Research Project Portfolio

University of Nottingham
School of Medicine
Division of Psychiatry and Applied Psychology

Doctorate in Clinical Psychology

2018

Holding out for hope:
Discourses of dementia and their implications for care on an acute organic assessment and treatment ward

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Submitted in part fulfilment of the requirements for the
Doctorate in Clinical Psychology

Acknowledgements

I would like to thank Dr Danielle De Boos for encouragement, supervision and support throughout the project. I also owe gratitude to Professor Roshan das Nair and Dr Nima Moghaddam for their input. I would like to express my appreciation to Dr Mike Rennoldson for inspiring the values behind this project, and for supporting me with the design during the planning stages.

I wish to acknowledge all of the participants in the study, the unsung heroes in dementia care, your hard work and commitment cannot be praised enough. And thank you to Dr David Connolley who kindly provided field supervision, and whose unending enthusiasm and dedication I admire so much.

To Grannie and Mummy, the inspiration behind all of this. Thank you for being present in my heart, and for helping me to believe in myself. Daddy, this is for you too, I hope I can make you proud.

I will always be thankful to my wonderful, gracious and loving friends and Husband. Thank you for always being there for me. I don’t know what I would do without you.

And last but not least, to the most important person in my life… Edward, thank you for bearing with me, and for being so patient, loving and gracious. You have helped to keep me grounded and always offered laughter, love and cuddles when they are most needed. You teach me so much, and more than I could ever have imagined. I love you enormously sweetheart.

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Thesis Abstract

Introduction: Dementia is an umbrella term used to describe a cluster of symptoms in which impairment in memory is a primary feature. Further symptoms include cognitive deficits such as difficulties with language, attention, orientation and judgement, as well as social and communication difficulties, personality changes and mood disturbance. Conceptualisations of dementia have evolved over time, from early understandings of dementia as being solely a neurological condition, to more recent conceptualisations where dementia is considered in relation to a person's context. There is currently no known cure for dementia. However, the symptoms associated with the condition are treated in a variety of ways, including acute in-patient wards.

Objective: This study aims to initiate an investigation of spoken dementia discourses in acute dementia care, so that future research may build upon these findings. Discourses of dementia in academic, political and public domains have previously been investigated. However, there has been a lack of investigation about the spoken, 'professional' discourse of people who provide assessment and treatment in acute dementia care. Discourse analysis makes claims about how language constitutes reality. Therefore, the way that healthcare professionals construct dementia may have important implications for the care that they provide.

Design: A discourse analysis approach was taken, drawing on a Foucauldian framework of ideas. This methodology is considered to be sensitive to the changing social and historical aspects of discourse. A social constructionist epistemology underpins the study, which argues that language can shape human experience by constraining or enabling what can be said, done or felt. From this stance, language is considered to create rather than reflect reality.

Method: This article uses naturally occurring talk from an acute organic assessment and treatment ward to explore how healthcare professionals construct dementia. Discourse analysis strives to highlight variance rather than similarity and therefore discourse was sought from professionals in a variety of roles. The talk was gathered from group discussions between fifteen multidisciplinary staff across five different meetings where patient care was discussed.

Results: This study highlights the conflicting narratives that healthcare professionals operate in. Across the talk, four central discourses were identified which related to: dementia as an unstable inner state that can fluctuate in severity, dementia as an illness that will inevitably progress, and dementia as a condition that can take away a person's insight. Implications for care resulting from these discourses was considered, through examining the subject positions that were made available, including the patient's opportunity to be active in shaping their care. A final discourse relevant to care practices was identified, where healthcare professionals resisted a dominant medical discourse. Through the initial adoption of a medicalised narrative, staff were able to un-medicalise the care they provided. Within this discourse the professionals acknowledged the limitations of their role, which opened up a space for hope, and innovative care practices focussing on the individual rather than their symptoms.

Discussion: The findings are considered in light of discourse analysis theory and the writings of Foucault. Implications of the study are also discussed, through examining the subject positions that were made available, as well as suggestions for future research.

Statement of Contribution

I, Hannah Matkin, declare that this research is the product of my own original work conducted since my commencement of the Trent Doctorate in Clinical Psychology in 2014. The project design was developed in consultation with my research supervisors Professor Danielle De Boos, Professor Roshan das Nair and Dr. Nima Moghaddam, from whom I also received regular guidance and supervision. I have been the sole researcher, responsible for obtaining ethical approval, collecting and analysing the data, conducting the literature review and writing this thesis. Appropriate recognition has been given where reference is made to others.

This literature review is aimed for submission to Quality in Ageing and Older Adults[1]

Experiences of residential nursing care: A systematic review

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Abstract

Purpose: To conduct a systematic qualitative review of published articles on the subjective experiences of older adults living within nursing homes. To evaluate the quality of the articles and provide recommendations for future research.
Design: The following databases were searched: Medline, PsychINFO, Embase, and Cumulative Index to Nursing and Allied Health Literature. 9 studies meeting the inclusion criteria were assessed for quality and synthesised by a narrative review.
Findings: Four main themes emerged as being important: lack of choice in admission due to failing health, dullness of daily life, lack of meaningful relationships, and a longing to die.
Value: the review supports existing literature highlighting the need for relationship-centred approaches to care, and emphasises the need to tailor care to individual needs – particularly an awareness of spiritual, cultural and gender differences. Practice and research recommendations are outlined, as well as ways to improve the methodological quality of future research.
Keywords: Lived experiences, residential care, nursing/residential care homes, older people, qualitative review

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[1] This paper has been prepared in accordance with the guidelines for authors intending to submit to this journal, available via http://www.emeraldgrouppublishing.com/products/journals/author_guidelines.htm?id=qaoa

Introduction

The world's population is said to be ageing due to improvements in health care over the past century (World Health Organisation, 2012). Currently over 11.4 million people in the UK are over 65 years old (AGE UK, 2014). The latest projections for the number of people over the age of 65 living in the UK in the next 17 years is set to rise by nearly 50%, to over 16 million (UK Office for National Statistics, 2013). There is some uncertainty about predicting population growth, as it rests on assumptions about future demographic behaviour. It does however, provide a common framework for planning for the future across a range of public policy areas.

