (chapter 5) reported, at micro level, the dyadic relational dimension of dementia caring through a thematic synthesis of the findings. This review aimed to further the understanding over the interactional dynamics between family carers and people with dementia and inform the questions that were used for the qualitative interviews with participants during the dyadic interviews.

The empirical phase comprised two qualitative inquiries into the experience of mental health crisis for people with dementia and their carers and how to promote decisional power in the delivery of care for crisis (chapter 6 for dyadic interviews on the experience of mental health crisis, chapter 8 for focus groups with family carers and dementia crisis teams on how to promote the active involvement of people with dementia in the delivery of care for crisis). I reported in Figure 1.2 the qualitative research plan for the empirical phase of the study.

The first study (chapter 6), took as object of inquiry the dyad and aimed to explore the strategies and types of coping skills employed by the person with dementia and their carer as a whole, and how they called for professional help when most needed, I interviewed participants over the course of one month. This was a very intensive and rich investigation over couple dynamics. The longitudinal interviews with them allowed to also get an understanding of the role of each agent when decision needs to be taken and the way they negotiated their responsibilities for care.

The second study (chapter 7) aimed to explore the way the ‘others’ created a care environment that could promote the active involvement of the person with dementia in making informed and autonomous decisions. I took a slightly different approach

methodologically, as I interviewed family carers and staff members of dementia crisis teams through focus group interviews.

Chapter 8 represents the discussion of the thesis, a synthesis of the findings that was informed by the concept of 'emergence' in social theory by Elder-Vass (2010). The concept of emergence proved effective in graphically describing findings in a way that the resulting line of argument of the thesis is more than the sum of the findings ensuing from each individual chapter. I shall describe this concept in detail in the relevant discussion chapter.

1.5.3 Justification of methodology

To maximise the quality of the study, attention was particularly paid to finding most effective methods for each of the reviews conducted and for the empirical investigations.

1.5.3.1 Methodology used in the systematic reviews

For the systematic reviews based on individual empirical studies, the search strategy was informed by the PICO format (Population, Intervention, Comparison, Outcome) (Sackett, Richardson, Rosenburg, & Haynes, 1997). The format, however, only helped define the population and outcomes of the review, as the reviews did not aim at comparing neither types of interventions nor groups.

With respect to the screening process, this was tailored to the scope of investigation of each systematic review, and to the most related discipline informing the topic of each review (history of medicine, sociology, psychology). In addition, an experienced librarian based at the University of Nottingham helped refine the search strategy in regard to the most appropriate databases to include. For example, The Wellcome Library database was only used for the systematic review on the historical

representation of dementia through history (Chapter 2), as this database proved effective in retrieving historical medical primary and secondary documents for the review. Other databases (PsychNFO, CINAHL, IBSS, EMBASE and MedLine) were instead used contingently to maximise the scope of the search and they were used mainly to cross reference studies reporting historical sources.

The third review around agency in dementia care, was explorative and for this reason, I strategically aimed at targeting as many articles as I could through databases to retrieve studies from different disciplines. I needed to consult databases that could inform my review on how agency was promoted or discouraged during the delivery of care, and I needed studies reporting direct quotations of participants with dementia from disciplines close to social and health care medicine. For this reason, I consulted PsychINFO for psychology studies, CINAHL for nursing and health care-based studies, IBSS for sociological studies on ageing, EMBASE to widely retrieve medical studies. In addition, Medline (Ovid platform) enabled a selective search through the use of Medical Subject Headings (MeSH) terms on ageing and dementia.

The fourth review on personhood in dementia care was also explorative. I was interested in exploring examples of good practice around promoting personhood in dementia, and because personhood is a term used mainly in social and health care settings, I decided to narrow the search to ASSIA for sociological studies, PsychINFO for psychology and EMBASE. This strategy allowed me to cast a wide net to retrieve studies from medicine and allied disciplines.

The fifth review on the dyadic construction of dementia, required a similar strategy that was used also for the review on agency (Chapter 3) and in addition to traditional databases (PshichINFO, CINAHL, EMBASE, MedLine), I included ASSIA. This

proved key in retrieving important social care studies around the experience of dementia caring which would have not been possible if an extensive search had not been performed otherwise.

With respect to data analysis, different methods were used across reviews; choices were informed by the type of data that were used in the single studies selected (e.g. qualitative data vs policy documents) and according to the objectives of the review.

Meta-ethnography by Noblit and Hare's (1988) was consistently used across reviews (Chapter 3, 4, 5) analysing qualitative data (i.e. participants' quotations). This methodology was instrumental to systematically differentiate types of experiences with respect to the object of investigation. Through meta-ethnography I could graphically report the degrees of interpretation from first order accounts (participants' quotation as reported in each single study selected in the reviews), and second order interpretations (the authors' interpretation of the study selected), to a third order interpretation, which was my understanding of the previous two interpretative layers.

Content analysis was instead favoured for the analysis of non-empirical study reporting descriptive textual accounts, such as policy and or historical documents. This type of analysis enabled an easy categorisation of the information into broad themes, with an interpretation defined a priori, as naturally emerging from the text.

There were instances when different reviews required the use of specific methods belonging to the same analytical framework, yet they required a slightly different degree of data interpretation (deductive vs inductive analysis). For example, I used deductive content analysis (Elo & Kyngas, 2008) for the first review on the historical construction of dementia (Chapter 2) as this method provided me with an analytical

framework to categorise deductively the content of historical documents. Conventional inductive content analysis (Graneheim & Lundman 2004) was instead used for the scoping review on policy documents on personhood and dignity in dementia (Chapter 4). Although similarly focussed on textual documents rather than individual empirical studies, this type of scoping review required an inductive approach to content analysis, as different policies used different terminologies to report on personhood and dignity. This type of analysis enabled the categorisation of texts into meaning units and the interpretation of these units that was inductively performed, thus, an analysis that was not determined a priori (Graneheim & Lundman, 2004).

1.5.3.2 Methodology used in empirical studies

Two different qualitative methods for data collection were used according to the object of the investigation, longitudinal dyadic interviews and focus groups.

For this reason, I used longitudinal qualitative interviews with each dementia dyad. In line with Lewis (2007), I opted for longitudinal interviews, as they allowed me to explore the multidimensional nature of change over time. It further enabled the understanding of the mechanisms involved in promoting or discouraging change, as participants retold their stories at later interviews. This qualitative method allowed me to explore how each member of the dyad negotiated each respective role and responsibility to manage the crisis and the role of teams in supporting them over time. Longitudinal interviews were key in building trust in participants nonetheless, as in most cases my external presence required some time during the first interview to promote a safe disclosure of information (Lewis, 2007).

Focus groups were instead used for the qualitative interviews with staff of TMCDs and family carers. This qualitative method for data collection facilitated the process of clarifying certain ideas or beliefs maintained by participants, as a group, rather than as individuals (Stewart & Shamdasani, 2014). I opted for focus groups as I wanted to maintain the resemblance of what would normally occur in staff meetings. I was interested in exploring how a certain course of action designed for patients were informed by group dynamics, and power relationships within the team. The use of prompts helped refocus the discussion on themes that were relevant to the objective of the study. Teams guided the flow and they were given broad topics to reflect on as a group. Focus groups were used for family carers with the aim to create a fertile discussion around crisis management and agency in care by having them reach consensus around the topic. I felt that carers needed a group space to discuss about their own experience and my qualitative study was optimal to promote such sharing of experiences.

With respect to data analysis, I used thematic analysis for dyadic interviews, as through constant comparison (Strauss & Corbin, 1990), I could clarify the relationship between each preliminary code developed and the relevant piece of text in the transcripts; I further analysed dyadic interviews by means of narrative inquiry as this method enabled the development of a story line across cases, according to the longitudinal experience of the crisis.

In regard to the focus groups with TMCDs and carers, I instead opted for framework analysis (Ritchie and Spencer,1994), as its analytical process entails the mapping of each participants' quotations into a matrix. The matrix enabled to reach a clearer understanding of the way each participants' narrative linked with or differed from one another. Data analysis for each qualitative inquiry is further explained in their

respective chapters (chapter 6 for narrative inquiry, Chapter 7 for framework analysis).

1.5.3.3 Systems Theory and cultural transmission theory

I applied ecological system theory by Bronfenbrenner (1979) to explain how people with dementia influence and become influenced by their environment through interaction. The study of different ecological systems was an attempt to understand their everyday life experiences, how for example, their social care environment could promote or discourage their identity, or their sense of autonomy. This theoretical model maintains that every person is enmeshed in a variety of ecological systems, from the micro and intimate system of the home and family, to a larger system of the community centre, to the largest system of society and culture, intended in more general terms. The model is further explained in chapter 4, however, what is important here to highlight, is the function of different types of environments that contribute to the overall quality of life of the person, the role of culture in influencing the degree of interpretation that the person maintains with respect to their interaction with the environment, and how culture helps transfer specific beliefs around the condition over time and across societies. As I further reported in chapter 2, I found helpful to draw from the system theory by Von Bertalanffy (1968) to explain how people with dementia live in an open system where all the different environments, he is enmeshed in, are interconnected. Hence, their experience of care, for example, is the result of the connection of various systems fitting together as a whole. Cultural transmission theory, was further instrumental to describe the concept of dementia as having a cultural base and being socially spread (Martin, 2004).

1.5.4 Theoretical framework

This study explores the dyadic experience of mental health crisis of carers and people with dementia and how this experience impacts on the relational dimension of the dyad. For this reason, I opted for an epistemological investigation based on social constructivism and the qualitative theoretical framework based on interpretivism, influenced by symbolic interactionism. An important distinction has been made with respect to what is social constructivism and how it relates to social constructionism. Whereas both frameworks are often used interchangeably in dementia care research, owing to the fact the both focus on the construction of meaning through interaction with the external world, social constructivism foregrounds the individual in the social interaction, and social constructionism foregrounds the social interaction. In regard to ontology, both approaches are relativist, while in relation to epistemology, they are interactive subjectivist. Furthermore, their differing views seem to coalesce in terms of 'constrained constructivism' in that while it maintains a relativist stance, it points at an active construction of reality that is meaningful for the person and that occurs through the dynamic interaction with the external world (Hayles, 1993).

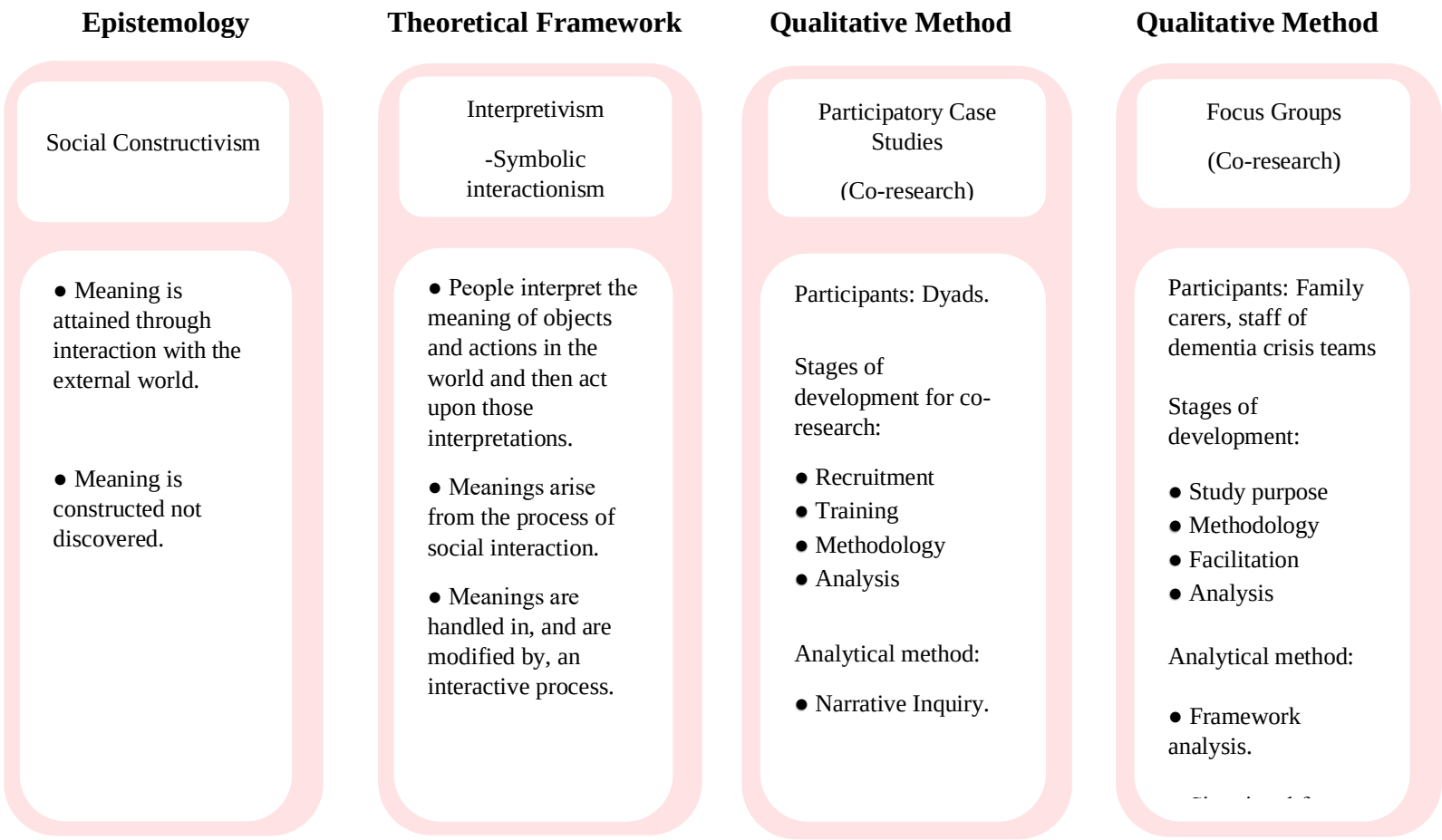
As in this study I am interested in the relational dimension of the dyad, I shall reference both approaches when needed under the term of social constructivism as I retain that it best represents the function of the person situated in the social world.

Owing to the relational stance of the investigation around the dyadic experience of care, I opted to draw also on symbolic interactionism to analyse and interpret the findings for it contends that individuals socialise through shared symbols (e.g. language, actions) (Charon, 2007). According to this approach, during communication with others, individuals convey a series of gestures and symbols that affect recursively the other person's behaviours in a transactional process between

objective and subjective reality (Laing & Esteron, 1964). This approach to reality will be especially helpful in the interpretation of the findings from the focus groups whereby the social discourse is permeated with shared meanings and symbols.

In addition, I used a pragmatic approach to my study. Although the structured process I used in my reviews (e.g. specific databases consulted for the screening of articles, the calculation of inter-rater reliability) may be close to a positivist paradigm, my intention was to bridge the existing need for better quality in research (i.e. clearly report on the research process used to reach any data interpretation) with the need to maintain a relativist paradigm in regard to individual construction of the phenomenon being observed.

Figure 1.2 Empirical phase: Qualitative research plan.



1.5.5 Reflexivity

Reflexivity is systematised and reported by taking into account the temporal dimension of the research project. I kept a weekly journal which was cathartic and it was a personal space where I could write my personal notes around the experience of my PhD journey (a summary is found in Appendix 1). For the process of systematisation, I further followed a series of steps that have been proposed in the literature on reflexive research methodology (Breuer and Roth, 2003) and I reported reflexivity throughout the thesis. These steps are:

1) Report on one's own position with respect to the research hypothesis (e.g. how and why I chose to engage in such research?) with a focus on personal beliefs, values and emotional response to the object of research.

2) Report on one's own position with respect to the methodology used (e.g. How did I structure my knowledge in regard to the methodology chosen for the project?). In this case the focus will be also on the theoretical framework that has been used.

3) Report on one's own positioning in regard to the involvement of participants (e.g. How do I manage gatekeeping? How do the answers given by participants impact on the way of asking questions during the interview?)

4) Report on the strategies used to record the qualitative data (e.g. does my (the researcher's) language/vocabulary influence the answers given by participants?)

5) Report on data analysis and interpretation of findings (e.g. what do I exclude from the analysis, and why?).

6) Report on the perspective used to represent the findings (e.g. What is the audience? What genre influence the writing?).

In regard to the temporal dimension, as mentioned earlier, I made use of diaries and observational notes to report on the experience and personal views around the involvement in the research process (Blaxter, Hughes and Tight, 2001).

1.5.6 Overview and structure of the thesis

This project constitutes part of my four-year doctoral studies at the University of Nottingham. I further completed the 200 master bearing credit points as required by the funder. I am responsible for the overall project, including the writing of the protocol, the ethical applications, the recruitment of participants, data collection and analysis, the writing of the final report and the dissemination of findings.

The Overall length of the study was from 1st January 2018 to 30th September 2020. Sponsorship from the University of Nottingham was received on 22nd December 2017, a validation letter from the Research Ethics Committee (REC) on 3rd January 2018, a REC favourable opinion letter on 27th March 2018 and final HRA approval on 28th March 2018. Final clearance from the R&I office to begin recruitment was obtained in April 2018 (Appendix 2-15).

Chapter 2. The social construction of dementia: A systematic review and metacognitive model of enculturation.

Bosco, A., Schneider, J., Coleston-Shields, D. M., Higgs, P., & Orrell, M. (2018). The social construction of dementia: Systematic review and metacognitive model of enculturation. *Maturitas*. https://doi.org/10.1016/j.maturitas.2018.11.009

The article has been assessed for 4* REF (Research Excellence Framework) Review (Appendix 16).

Abstract

Background. Stigma in dementia may be influenced by how the condition has been socially constructed through history.

Objectives. To conduct a systematic review tracing the historical representations of dementia, through the perspective of cultural transmission theory and social constructivism.

Methods. A systematic search was run on five electronic databases: Wellcome library, PsycINFO, CINAHL, IBSS, and EMBASE. Articles were screened and analysed through deductive content analysis. We further applied a communication system theory to graphically describe how dementia has been experienced through time.

Results. Ten primary sources and 33 secondary sources were consulted. Seven themes emerged from the analysis: A problem of aging, use it or lose it, divine punishment, loss of agency, psychosis and insanity, brain degeneration and objectification, and dementia as a social condition. Each theme corresponds to a particular way of conceptualising dementia and has influenced modern representations of the condition.

Conclusion. Past characterisations of dementia have influenced modern views of the condition. It is through enculturation that these views are interpreted, assimilated, or rejected by individuals and transmitted within and across cultures. A better understanding of the social construction of dementia can improve public health approaches to rehabilitation and care.

2.1 Historical context of the construction of dementia

Dementia is a neurodegenerative syndrome affecting over 47 million individuals worldwide and damaging the individuals' cognition, social functioning, and their ability to engage in everyday tasks (World Health Organisation, 2017). The condition has also an impact on the life of all the agents involved in the process of care (e.g. family, friends) at the physical, psychosocial, and economic levels (World Health Organisation, 2017).

The way individuals perceive of dementia has been influenced by socio-cultural and political contexts throughout history and holds different meanings across cultures (Kane, 2002). Moreover, the social context influences the way individuals have experienced dementia through history also relating to the way the condition is socially constructed in modern societies (Shadlen & Larson, 1999).

The socio and cultural climate of specific historical periods, or 'Zeitgeist', has fostered various perceptions around dementia within society. Previous historical reviews on the concepts of dementia have described how people living with the condition in certain time periods were socially condemned as sinners (Berrios & Porter, 1995), or deserving of a divine punishment due to past sins before the manifestation of symptoms (Feldman, 2007), or were sometimes institutionalised

because retained unfit to exercise their basic human rights as citizens (Boller & Forbes, 1998).

However, cultural transmission theory suggests that these beliefs are learned through social interaction and they are not only specific of their time, but also transmitted through time (Cavalli-Sforza, Feldman, Chen, & Dornbusch, 1982). Unlike the experiential learning process, cultural transmission does not require active participation, as knowledge is passively acquired by simply living in a certain societal milieu (Grusec & Hastings, 2014). This is explained in terms of enculturation, a process through which some beliefs to be shared between generations and consequently through time (Grusec & Hastings, 2014). For example, person-centred care in 1980s sparked from the previous disability rights movement in the USA in the 1970s, which acted against the medicalisation of mental health disorders, in favour of a more socially-accepted interpretation of non-communicable conditions. In turn, the protest in the 1970s against the medical model, was fuelled by previous socio-cultural and political contexts that privileged exclusively the neuropsychiatric examination of mental health disorders (Mental Health Foundation, 2015).

Previous historical analyses of the concepts of dementia have focussed largely on the clinical symptoms and pathology, these were mainly time-bound. Empirical work has been done into the current imagery of dementia intended as conundrum (Lock, 2013), in which the scientific effort to find a cure of the condition does not match with the call for improved quality of care, or pointing at the strong association between negative views on dementia and the poor quality of care received (Beard, 2016). However, no in-depth historical study of the social constructs of dementia at

the societal level has been conducted and no analysis has taken into account the process of enculturation for the forming of modern belief(s) around dementia.

2.1.1 Aims and objective of the review

This review explores changes in societal concepts of dementia reflecting historical milestones, with the aim of improving the understanding of modern social representations of the condition. We aimed to accomplish this by conducting a systematic review tracing the historical representations of dementia, through the perspective of cultural transmission theory and social constructivism.

2.2 Methods

As the scope of our investigation is broad and concerns the history of a health condition, we opted for a systematic review to explore the topic, and undertook deep analysis of the texts identified, in order to map possible key elements, with reference to different points in history. Two theoretical frameworks were used to guide the enquiry and analysis:

- ***Cultural transmission theory.*** Health conditions have historical cultural bases and the concepts are *'socially distributed, culturally administered and culturally functional'* (Martin, 2004). We therefore looked for historical accounts in documents, by retrieving information on the social policies and social conditions. These may be expected to influence the social construction of dementia, as well as to be influenced by it.
- ***Social constructivism.*** According to social constructivism, reality is not a given, nor defined a priori, but rather it is transformed and shaped by socially-interacting individuals. Applied to the experience of dementia, individuals enact their condition and experience it by developing a meaning

for it, which is socially and culturally bound through time and place. We used social constructivism to organise the findings, along with interpreting and synthesising the results of our searches.

Since the relevant literature is not quantitative, we followed the standards of good practice in qualitative research set by Guba (1981) (i.e. credibility, transferability, dependability and confirmability). By doing so, we aimed to reach adequate levels of validity in our findings (Lincoln & Guba, 1985). We also triangulated the information we retrieved against other sources (i.e. secondary historical sources that reported different historical versions compared to those reported in the studies that we included in the review), according to the principle of 'confirming/disconfirming' (Patton, 1990; Patton, 2002).

2.2.1 Data collection

We used purposive searching for the retrieval of empirical studies and historical documents. This approach enables us to consider each study identified as a case and to select only those providing the information most relevant for our enquiry, which could be synthesised for the review (Patton, 1990; Patton, 2002). For this purpose, we followed the principle of 'intensity' (i.e. how rich and accurate is the information the studies provide), and 'relevance' (i.e. how socio-politically relevant is the information the studies provide) (Patton, 1990; Patton, 2002).

The search included five databases: Wellcome Library (History of Medicine collection and medical archives), PsycINFO, CINAHL, IBSS (The International Bibliography of the Social Sciences), and EMBASE. In consultation with an expert librarian at the University of Nottingham, we used the following search domains to define our search strategy:

- Dementia: dement*, alzheimer*.
- History: Histor*

These terms were adapted for each of the databases.

2.2.2 Eligibility criteria

The document is:

a) About dementia with or without comorbid physical or mental health diagnosis.
b) A primary historical source (i.e. document reporting raw data of events) or secondary historical source (i.e. document analysing primary documents).
c) A report on the history of dementia, with a primary focus on:
    - How the concept of dementia has developed through the years.
    - How the condition was experienced by societies.
    - Historical milestones at a societal level.
    - The socio-cultural debate around the condition and any dementia-relevant reforms.
d) In English or has been translated into English.
e) A contemporaneous or retrospective account concerning dementia. The former may confer a deep knowledge of the political conditions impinging on societal shared beliefs and values at a certain period in time. The latter may be examined against important historical changes such as political and social movements through time.

We also engaged in a broader search and considered alternative historical reproductions (e.g. artistic photos, novels, poems), such as the work by Thane (2007) on *'The Long History of Old Age'*, when these helped factor in how either dementia

or aging was depicted at the time, as both terms have often been associated through history.

2.2.3 Identification of primary sources and quality appraisal of secondary sources.

To maximise the retrieval of primary sources, other than retrieving primary sources through electronic databases, we further extended our search to include grey literature, by considering the first 100 hits on Google scholar. We also consulted the 'NU-search' library catalogue of the University of Nottingham to retrieve relevant information on textbook and hardcopies. All the sources selected for review were cross-referenced.

We described primary sources around 1) the main argument presented, 2) how the argument challenges (if applicable) the contemporary values and beliefs, and 3) and the aims of the authors (Table 2.1). We did not formally evaluate primary sources. Also, the research team included translations of primary documents and considered these primary sources through agreement.

In regard to the quality appraisal, the first author (AB) developed a screening tool adapted from the Critical Appraisal Skills Programme (CASP) checklist (CASP, 2017) to evaluate the secondary sources (Table 2.2). This checklist enabled us to conduct a systematic assessment of the methodology used for data collection and analysis, and to explore the clarity and quality of reporting of the study objectives, findings and contribution to knowledge in each case. Documents were not excluded on the grounds of clarity, nor for decreased quality in their reporting.

Table 2.1 Description of primary sources (n=11).

Primary sources			
Historical era	**Author**	**Primary documents**	**Description**
Classical Antiquity	Solon (translated by Rhodes & Leao, 2016)	The Laws of Solon: A New Edition with Introduction, Translation and Commentary	The authors report translated versions of Solon's writings into English with added commentaries on Attic society. Both authors have extensive expertise on Athenian law-making institutions. Rhodes has extensively produced work on Athenian politics (e.g. The Athenian Boule -Oxford, 1972) and on Aristotelian society (e.g. Athenaion Politeia - Oxford, 1981). Leao has produced work on Plutarch. It caters to an educated audience. Dementia was associated with altered states of judgement and awareness.
	Cicero	Cato Maior de Senectute	'On old age' is Cicero's treatise on aging and death. The narrative takes the form of a dialogue. We find the main character Cato who engages almost in a monologue throughout the work. We further find typical characteristics of aging in the character whose wordy and confusing speech recalls the inevitable cognitive decline posed by old age. However, Cicero maintains also a positive view of old age in that he contends that old people who remain alive after a certain age are to be considered strong and fit to practise their will. It caters to an educated audience.
	Celsus	De Medicina	Celsus's work De Medicine remains one of the few sections of a larger encyclopaedia still available and it is regarded as a treatise of Alexandrian medicine. The work is divided in 8 books around diet and exercise, causes of disorders, and treatments. The language used in the text is complex and it carers to a professional audience. Celsus provided one of the first differentiation of dementia from delirium defined as phrenesis. Dementia was considered a more deteriorating condition that manifested after delirium.
	Galen (translated By Johnston, 2006)	Galen: On Diseases and Symptoms	Galen's work on the classification of disorders provide a bridge between the theoretical foundations and clinical practice. The language used is moderate in tone which reflects the dogmatic views on medicine of the time. It caters to an educated audience. Galen defined dementia as morosis and linked the condition to a process of ageing.

Modern History	Willis	Practice of Physick	Willis uses a terminology based on negative connotation of old age to characterise cases of what at the time dementia symptoms may have been at the time (morosis, stupidity). It caters to a medical audience.
Late modern history	Cullen	First lines in the practice of physic	In his work, Cullen described dementia as amentia and as a subclass of disorders affecting judgement. One type of amentia was linked to memory problems and defined amentia Senilis, which was regarded as a condition consequent to ageing. Cullen's work mainly caters to a medical audience. Dementia was considered a failure of mental and cognitive functioning.
	Esquirol	Des passions considérées comme causes, symptômes, et moyens curatifs de l'aliénation mentale	Esquirol's medical thesis was greatly influenced by the work of Pinel. In his work, Esquirol reported case studies and maintained the firm idea on the association of psychological and somatic disorders and the highly interconnection of thoughts and feelings. In his case studies, the author reported the use of restrictive and punitive therapeutic courses in asylums as opposed to the use of alternative treatment for mental disturbances. It caters to a medical audience. Dementia was considered a consequence of acquired disease.
	Wilks	Clinical notes on atrophy of the brain	In his work, Wilks attributed the abnormal changes of brain atrophy to senile dementia. He further reported a modern description of the brain hemispheres. It mainly caters to medical audience. Wilks proposed one of the first classification of dementia as organic brain syndrome.
	Alzheimer	Uber eine eigenartige Erkrankung der Hirnrinde (Translated by Hurley & Wells, 1999)	Alzheimer's case work contains clinical observations of aggressive form of dementia with an early onset. In order to maintain the original contents of the author's work, the English translation has not respected some of the English grammar conventions, and the structure of the sentence has been reported as used in the original language. It caters to a medical audience.
Post-Modern Movement	Kitwood	Dementia reconsidered	Kitwood's work opened the stage to a public debate on dementia by critically discussing the inadequacy of the medical model in exampling the psychosocial symptoms of the condition and the role of the social environment in shaping such experience. Kitwood employs a dialogue form in the text, whose content is referenced by previous research and professional experience. It mainly caters to social care professionals.

Table 2.2 Appraisal checklist for reviews on historical documents.

Checklist			
Screening questions	Yes	Can't tell	No
1. Did the review address a clearly focused question? *Hint: Problems may be in the following:* - *The years covered in the article.* - *The historical processes.*			
2. Did the authors look for the right type of documents? Hint: *'The studies should* - *Be relevant to the scope of the study.* - *Be a primary source (or consult different secondary sources to compare and contrast the validity and accuracy of the information reported.*			
Detailed Questions*			
3. Do you think you considered all the relevant documents? *Hint: Search for* - *Databases consulted.* - *Follow up from reference lists.* - *Personal contact with experts.* - *Search for unpublished as well as published studies.* - *Search for non-English language studies.*			
4. Did the review's authors assess their quality? *Hint: Did the authors assess the quality of the information from other sources.*			
5. If there was differing information from other sources, did the authors reported this in the review? *Hint: Look for* - *The information was similar from study to study.* - *The reasons for any variations in the information reported are discussed.*			
6. Did the authors favoured the use of primary sources? *Hint: See if* - *The document reports the current contextual factors.* - *The document report first-hand account.*			
7. Does the review clearly discuss the findings in reference to the context within which it is situated? *Hint: Look for* - *Implication for policy, practice.* - *Historical determinants influencing current socio-political decisions.*			
8. Can the findings be applied to the local context? *Hint: The social context covered by the review could be sufficiently different to your social context to cause concern.*			
9. Do the authors report if the findings apply to other social contexts? *Hint: If the authors reported their findings to be generalizable to an international context, and how if they did.*			
10. Were all important outcomes considered? *Hint: Do you think the authors would have required more information?*			

Items 1, 2, 3, 4, 5, and 10 were adapted from the CASP checklist.

* Items 3 to 10 are applicable only if items 1 and 2 have received a positive response.

2.2.4 Data analysis

Deductive content analysis (Elo & Kyngas, 2008) was used to investigate the historical processes underlying the societal experience of dementia and the way it has been socially constructed through history. Content analysis proves effective in categorising data from socially defined phenomena, and for creating a conceptual map of those events that influenced the determining of these phenomena (Elo & Kyngas, 2008), as it is the case of our investigation of dementia and its usage in history. The main elements of non-material culture by Matsumoto (1996) around aging and dementia (i.e. social norms, ideas, beliefs, values, and shared symbols) informed the synthesis of the findings. It is to be acknowledged that culture is both a social construct and an individual construct (Avruch, 1998), for this reason, as much as our analysis was made in reference to existing sources, we used our own 'culture' to interpret our findings (i.e. Western European culture).

In order to reach rigour and robustness in our findings, we undertook the three phases of preparation, organising and reporting as described by Elo and Kynga (2008). Specifically, (AB) created a structured matrix for categories that enabled the coding of data according to each pre-defined category. In order to avoid losing important concepts, the research team did not discard data that did not fit with the categories, but rather, we considered them as new categories, in case they added new information. The process of data extraction and organisation was facilitated by the use of NVivo 11 (QSR International, 2012).

During our analysis we found that the influence of authoritative figures of the time was key in persuading societies to adopt specific beliefs around dementia. We therefore felt that it was appropriate to utilise a paradigm that could explain how the

message is transmitted within the society and how authoritative figures influence or maintain a belief at the societal level.

For this reason, the analysis was informed by the systems theory paradigm (Von Bertalanffy, 1968) to describe the process of forming a collecting understanding of dementia through communication occurring in specific periods in history: how authorities at the time influenced the shaping of the concept, the way the message was conveyed to persuade the person (and society at large) to adhere to the belief, and the role of the general population in the transmission of the message. From the evidence gathered, it was evident that the transmission of the belief/message around dementia was not a one-way process, but rather included feedback that the decoder of the message (receiver) would send back to the encoder (those influencing the transmission of the belief) within a social cultural context and in a specific time in history. We therefore also used an interaction model of communication theory to explain what promoted the enculturation around specific views on dementia in modern times (Deetz, 1994).

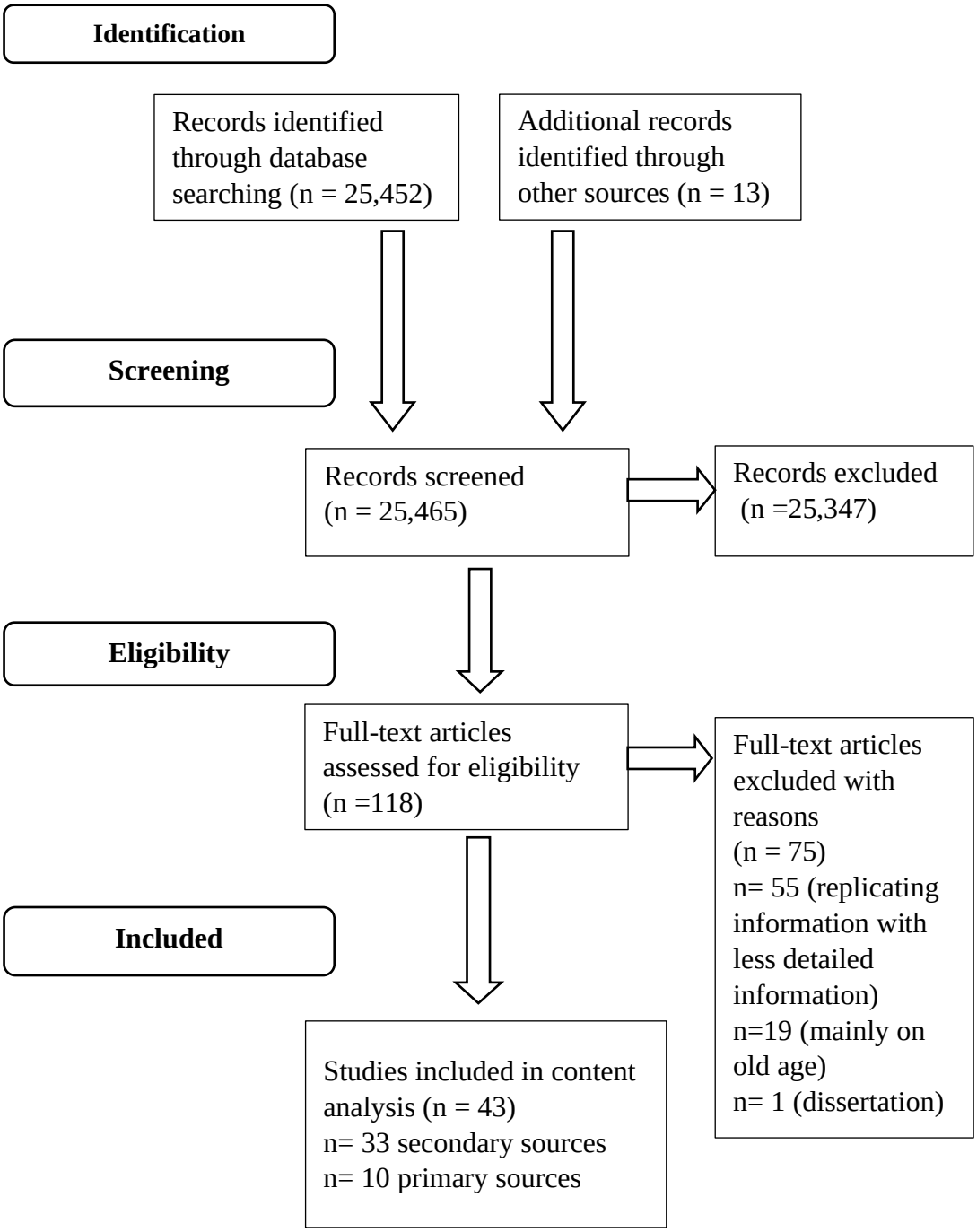
2.3 Results: Themes of social construction

The systematic search was conducted on 15th October 2017. Out of 25,452 documents retrieved (EMBASE: 15827; PsycINFO: 4894; Wellcome Library: 3138; CINAHL: 46; IBBS: 1547), 43 were included in the analysis (33 secondary sources and 10 primary sources) (Figure 2.1 for study flow chart).

The quality appraisal was conducted only on 33 secondary sources as we found it not feasible to use quality screening tools on primary documents as there was no systematic reporting of methods nor of paradigm used. Documents were found to be

of high quality in the way they clearly reported the use of multiple sources for interpretation. However, we found it difficult to attribute scores for items 3 and 4.

Figure 2.1 Flow chart for selection of papers.



Seven themes were identified, each emerging in different periods in history.

2.3.1 A problem of aging

Early remarks on dementia trace back to classical times, when the condition was associated with aging rather than illness (Cipriani, Dolciotti, Picchi, & Bonuccelli, 2011). Old age was depicted as a period in life in which most human decay occurs and much of this decay is responsible for the mental regression affecting aging individuals. The five life stages model attributed to Pythagoras (570–495 BC) in the 7th century B.C., is one of the earliest representations of how life was understood at the time. According to Pythagoras, age 63 and 81 constituted the 'senium' period of life, when cognitive and mental decline were inevitable (Poulakou-Rebelakou, Kalantzis, Tsiamis, & Ploumpidis, 2012; Cokayne, 2003). The senium may also be regarded as one of the earliest portrayals of dementia, as Pythagoras contended that old age was the period when *"The scene of mortal existence closes…* and *… the system returns to the imbecility of the first epoch of the infancy"* (Poulakou-Rebelakou, Kalantzis, Tsiamis, & Ploumpidis, 2012; Laertius, 1972).

This association of aging with dementia led to the social construction of the condition as a natural life manifestation and arguably also to stigmatising societal views around the process of aging. Such negative social construction around old age and decreased judgment was also reflected in different spheres of society, including the legal system (Berchtold & Cotman, 1998). Court judge Solon (638-558 BC) in 500 B.C. amended the inheritance laws and legislated that inheritance could be passed on to *'extra-family'* heirs, only if they were not affected by decreased judgment caused by old age (Berchtold & Cotman, 1998; Rhodes, D.F. Leao, 2016). The association of aging with mental failure was also addressed by Hippocrates, who

used “paranoia”/imbecility to describe the mental decline in old age (ca. 460–377 B.C.) and later by Plato (424-423 BC) and Aristotle (384–322 B.C.) (Berchtold & Cotman, 1998; Feldman, 2007).

Galen (129-200 AD) provided the term ‘morosis’ to define dementia (Ban, 1991; Berchtold & Cotman, 1998; Johnston, 2006). The term ‘morosis’ described a condition in which ‘the knowledge of letters and other arts are totally obliterated’ and where the affected individuals find it difficult to retrieve easy information from their memory, including their names (Berchtold & Cotman, 1998). Given the existing societal views associating inevitable deteriorating cognitive abilities with aging (Boller & Forbes, 1998), Galen’s views prevailed, and dementia continued to be considered a condition of old people, who were often referred to as demented or cognitively and mentally impaired.

This association with mental failure has also been reported in other periods in history. William Shakespeare (1623) describes the seven ages of man, with the last characterised by ‘*second childishness and mere oblivion, Sans teeth, sans eyes, sans taste, sans everything’*. These negative connotations of aging, cognitive and mental failure still permeate in modern times:

"I was one of them, dreaming of a perfect and healthy old age...Now, at fifty-eight, I realize the foolishness of my dreams as I watch my brain self-destruct from Alzheimer's." (DeBaggio, 2002)

A more realist representation of ageing is provided by Alice Munro’s ‘*Winter Wind’* (1978), where the character of a nursing home resident is characterised by unrecognizable memories of the past, and whose life is devoid of positive emotions for the future. In ‘*Picture of the Ice’* (1990), her character Austin tries to mask his

signs of ageing to avoid discrimination. This portrayal of old age reflects the expectations posed by the Western culture on ageing found in the early and middle 20th Century celebrating youth (Goldman, 2017).

2.3.2 Use it or lose it

In contrast to the Greek philosophers, the Roman poet Cicero (106-43 BC) contended that the causes for *'senile debility'* were not to be found in the aging process, but rather in a passive way of living life – a life devoid of active engagement and proactive thinking (Loeb Classical Library, 1923). In the essay *'Cato Maior de Senectute',* Cicero argued that, through engaging in active life, a person could fight off disease and mental regression (Loeb Classical Library, 1923). The concept of successful aging in terms of active participation in life resonates in modern times to similar extents. For example, in Vietnamese culture there is a *'use it or lose it'* approach to life, according to which dementia takes over if no active life is maintained (Alzheimer's Australia, 2008). Research evidence similarly points at the role of active training for the preservation of mental functioning in older people as a way to prevent the onset of dementia symptoms (Orrell & Sahakian, 1995). The role of neural stimulation in increasing the density of neocortical synapses seem to be key in favouring the preservation of healthy brains (Katzman, 1993, 2004; Stern, 2002; Valenzuela, 2008). Several studies seem to point at this association, with authors reporting education as one protecting factor against the forming of pathological brain structures that could lead to dementia, such as amyloid load (Bennett, Schneider, Bienias, Evans, & Wilson, 2005), or neuritic plaques in the grey matter of the brain (Koepsell et al., 2008; Roe, Xiong, Miller, Cairns, & Morris, 2008).

However, in classical period, this theory was overpowered by the concept of dementia as an inevitable condition, irrespective of any individual mechanisms that could be acted out to fight off the mental deterioration and which reflects the strong influence of Aristotle over classical Roman thinking (Berchtold & Cotman, 1998; Thane, 2007).

2.3.3 Divine punishment

During the early Middle Ages dementia was considered to be a consequence of original sin, an external force limiting free will (Beach, 1987; Metzler, 2013). This led to the association of dementia with divine punishment. Theological doctrines permeated much of the cultural belief of the time, but a first sign of change was when Roger Bacon (1214-1294) argued that the understanding of complex phenomena required empirical (i.e. scientific) observation (Beach, 1987). Victimised for his views by religious authorities, Bacon was imprisoned on accusation of witchcraft (Beach, 1987; Classen, 2007; Bacon & Montagu, 1857).

The religious dogma exacerbated the stigma associated with aging and favoured the construction of both aging and dementia in terms of divine punishment (Venzmer, 1968; Berchtold & Cotman, 1998). Consequently, in 1400-1500, in Western European countries, many individuals with cognitive impairment (and dementia in many cases) were trialled, as they were retained not worthy of the glory of God. The court sentences inflicted to them were deemed essential to prevent that their sins could ‘infect’ the ‘pure of spirit’. Similarly, anyone acting against this doctrine was banished (Feldman, 2007; Gilleard, 2002).

Religion has represented a channel for the transmission of the meaning around dementia. In modern times, Christianity, holds unclear views, or perhaps simply

differing interpretations on whether dementia is a consequence of sinful acts practised by the individual before the diagnosis, a deserved condition of all human beings for they are descendants of Adam's race, or still, for some Puritans, a form of sin linked to insanity and to which all humans are destined to (Radde-Antweiler, Grünenthal, & Gogolok, 2018). Although the religious interpretations of the Bible are what fuels the transmission of the message, compared to the past, the sociology of religion points at the role of the organisation within doctrines and their use of the social media for the forming of modern constructions of dementia (Radde-Antweiler, Grünenthal, & Gogolok, 2018). The mediatisation of religion, the use of social media to promote religious values, is responsible for the modern characterisations of the condition, with some messages still promoting the association between human action and divine punishment, by contending, for example, that *'blogging sometimes leads to dementia, doesn't it?'* (Reported by the Cardinal Marx, leader of the German bishop conference in 2015) (Katholisches, 2015; Radde-Antweiler, Grünenthal, & Gogolok, 2018).

Christianity has not been the only doctrine favouring the spread of such meaning around dementia. According to Sikhism, each member of the community has to respect the principle of *'seva*' and support the congregation through selfless acts (e.g. caring for the sick, helping the poor) *'with the exception if you have dementia, then you have to repent your sins'* [p.279] (Khan et al., 2015). This brings stigmatising views on dementia not only to the person living with the condition, but also to the rest of the family. Similarly to Christianity and other monotheistic religions, disciples of Sikhism learn that mental and physical conditions need to be cared for within the family or the congregation. Dementia becomes then a family matter whose sin of the person with the condition is shared by the whole family (Khan et

al., 2015). Still in some African countries (e.g. Nigeria) the behavioural psychological symptoms of dementia are considered signs of evil possessions affecting those with weakened spirits (i.e. sinners) (Uwakwe, 2000). Such collective construction of dementia in terms of sinful act and divine punishment inevitably leads to stigmatising views around the condition with consequences of social withdrawal and exclusion for the person living in the community and the family. From the words of a residential facility nurse in South Africa:

"When persons act in strange ways the talk starts in villages and townships: they say 'that one has been bewitched'…they go to these old people, vandalise their houses, burn their houses... they accuse them of being witches" (p. e172;) (Mkhonto & Hanssen, 2017).

Delayed engagement with health and care services is a consequence of such association nonetheless (La Fontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007). Similarly, for some traditional members of the Macedonian community, dementia is considered a punishment for past sinful acts, or a curse for exhibiting inappropriate behaviours that are condemned by the community. Receiving a diagnosis of dementia becomes associated with self-exclusion from social activities. Members of the community who are not directly related to the person with dementia, may even withdraw from participating to community events if either the person with the condition or his/her family members continue to attend (Alzheimer's Australia, 2008).

2.3.4 Loss of agency

Following the period of scientific development called the Enlightenment, during which the dominance of religious authority was challenged, the religious belief

linking dementia to divine sin was less prevalent, although there was still confusion around the condition and several speculations were made around terminology (Berchtold & Cotman, 1998; Cipriani, Dolciotti, Picchi, & Bonuccelli, 2011). Terms such as *'lethargie'* (Cosin, 1592), *'stupidity'* (Willis, 1684), and *'insensitivity'* (Battie, 1758), were used to describe the condition (Foerstl, Howard, Burns, & Levy, 1991). These terms denoted a negative characterisation of dementia, viewed as decreased sensitivity acquired with age. For Willis (1621-1675) in his *London Practice of Physick* (Willis, 1684), the ageing person becomes *'by degree dull'*. A key correlate of this process seems to be that the person affected also loses entitlement to practice agency because of his/her decreased intellectual capacity (Berchtold & Cotman, 1998). Even at the end of the 18thcentury, the classification of mental conditions produced by Cullen (1710-1790) in 1776, reported *'Amentia Senilis'* as a neurosis, characterised by the decay of cognitive and mental functioning (Feldman, 2007).

A growing sense of what we might call individual responsibility can be seen, in Western Europe, as an effect of the Reformation with the dissolution of the monasteries having a big impact on the issue of caritas, shifting the responsibility from the church to the civil society. The implementation of the poor law spread across Europe as eligibility criteria for relief became widespread instead of 'works of grace'. Such societal responsibility was further prompted by the Enlightenment ideas on communitarian support. This is reflected in writings about *'the unshaken collective responsibility of care'* towards old people experiencing failing physical and mental capacities (Feldman, 2007). Generally, the provision of care was seen as a tripartite responsibility: the old person (who had to retain agency until loss of capacity), the family (having a duty of care), and the community (providing support

where all else failed, through charities, for example) (Berrios, 1991; Berchtold & Cotman, 1998). Social upheavals such as the agrarian revolution, and the beginnings of industrialisation, with mass migration to towns, separated aged parents from their traditional carers and so communities had to come up with substitutes. Workhouses where indigent people were given very basic shelter in return for labour became the last resort for people of all ages with cognitive impairment (Higgs & Gilleard, 2015). Despite a change has been made in the living conditions of people with dementia, and independent forms of living have replaced shelters, the frailty of people with the condition may still be experienced as a lack of capacity to reason.