Ageing from 65 is characterized by critical changes, such as significant bereavements, health problems, an increased need for care, and the possibility of moving into a nursing home[2] (Reidl, Mantovan & Them, 2013). According to a recent survey, there are 426,000 elderly and disabled people in residential care in the UK, approximately 405,000 of whom are aged over 65 years (Laing & Buisson, 2014). There is reason to believe that the challenges faced by healthcare services today will increase as the population increases, as it is likely that more individuals will need to spend time in residential care.

The move from one's own home to a care home is a major life adjustment, and often the last move a person ever makes. The median period from admission to death is 462 days, although approximately 27% of people live in care homes for three or more years (Forder & Fernández, 2011). Nursing home placement is often referred to in the literature as a stressful life event and a challenge for older people (Haight et al. 1998) but it is important to acknowledge that the move is likely to happen in response to other stressful life events. Bowman *et al.* (2004) found that in 90% of cases ill health and associated disability had been the reason why people had entered a care home. Where a move is necessitated by a decline in physical or mental health, this arguably also represents a reduction in, or even the end of independence for many people. The

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[2] The terms 'care home', 'nursing home' and 'residential care' will be used interchangeably throughout this paper. This reflects the language of the reviewed articles where two papers described the setting as a care home, one referred to a long-term residential care setting, and six were described as nursing homes.

demands of adjusting to ill health as well as a new home may stretch people to the limits of their resources.

These losses are further compounded by the loss of relationships, as well as the home environment in which emotions and memories are likely to be invested (McKee et al, 2005). Chaudhury (2003) notes that the majority care homes are “non-places” that afford few links with one’s personal or cultural past. Living in a care home can therefore serve to undermine people’s sense of self. The change in social status, impact on autonomy, change to social contacts and the reduction of habitual activities can threaten the person’s identity (Porter & Clinton, 1992).

Despite these issues, there is growing evidence that the contribution of doctors, health care professionals and specialist services for older people is limited in care homes (Age UK, 2014). Even with the extent of recent policy relating to care homes in the UK, relatively little is known about the lived experience of residents (DOH 2009). Residents are often marginalised and excluded from research, reflecting the liminal status of older adults inside and outside of the health and social care system (Dening, 2011). Work by The National Development Team for Inclusion (2009) and Bowers et al. (2009) focusses on finding out what determines a ‘good life’ for people in care homes. Frailty, communication difficulties and dependency on others means that residents’ voices are often constrained.

To date, understanding of the experiences of older people living in residential care has been largely derived from observational and questionnaire-based studies. Some studies have attempted to seek the perspectives of care home residents on specific issues such as factors relating to quality of care, quality of life, or living with particular health problems. Although these studies provide valuable information, research focussing on pre-defined constructs, although relevant and useful, provide a specific, delineated perspective shaped by particular research questions.

Although residents live under similar conditions, the experience of nursing home life was unique to individuals (Running, 1994), and we should acknowledge the diversity of older people, rather than ‘pigeon-holing’ them (Association of Charity Officers, 2005). Qualitative studies allow a broader approach to understanding experiences, accessing themes that are important to the participants, rather than focussing on constructs pre-determined by researchers. By relating to participants with openness and inquisitiveness it is possible to gain insight into what matters to the individual (Wells, 2005). Kahn (1990) argued that where residential experiences are interpreted as involving multiple, ongoing losses, adjustment must be considered a continuous process as the individual copes with threats on a daily basis. However, according to Lee *et al.* (2002) many studies into adjusting to care home life handle the phenomenon as if it is ‘static’. In their review, Lee *et al.* (2002) concluded that there is a need for more research on residents’ experience of living in a nursing home beyond the first few weeks of placement.

A recent systematic review examined qualitative studies about residents’ attitudes about quality of life in care homes. One conclusions that was drawn was residents need to accept and adapt to their situation, and take on a ‘positive attitude’ (Bradshaw et al. 2012). However, the review failed to clearly state what kind of life residents were being expected to adjust to. There is currently a significant gap in our knowledge, presenting an ethical dilemma. It is argued that recommendations such as ‘acceptance’ and ‘adaptation’ should not be encouraged, until it is understood what circumstances people are expected to adapt to. Transferability of qualitative studies is often limited by small sample sizes, and researchers’ subjective interpretation of data. A broader use of findings may be possible if individual qualitative studies in this area consistently identify similar themes, hence the need for the current review. This could aid understanding and inform the delivery of high quality care.

Review aims

1. Synthesise existing qualitative research into the lived experiences of older adults living in residential care homes, to inform understanding of this experience.
2. To assess the quality of the research to date.

Method

Search strategy

Studies were identified by searching peer-reviewed journals on four databases, namely Medline, Cumulative index to nursing and allied health literature (CINAHL Plus), EMBASE and PsychINFO. The search was run on 09/10/2015. A range of search terms were used to capture a broad range of articles. Relevant synonyms, thesaurus entries and Medical Subject Headings (MeSH) were adapted according to the database. (See table 1 for the search strategy for Medline). Truncation symbols such as $ and * were used, for example “elder* perception*” captured variations of this including “elder’s perceptions” and “elderly perception”. Search terms were combined using Boolean operators such as “OR” to gather records matching any of the specified search terms and “AND” to contain all of the specified search terms.

Google Scholar was also searched and the first 100 papers elicited were checked. References for returned studies were exported into Mendeley, a referencing management tool and duplicates were removed.

Table 1: Search strategy for Medline

Search Number	**Keyword**	**MeSH (explode and focus selected)**	**Operations Completed**
1	Care Home* OR Carehome*		
2	Nursing Home*	Homes for the Aged Health services for the Aged	
3	Residential Care*	Residential Facilities Nursing Home	
4	Elder Care OR Eldercare		
5	Old Pe* Home		
6	Retirement Home*		

7	Rest Home*		1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7
8	Lived Experience*	Qualitative Research	
9	Subjective Experience*		
10	First person narrative* OR First-person narrative*	Narration	
11	Patient* experience* OR Patient* Perception*		
12	Resident* experience* OR Resident* Perception*		
13	Elder* experience* OR Elder* Perception*	Aged 80 or over Aged	8 OR 9 OR 10 OR 11 OR 12 OR 13
14	Old* Adult*		
15	Over sixty-five OR Over 65 OR Over sixty five OR Over sixtyfive		
			14 OR 15

*Key: *indicates truncation, Caps lock indicates Boolean terms*

Where the title or abstract provided insufficient information, full copies were reviewed to determine relevance. Reference lists of each relevant article were hand searched using the same criteria and Google Scholar was used to source the abstracts where necessary.

Inclusion criteria

For the purpose of this review, *a priori* inclusion criteria were defined.

Articles were included if they:

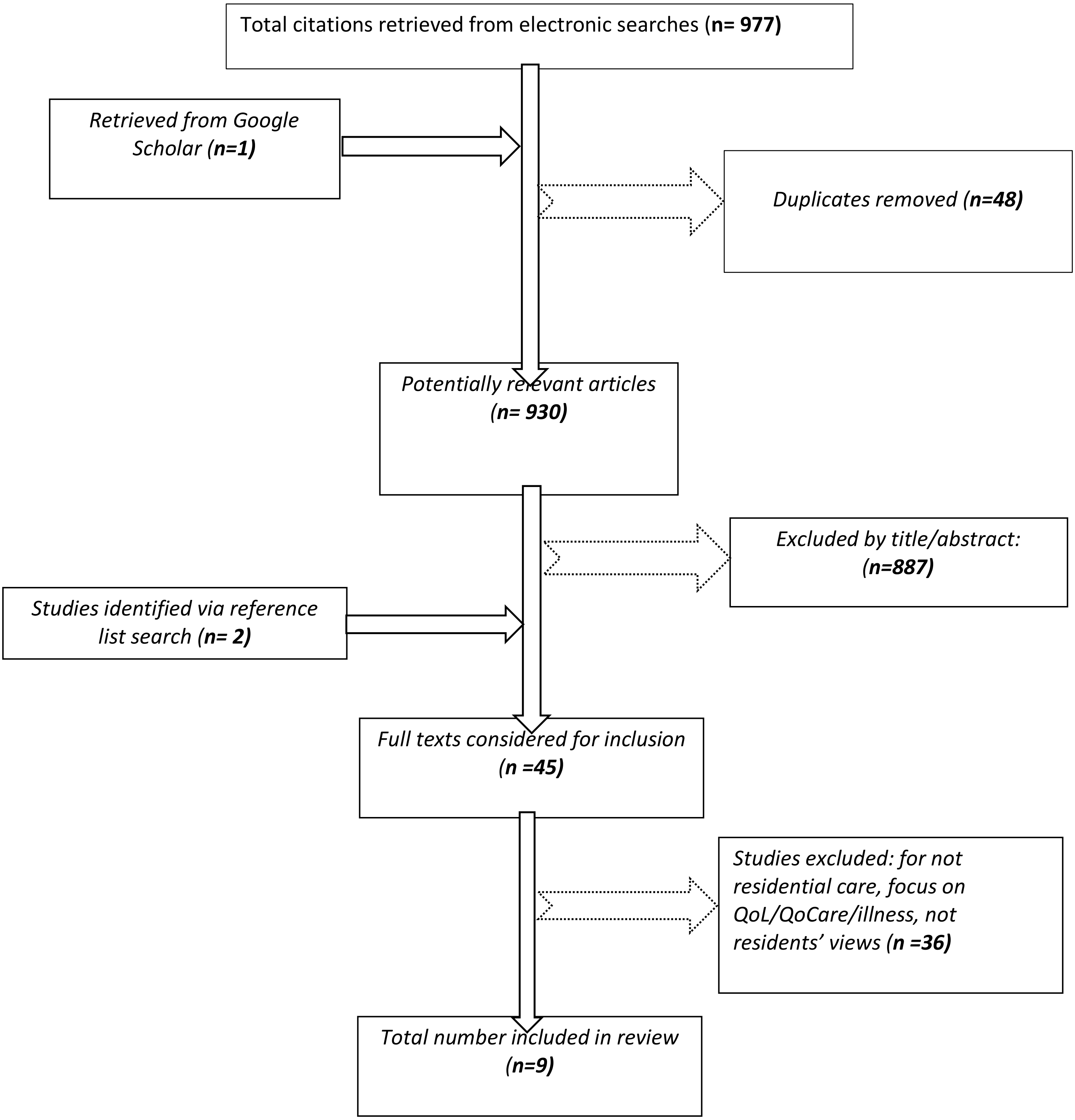
- Were written in English.
- Included the views of residents in a care home. Care home refers to residential and nursing homes.
- Were published in a peer-reviewed academic journal. This was included a pragmatic minimum-quality threshold.

- Used qualitative or mixed-methods methodology, if the qualitative aspect of the research was reported separately.

Articles were excluded if:

- Residents' views could not be extracted from the data. Studies that used focus groups of staff, carers and residents were excluded if data had been combined and it was not possible to determine which extracts were from residents.
- Accommodation was described as community-villages, acute hospital wards, supported living or respite.
- Studies reported narratives without data analysis.
- They focussed on early adjustment to care homes, crisis admissions or temporary, respite stays.
- Focus was on quality of life or quality of care.
- They used quantitative methodology only.
- Residents were described as having acute illnesses, which were the focus of the study.

Quorum diagram illustrating flow of retrieval



Quality assessment

Quality assessment can help researchers appraise the contributions of studies, and guide the interpretation and synthesising of findings (Kitchenham, 2004). However there is no widely accepted ‘gold standard’ tool to aid critical appraisal of data, and no tool can be applied equally well across designs (Katrak et al. 2004). Tracy (2010) discusses how values for quality are ever changing, and situated within local contexts and dialogues. For this review studies were evaluated against a specifically developed checklist, based on a well-established existing set of quality appraisal tools by Critical Appraisal Skills Programme (Public Health Resource Unit, 2013).

This adapted quality appraisal framework provided a rigorous structure to evaluate the articles. See Table 2.