2.3.5 Psychosis and insanity

In the 19th century, a gradual differentiation between senile dementia and other forms of dementias emerged more prominently (Forstl, 2005). Esquirol (1772–1840) introduced the importance of conducting a systematic clinical observation to identify subcategories of mental disorders (Berchtold & Cotman, 1998) and differentiated dementia (a cognitive decline and mental impairment consequent on acquired disease) from amentia (decreased intellectual functioning acquired before birth or at the early stages of human development). However, old people with dementia still experienced institutionalisation for their condition, and a labelling of insanity was still applied to this group of patients (Blumer, 1907).

The construction of dementia in terms of insanity was maintained because of the similarities that the condition shared with psychosis in regard to lethargic behaviour. Hence, patients who were detached from reality ‘psychotic’, but whose behavioural symptoms were not active enough to confirm a diagnosis of mania, were classified as having dementia (Blumer, 1907; Berrios & Porter, 1995). The association with

psychosis reinforced the assumption that people with dementia had psychotic behavioural alterations, and therefore lunatic asylums were regarded as optimal care settings for both populations (Hill & Laugharne, 2003). The association with psychoses also led to Kraepelin's (1856-1926) definition of schizophrenia as 'dementia praecox' in 1891 and to differentiating dementia occurring in old age as *'senile dementia',* caused by a loss of cognitive functioning (Berrios, 1990; Hill & Laugharne, 2003; Kraepelin, 1910). Towards the end of the 19th century, empirical observation was regarded as the gold standard for the ascertainment of different aetiologies of dementia (e.g. vascular and senile) and for the study of the epidemiological relevance of senile dementia in aging individuals, compared to other mental health conditions (Berchtold & Cotman, 1998).

Still today, the association with insanity remains in some artistic representations and work of literature. According to Foucault (Khalfa, 2009) some of the clinical manifestations of dementia are found in conditions that Thomas Willis defined as *'stupiditas, sive morosis'* in the De Anima Brutorum (p.235) (Hunter & Macalpaine, 1982). The concept of stupidity or 'unreason' ((Khalfa, 2009) has permeated in modern times. It is not surprising then, that the work by Theodore Gericault in *'The Portrait of The Insane'* (1983), influenced the photographs by Nicholas Nixon on people with dementia, in which the artist captures their elusive gazes in moments of unawareness. Although the mouth of the subjects is open they do not communicate words and their empty gaze transmits no meaning. The audience is left with no imagination on what the person with dementia may think or say.

There is still stigma around dementia in modern societies. For example, In Arabic culture, dementia is translated in *'kharaf'* and most commonly used to indicate that a

person has *'lost her/is mind'* (Alzheimer's Australia, 2008). The fear of becoming victims of prejudice for carrying a diagnosis, leads people with dementia to hide their symptoms and their family members to limit their visits to their loved ones with the condition (Alzheimer's Australia, 2008).

2.3.6 Brain degeneration and objectification

Societal views of dementia were still anchored in the association of the condition with psychosis, hence in the concept of 'insanity', but efforts were made by 19th Century scholars to conduct systematic ('pathological') examinations of the condition, investigating brain atrophy and vascular degeneration post mortem (Virchow, 1859; Wilks, 1864).

In the early 20th century, in both Europe and the United States, mental health disorders and cognitive impairments came to be explained through a brain disease discourse that belonged to the medical profession (e.g. Alzheimer, 1907). Neurology and psychiatry vied for ownership of clusters of symptoms, which, grouped into different mental health conditions, led to the conceptualisation disorders as unique entities. This was reflected on dementia as well, which was classified as organic brain syndrome in the Diagnostic and Statistical Manual of Mental Disorders (DSM-1) in 1952, and later acquired the criteria for dementia and Alzheimer's disease (DSM-III-R, DSM-IV and DSM-IV-TR) (McKhann et al., 1984; Lopez, McDade, Riverol, & Becker, 2011). Dementia was more and more conceived of as an organic disorder. From here dementia was conceived as a 'neuro-psychiatric' condition (Raskind & Storrie, 1980).

The emphasis on the process of scientific diagnosis and the categorisation of symptoms into diseases or disorders tended to result in the objectification of patients,

who were often reduced to their symptoms or diagnosis, regardless of other human characteristics This objectification of the person as a mere 'host' of a degenerative disease prevailed throughout the first half of the 20th Century. However, this reductionist approach proved increasingly unsatisfactory as an explanation of the clinical symptoms of dementia. The medicalisation of dementia tended to make health services responsible for its care. Consequently, there was a containment strategy as part of the state provision in which patients who could not be rehabilitated, as in the case of people with advanced dementia, tended to live out their remaining years in a hospital or poor law infirmaries, often at the expense of the state. Where state provision was not forthcoming, families provided nursing care. Medicalisation of dementia still permeates the care pathway in dementia, from the time of diagnosis, when medical categories are used to discriminate between disorders to the care package containing difficult medical terms and given to people living with the condition for the treatment of symptoms. This medical approach to dementia is still responsible for experience of decreased dignity and consequent objectification in people with dementia (Pinner, Hillam, Branton, & Ramakrishnan, 2011).

2.3.7 Dementia as a social condition

Late 20th century critiques such as the anti-psychiatry movement challenged the medical model of mental illness (Szasz, 1997) and pointed to the influence of social factors over mental disease. The notion of institutionalisation was formed (Goffman, 2017) and the tendency for formal care settings such as long-term hospitals to deprive people of their self-determination was recognised (Wing, 1992). Economic forces converged with social movements to reduce the provision of long-term hospital care for people with dementia as well as people with other diagnoses. This

led to an increase in the provision of community care (e.g. in nursing homes) and a rapid decline in the numbers of psychiatric beds within the National Health Service (NHS) (. Davidge, Elias, Jayes, Wood, & Yates, 1993). This trend was favoured by the uncapped DHSS (Department of Health and Social Security) board and lodgings payment budget, with nursing homes taking advantage of this source of income. The effect was having a disproportionate number of people diagnosed with dementia (Department of Health and Social Security, 1981).

Kitwood's theory suggesting that neurological impairment could be exacerbated by malignant social psychology helped to foster the development of a new framework of care that could replace the 'old culture of dementia care' (Kitwood, 1997). This was a new social construction of dementia that emerged from challenging the 'standard paradigm' of the medical model and was underpinned in the concept of positive care relationship: through positive care practice, the personhood of the people with dementia can be promoted (Kitwood, 1997). It followed that the person with dementia was placed at the centre of the care 'conversation'. People with dementia were to be considered persons rather than 'patients' or 'simply rational individuals'. Person-centred care, also known as patient centred care, client-centred care, or resident-centred care (Nolan, Brown, Davies, Nolan, & Keady, 2006), came to be regarded as the gold standard for care (Ballenger, 2006; Mental Health Foundation, 2015) and inspired other models of care based on positive care relationships (i.e. relationship care model as in the senses framework) (Nolan, Brown, Davies, Nolan, & Keady, 2006).

In recent decades, the presentation of dementia in the media has often been more respectful, better reflecting the views and needs of people with dementia. This has

favoured the increase of dementia awareness at the societal level through literature and arts, for example. Photography is one of the artistic productions that catered much of the attention on dementia. Artists started to use this modern medium to capture the eyes and ageing bodies of people with dementia through an intersubjective stance that could promote a sense of empathy in the audience. Through the work series *'portraits of dementia sufferers'*, Jeff Bowering constructs a realist meaning around the faces of his models, a meaning that humanises them and paralyses the audience through the use of dramatic representation of people with dementia: their gaze is human, and different from a vegetative state typical of past characterisations of the condition (Hsu, 2014; Sontag, 1979).

Similarly, on a policy level, there started to be legal acknowledgements for people with dementia. Much of the influence was brought by the UPIAS's (Union of the Physically Impaired Against Segregation) views around the social barriers experienced by people with physical difficulties (Thomas & Milligan, 2015). Steps forward were made with The Human Rights Act (1998), with the inclusion of dementia in the Equality Act (2010), and through the United Nations Convention on the Rights of Persons with Disabilities (2006) to protect people with dementia (among others) against stigma and discrimination. This coupled to the discourse around 'successful aging', has pushed new boundaries to the entitlements of people with dementia and their role in society. People with dementia are becoming active citizens, able to influence positive views around dementia through network communication, advocacy programmes and charity campaigns.

2.4 Discussion

This review synthesises and conveys the socio-cultural processes underpinning the construction of dementia across a broad period of human history to help explain how

certain socio-cultural meanings developed around the concept of dementia, and how these evolved.

2.4.1 Cultural transmission theory in dementia.

By interpreting our findings through cultural transmission theory, we found that specific meanings resonated through history and shaped the way we conceive of the condition today. This is to say that the way dementia is experienced in modern times is a product of past constructions of the condition and that different meanings are not time-bound. For example, the association of dementia with divine punishment that was maintained in the middle ages, is still today practised in some religious groups and explained in terms of God's wrath (Adamson, 2001), karmic punishment for past sinful acts (Hinton, Tran, Tran, & Hinton, 2008) or witchcraft possession (Jett, 2006). As reported in our review, there are multiple views around dementia that are present in contemporary societies. It is through enculturation that these views are transmitted and maintained in accordance with the values and beliefs shared by different cultures. The meanings around dementia are interpreted, assimilated, or rejected by individuals in their socio-cultural context (Kontos & Martin, 2013). Hence, meanings are negotiated by individuals based on their social location (e.g. gender, social class) their biography (Sweeting & Gilhooly, 1997; Kontos & Martin, 2013), but also according to the level of self-awareness (Bar-On, 2001). As poor self-awareness may lead to decreased levels of assertion towards their role in society and promote or maintain negative connotations around dementia. In addition, the forming of these meanings is influenced by the presence of other social constructions, such as the social representation of aging (Hulko, 2009).

These views when negative (e.g. when they are associated with stupidity, divine punishment, insanity) can generate stigma and have negative consequences for the

person with dementia and their family, but also for agents directly involved in the delivery of dementia care (e.g. health care professionals) and for society at large (Swaffer , 2014; Aldridge, Fisher, & Laidlaw, 2017).

2.4.2 Enculturation around the concepts of dementia in modern times.

In this review, the interaction model of communication describes the forming of the collective understanding of dementia, how the meaning around the condition has formed and has been transmitted in modern society. Although, it holds true that meanings are transmitted through generation, in the last two decades, globally-networked communication capability has spurred a new form of public opinion, with a change in the distribution of power to influence ideology and beliefs. This has promoted a more participatory democratic citizenship, where the actors (i.e. citizens) have a channel to share their views with the larger community (i.e. the rest of the population) for good or ill (i.e. in presence of positive or negative meanings around dementia) (Sørensen & Torfing, 2003). It is to be acknowledged, that network communication is also used by the authorities (e.g. to promote political campaign, reinforce maintained beliefs) with the aim to persuade and control the masses. What has changed from the past, however, is the growing interdependence of each member of the society and the authorities, hence translated into our model, between the authority (e.g. policy makers) and the person with dementia (Figure 2.2 for an illustration of the model of enculturation).

As illustrated in this model, the message around dementia is not passively experienced by the person with the condition, as s/he applies an interpretation to the concepts by means of her/is own understanding of dementia. Through self-awareness, the person may assert her/is own identity and influence at societal level a more positive construction of the condition. In case of negative connotations of

dementia (e.g. mainly focused on the fact that dementia is a non-curable condition) and in presence of poor levels of self-awareness, the person is unable to actively influence positive imaginary of dementia. Consequently, negative meanings around the condition may be spread across and within societies. When there are no opportunities at societal level promoting positive views around dementia, there is risk to create barriers in institutional and community practises for social equity and cultural diversity (e.g. barriers impeding the creation of dementia friendly community). These barriers may lead to what Thomas and Milligan (2015) defines as psycho-emotional disablism, a term describing all those negative behaviours that are unintentionally or intentionally acted out by the large community of people without dementia towards people with the condition. Psycho-emotional disablism can act as a vicious cycle and affect the personal dimension of the individual with dementia and have an impact on her/is self-esteem and decisional power, hence proving limiting for her/is social action. However, positive levels of self-awareness can help the person to practice self-assertion in presence of these social barriers.

Such process of democratisation of dementia, may occur through social capital, when the organisation of the society promotes the active involvement of people with dementia and their carers in the socio-political life of the community. In contrast with the horizontal view of knowledge distribution (Putnam, 2002), we feel that active participation should be across systems, actively informing the development of social policies across all different sectors of the societies (e.g. health and social care, housing). These social policies may be promoted by the modern accessibility of information, through online discussion forums for example (i.e. Alzheimer's Society). These online platforms (e.g. Facebook, Twitter) both positively and

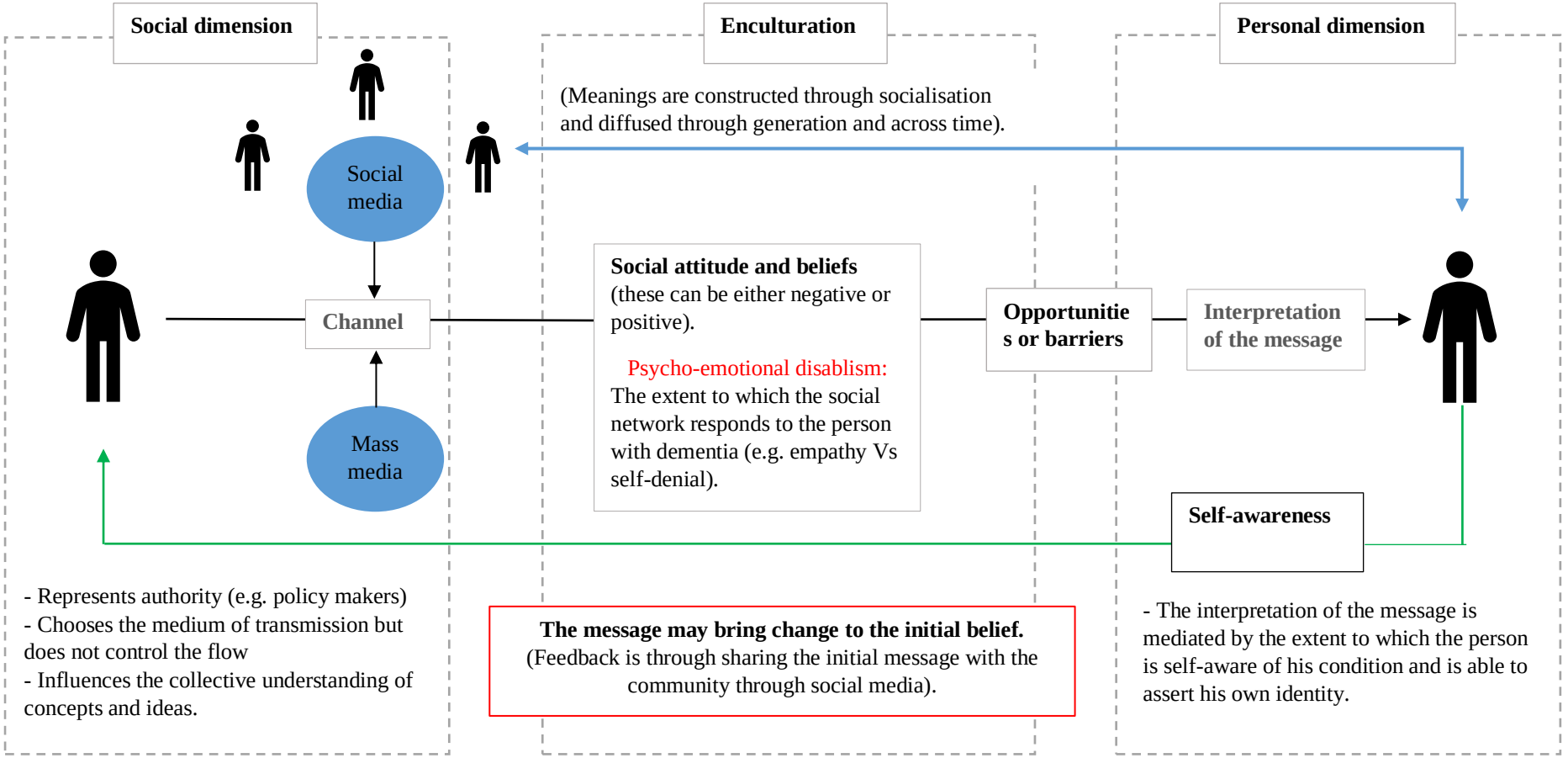
negatively impact the perception and stigma around dementia in contemporary societies.

2.4.3 Strengths and limitations

A strength of this paper is the systematic methodology used for the retrieval of articles. This follows the PRISMA checklist (Moher, Liberati, Tetzlaff, & Altman, 2009). The scope is broad, since we used five databases with quite diverse specialisms, ranging from the social sciences, psychology, to more specific databases within the biomedical domain, and history-specific domain as in the case of the Wellcome Library. This strategy enabled us to retrieve major works relevant to the objectives of our investigation, but it also gave us the ability to screen a large number of documents that would not be possible otherwise.

The principles of confirming/disconfirming to triangulate the information reported in the studies was selected for the analysis with other secondary sources when these reported differing historical versions of the events. In addition, the research team met multiple times to refine the search strategy, to agree on the methodology to use for data extraction and to engage in the quality of data reporting. A librarian based at the University of Nottingham was consulted for the search strategy and to determine which checklist to use to assess the quality of the documents retrieved.

Figure 2.2 The social construction of dementia: A metacognitive model of enculturation.



In regard to the limitations, these lay mainly in the use of the CASP checklist, which was more limited in determining the quality of primary and secondary historical documents. It is important to acknowledge though, that this was out of our control as the current systems for the quality appraisal of historical documents only target authenticity (i.e. type of paper utilised, material used for printing) and conservation of these resources (i.e. how to conserve the document through time, the existence of proof such as receipt for its conservation). However, we developed a checklist adapted from the CASP that could prove effective in the appraisal of historical reviews. Another limitation relates to the very exploration of the social construction of dementia, as this requires the analysis of different forms of documents e.g. letters, artefacts, we were only able to consider the documents listed in the databases we consulted.

Also, it is to be acknowledged that this inquiry was mainly based on western-centred societies and although we were able to retrieve some examples of eastern cultures, these were mainly reported in documents whose authors were from western countries. A quite large period of human history has not been covered chronologically as we were interested in social meanings around the condition rather than a chronological description of the history around dementia.

2.5 Conclusion

Through history dementia has commonly been associated with ageing and decline. In recent decades as life expectancy and years of active life has increased, the notion of ‘successful ageing’ has been incorporated into the discourse around dementia. While such consideration of people with dementia promotes positive views around the condition, and may favour their equal consideration as active agents able to operate in society, it does require the establishment of a dementia-friendly society that can

accommodate the needs of this population and to avoid that people living with dementia may feel overwhelmed by the attempt to fulfil these expectations (Heese, 2015). In addition, there is the risk that people with dementia may prefer to be socially excluded rather than engaging in a society designed for the young and able-bodied. A discourse around co-production, explained as a communal effort *'to find a shared solution',* may prove effective in acknowledging the need for support of people living with dementia and at the same time empowering them (Social Care Institute for excellence, 2013). Work still needs to be undertaken to bring the rights of people with dementia on an equal positioning with the rest of the population. For this purpose, new models of care aim to set benchmarks of good care through the active involvement of people with dementia in co-producing their own care pathway.

Chapter 3. Agency in dementia care: Systematic review and meta-ethnography

Bosco, A., Schneider, J., Coleston-Shields, D. M., Jawahar, K., Higgs, P., & Orrell, M. (2019). Agency in dementia care: systematic review and meta-ethnography. *International psychogeriatrics, 31*(5), 627-642. https://doi.org/10.1017/S1041610218001801

Abstract

Objectives. Dementia often limits the agency of the person to such an extent that there is need for external support in making daily life decisions. This support is usually provided by family members who are sometimes legally empowered to engage in decision making on behalf of the person for whom they care. However, such family carers receive little or no information on how to best provide support when there is a lack of capacity. This may have an impact on the agency of the person with dementia. This review explores the experience of agency in people living with dementia.

Design. A systematic search was conducted on IBSS, MedLine, PsychINFO, EMBASE, and CINAHL. Two independent researchers screened the studies and conducted the quality appraisal. We used meta-ethnography for data analysis. As part of the synthesis, we identified behavioural mechanisms underlying the process of decision making and looked at how the support of carers comes into play in making deliberate choices.

Results. The meta-ethnography involved 20 studies. Three levels of third-order constructs were identified, each describing a decision-making pathway and reflecting the degree of autonomy of the person with dementia: autonomous decision-making, shared decision-making, and pseudo decision-making. Findings highlight those inter-

relational processes that promote or negatively impact on the agency of people with dementia.

Conclusions. This review provides health and social care personnel with an understanding of the role of the carer in the decision-making-process, and therefore which mechanisms need to be promoted or discouraged through training.

3.1 Background information on agency in dementia care

Dementia can limit the agency of people with dementia, whose decreased ability for risk assessment, makes them more vulnerable to abuse, accidental self-harm, or self-neglect (Hegde & Ellajosyula, 2016). Although dementia is associated with reduced ability to make informed choices, the UK Mental Capacity Act (2005) explains that decision-making capacity is specific to the time when it needs to be taken (situational), rather than as a capacity that the individual either has or lacks (Department of Health, 2005). The United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD) asserts that all persons, irrespective of their disabilities, are entitled to exercise legal capacity and receive adequate support, if needed (UN-CRPD, 2006).

In case the individual is found to lack capacity, family members are faced with the difficult task of supporting them in their decisions or making decision on their behalf when necessary (Mental Capacity Act, 2005). These family members are usually providing direct and intensive care and may, in the UK, hold Lasting Power of Attorney (LPA) for the person with dementia or be appointed as Deputies by the Court of Protection. The role of the family carer then becomes that of balancing their tasks of caring for the person with dementia with the tasks of intervening in complex life decisions (Livingston et al., 2010). This balance may be challenged by the onset

of a crisis in the person with dementia, when health professionals turn to family members to make momentous decisions on limited care options (ADI, 2016). This is source of distress for carers and a threat to the agency of their relatives with dementia (ADI, 2016).

In this review, agency in dementia is understood of as the *'ability to initiate social action or at least influence their own personal circumstances'* (Boyle, 2014, p.1130), using a social constructivist standpoint for agency, intended as action acted out by socially-situated individuals through human interaction (Berger & Luckmann, 1991). Social reality is then explained as a product of human inter-relations. This interpretation is further informed by structuration approach to explain social change, in how social structures lie within the reflexivity of both individuals and institutions which combine to influence human behaviour without necessitating a deterministic temporal ordering (Giddens, 1986). This means that social structures can influence agency across time, as previous social structures can influence current behaviours and existing structures can affect future human behaviours (Giddens, 1986). It is also important to realise that discussing agency in relation to dementia can be problematic for notions of selfhood, which may necessitate other modes of expression such as personhood (Higgs & Gilleard 2016). This has often presented itself as an 'absent presence' constituting one of the dimensions of the fourth age - ageing without agency (Gilleard & Higgs, 2010).

The aim of this review is to explore how decision-making is expressed by the person with dementia living in the community and promoted by their carers.

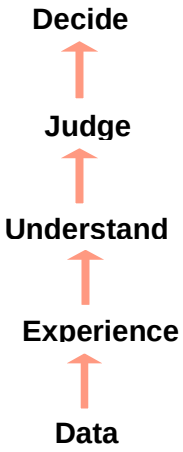
3.2 Methods

The study complied with the PRISMA checklist (Moher et al., 2009).

3.2.1 Hierarchical modelling for decision making

Decision making and agency require a degree of cognition to influence social change, and for this reason, the five-level hierarchical cognitive model, proposed by Lonergan (2000), may be used to explain the process of agency (Figure 3.1).

Figure 3.1 Lonergan's (2000) hierarchical cognitive model of decision making.



In the model, the first four levels represent the 'insight' of the individual, a conscious process requiring the awareness of each of the ascending levels (Lonergan, 2000). Individuals first attend to the data through the senses or feelings, then data are experienced through cognition and an understanding is then attained. When individuals understand the experience (i.e. data), they form a judgment of it; a self-oriented process that answers the question 'is this correct'? Finally, they are ready to make a decision (Lonergan, 2000). The process may also be recursive when new questions arise during the process, either self-oriented, or posed by the event. We used the cognitive model by Lonergan (2000), as a meta-model to inform the translation process of the meta-ethnography.

3.2.2 Identification of qualitative data

The Patient Intervention Comparison Outcome (PICO) format identified the population and outcomes of our search strategy (Sackett et al., 1997), conducted on

15.02.2018 on five databases: IBSS, MedLine, PsychINFO, EMBASE, and CINAHL. The Medical Subject Headings (MeSH) terms ('decision-making', 'shared decision-making', or 'patient decision-making') were added to the search and combined with the terms 'dementia' and 'Alzheimer's'. We further cross-referenced articles and conducted an explorative search of the first 100 hits on Google Scholar and Google search engine (Appendix 17 for search strategy).

The lead author (AB) developed the search strategy, which was checked for accuracy by an experienced librarian (EY). Two rounds of process plan were necessary. A three-stage process was followed for the screening and selection of relevant sources: Firstly, the qualitative researcher (AB) and a Specialty Registrar in Psychiatry (KJ) independently ran preliminary title and abstract screening against the inclusion/exclusion criteria; secondly, AB screened the full text of the remaining articles. A final stage involved the independent appraisal of the selected articles.

3.2.3 Inclusion criteria for the selection of studies

Qualitative empirical studies were considered when their primary objective was one or more of the following: Agency, decision making, active participation in health care delivery (e.g. care plan) or activities of daily living (ADLs).

Inclusion criteria:

- Used qualitative methods and reported first order constructs (quotations from participants).

- Key word dementia or Alzheimer's.

- Published from 2005 onwards.

- Reported on the experience of agency in people with dementia living in their own homes. Multiple perspectives may be present, (e.g. how agency is experienced by family carers or promoted by health care professionals).

Exclusion criteria:

- Concerned palliative care or decision making during end-of-life care.

- Commentaries, clinical discussions around case studies with no reported quotations from participants.

3.2.4 The role of the expert team

The expert team comprised three professionals with expertise in old age psychiatry (MO), social care in dementia (JS) and neuropsychology of old age (DMCS). They advised on strategies for the retrieval of articles and contributed to the synthesis of the findings.

3.2.5 Data analysis

The quality appraisal of the studies was conducted by two researchers independently (AB and KJ), through the Critical Appraisal Skills Programme (CASP) checklist for qualitative research.

Inter-rater agreement was assessed with the Kappa coefficient (Cohen's Kappa) (Cohen, 1960). Discrepancies were addressed through consensus. The parameters were based on the ranges by Landis and Koch (Landis & Koch, 1977): 0.81–1.00 = almost perfect; 0.61–0.80 = substantial; 0.41–0.60 = moderate; 0.21–0.40 = fair; 0.00–0.20 = slight; < 0.00 = poor.

Meta-ethnography

Noblit and Hare's (1988) approach was used for analysis. We used Schultz's (1962) categorisation of first-order constructs (participants' quotations) and second-order constructs (authors' interpretation of participants' quotations) to derive our third-order constructs on which we base our interpretation of the review results. We also followed the principles of 'reciprocal translation' by Noblit and Hare (1988) to analyse the emerging themes as they were presented in each of the studies included in the review. In addition, we developed a linear model to graphically represent the translation process of our third-order constructs. A line of argument further explained our analytical interpretation of data synthesis and was reported graphically and explained by means of a self-regulating model in decision making, which was informed by the organisational model by Jones (1997).

In regard to the identification of concepts/themes, our approach was iterative, in that we read and re-read the studies included in the review, with a focus on the first-order constructs (reported in the analysis/results section) and the second-order constructs of the studies (reported in the results and discussion sections). This analytical process entailed the qualitative researcher (AB) extracting the first- and second-order constructs by text units (i.e. paragraphs) onto NVivo 11 (QSR International, 2012) for the re-organisation of the layers of interpretations. For this purpose, the use of NVivo helped create a conceptual map for theme development in the form of a table, in which each column mapped themes against first- and second-order interpretations.

Initial themes were found around the degree of involvement of the person with dementia and their carers in decision making with respect to ADLs, and advanced care planning at different stages of the condition; themes were also found around the

behaviours of the carer and the person with dementia to promote and retain autonomy, and the active involvement of health professionals in providing support for making health care decisions.

A discussion was held with the expert team to check for accuracy. Lonergan's hierarchical model was employed to organise themes according to the mechanisms relating to different decision-making pathways. For this purpose, theme categories around what promotes or prevents autonomous decisions informed our third-order construct *'autonomous decision-making pathway'.* The role of the carer in shared decision making and the strategies employed to make consensual decisions constituted the third-order construct *'shared decision-making pathway'.* Themes relating to false or staged decision making and contributing factors guided the synthesis of the third order construct *'pseudo-decision-making pathway'*.

3.3 Results

The search retrieved 6,447 studies (IBSS: 730; CINHAL: 519; PsychINFO: 776; Ovid MEDLINE: 2055; EMBASE: 2367). Fifty-three articles were matched against our inclusion/exclusion criteria; 33 were excluded with reasons (e.g. on palliative care, studies on nursing homes) and 20 were analysed through meta-ethnography (Figure 3.2).

3.3.1 Study characteristics

The included studies were published in peer-reviewed journals between 2005 and 2017, five studies employed mixed methods design and the remaining 15 used qualitative methods only for data collection and analysis (Table 3.1). The studies could be grouped into six broad categories around decision making: Every day decision making (n=9), proxy decision making (n=4), Advanced Care Planning

(n=3), gender categorisation in decision making (n=2), driving cessation (n=1), and financial management (n=1).

Figure 3.2. Flow chart for selection of papers.

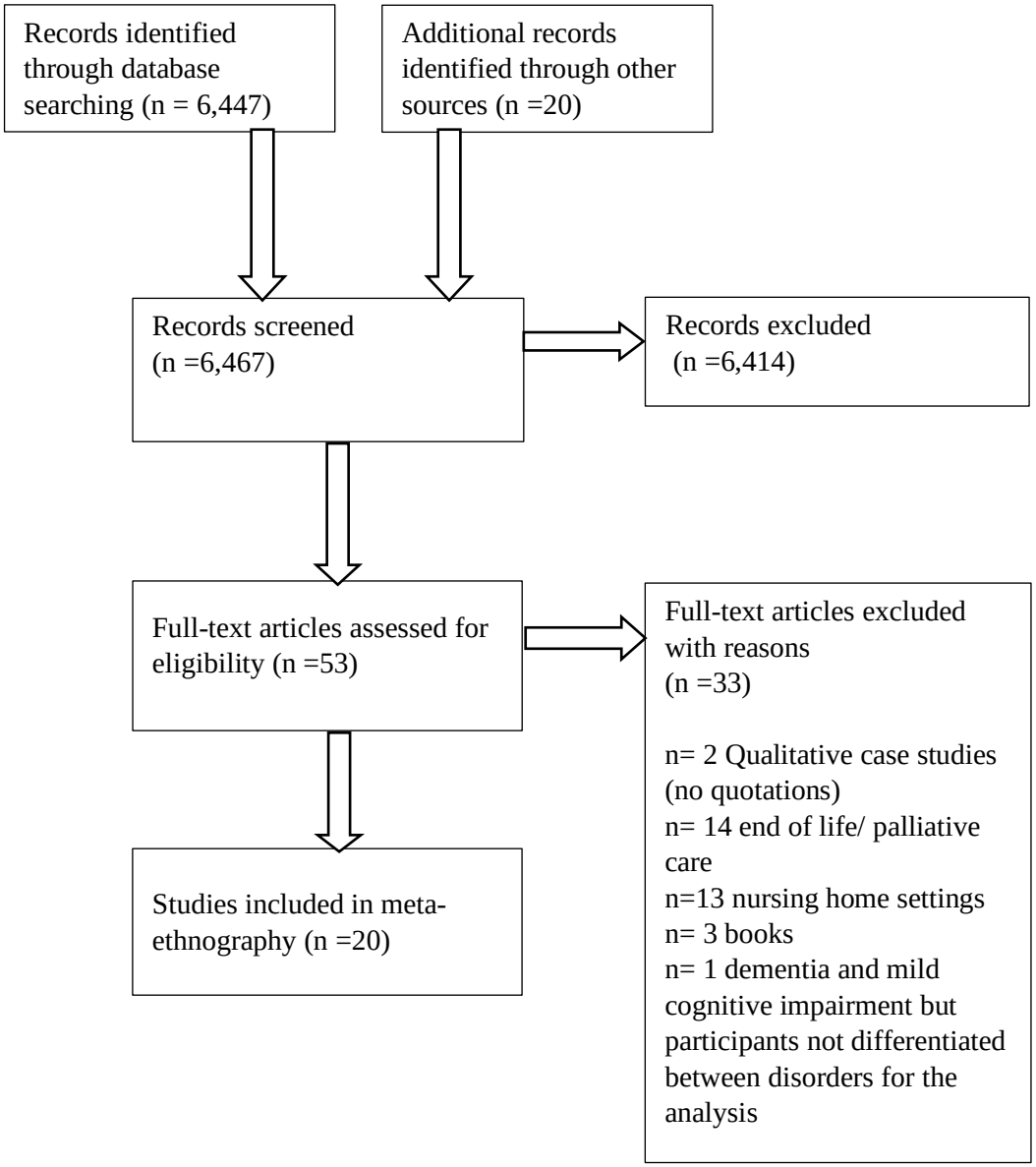


Table 3.1 Study characteristics (n=20).

Author	Year	Theoretical framework	Study design	Data collection	Data analysis	Focus	Participants
Adler	2010	Thematic analysis†	Mixed method	Focus groups	Deductive thematic analysis*	Driving cessation	65 participants PWD=20; FC=45
Bantry	2014	Grounded theory*	Qualitative	Semi-structured interviews	Grounded theory	Proxy decision making	FC=10
Berry	2015	Grounded theory*	Qualitative	Longitudinal individual interviews	Grounded theory	Proxy decision making	FC=15
Boyle	2013a	Thematic analysis†	Qualitative	Ethnographic observation and interviews	Thematic analysis	Financial management	42 participants (21 married couples)
Boyle	2013b	Thematic analysis[1]	Qualitative	Ethnographic observation and interviews	Thematic analysis; comparative analysis	Gender categorisation in decision making	42 participants (21 married couples)
Boyle	2014a	Thematic analysis[1]	Qualitative	Ethnographic observation and interviews	Thematic analysis; comparative analysis	Every day decision making	42 participants (21 couples)
Boyle	2014b	Thematic analysis†	Qualitative	Ethnographic observation and interviews	Thematic analysis	Gender categorisation in decision making	42 participants (21 couples)
Couture	2012	Symbolic interactionism[1]	Qualitative	Longitudinal individual interviews	Grounded Theory (comparative analysis)	Advanced care planning	FC=18
Dickinson	2013	Thematic analysis[1]	Qualitative	Semi-structured interviews	Thematic analysis	Advanced care planning	46 Participants PWD=17; FC=29

Fetherstonhaugh	2013	Phenomenology[1,2]	Qualitative	Individual interviews	Phenomenological analysis	Everyday decision-making	PWD=6
Fetherstonhaugh	2016	Thematic analysis†	Qualitative	Semi-structured individual interviews	Thematic analysis	Proxy decision making	FC=34
Groen-van de Ven	2017	Grounded theory[3]	Qualitative	Longitudinal individual interviews	Constant comparison content analysis	Every day decision making	113 Participants PWD=23 FC=44; PC=46
Harrison Dening	2016	Thematic analysis*	Mixed method	Semi-structured interviews	Thematic analysis	Advanced care planning	13 participants PWD=6; FC=7
Juárez-Cedillo	2013	Content analysis*	Qualitative	Individual interviews	Content analysis*	Proxy decision making	FC=8
Livingston	2010	Content analysis†	Qualitative	Group and individual interviews	Content analysis	Every day decision making	FC=89
Macquarrie	2005	Grounded theory[3]	Mixed method	Individual interviews	Constant comparative analysis	Every day decision making	PWD=13
Sampson & Clark	2016	Thematic analysis†	Qualitative	Individual interviews	Thematic analysis	Every day decision making	FC=9
Samsi and Manthorpe	2013	Thematic analysis†	Qualitative	Dyadic interviews	Thematic analysis	Every day decision making	30 participants PWD=15; FC=15
Smebye	2012	Hermeneutic interpretivism[1]	Mixed method	Semi-structured interviews and observation	Hermeneutic Interpretive analysis	Every day decision making	30 participants PWD=10 FC=10; PC=10
St-Amant et al.	2012	Critical ethnographic tradition[1]	Mixed method	Longitudinal semi-structured interviews	Theme development analysis	Every day decision making	41 Participants PWD=9 FC=25; SM=7

*Not reported in detail by the author(s). Paradigm: [1]Constructivist/Interpretive; [2]Descriptive/eidetic; [3]Positivism; [4]Pragmatism; Not reported[5] (Definition of paradigm informed by Mayan, 2016). †Thematic analysis/Content analysis is used as both theoretical framework and analytical method.

3.3.2 Quality appraisal

All studies were found of moderately high quality (range 0.63-0.87). It was relatively difficult to assess articles on the clarity of methods used for data collection and on the appropriateness of recruitment strategy, as the authors rarely reported on these aspects.

3.3.3 Meta-ethnography

Three third-order concepts emerged from the analysis, each reflecting a different pathway of decision making according to the degree of autonomy in the person with dementia: autonomous decision making, shared decision making, and pseudo-autonomous decision making. Each third order construct comprised theme categories as shown in Table 3.2. The conceptual map on decision making was reported in Figure 3.3. Although autonomous decisions could be made during any stages of the condition, it appeared that they were more likely to occur in early stages of dementia (Hirschman & Xie, 2004). Judging by the evidence gathered, people with moderate dementia are more likely to require a substantial support from their carers and to express their wishes and preferences through shared decision making. In advanced stages of dementia, when symptoms restricted the expression of agency, decisions tended to be made on behalf of the person, and this appeared to take place through pseudo decision making (Hirschman & Xie, 2004).

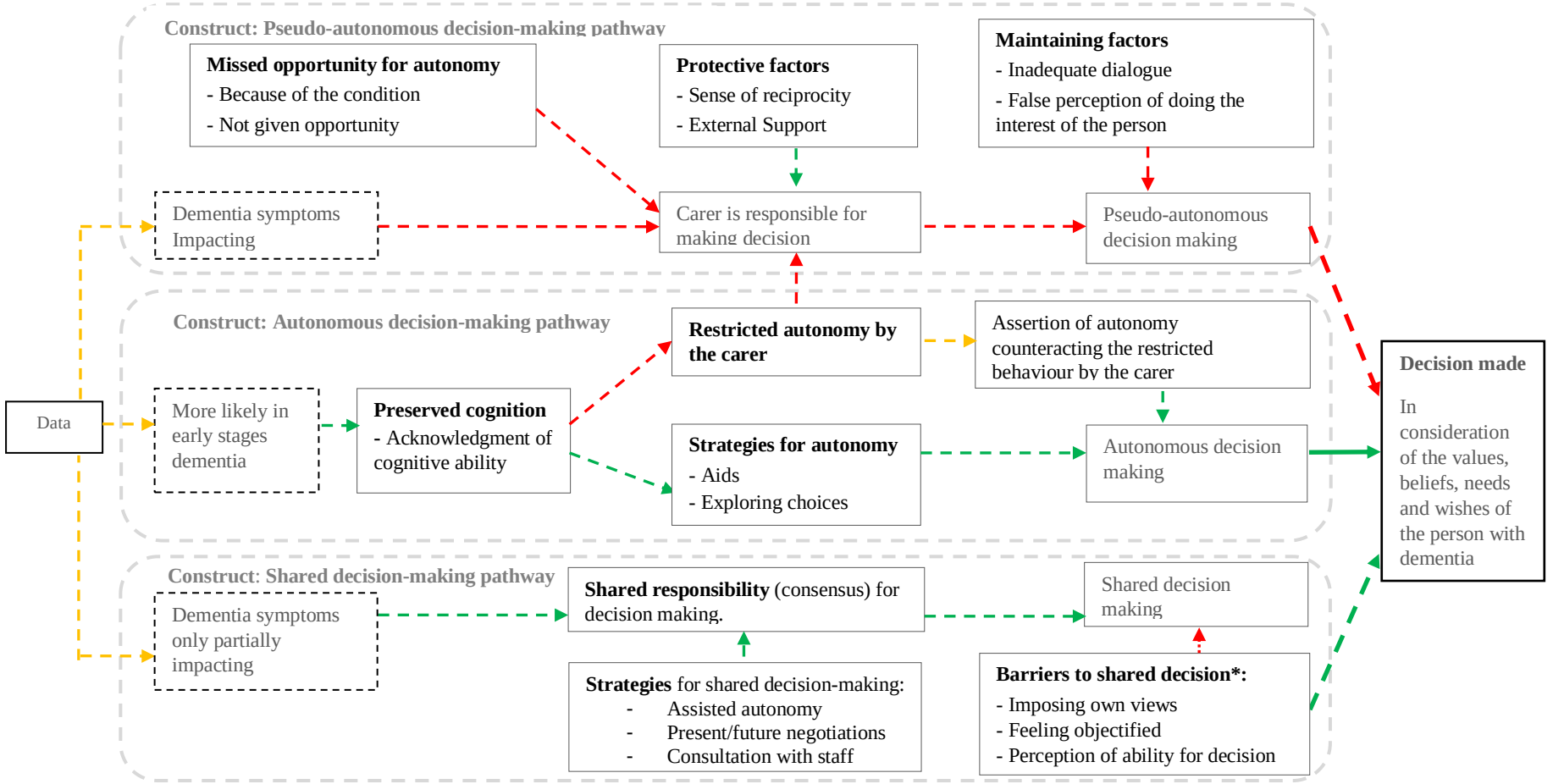
Following Lonergan's (2000) cognitive model, metacognition emerged as an enabler for people with dementia to practise their agency autonomously. Metacognition is a self-characterising process and comprising processes of self-awareness, self-monitoring, and making judgment with respect to a situation (Prinsloo & Barrett, 2017). Hence, metacognitive processes are predictors of capability (Prinsloo & Barrett, 2017).

Table 3.2 Meta-ethnography: Third order constructs.

Third order constructs	Theme Categories
Autonomous decision-making pathway	***Preserved cognitive ability***
	- *Acknowledgment of cognitive ability* (Smebye et al., 2012; Boyle, 2013a; Fetherstonhaugh et al., 2013).
	Strategies to promote autonomous decisions
	- *Aids* (Adler, 2010; Fetherstonhaugh et al., 2013; Livingston et al., 2010).
	- *Exploring choices* (Smebye et al., 2012; Boyle, 2013b; Boyle, 2014a; Fetherstonhaugh et al., 2016; Groen van de Ven, 2017; Dickinson et al., 2013; Berry et al., 2015).
	- *Assertion of autonomy* (White, and Montgomery, 2014; Berry et al., 2015; Macquarrie, 2005)
	Restricted autonomy by the carer (Bantry et al., 2014; Berry et al., 2015)
Shared decision-making pathway	***Shared responsibility***
	- Consensus decision (Groen-van de Ven, 2017; Harrison Dening et al., 2016; Samsi & Manthorpe, 2013)
	Strategies for shared decision making
	- *Assisted autonomy* (Bantry White and Montgomery, 2014; Smebye et al., 2012; Boyle, 2013b; Boyle, 2014b; Samsi & Manthorpe, 2013).
	- *Connecting present and future negotiations* (Smebye et al., 2012).
	- *Consultation with professionals* (Adler, 2010; Livingston et al., 2010).
	Barriers to shared decision making
	- *Imposing views on the person.* (Boyle, 2013b; Harrison Dening et al., 2016).
	- *Feeling objectified.* (Macquarrie, 2005; Sampson & Clark, 2016).
	- *Perception of ability for decision making.* (Smebye et al., 2012; Boyle, 2013b).

Pseudo-autonomous decision-making pathway	***Missed opportunity for autonomous decision***
	- *Not given opportunity* (Smebye et al., 2012; Boyle, 2013b; Boyle, 2014b; Fetherstonhaugh et al., 2013; Fetherstonhaugh et al., 2016; St-Amant et al., 2012; Sampson and Clark, 2016).
	- *Justified by the condition* (Smebye et al., 2012; Boyle, 2014b; Couture et al., 2012; Harrison Dening et al., 2016; Livingston et al., 2010; Samsi and Manthorpe, 2013; Juárez-Cedillo et al., 2013).
	Protective Factors
	- *Sense of reciprocity* (Juárez-Cedillo et al., 2013; Smebye et al., 2012; Boyle, 2013b; Samsi & Manthorpe, 2013; Sampson & Clark, 2016).
	- *External support* (Smebye et al., 2012; Couture et al., 2012; Livingston et al., 2010; Samsi & Manthorpe, 2013).
	Maintaining factors
	- *Inadequate dialogue* (Fetherstonhaugh et al., 2013; Fetherstonhaugh et al., 2016; Harrison Dening et al., 2016).
	- *False perception of doing the interest of the person* (Smebye et al., 2012; Harrison Dening et al., 2016; Sampson & Clark, 2016).

Figure 3.3 Conceptual map of decision-making pathways in dementia care.



3.3.4 Autonomous decision-making pathway

Autonomy is dependent on the preserved cognitive abilities in the person with dementia to effectively understand the situation and make a judgement over possible decisions, and on the strategies put in place to moderate the symptoms of dementia. The degree of assertion of autonomy in the person with dementia when making decisions, proves also key in determining their ability to express an autonomous response.

3.3.4.1 Preserved cognitive ability

During the early stages of dementia, having their cognitive abilities acknowledged helps contain the negative effects of cognitive decline and increase the opportunities to participate in deliberate decisions. The carer can help retain a positive view towards the selfhood of the person with dementia and extends opportunities for them to initiate social action:

'… She still does pay most of the bills…just said to her…'I haven't paid the water bill' and she says, 'oh, I've paid it'. (Family carer, p.557, Boyle, 2013a)

Acknowledging people with dementia as active agents can lead carers to negotiate between the actual ability of the person they care for and what is best to do to promote a sense of autonomy. This is especially found in decision making around activities promoting a sense of identity:

'I've thought about it [stopping driving] ... *He's already unhappy to lose a job.... And now for him on top of that to not being able to drive – it's not good.'* (Family carer, p.51, Adler, 2010)

The act of acknowledgement is not only external to the individual and promoted by others, but it is also self-directed. When people with dementia maintain positive

views around their 'ability of being', they are more likely to engage in social action. Self-awareness with respect to cognitive impairment is associated with the ability to effectively engage in autonomous decision making. As such, the person is able to experience the context by consciously assessing the risk before making a final decision: '*I still drive, although, by the way, I wouldn't drive today!'* (Person with dementia, p.147, Fetherstonhaugh et al., 2013).

A powerful sense of one's autonomy may struggle against awareness of the dementia diagnosis when a person considers their own capacity for self-determination:

'…I'm in complete control of my own, whatever I want, intend to do... So I don't have any sense of being lost control of my actions or my thoughts…if that's what you do if you've got Alzheimer's…What is [sic] the traits of Alzheimer's?' (Person with dementia, p.437, Macquarrie, 2005)

3.3.4.2 Strategies to promote autonomous decisions

Autonomous decisions seem to rely on certain support strategies that are either self-enacted (i.e. by the person with dementia) or carer-enacted. These strategies target the metacognitive regulation process to effectively orientate, monitor, and test the response to the event (Brand-Gruwel et al., 2009).

People with dementia make use of aids to enact their agency and to mediate their cognitive decline. Self-enacted strategies also increase a sense of independence (Fetherstonhaugh et al., 2013). A person with dementia used a daily diary and monitoring, and testing processes were key for her to make plans:

'It jogs the memory all the time. 'Oh I remember we had that heavy rain', and 'The cleaning lady came'. If I didn't have this little book, I'd be lost.' (Person with dementia, p.147, Fetherstonhaugh et al., 2013)

The use of technology can also be crucial to orientate oneself in regard to the situation. Likewise, carer-enacted strategies aim to instil a sense of autonomy in the person with dementia. For example, in order to maintain independence in the person with dementia, a carer decided to *'make a point of riding with him at least once a week just, you know, for my own benefit of making sure that he's still in command of the vehicle.'* (Family carer, p.51, Adler, 2010)

Collaboration between the carer and the person with dementia seems to be key to maintaining agency. The collaboration should ideally aim at supporting the person without directing them, and at making shared decisions. A common adaptive strategy among carers, is to decrease the number of choices, and limit the decision only to the most important matters.

As explained by some authors, in certain cases people with dementia are still able to convey their wishes despite lacking capacity at the time the decision needs to be taken. This occurs through formal directives prepared in advance to represent the will of the person in anticipation of cognitive decline and consequent loss of mental capacity, known as advanced care planning.

As part of their advanced care planning, people with dementia are often required to express their preferences around residential accommodation well ahead of time. Exploring alternatives for future care can confront a person with the real challenges that dementia poses on their life:

'I have no thoughts of going into care but… I know that there's every possibility like other people I could have to go into care and I think about it'. (Person with dementia, p.2017, Dickinson et al., 2013).