Table 2. Methodological characteristics of qualitative studies

0 = untrustworthy/not described
1 = significant flaws
2 = some flaws
3 = no or few flaws found

Study	Clear aims/ goals	Methods appropriate	Design justified	Recruitment strategy appropriate	Data collection appropriate	Participant-researcher relationship appropriate	Ethical clarity	Researcher bias, and epistemological position	Rigorous analysis	Clear/valuable findings
[1] Fiveash (1998)	3	3	2	2	2	3	1	0	2	2
[2] Dybvik, Gjengedal, Lykkeslet (2014)	3	3	3	3	3	3	3	3	3	3
[3] Hsiu-Hsin Yun-Fang (2007)	2	3	0	2	3	3	3	0	3	3
[4] Riedl, Mantovan, Them (2013)	3	3	3	1	2	2	2	0	3	3

[5] Pilkington (2005)	2	2	2	3	2	2	2	3	3	2
[6] Wadensten (2007)	3	3	3	3	3	3	3	0	3	3
[7] Bland (2005)	0	2	3	1	2	2	0	1	1	2
[8] Djivre Levin Schinke Porter (2012)	0	2	3	3	3	2	2	3	3	1
[9] Clare Rowlands Bruce Surr Downs (2008)	3	3	3	3	2	2	2	0	3	3

Process of analysis

Narrative synthesis was used for this review, to synthesise findings from the diverse studies. Narrative synthesis relies on the use of words to tell the story of the findings of the synthesis. Guidance provided by the ESRC Methods Programme was used as a framework for the process of synthesising (Popay et al., 2006). Table 3 describes the stages of his process.

Table 3: Framework for Narrative Synthesis

Stage	Process
1) Preliminary synthesis	Organising findings to provide an initial description of patterns across the studies. Textural descriptions, tabulation, grouping and clustering, thematic analysis.
2) Exploring relationships	Relationships between study results and the key aspects of the study population, intervention and context. Relationships between the findings across different studies, exploring study heterogeneity, case descriptions, translation. Identification of themes within results, and tabulating the occurrence of themes across the studies.
3) Exploring robustness	Assessing the strength of evidence for drawing conclusions about the results of synthesis.
4) Critical reflection	Critically reflecting on the review.

Results

Study characteristics

Information extracted from the included articles is shown in table 4.

Table 4. General characteristics of the nine articles

Authors	Study aims	Sampling strategy, sample size and composition	Data collection	Data analysis	Key findings
[1] Fiveash (1998)	To explore resident's experience of nursing home life, and offer residents an opportunity to voice their opinions.	Purposeful sampling. 8 participants living in 2 nursing in New South Wales, Australia. Gender: not reported. Age: not reported.	Open-ended interviews: 6 participants were interviewed three times, 2 were interviewed twice. Participant observation: 2 hours, once a week for 6 months.	Ethnographic approach used. Analysis not specified however themes in data were gathered.	• Whilst some residents find the experience acceptable, for others the experience is constraining and dehumanising. • Some residents believed their admission was temporary as they had not been consulted about the admission. • Living in the nursing home is restrictive. • Living with disabled people served as a reminder about their own inevitable decline.

						• Daily life was described as monotonous and tedious.
[2]	Dybvik, Gjengedal, Lykkeslet (2014)	Gain knowledge and understanding of the significant factors associated with a good life in a nursing home.	Sampling strategy not stated. 6 nursing home residents in 3 middle-sized, long-term nursing homes in Norway. Gender: Both sexes Age: average 86.	In depth interviews following a guide. Interviews lasted between 30 and 60 minutes	Giorgi's (1985) phenomenological model of analysis was used	• Residents have positive reactions to receiving help, feel safe and cared for. • Residents expressed a desire to feel useful and for relationships outside the nursing home. • For those who have meaningful activities during the day, time passes quickly. For those who do not, time is slow. • Residents feel that staff do not have time to look after everyone and may not ask for help when needed.

[3] Hsiu-Hsin Yun-Fang (2007)	Exploration of the lived experiences of older nursing home residents in Taiwan	Purposive sampling. 33 older residents at 8 nursing homes in northern Taiwan. Gender: 24 females and 9 males Age: average 75.3	Focus groups with between 2 and 9 participants. Followed by in-depth interviews, at least 2 weeks later. Each participant interviewed 1 – 4 times.	Thematic analysis (van Manen, 1990)	• Participants' descriptions of life in the nursing home was as a temporary experience to nurture health. • Everyday life was characterised by a structured lifestyle with restricted activities. • Many residents felt safer living in the nursing home, they worried whether their finances would meet the costs. • Social interactions with family, staff and other residents gave residents' a sense of belonging and a feeling of being loved.

[4] Riedl, Mantovan, Them (2013)	Explore what nursing home residents need to maintain their identity and self-determination	Sampling strategy not stated. 20 residents from 3 nursing homes in Salzburg, Austria. Gender: 15 women, 5 men Age: 71 - 93, average = 82.35 years.	Semi-structured, problem-orientated, interviews according to Witzel (2000). Interview duration between 16 and 78 minutes. Average = 35.5 minutes.	Content analysis (Mayring, 2007).	• Residents resist having decisions taken away from them, and fight for independence. • Residents draw strength from their faith • Participants developed a new identity close to their previous identity by maintaining autonomy and mobility, and focusing on the future.
[5] Pilkington (2005)	Exploring the lived experience of loss within a long-term care facility, and provide insights for enhancing quality of nursing	Purposive sampling. 10 people living in a long-term residential care facility, in Canada.	Dialogical engagement rather than an interview. Free-flowing attentiveness on the phenomenon.	Parse's (2001) methodology. Extraction-synthesis	• Participants were painfully aware of being alone, and continued to prize any connection with people (living or deceased0.

	practice with older adults in residential care.	Gender: 9 men and 1 woman. Age: 70 – 92.	Dialogues lasted between 20-60 minutes	used to construct a story for each participant.	• Residents could feel lonely while in the company of others. • Participants were concerned with the loss of things that they valued: abilities, mobility and independence. • Almost all participants had an awareness of impending death, and a realization that they would remain institutionalized until they died.
[6] Wadensten (2007)	To investigate nursing home residents' opinion of their life in a nursing home and of their earlier life.	The home was randomly selected from a list of nursing homes in Sweden.	Informal interview technique (Kvale, 1996) using an interview guide. Interviews between 30 and 70 minutes.	Content analysis (Cavanagh, 1997).	• Most residents expressed that it was good for them to live in the nursing home so that they could be cared for.