3.3.4.3 Restricted autonomy by the carer

At times the challenges posed by dementia impact on the overall quality of making deliberate decisions. Bantry et al. (2014) explain that carers may feel the need to prioritise the safety of the person they care for, even if this means restricting their freedom of choice and right for privacy. The authors report the use of GPS to locate their loved ones as a common tracking aid, even if its use was not previously discussed with the person:

'If she knew it was in there there's a possibility she would take it out because she wouldn't know what it was' (Family carer, p.227, Bantry et al., 2014).

These behaviours on the part of the carers may impact on the autonomy of the person with dementia and lead to pseudo decision making (Berry et al., 2015), whereby all decisions are effectively made by the carer and passively experienced by the person with dementia.

However, Macquarrie (2005) explains that there are strategies employed by the person with dementia to avoid being objectified and retain power for decision making. These include expressing an assertion of autonomy:

'I stand up for myself more. Like when (spouse) says something about ''We'll do it another time. We don't need them right now.'' Well I mean I might just say, ''Well, I'm going out for a walk.'' And I'd end up down at the store buying what I want anyway.' (Person with dementia, p.433, Macquarrie, 2005).

As explained by a person with dementia, asserting own independence: '*keeps my independence. It makes me independent. Rather than have somebody say, 'Well we will pick them up next week.'That annoys me. Cause if I want them, I want them now.'* (Person with dementia, p.433, Macquarrie, 2005).

3.3.5 Shared decision-making pathway

This third-order construct describes the instances when the person, because of the symptoms of dementia, needs some external support to fully express agency. A sense of autonomy may still be promoted through shared decision making; however, the degree of involvement of people with dementia depends on the amount of control they relinquish, on whether strategies are employed to sustain their independence, and on the presence of factors that may prevent them from making deliberate choices.

3.3.5.1 Shared responsibility

Being supported in practising agency requires people with dementia to accept the perspective of the carer in regard to the situation and to relinquish some of their decision power. This perspective-taking process becomes key to retaining agency when the person's ability for self-regulation is affected by dementia:

'I probably take more advice than I used to. I used to be quite bombastic about it: "No, we'll put up number 2 and that's it!" Now, it's: "Well I think number 2, what do you reckon lads?" (Person with dementia, p.148, Fetherstonhaugh et al., 2013)

Shared views are key to finalising social actions. Consensus may be reached by both agents, and its importance may influence the cognitive appraisal of the situation:

'Well, we discuss it for a start and see what each one would say and then decide to come to a decision' (Person with dementia, p.7, Harrison Dening et al., 2016)

Samsi and Manthorpe (2013) suggested that to preserve autonomy in the process of making choices, consensus is to be reached by acknowledging each other's needs. This can be achieved through knowing the person for a long time (e.g. being married

for many years) or through employing an altruistic stance in the relationship, whereby some of the wish for control is released:

'... I like being at home. We [wife and him] ...decide what we're going to do all day…but if she has one of her Ramblers' (organized walking in countryside) outings, I don't stop her.' (Person with dementia, p.955, Samsi & Manthorpe, 2013).

3.3.5.2 Strategies for shared decision making

Just as in autonomous decision making, certain strategies can be identified in the process of making shared decisions. Carers have a key role in supporting the autonomy of the person with dementia. They may, for instance, offer encouragement to engage in tasks requiring a level of perception and understanding of the situation that is adequate to their capabilities.

When the situation requires skills that do not match with the cognitive ability of the person, a strategy to support autonomy is to break down the process of decision making into a series of steps.

To support the cognitive performance of the person with dementia, a further strategy deployed by formal and informal carers is to create structured contexts, whereby the practice of agency becomes function of previous knowledge and negotiations. For instance:

'It is Friday today and on Fridays we have an agreement about showering. Look at your plan for the week written on your board. Come let me help you!'
(Community nurse, p.12, Smebye et al., 2012)

At times, decisions are taken out of the hands of the person with dementia, and carers may turn to health professionals to defray the damage that this could cause to

their relationship with the individual with dementia. A husband of a driver with dementia felt: *'I think it's better for the doctors to do it, you know, to tell her not to drive anymore.'* (Family carer, p.54, Adler, 2010)

This is decision making shared between the carer and the professional, but the involvement of the person with dementia is absent and assumptions are made about her wishes.

3.3.5.3 Barriers to shared decision making

A person's autonomy can be threatened in instances when the carer or the health professional impose their views, when the person with dementia feels objectified, or when there is a mismatch between the actual capabilities of the person with dementia and what others think the person is able to do. These factors, if not addressed, may lead to pseudo-decision making.

The role of professionals can negatively impact on the relationship between a person with dementia and the family carer. This has been reported when the support of the professional does not match with the awareness that the person with dementia has of the situation, for instance:

'[O]ur primary physician . . . said to my husband I don't think you should continue to drive.... And he [driver] was mad at me after the visit because I am the one who told the doctor he [driver] shouldn't drive.' (Family carer, p.54, Adler, 2010)

Dementia symptoms may affect the structuring cognitive process of people delivering care and lead to biases. This affection is reported in the ability of carers to discriminate between tasks that the person with dementia is able to undertake and leads to generalisations around their ability to promote social change (Boyle, 2013b).

These beliefs may lead carers to being more controlling and people with dementia to feeling objectified:

'Annoying thing is she keeps me under observation. Probably a lot to do with household survival.' (Person with dementia, p.432, Macquarrie, 2005)

When the factors that prevent shared decision making outweigh the opportunities for this, then individuals with dementia may be subjected to pseudo-autonomous decision making.

3.3.6 Pseudo-autonomous decision-making pathway

In pseudo-autonomous processes of decision making the carer takes full responsibility to make decisions on behalf of the person with dementia. As explained by Smebye, Kirkevold, and Engedal (2012), through this process, the preferences, views and needs of the person with dementia are only indirectly considered, and decisions are *'implicit rather than explicit'*. This decision-making pathway represents instances of missed opportunity for social action, when maintaining factors promote the lack of autonomous decisions.

3.3.6.1 Missed opportunity for autonomous decision

Receiving a diagnosis of dementia is often associated with decreased agency in people with dementia, as they are offered less and less opportunities for social action. Having fewer opportunities affects the decisional power of the person with dementia, who may become a passive recipient of the carer's will. This may be especially relevant in cases where power imbalance already occurred in the relationship before diagnosis.

Pseudo-autonomous decisions are made also when people with dementia are still able to practise their agency, but because of their decreased cognitive abilities, it

would take time for them to express themselves and for this reason, carers perform agency on their behalf:

'...She's rather slow at describing what I can do in six words. I then let the doctor take over but I'm the one who goes in and says 'right, she's having difficulty with her knee...' (Family carer, p.233, Boyle, 2013b).

Gaining more decisional power in the presence of cognitive impairment creates a power imbalance within the care dyad, whereby the carer can become a depository of agency:

'But I mean he would come and say 'anything I can do?' I mean he'd come in the kitchen ...and I say, 'well, I've done it now, thank you', you know.' (Family carer, p.342, Boyle, 2014b).

Some authors report cases when the person with dementia opts out of some social action when aware of their progressive cognitive decline:

'I think gradually ... I have, um ... opted out of major decision-making ... I'm not taking as much responsibility for our lives...It seems to be the natural thing ... As though it's evolved ...' (Person with dementia, p.7, Harrison Dening et al., 2016).

There were examples of choice being restricted by organisational policies, communicated by professionals, with the effect of disempowering the person with dementia and even causing distress:

'We had a meeting with the social worker and he stated that if we did not want to place her, she had to go two times per week at the day hospital for activities. It was chaos because we had to go there in the morning to get her ready.' (Family carer, p.287, Couture et al., 2012).

3.3.6.2 Protective factors

The outcome of pseudo decision making may be positive when choices are made in concert with the views and preferences of the person with dementia. A sense of reciprocity has been reported as a function of quality in decision taken on behalf of the person (Boyle, 2013b). In addition, when agency is ascertained through a range of modes of communication (e.g. through smile to indicate preference), there is increased likelihood of reaching adequate levels of information to ensure that the wishes and needs of the person with dementia are met:

'Yeah, I'd ask her and she'd say, she wouldn't really answer 'yes' or 'no', but she might smile or something like that.' (Family carer, p.233, Boyle, 2013b).

Pseudo decision making is mainly reported in advanced dementia or at times of mental health crises, when a lack of capacity shifts responsibility for making decisions from the person with dementia to the carer or the health professional. Couture, Ducharme, and Lamontagne (2012) present the role of health care staff as 'guarantors of quality' for such care decisions, especially at times when the carer becomes disorientated by the variety of choices being explored:

'I talked to the social worker because they didn't know whether or not she would be institutionalized since she was very confused. They said they don't want to remove elderly persons from their current environment because a change in living environment makes them deteriorate faster.' (Family carer, p.287, Couture et al., 2012).

3.3.6.3 Maintaining factors

It is important to report that there are maintenance factors to pseudo autonomous decision making, which are mainly found in instances when there is inadequate

communication between the person with dementia and the carer about the choice to make or when there is a false belief held by the carer over the wishes of the person with dementia.

Smebye et al. (2012) highlighted how in the presence of important health care decisions that may impact on the life of the carers, choices tend to respond to the carers' needs, rather than those of the person with dementia. For instance, when inquired about the change of residential accommodation from home to nursing care setting for the person with dementia, a carer responded:

'I'm not quite ready for that yet! ... I always need something to do. If not, time passes by so slowly.' (Family carer, p.6, Smebye et al., 2012).

3.4 Discussion

This review explored how intrapersonal and interpersonal factors impinge on the quality of making autonomous decisions.

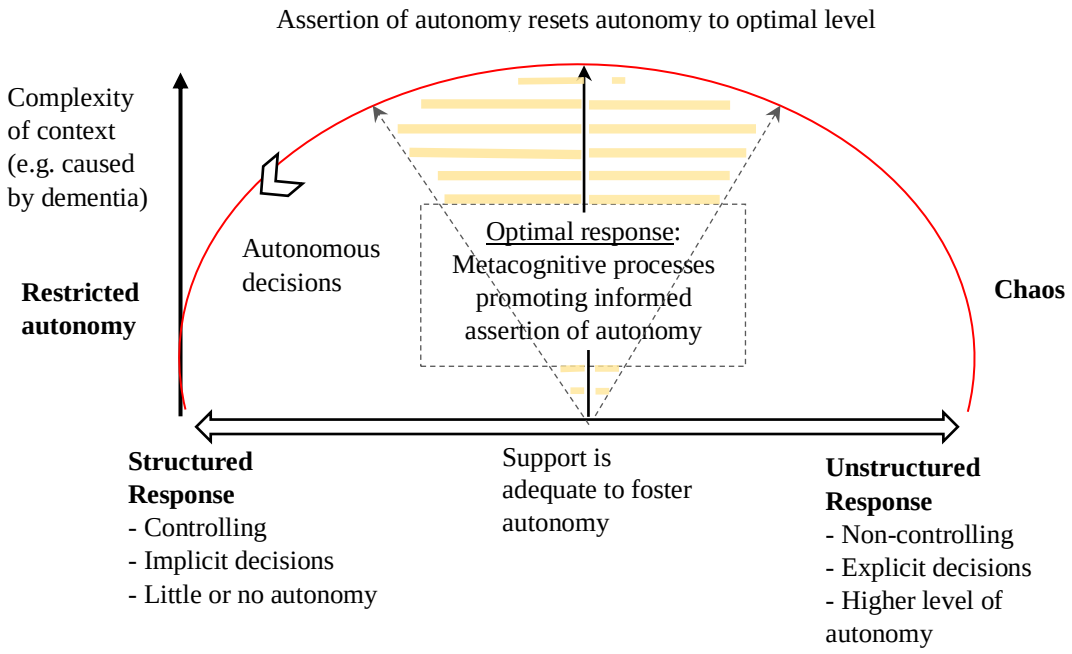
3.4.1 Line of argument

Through meta-ethnography we found three different pathways, each influenced by the degree of autonomy of the person with dementia: autonomous decision-making pathway, shared decision-making pathway and pseudo autonomous decision-making pathway. The ability of the person to engage in either pathway is time-bound, hence influenced by the stage of dementia and the physical/behavioural symptoms experienced (e.g. episodes of crises). In addition, we found that the agency of people with dementia is a function of the quality of care they receive and is mediated by the level of ability of the person to engage in metacognitive processes of self-awareness, monitoring and regulation. These metacognitive processes are essential for the quality of assertion of autonomy practised by the person with dementia, as poor self-

awareness with respect to the situation but high assertive response for autonomy may lead to risky and poorly judged decisions.

When the organisational model by Jones (1997) is applied to our findings (Figure 3.4), the negotiation around autonomy between the agents in care is explained as an inverted pendulum that shifts from a structured controlled environment (on the left side of the model) to a complete unstructured environment (right side of the model). An optimal point is reached when the autonomy of the person with dementia is promoted through adequate support and when people with dementia are aware of what they are able to do. This process of self-awareness enables the person to self-regulate with respect to the situation, to practice an adequate level of assertion of autonomy, and to ask for adequate levels of support. The less the ability to engage in the meta-cognitive process of self-regulation the less the likelihood to retain autonomy and make positive deliberate choices.

Figure 3.4 Metacognitive model of self-regulation in decision making (informed by Jones, 1997).



3.4.2 Tripartite negotiations in complex social contexts

Our findings also evidenced that there is constant negotiation between the agents in care (i.e. the person with dementia, the carer, and the health or social care professional). In concert with information systems research and cognitive system theories (Gimpel, 2008; Kristensen & Gärling, 1997), we found that tripartite negotiations differ in degree and require different distribution of powers among the agents. Each agent's position in negotiations depends on the degree of autonomy exercised by the person with dementia.

It follows that, in autonomous decision making, little or no negotiation is needed, as the person with dementia is able to practise agency with little support. The power retained by the person with dementia exceeds the control that others assert over him or her. Metacognitive processes help factor in the changes occurring as a consequence of dementia and assist the person to monitor and regulate themselves in regard to the decision to be made. Chaos is avoided when there is self-awareness. However, the more complex the situation requiring a decision, the more complex the metacognitive processes involved.

In shared decision making, the degree of negotiation is higher and requires a shift of power in favour of the carer. Entropy is avoided when both the carer and the person with dementia adapt dynamically to the situation and when agreement is reached. Here a perspective-taking process needs to be fostered in which both agents in care self-regulate their own responses with respect to the situation and consider each other's perspective. Shared decision making is characterised by a constant search for balance to deal with the complex decision in hand.

In pseudo decision making, the person with dementia retains little or no power to negotiate and the professional and family carer effectively become decision makers by proxy. Pseudo decision making occurs in structured and complex care contexts where mental capacity is lacking. Entropy is avoided when decisions find common ground between the parties concerned and reflect the wishes and needs of the person with dementia. This can sometimes be encouraged through attending to non-verbal modes of communication.

3.4.3 Time ordering and fourth age in dementia care

Decision making in dementia gains a time-ordering effect, as the extent to which the person engages in autonomous decisions is bound to the stage of the condition and episodes of crises. This time-ordering effect has favoured the development of the social discourses around the fourth age (Higgs & Gilleard, 2015) and the linked associations of old age, dementia, lack of volition and autonomy. We believe that such social imagery construed around the new contextualisation of ageing, highly impacts on the degree to which agency is practised by people approaching later stages of life. The social imaginary of the fourth age, denotes the unknown nature of old age and it is in contraposition with the cultural dynamics of the third age characterised by ‘personal fulfilment and autonomy’ (Gilleard & Higgs, 2010). This significantly affects the way agency in dementia is promoted at different levels of society (i.e. within the community and in social and health policy).

3.4.4 Strengths and limitations

This review is the first to explore the impact of metacognitive processes on the practice of autonomy in the person with dementia, and how the role of carers and health professionals influences the outcomes of decision making through negotiation. Its strengths include the use of a powerful search strategy and in the

systematic screening of articles conducted independently by two researchers. In addition, the quality of the findings of the meta-ethnography was checked by three experts in dementia care and old age psychiatry.

Limitations are acknowledged in the use of the CASP checklist for qualitative studies, as its methods-oriented approach to screening may not be appropriate for studies employing different epistemological paradigms. A possible limitation is the use of 'negotiation' as concept to describe the interaction between the participants, as this term denotes a dynamic exchange occurring in complex care contexts. This assumes a relatively equal distribution of power, but the actual trend is a decrease of power of the person with dementia as the disease progresses.

3.5 Conclusions

Our analysis helps increase the understanding of the role of the carer in the decision-making process. It identifies strategies (e.g. the use of daily diaries to help make plan, technology for orientation in the environment) that may help to prevent the disempowerment of people with dementia and to promote their autonomy. It also highlights potentially-detrimental tendencies that can operate and mechanisms, as reported in Figure 3.3 that may act as promoters and barriers to autonomy in decision making. These mechanisms, positive and less, could potentially be addressed through training (e.g. assertiveness courses to deal with restrictive and controlling environments). It may also be possible to take account of this tripartite formulation of decision pathways in the implementation of the Mental Capacity Act, for example, or in the implementation of advanced directives.

Chapter 4. Dementia care model: Promoting personhood through co-production

Bosco, A., Schneider, J., Coleston-Shields, D. M., & Orrell, M. (2018). Dementia care model: Promoting personhood through co-production. *Archives of gerontology and geriatrics, 81*, 59-73. https://doi.org/10.1016/j.archger.2018.11.003

Abstract

Background. Despite robust evidence on its effectiveness, current approaches that aspire to person-centred care (PCC) frequently locate people with dementia as passive recipients rather than as active agents in the care process. We define active involvement in care as 'co-production'. In order to investigate co-production, we set out to review the evidence concerning personhood and dignity in dementia care.

Method. We adopted a meta-ethnographic approach to synthesise the predominantly- qualitative literature on personhood and dignity in dementia care using EMBASE, PsycINFO, and ASSIA databases. We also included relevant policy documents. Members of Patient and Public Involvement (PPI) group were consulted throughout.

Results. A total of 14 empirical studies were subjected to content analysis. Three themes were identified: dignity and personhood, coping with dementia, and barriers to dignity in care. The findings suggest that positive strategies and coping mechanisms are associated with superior outcomes in relation to: sense of self, dignity and quality of care. The 22 policy documents yielded six themes pertaining to co-production: the part played by the person with dementia, family, environment, behaviour, civil rights, and health care partnership.

Conclusion. Personhood in dementia care is enhanced through co-production, by actively participating in social, civic and political life. This is promoted through behavioural changes at the micro and macro levels of society, including providers of care being trained in co-producing care and policy makers creating opportunities with, rather than for people with dementia.

4.1 Introduction on personhood in dementia care

According to estimates, over 47 million individuals worldwide are living with dementia (WHO, 2017). Given the progressive cognitive impairment that dementia entails, people living with the condition have often been divested of their identities and their roles in society, even before the cognitive impairment disables them from self-expression and social participation (WHO, 2017). Consequently, the entitlement of individuals with dementia receiving care to exercise autonomy and choice has frequently been overlooked.

Person-centred care (PCC) has become synonymous with high standards of care in dementia, promoting decision-making and user engagement in health care planning (Kitwood, 1997). PCC aims to promote the personhood of the person with dementia through an existentialist and humanistic consideration of their needs, values and beliefs (Kitwood, 1997). Successive models have tried to expand on Kitwood's framework, acknowledging the role of other agents in promoting personhood through care (i.e. the family or close social network) (Brooker, 2004). These models are grounded in the principles of social reciprocity, whereby all agents involved in the process of care influence each other and care outcomes through continuous social interaction. Despite the advances ensured by further development of the PCC framework, however, people with dementia have reported feeling passive recipients, rather than active agents, in the process of care (Armstrong, 2011). Examples of

inadequate standards of care devaluing the self of the person with dementia and failing to meet their individual needs may be exacerbated in the context of hospital admissions, where staff may adopt a medical paradigm and objectify people with dementia in the process of care, thus failing to acknowledge their human rights:

'Her family complained that their mother's care and treatment in hospital were inappropriate. They felt her care had been ignored due to her Alzheimer's and provided us with examples of her being treated with disrespect; these included being washed with the curtains drawn back and being left sitting in faeces during visiting time'. (Armstrong & Byrne, 2011, p. 13).

The excerpt above reflects circumstances whereby, although the person with dementia was at the core in the delivery of care, as it is widely acknowledged in contemporary social and health care (Higgs & Gilleard, 2016), such centrality did not necessarily entail promotion of the person's dignity and personhood. This is also an example of the lack of autonomy and choice. A culture of care for people with dementia that permits such circumstances to occur points to a gross power imbalance between carers and cared-for, despite the lip-service paid to PCC. One challenge to redressing this imbalance is how to ensure that people with dementia are granted a truly active role and equal positioning in the delivery of care.

In this review, we define active engagement of people with dementia in terms of co-production, which according to the definition suggested by the SCIE (2013) it is *'a meeting of minds coming together to find a shared solution'.* Ecological system theory provides the theoretical foundation to explain how personhood of the person with dementia can be promoted across different care systems as the person is enmeshed in different contexts or systems. Each system is not disjointed from the other, and the person finds her/himself simultaneously influenced by them. These

systems represent different environments from the micro ecosystem of the home to the outward system of the community (e.g. Alzheimer's café) moving towards more outward levels of societal involvement (e.g. government).

4.1.1 Study aims

In this paper, we aimed to develop indicators for best PCC practice in dementia care through a synthesis of evidence on personhood in dementia.

4.1.2 Methods

As promoting personhood and dignity in dementia care has potential implications for research, policy and practice, it is of relevance to academics, policy makers, practitioners and members of the general public, so the research team felt that a holistic approach to the topic should be taken. The team comprised researchers and clinicians operating in the health and social care sector who consulted with members of the public who volunteered to advise on the topic. Four phases of knowledge appraisal and theory development were undertaken: a systematic review on personhood and dignity in dementia that could explore examples of good and bad practice in dementia care (phase 1), a scoping review of policy documents around the preservation and promotion of either concepts (phase 2), the development of an integrated model of care ensuing from the findings of the two reviews (phase 3), and the validation of the model through consultation with members of the patient and public involvement group (PPI) (phase 4).

4.2 Phase 1. Systematic review on personhood in dementia care

The review complied with the PRISMA checklist (Moher, Liberati, Tetzlaff, & Altman, 2009). We followed the PICO format to determine our search strategy (Sackett, Richardson, Rosenburg, & Haynes, 1997).

4.2.1 Inclusion and exclusion criteria

The study explores the concept of personhood and employs either a qualitative method or mixed method for data collection and analysis with direct quotes of participants. The study focuses on the positive factors (i.e. promoting/maintaining personhood) or negative factors (i.e. undermining personhood). The study is on dementia without comorbid organic disorders.

Owing to the overlapping use of the terms ‘dignity’ and ‘personhood’, and their highly relatedness (Jacobsen, 2007), studies focusing on the preservation of dignity (both when reporting on how dignity helps support personhood and/or when exploring uniquely the promotion of dignity) were included when emerging from our search. Any language and publication year.

The Study is excluded if not empirical, (e.g. review, commentary, editorial, discussion paper), when not clearly reporting on personhood and/or dignity. The study is further excluded when is on palliative care, as the preservation of personhood and dignity may require more focussed and individualised strategies during the end of life care.

We ran searches on three databases, each from a relevant discipline: EMBASE (Medicine), PsycINFO (Psychology) and ASSIA (Social Sciences). The defining domains of our search were based on the concepts of dementia (i.e. dement* or Alzheimer*); personhood/dignity (i.e. personhood, self, selfhood, identit* or dignity); preservation (i.e. sustain* or maintain* or preserv*). We adapted the terms according to the characteristics of the individual databases. We further considered the first 100 hits on Google scholar and Google search to retrieve relevant grey literature.

The lead author (AB) undertook a two-stage process for the identification of articles to include in the review. The screening process was attained through the electronic databases used for the retrieval of the studies and comprised the following stages: 1) the titles and abstract of the articles were first screened against the inclusion/exclusion criteria of the review, 2) when the articles appeared relevant to the scope of the study, a second systematic screening was made and consisted in reading their full text against the inclusion/exclusion criteria. Upon completion of the screening process, for the included studies, information was extracted into NVivo 11 (QSR International Pty Ltd., 2012) on study design, qualitative method and methodology, theoretical framework used for the concept of personhood, participants' demographics and area of investigation.

Although the search terms were in English and this may have automatically excluded studies published in other languages, we found that the majority of the articles we found in other languages were accompanied by an English abstract. This allowed us to include/exclude articles in the first screening process. A strategy was in place to involve foreign translators in case a study was found relevant for our review.

We conducted a quality appraisal of the articles through the Critical Appraisal Skills Programme (CASP) checklist for qualitative research (CASP-UK, 2018). The first two items of the CASP checklist were used to exclude articles, if they did not clearly report on the aims of their investigation (item 1), and when the methodology they used was not appropriate for their research inquiry (item 2). The remaining eight items of the checklist were used for quality screening only.

4.2.2 Data analysis

We used meta-ethnography for the extraction and synthesis of qualitative data and followed the seven steps by Noblit and Hare (1988) to reach third order interpretations deriving from the first and second order constructs reported in the studies. Meta-ethnography proves effective when developing theoretical models from interpretation of qualitative findings across studies (Atkins, Lewin, Smith et al., 2008), as it is in our interpretative analysis on the experience of people with dementia and their carers in regard to personhood and dignity in care.

As part of the analysis, the lead author (AB) extrapolated the relevant direct quotes from study participants (first order construct) and their interpretation as given by the authors (second order construct) and coded these into text units (by sentences). Constant comparative analysis was then employed to develop theme categories from first- and second-level interpretations. Constant comparative analysis enabled us to reach an understanding of social reality through generating concepts across studies (Charmaz, 2006).

The process of interpretation and synthesis was reviewed within the research team over several meetings, until consensus was reached. The research team included professionals with expertise in old age psychiatry, social care, and neuropsychology with a focus on dementia care. A final expressed synthesis included a graphic representation for clarity in interpretation of our findings.

4.3 Phase 2. Scoping review on personhood and dignity in dementia – policy documents

We conducted a systematic search on governmental/policy documents (i.e. white papers, policy briefs) on dignity in care and personhood by searching for the terms

‘dignity’, ‘personhood’ and ‘dementia’ on the full databases on the NICE (National Institute for Health and Care Excellence), SCIE (Social Care Institute for Excellence), EUROPA (European Commission), UNECE, United Nations (Economic and Social Council), and Google web platforms. We further contacted members of the Global Action on Personhood (GAP) from participating countries (Italy, Canada, Japan, Norway, Singapore, and Spain) to ensure that existing relevant policies were not excluded from the search. A first screening was attained through the electronic databases and conducted by the lead author (AB). All policies were considered when meeting the inclusion criteria, be it issued at provincial level or national level. After the first screening, policies were screened against the inclusion/exclusion criteria and included if relevant to the scope of the review. When a policy at provincial/county level was found to replicate the national policy of the country in question, only the national policy was included. This did not apply to European and international policies as we found they contained different or more comprehensive information compared to country-specific policies. However, they were still screened against the inclusion/exclusion criteria.

4.3.1 Inclusion and exclusion criteria

The document is national guidance, a position statement such as a white paper or policy briefing (e.g. governmental report). It concerns personhood, or dignity in dementia care and has been issued in the period 2007 to 2017, as policies and health care guidelines may change overtime. The document is in English and has been issued by any government with diplomatic recognition (United Nations, 2017).

The document is on palliative care, an adapted report from sources previously published from other governmental agencies, or a green paper. Updated versions of

the same policy document were considered as secondary sources and were included only if adding new information.

4.3.2 Data Analysis

We conducted a conventional inductive content analysis (Graneheim & Lundman, 2004), which is ideal in topic areas when the understanding of a phenomenon is fragmented and broad (Graneheim & Lundman, 2004), as it is the case of dignity and personhood in dementia care policy. The analysis comprised the following steps:

1) Familiarising with the content;
2) In-depth reading of the documents to generate meaning units;
3) Discussing within the research team the relevance and accuracy of the meaning units;
4) Developing themes and subthemes.

Any disagreement around themes and subthemes within the research team were resolved by consensus. We followed the criterion of credibility as described by Lincoln and Guba (1985) to reach study's rigour through the use of analyst triangulation by having members of the research team check the initial interpretations.

4.4 Phase 3. Development of an integrated model of care

Following findings from the reviews carried out in phase one and two, we developed an integrated model which aims at co-production in the delivery of care in dementia, where all agents involved are granted equal consideration of their personhood. The model takes into consideration human psychological needs as proposed by Kitwood (1997) and is grounded in Bronfenbrenner's framework of the self as situated in an ecological systemic parlance of life organisation (Bronfenbrenner, 1979). This

theory was adopted for it helps describe the role of the person with dementia in society and helps factor in the different contexts whereby s/he operates.

4.5 Phase 4. Consultation with members of the PPI group

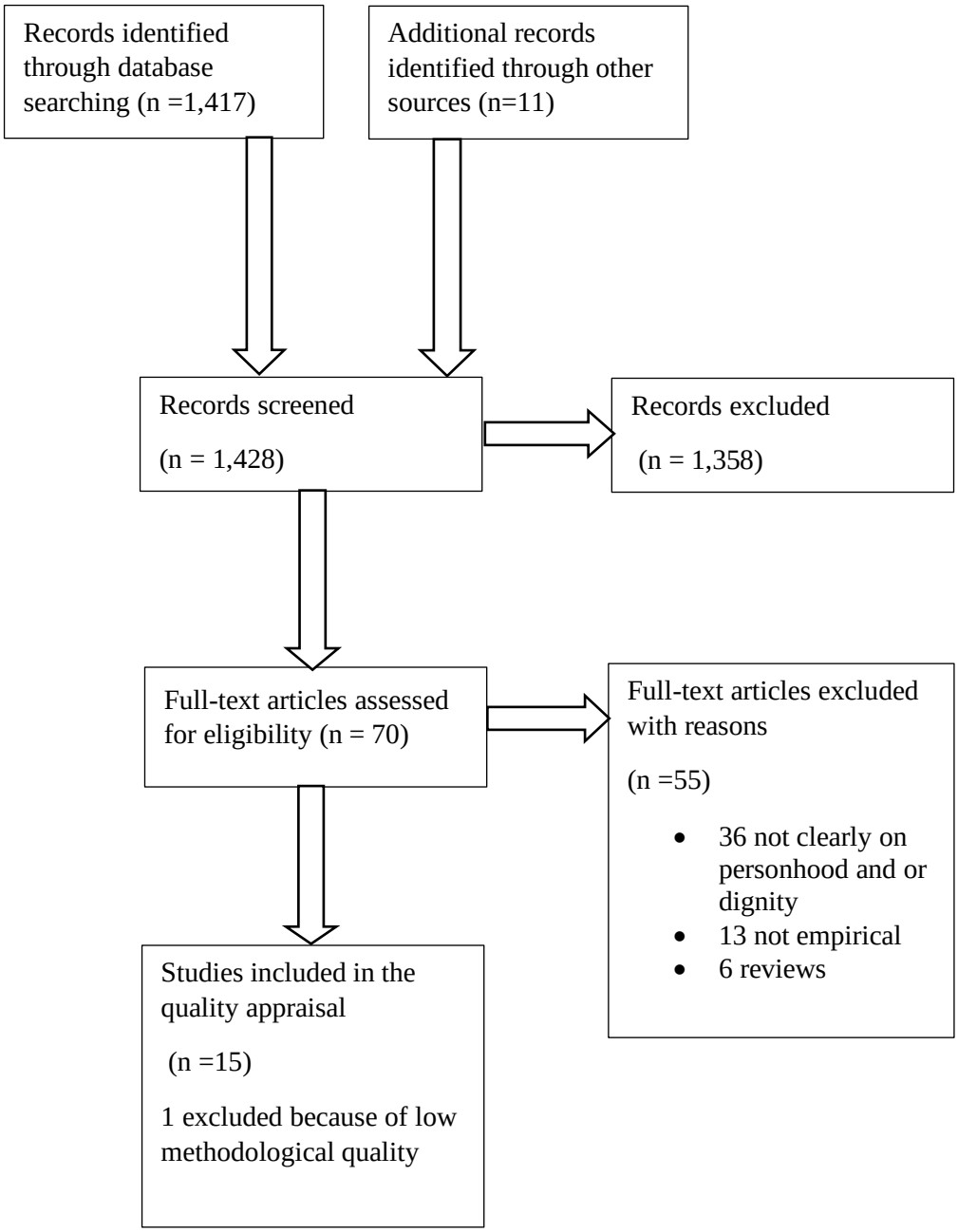
The study was discussed at two PPI sessions, comprising people with dementia and their carers who were already part of an established PPI group at the Institute of Mental Health, Nottingham. The first session involved the development of the questions that we later used in the second session to gather views on the relevance, feasibility and coherence of the model of care we developed. Examples of the questions discussed during the meeting were: 'do you think that these findings reflect the everyday life needs and preferences of people with dementia and their carers? If yes, in what ways?' A second meeting took place two weeks later to comment on the actual findings of the paper by means of the pre-developed questions.

4.6 Results

4.6.1 Phase 1. Systematic review and meta-ethnography on personhood in dementia

The systematic search initially retrieved 1,417 studies. We identified 11 additional records through Google. Of 1,428 records, we excluded 1,358 sources, which were clearly ineligible. The full texts of remaining 70 articles were assessed for eligibility against the inclusion/exclusion criteria. We excluded 55 articles, thus including a final number of 15 articles for the quality appraisal. The selection process is reported in Figure 4.1 through a PRISMA flow diagram (Moher et al., 2009).

Figure 4.1 Flow chart for selection of papers.



4.6.1.1 Quality Appraisal

Fifteen studies were appraised for their quality using CASP (Table 4.1). One study was excluded as it did not clearly report the aims, the qualitative methods for data collection and information on data analysis. Overall, the 14 studies included were found to be of moderate-good quality (scores ranging 6-9 out of 10). We found it challenging to score the studies in relation to reporting bias (item 6) (e.g. the authors commenting on potential bias ensuing from their involvement in the study and in the development of questions for the interviews) as 11 out of 15 studies did not clearly report on this. In addition, discussing ethical issues (item 7) was the second least reported item of information across studies and this information was missing in 9 out of 15 studies.

4.6.1.2 Study Characteristics

The studies selected were all published in peer reviewed journals from 2002 to 2017 (Table 4.2 for single study characteristics). Three studies were conducted in the UK, four in Canada, two in the USA, two in Norway and one each in Sweden, Australia and the Netherlands. A total of 251 participants were recruited (people with dementia: n=112, age=60+; carers: n=114, age=40+; health staff: n= 25, age=30+). Most studies approached their investigation from the perspective of personhood (n=12), and the remainder framed their enquiries with the concept of dignity (n=2). The studies used qualitative methodology. With respect to data collection, the most frequently used methods were one-to-one interviews (n=12) and participant observations (n=3), the most used method for data analysis, was interpretative phenomenological analysis (n=4). Most studies explored the experience of residential care (n=7), community living (i.e. person accommodation) (n=5), only

one study did not clearly report the setting and one included both participants from residential care and community living.

Through the analysis we found preliminary themes around community belonging, activity involvement, and accessibility of the environment, the role of social networks, the function of interaction, active participation, and preservation of dignity. From these initial theme categories, we then reached our third order constructs, which represented our interpretation of the material.

Table 4.1 CASP Checklist – Quality appraisal of studies (n=15).

Studies	**CASP**											
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Include**	**Exclude**
Dran	Y	Y	Y	Y	Y	Can't tell	**N**	**N**	Y	**N**	X	
Haggerstad, Nortvedt, & Slettebø	Y	Y	Y	**N**	Y	Y	Y	Y	Y	Y	X	
Hung, Chaudhury	Y	Y	Y	Y	Y	**N**	**N**	Y	Y	Y	X	
Milte et al.	Y	Y	Y	Y	Y	**N**	**N**	Y	Y	Y	X	
Nowell, Thornton, & Simpson	Y	Y	Y	Y	Y	**N**	Y	Y	Y	Y	X	
Palmer	Y	Y	Y	Y	Y	**N**	**N**	**N**	Y	**N**	X	
Perry, & O'Connor	Y	Y	Y	Y	Y	**N**	**N**	**N**	Y	Y	X	
Phinney, Dahlke, & Purves,	Y	Y	Y	Y	Y	**N**	**N**	**N**	Y	Y	X	
Surr	Y	Y	Y	Y	Y	**N**	**N**	Y	Y	**N**	X	
Tolhurst &Weicht	Y	Y	Y	Y	Y	Y	Y	Y	Y	**N**	X	
Tranvag, Petersen, & Naden	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	X	
vanGennip et al.	Y	Y	Y	Y	Y	**N**	**N**	Y	Y	Y	X	
Vézinaa, Robichaudb, Voyerc, & Pelletier	Y	Y	Y	Y	Y	**N**	**N**	Y	Y	**N**	X	
Vittoria	**N**	Y	**N**	**N**	Y	**N**	Y	**N**	**N**	**N**		X
Zingmark, Sandman, & Norberg	Y	Y	Y	Y	Y	**N**	Y	Y	Y	Y	X	

Table 4.2 Study characteristics (n=14).

Author	**Year**	**Country**	**Study design**	**Published venue**	**Theory on Personhood/ dignity**	**Qualitative methods of data collection**	**Qualitative methods of data analysis**	**Sample demographics**
Dran	2008	USA	Qualitative	Journal	Personhood (Kitwood 1997)	One-to-one interviews	Narrative analysis (Vignette)	N=3 staff (residential care)
Haggerstad, Nortvedt, & Slettebø	2015	Norway	Qualitative	Journal	Person-centred approach and relationship cetred approach (Kitwood, 1997; Nolan, Davies, Ryan, and Keady, 2008)	Multi method Participant observation One-to-one semi structured interview	3-steps of analysis (Kvale & Brinkmann, 2009)	N=22 PWD= 15 Aged 70+ Carers= 7 (Female=5) (residential care)
Hung & Chaudhury	2011	Canada	Qualitative	Journal	Kitwood's (1997) approach	- participant observations, -focus groups	integrated deductive–inductive approach*	N= 20 PWD Aged 70+ (residential care)
Milte et al.	2015	Australia	Mix-method	Journal	Kitwood and Bredin (1992) 'Twelve indicators of well-being in dementia'	-In-depth one-to-one semi structured interviews - focus groups	Thematic analysis constant comparative analysis (Richards, 2005).	N=41 PWD=15 (Female=9) Mean age=79(SD=11) Carers=26 (Female=18) Mean age=75(SD=9) (residential care and community living)

Nowell, Thornton, & Simpson	2011	UK	Qualitative	Journal	(Bradford Dementia Group, 1997; Kitwood, 1998)	One-to-one semi-structured interviews	Interpretive Phenomenological analysis	N=7 PWD Aged (60+; Mean=74) (not clearly reported)
Palmer	2013	USA	Qualitative	Journal	Kitwood, (1997)	One-to-one open ended structured interviews	Interpretive phenomenology analysis*	N=15 carers Aged 40+ (residential care)
Perry, & O'Connor	2002	Canada	Qualitative	Journal	Social constructionist perspective	One-to-one unstructured interviews	Constant comparative analysis (Strauss & Corbin, 1990)	N=38 carers (Female=26) (community living)
Phinney, Dahlke, & Purves,	2013	Canada	Qualitative	Journal	Kitwood 1997	Multi method: One-to-one in depth interviews Dyadic interviews Group interviews Participant observation	Interpretive phenomenological analysis (IPA)	N=7 PWD=2 (all males) Carers=5 (all female) (community living)
Surr	2006	UK	Qualitative	Journal	socio-biographical theory of self *	One-to-one unstructured interviews	interpretive biographical analysis	N=14 PWD (Female=13) Aged 70+ (residential care)
Tolhurst &Weicht	2017	UK	Qualitative	Journal	Higgs & Gilleard, 2015.	Semi structured dyadic interviews	Narrative analysis (Riessman, 2008)	N=14 dyads (Aged 50+) (1 same sex dyad) (Female=13) PWD=14 (all males) (community living)

Tranvag, Petersen, & Naden	2014	Norway	Qualitative	Journal	Dignity in care	One-to-one semi structured interviews	Interpretive hermeneutic analysis Gaidys (2003)	N=11 PWD (community living)
vanGennip et al.	2016	Netherlands	Qualitative	Journal	Kitwood and Bredin 1992*	One-to-one in-depth interviews	Thematic analysis Braun & Clarke, 2006 Constant comparison analysis (Strauss & Corbin, 1990).	N=14 PWD Aged= 50+ (Female=6) (community living)
Vézinaa,, Robichaudb, Voyerc, & Pelletier	2011	Canada	Qualitative	Journal	Kitwood 1997	One-to-one semi directive interviews	Manifest content analysis*	N=21 carers and health care professionals Carers=9 (Female=7) (Aged 40+) Health care professionals = 12 (Female=11)* (residential care)
Zingmark, Sandman, & Norberg	2002	Sweden	Qualitative	Journal	Dignity in care	One-to-one semi structured interviews	Interpretive phenomenological analysis (Soderberg, 1999; Talseth et al., 1999)	N=10 staff (Nurses) (Aged 30+) (residential care)

*Not clearly stated/no further information was provided.

4.6.1.3 Meta-ethnography

Three levels of third-order constructs emerged from the analysis of 14 studies (Table 4.3): (i) dignity and personhood, (ii) coping with dementia, (iii) barriers to dignity in care. The expressed synthesis of our findings is reported in Figure 4.2.

4.6.1.4 Dignity and personhood

This theme pertains to a range of variables involved in the preservation of dignity and of strategies employed to promote personhood in the person with dementia.

Dignity and its preservation.

Dignity is an abstract term and there is no consensus over its meaning. When inquired about how they conceive of dignity, people with dementia gave differing views based on their personal life experiences (VanGennip et al., 2016). Some attached a feeling of loss to the concept of dignity:

'Dignity means you can be yourself, you're still in control of your own thoughts, you can do what you want…But I'm not like that anymore.' (person with dementia) (vanGennip et al., 2016, p. 494).

A sense of belongingness to family and a social role within the wider community seem to preserve dignity and a meaning to one's life, as much as engaging in meaningful activities:

'Yes, digging in the garden... It really does me good. I worked in the garden yesterday or the day before…And it makes me feel so much better' (person with dementia) (vanGennip et al., 2016, p. 494).

Strategies to promote personhood.

The environment plays an important role in promoting personhood in the person with dementia. For example, large spaces, low staffing or a noisy environment can be counterproductive (Hung & Chaudhury, 2011).By contrast, large windows and natural light have been found to promote a sense of wholeness with nature and the outdoors, especially for those who are not able to spend time outside. When living in residential care, a home-like environment appears to be beneficial. Therefore, residents are sometimes encouraged to personalise rooms. The impact of the physical environment is reported by several members of staff in care homes, who acknowledge that rooms where pleasant activities take place are favoured over others (Milte et al., 2015).

Family carers contend that behaviour and attitude on the part of the staff are also crucial to preserve dignity and personhood:

'They [people with dementia] need to be confirmed all the time, so that they may feel that they are individuals, and human beings' (Carer) (Haggestad, Nortvedt, & Slettebø, 2015, p. 833).

Family carers seem to appreciate when their loved ones are treated with respect:

'She's [a carer's mother] respected as the person she is; they don't treat her as a 'demented person' in a wheelchair who isn't able to move.' (Carer) (Haggestad, Nortvedt, & Slettebø, 2015, p. 833).

An effective way for staff to promote dignity in care is promoting human connectedness with gestures of affection, which show heartfelt commitment to their emotional wellbeing (Hung & Chaudhury, 2011) or by behaving kindly while maintaining eye contact when speaking to the person, to show they are valued as

human being (Hung & Chaudhury, 2011). Good interaction is further promoted by using positive statements during the conversation, as these may encourage the person with dementia to remain engaged.

4.6.1.5 Coping with dementia

This theme relates to a series of mechanisms acted out by the person with dementia to cope with the condition, and a series of techniques used by the carers to improve the experience of dementia in their loved ones.

Coping with one's own identity.

Being with peers was found to help some people with dementia safeguard a positive sense of identity: *'I've found that people here are like me, that aren't sure about what is going on... it makes me feel saner.'* (Person with dementia) (Nowell, Thornton, & Simpson, 2011, p. 403). However, residents may not always be willing to engage with peers, as they may feel a lack of empathy, given the highly subjective experience of the condition. Carers can also help promoting a positive sense of identity for the person with dementia by avoiding pointing out any inconsistencies between past and present events. In fact, the fluidity between past and present typical of dementia may prove beneficial for some people with dementia, who resort to the memories of past events to find strategies to cope with the issues of the 'here and now' (Phinney, Dahlke, & Purves, 2013).

Active engagement is also found to be instrumental in preserving one's own identity, as it gives continuity to life before and after the diagnosis of dementia (Milte et al., 2015). Given that the person with dementia may still be active, it is important to promote self-agency by finding suitable activities. A lack of stimulation may otherwise lead to apathy (Milte et al., 2015). Quite crucially, a person's condition

may fluctuate over time and staff need to be prepared to grasp any opportunity for the person to get active (Zingmark, Sandman, & Norberg, 2002).

Family carers' perspective.

The family carers reported feeling a duty of care towards the relative with dementia, especially in the presence of marital vows:

'Because I'm taking care of a person I feel I have to, because he's my husband. And it was a commitment I made.' 'So I'm bound by that commitment.' (Carer) (Perry & O'Connor, 2002, p. 56).

The family carers felt that maintaining a positive view of the person by recollecting memories helps them deal with the present care duties:

'*He was an excellent dancer… And the first five years of our marriage we danced every week…He always helped cook, he always helped.* (Carer) (Perry & O'Connor, 2002, p. 56).

In order to support the preservation of self-worth in their relative, family carers sometimes justify the person's behaviours, making excuses for their diminished cognitive abilities or compensating for their lack of mental capacity (Perry & O'Connor, 2002). Another strategy is to operate on the environment, as explained by one carer:

'*He's always wanting to wash dishes. Yesterday I let him wash a whole bunch of stuff that was already washed but [I just gave him the] plastics, you know.'* (Carer) (Perry & O'Connor, 2002, p. 58).

4.6.1.6 Barriers to dignity in care

This theme includes negative intrapersonal and interpersonal factors which can negatively affect the personhood and dignity of residents with dementia.

Intrapersonal factors.

Trying to fit in with the system's regime and rules of care homes may create barriers to expressing one's own identity and impact on the experience of care. A resident reported:

'You're living by their rules and regulations. You have to abide by their rules and regulations and I think that confines everybody in here to those aspects.' (Resident) (Nowell, Thornton, & Simpson, 2011, p. 399).

Another resident acknowledged that the rigidity of rules affected his self-determination:

'It's a lot of filling up time here, you have to do as you're told. You can't always have your own way.' (Person with dementia) (Nowell, Thornton, & Simpson, 2011, p. 400).

External factors.

The conduct of staff has consequences on the quality of care provided. For example, the members of staff may engage in mechanical behaviours which devalue the person's dignity:

'They are sitting and feeding a person… just mechanically put something into the resident's mouth. It's terrible!' (Carer) (Haggerstad, Nortvedt, & Slettebø, 2015, p. 835).

Another example of negative behaviour includes members of staff showing no interest in engaging in conversation with the person, while carrying out daily tasks:

[Staff]: 'Are you finished? [Resident]: What? What? [Before the resident has finished asking the question, the staff left] (Field notes) (Hung & Chaudhury, 2011, p. 5).

Quality of care is also negatively impacted by the patronising culture of some members of staff, which is reflected in the statement:

'To me, residents are like babies. I feed them, clean them, and put them to sleep.' (Hung & Chaudhury, 2011, p. 7).

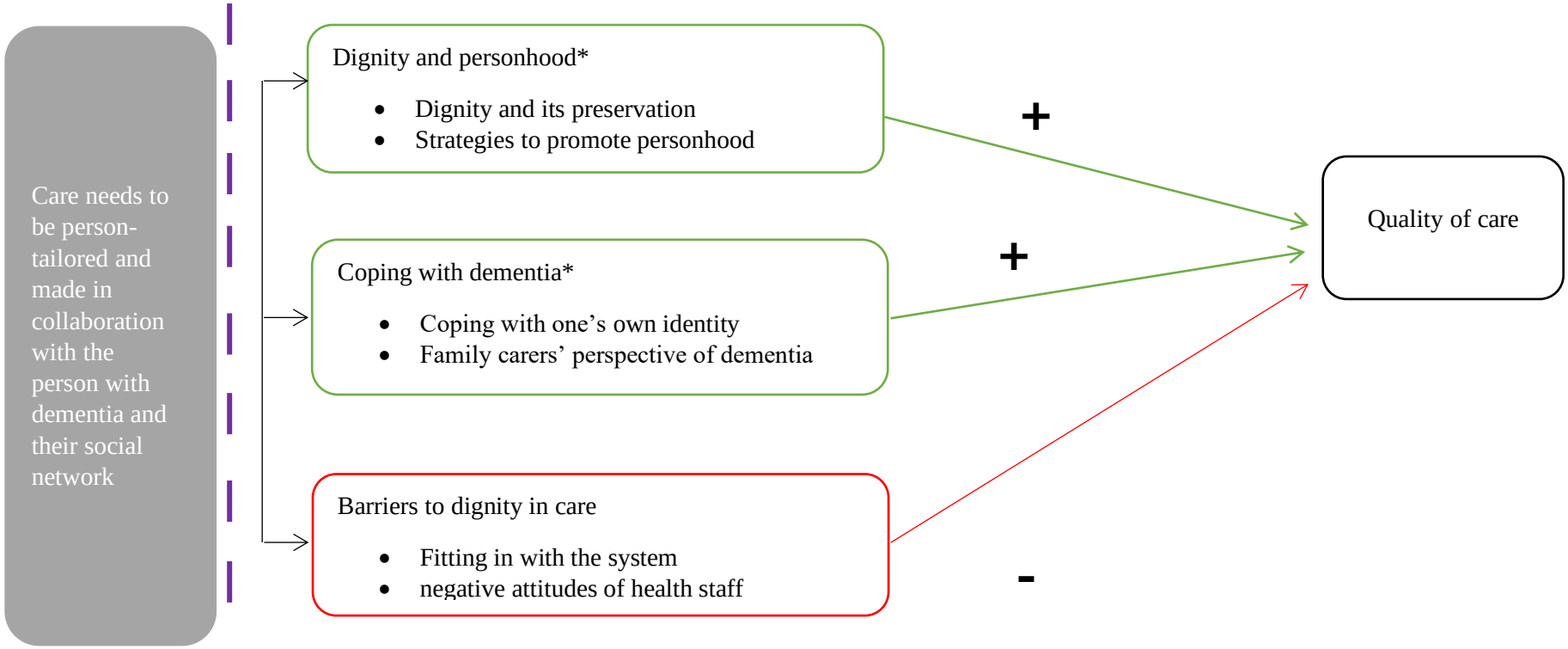
A classic example of a patronising interaction with a person with dementia was reported by Hung and Chaudhury (2011):

[Resident]: I need to use the bathroom. [Staff]: No, you don't. You just went not long ago. Now, it's time to eat, you eat! (Field notes) (Hung & Chaudhury, 2011, p. 5).

Table 4.3 Third order construct for the Meta-ethnography of the studies.

Third order constructs	**Categories**	**Themes**
Dignity and personhood	Dignity and its preservation	• Community belongingness (vanGennip et al., 2016) • Activity involvement (vanGennip et al., 2016)
	Strategies to promote personhood	• Environmental factor (Hung & Chaudhury, 2011; Milte et al., 2015; Zingmark, Sandman, & Norberg, 2002) • Quality of interaction (Dran, 2008; Haggerstad, Nortvedt, & Slettebø, 2015; Hung & Chaudhury, 2011; Zingmark, Sandman, & Norberg, 2002) • Social inclusion (Milte et al., 2015; Hung & Chaudhury, 2011; Haggerstad, Nortvedt, & Slettebø, 2015; Tolhurst & Weicht, 2017)
Coping with dementia	Coping with one's own identity	• Social network (Nowell, Thornton, & Simpson, 2011; Surr, 2006) • Dealing with past/present roles (Dran, 2008; Nowell, Thornton, & Simpson, 2011; Phinney, Dahlke, & Purves, 2013; Tranvag, Petersen, & Naden, 2014) • Active engagement (Milte et al., 2015; Palmer, 2013; Tolhurst & Weicht, 2017; Zingmark, Sandman, & Norberg, 2002)
	Family carers' perspectives	• Feeling a duty of care (Perry & O'Connor, 2002) • Maintaining a positive view of the person (Perry & O'Connor, 2002) • Justifying behaviours/cognitive decline in dementia (Vezina et al., 2011) • Manipulating the physical environment (Perry & O'Connor, 2002)
Barriers to dignity in care	Factors	• Negative attitudes of health staff (Haggerstad, Nortvedt, & Slettebø, 2015; Hung & Chaudhury, 2011; Milte et al., 2015; Palmer, 2013; vanGennip et al., 2016)

Figure 4.2 Expressed synthesis. Promoting dignity and personhood in dementia care.



*When positive strategies and coping mechanisms are present there is increased likelihood to experience better sense of self, dignity and have improved quality of care. Conversely, the more negative the barriers to dignity, the less positive the strategies and coping mechanisms, the less positive the quality of care experienced by the person with dementia and their carers.

4.6.2 Phase 2. Scoping review and content analysis of health care policy documents on personhood and dignity in dementia.

For our scoping review, we retrieved 482 documents. Based on our inclusion criteria, we selected 22 policy documents, which were published between 2009 and 2017 (Table 4.4).

Three documents were issued by the NICE, two by the UK Department of Health (DoH), one by the European Commission, one by the Mental Welfare Commission for Scotland, one by the World Health Organisation (WHO), one by the U.S. Department of health & Human

Services, one by the United Nation Economic Commission for Europe (UNECE), one by the Alzheimer's Europe, and one by the RTI International. One document was a collaboration between the National Institute of Health and Research (NIHR) and the UK Department of Health, and one between the National Health Service, AgeUK and the Local Government Association. We further retrieved one policy document from each of the following governmental offices: The Irish Department of Health, the Norwegian Ministry of Health and Care Services, the Maltese Parliamentary Secretariat for Rights of Persons with Disabilities and Active Ageing, the Italian Ministry of Health, the Flemish Ministry for Welfare, Public Health, and Family, the Ministry of Social Affairs and Health, Government of Gibraltar, the Israeli Ministry of Health, and the Dutch Ministry of Health, Welfare and Sport.

International policy was the aim of 9.1% (n=2) of the documents, while 81.8% (n=18) aimed at national policy (6 at the UK, 2 at the USA, and one at Australia), and 9.1% (n=2) at European policy. The majority (n=21) were easy to read and accessible to a non-expert audience, whereas one was in accessible format for people

with dementia (DH, 2009). The documents focused on the following topics: Dementia-friendly communities, health care needs in dementia, overview on dementia, quality care in dementia, dignity in dementia care, person-centred care in dementia.

Seven themes emerged from the content analysis (participation, family, environment, behaviour, policy and law, health care partnership, autonomy) and most themes comprised a variety of subthemes (Table 4.5). The frequency of the themes was evenly spread across documents, with the most frequent being 'environment', which was reported in 18 documents (81.8%). One theme, 'health care partnership' was reported in 16 documents (72.7%). Two themes (participation and family) were reported with the same frequency (n=15; 68.1%). The themes 'civil rights' and 'behaviour' were retrieved in 13 documents (59.1%) and ten documents (45.4%) respectively.

4.6.2.1 Participation

This theme refers to the active involvement of people with dementia in decision making and in the social, civic and political life (Irish Depart. of Health, 2014; Norwegian Min. of Health, 2015; Maltese Parliamentary Secretariat; 2014; Flemish Minister for Welfare, 2016; H M Government of Gibraltar, 2015; Dutch Ministry of Health, 2009). It further describes their active participation in the development of health care plans. (Alzheimer Europe, 2015; DoH, 2009; DoH, 2014; Mental Welfare, 2013; NHS AgeUK, 2012; NICE, 2013, 2017; Flemish Minister for Welfare, 2016).

Table 4.4 Documents selected for the scoping review (n=22).

Issuer	Document Title	Year	Type of document	Topic	Relevance
Alzheimer Europe	"Is Europe becoming more dementia friendly?"	2015	Dementia in Europe Yearbook 2015	Dementia-friendly communities	European level
Department of Health	"Living well with dementia: A National Dementia Strategy"	2009	National Dementia Strategy Accessible Summary	Health care needs in dementia	National level (UK)
Department of Health	"Supporting people with dementia and their families and carers"	2014	Victorian dementia action plan 2014–18	Health care needs in dementia	National level (Australia)
European Commission	"Implementation report on the Commission Communication on a European initiative on Alzheimer's disease and other dementias"	2014	Commission staff working document	Overview on dementia	European level
Flemish minister for welfare, public health, and family	Flanders dementia strategy 2016-2019 (Update of 2015-2020 strategy plan)	2016	National strategy report	Dementia-friendly communities	National level (Belgium)
Government of Gibraltar	National Dementia Vision and Strategy for Gibraltar	2015	National strategy report	Quality care in dementia	National level (Gibraltar)
Irish Depart. of Health	The Irish National dementia strategy	2014	National strategy report	Quality care in dementia	National level (Ireland)
Israeli Ministry of Health	Addressing Alzheimer's and other Types of Dementia: Israeli National Strategy	2013	Summary Document	Quality care in dementia	National level (Israel)
Italian Ministry of Health	The new Italian national strategy	2014	National strategy report	Overview on dementia	National level (Italy)
Mental Welfare Commission for Scotland	Dignity and respect: dementia continuing care visits	2013	Visit report	Quality care in dementia	National level (UK)

Ministry of Health, Welfare and Sport	Guideline for Integrated Dementia Care	2009	Governmental document	Quality care in dementia	National level (Netherlands)
Ministry of Social Affairs and Health	National Memory Programme 2012-2020	2013	Policy brief	Dementia-friendly communities	National level (Finland)
NHS, AgeUK, Local Government Ass.	"Delivering Dignity"	2012	Report on dignity in care	Dignity in dementia care	National level (UK)
NICE	"Dementia: independence and wellbeing"	2013	Quality standard report	Quality care in dementia	National level (UK)
NICE	"Dementia: supporting people with dementia and their carers in health and social care"	2016	Clinical guidelines (2006) updated in 2016	Quality care in dementia	National level (UK)
NICE	"Dementia overview"	2017	Governmental document	Quality care in dementia	National level (UK)
Norwegian Ministry of health and care services	Dementia plan 2020	2015	National plan report	Dementia-friendly communities	National level (Norway)
Parliamentary Secretariat for Rights of Persons with Disabilities and Active Ageing	National dementia strategy 2015-2023	2014	National plan report	Quality care in dementia	National level (Malta)
RTI International	"The Alzheimer's Voice: Person-Centred and Person-Directed Dementia Care"	2014	Report on Person-centred care	Person centred care in dementia	National level (USA)
UNECE	"Dignity and non-discrimination for persons with dementia"	2015	Policy brief	Dignity in dementia care	International level
U.S. Department of health & Human Services	National Plan to Address Alzheimer's Disease: 2016 Update	2016	National plan report	Health care needs in dementia	National level (USA)
WHO	"Dementia: A public health Priority"	2012	Policy report	Overview on dementia	International

Table 4.5 Frequency of themes across documents.

Themes (n=6) / **Subthemes (n=13)**	**Issuer**																					**N (%)**
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**19**	**20**	**21**	**22**	
Participation	x	x	x		x	x	x		x	x	x			x	x	x		x		x		x	***15 (68.1)**
- Active participation (social, policy)	x	x	x		x		x		x	x	x			x	x	x		x				x	13 (59.1)
- Self-agency (decision making, job, driving)	x	x	x			x	x		x	x	x			x				x		x		x	12 (54.5)
- Co-production in care	x	x	x		x	x	x		x									x					8 (36.3)
Family (e.g. carers' health)			x		x		x	x	x		x	x	x		x	x		x	x	x	x	x	**15 (68.1)**
Environment	x		x	x	x	x	x	x	x		x	x	x	x	x	x		x	x	x		x	***18 (81.8)**
- Care setting			x	x	x				x		x			x	x	x				x		x	10 (45.4)
- Transportation	x				x	x	x	x	x		x	x	x									x	10 (45.4)
- Support network	x		x	x								x		x	x	x		x	x			x	10 (45.4)
- Housing	x		x	x	x		x	x	x		x	x		x	x	x		x	x	x			9 (41)
- Outdoor space	x		x	x	x						x	x			x								7 (31.8)
Behaviour	x		x			x	x		x	x	x		x		x					x			***10 (45.4)**
- Communication						x	x			x			x	x	x								6 (27.2)
- Relationship	x		x				x		x	x	x		x	x	x								10 (45.4)
- Normalcy/Equality	x								x	x			x	x	x					x			7 (31.8)

Civil rights			x	x		x		x	x	x	x	x	x	x	x	x		x					***13 (59.1)**
- Lack of capacity			x	x					x	x	x	x	x	x	x	x							10 (45.4)
- Human rights (safety/independence)				x		x		x			x	x	x	x		x		x					9 (41)
Health care partnership		x	x	x	x	x		x	x		x	x		x		x	x		x	x	x	x	**16 (72.7)**

*This was calculated by considering when any of the related subthemes was present without summing all their frequencies as to avoid multiple counting.

1) Alz. Europe (2015) 5) Mental Welfare (2013) 9) NICE (2017) 13) WHO (2012) 17) Italian Ministry of Health (2014) 21) Israeli Ministry of Health (2013)

2) DoH (UK) (2009) 6) NHS AgeUK (2012) 10) RTI Int. (2014) 14) Irish Depart. of Health (2014) 18) Flemish minister for welfare (2016) 22) Dutch Ministry of Health (2009)

3) DoH (AU) (2014) 7) NICE (2013) 11) UNECE (2015) 15) Norwegian Min. of health (2015) 19) Finnish Ministry of Social Affairs (2013)

4) EU Comm. (2014) 8) NICE (2016) 12) U.S. DoH & HS (2016) 16) Maltese Parliamentary Secretariat (2014) 20) Government of Gibraltar (2015)

In people with dementia, dignity can be promoted through their engaging in meaningful roles in life, be it in the job market for those of working age, in advocacy projects (e.g. to promote emancipation, to fight off stigma), or helping in policy development. Examples of positive engagement included acting as volunteers in charities and advocacy groups, acting as representatives in the national, European Parliament, and international organisations, taking part in the development of programmes for 'Alzheimer's Cafes' and being part of self-help groups (UNECE, 2015; Alzheimer Europe, 2015; NICE, 2017; Mental Welfare Commission for Scotland, 2013).

While participation at national or international level was possible for only a small number of people with dementia, there is potential for all to be actively involved in the planning of their own care. The type of involvement is different at different points in the progression of the cognitive impairment. Advance care planning is advisable for people in the early stages so that their wishes are known when they can no longer express themselves (WHO, 2012).

This point has been addressed prominently across policies, due to a lack of perceived involvement by people with dementia (NICE, 2013, 2017). There is also a strong need of involvement in the delivery and evaluation phases of services, which seems more possible when the providers of care are adequately supported by the local authorities and health commissioners (NICE, 2013, 2017).

4.6.2.2 Health care partnership

This theme acts as an umbrella term to describe different types of partnerships: between health care professionals, between health care professionals and people with dementia and their families, between researchers and people with dementia and their

carers (NICE, 2016, 2017; UNECE, 2015; DoH, 2014; DoH, 2009). The focus is on integrating geriatrics with primary care services to increase health literacy among health professionals around the bio-psychosocial determinants of dementia; developing care services targeting the needs of the person with dementia and their carers at the individual, community and societal levels; delivering dementia friendly programmes to increase awareness in the community and reduce social exclusion (U.S. Department of health & Human Services, 2016); creating partnership between advocacy agencies and people with dementia to promote equality and social justice among those who have decreased or no capacity for their rights to be upheld.

The involvement of people with dementia and their carers in research is of the utmost importance for the assessment and delivery of health care services (Irish DoH, 2014; Maltese Parliamentary Secretariat, 2014; Finnish Ministry of Social Affairs, 2013; Government of Gibraltar, 2015; Israeli Ministry of Health, 2013; Dutch Ministry of Health, 2009). Therefore, policies strongly advocate for private and public investment in research.

4.6.2.3 Family

In most policies, dementia was regarded as a family condition owing to the negative implications it also has on the relatives. It is often the case that family members provide the most of care, thus being frequently exposed to increased burden and mental health problems (UNECE, 2015), which could all negatively impact on the quality of care provided for the person with dementia (Maltese Parliamentary Secretariat, 2014; Finnish Ministry of Social Affairs, 2013; Israeli Ministry of Health, 2013; Dutch Ministry of Health, 2009).

Strategies to support family carers in their journey into dementia are mainly focussed on support groups, information papers provided by local care agencies, engagement in advocacy and voluntary organisations, consultation with general primary care medical practices, and contributing to legal and financial information provided by advocacy groups (NICE, 2013, 2017).

Few policies (3 out of 22) address the importance of 'care plans for carers' that have potential to promote carers' dignity and preserve their identities. These plans comprise multiple elements based on group psychoeducational programs, peer support groups, easy access to web support programs through charities and voluntary organisations (e.g. Alzheimer's Europe), the involvement of other family members at health care meetings for people with dementia, and the employment of 'dementia buddies' for carers. Strategies to develop effective care plans for carers should be culture-sensitive (U.S. Department of Health & Human Services, 2016; NICE, 2013, 2017).

4.6.2.4 Environment

Policies used the term 'environment' to report on the quality standards and strategies needed to design dementia friendly settings (i.e. care settings, transportation, support network, housing and outdoor space) which promote dignity and a positive sense of self in people with dementia (Irish DoH, 2014; Norwegian Ministry of Health, 2015; Maltese Parliamentary Secretariat, 2014; Government of Gibraltar, 2015; Dutch Ministry of Health, 2009). Most strategies are consider accessibility (e.g. the use of sign posting, lighting, floor covering, and clutter-free rooms), the delivery of activities in the home of the person with dementia; and the use of assistive technology based on the preferences and needs of the person with dementia.

Strategies targeting community inclusion focus on social activity programmes (e.g. bridge club, writing groups, book clubs, choirs) which are run at Alzheimer's cafés, libraries, churches, or other community settings (NICE, 2017; UNECE, 2015; U.S. Department of Health & Human Services, 2016).

4.6.2.5 Behaviour

This theme refers to the style of communication between health professionals and people with dementia and their carers, to their quality of relationship, and to a series of behaviours acted out by health professionals that promote normalcy and a sense of equality in people with dementia (Norwegian Min. of Health, 2015; Government of Gibraltar, 2015).

The behaviours of health staff may be at times stereotyping, when they inadvertently exhibit courtesy-stigma (e.g. not allowing the person with dementia to be in the community to avoid stigma from a non-friendly environment). In fact, this approach may lead to negative outcomes, including social exclusion. To change staff attitudes towards dementia and promote positive relationships, policies set strategies targeting effective communication, dementia awareness and positive interaction with people with dementia. These policies advocate that the health organisations where health staff operate need to encourage positive behaviours and implement good training and consistent monitoring of performance. Training should prepare health staff to attend to the needs and preferences of people with dementia (e.g. being warm and empathetic) (NICE, 2017; RTI International, 2014; WHO, 2012). The benefits of these techniques are maximised when there is co-operation between staff, and when the same health care staff are matched consistently with the person with dementia.

4.6.2.6 Civil rights

This theme covers fundamental human rights warranting the attention of the general public, providers of care, and at a macro level, the attention of health commissioners and policy makers. This theme was used instrumentally across documents to differentiate the medical model from a 'human rights-centred approach', in which people with dementia are not divested of their rights to intimacy, self-agency, love and dignity in the care they co-produce (Irish DoH, 2014; Maltese Parliamentary Secretariat 2014; Flemish Minister for Welfare, 2016).

The documents further describe the key role of 'others' in the late stages of dementia, setting principles for good practice in guardianship (e.g. the person with dementia should be able to nominate at an early stage of the condition the person they prefer to act as guardian and they should be able to handle financial assets until capacity is compromised) (NICE, 2017, 2016; UNECE, 2015; RTI International, 2014; WHO, 2012).

4.6.3 Phase 3. Development of an integrated model of care

Owing to its complexity, the model consists of three sections informed by the ecological system theory by Bronfenbrenner (1979), by the concept of social reciprocity and dignity in care and by the indicators for the promotion of personhood ensuing form the findings of the systematic review on the qualitative evidence on personhood and dignity and the scoping review of policy documents on the promotion of personhood in dementia care. The model is illustrated in Figure 4.3.

4.6.3.1 Dementia dyad living in an ecological system

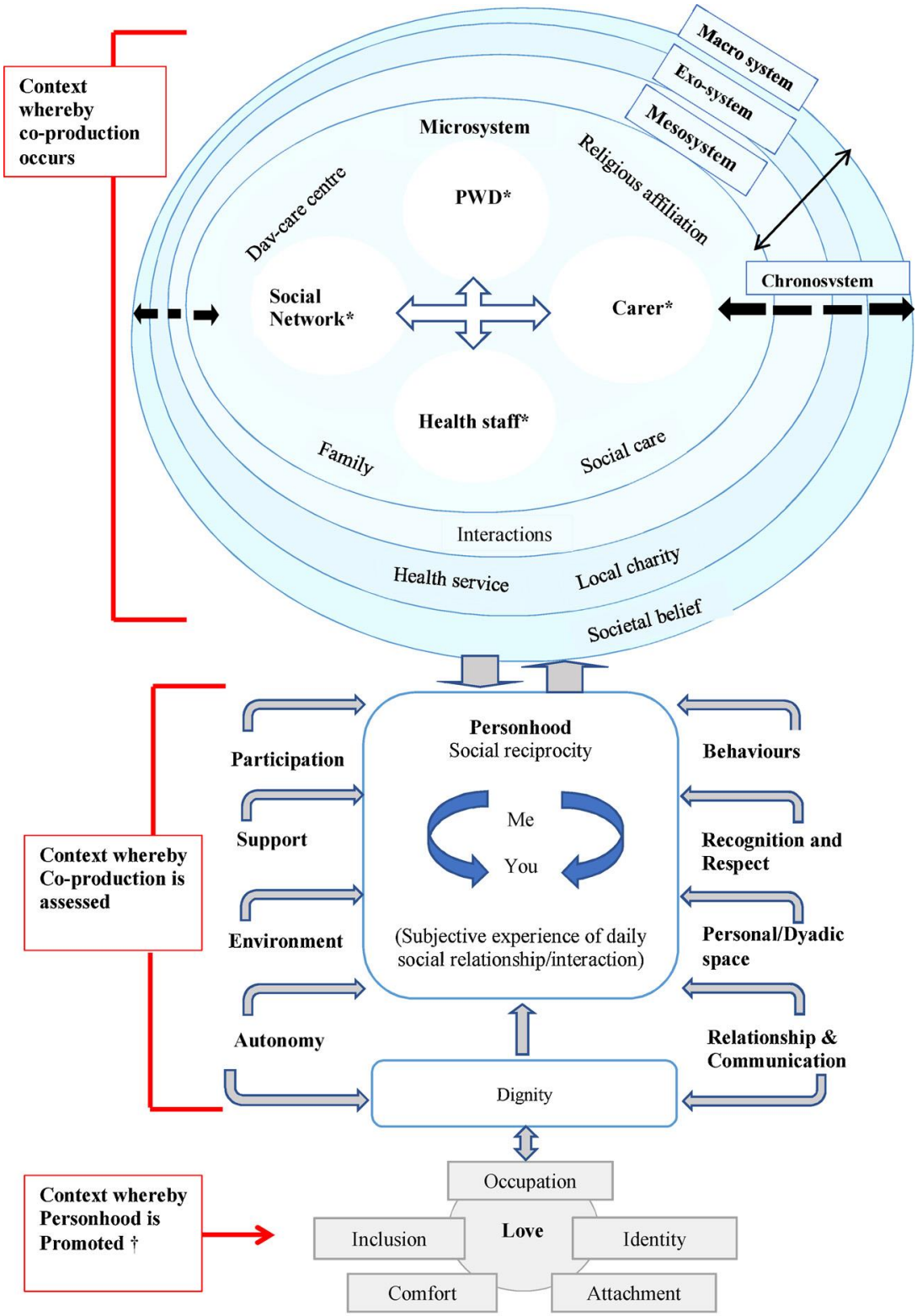
We argue that the person with dementia, their carer, their social network and health staff are all situated in an ecological system based on Bronfenbrenner's idea of

'nested arrangement of structures, each contained within the next' (Bronfenbrenner, 1979). In the model, the microsystem represents the immediate set of inter-relations existing between the person with dementia and the context, the carer and the context but also the dyad and the context (e.g. day care centre, neighbourhood). This also applies to members of the social network of the person with dementia and to health staff. We conceive of the personal dimensions of these four groups of agents as four inter-related circles, each agent bringing into the interaction their own biopsychosocial dimensions, cultural heritage, and biography.

In the mesosystem, we find the inter-relations between all the contexts and the experiences of the agents involved in the care. The exo-system, represents an extension of the previous system with the inclusion of other social structures that impact on the context (e.g. economic status, local charities, and governmental agencies). In the macrosystem, we find the cultural and societal values and beliefs impinging on the context and structures of the systems. In relation to dementia, a further system, the chronosystem, comes to play a central role, representing the development of the condition over time, which impacts on all the other systems.

When the Bronfenbrenner's ecological framework is applied to our model, a detailed description of the personal dimensions, levels of structural influences and systemic organisation of context-based experiences begins to emerge. The aim of this review though, is not to give a comprehensive description of all the variables influencing the systems in the model, as each individual is nested in a different social parlance, but to provide a heuristic to better understand how each agent operates and influences each other's ecological systems. This interpretation sets the basis for the following two blocks of the model and describes the context whereby co-production should occur.

Figure 4.3 Dementia care model to promote personhood through co-production.



* Individual domains brought into interaction: Biopsychosocial, cultural heritage, biography.

† Personhood is promoted through interaction with all agents involved in the care (i.e. micro system)

4.6.3.2 Social reciprocity and personhood

In line with Brooker's (2007) standpoint, we consider social reciprocity as a key function of personhood among actively interacting agents. In this regard, personhood is promoted through the social interaction between the person with dementia, carers and other influential agents providing care. The person with dementia, therefore, plays an active role in promoting personhood through their own social behaviours (either verbal or non-verbal) enacted toward the other agents. The same applies to the other agents. Social reciprocity becomes therefore instrumental in meeting what Kitwood defined "psychological needs" (Kitwood, 1997), which include occupation identity, inclusion, comfort and attachment. These all culminate in the need for love and meaning, that is intrinsic to all human beings.

4.6.3.3 Standards to assess dignity in care

In regard to dignity, in this model we applied the definition proposed in the Social Care Institute for Excellence (SCIE) guidelines whereby it is:

'A state, quality or manner worthy of esteem or respect and self-respect. Dignity in care is therefore the care that promotes and does not undermine a person's self-respect irrespective of any difference' (SCIE, 2006).

Although dignity remains a concept grounded in individual needs and life circumstances, what seems to be agreed on is that people know when they are not treated as such (SCIE, 2006). In our model, dignity in care is related to the promotion of personhood and is addressed through eight factors that we derived through interpretation and team discussion from the findings of the meta-ethnography and content analysis of the two reviews we undertook. Each factor contributes to positive personhood in the recipient of care and in the carer:

behaviours, participation, support, recognition and respect, environment, personal space, relationship and communication, autonomy. These eight factors represent standards with each containing a number of indicators to assess/identify whether co-production is attained (Table 4.6 for standards and indicators to assess dignity in care). These indicators are not to be considered universally applicable as these function as examples of positive care environment.

4.6.4 Phase 4. Consultation with members of the PPI group

The members of the PPI who volunteered to be involved in our research project had lived experience of dementia caring (e.g. hospitalisation, interaction with health staff, paid carers, GP, care home settings). Their views helped set the benchmarks for the promotion of personhood in dementia care. The first meeting lasted 45 minutes and the second meeting lasted 1:15 minutes. Each meeting included an initial 15 minutes debriefing session on what would happen during the day. Different participants attended the two meetings.

In the first meeting, the qualitative researcher (AB) met with 1 person with dementia to help refine the questions that were previously developed by the qualitative researcher (AB). In the second meeting, four people with dementia and two carers were present. They reported on the relevance of the integrated model of care and how well reflected their daily life experiences of social interaction with health staff. They commented on how it may be difficult at times to integrate the views of health professionals in their everyday life, especially in situations where complying with their suggestions means changing their routine (e.g. going to respite care, receiving care form social services).

Table 4.6 Promoting positive personhood through dignity in care: Context whereby co-production is assessed.

Variables	Standards for dignity in care	Indicators of dignity in care
Behaviours	People with dementia and their carers feel valued at all times during care. The care people receive is considerate of their values and beliefs. The relationship with the carer is valued.	- Misconception of Dementia is challenged in favour of a holistic view of the individual situated in a social context (e.g. social interaction with the carers, friends). - Staff views around dementia are challenged. - Staff attitude toward people with dementia and their carers is adequate and respectful. - Strategies are used to maintain adequate standards of behaviour with the person with dementia and their carer (e.g. eye contact, make sure everyone is introduced when talking to the person with dementia, treating the person with dementia as human not diagnosis, valuing the role of the carer at all time). - Individual needs are acknowledged and met (people with dementia have unique needs especially for the behavioural psychological symptoms). - Participants' preferences are accommodated. - Relationship with the carer is acknowledged.
Participation	There is active involvement of people with dementia and their carers.	- People with dementia and their carer (when this is applicable) actively participate in decision making for health/social care. - Carers' views are not collected on behalf of the person with dementia, yet rather they are gathered to complement their views when they lack capacity.
Support	For the dyad but also for each individual agent.	- Development and implementation of effective ways to support the relationship between the agents involved in the relationship (e.g. carer, people with dementia, dyad and health care services) - Dynamic support that accommodates the needs of the person with dementia and the carer during the stages of dementia.

		- Support provided in an effective way whereby the needs of the person with dementia are reviewed and the views of the carers are considered. - Encouragement in the promotion of activities that are inclusive of the carers as well as the person with dementia. - Effective support is provided for vulnerable carers (e.g. young carers with little expertise in caring, old people caring for a person with dementia).
Recognition and respect	Of the carer and of the person with dementia.	- Relationships are acknowledged and respected irrespective of its nature (e.g. relationships between person with dementia and health care professionals, person with dementia and carer, person with dementia, carers and the community in general) - Relationships change over time and their new status need to be respected at all time alongside the individual needs and the dyad's needs. - Relationship based on social reciprocity need to be valued and respected (e.g. promoting social interaction) - Social interaction may change over time because of the severity of the condition and when this occurs it needs to be valued and promoted (e.g. body touch instead of spoken words may be needed in severe stages of cognitive decline) - Recognition of the need to receive care from other agencies (outside the home) when applicable. - Recognition of the role of the carer as fundamental for the daily support of the person with dementia and in promoting their life in the community.

		- Recognition of the different perspectives of the person with dementia and their carer (they may be a dyad but not necessarily share the same belief and values). - Search for and respect the expertise and knowledge of the carer with respect to the support delivered to the person with dementia.
Environment	The care is provided in a way that the familiar environment of the person (and that of the carer when applicable) is respected. The environment is experienced as safe throughout the care.	- In case of residential accommodation, the layout of the bedroom is similar to the person's own bedroom at home (e.g. person's family pictures are displayed). - Person's hobbies are promoted (e.g. music, movies) as part of the care plan. - The person with dementia feels safe and staff makes sure that this feeling is maintained during care (e.g. go somewhere quite as to avoid crowded and noisy places that could scare the person). - Avoiding breaking the routine of the person without alerting her/him beforehand. - The carer is actively involved in the daily activities of the person with dementia (e.g. they help develop new activity programs and are consulted frequently alongside the views of the person with dementia)
Personal space/Dyadic space	Individual needs of people with dementia and their carers are considered at all times during care. People with dementia feel free to go to a private place during care and being on their own and or with the carer.	- Person-centred care is respected along with a sense of personhood conceived of in terms of social reciprocity. - Strategies are implemented with respect to entering the personal space of the person with dementia and their carers (e.g. avoiding physical contact, respecting the dyad's privacy). - The care plan (if any) takes into account the wish of the person with dementia to stay on their own and have their privacy respected.

		- Topics that are potentially invasive of their privacy need to be approached sensibly with people with dementia and their carers (e.g. discussion about toiletry, sexuality).
Relationship and communication	The relationship with staff is experienced as effective during care.	- The care plan (if any) is explained to people with dementia and their carers (or social network) by including them in the conversation. - Information about the care should be given in an accessible format (e.g. booklet with images). - Communication between health professionals (in case of staff team) should be consistent and communication with the person with dementia and their carers not patronising (e.g. staff talk to the person like adults, avoid abstract concepts, avoid talking to the carer when referring to the person with dementia). - Reciprocity (carers and staff benefit from delivering a dignified care as much as the person with dementia does). - Time necessary to explain the care plan is divided in multiple visits if too much information needs to be taken in.
Autonomy	Strategies aiming at the promotion of independence/autonomy of the person with dementia need to be implemented Autonomy needs to be promoted until capacity	- The use of assistive technology that can support people with dementia in their daily tasks (e.g. navigation systems for orientation, calendar clocks). - The role of guardians should only be supportive until the person with dementia lack capacity. The person with dementia has the right of engaging in decision making at all times.

They also commented on the important role of social networks for people with dementia. There was in fact consensus among PPI members on how the role of neighbours becomes crucial when the behaviour of the person with dementia is challenging and an extra support is needed. The group further advised that it would be important to gather the views of people with dementia, their carers and health staff with respect to how effectively promote co-production in dementia care. They reported on how the indicators of the model we developed (Table 5.6) for the assessment of co-production can effectively help the person with dementia and their carers to assess (or have a sense of) whether their views are actively taken into consideration and their needs and preferences taken into account. The person with dementia also added on how the indicators may provide people with dementia with an instrument to use when receiving care and feedback to health staff or their carer to show points where co-production has not been promoted. A carer felt that although some of the points are described in previous care guidance, these indicators well summarise the main areas to self-assess good quality of care. These were the views of a small number of people attending PPI meetings and not necessarily representing the views of the larger population with lived experience of dementia, however their active involvement in our study proved a key example of work on co-production.

4.7 Discussion

The current work aimed at the development of a theoretical model to strengthen the power of people with dementia in relation to their self-determination. The model was informed by the findings of a systematic review on personhood and dignity, and by findings of a scoping review of policy documents on personhood and dignity in dementia. These reviews identified the factors that impinge on the quality of care when engaging with people with dementia and their social networks. As evidenced

in the literature and as also reported during the PPI meetings, people with dementia experience dissatisfaction with the way they are considered in the health care system, and in society at large, despite the delivery of PCC. For this reason, we created a model that was based on the ecological theory of social interaction across systems. The ecological system theory helped us situate the person with dementia and all the agents involved in their daily care at the centre of the system (microsystem).

Through social reciprocity the personhood of the agents is promoted or discouraged according to the quality of interaction and the level of co-production (partnership) experienced. It is through co-production that equal positioning and autonomy are preserved among agents.

Health care requires high degree of specialisation, and the context whereby care is delivered is becoming complex with time. The risk of power imbalance between agents is increased with the process of specialisation and this warrants a shift of positioning in which the person with dementia needs to be acknowledged as an active agent 'citizen' rather than patient. This means, that the person with dementia, as much as other individuals, needs to be able to operate in society, not only in health settings but in civic and political life and in other community contexts. The challenge is how to support active involvement in the face of a progressive neurodegenerative condition like dementia,

We found evidence that this can be achieved. In concert with what has been proposed by the Advanced Dementia Practice Model (Alzheimer Scotland, 2015), we found that it is important to promote social inclusion at any stages of the condition through creating opportunities for self-expression and socio-cultural partnership in community settings. In line with the findings from the Essence of Care

report (Department of Health, 2010), we also found that elements of dignity promoting personhood are also important for the promotion of co-production. As evidenced in our model, personhood, dignity and co-production are inter-related concepts, hence it follows that the safeguard of personhood, for example, is crucial to fulfil also the degree of freedom in which the person with dementia operates (co-produces) in the system, and the level of dignity experienced during the delivery of care (Nuffield Council on Bioethics, 2009). Similarly, partnership should also aim at the development of health care plans and at the creation of accessible places, as they can address some of the difficulties posed by the symptoms of dementia.

The strength of our review lies on the development of indicators that provide the agents involved in the care (i.e. health professionals, people with dementia and their carers) with a direct assessment of the quality of care delivered, as shown in Table 4.6. These parameters may be used to assess whether personhood and dignity have been promoted and whether co-production was discouraged or encouraged. Although the model does not constitute a systematic tool for the assessment of co-production, it may still provide the agents in care with an idea about the quality of care they received or delivered and about the domains that may require some more attention if not fully addressed.

As much as we consider important the preservation of the identity of people with dementia, we also need to take into consideration that because health professionals are still regarded as ‘the experts’, partnerships with people with dementia may represent a threat to their identities (Nolan, Davis, Brown, Keady, & Nolan, 2004). Future studies may look into the experience of co-producing care with people with dementia and their carers from the point of view of health staff. Questions include what are the essential ingredients in the promotion of participatory care at

organisational level? For example, what preparation or training is needed on both sides to achieve active participation in the delivery of care, if and in what ways peer support may boost participation.

4.7.1 Limitations

The current work has some limitations. In regard to the systematic review and meta-ethnography, the search of studies and the subsequent analysis has been conducted by one researcher and although a team of experts in dementia care and old age psychiatry checked the search strategy, retrieval of studies and analysis of findings, the absence of an independent researcher assessing the quality of the work may increase the experimenter bias in the results. For the scoping review, we searched our terms on English-language governmental databases, it may be the case that non-English speaking foreign countries have policy documents that are relevant for the review, that were missed. As health policies are highly culture-sensitive, the review findings should be treated cautiously. Also, there are policies in which stakeholders have not been involved and therefore, they may not necessarily reflect the current needs or views of people with dementia and their carers. In regard to the model, we engaged with PPI members for validation, however they comprised individuals who shared similar socio-demographics characteristics (white British, aged between 60 and 70), thus further validation with people from different socio-cultural backgrounds is needed. Much wider consultation with people with dementia and carers could help to refine the model and ensure that their views are fully represented.

4.8 Conclusion

Our review has implications for change at the micro and macro levels of society. It highlights how behaviour of health and social care professionals can ideally promote normalcy and a sense of equality in people with dementia. Yet there may be needs for training to prepare professionals to work on a more equal basis with individuals with dementia in co-producing health care. The same may be true for policy makers whose task is to create opportunities with, rather than for, people with dementia. Our analysis highlights policy that promotes dignity and a positive sense of self in people with dementia living in the community, but this is far from universal. Person-centred care needs to incorporate the principle that people with dementia have human rights of autonomy and dignity throughout the course of dementia, and they should be empowered to engage in decision-making while they have capacity to do so.

Chapter 5. Dyadic construction of dementia: Meta-ethnography and behaviour process synthesis

Bosco, A., Schneider, J., Coleston-Shields, D. M., Sousa, L., & Orrell, M. (2019). Dyadic construction of dementia: meta-ethnography and behaviour-process synthesis. *Aging & Mental Health, 23*(6), 651-659. https://doi.org/10.1080/13607863.2018.1450836

Abstract

Objectives. Positive identity in people with dementia is maintained when there is good interaction with family caregivers. However, research on the experiences of dyadic interaction in dementia care is still limited. For this reason, we aimed to systematically review the dyadic experience of dementia caring.

Method. Studies were identified through searching five databases: MedLine, EMBASE, PsycInfo, ASSIA, and CINAHL. Eligible studies employed qualitative or mixed method design, reported the experience of dyads of dementia with no comorbid organic or psychiatric disorders. No restrictions were made on language or year of publication, nor on sex or age of participants. The quality appraisal of studies was conducted by two researchers independently. We used meta-ethnography to synthesise data and developed a behavioural model to explain dyadic interaction.

Results. A total of 17 studies were included in the review. The meta-ethnography generated two third-order constructs: Personal orientation and noises. When both people with dementia and their carers opt for dyadic oriented goals, their behavioural responses are likely to promote positive interaction. When only one partner opts for dyadic goals, the stress posed by the context may affect the interaction because of no perceived shared understanding of the situation.

Conclusion. Our findings suggest that unequal power distribution within dementia dyads, can cause significant stress especially when coping strategies are impaired. Implications are found for family carers, people with dementia, and health professionals as the model we derived enhances the understanding of dyadic dynamics to care.

5.1 Introduction on dyadic interaction in dementia

An estimated 670,000 informal carers provide care to people with dementia in the UK, the majority of whom comprises middle-aged female family members (i.e. spouses, daughter) (Dementia Research Group, 2004). Family carers are often defined as the 'invisible patients' and as the 'first port of call' (Brodaty & Donkin, 2009), owing to their crucial role for the maintenance of quality of life and decreased hospitalisation in the person with dementia. Carers' responsibilities are plenty: They offer practical support, providing hands-on care, managing finances and general day-to-day activities; they act as care managers, arranging for other people to support the person with dementia, and they offer key emotional support (Archbold, 1981). The identity of the carers becomes threatened when the person with dementia is perceived as being particularly difficult to manage as the carers attempt to manage the emotional and behavioural difficulties of the person with dementia, yet failing to do so, they absorb the overwhelming experience of caring (Harris & Keady, 2009). In order to overcome such negative experience, Harris and Keady (2009) point at the safeguarding of the identities of both the carer and the person with dementia by virtue of the fact that the management of their identities is intimately interconnected. Such interconnection places the continuity of the self at the core of the caring process (Åberg, Sidenvall, Hepworth, O'Reilly, & Lithell, 2004).

The study of dyadic interactions may represent an opportunity for the carers to understand/challenge their own views and to position themselves with respect to the experience of dementia care. Although there is extensive literature on the experience of carers of dementia, research is still far from robust on the dyadic interaction in dementia care. We aimed to explore the experience of social interaction between people with dementia and their family carers. Specifically, our review responds to the question: What is the experience of dyadic interaction in dementia care?

As part of our analysis we developed a behavioural model, defined here as 'behaviour-process synthesis' to explain the behavioural process of dyadic interaction in the context of dementia care.

5.2 Methods

This review complied with the PRISMA checklist (Moher, Liberati, Tetzlaff, & Altman, 2009). Two Initial meetings were held between the qualitative researcher (AB), one professional with expertise in old age psychiatry (MO), one expert in social care in dementia (JS), and one with expertise in neuropsychology of dementia (DMCS) to define the scope of the review and to agree on the subsequent development of the review protocol.

5.2.1 Theoretical framework

We used social constructivism to interpret the qualitative findings of the studies, as we believe that the reality is shaped by cultural and social forces, and people's values, beliefs and attitudes. As such, we understand dementia as a social construction which denotes different meanings and ways of acting towards the person with dementia. For this reason, we prioritise the familial bond and dyadic

relationship as function of increased perceived quality of life and wellbeing in carers and people with dementia.

We applied two main elements of social constructivism, the concept of 'subject position' informed by the notion of interpellation as theorised by Althusser (1971), and the concept of inferential communication (Hutchby & Wooffitt, 1998; Potter, 1996).

The subjective positioning in interaction, that we define here as 'personal orientation', contends that interactional practices entail that individuals take up social roles, and that these roles are characterised by certain rights and duties (Harre' & van Langenhove, 1999). Applied to the context of our review on dyadic interaction, the agents in care, the person with dementia and their carer, offer each other different subject positions (i.e. personal orientation in regard to the situation) which lead to inferences on their own identity and on that of the other agent involved in the interaction.

We drew on inferential communication to describe how dyads construct meaning through interaction. Various inferences about meaning are made available during interaction and through inferential communication their social practices (e.g. talk) become means of *'constructing understandings, identities, relationships and even dementia itself'* (Forbat, 2003).

5.2.2 Eligibility criteria

a) The study is qualitative or contains an element of qualitative analysis, with reported quotes in the analysis/result section.

b) The study reports on the experience of dyads of the dementia caring process.

c) No restriction is made on the stage of dementia caring because:

i. Participants' experience of early diagnosis or late stage dementia are consequential, and they are both essential for the understanding of the dynamics of caring.

d) Articles need to be on dementia with no comorbid diagnosis with other organic or mental health conditions.

e) No restriction based on age or sex is made.

f) No restriction on language or year of publication.

Studies were excluded when their analysis mainly reported the interpretation of the authors with no reference to the direct experience (quotes) of participants, and when they reported on the experience of people with dementia and their carers with respect to life domains different from dementia caring (e.g. interaction with primary health care providers, experience of therapeutic interventions for behavioural psychological symptoms of dementia). In addition, studies were excluded when they clearly reported on the qualitative methods for data collection but not on the method employed for the analysis of data.

5.2.3 Information sources

Our search strategy was informed by the PICO format (Sackett, Richardson, Rosenburg, & Haynes, 1997) only to define the population and outcomes of the systematic review. We run our search on five databases: MedLine, EMBASE, PsycInfo, ASSIA, and CINAHL. Different domains of investigation have been defined to retrieve articles:

a) Dementia domain: dement*, alzheimer*.

b) Participant domain: caregiver*, relative*, spouse*, dyad*, carer*, partner*.

c) Relational domain: communicat* or relation* or interaction*.

d) Experience domain: experienc*, social* constru*.

Table 5.1 contains the terms used to run EMBASE.

The above terms have been adapted for the other databases. In order to include relevant grey literature and campaigning literature from charities, we also considered the first 100 hits on google scholar and cross reference the studies retrieved. We had the search strategy checked for accuracy by an independent librarian based at the University of Nottingham. Two rounds of search strategy were necessary to refine our searching method.

Table 5.1 Search strategy run for EMBASE (1980 to 2017 Week 05).

	Defining Terms
1	exp dementia/
2	exp alzheimer's disease/
3	(dement* or alzheimer*).ti,ab.
4	exp family relation/ or exp human relation/ or exp sibling relation/
5	exp social interaction/ or exp family interaction/
6	exp interpersonal communication/
7	exp experience/ or exp personal experience/
8	experienc*.ti,ab.
9	"social* constru*".ti,ab.
10	(caregiver* or relative* or spouse* or dyad* or carer* or partner*).ti,ab.
11	(communicat* or relation* or “social interaction*” or “famil* interaction*” or “dyad* interaction”).ti,ab.
12	1 or 2 or 3
13	exp caregiver support/
14	exp caregiver/
15	4 or 5 or 6 or 11
16	10 or 13 or 14
17	7 or 8 or 9
18	12 and 15 and 16 and 17

5.2.4 Study records

In regard to the selection process of articles, we used three-levels screening. The first level consisted in two reviewers (AB and LS) independently screening titles and abstracts of the articles retrieved through the electronic database against the inclusion/exclusion criteria, the second level, consisted in the critical appraisal of the

full text of each of the studies which passed the first screening, the third screening consisted in the use of the quality appraisal checklist for a final assessment of the studies.

In regard to the second screening the two researchers assessed whether the studies met preliminary criteria around research question (i.e. do the authors clearly address the research question), methods for data collection and analysis (do the authors employed valid method pertinent with their research question), and around whether their findings were relevant to the aims and objectives of this review. Only those studies that did not meet any of the criteria did not reach the final third level of screening.

With respect to the third level of screening this was made independently by two raters (AB and LS) by employing the Spencer et al.'s framework (Spencer, Ritchie, Lewis, & Dillon, 2003) for quality assessment in qualitative research. This framework analyses the articles against four guiding principles of good practice in qualitative research: contributory to knowledge, defensibility in design, rigorousness in conduct and credibility in claim. The robustness of the findings (i.e. the quality of the studies) and their relevance will be graded as low, medium or high. The agreement of rating between the two reviewers were assessed by means of inter-rater agreement and in the presence of discrepancies between raters, these were resolved through consensus or through consultation with a third external assessor. Inter-rater agreement was measured through Kappa coefficient (Cohen's Kappa) (Cohen, 1960) and the parameters were based on the ranges by Landis and Koch (Landis & Koch, 1977): 0.81–1.00 = almost perfect; 0.61–0.80 = substantial; 0.41–0.60 = moderate; 0.21–0.40 = fair; 0.00–0.20 = slight; < 0.00 = poor.

We extracted the data of the studies included in the review, onto NVivo 11 (QSR International, 2012). Data were extracted for study design, qualitative methods of data collection and analysis, theoretical framework, participants' demographics, and areas of appraisal (e.g. experience of caring, quality of relationship, style of dyadic interaction).

In case of duplicates of study findings, we selected the publication containing the most complete and updated information as the primary source of reference. The remaining papers were considered as secondary sources.

5.2.5 Data synthesis

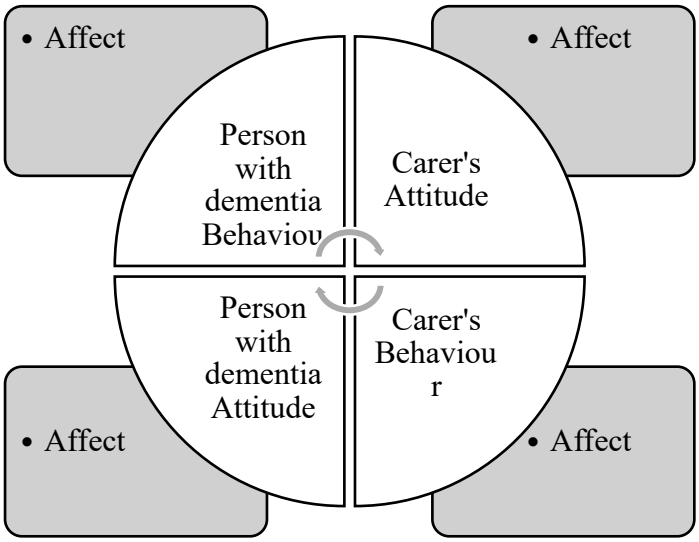
We used meta-ethnography as proposed by Noblit & Hare (1988) and applied Schultz's (Schütz, 1962) definition of third order constructs (i.e. our interpretation), first and second order interpretations (i.e. the first order construct representing the participants' reported life experiences, the second order construct representing the authors' interpretation of the first order constructs). The analytical process was iterative and required the monitoring of an external researcher (LS) for the accuracy and quality of the synthesis of the data and to reach the third order interpretations.