		The sample was a convenience sample. 16 residents participated. Gender: 10 female, 6 male. Age: 86 - 96 years.			• All residents had some disabilities or diseases. Most felt that this was to be expected in old age, and some expressed that dying would be preferable to living in pain. • Residents who described feeling healthy also expressed a longing to die, feeling that they had already lived their life.
[7] Bland (2005)	Describing the challenge of becoming a nursing home resident and then trying to establish a new sense of 'home'.	Sampling strategy not described. 27 residents from 3 nursing homes in New Zealand.	Participant observation, document examination and formal semi-structured interviews with residents and staff.	Thematic content analysis as outlined by Burnard (1991).	• Every participant described major emotional upheaval associated with leaving the family home and entering the nursing home.

		Gender: not reported. Age: not reported.			• Although home is normally a private space, nursing homes are constantly on display, leaving residents with a feeling of ‘homelessness’.
[8] Djivre Levin Schinke Porter (2012)	To explore personal meanings given to the experience of living with death in a nursing home.	Convenience sample of 5 older adults from a single care home in Canada. Gender: 4 male, 1 female. Age: 65 - 92. Mean average = 77.6	Semi-structured interviews.	Hermeneutic phenomenology, inspired by van Manen (1990). Data was validated using a follow-up approach similar to	• Family-like relations emerge between residents as a result of feeling solidarity from living together. • Residents shared the experience of feeling overwhelming emotional pain, sadness, trauma and sense of emptiness following the death of significant peers in the nursing home. • Residents had a desire to connect with the community

				selective coding use in Grounded Theory (Glaser & Strauss, 1967).	by asking questions and discussing peer deaths.
[9] Clare Rowlands Bruce Surr Downs (2008)	To explore the subjective experience of life with dementia in residential care from the perspective of the person with dementia. And to understand the psychological impact of being in this situation.	Participants drawn from a wider study among people in care homes. 81 participants in 10 different care homes in England and Wales. Gender: 69 women, 12 men.	Unstructured conversations led by participants. Field notes also made.	Interpretive Phenomenological Analysis.	• Resident’s; experience was characterized by suffering, uncertainty, loss, fear and loneliness. Participants seemed to lack any sense of having been consulted informed about their admission, adding to feelings of helplessness. • Despite suffering, most participants found

	Age: 59 - 96, mean average = 83.4.		constructive ways to cope, by trying to find ways to be useful, and taking pride in themselves and their past life.

Note. [X] = article reference numbe

Description of studies

Findings were incorporated from 9 papers. The included studies had a total of 206 participants. Two studies did not specify an age range or average age of participant (Fiveash, 1998; Bland 2005), and two only reported an average age (Dybvik, Gjengedal & Lykkeslet, 2014; Hsiu-Hsin & Yun-Fang, 2007). Of the five studies that did, participants' ages ranged from 59 to 96 years. Three papers did not clearly report gender characteristics (Fiveash, 1998; Bland 2005; Dybvik, Gjengedal & Lykkeslet, 2014) accounting for 45 participants out of the total 206. Of the five articles that did, 120 were female and 45 were male. The research was carried out in care homes in eight countries. All studies detailed where the care home was located, however none reported participants' ethnicity. One study which reported that all participants were born in Northern Europe (Wadensten 2007). Lack of details across the studies leaves the reader to make assumptions about ethnicity of participants, which may be misleading.

Study quality

Overall the studies varied in quality with relation to the appraisal markers. Despite this, no study was excluded from the review as it was considered that all contributed to the research aims. Of the nine studies, only one failed to mention a well-established analysis method (Fiveash 1998) although information on those conducting the analysis was provided. Only four of the nine studies mentioned reflexivity; a reflexive account of qualitative enquiry is thought to increase rigor (Jootun *et al.* 2009). Five articles did not outline the researcher's epistemology or effect of this on the analysis. Measures taken to minimise bias included bracketing (Djivre et al. 2012; Dybvik et al 2013), audit trails (Riedl et al. 2013; Hsiu-Hsin & Yun-Fang, 2007)and checking of codes (Wadensten, 2007; Clare et al, 2008). Three articles did not outline this (Bland, 2005; Fiveash, 1998; Pilkington, 2005), presenting a difficulty in ascertaining a framework from which the findings were analysed.

Themes

“They take good care of me, but what choice do I have” [6]

This theme relates to residents’ acknowledgement that they had no choice other than to live in a care home. Most residents considered the main reason for their relocation as poor health, or having no one else to care for them [1, 2, 3, 6, 8, 9]. It was acknowledged that physical health care was a priority for staff [1,2,3,4,8], and there were few complaints about healthcare needs being met. Occasionally the nursing home was described as preferable to living elsewhere; *“I can have better care than at home”* [3].

A subtheme was residents blaming themselves for their poor/failing health, considering this an unpreventable consequence of ageing (*“I have put it on myself that I am here” [7], “I have no health – I have survived too long” [6]).* Residents often expressed the belief that the only way they could access health care is to move into the care home (“*who would come here if they were in good health?” [3]).*This was supported by descriptions of how staff and relatives might take for granted that they would adapt to the nursing home and all aspects of it, reinforcing the idea that there were no other options available. *(“My son … He says, ‘Mom, all you have to do here is to nurture your health. You don’t have to think too much’” [3]).* As a result many residents expressed feeling trapped – both in their deteriorating body, and the confines of the nursing home. Although residents expressed gratitude for the care that they received, it seemed that there was a price to pay for having their healthcare needs met. Residents were painfully aware of sacrificing things that they valued as important for good health, such as nutrition, activity/exercise, social contacts/relationships and stimulation [1,2,3,4,5,6,7,8,9]. This conflict resulted in feeling as though their lives had a lower value inside the home. However it was often felt that there was little point in complaining *(“I know it has to be like this, but it is an awful way to live” [1])*, and residents became passive and resigned to their situation.