In brief, we undertook the following stages of analysis: First the researcher (AB) read the articles in-depth and determined how studies were related, which required an iterative process. For this purpose, the second and first order constructs were divided into text units (i.e. paragraphs) and coded by paragraphs. Then we used constant comparative method to generate theme categories from first and second order constructs. Constant comparative method is key in the process of finding concepts across studies that could explain social reality (Charmaz, 2006).

The studies included in the review were found to have a similar focus around the effects of dementia on dyadic communication, and on quality of interaction. We found through constant comparative analysis themes around participants' behaviours, the consequences of these behaviours on the quality of interaction and the response of participants to the behaviours. The initial themes we found were: dyadic communication, mutual engagement, role sharing, shared commitment, ambivalent relationship, inability to engage in communication, sense of duty, loss of affection, increased tension in dyadic relationship, loss of mutual understanding).

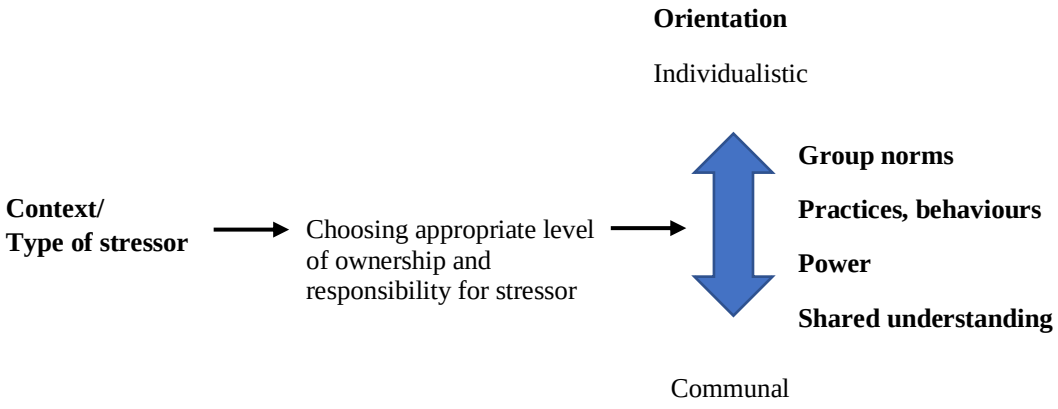
The research team discussed on the accuracy of these preliminary themes and decided that a quality improvement theory based on the Betari model as a framework (Figure 5.1), could be effectively used to organise themes according to the cyclical patterns of behaviours, the interconnection of attitudes, beliefs and behaviours of carers and people living with dementia. The Betari box (also defined as attitude and behavioural cycle) entailed for example, that when the carers' attitude or emotions are friendly and inclusive, this will be exhibited in their behaviour. This, will then have an impact on the attitude or emotions of the person with dementia and in turn it will impact on their behaviour and so on. By organising themes according to the interconnection of attitudes and behaviours of people with dementia and their carers during interaction, we reached our third order interpretations by translating the negative factors impacting on the dyadic interaction into 'noises buffering the quality of interaction', and the way they orientated themselves with respect to the situation and in reference to each other's attitudes and behaviours into 'personal orientation in presence of a stressor'.

Figure 5.1 Betari Box.



We expressed the synthesis through the development of a linear model that could facilitate the understanding of the translation process. The model has been informed by the concepts of orientation and responsibility described by Afifi, Hutchinson, and Krouse (2006) (Figure 5.2). In brief, the model suggests that the context dictates whether in presence of a stressor, this is owned and dealt with by each single individual in the interaction or collaboratively. The inter-relational dynamics between the agents determine whether there is shared ownership and responsibility to manage the stressor (Afifi. Hutchinson, & Krouse, 2006).

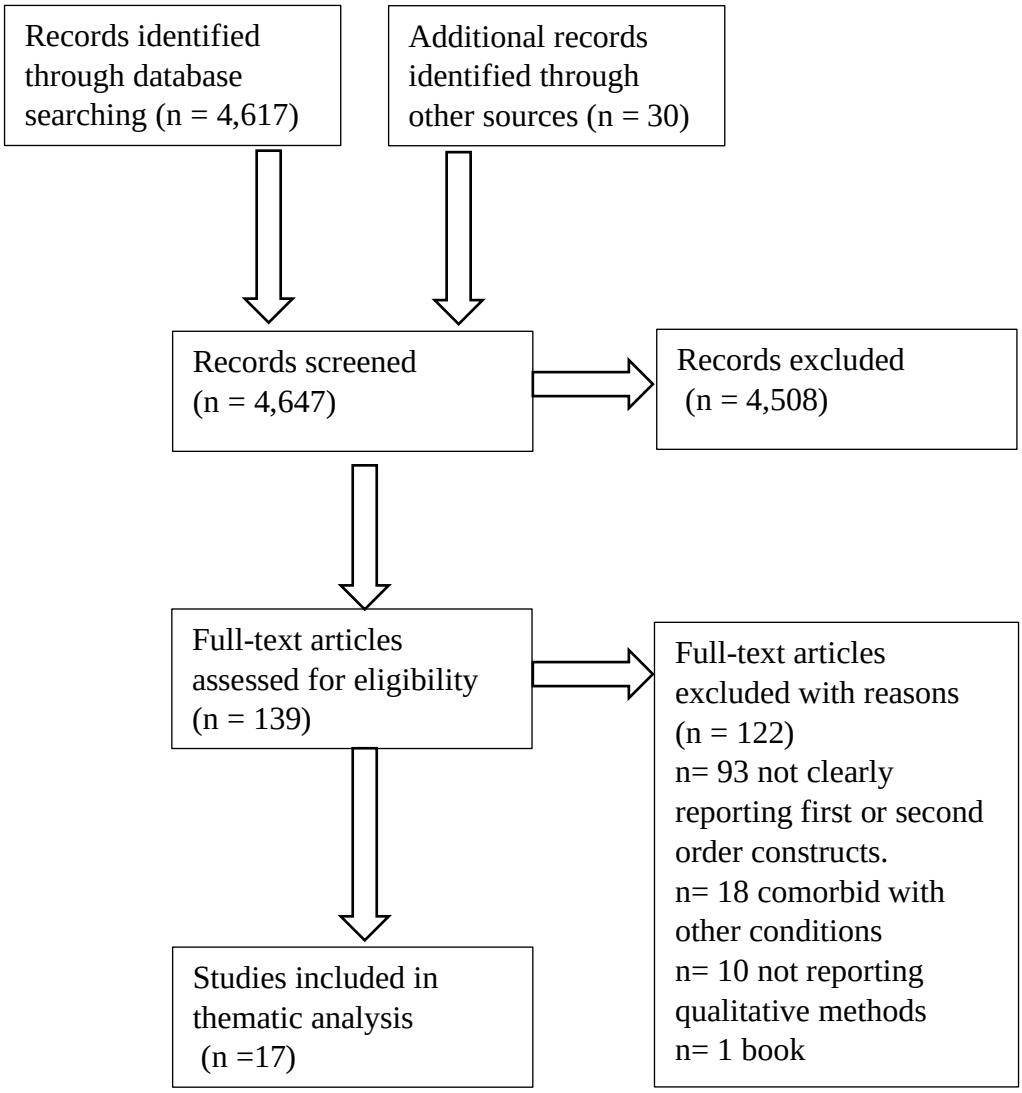
Figure 5.2 Dimension of communal coping by Afifi, Hutchinson, and Krouse (2006).



5.3 Result

Our systematic search yielded a total of 4,647 studies (30 studies were retrieved from addition sources). After screening for title and abstract, 4,508 studies were excluded and the remaining 139 were screened for eligibility against our inclusion/exclusion criteria (Figure 5.3 for the flow chart of the selection process). We further excluded 122 studies with reason and included in the review 17 studies.

Figure 5.3 Flow chart for selection of papers.



5.3.1 Studies characteristics

The 17 studies we included, were published on peer reviewed journals (1999-2016) (Table 5.2 for single study characteristics). Most studies were from the UK (n=6), Canada (n=4), Sweden (n=3) and the USA (n=2). Only one study was from France and one from Singapore. We found five most frequently reported themes across studies: Experience of dementia caregiving (N=10), dyadic experience of dementia (N=4), carers' strategies in dementia caregiving (N=1), conversational interaction between dyads (N=1), dyadic coping with dementia (N=1).

5.3.2 Quality appraisal of included studies

All the studies were found of medium/high quality, with some reporting medium scores only for the clarity in reporting data sample and analysis. The inter-rater agreement ranged from moderate (k= 0.48) to almost perfect (k= 0.88). We found difficult to rate studies on ethical issues as this information was not clearly stated.

5.3.3 Meta-ethnography

From the meta-ethnography, two third-order constructs emerged: Personal orientation and noises. Each third-order construct has associated theme categories (Table 5.3). The expressed synthesis is illustrated in Figure 5.4. Our expressed synthesis is informed by a previous model on communal coping with a focus on the appraisal of the event and the actions made by each interacting agent. In our behaviour-process model, we highlight (i) how different care scenarios in dementia can elicit different appraisals of the situation, (ii) how these appraisals lead to various behavioural responses, (iii) the different levels of responsibility and personal orientation that each agent holds with respect to stressors posed by dementia (i.e. they either self-orient or consider the stressor as a shared responsibility, a dyad-oriented response to the event).

Table 5.2 Characteristics of studies (N=17).

Author	**Year**	**Country**	**Study design**	**Theoretical framework**	**Qualitative methods of data collection**	**Qualitative methods of data analysis**	**Themes**	**Sample demographics**
Clare & Shakespeare	2004	UK	Qualitative	[4]Dialectical interactionist	Dyadic observation	Conversational analysis (voice-relational analysis)	Conversational interaction between dyads	N=10 couples (all aged 50+) PWD= 10 (female=2) Carers=10 (female=8)
Harris, Adams, Zubatsky, & White	2011	USA	Qualitative	[2]Descriptive Phenomenology	One-to-one interview with open ended questions	Descriptive phenomenological analysis (meaning unit) *	Experience of dementia caregiving	N=10 carers (Aged 50+) (Female=6)
Hellström, Nolan, & Lundh	2007	Sweden	Mix-method	[1]Grounded theory	Longitudinal interviews (152)	Inductive thematic analysis	Dyadic coping with dementia	N=20 couples (aged 60+) PWD= 20 (Female= 8) Carers= 20 (Female= 12)
Kindell, Sage, Wilkinson, & Keady	2014	UK	Qualitative case study	[1]Narrative	One-to-one semi-structured interviews	Narrative Inquiry (thematic narrative analysis)	Experience of dementia caregiving	N=2 family members (wife and son of PWD)
Merrick, Camic, & O'Shaughnessy	2016	UK	Qualitative	[1]Phenomenology	Dyadic semi-structured interviews	Interpretive phenomenological analysis (IPA)	Dyadic experience of dementia	N= 7 couples (Aged 60+) PWD= 7 (Female=2) Carers =7 (Female=5)
Molyneaux, Butchard, & Murray	2011	UK	Qualitative	[1]Constructivist Grounded theory	Dyadic semi-structured interviews	Thematic analysis	Dyadic experience of dementia	N=5 couples (aged 70+) PWD=5 (Female=2) Carers=5 (Female=3)
Netto, Jenny, & Philip	2009	Singapore	Qualitative	[1]Grounded theory	One-to-one semi-structured interviews	Axial selective coding	Experience of dementia caregiving	N=12 carers (aged 30+) (Female= 10)

O'Shaughnessy, Lee, & Lintern	2010	UK	Qualitative	[1]Phenomenology	One-to-one semi-structured interviews	Interpretive phenomenological analysis (IPA) (Thematic analysis)	Experience of dementia caregiving	N=7 carers (aged 50+) (Female=5)
Oyebode, Bradley, & Allen	2013	UK	Qualitative	[1]Phenomenology	One-to-one semi-structured in-depth interview	Interpretive phenomenological analysis (IPA) (Thematic analysis)	Experience of dementia caregiving	N=6 carers* (Female=2)
Perry	2002	Canada	Qualitative	[1]Symbolic interactionism	One-to-one semi-structured in-depth interview	Grounded theory (Strauss & Corbin, 1990)	Experience of dementia caregiving	N= 20 carers (Aged 50+) (Female=20)
Phinney	2006	Canada	Mix-method	[1]Phenomenology	Multi method: - In-depth conversational interviews - Participant observation	Interpretive phenomenological analysis (IPA)	Carers' Strategies in dementia	N=8 families (7 couples + 1 mother and daughter). PWD= 8 (aged 60+) (female=4) Carers= 8 (aged 50+) (female=6)
Phinney, Dahlke, & Purves	2013	Canada	Qualitative	[1]Phenomenology	Multi-method In-depth Interview and participant observation	Interpretive phenomenological analysis (IPA)	Experience of dementia caregiving	N=7 (2 aged 60+) Men (N=2) All members of one family
Shim, Barroso, & Davis	2011	USA	Mix-method	[3]Content analysis†	Longitudinal interview	Content analysis (Boyatzis, 1998)	Experience of dementia caregiving	N=21 carers (Aged 50+) (Female=16)
Siriopoulos, Brown, & Wright	1999	Canada	Qualitative	[2]Descriptive Phenomenology	One to one Semi-structured interviews	Descriptive phenomenological analysis	Experience of dementia caregiving	N=8 carers (Aged 60+) (all male)

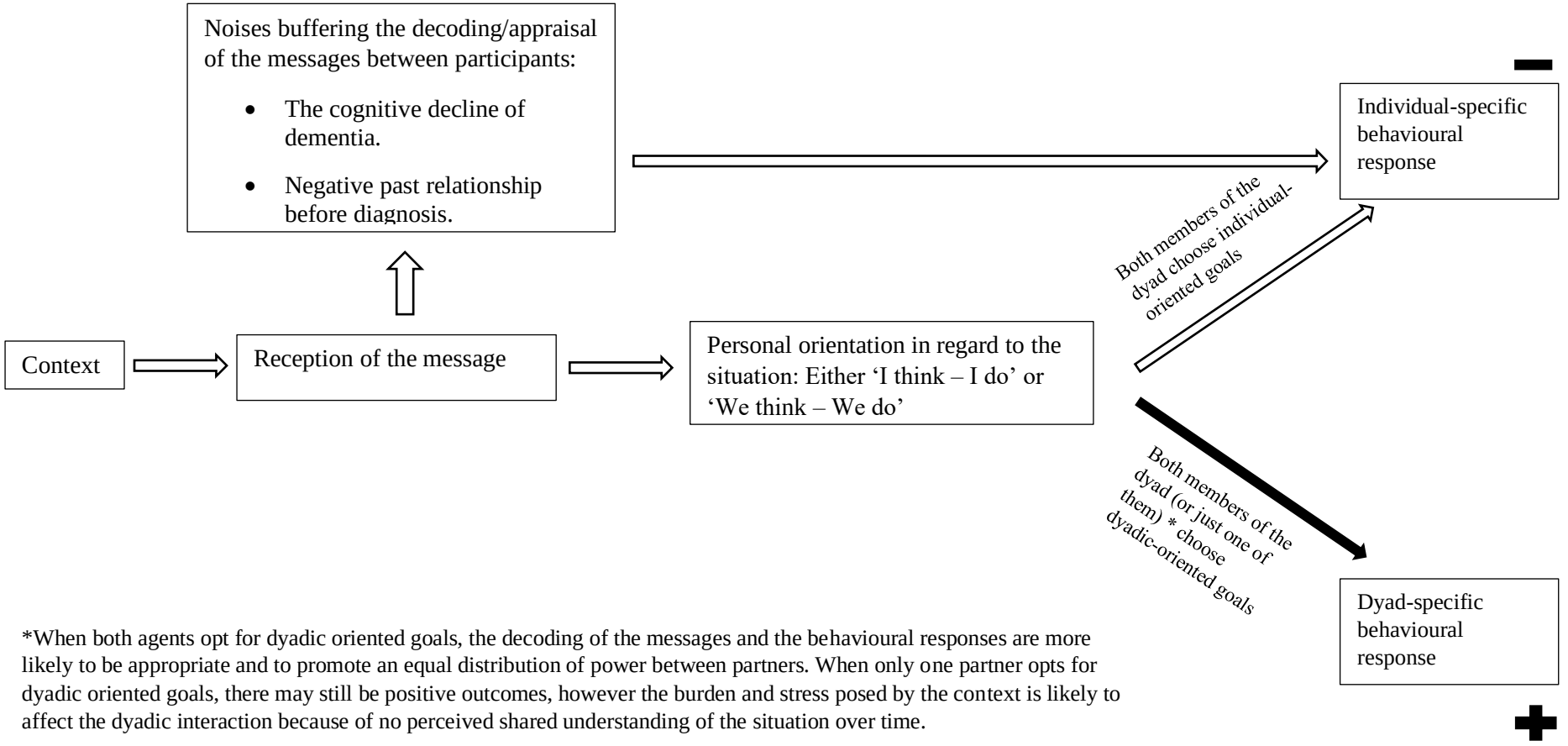
Svanstrom & Dahlberg	2004	Sweden	Qualitative	[2]Descriptive Phenomenology	Multi methods: Diary-Based open-ended Interviews with each member of the couple	Descriptive phenomenological analysis (Giorgi's approach to meaning unit)	Experience of dementia caregiving	N=5 couples PWD= 5 (Aged 70+) (Female=2) Carers= 5 (Aged 70+) (Female=3)
Vikstrom, Josephsson, Stigsdotter-Neely, & Nygard	2008	Sweden	Mix-method	[1,4]Grounded theory [a]	One-to-one interview	Grounded theory (Constant comparative method) (Strauss and Corbin, 1990)	Dyadic experience of dementia	N=26 couples PWD= 26 (Aged 60+) (Female=12) Carers= 26 (Aged 50+) (Female=14)
Wawrziczny, Ducharme, Kergoat, & Pasquier	2016	France	Mix-method	[1]Phenomenology	dyadic semi-structured interviews.	Interpretive phenomenological analysis (IPA)	Dyadic Experience of dementia	N= 16 couples PWD= 16 (Age Mean 57.3) (Female= 9) Carers= 16 (Age mean 57.4) (Female= 7)

Paradigm: [1]Constructivist/Interpretive; [2]Descriptive/eidetic; [3]Positivism; [4]Pragmatism. (Definition of paradigm adapted from Mayan, 2016).
*Not clearly defined by the author/s. †Thematic analysis/Content analysis is used as both theoretical framework and analytical method.
[a] Although not clearly stated in the study, we interpreted the use of grounded theory as based on both interpretivism and pragmatism paradigms as the article aimed at the understanding of knowledge and the promotion of change (Goldkuhl, 2012).

Table 5.3 Meta-ethnography: Third order constructs.

Third order constructs	Theme Categories
Personal orientation in presence of a stressor	**PWD appraisal and response** (I think I do) i. *Dyadic oriented goals* (Hellström, Nolan, & Lundh, 2007; Netto, Jenny, & Philip, 2009; Phinney, Dahlke, & Purves, 2013; Wawrziczny, Ducharme, Kergoat, & Pasquier, 2016; Phinney, 2006; Merrick, Camic, & O'Shaughnessy, 2016) ii. *Individual oriented goals* (Molyneaux, Butchard, & Murray, 2011; Clare & Shakespeare, 2004)
	Carers' appraisal and response (I think I do) iii. *Dyadic oriented goals* (Phynney, 2006; Wawrziczny, Ducharme, Kergoat, & Pasquier, 2016; Harris, Adams, Zubatsky, & White, 2011; Kindell, Sage, Wilkinson, & Keady, 2014; Oyebode, Bradley, & Allen, 2013; Hellström, Nolan, & Lundh, 2007) iv. *Individual oriented goals* (Oyebode, Bradley, & Allen, 2013; Perry, 2002; Shim, Barroso, & Davis, 2011; Harris, Adams, Zubatsky, & White, 2011; Molyneaux, Butchard, & Murray, 2011; O'Shaughnessy, Lee, & Lintern, 2010; Vikstrom, Josephsson, Stigsdotter-Neely, & Nygard, 2008; Kindell, Sage, Wilkinson, & Keady, 2014)
	Dyad-specific behavioural response (We think we do) v. *Shared commitment* (Merrick, Camic, & O'Shaughnessy, 2016; Molyneaux, Butchard, & Murray, 2011; Clare & Shakespeare, 2004) vi. *Balancing roles* (Hellström, Nolan, & Lundh, 2007; Merrick, Camic, & O'Shaughnessy, 2016) vii. *Reciprocity* (Molyneaux, Butchard, & Murray, 2011)
Noises buffering the quality of interaction	**Dementia symptoms** viii. *Cognitive decline* (Siriopoulos, Brown, & Wright, 1999; Harris, Adams, Zubatsky, & White, 2011) ix. *Behaviour problems* (Svanstrom & Dahlberg, 2004)
	Past experiences x. *Bad relationship carried on with dementia* (Shim, Barroso, & Davis, 2011)

Figure 5.4 Expressed Synthesis: Behaviour-process synthesis of dyadic interactions in dementia care.



*When both agents opt for dyadic oriented goals, the decoding of the messages and the behavioural responses are more likely to be appropriate and to promote an equal distribution of power between partners. When only one partner opts for dyadic oriented goals, there may still be positive outcomes, however the burden and stress posed by the context is likely to affect the dyadic interaction because of no perceived shared understanding of the situation over time.

5.3.3.1 Personal orientation in presence of a stressor

This theme refers to the ways the agents involved in the social interaction orientate themselves with respect to the situation. In other words, this theme describes the appraisal and behavioural responses of each interacting agent and whether these are individual-oriented or dyad-oriented. This theme comprises three subthemes: The first describes the way people with dementia appraise and respond to the stressful event and how this response is experienced by the carer; the second describes the carer's appraisal and response to stressful events and how their response is experienced by the person with dementia; the third describes how the stressful experience is shared by the dyad collaboratively and dealt with through co-ownership and responsibility of their response.

PWD appraisal and response (I think I do).

The way people with dementia experience the situation and the social interaction with their carers is highly influenced by the extent to which their primary appraisal is dyad- or individual- oriented. Establishing an open communication with the carers, enables the person with dementia to appreciate the carers' views of the situation and to give an empathic and altruistic response that attend to the needs of both agents:

'I'm drawn closer because of his condition and the frequent contact with him and everything. Pain, he ask me to massage, I massage. Very close contact now, so learn to love him better.' (Netto, Gyn, & Philip, 2009).

Considering the carer's perspective on the situation, leads the person with dementia to compromise at times in order not to send a negative message to the carer:

'I have a greater autonomy margin than she thinks, but there again, I do not want to upset her, so I often give in.' (Person with dementia) (Wawrziczny, Antoine, Ducharme, Kergoat, & Pasquier, 2016).

Another author reported how some people with dementia avoid also showing problems they have because of dementia to maintain a positive appraisal of the situation in the carer:

'I'm well aware that there are some things that are not working at all anymore, that I no longer react as I used to. I realize it but I avoid talking about it, I avoid showing it too much and [talking to his wife] it's for you, I know you're going to worry about it.' (Person with dementia) (Wawrziczny et al., 2016).

The sense of reassuring that people with dementia experience as a result of the carers' support, buffer the quality of appraisal of the situation and better the experience of caring: *'She looks out for me... If I'm feeling a bit funny she'll come and give me a cuddle ...'* (Merrick, Camic, & O'Shaughnessy, 2016).

Whereas dyad-oriented goals positively influence the dyadic interaction, an individualistic orientation focussed entirely on own needs, will lead to an individualistic behavioural response to the situation, which will in turn affect the appraisal and behavioural response of the other agent involved in the social interaction.

In the next excerpt, an author reported on a conversation between a wife with dementia and a carer in which the negative experience of dementia has led the dyad to feel a sense of disconnection. In fact, the fear and distress caused by the new identity of the partner (now the carer) creates a sense of inadequacy in the person with dementia who used to equally support each other before the diagnosis:

‘I think Jim’s more of a carer than I am.’ (Person with dementia) (Molyneaux, Butchard, Simpson, & Murray, 2011).

Despite the effort of the carer to re-orientate the goal of the appraisal from the individual to the dyad, the person with dementia holds a meaning of the new role of the husband as that of a carer, feeling this way disconnected from the very nature of their relationship. The behavioural response becomes entrenched with a feeling of detachment and a socially constructed role of recipient of care emerges from the interaction: *‘Well what about what a wife does?’* (Person with dementia) (Molyneaux et al., 2011).

The constructed role of care recipient, is triggered by the condition of dementia, and reinforced by the lack of intimacy and closeness emerging from daily interactions:

‘There’s no way I want to be gaga with somebody looking after me all the time, not by anybody. (Person with dementia) (Clare & Shakespeare, 2004). This leads to an increased sense of inadequacy in the carer who impulsively reply in an attempt to manage the fear and anxiety posed by the situation: *‘Well, don’t worry about it.’* (Carer) (Clare & Shakespeare, 2004).

Carers’ appraisal and response (I think I do).

Similarly to what occurs for people with dementia, carers’ appraisal of the situation and behavioural response is influenced by their orientation with respect to the interaction/event. For example, the use of scaffoldings by the carers help the person with dementia engage in a conversation with decreased risks that their memory loss could negatively impact on their social interaction and on the functioning of the relationship. This dyad-oriented strategy promotes positive communication between the agents:

'I'll say things more like, "It . . . wasn't it fun when we, when we took a trip to Colorado?" and she'll think about it and say, "Yeah, I remember that. It was fun." And, uh, rather than saying, "Remember when we were in Colorado, we did such-and-such?' (Carer) (Phinney, 2006).

Maintaining conversation with the person with dementia is key in determining the quality of interaction between partners. One way to keep the flow of conversation is to stimulate engagement in the person with dementia. This is a behavioural technique that carers act out in response to the lack of participation of the person with dementia in every-day life activities:

'I suppose I've got into a routine now…. If we sit to have a meal, I'll make sure there is conversation, or if he's watching television I will comment on it. Even if it's commenting on the adverts [advertisements] to see what he will say about them. For example, there's a silly car advert . . . and I do it every time.' (Carer) (Kindell, Sage, Wilkinson, & Keady, 2014).

In order to avoid the person with dementia feel a burden, carers make their caring tasks less explicit:

'We always hope to be together. That is what we say every night, 'I can't manage without you', he tells me. He is incredibly thankful for whatever I do. I don't want him to feel like a burden for me. Instead I always try to cover up [some of my caring]. (Carer) (Hellstrom, Nolan, & Lundh, 2007).

Lack of open communication and shared understanding of the situation leads the carers to greater responsibilities, disappointment and to an appraisal of the situation made in terms of individual-oriented goals (i.e. I think I do and I feel I need):

'I've got to keep, well, going through the act of making love once a week for him, because I know it will upset him if we hit that on the head [give it up] completely . . but I can't wait for it to be over as quickly as possible, because I get no enjoyment out of it at all. And also I'm a carer, a mother, a nurse. I'm treating him like a child three quarters of the time, and then I've got to reverse my roles to be wife again, and a lover, and one thing and another.' (Oyebode, Bradley, & Allen, 2013).

This negative scenario leads the way to a mechanical interaction between agents, with the carers disengaging from a genuine display of emotions:

'I am mentally so filled with sorrow. In practical situations I go on like a machine. And emotionally, I also go on like a machine. You just go on, and on, and on. My frustration increases, and my husband is victimized by it.' (Vikstrom, Josephsson, Stigsdotter-Neely, & Nygard, 2008).

Dyad-specific behavioural response (We think we do).

Dyad-oriented goals represent the instances in which interacting agents take co-ownership and responsibility of their actions in order to maintain a positive relationship. Communal efforts are made and the agents socially construct a unifying entity, that of the 'dyad' through the use of the pronoun 'We': *'It is WE that is going through this. It isn't him-me.'* (Carer) (Merrick et al., 2016). This clearly defines a shift from a 'self-centred' appraisal to an 'altruistic' appraisal of the situation. In other words, a shift from a behavioural response aiming at individual-oriented goals to a behavioural response aiming at communal/dyad-oriented goals. Also, through balancing roles, each agent acknowledges the autonomy, views, and preferences of the other. It follows that a sense of belongingness to the dyad is felt through reciprocity:

'I mean it works very well. She does the laundry and ironing, we clean together. I hoover and she dusts, so it works well, and then we go shopping together as much as we can…' (Hellstrom et al., 2007).

5.3.3.2 Noises buffering the quality of interaction

These represent the variables that negatively impact on the quality of interaction of the dyad. The variables are the dementia symptoms and the negative past experiences that are carried on in the interaction. When these are present, the ability of the agents to aim at dyad- oriented goals becomes altered. It follows that the appraisal of the situation is made according to each individual sets of goals, thus, an individualistic behavioural response is favoured.

Dementia symptoms.

The cognitive decline of the person with dementia may prove difficult to manage for the carer and when this leads to increased burden, the carer elicits a behavioural response denoting frustration: *'Her mind is sort of blank and it is frustrating for the caregiver 'cause you sort of get mad.'* (Carer) (Siriopoulos, Brown, & Wright, 1999).

Past experiences.

Negative past experiences with the person with dementia buffer the ability of the carer to appraise and orientate the aims of the response in terms of communal goal:

'He always puts me down and I haven't felt like I was capable of doing anything. He still wants to be the head. He insults me. [. . .] I've never had any sympathy from him so to speak.'' (Carer) (Shim, Barroso, & Davis, 2012).

5.4 Discussion

This review aimed at the exploration of dyadic interaction in dementia care, between people with dementia and their carers. We were interested in how these agents construct their experience of care through conversation. What we found is that in the context of dementia care, and in presence of stressors posed by the condition, the interaction between agents is mediated by the degree to which they pursue either individual or dyad-oriented goals.

5.4.1 Line of argument

The personal orientation of the agents involved in interaction during dementia care proves key in influencing their appraisal and decoding of the verbal/non-verbal messages and in determining their behavioural responses. It follows that when both agents set dyad-oriented goals, their decoding of the messages and their behavioural responses are more likely to promote an equal distribution of power. When only one partner opts for shared goals, there may still be positive outcomes, however the burden and stress posed by the context is likely to affect the dyadic interaction because of no perceived shared understanding of the situation over time.

5.4.2 Dyadic construction of the event/situation

In line with previous findings on communal coping (Hobfoll, Schroder, & Malek, 2002; Kowal, Johnson, & Lee, 2003), our review confirmed the existence of the inter-dependant process of appraisal of an event between interacting agents of the dyad. This interpretation of coping in terms of dyadic effort, points at the role of different individuals in confronting the adverse event or situation. It follows that during interaction, the agents construct the event and the response to the event as a shared problem and having co-ownership of the experience. From this point of view, we are close to Lyon, Mickelson, Sullivan, and Coyne's (1998) description of

communal coping as involving both a shared appraisal and understanding of the situation and the *'the pooling of resources of several individuals'* to manage the situation. Contrary to the line of argument proposed by the literature on collective coping (Hobfoll et al., 2002), in which members of a group respond to the stressor with no shared responsibility and co-ownership of the experience, our review was based on concepts of shared meaning and responsibility of the event -A collaborative effort to aim at communal oriented goals.

5.4.3 Strength and limitations

To our knowledge our review is the first to explore dyadic interaction in dementia care through the lens of social constructivism and to develop a behaviour-process model to express the synthesis of our findings. We engaged in a systematic search with pre-defined search criteria, whose strategy was checked for accuracy by an experienced librarian, the selection of studies was undertaken by two researchers independently and the synthesis process of meta-ethnography was checked by three experts in dementia care. As our studies were all of high quality, to decrease bias in the interpretation of our third order constructs, we further checked our interpretations against those studies that we excluded with reasons (e.g. because not clearly reporting qualitative methods, comorbid with other conditions). This strategy allowed to find new themes, however, we found that these were reflected in the data that we analysed to reach third order interpretations. Limitations may reside in the concept of dyadic coping, as it implies continuous negotiations between agents, rather than a static meaning-making process of coping between agents. In concert with system theorists (Minuchin, 1974; vonBertalanffy, 1968), the behavioural response of the members of the dyad (be it a family, or social network), is mediated by their interaction with one another and by the level and quality of communication

they establish. This means that our findings may not adequately reflect the fluid interactional dynamics that occur between multiple interacting agents in care.

5.4.4 Implications of the behaviour-process synthesis

The model we derived has important implication for family carers and people with dementia as it provides a conceptual illustration of how interactional dynamics are influenced by the social construction of communal coping aiming at dyad-oriented goals. Our relational model further emphasises the transactional process of coping in dementia care which is influenced by the constant exchange of messages and experiences during social interaction. However, further research is needed to explore the extent to which and how the interacting members of the dyad negotiate the strategies to cope with the stress posed by the situation, and to what extent for example, people with dementia feel the need to conform to family carers' request.

Chapter 6. How couples accessing crisis teams choose to cope: Narrative inquiry on case studies of crisis in dementia

Bosco, A., Schneider, J., Coleston-Shields DM., & Orrell M. Narrative inquiry on case studies of crisis in dementia. *Quality in Ageing and Older Adults* (Under review).

Abstract

Objective. This study explored how people with dementia and their carers (i.e. the dyad) manage episodes of crisis.

Methods. This was a case study. Participants were recruited from two teams managing crisis in dementia in the UK. We employed multiple qualitative interviews with people with dementia and their family carers over the course of one month. The analysis was first performed through thematic analysis. Inter-rater reliability was measured through Cohen's kappa (*k*) and disagreements resolved through consensus. Data were further analysed through narrative inquiry to create a story line for our findings.

Results. Five dyads were interviewed and a total of 16 interviews were conducted. Three dyads were husband-wife and two were daughter-mother relationships. The mean age was 67.4 for carers and 79.8 for people with dementia. Inter-rater reliability was 'substantial' ($k = 0.73$). In these cases, the carer assumed responsibility for managing the episode and was more likely to seek formal help if a pre-existing plan was in place. Otherwise, when a crisis arose, dyads preferred to avoid involving professionals.

Discussion. The findings indicate that crisis teams are key for crisis support, and that early development of care plans is important to support the couple effectively. Planning ahead for problems is crucial from the earliest stage of diagnosis, and information around crisis teams should be provided at the time of diagnosis.

6.1 Background on dyadic coping in dementia

Challenging behaviour or deterioration in dementia can be experienced as a crisis by the person with dementia and the carer (Pink et al., 2018). Examples of behaviours associated with crisis are agitation/aggression, delusions, wandering, dysphoria, and resistance to care (Backhouse, Camino, & Mioshi, 2018). Crises can further lead to increased hospital admission and decreased quality of life (Ledgerd et al., 2016).

In the UK, professional support for dementia crisis is provided by a range of secondary care teams managing crisis in dementia (TMCD). TMCD provide multidisciplinary assessment and a range of short-term care services (telephone consultation, case management, multidisciplinary meetings, home visits, psychosocial interventions and medication), that are usually provided for up to 6 weeks, with the person with dementia being referred to appropriate longer-term teams or care providers if necessary. The wide range of services provided and the different team structure among TMCD create inconsistency in care provision for crisis. Furthermore, few dementia-specific crisis teams exist to effectively manage critical episode in this population (Streater et al., 2017). As the primary providers of care for people with dementia, family carers may experience a sense of burden and decreased mental health. Crises, in turn, may destabilise the support systems of the dyad (Toot et al., 2013**)**.

As explained by Fingerman and Bermann (2000) individuals expect the family system to maintain a certain tone, which is based on a series of behaviours that is expected of other family members to maintain. This is to ensure systemic homeostasis within the family. As individuals age, so does the family system, and with ageing it can be more difficult for family members to tolerate changes other than trying to maintain same familial roles. For this reason, a state of equilibrium is

preferred. Research on dementia caring report that family members tend to favour homeostasis when facing critical changes engendered by dementia rather than challenging each respective role with respect to the situation (Vroomen et al., 2013; Jones & Miesen, 2013).

When the demands of care made by the person with dementia do not adequately match with the resources available to the carers (personal resources such as self-efficacy or external support for friends or peers), the carers may experience a series of deleterious implications for their wellbeing (Sörensen & Pinquart, 2005). These implications seem to be more impactful when carers do not adapt to the situation but rather adopt roles they had pre-diagnosis (Pinquart & Sörensen, 2006).

Bosco et al. (2018) described how relational processes influence the coping strategies that both members of the care dyad enact when dealing with adverse events posed by dementia and when the dyad is confronted with a situation (be it challenging and requiring more coping mechanisms or of everyday concerns) the members of the dyad engage in an inter-dependant process for the appraisal of the event and its management.

This process of communal coping, as previously contended by Lyon, Mickelson, Sullivan, and Coyne (1998), requires a certain degree of shared responsibility towards the event. It follows that when both the carer and the person with dementia assume co-ownership and responsibility for managing the situation (dyadic coping style), there is more equal distribution of power and the event is less likely to negatively affect the care agents (be it the person with dementia or the carer) (Bosco, Schneider, Coleston-Shields, Sousa, & Orrell, 2019; Bolsover, 2017; Egdell, 2013). Conversely, when only one member or none engages in communal coping

(individual coping style), for example both person with dementia and the carer maintain differing views on how to manage the situation, it is more likely that the stress posed by the event have a major impact on the care system (Bosco, Schneider, Coleston-Shields, Sousa, & Orrell, 2019; Bolsover, 2017; Egdell, 2013).

Although research on familial roles and identities has been conducted in dementia research (Cohen-Mansfield, Papura-Gill, & Golander, 2006), still little is known about how people with dementia and their carers cope with mental health crises and, in particular, how they manage those critical situations that appear to determine whether the individual can cope in the community or needs care home placement or hospital admission.

This project therefore aimed to explore the ways the family carer and the person with dementia manage episodes of mental health crisis across time. We used the definition of crisis by MacNeil et al. (2013): 'a process where there is a stressor(s) that causes an imbalance requiring an immediate decision which leads to a desired outcome, and therefore crisis resolution. If the crisis is not resolved, the cycle continues'. The perspective of coping styles informed the enquiry, and we also set out to identify barriers that could influence the likelihood of seeking professional help from teams managing crisis in dementia (TMCD).

6.2 Methods

6.2.1 Study design

This study used a participatory approach and employed a case study design to undertake longitudinal dyadic interviews over the course of one month, as detailed later in this chapter. We complied with the COREQ checklist for qualitative reports (Tong, Sainsbury, & Craig, 2007).

6.2.2 Participatory research as meta-method

The study utilised a community-based participatory approach informed by the tenets of co-operative inquiry into health care practice (Borg *et al.*, 2012) where knowledge is created through a co-operative process between researcher and participant, between science and everyday life experiences. The process is enhanced through the involvement of a co-researcher with lived experience of the health care condition being observed. The co-researchers generally encourage participants' involvement in research and facilitate the disclosing of life experiences. They also help the research team engage in reflection by offering a real-life context to an otherwise research-led perspective topic. Because of these advantages, our study employed a co-researcher with lived experience of dementia in the development of study materials and in the delivery of interviews. Hence, the co-researcher offered shared experience of care for crisis (e.g. accessing similar crisis teams in dementia) and knowledge (e.g. personal experience of crisis) of participants to the study.

6.2.3 Inclusion and exclusion criteria

The person with dementia was eligible to the study if s/he:

- Was on a caseload of TMCD.
- Was 50 years old or above.
- Received support from an informal carer.
- Had a formal diagnosis of dementia.
- Was identified by staff of one of the participating TMCD as being cognitively able to participate in the interview.
- Was aware of their diagnosis of dementia and willing to talk about dementia.
- Spoke English.

The carer was eligible if s/he:

- Was a family carer of a person with dementia (either spouse or children) who met the above inclusion criteria
- Was willing to discuss dementia and their experiences of mental health crisis.

The person with dementia was excluded from the study if s/he did not understand written and oral English or if deemed unfit to participate by the team leader, the carer, or the research team and/or was unable to give full consent. Consultee advice under the Mental Capacity Act was not considered a viable alternative. The study was granted ethical approval from the Health Research Authority, the East Midlands – Derby Research Committee (reference 18/EM/0023).

6.2.4 Patient and Public Involvement (PPI)

An advisory group was formed for the project from members of a local Patient and Public Involvement group. The group informed on research design and helped develop topic guides for interviews. A total of two meetings were held with the group (one meeting to explore the relevance of the aims and objectives, a second meeting after 8 months during the development of study material). The support they provided consisted in sharing their ideas on how relevant the study was to better understand the experience of crisis in dementia. We based the PPI on the National Institute for Health and Clinical Excellence (NICE) (NICE, 2014) guidelines on conducting health and social care research.

6.2.5 Recruitment and training of co-researchers

The co-researchers with dementia were identified during PPI meetings and asked if they were willing to participate in the research study. They were recruited if they were 50 years old or above, had a formal diagnosis of dementia, and were cognitively able to conduct the interview in English. The carer co-researcher was a family carer of a person with a formal diagnosis of dementia. No restrictions on age

or sex were applied. A total of six co-researchers were identified (two carers and four people with dementia) as eligible to participate. Four agreed to take part in the initial briefing about the study (i.e. to explain the study and the implications of acting as co-researcher) but did not continue because they were unable to commit to it regularly. Thus, two co-researchers (one person with dementia CB and one carer DC) received training in delivering qualitative interviews and helped to analyse data. Only DC helped the research team deliver the interviews. However, DC could help deliver interviews for only one dyad as the other dyads preferred not to have more than one interviewer in the room to avoid confusion in the person with dementia. For this reason, AB delivered the remaining interviews alone. AB and CB presented the study to a dementia PPI group at the University of Nottingham (Appendix 18).

Training of co-researchers followed recommendations reported by the literature (Di Lorito *et al.*, 2017). It aimed to build confidence in the delivery of qualitative interviews (i.e. they practised through mock interviews) and to convey the responsibilities of research (e.g. ethical issues involved). Attention was particularly paid to training in interview techniques targeting social skills (i.e. empathy, non-verbal cues), as these would enable the gathering of information from the interviewees (Scottish Dementia Working Group, 2014).

The training consisted of two pre-interview and one post-interview sessions. The pre-interview sessions were held on consecutive days, lasted for two hours each, and consisted of role play scenarios concerning dyadic interviews and focus groups. In addition, a 20-minute briefing was held on the day before the interview to discuss the process in detail. The follow up session was held immediately post-interview and consisted of a 10-minute de-briefing. CB reported no discomfort or concern.

6.2.6 Procedure

As part of the recruitment strategy, AB first contacted the team leaders from the crisis services in the region to explore research capacity in their sites. AB presented the project to a team meeting and advertised it through a poster that was displayed in the service premises. The team leader then identified potential participants based on the inclusion/exclusion criteria. These dyads were asked if AB could attend their next home visit to present the research study, provide them with the information sheet and answer any questions. Following this initial meeting, participants were given 48 hours to read the information sheet before AB contacted them to see if they were interested in taking part in the study. AB then notified the team leader of each service where a couple agreed to participate and scheduled the interview dates.

6.2.7 Data collection

The qualitative dyadic interviews were conducted by AB and one co-researcher (DC). As the therapeutic input of TMCD lasts up to 6 weeks, up to four interviews were conducted with each dyad (i.e. person with dementia and carer interviewed together at the same time) over the course of one month. This was to ensure that each dyad was receiving support from the team at the time the interviews took place.

In concert with Legard et al. (2003), we used an individual-oriented perspective for saturation and stopped conducting new interviews with each dyad when no new information was being generated during the interviews. Sampling instead, was decided in consultation with TMCD to explore the adequacy (considering possible risks associated) of recruiting new participants. Interviews lasted around 90 minutes for each of the four interview sessions (this time included 30 minutes for obtaining consent and 10 minutes for debriefing).

Findings from a previously published systematic review (Bosco et al., 2018), guided the topics for the interviews with dyads and represented a first analysis (literature-based) of carers' narratives on the way they attempted to make meaning of their relational experience of the caring process. For example, questions around dyadic coping were used during the interviews (e.g. how do you manage the crisis as a couple?). This line of inquiry enabled a first exploration of the type of coping mechanisms used by each dyad (e.g. dyadic coping style when during the interview both members of the dyad showed a shared understanding of the crisis and agreed on how to manage the event and individual coping style when there was disagreement within the dyad about what constituted a crisis and how they thought it was best to manage it). This approach was informed by Foucault (1985) and focussed on the power relations between the couple. Further questions looked at how dyads constructed the experience of crisis, and the reasons leading to a call for professional help. Questions also explored the process of contacting the crisis teams and the quality of care received. At the end of the series of interviews, each dyad was asked to reflect back on the resolution of crisis as to better understand if and in what ways they learned how to manage future crises.

6.2.8 Data analysis

All qualitative interviews were audio-recorded, transcribed and transferred onto NVivo 11 for categorisation (QSR International, 2012). The analysis was performed within cases (i.e. the interpretation of the transcripts for each dyad was treated as a single case) and across cases (i.e. a thematic interpretation of the transcripts was made across cases to find common themes). Thematic analysis was instrumentally used to identify, analyse and report themes or patterns across cases. We used

constant comparison (Strauss & Corbin, 1990) to explore participants' responses both within and between cases.

The initial coding of the interview transcripts was performed by paragraph, and memos were recorded for each code, to clarify the relationship between the code and the relevant piece of text. Memos proved key to the analytic process, enabling more abstract categorisation through axial coding. Emerging themes were checked for relevance and validity by two independent researchers AB and AN.

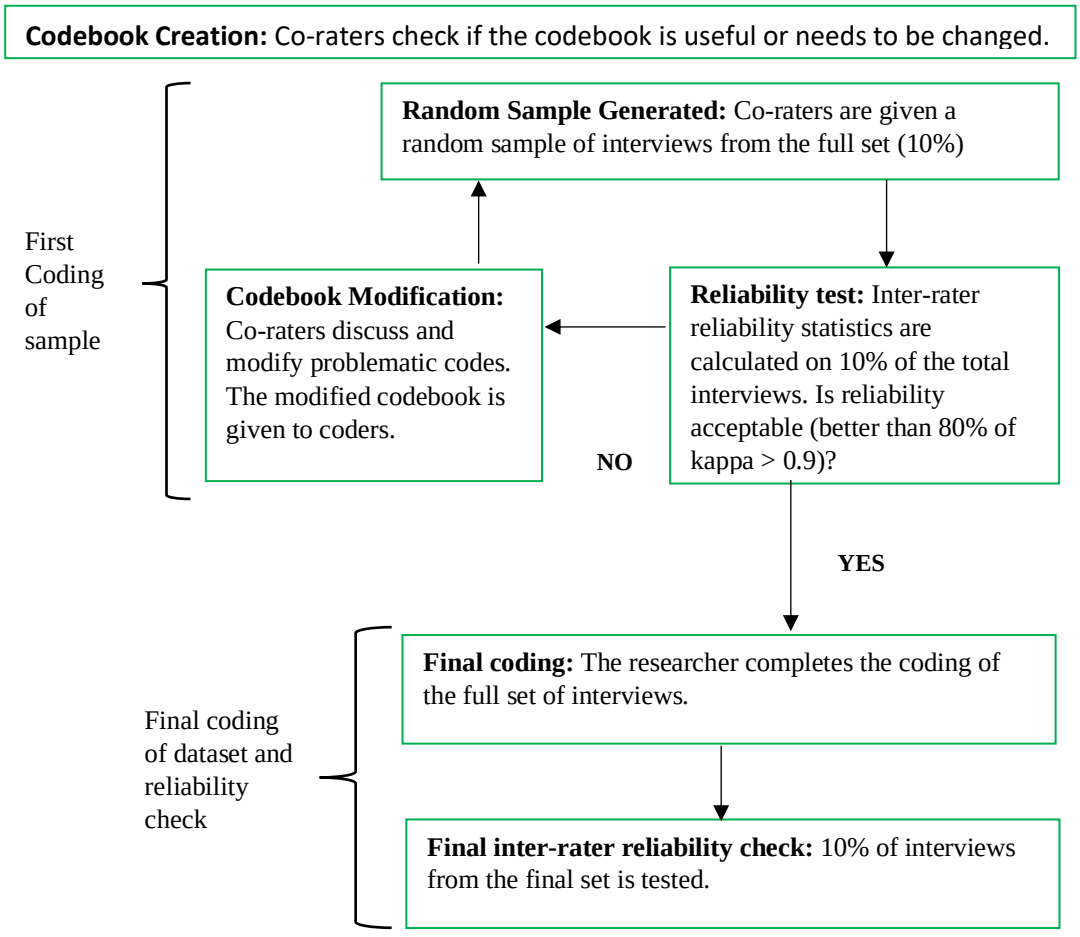
To ensure reliability, AB drafted a codebook (Figure 6.1) in accordance with the initial codes identified and according to guidelines (Hruschka *et al.,* 2004). This was used by both researchers (AB and AN) to code the interview transcripts. They both coded 10% of the interview transcripts to test inter-rater reliability by means of Cohen's Kappa coefficient (Cohen, 1960). The parameters proposed by Landis and Koch (1977) were used as ranges for reliability: 0.81–1.00 = almost perfect; 0.61–0.80 = substantial; 0.41–0.60 = moderate; 0.21–0.40 = fair; 0.00–0.20 = slight; < 0.00 = poor.