“I am definitely bored to death” [1]

This theme reflects residents' complaints about the dullness of life in the care home, and lack of activity *("Time is long when it is spent sitting in a chair" [2])*. Many reported feeling confined and longing for independence [1, 3, 6, 7, 9]. The psychological experience was one of boredom, annoyance, and frustration. When the care home was described as restricted or regimented, life became routine and boring, and a sense of institutionalised living occurred. When residents experienced a loss of role/purpose in daily life, their existence was experienced as pointless (*"Life is meaningless now" [6])*. Many felt that life had a lower value if unable to take care of themselves (*"All I can do is eat; [I am a] useless person" [3]; "I … really lost it" [9])*. Despite this, through their accounts, some residents emerged as agents actively seeking to cope with their circumstances. Some made efforts to be useful in order to feel achieve a level of satisfaction and contentment. Meaningful daily life, characterised by the care home providing opportunities to go out [1,4,7] and appropriate activities [2,3,4,5] allowed autonomy. The desire of residents to achieve a meaningful daily life emphasises the importance of the care setting as a home, recognised in conjunction as a place that provides care.

"I feel I'm not attached to me family" [9]

This theme relates to the loneliness that many residents felt, feeling disconnected from relationships both inside and outside of the home. The result was a feeling of isolation and alienation *("I don't know why people don't talk to me much. I feel to be an outsider [2]*") amounting to depression, and fear for many. Relationships with peers and staff were also considered fruitless for some [], due to the high turnover of staff within the home, and the likelihood of peers passing away due to illness. Lack of connection was also attributed to social incompatibilities that occurred within the care home (*"it's not very interesting to play cards with people like that" [8]).* For some, living with other people who all had their own difficulties could be frustrating, distressing and hard to tolerate *("gets on your wick sometimes; I feel … I could blow up" [9]).* Being around ill/disabled residents was seen as a reflection of one's own reduced circumstances. This led to some residents withdrawing in order to cope [], resulting in further isolation. Conversely, some residents described bonding with room-mates, members of common-interest activities and residents who knew each other prior to admission.

Family-like relations developed as a result of feeling solidarity from living closely (*"The elderly knit together. We have the same thing in common because we are here" [8]).*

"I hope to pass away as soon as possible" [3]

This final theme represents residents' awareness of their own impending death, and a realization that they would remain institutionalized until they died *("There is nothing else I can do here but wait to die" [1]).* Residents spoke about how they felt that life was no longer worth living because it was so bad, and that death was preferable. Some residents, who expressed feeling healthy even if they had sickness, also expressed a longing to die, saying they had lived their life and felt finished with it.

There was a sense that residents became increasingly unfit for their environment as they aged, and some expressed a fear of what would happen if they continued to live (*"I'm scared I'll fall and end up like her"; "I hope I don't go blind, like him. It would be awful. Oh, I couldn't stand it" [1]).* A subtheme within this theme was residents feelings of guilt and shame at their reliance on others (*"It is a disgrace to be so dependent" [6])*. Therefore death was considered a relief, and solution to this predicament. Comfort was sought through religious practices such as prayer, and faith in life after death

Discussion

The review highlighted a lack of good quality qualitative research on the lived experiences of older adults in care homes. When synthesising the studies, the higher quality research was drawn on more heavily. However it was decided not to exclude the lower quality research, and this was retained for purposes of reliability.

The search process uncovered how the majority of studies which attempt to understand care home life rely on observational and questionnaire-based studies. This arguably minimises the voices of participants, as the focus is the meaning that the researchers bring to the study, obscuring meaning that participants hold (Creswell 2012). A criticism of the available literature is that studies often rely on third party/caregiver views. However studies by (Milne 2011) and (Droes et al. 2006) highlighted how residents prioritise different domains to those identified by relatives and staff when asked about their quality of life. Reliance on others to speak for them could disempower older people, and reinforce the idea that they are not reliable commentators. This adds to the argument for more research involving care home residents as this could aid the development of research tools, for example, those that measure quality of life. Therefore addressing the tension between the objective evaluation of quality of life, and broader conceptual issues of how quality of life is evaluated and understood by older people.

A narrative synthesis framework helped to organise and summarise findings, by identifying similarities and differences within articles. Four main themes were highlighted; lack of choice in admission due to failing health, dullness of daily life, lack of meaningful relationships, and a longing to die. The first theme can be linked to the idea of ‘passive acceptance’ as described by Lee *et al.* (2002). This is understood as a way to deal with the difficulties of moving into care home by conforming (Iwasiw et al. 1996). It is possible that the process is influenced by individuals end-of-life expectations and an attempt to fulfil these roles.

The theme of boredom was also identified by and Train *et al.* (2005) and supported by observational studies (Ballard *et al.*, 2001). Barriers to preventing engagement in activity have been identified as; inadequate tailoring of activity to individual needs, poorly communicating what is on offer (Kolanowski *et al.* 2002) and overlooking gender preferences (Buron, 2014). This links to the third theme of disconnection with others. Studies have shown that family contacts can make a significant contribution in re-engaging residents with the outside world (Rowles & High, 2003). Contrary to popular belief, families are often desperate to maintain relationships with relatives in care homes (Kellett, 2000). Finally, recognising spiritual and cultural needs of residents is important. Helping to maintain a connection with religion has the potential to improve well-being and coping with the prospect of facing death. This has been recognised in the UK in the National Service Framework for Older People (DOH 2001).

Implications

This review indicates that a focus for improvement in care homes would be the extent to which residents are engaged in appropriate activity and occupation, to support the expression of agency and maximise autonomy. Ideally, residents in care homes should be encouraged to experience a sense of control, choice and independence in day to day life. Sensitivity and awareness of cultural and gender differences is necessary to encourage meaningful engagement. Families should be encouraged to nurture connections with their relations in care homes. Fostering positive relationships with staff and peers is also vital (Edwards et al. 2003). Matching compatibility of roommates could promote meaningful engagement between residents.

Service user empowerment and involvement is central to NHS values (NHS choices, 2014). Some articles reported that residents complained that they were often asked about practical aspects of life in the home, indicating a need to narrate about other aspects of their lives that are important. Therefore involvement in research could benefit residents by providing further opportunity for expression. Future research could ask questions about why, in a social environment, residents are experiencing boredom and loneliness, and consider ways to overcome this. Gathering the views of older people who may be cognitively frail is difficult and requires time and skilled communication (Tester et al, 2004). Future research could address this challenge, considering creative and effective ways to aid communication.