The thematic analysis helped organise the qualitative data according to a definite structure which informed the formation of a coherent flow for the argument around managing crisis in dementia. This flow helped create a story line through narrative inquiry. In this respect, the lead author analysed the dyadic interviews to form a narrative to explore individuals' experiences (Clandinin and Connelly 2000). Three features of narrative inquiry, temporality, social aspect and place constituted the analysis of complex relational dynamics of individuals' lived stories. Explanatory narrative methods by Kleinman (1980) and Williams (1984) were used to describe how dementia dyads (if memories attached to past crises were easily retrievable by

either member of the dyad) constructed retrospectively crises events. These were recent memories of crisis occurring during the month the dyad was receiving support from TMCDs. For this task, the researcher (AB) employed a what-if strategy to explore what has occurred in the dyad and what has not occurred to them during crises. Would a certain outcome have changed if a particular behaviour was not exhibited during crises?

We adapted the two-stage narrative structure (i.e. looking at the content and form of the narrative) by Burnell et al. (2009) with the individual and dyadic coping mechanisms (i.e. enacting dyad- or individual-specific appraisal and responsibility) by Bodenmann (1995).

Figure 6.1 Process for Inter-rater Reliability. Adapted from Hruschka et al (2004).



6.3 Results

Five dyads were interviewed over one month, for a total of 16 interviews. Three dyads were spouses (i.e. husband-wife) and two were in daughter-mother relationship. The mean age for carers was 67.4 and for people with dementia was 79.8 (Table 6.1 for participants' characteristics). The interviews lasted on average 46.3 minutes. All the married dyads were living together (married for more than 20 years) but in a different household from their adult children. The daughter-mother dyads lived separately but in the same neighbourhood.

The interrater reliability test revealed a 'substantial' agreement (k=0.73; Landis & Koch, 1977).

From the analysis of power relations, we found that couples differed in their style of appraising the crisis and assuming responsibility for its management. Participants fell into two categories: a dyadic coping style (N=2) or an individual coping style (N=3). The narrative approach led us to structure findings into three 'acts' representing the setup, confrontation and resolution of crises (Table 6.2 describes the coding process). As the crisis unfolded the narratives differed according to whether couples used dyadic or individual coping styles.

6.3.1 First act – Setup and antecedent of crises (Past narrative pre-crises)

The first act concerns the life-story of each participant, and for the dyads their characteristic roles and relationships. The first act also reports how dyads typically negotiate everyday life in the absence of a crisis. The events that led to the crisis under examination represent the end of the first act, the first plot point.

Table 6.1 Participants' characteristics.

Dyad	**relationship**	**Coping style**	**Participant with dementia**	**Age person with dementia**	**Age carer**	**Interviews** (N)	**Team case load at time of interview** (N weeks)	**diagnosis**
D1S1	Mother-daughter	Dyad-specific	Mother	80	54	4	2nd week of being in caseload	Alzheimer's and vascular dementia
D2S1	Mother-daughter	Individual-specific	Mother	75	48	2	1st week of being in caseload	Alzheimer's
D3S1	Husband-wife	Dyad-specific	Husband	93	82	4	4th week of being in caseload (discharge time)	Alzheimer's
D1S2	Husband-wife	Individual-specific	Husband	78	75	4	3rd week of being in caseload	Fronto-Temporal dementia
D2S2	Husband-wife	Individual-specific	Husband	73	78	2	2nd week of being in caseload	Alzheimer's

6.3.1.1 Triggers for crisis

Different stimuli acted as triggers for a mental health crisis in people with dementia. Such stimuli may be caused by the symptoms of dementia or be external to the individual. What seems to be a common factor is the disequilibrium that such stimuli may create in the person. People with dementia in three dyads reported triggers for crises that were associated with hallucinations. These were described as *'alterations of reality'* by one participant. The same person spoke of 'seeing' his wife cheating on him with other men from his past when in fact she was sleeping in the bed next to him.

This couple exemplified a dyadic-focussed coping style, illustrated by the wife's account of how she felt before the situation escalated to an episode of crisis:

'He was very threatening but in my heart I knew he was not going to do any harm. He constantly thinks that I am cheating on him with other men. It is just an hallucination…' (D3S1).

When hallucinations are coupled with memory problems, the person may feel disoriented and unable to experience the environment clearly. This was the case for a woman with dementia who reported 'seeing' her husband in the room at night when in fact he had died some time ago. As her daughter explained:

'My mum would call you at night if she thinks she has seen my dad next to her, she would get scared because he was not an easy man but she is not able to remember that my dad is now gone' (D2S1).

An individual-specific coping style characterised this (mother-daughter) dyad, with the mother maintaining her firm belief that that situation, as described by the daughter, was not related to crisis:

'That was not a crisis for me, and was not going to be one, you say it was, but again for me it was normal I was fine' (D2S1).

Triggers may also come from the social environment when the person feels s/he is not being acknowledged. A wife explained that the feeling of 'being ignored by her' upset her husband so much that he would cry in his chair (D1S2).

Constant anxiety was a feature of the situations studied. This affected even distant family members who were apprehensive about receiving phone calls concerning a crisis and in turn it could prove overwhelming for those providing more direct care. This feeling was common to dyads with either coping style. One carer reported:

'…my brother lives away, my sister panics because she does not drive and it would take ages for her…, so everything is on me really, that I want it or not…'(D2S1).

Although many symptoms associated with dementia were deemed difficult to manage (e.g. getting lost, continual crying), dyads reported that what constituted a crisis was not necessarily the severity of the behaviour but rather their inability to deal with the situation. As a carer pointed out, a crisis means being left with no clue about how to help the person:

'*…He looks very angry but I really believe I am safe, but how can I help him? I am old and tired, I never had to deal with this before…'* (D3S1).

Having described how crises come about and what features they seem to share, as well as identifying different coping styles, the analysis next developed accounts of how the crisis unfolds.

6.3.2 Second act – Confrontation - Being in crisis (Present narrative at the time of appraisal and response)

The second act featured the 'rising action' of the story, a narrative around the way dyads made sense of the crisis and how they attempted to cope with the difficult situation. Sometimes they failed, sometimes they learned new skills to manage the situation. Through confronting the crisis, dyads developed a sense of awareness of the critical situation and reached a point that may be seen as transformational - a *'character arc'.* This phase of development seemed to be promoted by external support, which could include the help of close friends or teams of professionals with a remit to manage crises in dementia.

6.3.2.1 Appraisal

Dyads displayed either a shared appraisal or an individual appraisal of the crisis. Open communication was usually fostered for both appraisals of the event. Dyads with shared understanding of the situation tended to first acknowledge the existence of the crisis and to evaluate together whether or not they had enough resources to cope with the situation through a perspective-taking process. In one case, warning signs included clenching teeth and prolonged eye contact (D3S1), or irritability (D1S2). While these signs were not always acknowledged by the person with dementia, he knew that something was not right with his behaviour because the carer would sit next to him to calm him down:

'Yes the armchair is the safe place we sit together and then I calm down…I now know when something is wrong because I usually sit with her on here' (D3S1).

This illustrates shared appraisal and dyadic coping. Conversely, dyads with individual approaches sometimes differed in their appraisal of on whether a given

episode was a crisis. In one case, the memory of the participant with dementia was not at issue, rather, that person firmly held to their own experience of the event, '*It was OK for me, full stop. No crisis'* (D2S1). This was in direct contrast to the carer's appraisal.

The 'second appraisal' of the event, the phase in which dyads evaluate whether or not they have enough resources to manage the situation, is when they are most likely to engage in help seeking behaviour. At this point, dyads evaluated their response options to the event, weighing the advantages and disadvantages. Data from the interviews suggested that the advantages were seen in terms of assistance with problems, while disadvantages consisted of having professionals involved.

6.3.2.2 Calling for help to manage crisis

Although the intensity of the crisis may lead to a more rapid call for help, dyads with either coping style seemed to decide based on when the decision needed to be made. During an episode of crisis, if the call for help needed to be made, dyads balanced the presence of 'too many problems to manage' against the consequences of making such call for help for example, having many professionals in the house, changes to routine and relationships. A carer told a brief anecdote of when she was considering calling for help:

'If I see the crisis is so intense of course I call the ambulance…but usually…the first thing I do is to think "Okay, he is in crisis now." I definitely plan to call the team tomorrow or the day after. There is no way I call for help the same moment he is in crisis, that would make him even more confused and I do not have the strength really to deal with everyone here' (D2S2).

During an episode of crisis, if the dyads were presented with the scenario of calling for help 'right now' the members of the dyad (usually the carer) had to weigh up the undesirable consequences against the utility factor (help received). The dyad or the carer were more likely to delay calling for help when episodes were more intense and unmanageable:

'When I feel agitated, I prefer my wife to help me and not having all 'strangers' (team) here, they would get me more confused than I already am, so if she asks I tell her not to call for help' (D3S1).

6.3.2.3 Threshold for seeking help

Dyads seemed to reach a threshold for help-seeking behaviour, and this was dependent upon the level of awareness that either member of the dyad (or both members) had of the crisis. It was usually the responsibility of the carer to call for help even when both members reached full awareness. As recounted by a carer, this was mainly the case when the person with dementia had decreased capacity to call for help (in case of dyad-focussed coping style) or when in case of dyads with individual-specific coping style, the person with dementia felt that the crisis was a family matter and not something to share with strangers, yet the carer because unable to manage the situation decided to contact the multidisciplinary team for crisis in dementia:

'I do try to manage things together as a couple but she won't. She does not allow herself to think she is capable and this gives all the responsibility to other people for support, when in fact it should be between us, not the team…' (D2S2).

6.3.2.4 Level of support

When the professional, external support was offered or provided before an episode of crisis arose and information was shared within the couple from the time of diagnosis, dyads seemed to engage in help seeking behaviour more rapidly. One couple commented on how *'receiving information from a professional right from the beginning takes away so much responsibility'* (D1S1) for action and diminished any potential disappointment within the dyad. This viewpoint was shared by all dyads irrespective of their individual- or dyad-specific appraisal and responsibility:

'... I think I have been lucky to have received information from my GP, it was helpful as some of the decisions helped me make did not make me feel bad as much as it would if I had made them on my own, you know G (PWD) has got temper' (D2S2).

Where the dyad's coping style was led by the individual, the carer tended to delay the search for information because the person with dementia did not necessarily recognise or acknowledge the experience of crisis:

'Not feeling able to make judgment about the severity of the situation, I am not sure I am the only one thinking it is a crisis' (D2S1).

Individual appraisal style tended to delay the search of information because of a firm division of roles, typified into that of *'carer'* and *'cared for'* that was silently accepted and almost unconsciously enacted within the dyad:

'This is a job for my wife, isn't it? I have got dementia, as she puts it, I could get it wrong with the information I'm looking at' (D2S2).

6.3.3 Third act – Resolution and reappraisal time (future narrative)

A sort of resolution to the crisis was deliberately fostered by the research process. Dyads were asked to reflect back on their accounts of crisis to explore how their strategies to cope with the crisis changed over time. This approach yielded rich data around their experience of managing crisis. Not surprisingly, people with dementia found it relatively difficult to remember what was discussed in previous interviews and required assistance from their carers to answer the questions. Differing only according to whether they operated a joint or individual coping style, what they all said was similar: 'I/we have a problem, I/we call for help'.

6.3.3.1 Re-enactment of previous learned behaviour

Carers demonstrated some learning about what tactics proved effective in a crisis. A carer reflected on how a previous crisis made her aware of how to tackle future crises:

'…we help her also with food, cleaning the fridge from food that is no good anymore because my mum has problems checking the dates and after eating meats she would get agitated and calling everyone saying "I am poisoned"…' (D1S1).

Another carer reported that contacting the team to help with the crisis made her aware of the fact that is best not to delay the call for help as they may work best if an early intervention is provided:

'*I can manage everyday problems but not crises, I think the earlier they help the better it is… straight from diagnosis'* (D1S2).

There were situations in which different views between the team and the carer about why a certain coping strategy should be avoided, led the carer to keep employing the same technique over time because in her view it proved helpful to prevent crisis:

'They say (team) I should not give my mum cakes for meals as they give her too much sugar, but I find them to sooth her agitation more than talking or meds…and to be honest it is the only thing she wants to eat' (D2S1).

In addition, there are instances when a carer felt the need to contact the team, as in the past they helped manage the crisis:

'I do not understand why I cannot call the team when I need them, they just said they are for crisis, but who says what I am calling for is not a crisis?' (D2S1).

It appears that in this case the team did not feel that the episode required professional help. It was not possible to judge the longer-term impact of this response on that carer's help-seeking behaviour.

Table 6.2 Analytic description of dyadic interviews.

Theme category	**Narrative interpretation**	**Example of coding per theme**
First act – Setup and antecedent of crises (N=14)	Triggers for crisis	'I saw A. (FC) laying on the floor with other men… I thought you were with other men laughing at me' (D3S1).
Second act – Confrontation - Being in crisis (N=96)	Appraisal	'That was not a crisis for me…you say it was, but again for me it was normal I was fine' (D2S1),
	Calling for help to manage crisis	'If I see the crisis is so intense of course I call the ambulance…but usually the first thing I do is to think ok he is in crisis now I definitely plan to call the team tomorrow. There is no way I call for help the same moment he is in crisis, he would make him even more confused…' (D2S2).
	Threshold for seeking help	'I do try to manage things together as a couple but she won't. She does not allow herself to think she is capable and this gives all the responsibility to others' (D2S2).
	Level of support	'…I have been lucky to have received information form my GP, as some of the decisions helped me make did not make me feel bad as much as it would if I had made them on my own, you know G (PWD) has got temper' (D2S2).
Third act – Resolution and reappraisal time (N=10)	Re-enactment of previous learned Behaviour	'I do not understand why I cannot call the team when I need them, they just said they are for crisis, but who tells what I am calling for is not a crisis?' (D2S1).

6.4 Discussion

This study explored the way the primary carer and the person with dementia cope with mental health crises finding different coping styles and identifying issues that appear to influence the likelihood of seeking help from crisis teams (Figure 6.2).

In line with previous literature (Toot *et al.,* 2013), such experience creates an imbalance in the person's ability to adapt to the changes of the situation, especially in presence of hallucinations, as these would alter the person's understanding of what is real and what is not. This led to immediate and at times inadequate responses by either agent within the dyad. The support of the team was key to also providing information on how, when and whom to contact in an emergency. Interviewees agreed that early information (ideally, at the time of diagnosis) was better for coping and for making a timely call for help in crisis.

6.4.1 Dyadic coping with crises

In line with Shim, Barroso and Davis (2012), this study found that, when the two members of the dyad had no shared understanding of the event, and focussed on individual needs rather than on the needs of the dyad as a system, then it was more likely for the carers to have negative experience of caring.

Also, the cognitive mechanisms behind a decision to call for help did not follow a logical sequence, where the decision is over the strengths and weaknesses of possible choices. During crisis the decision became a function of time. This may be explained in terms of 'preference reversal'. Yukalov and Sornette (2015) report that, when individuals engage in decision making, their preference is based on the difference between utility (what is the ideal outcome) and attraction for the considered choice. This attraction is made up of behavioural biases and it can be influenced by when the

decision needs to be taken. The theory has been previously tested on data concerning smoking cessation (e.g. Walsh and Sanson-Fisher, 2001). Similarly, a preference reversal mechanism appeared to occur in dementia care when the dyad was confronted with the decision to call for professional help. In our study, in anticipation of an imminent crisis (e.g. in the next days), carers engaged in help-seeking behaviour. However, in the midst of a crisis, they reversed their preference and chose to postpone professional support for times when the crisis was more intense and severe. As reported in the narratives of our participants (mainly carers), this occurred because the detractors (e.g. having strangers in the home, fear of changes in relationship) 'won' over utility (i.e. receiving help for crisis). Future reappraisal of crisis was influenced by past successful appraisal and response and with time they could repeat previous coping strategies that had worked in past episodes (e.g. when the person with dementia becomes aggressive the carer sits with him to calm him down).

6.5 Conclusions

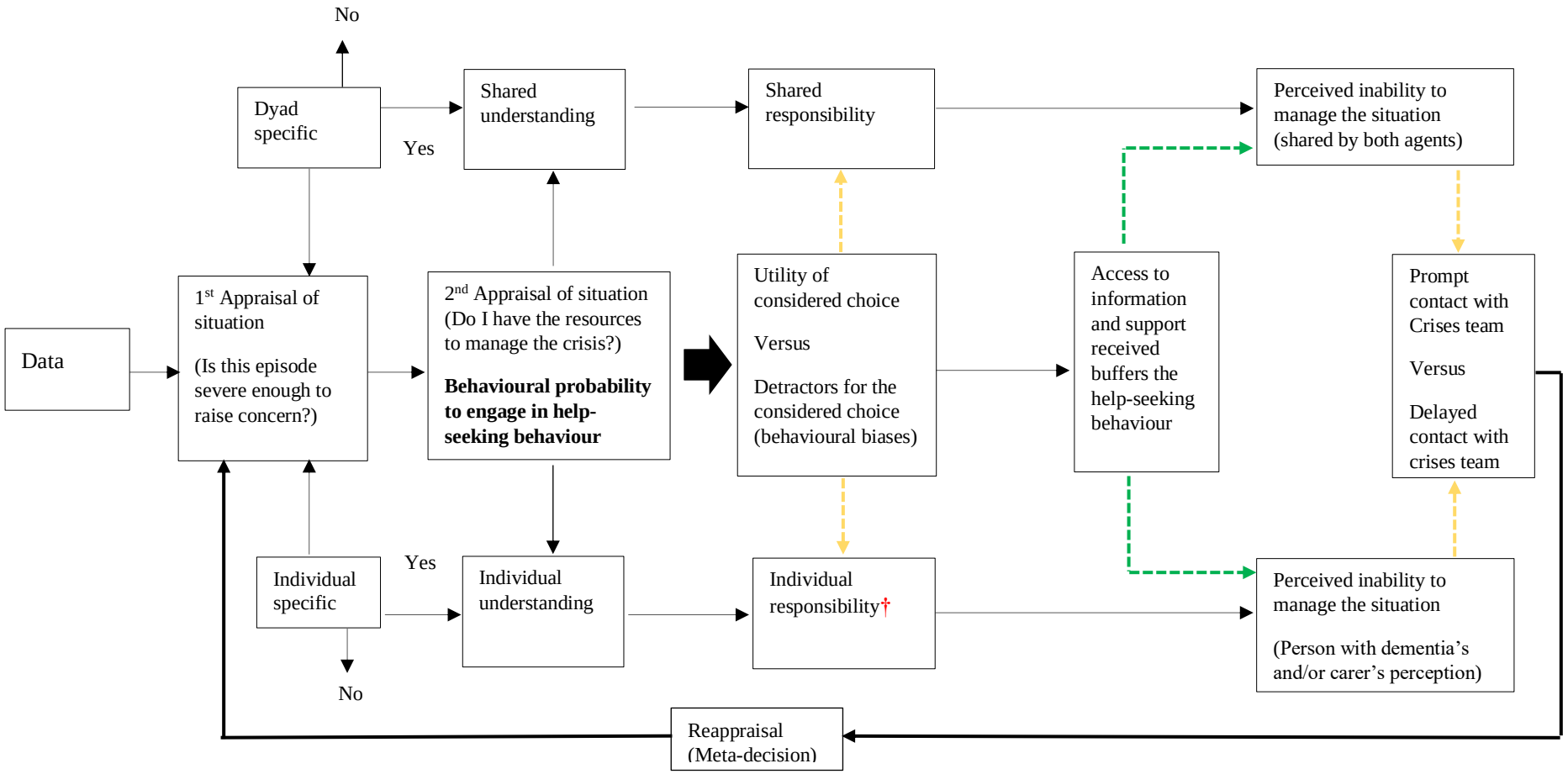
This is the first dyadic, qualitative inquiry into the experience of mental health crisis for people with dementia and their carers. We used two qualitative methods for data analysis based on thematic analysis and narrative inquiry and reliability of coding was good. A limitation is the lack of diversity in the participants who were all middle-class white British in heterosexual marriage, or in daughter-mother relationship. Also not included were other family members providing care, or paid carers. These groups might have added new knowledge and insights into coping with crises and accessing professional help.

Receiving prompt support from secondary services may help a person with dementia stay at home in a familiar environment with little or no disruption to their everyday

life and social contacts. Take up of crisis services is influenced by subjective factors on the part of potential clients including delaying calls for support until the crisis has receded. From the start of their dementia 'journey' individuals with a diagnosis and their care partners need to understand the role of these teams and how to access them appropriately.

The care context whereby the primary carer but also the health professionals operate is complex and requires important decisions to be made in a timely manner (immediate for the carer and around 6 weeks for the team). For this reason, it is advisable to have information in place at the time of diagnosis about what constitutes a crisis and how to manage such difficult situations. Although our participants favoured information provided by health professionals as deemed more reliable, it may also be useful to create opportunity through social media to report on shared experiences of people with dementia. The media may act as channels to convey important messages around care responsibility and how to avoid employing deviant coping strategies and to effectively manage critical situations and/or call for help.

Figure 6.2 Coping with mental health crises: How dyads engage in help-seeking behaviour.



Chapter 7. Co-producing care for mental health crisis in dementia: The experience of carers and staff of dementia crisis teams

Bosco, A., Schneider, J., Coleston-Shields DM., & Orrell M. Co-producing care for mental health crises: The experience of family carers and staff members of dementia crisis teams. *Sage Open* (Under review).

Abstract

Background Co-production is increasingly covering public health agenda as ideal approach to care to empower patients through active participation in care planning and delivery and to improve the effectiveness of care. Owing to its behavioural symptoms and cognitive deterioration, dementia often poses a considerable challenge for staff and carers to effectively involve the person with dementia in times of crisis, with carers being usually responsible for managing critical situations and considered the point of contact for dementia crisis teams. Little is known about the attitudes and views of crisis teams and family carers about co-production. Questions include how care plans are developed or delivered, and how co-production of care is experienced by all concerned.

Methods Focus groups were held with family carers and staff of multidisciplinary crisis teams from three NHS Trusts in the UK. Recorded and transcribed data were coded and explored using framework analysis. Coding was undertaken by two raters for 10% of transcripts and inter-rater reliability was measured through Cohen's Kappa (*k*).

Results A total of three teams were interviewed and one focus group was run with each team. A total of 22 staff members participated in all three focus groups. Three family carers were interviewed over two focus groups. Inter-rater reliability for data

coding was high (k=0.82). Data clustered around strategies used to promote the active involvement of the person with dementia, and the challenges experienced when delivering the care. Staff members reported that building trust with the person with dementia and the carer was key for any therapeutic outcomes, while achieving a therapeutic relationship was fundamental to achieving co-production of care. Miscommunication, such as could occur when there was a failure to recognise roles and responsibilities within the team and between the team and the households receiving the care, adversely affected the quality of care delivered.

Conclusion Information concerning crisis teams and episodes of crisis should be communicated effectively at the time of diagnosis, and reinforced at intervals to enable the person with dementia and the carer to contact crisis teams appropriately when the need arises.

7.1 Overview on crisis care in dementia

A mental health crisis often means that the person does not feel able to cope or be in control of a situation (Vroomen, Bosmans, van Hout, & de Rooij, 2013). The situation may not necessarily be challenging for everyone and an episode of crisis may be experienced differently by different individuals. In the UK, secondary care, multidisciplinary teams have been established to avert crises. These teams may be called different names in different places, and there are instances different terminology is used within the same Trust (Streater, Coleston-Shields, Yates, Stanyon, & Orrell, 2017). Consequently, there is confusion amongst patients and carers about the roles and responsibilities of different care teams.

Teams managing crisis in dementia (TMCD) consist of health professionals from different disciplines whose diverse make up ideally guarantees a variety of skills

needed to deliver effective care. However, unless the roles are well defined, and responsibilities acknowledged within the team, the patients may feel confused by different professionals conveying different information (Jenkins, Fallowfield, & Poole, 2001).

In addition, what makes it difficult to deliver effective care to people with dementia experiencing a crisis, is the differing views of what constitutes a good outcome. There are instances in which different agents in care may seek differing outcomes, and because of the cognitive impairment, the person with dementia risks being given little or no opportunity to make decision on their care plan (Jenkins, Fallowfield, & Poole, 2001). This scenario becomes more challenging when during a crisis, when the carer becomes primarily responsible for making immediate and important care decisions (Bosco et al., 2019).

Promoting democratisation in decision making in dementia crisis care requires a process of reciprocal relationship between health professionals, people with dementia and their primary carers. Promoting a clear team organisation and responsibility of roles within the team and creating a partnership between staff, the person with dementia and the carer, may create opportunity for collaborative work around crisis. This collaboration may in turn promote the sharing of views and possible concerns about therapeutic outcomes and improve the overall experience of care. Although in the UK, co-production has been increasingly featured in health care initiatives (Seale, 2016; NHS Scotland, 2016; Bevan Commission, 2015), very few studies have explored clinicians and carers attitudes to co-production in dementia care and knowledge is still scant around finding effective strategies to empower people with dementia accessing TMCD through promoting their active participation and decisional power in the planning and delivery of care for crisis

(regarded here as ‘co-production’). Without the proper involvement of people with dementia and carers, engagement in the care package is likely to be limited impeding the work of crisis teams and adversely affecting outcomes.

The aim of this study was to explore the experience of co-producing care for family carers and health staff of crisis teams and generate a better understanding of how it could be improved.

7.2 Methods

This was a qualitative study which was funded by the Economic and Social Research Council (UK) and received ethical approval from the Health Research Authority, the East Midlands – Derby Research Committee (reference 18/EM/0023).

7.2.1 Study design and sample

We used focus groups to consult health professionals of TMCD and family carers of people with dementia accessing these services in the North-east and East Midland regions in the UK. Focus groups were intended as representations of group dynamics, and in accordance with Freeman (2006), our object of inquiry, co-production, was investigated by stimulating different views at once, as it would occur in everyday team meetings, and carer group meetings.

Health professionals were eligible to participate if they were working in a multidisciplinary community team managing crises in dementia.

Family carers were eligible if they were willing to discuss their experience of dementia caring and mental health crises, were English speakers, and whose relative with dementia was 50 years old or over, had a formal diagnosis of dementia, and was on a crisis team caseload.

Stages for the planning and delivery of focus groups were implemented (Table 7.1). These aimed to explore the most relevant topics that could be covered during the interviews by familiarizing with the existing literature on co-production in health care settings, and by planning the logistics (e.g. booking the interview room) for the interviews.

These stages were explored with a co-researcher with dementia and a family carer who formed an advisory team for the study and were recruited from the Patient and Public Involvement group (PPI) at the School of Medicine at the University of Nottingham.

Table 7.1 Planning phase for focus groups.

Task	**Time before the focus group took place**
Development of study purpose	6-8 weeks
Identification of participant	6-8 weeks
Question development	4-6 weeks
Development of script	4-6 weeks
Rehearsal and revision	4 weeks
Recruitment of participants	4 weeks
Reminder (email) sent to participant	4 weeks (Once every week)
Booking of setting	2 weeks
Reminder call to participants	3 days

7.2.2 Procedure

The lead author (AB) contacted the service manager of each participating team and provided them with study information sheets and a poster for the team office to recruit health professionals from within their service. A similar strategy was

followed for the recruitment of family carers. The service manager, in consultation with TMCD clinical staff members, contacted those family carers who met the eligibility criteria of the study.

Four weeks before the focus groups, all participants received information about the study aims and objectives. This called for them to reflect on their experience of the management of mental health crises in dementia, and how the active participation of the person with dementia could be promoted for making important health care decisions.

All participants were asked to sign a consent form before taking part in the focus groups. These took place in one of the meetings rooms in the NHS premises where the multidisciplinary teams operate. The time allocated for each focus group was 120 minutes (80 minutes for the interview, 30 minutes for consenting and 10 minutes for debriefing that took place at the end of the interview). In order to give more time to family carers, smaller groups were held. This decision was in concert with what is suggested in the literature on qualitative group interviews in health care settings, suggesting that more time is allocated to participants who are invited to discuss on sensitive topics (Nieswiadomy, 1998) such as their experience of crises and everyday life with their relative with dementia.

7.2.3 Focus groups topic guide

Focus groups were used. AB had the role of moderator and prompted participants with questions to guide the discussion over topics that were relevant to the objectives of the study. For health professionals the topic guide was tailored around key determinants for co-production in care with the person with dementia. For example, how they managed the crisis (e.g. if they felt they received the necessary training for

the management of crisis in dementia), what types of crises they managed, barriers and facilitators they experienced, and how to promote the active involvement of people with dementia and their carers in the development of the health care plan.

Topics for the focus groups with family carers included the status of their relationship with the person with dementia (e.g. daughter-mother, spouses), the nature of crises and stage of the condition, and how they felt that the active involvement in the delivery of care could be promoted with the person they care for.

7.2.4 Framework analysis

Framework analysis (Ritchie and Spencer,1994), informed the interpretation of the findings, which followed the analytical steps of familiarization, thematic framework, indexing, mapping and interpretation. This process permitted changes to the interpretation of the findings during the analytical process, incorporating data from multiple sources and different time points. AB became familiar with the data, by listening to the audiotapes, and formulated preliminary ideas around the interview transcripts. Based on these, broad themes were identified which were then applied to categorise the data. NVivo 12 (QSR International, Warrington, UK) was used to code the data. The final steps of mapping enabled the layout of themes into a diagram which portrayed the associations between themes intended to reflect the beliefs and experiences of participants in the study.

To maximise the quality of data analysis and contain research bias for the internal validity of the findings, at the time of analysis, anonymised data were managed by the lead author (AB) and an experienced dementia researcher (EB). As part of the analysis, AB developed a codebook to facilitate the coding process between raters. The codebook was informed by the guidance provided in the Centers for Disease

Control and Prevention (CDC) Process for Generating Inter-coder Reliability (Hruschkah et al. 2004). The codebook was used as guidance for 10% of coding by two independent raters (AB, EB). The process of generating the codebook and analysis of interrater reliability was informed by a previous process plan published by the authors (Bosco et al., 2019). The inter-rater reliability was measured by means of Kappa coefficient (Cohen's Kappa) (Cohen, 1960) and the parameters used were based on those proposed by Landis & Koch, 1977: 0.81–1.00 = almost perfect; 0.61–0.80 = substantial; 0.41–0.60 = moderate; 0.21–0.40 = fair; 0.00–0.20 = slight; < 0.00 = poor.

7.3 Results

A total of three focus groups conducted with 22 staff members and two focus groups with the same three family carers. The group lasted on average 57.2 minutes with staff and 45.7 minutes with family carers.

There was a mix of professional backgrounds among staff from three TMCDs (i.e. one clinical psychologist, three service managers, six community mental health nurses, eight community support workers, three occupational therapists, one of whom was a trainee, and one assistant practitioner). All members of staff worked full time except for the trainee student (mean age= 45).

Family relationships included a daughter and father where the father had dementia, whereas (FC-01) two carers were in a spousal relationship; one where the wife had dementia (FC-02) and one where the husband had dementia (FC-03) (Mean age= 64). The inter-rater reliability was almost perfect (k=0.82). Four themes and ten subthemes emerged from the thematic analysis (Table 7.2 for theme categorisation): the positive and negative experience of working in collaboration; the forming of a

coalition of care; strategies to promote involvement in decision making; and shared beliefs around crisis. The latter determined the extent to which different agents in care held a common understanding of the episode, which in turn influenced the degree of agreement on how to manage the situation.

7.3.1 Forming a coalition for care

In order to promote co-production in care, participants reported the need to create equal partnership whereby everyone involved in the delivery of care was considered part of the team. Barriers were found when collaboration was not promoted (e.g. the carer decided on behalf of the person with dementia), there was an unequal distribution of power among parties, or the care environment was challenging and negatively impacted on the way the team could effectively deliver the care.

7.3.1.1 Legitimacy and recognition

When asked how coproduction would occur, staff felt that it would important to create a bond with the person with dementia and the carer, but that this could require some time to develop, especially during the very first meetings when a discussion around the diagnosis is to be made:

'Sometimes people find it difficult to describe their condition and only after you establish a bond…Sometimes it takes weeks and weeks before you are able to build up that rapport and make them aware of their condition, so this has an impact on the support we provide' (Staff-S1-01, Male).

Table 7.2 Analytic description of coding.

Coding per theme (N)	**Narrative interpretation**	**Example of coding per theme**
1.Forming a coalition for care (N=33)	1a. Legitimacy and recognition	'It happened repeatedly to me that GP talked to my wife looking at me I always try to encourage him to address my wife when talking about her…' (FC-03, Female).
	1b. Reaching agreement	'I think as first thing we are all going to exclude anything physical I think all the team is onto that, to see any changes in the person with dementia and we get hold of the GP and this is for all of us it is across the board really…' (Staff-S1-01, Female).
	1c. Roles and responsibilities	'… many of the carers have been carers for so many years and when we get there they feel we get into their self-identity, their role... so we need to be careful and work very creatively so that they do not have that fear' (Staff-S1-02, Female).
	1d. Barriers to co-production	'…Yeah and it is very difficult to talk to the carer to do it the right way, because you do not want to say to them 'oh you are doing this wrong', as you need them on your side…' (Staff-S1-01, Female).
2.Strategies to promote involvement (N=37)	2a. Caring for the carer	'… she has advanced dementia and she has become very resistant with anyone going there and the carer became so exasperated that we felt they both needed help. The husband in fact had quite few memory problems as well, and this had an impact on his health' (Staff-S2-01, Female).
	2b. One to one communication with the PWD	'I think as a team we are quite good at managing that the person has their voice heard because you know the carer may think they doing well because you know they are helping answering questions and then it is about saying *'you know we would like to talk to him for 10 minutes'* so that we get their views' (Staff-S1-01, Female).
	2c. Proxy decision	'Yes, I mean, we work quite intensively with the person with dementia to grasp what they need or want. But the carer's help is useful*'* (Staff-S2-01, Female).
3.Communication across services (N=20)	3a. Communication between services	'Yeah. Because difficult communication can also happen in emergency cases like communication with A&E, and we are not aware of but they change the medication' (Staff-S3-01, Female).
	3b. Support from within the service	'I think the support workers in the team are very experienced in dealing with people with mental problems and a diagnosis of dementia. We have also a good support from our consultant psychiatrist' (Staff-S2-01, Female).
4.Meaning of crises (N=11)	4a. Beliefs around crises	'…I guess a crisis in dementia is when the current situation is so terrible that you cannot make sense of what is happening, because with dementia you know it is going actually get worse, …the carer strain or whatever it is no longer manageable in that situation and crises kick in' (Staff-S1-01, Female).

7.3.1.2 Reaching agreement

An occupational therapist was concerned with the fact that some carers often acted as gate keepers for the delivery of care, and that reaching an agreement with the carer about what was needed for the person with dementia proved often difficult to attain. Having the carer on board seemed to be a key element for any therapeutic course being designed:

'I think most of time family carers and their relatives do not understand why what is happening is happening, …and why maybe support is needed…, and it gets quite difficult' (Staff-S1-01, Female).

7.3.1.3 Roles and responsibilities

Family carers accepted that most of the time they found themselves being the main spokesperson during medical appointments, and the person with dementia was not acknowledged by the doctor, even if the discussion was around her/his own care:

'It happened repeatedly to me that GP talked to my wife looking at me I always try to encourage him to address my wife. I think that no matter the level of capacity it is important to acknowledge the person…about their own care' (FC-02, Male).

7.3.1.4 Barriers to co-production

One family carer felt that in order to promote an active involvement of the person with dementia during conversation with health professionals it is important to take into account her/his level of capacity at the time their views are needed:

'…I think we do not want to promote co-production without acknowledging the deteriorating phases of dementia. You want co-production going on but it needs to be promoted in accordance with the level of capacity of the person' (FC-01, Female).

Although reaching agreement was a key topic mostly for staff members, this was similarly shared by a family carer. A wife lamented that fact that when discussing about advanced care planning with his husband with dementia, she disagreed with any ideas of making future adjustments in her life, affecting any collaborative effort for future discussion with the team:

'I have come across cases where being simply in denial about advanced care plan is so strong that you cannot really start the discussion at all, and this does not help when you want to discuss with the team and include her in the discussion, she would just say no' (FC-03, Female).

The same carer reported that proxy decision was necessary when the husband was adamant about making a decision that could not be ideal in his circumstance:

'He does not want to believe me or the team that the problem is not being at home and not using it (the scooter), it is the medication that he was taking that did not make him sleep well, and he was depressed and angry' (FC-03, Female).

In order to promote the active involvement of the person with dementia, staff reported that most cases required being attentive to the role of the carer, and not divesting them of their caring role. This was of utmost importance for creating a positive and productive care environment:

'…many of the carers that we have, have been carers for so many years and when we get there they feel we get into their self-identity, their role, and all they can see of us, is that we are going there to take their role away….we need to be careful and work very creatively so that they do not have that fear…' (Staff-S2-01, Female).

This was similarly shared by a carer, who felt that her role as a wife and as a carer needed to be constantly validated by the team:

'I feel that I need contact reassurance from professionals about what I am doing' (FC-02, Male).

Another carer shared that when the team was supportive, she felt reassured about the quality of decisions being made and felt that some of her responsibility of making the right choices were lessened:

'Yes I felt the professionals helped me take the right decision and at the end the psychiatrist said 'look it is time' and I knew it was but having the professional saying something like that released by fear of letting down my daughter…' (FC-01, Female).

When carers felt that their caring role was being threatened by the presence of the team, they often feared them and this scenario was reported by staff as being a barrier to their work. What the staff reported doing to contain such fear, was to explain from the very beginning their supportive and professional work:

'Sometime the carer gets the fear to be cut away so we make sure to explain that we are not cutting them away. There were instances when the carers did not allow them [the person with dementia] to be involved in any discussions for fear of altering any balance in the care environment' (Staff-S1-01, Male).

Barriers were also linked to the physical and or cognitive disability of the carer. As a community mental health nurse commented, it was often the case that when the carer had a cognitive problem there was little scope for collaborative work as the quality and extent of communication between them was very limited:

'Sometimes the carers have cognitive problems themselves on a slightly different side of the spectrum but that may be quite challenging for us to try and make it work

in a collaborative way, as they won't be able to understand what we are trying to deliver' (Staff-S1-01, Female).

Even when the person with dementia was given opportunity to practise agency, the staff felt that the decision made by the person with dementia was not always in their best interests. For example, one person acted against the advice offered by the team possibly because of traumatic memories generalised to the present situation:

'I think the person's personal journey can be an obstacle sometimes because when we are trying to help with personal care the person can experience it as some kind of abuse so you are trying to make another person be there as well so but it can bring something very dark to the person and this can be very difficult very distressing for them and they might not want you to do that and this can stop them from receiving the care really' (Staff-S1-01, Male).

7.3.2 Strategies to promote involvement

In order to promote equal partnership, there were strategies that teams needed to employ. These relied on caring for the carer who may have difficulties in dealing with everyday care, promoting an inclusive one to one communication with the person with dementia, and adequately supporting proxy decision making when this was most required.

7.3.2.1 Caring for the carer

Staff members felt that in order to create a fertile environment for collaboration, it was important to attend to the needs of the carer, as they would cope with the crisis to a similar extent as the person they were caring for. This was shared by staff working in the three teams interviewed, and as one clinical psychologist explained:

'... if we see that carers are finding especially difficult living with dementia, we can refer them to carer support groups who help them cope with daily aspects of the condition…we mainly focus on the person with dementia and at times we find it difficult to extend our help to the carers as well…' (Staff-S3-01, Female).

Sometimes staff members found extra time to support the carer by talking with them and exploring if and how they could decrease some of their care burden:

'When the person with dementia is not verbal, it is good for the carer to have us there to have someone to talk to, because with dementia he lost his wife, maybe friends. We would have a chat with the carer when we are there' (Staff-S2-01, Female). This proved particularly helpful for carers who had little or no external support from other family members or friends.

7.3.2.2 One to one communication with the person with dementia

Establishing one-to-one communication with the person with dementia was reported to be crucial to promote their active involvement in the collaboration, and when this was not possible because the carer, for good or ill, insisted answering all the questions, an occupational therapist explained their strategy to promote their active involvement:

'I think as a team we are quite good at managing that the person has their voice heard because you know the carer may think they doing well because you know they are helping answering questions and then it is about saying "you know we would like to talk to him for 10 minutes" so that we get their' (Staff-S1-01, Female).

A community mental health nurse felt that:

'...all our clinical assessment is about the patient and how the patient can benefit from it. I think they are our focal point…' (Staff-S1-01, Female).

7.3.2.3 Proxy decision

Staff members further explained that in circumstances when an active involvement was not possible because of limited cognitive ability to engage in decision making, it was inevitable for the carer to decide on behalf of the person with dementia through proxy decision making:

'Yes, I mean, we work quite intensively with the person with dementia to grasp what they need or want. But the carer's help is useful. Yes, the husband would be around and say "not she does not want it now" (Staff-S2-01, Female).

7.3.3 Communication across services

In order to effectively coproduce care for crisis, staff felt that a coalition of care needed to be formed among different agents in care, be it secondary care agencies, primary care providers and/or third sector organisations.

7.3.3.1 Communication between services

Miscommunication or a lack of proper contact between these agents proved challenging for the formation of any care coalition and indirectly led to inadequate levels of partnership and quality of support:

'...sometimes the information we get from the referrals from GPs really varies, ...sometimes we are given very vague information around things that really mean a lot for the patient and ultimately this has an impact on how we can involve the person in our work as everything gets delayed until we get the right information…' (Staff-S3-01, Female).

However, when questioned on whether a good communication could ease the process for the development of the care plan, a CMHN explained:

'... when there is good and prompt communication with the GP everything works better, we give them information, they have a clear picture of what is going on and are more ready to get on board with us to develop the care plan' (Staff-S3-03, Female).

Maintaining good communication with primary care services was not only important for partnership in care but it was also crucial to ensure that most updated information on care management would be filed for the safety of patients. A nurse commented on how the mishandling of medication is becoming an issue within the community, and how easily it could get confusing on the right dosage to give to the patient without clear information shared across services:

'And then if a medication needs to be altered then we keep the GP on the loop. Because it is an issue with medications in the community. I think that the issue is even more so when there is little communication across services…' (Staff-S3-02, Female).

Difficulties in interaction with social services was associated with ineffective crisis care. The constant turnover of social workers created confusion for those receiving care, as new people would visit them in their home. The professional further reported that there is often a long waiting list to access social services for respite and this may have consequences for the way either the carer or the person with dementia could effectively cope with the crisis:

'We could wait days for social services. Patients lament the fact that through social services always new workers go to their places to support them, there is no continuity and for the social service to get on a case for respite for example it would take up weeks if not months. Even if someone is in crises and they need something urgent they still need to wait unfortunately' (Staff-S3-01, Female).

7.3.3.2 Support from within the service

Staff felt that because services operate with very little economic resources and under time pressure, they most of the time need to maximise their input in what is most needed at the moment. This could create stress across services:

'…I just think all the services are under stress in terms of resources and they basically all try to push things to other services because they do not have enough time to manage the cases all by themselves' (Staff-S2-01, Female).

Better communication using medical records was needed without the need to constantly liaise with different services to access information:

'If everyone had the same electronic patient record, it would be much easier' (Staff-S2-01, Female).

7.3.4 Meaning of crises

There were different beliefs held around crisis in dementia.

7.3.4.1 Beliefs around crises

Staff lamented the fact that often there was a mismatch between what the carer and the person with dementia thought constituted a crisis. This would leave teams with the arduous tasks of managing different crises at once:

'We have many people who are with severe neglect. So they do not take medications, they forget to eat to drink, so you would think that that is the reason for their crisis but then the carer insists that the crisis is not having to do with that or that they really prefer to give priority to a different health outcome which is calming them down and not having them eat more. But they may be aggressive because they need more food or because they eat too much sugar…' (Staff-S2-01, Female).

Also, there were cases in which the GP would refer the person with dementia to the team because of allegedly crisis episodes, when in fact the team reported that the episode was not a crisis after observation:

'…Very often we get a referral from the GP and when we go out we see that they did not need us at all. So yeah the definition of crisis is very different for anyone' (Staff-S2-01, Female).

The above excerpt is an example of misinterpretation about what constituted a crisis across services, which could affect the workload of crisis teams if not appropriately identified.

7.4 Discussion

This was the first qualitative study exploring co-production for mental health crisis in dementia. This study helped develop an understanding of how crisis teams work and how carers and people with dementia should be more involved in decision making. The accuracy in the interpretation of study findings was increased by having multiple raters coding the data.

This study found that collaborative work was a key element in the delivery of care for dementia crisis. Teams recounted that there were strategies they employed and that these differed from case to case, according to the needs and views of their clients with dementia and their family carers. Strategies aimed to establish trust with the person with dementia and their carer, as this was a key factor for any collaborative work for the development of the health care plan.

Promoting proxy decision making was also regarded as crucial in the presence of decreased cognitive ability in the person with dementia. This was considered a last strategy to resort to for gathering the views of their clients but teams felt that this

form of decision making was expected to occur at some point during their dementia care. In line with previous literature around decision making in dementia (Harrison Dening, Sampson, & De Vries, 2017; Wendler & Rid, 2011; Vig et al., 2007), family carers felt that the responsibility that proxy decision entailed, led to increased responsibility for them to decide on behalf of the person with dementia and this in turn led them to feeling more distress and to increased perceived level of care burden. In some cases, teams contended that proxy decision was a strategy that carers, for good or ill, and irrespective of any cognitive impairment, employed to make decisions on what they thought to be the best care option at the time. In these circumstances, teams maintained that an effective strategy to involve their clients in decision making consisted in talking to them on a one-to-one basis, without divesting the carers of their role of primary carer. Teams explained that this was further attained by clarifying roles and responsibility of care within the team and with the carer. As reported by family carers, proxy decisions were favoured by some primary care providers, regardless of the cognitive ability of the person with dementia, as it proved time effective for them to explain care options (e.g. Harrison Dening, Sampson, & De Vries, 2017). However, this behaviour affected mostly primary care providers and less crisis teams, as carers reported that teams were usually attentive to finding strategies for care involvement for people with dementia.

Although strategies were consistently employed to maximise collaboration, there were factors which were not easily addressed by the team (e.g. poor communication and poor sharing of information across services). When these were present, they lessened the quality of involvement of the person with dementia in designing their own care plan. Receiving little information from GPs about patient's medication led the team to delay home-visits. Once the information was obtained, the team was left

with only the time to address the episode of crisis without adequately promoting co-production (e.g. by dedicating time to inquire on how to best interact with the person with dementia, or establishing longer rapport). Crisis teams provide their professional input in a very short time which varies by case (i.e. usually around 6 weeks). This short time may affect the quality of therapeutic alliance that can form with clients and the extent to which their preferences and views are taken into account, especially if these differ from those of the carer.

In addition, in concert with findings by Livingston et al. (2010), family carers felt that when the person with dementia was adamant about own decisions, it was very difficult to promote open communication and involve them in further discussion with the team to reach an agreement on care options. In these cases, the carer had to engage in proxy decision making to maximise the input of the team towards what was perceived to be a better outcome. In the presence of disagreement between the carer and the person with dementia about a specific course of action, teams reported following proxy decisions and explaining to the person with dementia why they took a particular therapeutic route to manage the crisis.

Although we inquired on the strategies used by the crisis teams and the carers to promote an active involvement of the person with dementia for their own care, we did not explore other elements of collaborative work that may have indirectly reduced the quality of collaboration (e.g. personality traits, type of leadership in each team interviewed and how this promoted or discouraged any patient's involvement in the formation of team partnership). As recruitment occurred through crisis teams, and their clients with dementia were in stressful and difficult situations, people with dementia were not sampled for focus groups. In order to reach a better understanding of care delivery for crisis, future studies with more resources (e.g. finance,

workforce) should conduct more interviews with people with dementia accessing TMCD across different sites in the UK. PPI members with lived experience of dementia were consulted through discussion groups to gather their views about the study findings.

7.5 Conclusions

This study highlighted the importance of promoting co-production in care delivery for crisis in dementia and exploring the views of people with dementia to deliver tailored and effective care to reduce possible relapses and hospital admission. In addition, as in episodes of crisis the professional input provided by TMCD is short term and immediate, through co-production, the time the team can dedicate to each case can be more effectively allocated and engagement in the plan from patients and carers should improve. More equal power and open communication can be fostered between clinicians and patients, with the latter becoming more knowledgeable about their human rights in care, when to call for professional help and learning new ways to self-manage and/or with the support of the carer less critical situations.