Ronch (2004) argues there is a need to change the way that people think about older adults, and that the current care model predisposes staff to take on the role of ‘custodian’. Further research into the cultural perceptions of older people, particularly those in residential care is necessary in order to open up further debate about this issue, and highlight attitudes which are unhelpful in residential care. It is recommended that future researchers outline their epistemological stance in order for readers to understand how findings have been interpreted. To increase transparency and credibility of findings, a clear outline of the data analysis would be useful, along with clear presentation of data linking to findings.

Limitations

Most studies (n=5) reported that staff identified participants, and some studies (n=3) did not report the sampling strategy. Therefore, gender and selection biases may have occurred. One study (Dybvik et al. 2014) reported how participants had been specifically chosen because it was assumed that they had a ‘positive view’ of life in the home. Therefore excluding potentially conflicting accounts. Five studies excluded participants with a diagnosis of dementia, yet almost three-quarters of people in care homes have some form of dementia (DOH, 2009). It has been recognised that the subjective experience of people with moderate/severe dementia is less understood (Downs 1997), but it is increasingly accepted that people in the middle/late stages of dementia retain capacity for emotional expression (Magai *et al.* 1996) and can reliably report aspects of their own experience (Kolanowski et al. 2002).

The extent to which participants in the studies disclosed their thoughts is likely to be influenced by the relationship with the researchers. Five studies did not report the relationship between the research and participants, or the researcher’s epistemological position. This lack of transparency makes it difficult for readers to draw conclusions about the extent to which the researcher may have influenced the findings. In addition, participants’ experiences will have been shaped by the challenges of living with deteriorating health, as well as the context of residential care. It is not possible to distinguish the specific impact of these two factors as they will be intertwined.

The review method may have introduced bias. Despite care being taken developing the search strategy and MeSH headings, it is possible that relevant studies were excluded. Also, not searching grey literature and limiting studies to English may have excluded relevant literature. Extraction of data could be considered subjective, as only one author conducted this process. However, findings were synthesised using an established method to consider the original theoretical perspective of each study and author’s interpretations. A strength of this review is the use of a checklist to evaluate and compare study quality. Use of triangulation with multiple reviewers could have improved it further.

Appenix 1.

Table 5. Key findings from articles - negative

Study	Helplessness	Guilt, feeling like a burden	Sense of ‘Homelessness’	Restrictiveness of life	Hopelessness	Loneliness/isolation	Fear	Lack of activity
Fiveash (1997)	+	+	+	+	+	–	+	+
Dybvik Gjengedal Lykkeslet (2013)	+	–	+	–	–	+	–	+
Hsiu-Hsin Yun-Fang (2007)	+	+	+	+	+	+	+	+
Reidl Mantovan Them (2013)	+	–	+	–	–	–	+	–
Pilkington (2005)	–	+	+	–	+	+	+	+
Wadensten (2007)	+	–	+	+	+	+	–	+
Bland (2005)	+	+	+	+	+	+	+	+
Djivre Levin Schinke Porter (2012)	+	+	–	–	+	+	+	–
Clare Rowlands Bruce Surr Downs (2008)	+	–	+	+	+	+	+	+

Key: + = theme present; - = theme not present

Table 5 (continued) Key findings from articles – positive

Study	Positive future	Physical wellbeing/being cared for	Safety	Connectedness with others	Faith as comfort	Looking forward to dying	Automony	Belief that admission was temporary
Fiveash (1997)	+	_	_	_	+	+	+	+
Dybvik Gjengedal Lykkeslet (2013)	+	+	+	+	_	_	_	_
Hsiu-Hsin Yun-Fang (2007)	+	+	+	+	_	_	_	+
Reidl Mantovan Them (2013)	_	+	_	+	+	+	+	_
Pilkington (2005)	+	_	_	+	+	+	_	+
Wadensten (2007)	+	_	_	+	+	+	_	_
Bland (2005)	_	_	_	_	_	+	_	+
Djivre Levin Schinke Porter (2012)	+	+	_	_	+	+	+	+
Clare Rowlands Bruce Surr Downs (2008)	_	_	_	+	_	_	_	_

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Note. References marked with an asterisk indicate articles included in this review.

JOURNAL PAPER

This paper has been formatted for submission to the journal Dementia. Author guidelines can be found at https://uk.sagepub.com/en-gb/eur/journal/dementia#submission-guidelines and in Appendix E

Holding out for hope
Dementia discourses and their implications for care

Abstract

The needs of individuals who receive a diagnosis of dementia can be complex, and can pose a challenge to those who care for them. Discourses around the construct of dementia have evolved over time, which has influenced care practices and policies. The way that healthcare professionals construct dementia may have important implications for the care that is provided. This article uses naturally occurring talk from an acute organic assessment and treatment ward to explore how staff construct dementia. A Foucauldian form of discourse analysis was used to analyse talk from fifteen multidisciplinary healthcare professionals. In this article we present a reading of this talk, where dementia is constructed as: an unstable inner state that can fluctuate in severity, an illness that will inevitably progress, and a condition that can take away a person's insight. Implications for care resulting from these discourses is considered through examining the subject positions that were made available. A final discourse relevant to care practices was identified, where healthcare professionals resisted a dominant medical discourse, which opened up space for hope and innovative care practices.

Keywords: dementia, healthcare professionals, constructions, discourse analysis, Foucault, power

Background

The world's population is ageing and as the number of older people increases, so does the prevalence of illnesses that accompany old age, such as dementia (World Health Organisation, 2016). There are currently around 815,000 people living with dementia in the UK, with numbers predicted to rise to over two million by 2051 (Alzheimer's Society, 2014). Dementia is a major cause of disability that can cause significant social and emotional stress for people who receive a diagnosis (World Health Organisation, 2016). The symptoms of dementia often present a challenge to caregivers and families, as well as healthcare systems, and those who work in them (Alzheimer’s Society, 2014). The growing population of people with dementia requires far-reaching economic and social adjustments (World Health Organisation, 2015). Research into dementia care and the influences of healthcare professionals is of paramount importance to ensure that a competent workforce is recruited and maintained to meet this challenge (Edvardsson, Fetherstonhaugh, McAuliffe, Nay, & Chenco, 2011).