It would be advisable to have information about crisis teams made available at primary care providers (e.g. GPs) at the very early stages of the condition. This would allow carers and people with dementia to familiarise with the role and responsibility of the teams, but it would also provide them with a sense of what they may experience at some point during their care (e.g. episode of crisis, receiving external support, designing advance directives before capacity is compromised by a progressive cognitive impairment).

In addition, early public health campaigns may further educate patients and carers, and groups such as the Alzheimer's Society about crisis prevention.

Chapter 8. Discussion

8.1 Line of argument: The social dimension of dementia crisis care

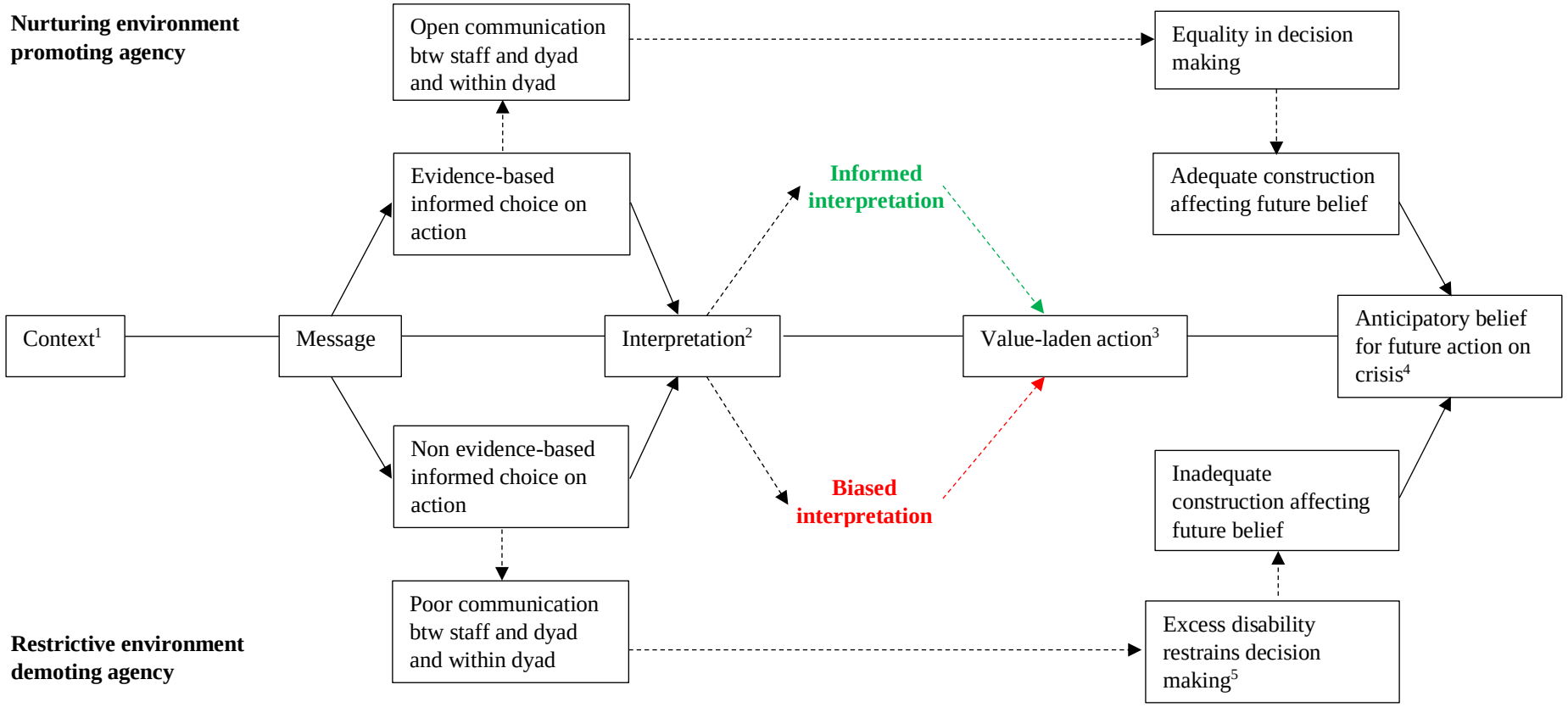
In dementia crisis care, as much as it would occur in other socio-cultural realities, the experience of crisis is socially constructed through constant inter-relations between the agents in care, be it the person with dementia and their carers, and or health professionals of TMCD. Through socialisation, people with dementia may express their experience of the crisis and enact a participatory role in influencing social action. Hence, the relationship with others proves key for the person with dementia in that it provides them with a social context where meanings around the crisis episode are formed; it further represents a conduit for social change in the way the meanings around crisis are constructed in the future (Figure 8.1).

The concept of 'emergence' by Elder-Vass (2010) proved effective in explaining the product of interaction between agents in care and it was used as meta-theory to graphically synthesise the main findings.

8.1.1 The concept of emergence in social theory around crisis

Elder-Vass maintains that when people gather, they form a system, whose product of their interaction is a new entity; an entity that is more than the sum of beliefs and experiences held by each interacting individual. When the concept of emergence is translated in dementia crisis care, it becomes clear how people with dementia and their social network (sometimes joining as a small group or dyad) form a new social entity with unique needs and views: their experience of crisis becomes intertwined and entrenched in each respective belief system around crisis. Figure 8.1 brings a novel contribution to crisis construction by synthesising previous published models by the author (Figure 4.3; Figure 5.4; Figure 3.3; Figure 6.2; Figure 2.2).

Figure 8.1 The social understanding of crisis in dementia: The role of agency and structure in determining future construction on crisis.



The synthesis was informed by previously published behavioural models by the author:[1]Figure 4.3; [2]Figure 5.4; [3]Figure 3.3 [4]Figure 6.2; [5]Figure 2.2.

As figure 4.3 showed, each person lives in an ecological system and brings their own beliefs and may influence each other through interaction. In the case of dyads, the degree of interpretation around the experience of crisis is determined by whether the dyad has a shared understanding of the situation and opt for dyadic oriented goals as opposed to an individual-oriented goal. As evidenced in Figure 5.4, in the presence of dyadic oriented goals the behavioural responses are more likely to promote an equal distribution of power and the construction of more positive meanings around dementia and crisis. When only one partner opts for dyadic goals, the behavioural response with respect to the crisis may still be adequate to the circumstance but the stress posed by the context may favour the construction of negative meanings around crisis.

In the construction of crisis, the role of TMCD becomes that of providing evidence-based information around most effective strategies to manage crisis and around role and responsibility of care. This information may help, for example, reset the beliefs that the dyad may have negatively constructed about the behavioural manifestations of dementia.

In contrast with a cognitive model of dementia, according to which emotions and behaviours are considered diseased manifestations of the condition (Finkel, 2000), the social model regards both emotions and behavioural outlets (e.g. the crisis episode) as drives for social action. This view is particularly relevant in dementia crisis care where a decreased cognitive ability of the person may impact on the degree to which the person is retained fit to make care decisions.

As illustrated in Figure 3.3, acknowledging their experience of crisis and promoting their participatory role in decision making helps the person with dementia find a

right context to practice agency (Burkitt, 2012; Boyle, 2014). Conversely, a theory favouring cognitive performance and neglecting emotions risk to create a dichotomic representation of the self, with the former being considered as major attribute and the latter as minor attribute of the self (Burkitt, 2008). This view is what fuelled the biomedical conceiving of dementia and the inadequate consideration of mental capacity for social change (Burkitt, 2008). This view could further lead to an excess of disability with the risk to inadequately support the person with dementia in maintaining independence and making autonomous decisions (Reifler & Larson, 1990). In addition, as reported in Figure 6.2, future re-enactment of previous negative construction of the experience; may create a negative belief system around crisis, within the dyad. Informed by Figure 2.2, negative meanings around dementia and crisis may promote psycho-emotional disablism which may affect the way the person is considered at societal level and the degree of autonomy exerted in decision making.

The study findings point to the need of people with dementia to practice agency, defined here as creative agency, through alternative forms of social action if necessary, be it in the presence of institutional constraints (i.e. negative behaviours acted out by others) and or more positive care practices (i.e. dementia friendly care environment).

8.1.2 The consequences of excess disability in dementia crisis care

As evidenced in the systematic review on the historical construction of dementia, dementia has often been associated with ageing and considered a natural course of an ageing brain. Although on a superficial level of analysis, this positive association may lead to positive views around dementia and people living with the condition,

as it would situate the person with dementia far from an abnormal entity, this association has led to a misconception of ageing and to confusing statements about capacity both in old age and in people with dementia: older people acquire dementia and lose capacity. This was reflected in the findings of the systematic reviews on agency in dementia care, the development of dementia care model, the meta-ethnography on behaviour process synthesis for dyadic construction of dementia and from findings of the longitudinal dyadic interviews.

Problems in the promotion of decisional power were reflected in the experience of mental health crisis. During an episode of crisis, people with dementia reported feeling disoriented about how to best manage the challenging situation. Although the critical episode and dementia alone may lead to decreased capacity, participants (people with dementia and their carers) felt that the concept of capacity itself was often misunderstood by primary care professionals, especially those with limited experience of the condition. This misconception often led to the term of capacity being regarded as an absolute entity something that the person because of the cognitive impairment either has or does not have. This meant that participants were often divested of their right to make own decision, in virtue of the fact that they were retained incapable of 'doing'. This led most of the time to an inadequate promotion of decisional power by the carer as well, who for good or ill, may have felt the responsibility to make prompt decisions (with the risk to employ ineffective coping strategies and or delay the calling for professional help). This could be the case when there was no shared understanding of the situation between the person with dementia and the carer. This could in turn lead the person to feeling incapable of 'being' and the recipient of care rather than being an active member of a collaboration with professionals for the design of their own care.

Dementia crisis teams and family carers, as reported during the focus groups, employed strategies to promote agency in the person with dementia at times of crisis, and this was attempted by establishing trust with the person, having an active communication (one to one communication to explain the care pathways and explore the views of the person with dementia and possible recommendations), and or by engaging in proxy decision making in the presence of perceived inability to decide for themselves. Crisis teams shared the preoccupation that the establishing of proxy decision, and the quality of their work was often limited by the presence of physical and or cognitive impairment in the carer.

The lack of a proper consideration of capacity in terms of fluidity and degrees of ability (e.g. the person may not feel able to make decision on medication, but may still be able to decide on the food to eat), could take out decisional power. Hence, negatively affecting the sense of autonomy and perceived level of independence in the person with dementia. Inadequate promotion of decisional power in the person with dementia (especially in the presence of some capacity) not only decreased the quality of care received by the client, but it also negatively affected care burden for the primary carers (i.e. by having more responsibility at hand), and indirectly increased the workload of the teams who needed more time to sort out alternative pathways of decision making (e.g. proxy decisions).

8.1.3 Capacity in dementia care

There is often an implicit way of assessing capacity in the person with dementia that is conducted by status, by assuming that because of the cognitive impairment, the person is unable to make decisions on all spheres of her/his life. It is often the case in clinical practice in dementia care that capacity is associated with the pure cognitive ability of the person, a sort of objective testing of performance of the person about

what s/he is or is not able to perform, based on scientific facts: the person has neural plaques affecting her/his ability to make consensus decisions, hence s/he is retained unfit to decide about own care.

While, such understanding of objective facts could provide with a true knowledge (i.e. status) of the affected area of the brain of the person, as contented by Merleau-Ponty (1962), there should be no separation between the physical experience of the person and the phenomenological experience: The person considered an embodied agent, as socially situated human being whose actions are both influenced and influence the surrounding (i.e. the environment). It follows that if capacity in dementia clinical practice is to be assessed, in concert with what was maintained by Hughes (2014), this should not be exclusively outcome specific, as the person has the right to be *'unwise'* about some decisions in her/his life, and professionals should not be allowed to assert any right to suggest any lack of capacity based on outcome (Hughes, 2014). This would limit the agency of the person to make free decisions and would give 'others' the power to decide who is fit or unfit and what is an adequate decision to be made. There could be the consequent risk to apply a value-laden evaluation about people's preferences for action, without appreciating the fact that they are socially and culturally situated agents whose life experience is different from that of others (Hughes, 2014).

Hence, if a broader understanding of capacity is to be attained, it cannot be regarded solely as the objective and functional ability of making decisions, as there is the need to take into account other key elements constituting the process of making such decisions, namely the evaluative (e.g. the ability to make sense of the information at hand, in reference to life choices) and volitional (e.g. the ability to action those information from a set of facts and beliefs) elements of decision-making (Hughes &

Heginbotham, 2013). In the next paragraph I shall delve more into the role of others in promoting decisional powers and or making surrogate decisions as dementia advances. I shall further explain how the Mental Health Act can be enacted to ensure good practice in the presence of perceived lack of capacity during episodes of crisis.

8.1.4 The role of others in dementia care

In concert with a social constructionism understanding of thoughts formation and human actions, it is helpful to conceive of the former as socially constructed and not just inner material of human brain, and the latter as the product of socially formed thoughts. I am here reporting on my theoretical positioning with respect to thoughts and actions which are fundamental components of making a deliberate decision (be it for minor life decisions, or more care-specific decisions such as advance care directives). By clarifying these concepts, I hope to be able to explain the reason why I favoured social relationship rather than individual responsibility as social category for decision making in the presence of cognitive impairment.

This is not to suggest that in dementia crisis care, others have a more important role than the person her/himself in making decisions, but that giving importance to the social dimension of the person helps understand what may be promoting or demoting personhood and autonomy in care. Hence, an understanding over the determinants of quality of care.

When our thoughts and actions are considered unfit by ‘others’, our decisional power is limited, and a consideration of our actions should not be limited by preconceived ideas that others may have with respect to what is right or what is wrong. As illustrated in Figure 8.1, a moral attitude with respect to capacity may limit one’s room for action and may create a value-laden assessment of who is fit when and

where. A broader assessment of one's autonomy should rather be appreciative of the socio-cultural contexts where thoughts are formed and actions are made. In the presence of cognitive impairment, the support of the carer is crucial to promote sustainable independence in the person with dementia, through a positive support that is nurturing and respectful of their views and needs. As dementia progresses, the role of the carer becomes even more evident for everyday life decisions and without a consistent positive care environment, the autonomy of the person could be limited, through restrictive practices for example, or by not discriminating between different tasks to assess the ability of the person to make own decisions. The person may in fact show more ability to make decisions in some tasks (e.g. in regard to medication) and less ability in others (e.g. cooking).

Even when the care environment is nurturing, there is no clear evidence on whether the views of the person with dementia are clearly expressed over time through surrogate forms of decision making (e.g. proxy decision making) (Miller, Whitlatch, Lee, & Caserta, 2018). This limited understanding over preferences and choices expressed through surrogate decision-making leads to a debate about whether proxy decision making could be an effective alternative to self-expression in more advanced stages of dementia and who is the most appropriate person entitled to make such proxy decisions. There may be occasions when a family carer is not necessarily knowledgeable about the wishes of their loved ones with dementia.

As dementia progresses, it would still be possible to have the person with dementia exercise a degree of agency by guaranteeing that their views are considered, even with the support of others. The concept of autonomy becomes entrenched in the very concept of dependence in old age and dementia, where autonomy is practiced in the

context of *'essential inter-relationship with other and the world'* (Agich, 2003). The person is immersed in the world; s/he is a social being.

Although proxy decisions should be limited in those instances when the person is unable to make decisions, it is often practiced even in situations where the person would still be able to practice agency with little support, through shared decision-making for example (Sudore et al., 2017). Although the Mental Health Act (2005) protects the rights of individuals with impaired ability to make decisions, by suggesting that capacity needs to be assumed unless it is otherwise evidenced, and that in case of doubt, an assessment needs to be made to explore whether the choice expressed by the person is valid in regard to the context, the right of people with dementia, for good or ill, is not always respected.

In episodes of crisis the situation may require a situation-specific approach (NICE, 2018). These critical episodes may occur at any stage of the condition and a mix of general care (e.g. reduced sugar intake) and specialist care (e.g. type of clinical tests to run) may be needed. It is often difficult to determine when a specific type of care is needed, and the consequent responsibility involved in making a decision, it could be a family carer, and/or professionals, it could be through shared decision making or proxy, depending on the level of capacity assessed at the time. What is urged to ensure quality of care in decision making is to act in the best interests of the person and avoid making pseudo-decision making, hence avoid having the views of the person with dementia only partially considered for the care. During crisis care, as evidenced in the focus groups with dementia crisis teams, it is often difficult to have the carer step down the responsibility of care and have the person with dementia speak up for her/himself. There could be cases when trying to involve the person with dementia may make the carers feel divested of their role, for this reason it is

important to establish an alliance based on trust but also deliver an open communication with the dyad and inform them of roles and responsibility for care. It is important to inform the dyad about decision making, the legal aspects but also the ethical aspects involved when decisions are made (Hughes, 2014).

8.2 Study findings in relation to the existing literature

As evidenced in the result chapter on dyadic interviews, when the dyads were confronted with the episode of crisis they usually preferred receiving informal support (e.g. neighbours, family) than professional support and this was in concert with previous literature on crisis (Toot et al., 2013). However, previous literature did not explain the behavioural mechanism underlying the delay in seeking professional help in dyads experiencing crisis in dementia. The current study revealed that such delay was dependant on the level of information the dyad had around crisis and around the role and existence of dementia crisis teams. The level of shared understanding with respect to the crisis could lead to a better consensus reached within the dyad about whether to contact the team for support. Hence, dyads who openly shared their experience of crisis with one another were more likely to make a prompt call for help.

All groups of participants from dyadic interviews and focus groups felt that education around ways to recognise the episode of crisis before its manifestation and how to manage the aftermath would prove key for the dyad to help them reach increased awareness with respect to the situation and help them prevent the crisis. These were reported to be associated with reduced perceived care burden in carers.

In addition, all dyads interviewed were receiving homecare support from social services, and dementia crisis teams confirmed during the focus groups that this was a

type of support they provided to all their clients as part of their intervention plan. What was reported by team staff as important, however, was to have homecare professionals that were knowledgeable about what constituted a crisis and experienced about providing care to old people with cognitive impairment. Some dyads in fact lamented the fact that many of them were inexperienced in managing everyday life care in old age population and that their high turnover affected the way they could establish a rapport with the dyad. This was in concert with previous findings (Toot et al., 2013).

Although the quality of the care provided by dementia crisis team was regarded as effective by dyads, their support was only for a short period of time (up to 12 weeks) and was commented by both members of the dyads and dementia crisis teams as a quick fix for crisis.

In concert with the findings from a scoping review on multidisciplinary teams managing crisis in dementia (Streater et al., 2017), the dementia crisis teams interviewed in the current study, reported managing cases of people with dementia without being ever designated as dementia-specific teams. They further reported, however, that because of their experience with clients in their old age, they could adapt their intervention easily to the problems of dementia.

8.3 Methodological consideration on bias

Strategies were employed to contain bias and increase the truth value, applicability, consistency, neutrality, dependability, credibility, confirmability, transferability, and generalisability of study findings (Guba, 1981; Onwuegbuzie & Leech, 2006; Schwandt, Lincoln, & Guba, 2007). Bias-specific containment strategies were made

with respect to the whole study across the three main stages of my research inquiry: research design, data collection, data analysis and interpretation.

In order to contain the risk to incur in biased knowledge and problems in theoretical validity and having insufficient literature to back up the theory used in the study, multiple systematic reviews were conducted.

None of these reviews aimed to provide a generalisation of human experience of dementia, as dementia, as much as any other social reality is dynamically constructed and not bound to a specific time period. Caution was taken when translating the findings from the systematic reviews onto the empirical work of the study. Hence attention was paid when developing research questions and the extent to which the findings from the systematic reviews could inform the line of questioning during the qualitative interviews for both the dyadic and the focus group interviews.

Internal credibility was informed by Onwuegbuzie's (2003) definition of truth value, consistency and credibility of study interpretations within the specific group and the following potential biases were identified and addressed for data collection and analysis: voluptuous legitimation, descriptive validity, structural corroboration. Voluptuous legitimation, or the over interpretation of data by the researcher (Lather, 1993), was contained by employing multiple raters in the coding of qualitative transcripts, both for the dyadic interviews and focus groups. I further engaged in multiple meetings with PPI members to ensure validity so that findings could reflect real clinical scenarios especially in the presence of outliers (exceptional cases ensuing form the analysis that diverged from the norm) which were further discussed within the research team, this further decreased the risk for structural corroboration (Eisner, 1991) as multiple sources/views were gathered to contradict or confirm the

analysis, and increased communicative validity as interpretation was reached by consensus.

In qualitative research, legitimation does not reveal a dichotomous outcome (e.g. valid/not valid) but it rather represents a degree of credibility and trustworthy interpretation (Brinberg & McGrath, 1985). External credibility was informed by the author's definition around the confirmability and transferability of the findings to the general population (Onwuegbuzie, 2003) and strategies were employed for the interpretation stage.

In this respect, a prolonged engagement (Lincoln and Guba, 1985) was maintained to ensure that adequate time was spent the day of the interviews to get a sense of the culture shared by participants (both among members of each interviewed dyad and participants of focus groups). Although this was easier to achieve with participants of longitudinal dyadic interviews as multiple meetings were attended over one month, I made sure that for focus group interviews with carers and staff members there was some time dedicated at the beginning of the session to interact with them and create a more informal setting. This allowed me for example to get a sense of their experience of dementia and of potential sensitive topics that they would prefer not to be sharing during the focus group (e.g. deep questioning around personal information of their loved one with dementia, in the interviews with carers).

For dyadic interviews I was further able to engage in persistent observation (Lincoln and Guba, 1985) and avoid the risk for example to focus too much on topics of discussion that were not deemed relevant for the study. These topics did not represent potential outliers, which although differing from the normative responses were important for the interpretation, but they rather represented narratives that were

not on dementia caring nor on crisis (e.g. third-degree cousin living in Australia). This was not possible during the focus groups with staff members and family carers, however, as these group interviews lasted for only one session, I was able with prompts to direct the attention of participants towards the study objectives. It was interesting to notice though, that it was not only my strategy that worked in this direction, but that the group dynamics helped maintain participants' attention towards the line of questioning.

In the case of interviews with staff members, there was a natural unfolding of hierarchical relationship within the team, which led to service managers or consultants to manage the flow of the conversation. This may have led some less senior staff to being more conscious about what to disclose or to express in the presence of more senior colleagues. My role, however, was that of a moderator as I did not want to influence any dynamics being formed within the group. I in fact aimed to recreate a naturalistic environment of team meetings and assume a neutral stance which helped decrease the inhibiting effects (i.e. researcher bias) that my presence could have otherwise brought to the discussion, affecting the credibility and generalisability of the interpretation.

Study findings from dyadic interviews and focus groups were triangulated by means of a preliminary work (systematic reviews), and PPI discussion meetings. Triangulation reduced the risk to have an interpretation based on chance, therefore it strengthened the accuracy and trustworthiness of study findings. Findings were also consistently checked by members of the research team who were afforded the role of assessing the quality and credibility of study reporting. This decreased the risk of misinterpretation. In addition, in concert with Lincoln and Guba (1985), one co-researcher (CB) acted as peer briefer to check the procedures and interpretation of

both systematic reviews and empirical studies. The co-researcher also helped develop and co-presented the one systematic review on agency in dementia care during one seminar of the PPI meetings at the University of Nottingham.

A threat to external credibility that needs to be acknowledged is the small sample of the study which was recruited through dementia crisis teams. This may have nonetheless affected the external generalisability of the findings as the sample could have represented an elite of the population with dementia receiving care from secondary crisis care teams. This was an explorative study however, and the risk to incur in biased interpretation was expected and contained by ensuring that a rich and thick description of the social reality of participants was attained throughout the longitudinal dyadic interviews. The same was attempted for focus groups by exploring questions around co-production with different groups of participants (interviews with teams and family carers).

8.4 Limitations of the study

Some limitations are found in the study. There was a small number of participants that was recruited for both longitudinal dyadic interviews and focus groups. Although the small sample did not impact on sample adequacy and this was agreed by the co-authors of the empirical manuscripts during discussion meetings, a larger sample size with participants recruited from different geographical areas could have provided with a richer snapshot of experiences of crisis in dementia.

As social constructivism informed the epistemology of the study, and the qualitative theoretical framework was based on interpretivism, the study interpretations were made with caution in terms of external credibility, as each individual may construct own reality of psychosocial phenomena, as it is the case of dementia in this study.

Although I aimed at purposive sampling to recruit participants who were on a caseload of dementia crisis teams at the time of the interview, this was not possible to some extent, as recruitment occurred through teams and for this reason staff members had to select those participants who were experiencing a less intense experience of crisis and or were in a less severe stage of dementia. This pre-selection of participants by the team diminished the degree of flexibility to choose individuals with more diversified background characteristics (i.e. all participants were white British) and dementia diagnoses, for example. In the study, over 90% of the sample participating in the dyadic interviews and focus groups, was female and co-habiting with the person with dementia. This in concert with findings from a recent report by Alzheimer's Disease International (2015) which evidenced that globally female carers represent two-thirds of informal providers of care.

A recent systematic review on ethnicity and dementia care services (Mukadam, Cooper, & Livingston, 2011), evidenced the positive association between being from a minority group and decreased access to specialist services for the condition. Among the causes for such association were the accentuated belief of dementia as consequent to normal ageing, feeling that caring for someone with dementia is a social and familial responsibility. The current study did not recruit participants from minority ethnic groups and exploring such association further with respect to dementia crisis services may have led to a better understanding on how to reach ethnic minority groups with public health programs for crisis management, and perhaps to tackle the misbelief around dementia still limiting the access to adequate care in this population (e.g. people with Asian ethnic background may consider dementia a family responsibility and this may lead to increased care burden and sometime to less effective care).

Dementia crisis teams acted as gatekeepers for recruitment, however, their support was necessary as I could minimise the risk of adverse events. In fact, recruiting individuals without the support of clinical staff who could advise on which cases would be more advisable to involve in the study, I could have risked that the interviews could have worsened the experience of those participants with an already compromised emotional situation and or care burden. The teams further followed the project throughout the delivery of interviews, and this contributed to optimal levels of data gathering. Consequently, the retention rate was good throughout the interviews, as participants did not withdraw from the study. In addition, no adverse events were reported following participation. Similar positive outcomes could have been attained by approaching participants through also non-clinical routes (i.e. dementia crisis services) but through dementia community centres and dementia PPI groups. This type of recruitment would have allowed more participants not accessing secondary services to take part in the study and have the opportunity to share their experience of crisis. By doing so, people with dementia and their carers with no prior experience of these services could have gained a knowledge about their type of support and provide the research study with important knowledge on why they did not access the crisis services and how they managed such critical situation son their own.

Results are constrained by not assessing individual variables of the person with dementia and that of their carers (e.g. perceived quality of care, perceived quality of relationship within the dyad) that could have impacted on their social construction of dementia and their experience of managing mental health crisis, as evidenced in previous findings (Williamson & Schaffer, 2001; Steadman et al., 2007). Informed by previous findings on coping styles (Afifi, Hutchinson, & Krouse, 2006; Traa, De

Vries, Bodenmann, & Den Oudsten, 2015), the study looked into individual-specific coping versus dyad-specific coping style and found that the latter favour a more open communication towards responsibility of care and help seeking behaviour, however, there may be different degrees of coping styles and grouping couples into two specific types of coping may be reductive. This decision was made to organise dyads into distinctive styles of coping that could help frame their responses clearly, however future studies should look into relationship quality and delivery of care by considering a wider range of coping style.

The interpretative stance of narrative inquiry may have led to problems of over-generalisability in the findings. This was an explorative qualitative inquire into cases (five dyads) with no intention to claim any objective truth. For this reason, readers need to take findings with caution as they may not reflect the totality of human experience of crisis in dementia, but they represent rather subjective experiences of participants, which may or may not represent other people's life experiences.

8.5 Implication for practice and way forward

Although the current study did not explore if and how proxy decision making proved effective in representing the views of the person, dyads with a shared understanding of the situation seemed to be more in agreement with the course of action for dementia care. It may be contended that specific forms of coping style exhibited during dementia care, may anticipate whether the carer could effectively make proxy decisions that are attuned with the views and needs of the person with dementia. For example, couples exhibiting a dyad-specific versus individual-specific coping style may be more likely to have a better understanding of each other needs and in turns, the carer may be equipped with the necessary confidence and perceived understanding to make future decisions.

8.5.1 Development of future studies

Future studies should investigate the relationship between different dyadic coping style and surrogate decision making, this line of inquiry could help design better informed campaigns around changes in dyadic relationship as dementia progresses. Such health educational program could help carers find ways to establish open communication with the person with dementia about for example advance care options, help promote activities they can share, and help them reshape new roles as dementia progresses.

For this reason, multidisciplinary team interventions for crisis should include support for carers and address any unmet needs they may have and that was caused by such crisis-related distress. Future studies may employ photo voice technique to give dyads opportunity to convey through daily photographs taken by themselves their experience of coping with critical situations. A possible study could look into the way dyads make sense of the episode of crisis through images and then discuss with the research team in what ways a particular image reflected their experience of caring and of dementia. These meanings could help the dyad openly discuss about their experience and negotiate each other's views on responsibility of managing behaviours that challenge. In addition, focus groups with dementia crisis teams and people with dementia could also inform them about the type and modality of their intervention and about the nature of the crisis whose experience may be episodic and re-experienced after the completion of the intervention. Acquiring this knowledge around crisis could prove effective in reducing unrealistic expectations that they may have towards the teams' intervention, for example, and educate the team to gather the views of people with dementia through active listening.

Future studies employing co-researchers, should pay attention to not over involve the person in tasks that may require advanced training in data analysis, as this was reported as potentially disempowering by the co-researcher involved in the study. He advised that the role of the co-researcher, because of their personal experience of the condition, should be mainly promoted in research tasks where no prior knowledge is required. It is to be acknowledged, though, that future studies having more financial, staff, and time resources to dedicate to co-research, may devote tailored training in analytical frameworks for data categorisation and interpretation.

8.6 Conclusion

The primary aim of the study was to explore the social dimension of mental health crisis in people with dementia and their family carers. This study is innovative in multiple ways. This was the first study to systematically review primary and secondary data to understand how at the societal level the condition was constructed and the role of others in buffering the ability of the person to influence the construction of dementia. In the presence of adequate levels of self-awareness with respect to the experience of dementia, the person is more likely to assert their own identity and mediate the interpretation spread around dementia at a societal level.

Self-awareness is important also in the promotion of agency in dementia care, whereby autonomous decision may be a function of the quality of the care environment (e.g. nurturing care), and of metacognitive processes of self-awareness, self-reflection and self-monitoring in regard to the situation. In the presence of negative responses from the care environment (e.g. controlling environment) the person may experience decreased autonomy and risk to have their views only partially considered through pseudo-autonomous decision making.

When there is an external individual supporting the autonomy of the person with dementia, autonomy is not only a matter of ability to action, but also of quality of support. Establishing a collaborative work with the person with dementia and their carer is key to enabling the creation of positive and nurturing care environment to promote social action.

Identifying dyadic style in dementia care may be important to adequately help the agents manage crisis in dementia, as dyads sharing a dyad-specific oriented goal may be more likely to exhibit adequate behavioural responses to the situation and promote an equal distribution of power for the responsibility of care. Conversely, when only one partner or none of them engage in dyad-specific oriented goals, the stress posed by dementia could more easily affect their dyadic interaction because of no perceived shared understanding of the situation. Having a shared understanding of the situation is further a key determinant for making a prompt call for professional help in the presence of crisis. Acknowledging the relationship of the dyad, their coping skills and way they prefer to make decisions on care are key elements for teams in order to establish trust and any therapeutic collaborations with people with dementia and their carers.

Taken together, the findings from the study suggest it is timely to develop psychosocial interventions that could take into account the way the dyad constructs the meaning of dementia and replace, when required, misunderstandings around the condition with evidence-based information. Psychosocial interventions should also aim to replace unhelpful coping strategies exhibited by the dyad for the management of crisis. It is further timely to develop community-based public health programs on dementia crisis prevention and management that are population tailored, which for example, can be adapted to specific cultural groups. In addition, setting up monthly

community meetings with a key staff member from a dementia crisis team and the person with dementia and the carer, discussing about the most effective ways to manage episodes and when and how to contact these specialised secondary care services are strongly needed.

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Appendix 1: Reflective notes

The journey into my PhD began three years and four months ago when I was awarded an ESRC funding for a four-year PhD programme (from October 2016 to September 2020) to explore how people with dementia and their family carers accessing TMCD manage mental health crisis. These past three years have been a good opportunity for my career development, a complex journey of self-discovery and a context for networking with professionals and with new friends, like Carole, the co-researcher who accompanied me in this journey.

This reflective note is a summary of a more elaborated weekly journal that I kept writing during my PhD studies, and which I am still doing until the submission of the thesis. The journal does not follow a fixed structure as it represents for me a cathartic moment to engage with my thoughts and an opportunity to make meaning and create a storyline around my life in the past three years. I believe that reality is socially constructed through human social interaction and the journal is a way for me to construct and reconstruct my experiences in view of what I was before the beginning of my PhD, of what I am now that I am close to the completion of my studies, and with respect to what I would like to be in the near future post-thesis submission.

This summary contains information around my experience and own positioning with respect to pre-study set up, data collection, dissemination and stepping into the academic job market.

My own position with respect to the research hypothesis

Before my PhD studies I worked in Trial studies and I had a more positivist view about what constituted quality in research. I felt in fact that testing hypotheses under a more controlled environment could give a better understanding of study outcomes. What made me appreciate the importance of conducting qualitative work during my PhD, was my involvement as researcher in a trial study, which aimed to determine the effectiveness of a behaviour support

intervention for challenging behaviours in adults with learning disability. Although the quantitative study findings evidenced a non-statistically significant reduction of challenging behaviours in participants with learning disabilities, following the delivery of the intervention, during the interviews, the participants and their family carers reported experiencing positive outcomes in terms of increased quality of life and better understanding of behaviour management, nonetheless. This led me to questioning the positivist paradigm in research and increased my curiosity towards a qualitative exploration of human experience. This led me to conducting and analysing a process evaluation of the intervention delivered in the trial to explore how participants constructed their realities and the mechanisms impacting on the overall experience of the intervention. I believe that constant social exchanges between different agents in care, be the person living with the condition and their carers and or health professionals, shape one's own meaning of reality, over time. It is for this reason, that I opted for social constructivism as theoretical framework for my study, as I was curious to explore how crises are constructed between agents and managed according to each respective role within the family (or dyad). My exploration was free from a positivistic determination of true experience, I was keen on exploring how participants constructed the social phenomenon (i.e. the episode of crisis) at the time the interview took place. My interest was not to find an objective understanding that I could generalise to the population of people with dementia, but rather finding examples of crises that were time bound and socially constructed through role negotiation between the person with dementia and their carers.

Navigating through the initial phases of study set up

As part of my PhD, I began the process of obtaining ethical approval in September 2017. During this time, I felt that the process to apply for ethics was quite rigid yet easy to follow. I undertook a three-stage process to check, revise, and refine my study protocol. I met three times with the PPI members at the School of Medicine to integrate their input around the quality of the study documents (i.e. patient's information sheet, consent form and debriefing

forms), around the relevance of having a co-researcher supporting me during the delivery of qualitative interviews and around the topic guides for the interviews on crises in dementia. At this point, I also felt I needed to discuss about my research with someone external to the research field, not only to check the quality of my work but also to see what someone living in the community and with no research experience thought about the relevance of my project. For this reason, I further met with a person with dementia who acted as external advisor to explore whether the views of a member of the community, not participating in the already established PPI group, could differ from the views I previously gathered during the PPI meetings.

I remember asking him: In which ways (if any) is my study relevant for people with dementia living in the community? My question at the time sounded positivist as I reckoned that a more constructivist question would inquire on how he felt my study could be relevant for his everyday coping with crisis, and not for the wider community. Although it sounded positivist, in line with the work by Berger and Luckman (1966) I believe that my question at the time was correct, as my questioning was influenced by the meaning of reality I maintained at the time of the interview, and by a series of societal and cultural expectations I had formed throughout my life: My questions were socially situated and influenced by past and present social interactions. In addition, it is my belief that asking questions which could potentially aim at generalisation does not necessarily pose a risk to the constructivist perspective, it was my aim to inquire on the way the person felt that a certain social phenomenon could be relevant to a multitude of individuals. The answer to the question would invite him to comment on how he socially situated himself with respect to the community, how he socially constructed (through interaction with members of the wider community) the concept of dementia and the need for support for crisis.

Overall, the external advisor and the PPI group commented favourably on the structure and methodology used in the research protocol. However, the following minor changes had to be made: 1) The definition of crises needed to be broad as to allow participants to unfold their

own meaning of crisis during the interview. For this reason, I decided to employ the definition as provided by the NHS which was then commented favourably by the PPI group in a later meeting. 2) The participant information sheet (PIS) for the person with dementia needed to be in accessible format. The PIS was made accessible and it was then given to participants with dementia along with the non-accessible format as to allow them to decide which document to use. 3) The PPI group further advised to ask participants whether they would like to have the co-researcher accompany me during the interviews, and not to automatically assume that they would accept the co-researcher because part of the research team. The PPI group commented favourably on the delivery of a research training in qualitative interviewing for the co-researcher. I felt I was able to establish a reflective dialogue with the co-researchers and share their views about the research study.

The study setup phase ran smoothly and I had very good support from my supervisory team. I further integrated the comments provided by the Chief Investigator of the study (MO) and my PhD supervisors (JS, DMCS). Negotiation took place with the Nottinghamshire Health Care Trust's Research and Innovation Team around the recruitment of participants (i.e. whether staff members of participating multidisciplinary teams managing crises would be involved in the recruitment of participants with dementia and their carers for the dyadic interviews; whether the focus groups with staff members and people with dementia and their carers would take place in the NHS premises). I obtained research capacity in two sites in Nottinghamshire Trust (City MHIR Team on 3/11/2017 and Gedling Integrated Community team on 06/11/2017). I subsequently obtained honorary contracts.

I received sponsorship from the University of Nottingham on 22nd December 2017, a validation letter from the Research Ethics Committee (REC) on 3rd January 2018, a REC favourable opinion letter on 27th March 2018 and final HRA approval on 28th March 2018. I received clearance from the R&I office to begin recruitment in April 2018.

Navigating through data collection and analysis

As new patients with dementia had not been referred to the teams in Nottinghamshire, in consultation with my supervisors I decided to make a minor amendment to the original protocol to add a new Trust for my study (Sheffield Health & Social Care NHS Foundation Trust). Upon consultation with the R&I office and the university sponsor, I submitted the amendment to the HRA on 12th June 2018 and received HRA approval on 15th June 2018. Recruiting participants accessing dementia crisis services proved quite daunting as people with dementia were in a very critical period in their life and many of them were retained unfit by the teams to take part in the study for safety reasons. Although disheartening from a researcher point of view, I felt that irrespective of the number of participants I could recruit, my study was explorative and deemed timely for people with dementia. In fact, no previous project ever attempted to explore how people with dementia and their family carers managed crisis with the support of dementia crisis teams.

I had a positive experience of the interviews, as participants from both the focus group and dyadic interviews actively participated in the sessions. Even though I was external to their team work (for staff members) and couple hood (for dyads with dementia) I was able to experience an honest attitude and welcoming atmosphere throughout. Couples with dementia were able to openly discuss around a sensitive topic such as crises, and around the challenges they experienced in the aftermath of the problem behaviour. The answers they provided to my questions, made me aware of how dementia as health condition provoked a quite strong feeling in me, I felt that dementia began to scare me as I was starting to feel closer to participants' care experience. I still feel that my views around dementia are being constantly challenged and my fear of losing consciousness is still quite frightening for me. I feel that with time my identity as researcher has given me the knowledge around different theoretical perspectives to explain social phenomena but has made me more scared of losing what I retain important for my work, for my being, maintaining knowledge of the social world. I believe that my research stance may have at times influenced participants'

responses during the qualitative interviews. In one occasion, a family carer sensed my emotional response to the topic around crisis, and asked me if I had a case of dementia in my family and she further reassured me that dementia was not as scary as it could seem.

I feel that in my interpretation of study findings I was able to maintain a health service perspective by interviewing TMCD and an individual perspective by being in constant discussion with co-researchers and members of the PPI group. My research stance acted as nearly neutral as I wanted it to be, to bridge both perspectives, although at times I felt closer to the needs of people with lived experience of dementia than that of the teams.

Through discussion with the teams though, I could appreciate the difficulty they experienced in balancing their workload and need for efficiency with the time required by participants to digest the information they were given around crisis management and teams involvement. It was in fact difficult for the teams to spend long time with the dyad to describe the intervention, as this would inevitably affect the time they could then dedicate to other crisis cases. As I have described many times in the interpretation of study findings, I feel strongly about giving more opportunity to people with dementia and their carers to be actively involved in care delivery and for this reason, I believe that having community support groups who are run also by people with dementia may help promote equity in crisis care.

Further training and public engagement for dissemination

As part of my ESRC program in Mental Health & Wellbeing, I completed all the 200 Master credits bearing courses and advanced training courses. I felt these courses added on my existing knowledge, especially those around quantitative and qualitative methodologies, however, I found it quite intense to undertake all the credits in the first two years considering that these added onto an already intense research work I was doing as part of study recruitment and data collection. I felt that it was beneficial to attend the course on research methods alongside data collection as it helped expand my views around the theoretical framework and my research position in view of data analysis.

In order to maximise my career and professional development, as part of my studies, I successfully secured funding from the ESRC (£3,750.00) to undertake an internship of three months (from 10th January to 9th April 2018) at the World Health Organisation in Geneva to train in international health policy.

With respect to dissemination, I feel I was able to share the knowledge gained from my PHD findings with academics and health professionals through attending international conferences (Alzheimer's Europe) but also with members of the general public and people with dementia living in the community by attending the Taking Action on Dementia health event at Rushcliffe Arena on 24th May 2019.

The 'one' main challenge

Challenges have been experienced in the recruitment of a co-research with dementia from members of the PPI as some of them struggled to find suitable referees to write a letter of reference that was required as part of the ethics. For this reason, I opted to have a minor amendment to the protocol and include also a carer who could act as co-researcher. This choice was not made to exclude the person with dementia from co-research, but rather as contingency plan to have extra support if necessary. I strongly feel that a culture around ethics for co-research need to be fostered among researchers but also among members of the PPI, to help promote a safe environment where being asked about DBS check and letter of references is not experienced negatively but rather as part of a normal procedure to obtain ethical approval.

Next steps forward

In the last months before thesis submission, I submitted a small grant application (15 November 2019) through Alzheimer Research UK to secure funding (£4,662.93) for a study aiming to (i) analyse the risk of dementia in people with ASD compared to people without ASD; (ii) assess the overlap between AD and ASD genetic variants; and (iii) determine age specific all-cause mortality rates in individuals with ASD. I am currently applying for a Post

Doc fellowship to continue with the line of inquiry started with my PhD and explore how alternative peer community support groups can help manage difficult behaviours and prevent crisis episodes in people with dementia. If successful, as part of the fellowship I will spend one-month overseas visit at the New York University in New York to explore differences in crisis care provision between UK and US health systems.

List of publications – PhD related:

Bosco, A.; Schneider, J.; Coleston-Shields, D.M.; Higgs, P.; Orrell, M. (2019). The social construction of dementia: Systematic review and metacognitive model of enculturation. Maturitas, 120 pp. 12-22. 10.1016/j.maturitas.2018.11.009.

Bosco, A., Schneider, J., Coleston-Shields, D. M., & Orrell, M. (2019). Dementia care model: Promoting personhood through co-production. Archives of gerontology and geriatrics. Arch Gerontol Geriatr, 81:59-73. doi: 10.1016/j.archger.2018.11.003.

Bosco, A., Schneider, J., Coleston-Shields, D. M., Jawahar, K., Higgs, P., & Orrell, M. (2018). Agency in dementia care: systematic review and meta-ethnography. International Psychogeriatrics, (5):627-642. doi: 10.1017/S1041610218001801.

Bosco, A., Schneider, J., Coleston-Shields, D. M., Sousa, L., & Orrell, M. (2018). Dyadic construction of dementia: meta-ethnography and behaviour-process synthesis. Aging & Mental Health, 23(6):651-659. doi: 10.1080/13607863.2018.1450836.

Bosco, A., Schneider, J., Coleston-Shields DM., & Orrell M. Co-producing care for mental health crises: The experience of family carers and staff members of dementia crisis teams. Quality in Ageing and Older Adults (Under review).

Bosco, A., Schneider, J., Coleston-Shields DM., & Orrell M. Narrative inquiry on case studies of crisis in dementia. Quality in Ageing and Older Adults (Under review).

List of publications – Not including PhD studies:

Bosco, A., Paulauskaite, L., Hall, I., Crabtree, J., Soni, S., Biswas, A., ... & Crawford, M. J. (2019). Process evaluation of a randomised controlled trial of PBS-based staff training for challenging behaviour in adults with intellectual disability. PloS one, 14(8), e0221507.

Strydom, A., **Bosco, A.,** Vickerstaff, V., Hunter, R., & Hassiotis, A. Clinical and cost effectiveness of staff training in the delivery of positive behaviour support (PBS) for adults with intellectual disabilities, autism spectrum disorder and challenging behaviour. BMC Psychiatry (Under review).

Oliveira, D., **Bosco, A.,** & di Lorito, C. (2019). Is poor health literacy a risk factor for dementia in older adults? Systematic literature review of prospective cohort studies. Maturitas, 124, 8-14. doi: 10.1016/j.maturitas.2019.03.010.

Bosco, A., Jones, K., Di Lorito, C., Blossom, S., Orrell, M., & Oliveira, D. People's opinions about changing their lifestyle for dementia risk reduction: Qualitative content analysis of a national UK survey. PloS one (in process of submission).

Bosco, A., Schneider, J., & Broome, E. (2019). The social value of the arts for care home residents in England: A Social Return on Investment (SROI) analysis of the Imagine Arts programme. Maturitas. 124,15-24. doi: https://doi.org/10.1016/j.maturitas.2019.02.005

Hassiotis, A., Poppe, M., Strydom, A., Vickerstaff, V., Hall, I., Crabtree, J., Omar, R., King, M., Hunter, R., **Bosco, A.,** & Biswas, A., 2018. Positive behaviour support training for staff for treating challenging behaviour in people with intellectual disabilities: a cluster RCT. Health Technology Assessment, 22(15), pp.1-110. doi: 10.3310/hta22150.

Di Lorito, C., **Bosco, A.,** Birt, L., & Hassiotis, A. (2017). Co-research with adults with intellectual disability: A systematic review. Journal of Applied Research in Intellectual Disabilities. 31(5):669-686. doi: 10.1111/jar.12435.

Kouimtsidis, C., **Bosco, A.,** Scior, K., Baio, G., Hunter, R., Pezzoni, V., ... & Hassiotis, A. (2017). A feasibility randomised controlled trial of extended brief intervention for alcohol misuse in adults with mild to moderate intellectual disabilities living in the community; The EBI-LD study. Trials, 18(1), 216. doi: 10.1186/s13063-017-1953-0.

Di Lorito, C., **Bosco,** A., Booth, V., Goldberg, S., Harwood, R.H., van der Wardt, V. Adherence to exercise and physical activity interventions in older people with mild cognitive impairment and dementia: A systematic review. Preventive Medicine (Under review).

Di Lorito, C., **Bosco, A.,** Pollock, K., Harwood, R.H., das Nair, R., Logan, P., Goldberg, S., Booth, V., Vedhara, K., Godfrey, M., Dunlop, M., & van der Wardt, V. (2020). External validation of the 'PHYT in dementia', a theoretical model promoting physical activity in people with dementia. Health expectations. (Under review).

Publication strategy (Gantt chart).

Manuscripts	**Month**															
	3	6	9	12	15	18	21	24	27	30	33	36	39	42	45	48
Preliminary work (Desk-based work)																
– The social construction of dementia: Systematic review and metacognitive model of enculturation.																
– Dyadic construction of dementia: Meta-ethnography and behaviour-process synthesis.																
– Dementia care model: Promoting personhood through co-production.																
– Agency in dementia care: Systematic review and meta-ethnography.																
Phase 1 (On the field)																
– How couples accessing crisis teams choose to cope: Narrative inquiry on case studies of crisis in dementia.																
Phase 2 (On the field)																
– Co-producing care for mental health crises: The experience of family carers and staff members of dementia crisis teams.																

Published. Preparing for submission

submitted

Project Time-line (Gantt chart).

Task	**Month**															
	3	6	9	12	15	18	21	24	27	30	33	36	39	42	45	48
Preliminary work																
Writing of protocol																
Writing of four systematic reviews																
Engagement in PPI																
Liaison with services																
Ethical approval																
Recruitment																
Data collection																
WHO Internship Geneva																
Data analysis																
Development of recommendations																
Dissemination of findings																
Writing of final report																

Work completed Currently working on

Work to be completed

Appendix 2: Certificate of achievement for the course on Good Clinical Practice



A practical guide to ethical and scientific quality standards in clinical research

Including EU Directives, Medicines for Human Use (Clinical Trials) Regulations & the Department of Health Research Governance Framework for Health & Social Care, as applied to the conduct of Clinical Trials & other studies conducted in the NHS

Modules completed:

Introduction to Research and the GCP standards
Preparing to deliver your study
Identifying and recruiting participants: eligibility and informed consent
Ongoing study delivery and data collection
Safety Reporting
Study closure

This course is worth 4 CPD credits



Delivering research to make patients, and the NHS, better

Appendix 3: IRAS Approval letter

IRAS project ID 238215

Email: hra.approval@nhs.net

Professor Martin Orrell

Room D07 Institute of Mental Health

Innovation Park

Triumph Road Nottingham NG7 2TU

M.Orrell@nottingham.ac.uk

28 March 2018

Dear Professor Orrell

Letter of HRA Approval

Study title: **The social understanding of mental health crisis in dementia.**

IRAS project ID: **238215**

Protocol number: **17108**

REC reference: **18/EM/0023**

Sponsor **University of Nottingham**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

Participating NHS organisations in England – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities

Confirmation of capacity and capability - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.

Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from the HRA website.

Appendices

The HRA Approval letter contains the following appendices:

A – List of documents reviewed during HRA assessment

B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators",* issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

Registration of research

Notifying amendments

Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.

Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.

The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found through IRAS.

Appendix A - List of Documents

IRAS project ID 238215

Document	*Version*	*Date*
Copies of advertisement materials for research participants [recruitment leaflet staff]	v1.0	22 December 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance]		
HRA Schedule of Events	1	19 February 2018
HRA Statement of Activities	1	19 February 2018
Interview schedules or topic guides for participants	1.0	05 November 2017
IRAS Application Form [IRAS_Form_02012018]		02 January 2018
IRAS Application Form XML file [IRAS_Form_02012018]		02 January 2018
Letter from sponsor [Sponsor letter]		
Non-validated questionnaire [Email Confirmation]		03 January 2018
Other [participant information sheet - focus group carers]	v2.0	22 February 2018
Other [Participant information sheet - focus group staff	v2.0	22 February 2018
Other [Consent form - staff members]	v2.0	22 February 2018
Other [participant information sheet - focus group people with dementia]	v2.0	22 February 2018
Other [CV supervisor - Donna Maria Coleston-Shields]	v1.0	22 December 2017
Other [debriefing people with dementia and carers]	v1.0	22 December 2017
Other [debriefing staff]	v1.0	22 December 2017
Other [participant information sheet - focus group people with dementia - Easy read format]	v1.0	22 February 2018
Other		
Participant consent form [Consent form - dyadic interviews	v2.0	22 February 2018
Participant consent form [Consent form - dyadic interviews people with dementia - Easy read format]	v1.0	22 February 2018
Participant consent form [Consent form - dyadic interviews people with dementia]	v2.0	22 February 2018
Participant consent form [Consent form - focus group carers]	v2.0	22 February 2018
Participant consent form [Consent form - focus group people with dementia]	v2.0	22 February 2018
Participant consent form [Consent form - focus group people with dementia - Easy read format]	v1.0	22 February 2018
Participant information sheet (PIS) [Information sheet dyadic interviews carers]	v2.0	22 February 2018
Participant information sheet (PIS) [Information sheet dyadic interviews people with dementia]	v2.0	22 February 2018
Participant information sheet (PIS) [Information sheet dyadic interviews people with dementia - Easy read format]	v1.0	22 February 2018
Research protocol or project proposal [Protocol - Mental Health Crisis in dementia]	v1.0	22 December 2017
Summary CV for Chief Investigator (CI) [CV - Martin Orrell]	v1.0	22 December 2017
Summary CV for student [CV - Alessandro Bosco]	v1.0	22 December 2017
Summary CV for supervisor (student research) [CV- Justine Schneider]	v1.0	22 December 2017

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations*, *capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Martin Orrell

Tel: 0115 823 1291

Email: m.orrell@nottingham.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments.
2.1	Participant information/consent documents and consent process	Yes	The applicant has confirmed NHS staff will be briefed about the research project and will receive an information sheet by the PI explaining their possible involvement in the focus group. Staff members will be provided with the information sheet so that they have adequate time (up to 48 hours) to read carefully through the document and appraise whether they are interested in taking part in the study. In case they accept to take part in the focus group, they will be asked whether a room could be used to deliver the focus group interview. The day of the interview, all the staff members participating will be asked to sign a consent form.

Section	HRA Assessment Criteria	Compliant with Standards	Comments
		Yes	The applicant has confirmed consent forms will not be stored on patient medical notes. As part of the applicant's response to REC Provisional Opinion, modified participant information sheets and consent forms were submitted to comply with HRA Standards (e.g separate PIS/ICF for patients and carers, inclusion of PALs/independent contact).
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The sponsor has submitted statement of activities and schedule of events for use as the agreement with the participating NHS sites. No other form of agreement is required, or will be used.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	External funding has not been secured to run the study at site.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	The applicant has confirmed collection of 'full date of accessing the service' will not identify participants as this will be kept separately to other data collected for the study. In addition to 2.1 (above), modified participant information sheets and consent forms were submitted to comply with the Data Protection Act

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			(e.g. retention periods of identifiable data and security/storage arrangements, inclusion of a statement confirming the data arrangements for participants who lose capacity during study).
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments.
5.3	Compliance with any applicable laws or regulations	Yes	No comments.
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	REC Favourable Opinion was issued on 27 March 2018.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is one site type participating in this study. All research activities are the same as detailed in the study protocol and supporting documentation.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website, the Chief Investigator, sponsor or Principal Investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research**.

Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.

The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A Local Collaborator is required at participating NHS sites and has already been identified.

Training – Not Applicable.

GCP training is not a generic training expectation, in line with the HRA/MHRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

Local members of staff that already have contractual arrangements in place with the participating NHS site do not require access arrangements.

Where arrangements are not already in place, network staff (or similar) undertaking any research activities listed in A18 of IRAS, would be expected to obtain an honorary research contract from one NHS organisation (if university employed), followed by Letters of Access for subsequent organisations. This would be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). These should confirm DBS checks and occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN

Portfolio.

The applicant has confirmed the audio recorder will be provided for the interviews/focus groups by the PI. Local services will be asked only to provide rooms for focus groups with staff members (arrangements required for the focus groups have also been detailed in the participant information sheet for staff).

Appendix 4: REC - Favourable Opinion Letter

Health Research Authority

East Midlands - Derby Research Ethics Committee

The Old Chapel
Royal Standard Place
Nottingham NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

27 March 2018

Professor Martin Orrell
Room D07 Institute of Mental Health, Innovation Park
Triumph Road, Nottingham
NG7 2TU

Dear Professor Orrell

Study title:	**The social understanding of mental health crisis in dementia.**
REC reference:	**18/EM/0023**
Protocol number:	**17108**
IRAS project ID:	**238215**

Thank you for your letter, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [recruitment leaflet staff]	v1.0	22 December 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance]		

Interview schedules or topic guides for participants	1.0	05	November 2017
IRAS Application Form [IRAS_Form_02012018]		02	January 2018
Letter from sponsor [Sponsor letter]			
Non-validated questionnaire [Email Confirmation]		03	January 2018
Other [CV supervisor - Donna Maria Coleston-Shields]	v1.0	22	December 2017
Other [Consent form - staff members]	v1.0	22	December 2017
Other [debriefing people with dementia and carers]	v1.0	22	December 2017
Other [debriefing staff]	v1.0	22	December 2017
Other [particpant infomration sheet - focus group carers]	v2.0	22	February 2018
Other [Participant information sheet - focus group staff members]	v2.0	22	February 2018
Other [Consent form - staff members]	v2.0	22	February 2018
Other [particpant infomration sheet - focus group people with dementia]	v2.0	22	February 2018
Other [participant information sheet - focus group people with dementia - Easy read format]	v1.0	22	February 2018
Other			
Participant consent form [Consent form - people with dementia and carers]	v1.0	22	December 2017
Participant consent form [Consent form - dyadic interviews carers]	v2.0	22	February 2018
Participant consent form [Consent form - dyadic interviews people with dementia - Easy read format]	v1.0	22	February 2018
Participant consent form [Consent form - dyadic interviews people with dementia]	v2.0	22	February 2018
Participant consent form [Consent form - focus group carers]	v2.0	22	February 2018
Participant consent form [Consent form - focus group people with dementia]	v2.0	22	February 2018
Participant consent form [Consent form - focus group people with dementia - Easy read format]	v1.0	22	February 2018
Participant information sheet (PIS) [Information sheet dyadic interviews people with dementia and carers]	v1.0	22	December 2017
Participant information sheet (PIS) [Information sheet dyadic interviews carers]	v2.0	22	February 2018
Participant information sheet (PIS) [Information sheet dyadic interviews people with dementia]	v2.0	22	February 2018
Participant information sheet (PIS) [Information sheet dyadic interviews people with dementia - Easy read format]	v1.0	22	February 2018

Research protocol or project proposal [Protocol - Mental Health Crisis in dementia]	v1.0	22	December 2017
Summary CV for Chief Investigator (CI) [CV - Martin Orrell]	v1.0	22	December 2017
Summary CV for student [CV - Alessandro Bosco]	v1.0	22	December 2017
Summary CV for supervisor (student research) [CV- Justine Schneider]	v1.0	22	December 2017

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

pp. V. Smith

Dr John S Fenlon

Chair

NRESCommittee.EastMidlands-Derby@nhs.net

Appendix 5: Consent form carers for dyadic interviews

CONSENT FORM – Carers **(Final version 2.0: date 22.02.2018)**

Title of Study: The social understanding of mental health crisis in dementia.

IRAS Project ID: 238215

Name of Researcher: Alessandro Bosco

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet regarding my involvement in the dyadic interviews, version number 2.0 dated 22.02.2018 for the above study and have had the opportunity to ask questions. ☐

1. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far may still be used in the project analysis. ☐

2. I understand that relevant sections of data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4. I understand that although what I say in the interview is confidential, if I disclose anything which the researcher feels puts me or anyone else at any risk, they may feel it necessary to report this to the appropriate persons. ☐

5. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐

6. I understand that all information which is collected during the course of the research will be kept strictly confidential, stored in a secure and locked office, and on a password protected database, and separate from consent forms. In accordance with the University of Nottingham Code of Research Conduct and Research Ethics, all records will be retained for at least 7 years or for longer if required. After this time your data will be disposed of securely. However, audio recording files of interviews will be disposed of immediately after being transcribed by the co-investigator. ☐

7. I agree to take part in the dyadic interview of the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the researcher site file. Participant consent form – Carers. Final version 2.0, 22 February 2018

Appendix 6: Consent form carers for focus groups

CONSENT FORM - Carers
(Final version 2.0: date 22.02.2018)

Title of Study: The social understanding of mental health crisis in dementia.

IRAS Project ID: 238215

Name of Researcher: Alessandro Bosco

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet regarding my involvement in the focus group interviews, version number xx dated xxxxxx for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far may still be used in the project analysis. ☐

3. I understand that relevant sections of data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4. I understand that although what I say in the interview is confidential, if I disclose anything which the researcher feels puts me or anyone else at any risk, they may feel it necessary to report this to the appropriate persons. ☐

5. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐

6. I understand that all information which is collected during the course of the research will be kept strictly confidential, stored in a secure and locked office, and on a password protected database, and separate from consent forms. In accordance with the University of Nottingham Code of Research Conduct and Research Ethics, all records will be retained for at least 7 years or for longer if required. After this time your data will be disposed of securely. However, audio recording files of interviews will be disposed of immediately after being transcribed by the co-investigator. ☐

7. I agree to take part in the focus group of the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the researcher site file. Participant consent form – Carers. Final version 2.0, 22 February 2018

Appendix 7: Easy-read consent form – Participants with dementia dyadic interviews

CONSENT FORM
(Final version 1.0: date 22.02.2018)



Title of Study: The social understanding of mental health crisis in dementia.

IRAS Project ID: 238215

Name of Researcher: Alessandro Bosco

Name of Participant:

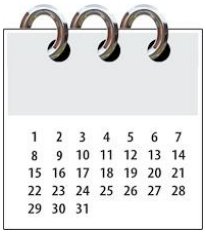
Please answer all the questions		✗	✓
Information sheet	I have read the information sheet about the research		



	Someone read the information sheet about the research to me		
Please answer all the questions			
	I can understand the things the information sheet told me		
	I was able to ask questions if I wanted to		
	I understand that it is my choice to take part in this study and that I will be interviewed with my carer		

	I understand that I can say **No** at any time if I want to stop		
Please answer all the questions		✗	✓
	I understand that this will not change the care I get		
	I agree to take part in an interview that will be tape recorded		

	I understand that when you write about the research, you will tell people what I said, but will not tell people my name		

	date
	my name
	my signature
	researcher's name researcher's signature
	date

2 copies: 1 for participant, 1 for the researcher site file. Patient consent form. Final version 1.0, 22 February 2018

Appendix 8: Consent form staff for focus groups

CONSENT FORM
(Final version 2.0: date 22.02.2018)

Title of Study: The social understanding of mental health crisis in dementia.

IRAS Project ID: 238215

Name of Researcher: Alessandro Bosco
Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet version regarding my involvement in the focus group, number xx dated xxxxxx for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without legal rights being affected. I understand that should I withdraw then the information collected so far may still be used in the project analysis. ☐

3. I understand that relevant sections of my data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4. I understand that although what I say in the interview is confidential, if I disclose anything which the researcher feels puts me or anyone else at any risk, they may feel it necessary to report this to the appropriate persons. ☐

5. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐

6. I understand that all information which is collected during the course of the research will be kept strictly confidential, stored in a secure and locked office, and on a password protected database, and separate from consent forms. In accordance with the University of Nottingham Code of Research Conduct and Research Ethics, all records will be retained for at least 7 years or for longer if required. After this time your data will be disposed of securely. However, audio recording files of interviews will be disposed of immediately after being transcribed by the co-investigator. ☐

7. I agree to take part in the focus group of the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the researcher site file. Participant consent form – Staff. Final version 2.0, 22 February 2018

Appendix 9: Participant debriefing sheet

Participant Debriefing Sheet
(Final version 1.0: 22 Dec 2017)

Title of Study: The social understanding of mental health crisis in dementia.

IRAS Project ID: 238215

Principal Investigator: Alessandro Bosco

Dear Research Participant

Thank you for your participation in this study. Your contribution was greatly appreciated.

What was the purpose of this study? The aim of this study is to explore the experience of mental health crisis for people with dementia and their family carers and to see how they can actively participate in the delivery of the care. The study will help us better identify what can be improved in the delivery of care for the management of mental health crisis in people with dementia.

Right to withdraw from the study: We would like to remind you that you have a right to withdraw from the study without providing any explanation up to one month from the completion of your last interview session. Your withdrawal will not affect in any way the care you are receiving. Upon withdrawing from the study, individual interview data could be removed from analysis but it would be difficult to remove contributions from focus groups. If you would like to withdraw from the study please notify one of the clinical members of staff in your ward, who will contact the Principal Investigator.

Further support: If for any reason, you feel that you need further support during or upon completion of the study, please refer to any clinical members of staff from the dementia crisis teams (nurse, OT, clinical psychologist).

Thank you for your contribution!

Alessandro Bosco
PhD student in Psychiatry
Division of Psychiatry & Applied Psychology
School of Medicine
University of Nottingham
Room 10, A floor, Institute of Mental Health, Jubilee Campus
Nottingham, NG7 2TU
Email: Alessandro.bosco@nottingham.ac.uk

Appendix 10: Staff debriefing sheet

Member of staff Debriefing Sheet
(Final version 1.0: 22 Dec 2017)

Title of Study: The social understanding of mental health crisis in dementia.
IRAS Project ID: 238215
Principal Investigator: Alessandro Bosco

Dear Member of staff

Thank you for your participation in the focus group. Your contribution was greatly appreciated.

What is the aim of this study? The aim of this study is to explore the experience of mental health crisis for people with dementia and their family carers and to see how they can actively participate in the delivery of the care. We were able to gather the views of people with dementia and their carers on the their experience of care by asking them about what helps with crisis, how crisis affects their everyday life and their relationships, but also by asking them how active participation in decision making can take place. The study will help us better identify what can be improved in the delivery of care for the management of mental health crisis in people with dementia.

What was the purpose of the focus group session? The purpose of the focus group session you took part in was to gather the members of staff's comments around the current barriers/facilitators for the delivery of care, and the strategies in place within the service to manage the mental health crisis in a way that takes into account the views of the patients. We aim to integrate the findings from this session with those emerging from the interviews with the patients, so that we capture the full range of perspectives.

Further information: If you would like to receive further information on the study or you would like to access the final report of the study, do not hesitate to contact the Principal Investigator Alessandro Bosco (Alessandro.bosco@nottingham.ac.uk) or his supervisors Martin Orrell (m.orrell@nottingham.ac.uk), Justine Schneider (justine.schneider@nottingham.ac.uk), and Donna Maria Coleston-Shields (Dons.Coleston-Shields@nottshc.nhs.uk).

Thank you for your contribution!

Alessandro Bosco
PhD student in Psychiatry
Division of Psychiatry & Applied Psychology, School of Medicine
University of Nottingham, Room 10, A floor, Institute of Mental Health, Jubilee Campus
Nottingham, NG7 2TU
Email: Alessandro.bosco@nottingham.ac.uk

Appendix 11: Carers information sheet - Dyadic interviews

Participant Information Sheet - Carers
(Final version 4.0: 22.06.2018)

IRAS Project ID: 238215

Title of Study: The social understanding of mental health crisis in dementia.

Name of Researcher(s): Alessandro Bosco

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 study is trying to explore the experience of mental health crisis of people with dementia aged 50 years old and above and of their carers, living in residential accommodations. We will explore their experience of crisis by asking people with dementia and their family carers about aspects of their daily life that may trigger the crisis and or that may help them with such negative experience, such as what they do together to manage crisis, how the experience of crisis affects their relationship, why and what made them call for help (e.g. IRIS team, Outreach team), how was the quality of care they received and how this impacted on their relationship.

We hope that by hearing about the experience of both people with dementia and their carers through their own voices, we can better identify if there are improvements that can be made in the delivery of future interventions for the management of mental health crisis.

Why have I been invited?

You are being invited because you are a family carer delivering daily care for a person with dementia who is receiving support for the management of mental health crisis from one of the local dementia team services.

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 legal rights.

What will happen to me if I take part?

We aim to investigate your experience of crisis and of the service through several steps, outlined below. If you agree, we would like to audio-tape the interview so that we do not miss any relevant information. Once the interview is finished, the principal investigator alone will transcribe it and will then destroy the tape.

We will need to meet with you up to 4 times over the course of one month (the interview will be with both the person with dementia and the carer). Each time the interview will be at your own place and will be around 90 minutes. A co-researcher (a person living with dementia or a carer) will be present the day of the interview to help the researcher conduct the interview. The co-researcher has shared experience of dementia so this may facilitate the interview.

1. Upon obtaining your written consent, we would like to ask you some information which will be helpful to get to know you better. This information includes demographics (age, gender, country of birth, marital status, ethnicity, race, education, job status), data on your support (date of accessing the service, length of stay, therapy or work being undertaken) and data on the health of the person you care for (type of dementia diagnosis, physical conditions).

2. Each interview will focus on your experience of crisis. For this purpose, we would like to know more about what caused the crisis, and for example how you managed the crisis.

Expenses and payments

You will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?

We do not anticipate any relevant risks or disadvantages for the participants in the study. However, if you find that any of the topics/questions make you feel upset or distressed during or after the study, please raise your concern with the study investigator, the study supervisors or any of the clinical members of staff delivering care for you (nurse, doctor).

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may enhance the understanding on the experience of mental health crisis in dementia for both people with dementia and their carers. This will potentially help increase their quality of care over time.

What happens when the research study stops?

You and the person you care for will still receive professional care if needed, however the research team will not be involved in exploring your experience of the care pathway.

Only participants who have capacity to consent can take part in the study. However, should a lack of capacity be ascertained the day of the interview, the principal investigator will stop the interview and reschedule it to a later date.

Data had already been collected on previous interviews will still be analysed and will constitute part of the findings.

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 Trust complaint procedure (Patient Advice and Liaison Service PALS, Tel: 0800-015-3367, email: pals@nottshc.nhs.uk).

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept strictly confidential, stored in a secure and locked office, and on a password protected database at the University of Nottingham. 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.

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.

Where possible information about you which leaves the [site] will have your name and address removed and a unique code will be used so that you cannot be recognised from it, however sometimes we need to ensure that we can recognise you to link the research data with your medical records so in these instances we will need to know your name and date of birth.

Your contact information will be kept by the University of Nottingham for 6 to 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

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. Should reporting be needed, you will be told by the Principal Investigator.

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 legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the research study?

Results from this study will be part of the doctoral dissertation of the study investigator and will also be disseminated through publications in relevant journals and at conferences at the national and international level. This will ensure that the findings of the study get the attention of the research community, healthcare professionals and policy makers on the experience of mental health crisis for people with dementia and their carers. During the development of the materials for dissemination, your data will always be kept anonymous. For example, what you stated during the interview may be used in the study report, but you will never be able to be identified. You will be able to ask access to the dissemination materials upon request. You will be able to access the dissemination materials upon request. If you are interested in receiving these materials, please contact

the research team on one of the contact details you were provided with this information sheet.

Who is organising and funding the research?

The research is funded by the Economic and Social Research Council (ESRC). Alessandro Bosco, the study investigator, is a PhD student at the University of Nottingham and he is conducting this research as part of his doctoral studies. Professor Martin Orrell is a consultant old age psychiatrist at Queens Medical Centre and director of the Institute of Mental Health and Head of the division of Psychiatry and Applied Psychology at the University of Nottingham. Justine Schneider is a professor of Mental Health and Social Care at the University of Nottingham. Donna Maria Coleston-Shields is a Consultant in Neuropsychology and Primary Research fellow at the University of Nottingham. They all supervise Alessandro during his PhD, but will not conduct research directly.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by East Midlands - Derby Research Ethics Committee.

Further information and contact details

If you have any queries or concern you may wish to discuss, feel free to ask a clinical member of the team managing your crisis or you can contact the study investigator, who will be able to assist.

The contact details of the study investigator are as follows:

Alessandro Bosco
ESRC PhD candidate Mental Health & Wellbeing
School of Medicine
University of Nottingham
Room 10, A floor, Institute of Mental Health, Jubilee Campus
Triumph Road, Nottingham, NG7 2TU
Telephone:
Email: Alessandro.bosco@nottingham.ac.uk

The contact details of the Chief investigator are as follows:

Professor Martin Orrell
Director - Institute of Mental Health
Head, Division of Psychiatry and Applied Psychology
Faculty of Medicine & Health Sciences
Room D07 Institute of Mental Health, Innovation Park
Triumph Road, Nottingham, NG7 2TU, UK
Telephone: 0115 8231291
Email: M.Orrell@nottingham.ac.uk

Appendix 12: Carers Information sheet – Focus group

Participant Information Sheet - Carers
(Final version 4.0: 22.06.2018)
IRAS Project ID: 238215

Title of Study: The social understanding of mental health crisis in dementia.

Name of Researcher(s): Alessandro Bosco

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 study is trying to explore the experience of mental health crisis of people with dementia aged 50 years old and above and of their carers, living in residential accommodations. We will explore their experience of crisis by asking people with dementia and their family carers about aspects of their daily life that may trigger the crisis and or that may help them with such negative experience, such as what they do together to manage crisis, how the experience of crisis affects their relationship, why and what made them call for help (e.g. IRIS team, Outreach team), how was the quality of care they received and how this impacted on their relationship.

We hope that by hearing about the experience of both people with dementia and their carers through their own voices, we can better identify if there are improvements that can be made in the delivery of future interventions for the management of mental health crisis.

Why have I been invited?

You are being invited because you are a family carer delivering daily care for a person with dementia who is receiving support for the management of mental health crisis from one of the local dementia team services.

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 legal rights.

What will happen to me if I take part?

We aim to investigate your experience of crisis and of the service through several steps, outlined below. If you agree, we would like to audio-tape the focus groups so that we do not miss any relevant information. Once the focus group is finished, the principal investigator alone will transcribe it and will then destroy the tape.

We will need to meet with you up to 4 times if you are taking part in the focus group or 6 times if you decide to be involved in the planning decision committee. If you accept to take part in the study, you will take part in a focus group along with other family carers (up to 8 family carers each focus group). During each focus group, there will be an introductory section where all the participants will be able to introduce themselves. After the introductory section, the principal investigator will ask questions to the group around dementia friendly initiatives that promote personhood during mental health crisis by tackling issues of health care, environment, socio-cultural partnership, civic-related and politics.

Each of the two meetings of the planning decision committee will include only one person with dementia and one family carer. Each time the focus group or committee meeting will be at one of the sites of the University of Nottingham and will be around 80 minutes. A co-researcher (a person living with dementia or a carer) will be present the day of the focus group to help the researcher conduct the focus group. The co-researcher has shared experience of dementia so this may facilitate the focus group.

Expenses and payments

You will not be paid to participate in the study. However, travel expenses will be offered for any visits incurred as a result of participation.

What are the possible disadvantages and risks of taking part?

We do not anticipate any relevant risks or disadvantages for the participants in the study. However, if you find that any of the topics/questions make you feel upset or distressed during or after the study, please raise your concern with the study investigator, the study supervisors or any of the clinical members of staff delivering care for you (nurse, doctor).

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may enhance the understanding on the experience of mental health crisis in dementia for both people with dementia and their carers. This will potentially help increase their quality of care over time.

What happens when the research study stops?

You and the person you care for will still receive professional care if needed, however the research team will not be involved in exploring your experience of the care pathway.

Only participants who have capacity to consent can take part in the study. However, should a lack of capacity be ascertained the day of the interview, the

principal investigator will stop the interview and reschedule it to a later date. Data had already been collected on previous interviews will still be analysed and will constitute part of the findings.

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 Trust complaint procedure (Patient Advice and Liaison Service PALS, Tel: 0800-015-3367, email: pals@nottshc.nhs.uk).

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept strictly confidential, stored in a secure and locked office, and on a password protected database at the University of Nottingham. 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.

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.

Where possible information about you which leaves the [site] will have your name and address removed and a unique code will be used so that you cannot be recognised from it, however sometimes we need to ensure that we can recognise you to link the research data with your medical records so in these instances we will need to know your name and date of birth.

Your contact information will be kept by the University of Nottingham for 6 to 12 months after the end of the study so that we are able to contact you about the

findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

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. Should reporting be needed, you will be told by the Principal Investigator.

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 legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the research study?

Results from this study will be part of the doctoral dissertation of the study investigator and will also be disseminated through publications in relevant journals and at conferences at the national and international level. This will ensure that the findings of the study get the attention of the research community, healthcare professionals and policy makers on the experience of mental health crisis for people with dementia and their carers. During the development of the materials for dissemination, your data will always be kept anonymous. For example, what you stated during the interview may be used in the study report, but you will never be able to be identified. You will be able to access the dissemination materials upon request. If you are interested in receiving these materials, please contact the research team on one of the contact details you were provided with this information sheet.

Who is organising and funding the research?

The research is funded by the Economic and Social Research Council (ESRC). Alessandro Bosco, the study investigator, is a PhD student at the University of

Nottingham and he is conducting this research as part of his doctoral studies. Professor Martin Orrell is a consultant old age psychiatrist at Queens Medical Centre and director of the Institute of Mental Health and Head of the division of Psychiatry and Applied Psychology at the University of Nottingham. Justine Schneider is a professor of Mental Health and Social Care at the University of Nottingham. Donna Maria Coleston-Shields is a Consultant in Neuropsychology and Primary Research fellow at the University of Nottingham. They all supervise Alessandro during his PhD, but will not conduct research directly.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by East Midlands - Derby Research Ethics Committee.

Further information and contact details

If you have any queries or concern you may wish to discuss, feel free to ask a clinical member of the team managing your crisis or you can contact the study investigator, who will be able to assist.

The contact details of the study investigator are as follows:

Alessandro Bosco
ESRC PhD candidate Mental Health & Wellbeing
School of Medicine
University of Nottingham
Room 10, A floor, Institute of Mental Health, Jubilee Campus
Triumph Road, Nottingham, NG7 2TU
Telephone:
Email: Alessandro.bosco@nottingham.ac.uk

The contact details of the Chief investigator are as follows:

Professor Martin Orrell
Director - Institute of Mental Health
Head, Division of Psychiatry and Applied Psychology
Faculty of Medicine & Health Sciences
Room D07 Institute of Mental Health, Innovation Park
Triumph Road, Nottingham, NG7 2TU, UK
Telephone: 0115 8231291
Email: M.Orrell@nottingham.ac.uk

Appendix 13: Easy-read information sheet participant with dementia – Dyadic interviews

Participant Information Sheet
(Final version 2.0: 22.06.2018)

IRAS Project ID: 238215

Title of Study: The social understanding of mental health crisis in dementia.

Name of Researcher(s): Alessandro Bosco



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 this study?



The study is trying to explore the experience of mental health crisis of people with dementia aged 50 years old and above and of their carers, living in residential accommodations. We will explore their experience of crisis by asking people with dementia and their family carers about aspects of their daily life that may trigger the crisis and or that may help them with such negative experience, such as what they do together to manage crisis, how the experience of crisis affects their relationship, why and what made them call for help (e.g. IRIS team, Outreach team), how was the quality of care they received and how this impacted on their relationship.

We hope that by hearing about the experience of both people with dementia and their carers through their own voices, we can better identify better ways to deliver future interventions for the management of mental health crisis.

Why have I been invited?



You are being invited to take part because you are 50 years old, living with dementia and you are receiving support for the management of mental health crisis from one of the local dementia team services.

If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

What If I do not take part?



It is up to you to decide whether or not to take part. 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 care and legal rights.

What will happen to me if I take part?



If you agree to take part in the study, we would like to audio-tape the interview so that we do not miss any relevant information. Once the interview is finished, the principal investigator alone will transcribe it and will then destroy the tape.



We will need to meet with you up to 4 times over the course of one month with you and your carer. Each time the interview will be at your own place and will be around 90 minutes.

A co-researcher (a person living with dementia or a carer) will be present the day of the interview to help the researcher conduct the interview. The co-researcher has shared experience of dementia so this may facilitate the interview.

And…

1. Upon obtaining your written consent, we would like to ask you some information which will be helpful to get to know you better. This information includes demographics (age, gender), data on your support and data on your health (type of dementia diagnosis, physical conditions).

2. Each interview will focus on your experience of crisis. For this purpose, we would like to know more about what caused the crisis, and for example how you managed the crisis.

Expenses and payments



You will not be paid to participate in the study.

What are the possible risks of taking part?



We do not anticipate any relevant risks. However, if you find that any of the topics/questions make you feel upset or distressed during or after the study, please let the study investigator know, or talk to the study supervisors or any of the clinical members of staff delivering care for you (nurse, doctor).

What are the possible benefits of taking part?



We cannot promise the study will help you but the information we get from this study may help the understanding on the experience of mental health crisis in dementia for both people with dementia and their carers. This will potentially help increase their quality of care over time.

What happens when the research study stops?



You and your family carer will still receive professional care if needed, however the research team will not be involved in exploring your experience of the care pathway.

Only participants who have capacity to consent can take part in the study. However, if there is a lack of capacity the day of the interview, the principal investigator will stop the interview and reschedule it to a later date.

Data that had already been collected on previous interviews will still be analysed and will be reported in the findings.

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 Trust complaint procedure (Patient Advice and Liaison Service PALS, Tel: 0800-015-3367, email: pals@nottshc.nhs.uk).

If something goes wrong and you are harmed during the research and this is due to someone's negligence then you have the right to start legal action for compensation against the University of Nottingham, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?



If you join the study, the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people 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.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, on a password protected database, and separate from your medical clinical notes and consent forms. The qualitative interviews will be recorded with a password protected audio recorder, this will help keep the information private. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

All records and study documents will be kept for at least 7 years. After this time your data will be disposed of securely. However audio recording files of interviews will be disposed of immediately after being transcribed by the co-investigator.

Although what you say in the interview is confidential, should you tell us anything which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. In this case, you will be told by the Principal Investigator.

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 legal rights 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?



Results from this study will be part of the doctoral dissertation of the study investigator and will also be disseminated through publications in relevant journals and at conferences at the national and international level.

During the development of the materials for dissemination, your data will always be kept anonymous. For example, what you stated during the interview may be used in the study report, but you will never be able to be identified.

You will be able to access the dissemination materials upon request. If you are interested in receiving these materials, please contact the research team on one of the contact details you were provided with this information sheet.

Who is organising and funding the research?

Dementia Research Team
Mental Health Crises

The research is funded by the Economic and Social Research Council (ESRC). Alessandro Bosco, the study investigator, is a PhD student at the University of Nottingham and he is conducting this research as part of his doctoral studies. Professor Martin Orrell is a consultant old age psychiatrist at Queens Medical Centre and director of the Institute of Mental Health and Head of the division of Psychiatry and Applied Psychology at the University of Nottingham. Justine Schneider is a professor of Mental Health and Social Care at the University of Nottingham. Donna Maria Coleston-Shields is a Consultant in Neuropsychology and Primary Research fellow at the University of Nottingham. They all supervise Alessandro during his PhD, but will not conduct research directly.

Who has reviewed the study?



All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by [*please add name of committee submitting* to] Research Ethics Committee.

Further information and contact details

If you have any queries or concern you may wish to discuss, feel free to ask a clinical member of the team managing your crisis or you can contact the study investigator, who will be able to assist.

The contact details of the study investigator are as follows:

Alessandro Bosco
ESRC PhD candidate Mental Health & Wellbeing
School of Medicine
University of Nottingham
Room 10, A floor, Institute of Mental Health, Jubilee Campus
Triumph Road, Nottingham, NG7 2TU
Telephone:
Email: Alessandro.bosco@nottingham.ac.uk

The contact details of the Chief investigator are as follows:

Professor Martin Orrell
Director - Institute of Mental Health
Head, Division of Psychiatry and Applied Psychology
Faculty of Medicine & Health Sciences
Room D07 Institute of Mental Health, Innovation Park
Triumph Road, Nottingham, NG7 2TU, UK
Telephone: 0115 8231291
Email: M.Orrell@nottingham.ac.uk

Appendix 14: Staff information sheet

Participant Information Sheet - Staff
(Final version 4.0: 22.06.2018)

IRAS Project ID: 238215

Title of Study: The social understanding of mental health crisis in dementia.

Name of Researcher(s): Alessandro Bosco

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 study is trying to explore the experience of mental health crisis of people with dementia aged 50 years old and above and of their carers, living in residential accommodations. We will explore their experience of crisis by asking people with dementia and their family carers about aspects of their daily life that may trigger the crisis and or that may help them with such negative experience, such as what they do together to manage crisis, how the experience of crisis affects their relationship, why and what made them call for help (e.g. IRIS team, Outreach team), how was the quality of care they received and how this impacted on their relationship.

We hope that by hearing about the experience of both people with dementia and their carers through their own voices, we can better identify if there are improvements that can be made in the delivery of future interventions for the management of mental health crisis.

Why have I been invited?

You are being invited to take part because you are a health professional working in a multidisciplinary team managing mental health crisis in people with dementia.

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 legal rights.

What will happen to me if I take part?

We aim to investigate your experience of supporting people with dementia and their carers with their crisis through several steps, outlined below. If you agree,

we would like to audio-tape the interview so that we do not miss any relevant information. Once the interview is finished, the principal investigator alone will transcribe it and will then destroy the tape.

We will need to meet with you once. The interview will be at the sites where your team is based in one of the rooms provided by your team and will be around 120 minutes. A co-researcher (a person living with dementia or a carer) will be present the day of the interview to help the researcher conduct the interview.

1. Upon obtaining your written consent, we would like to ask you some information which will be helpful to get to know you better. This information includes demographics (age, gender, country of birth, ethnicity, race, education, job status), data on the support you provide (therapy or work being undertaken, number of professionals working within your team).

2. The interview will focus on what types of crises you manage, on possible barriers and facilitators you experience when delivering the care, on how to promote the active involvement of people with dementia and their carers in the development of health care plan, and what support is available to carers.

Expenses and payments

You will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?

We do not anticipate any relevant risks or disadvantages for the participants in the study. However, if you find that any of the topics/questions make you feel upset or distressed during or after the study, please raise your concern with the study investigator, the study supervisors or any of the clinical members of staff delivering care for you (nurse, doctor).

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may enhance the understanding on the experience of mental health crisis in dementia for both people with dementia and their carers. This will potentially help increase their quality of care you provide over time.

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.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept strictly confidential, stored in a secure and locked office, and on a password protected database at the University of Nottingham. 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.

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.

Where possible information about you which leaves the [site] will have your name and address removed and a unique code will be used so that you cannot be recognised from it, however sometimes we need to ensure that we can recognise you to link the research data with your medical records so in these instances we will need to know your name and date of birth.

Your contact information will be kept by the University of Nottingham for 6 to 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data

protection laws differ to those of the UK and how we will protect your confidentiality.

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. Should reporting be needed, you will be told by the Principal Investigator.

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 legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the research study?

Results from this study will be part of the doctoral dissertation of the study investigator and will also be disseminated through publications in relevant journals and at conferences at the national and international level. This will ensure that the findings of the study get the attention of the research community, healthcare professionals and policy makers on the experience of mental health crisis for people with dementia and their carers. During the development of the materials for dissemination, your data will always be kept anonymous. For example, what you stated during the interview may be used in the study report, but you will never be able to be identified. You will be able to ask access to the dissemination materials upon request. You will be able to access the dissemination materials upon request. If you are interested in receiving these materials, please contact the research team on one of the contact details you were provided with this information sheet.

Who is organising and funding the research?

The research is funded by the Economic and Social Research Council (ESRC). Alessandro Bosco, the study investigator, is a PhD student at the University of Nottingham and he is conducting this research as part of his doctoral studies. Professor Martin Orrell is a consultant old age psychiatrist at Queens Medical Centre and director of the Institute of Mental Health and Head of the division of Psychiatry and Applied Psychology at the University of Nottingham. Justine Schneider is a professor of Mental Health and Social Care at the University of Nottingham. Donna Maria Coleston-Shields is a Consultant in Neuropsychology and Primary Research fellow at the University of Nottingham. They all supervise Alessandro during his PhD, but will not conduct research directly.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by East Midlands - Derby Research Ethics Committee.

Further information and contact details

If you have any queries or concern you may wish to discuss, feel free to ask your team leader or you can contact the study investigator, who will be able to assist.

The contact details of the study investigator are as follows:

Alessandro Bosco
ESRC PhD candidate Mental Health & Wellbeing
School of Medicine
University of Nottingham
Room 10, A floor, Institute of Mental Health, Jubilee Campus
Triumph Road, Nottingham, NG7 2TU
Telephone:
Email: Alessandro.bosco@nottingham.ac.uk

The contact details of the Chief investigator are as follows:

Professor Martin Orrell
Director - Institute of Mental Health
Head, Division of Psychiatry and Applied Psychology
Faculty of Medicine & Health Sciences
Room D07 Institute of Mental Health, Innovation Park
Triumph Road, Nottingham, NG7 2TU, UK
Telephone: 0115 8231291
Email: M.Orrell@nottingham.ac.uk

Appendix 15: Study leaflet



Appendix 16: Research Excellence Framework Review on 30.03.2019

Output Assessment Form

Output title	'The social construction of dementia: systematic review and metacognitive model of enculturation'

Please assign a score between 0-12 for the output originality, rigour and significance using the following scale and an overall quality score between 0-12, based on the three criteria.

Assessment criteria	**Point score (0-12)**
Originality	10
Rigour	10
Significance	10
Overall	10

Now record that point score again below and indicate the corresponding point grade. Use **bold** or red.

Rating	**4***			**3***			**2***			**1***			**U**
Point score	12	11	**10**	9	8	7	6	5	4	3	2	1	0
Point grade	4+	4	**4-**	3+	3	3-	2+	2	2-	1+	1	1-	0

Comments

In the box below, please provide comments on the reasoning that led to the overall quality score.

- You must provide clear justification for the score/grade given. Comments should be clear, comprehensive and helpful to the author. In the event of a **borderline mark** (e.g., 3+, 2+) please also indicate why the output fell short of being a 4* or 3*.
- You are encouraged to structure your comments in terms of originality, significance and rigour, but please refer to any other characteristics you think are important.
- There is no minimum no. of words required since the emphasis is on the quality of the feedback.

It is hard not to give at least a 10 for rigour when there is a well carried out systematic literature review forming the basis of the paper. However, bringing the broad sweep of literature together in the way that this paper has with a focus on social construction and utilising a metacognitive model of enculturation means that it also scores highly on originality. I think that this paper will become a reference point for people working in dementia as it has a broad appeal and significance. A clear 4 *, though perhaps not a high one perhaps due to the lack of an intervention to demonstrate the significance.

Appendix 17: Search strategy (Chapter 3)

1. exp dementia/
2. exp Alzheimer disease/
3. (dementia or alzheimer*).ti,ab.
4. 1 or 2 or 3
5. exp family decision making/ or exp shared decision making/ or exp patient decision
   making/
6. (decision making, or 'shared decision*', or 'family decision*').ti,ab.
7. 5 or 6
8. 4 and 7

Appendix 18: Presentation with Carole (Co-researcher) on 10.01.2018

The social understanding of mental health crisis in dementia

centre for dementia
the institute of mental health
Nottingham

Alessandro Bosco
ESRC PhD student Mental health & Wellbeing, University of Nottingham,
Alessandro.Bosco@Nottingham.ac.uk

Carole Brewster
Co-researcher, Member of PPI at the IMH, University of Nottingham,

Justine Schneider
Professor of Mental Health and Social Care, University of Nottingham
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AQUEDUCT Programme Manager
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Nottingham
E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL
Nottinghamshire Healthcare NHS
NHS Foundation Trust

STUDY AIMS

To explore the experience of mental health crisis for all the agents involved in the delivery of care and it comprises three phases:

Multiple couple interviews (four interviews with each dyad are expected) will be necessary to cover phase 1 and phase 2 of the research inquiry and each interview will last around 50 minutes.

Phase 1 aims to (i) explore the meaning making process of mental health crisis for people with dementia and their carers, (ii) and explore their experience of the caring process during crisis (i.e. coping mechanisms, quality of care).

Phase 2 aims to (iii) explore the extent to which and how co-production is experienced with respect to the health care plan for a mental health crisis:

a) Physical environment
b) Social inclusion and
c) Level of participation in civic and political life

PARTICIPANTS



The inclusion criteria for the person with dementia will be:

- Aged 50 years old or above.
- Having a formal diagnosis of dementia.
- Having been identified by the carer (when applicable) as being cognitively able to participate in the interview.
- Being in the caseload of dementia crisis team at the time of consenting to take part in the study.
- Being aware of their diagnosis of dementia and willing to talk about dementia and a sensitive topic such as mental health crisis.
- Being English speakers.

The inclusion criteria for the carers will be:

- Being a family carer of a person with a formal diagnosis of dementia (either spouse or children)
- No restriction on age or sex.
- Willing to discuss about dementia and their experiences of mental health crisis.
- Being English speakers.

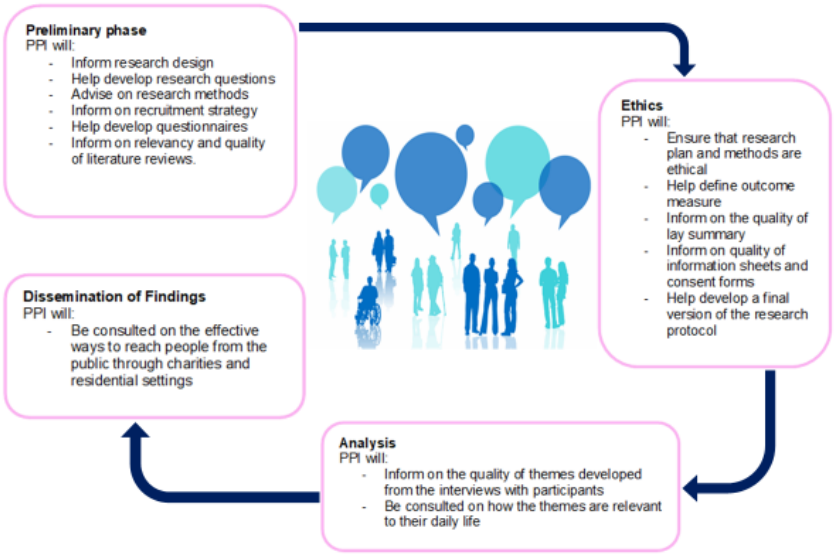
SAMPLE SIZE



Table 1. Expected total number of participants.

	People with dementia (N)	Family carers (N)	Staff members (N)	Total Participants (N)
Dyadic Interviews	4 to 6	4 to 6	-	8 to 12
Focus groups	-	Up to 5	Up to 8	Up to 24
Total participants	-	-	-	

USER AND PUBLIC INVOLVEMENT



Recruitment and Training of co-researcher

Table 2. Interview schedule with co-researchers (for couple interview and focus group).

Pre interview		
- Training on qualitative interviewing	Role play on dyadic interviews	Two hours over one day
	Role play on focus groups	Two hours over one day
- Debriefing on the day of interview	Discussing on the questions to ask to participants and the on the qualitative method to employ.	20 minutes
Post interview	Post interview briefing session to check on the quality of the questions and on how they experienced the interview.	10 minutes
	Contacting the co-researcher to ask whether any discomfort raised upon delivering the interview.	After two days from the interview
	Training on how to check on the quality and accuracy of the analysis of transcripts*.	Two hours over one day

Phase 1 and Phase 2.

Qualitative interviews will be conducted by the researcher and one co-researcher and will be conducted with couples, family carers and people with dementia:

Phase 1. The following topics will be: How people make sense of dementia and mental health crisis, the coping mechanism to manage crisis, and the experience of caring and how crisis impacts on the relationship.

Phase 2. The following topics will be: The experience of social interactions, physical environment (how accessible it is), active role in managing the situation.

Table 3. Interview Schedule Contents for couple interviews.

Introduction and establishing a rapport with the dyad	Introduction with the dyad and exploring: - The status of their relationship (e.g. daughter-mother, spouses) - The nature and stage of the condition - The type of community support they receive for their crisis (e.g. IRIS Team, Outreach team).	50 minutes interview
Phase 1 of research inquiry	In-depth discussion on their experience of crisis: - How they make sense of crisis. - The coping mechanisms (how was their emotional response to the crisis and how this impacted on their coping mechanisms). - Why and what made them call for help (e.g. IRIS team, Outreach team). - What was the process to contact the community teams for their crisis. - How was the quality of care they received and how this impacted on their relationship.	
Phase 2 of research inquiry	In-depth discussion on co-production and external support (non-professional) that helped them with the management of crisis: - Social interaction - Physical environment - Human rights respected in the delivery of intervention for their crisis - If their views and preferences where considered for the development of plans for their crisis.	

Phase 1 and Phase 2.

Qualitative interviews will be conducted by the researcher and one co-researcher and will be conducted with couples, family carers and people with dementia:

Phase 1. The following topics will be: How people make sense of dementia and mental health crisis, the coping mechanism to manage crisis, and the experience of caring and how crisis impacts on the relationship.

Phase 2. The following topics will be: The experience of social interactions, physical environment (how accessible it is), active role in managing the situation.

Table 4. Interview Schedule Contents for focus groups with carers and people with dementia.

Introduction and establishing a rapport with the group	Introduction with the group and exploring: - The status of their relationship with the person with dementia (e.g. daughter-mother, spouses) - The nature and stage of the condition - The type of community support they receive for their crisis (e.g. IRIS Team, Outreach team).	
Phase 3 of research inquiry	In-depth discussion on their experience of crisis: - How to create a friendly (accessible) physical environment (e.g. what accessible features in their homes helped with the prevention of crisis or managements of their crisis, what should be made more accessible in indoor and outdoor spaces) - How to increase social inclusion (e.g. Alzheimer's' café and events not related to dementia (community events). - to promote active involvement in the development of health care plan, and engagement in the civic and political life to address the needs of this population.	80 minutes interview

Table 5. Interview Schedule Contents for focus groups with members of staff.

Introduction and establishing a rapport with the group	Introduction with the group and discussion on their experience of crisis: - How the team manages the crisis (e.g. if they feel they received training for the management of crisis in dementia) - What types of crises they manage - Barriers and facilitators they experience when they delivery care	80 minutes interview
Phase 3 of research inquiry	How to promote co-production in the delivery of care for the management of crisis in dementia. - How to promote the active involvement of people with dementia and their carers in the development of health care plan. What support is available to carers.	