Discourses of dementia

The underlying causes of dementia are not well understood and the term cannot be easily defined because it has been subject to changing psychiatric, biomedical and cultural discourses (Berrios, 1987). Historically, dementia has been conceptualised as a disease defined by neurological deterioration (Davis, 2004). Over time theories of dementia have evolved and the importance of factors beyond neuropathology in the development and progression of the condition have been emphasised (Downs, Small, & Froggatt, 2006; Snowden et al., 2003). In the 1970s a sociocultural construction of dementia was suggested as an alternative to the biomedical discourse, which emphasised external, contextual factors and individual differences in the development of the condition (Ballenger, 2006; Herskovits, 1995; Downs, Clare, & Anderson, 2008). Since then, these non-medicalised constructions have gone on to influence the development of various influential models of dementia. e.g. Kitwood’s (Kitwood, 1993) dialectical model, the biopsychosocial model (Spector & Orrell, 2010) and the assimilation of problematic voices model (Cheston, 2013). These models are underpinned by the discourse of dementia as a condition that should be understood by considering each person within their context. As discourses of dementia continue to shift over time, approaches to care have also developed.

(See section 1.3 in extended paper for further discussion of the history of dementia, 1.4 for alternative models and 1.6 for discussion on contemporary discourses)

The early medicalization of dementia has been connected to the evolution of geriatric psychiatry, and the work of clinical neurologists (D'Alton & George, 2011; George, Whitehouse, & Ballenger, 2011). The Diagnostic and Statistical Manual of Mental Disorders 5th Edition (American Psychiatric Association, 2013) recently introduced the term Neurocognitive Disorder to label what had previously been classified as the 'Dementias'. This renaming stemmed from concerns that dementia had become a label that was pejorative and stigmatizing (Ganguli et al., 2011; George, Whitehouse & Ballenger, 2011), although some critics have argued that changes in terminology cause more confusion about the condition (Siberski, 2012). The drive to categorise dementia as a disease has facilitated funding and research into the condition (Ballenger, 2006). However, constructing dementia in this way implies that there may be a cure (Gubrium, 1986), and has been linked to the drive for early diagnosis (Milne, 2010). However, a downside of prioritising diagnosis and the search for a cure is that research and funding into care is often neglected (Dening & Milne, 2011; Kitwood 1993), and follow-up care post-diagnosis is experienced as poor (British Psychological Society, 2014; Samsi et al., 2014).

Dementia care

After a diagnosis of dementia people often require support and care, which may be accessed through the National Health Service (NHS). The need for different services tends to increase incrementally, the longer a person lives with dementia, but can also be required suddenly when there is an acute change in an individual's functioning (NHS England, 2017; National Institute for Health and Care Excellence, 2018b). However, there is widespread agreement that standards of care are poor and need to be improved (Ballard et al., 2001) (Alzheimer's Society, 2016). Lack of faith in the care that is available, and a fear of abandonment have been linked to increasing public anxiety about the condition (Kitwood & Bredin, 1992; Dening & Milne 2011). This further fuels narratives about the 'tragedy' of a dementia (McParland, Kelly, & Innes, 2017) where people with a diagnosis are positioned as 'victims' who are existing with a 'living death' (Behuniak, 2011; Aquilina & Hughes, 2005).

Traditionally, mental health care for older people in the NHS has been separated into two groups, under the labels ‘organic’ and ‘functional’ (Department of Health, 2001). People with a confirmed or potential diagnosis of dementia are categorised as having ‘organic’ disorders, whereas the so-called ‘functional’ disorders include mood disturbances, such as depression. Currently, there is variation across the country in the provision of in-patient wards relating to primary pathology, with some services providing separate in-patient wards for organic or functional disorders, and others making no such distinction (Mueller, 2017). The provision of in-patient services broadly falls into acute assessment wards or longer-term care (Bullock, Iliffe, & Passmore, 2007).

One task for healthcare professionals working on acute organic assessment and treatment wards is the observation of a patient’s difficulties, and judgement of whether their symptoms may be attributed to changes in brain structure, or environmental, relational or psychological aetiology (National Institute for Health and Care Excellence, 2018a; Orrell et al., 1992). Healthcare professionals therefore occupy an expert position, and the patient’s current and future care may be determined by their assessment. Typical care practices include the use of psychiatric medication or behavioural interventions, and may also include psychological treatment, input from social services, or referral to residential placements (Meuller, 2017). Therefore, the assessment and consequent interventions that are provided can also have implications for the patient’s long-term care.

Healthcare professionals operate within a system where there are competing discourses about dementia, and they are required to balance physical, social and psychological and spiritual needs as part of the care that they offer. Staff also play a role in the provision of services and in the social constructive processes through which understandings and representations of dementia evolve. The implication is that healthcare professionals, to varying extents, have the power to maintain or challenge discourses, and to position themselves and others in ways that could empower or marginalise.

Theoretical Framework: Foucauldian Discourse Analysis

Foucault argued that language makes possible certain ways of ordering, understanding and experiencing the world. His work has been influential in highlighting the importance of discourse in coding and regulating psychological phenomena (Cheek, 2004). According to Foucault, discourses systemically form objects and subjects of which they speak, and provide certain discursive positions that can be occupied (Foucault, 2006). These object and subject positions make available particular ways of seeing the world, and have implications for how we view and experience others and ourselves, and how others will view or experience us. Since discourses make available ways of seeing and being, they are strongly implicated in the exercise of power, as certain positions provide rights and responsibilities to those who occupy them (Harre & Van Langenhove, 1999). Foucault was concerned with how power worked as a positive and enabling force through the creation of certain identities (Benford & Gough, 2006). Dominant discourses are said to privilege the versions of reality that legitimate existing power structures. However, alternative constructions or counter-discourses remain possible, and can change over time (Parker, 2002). For Foucault, in order for power relations to come into existence there must be a degree of freedom on both sides, because if there was no opportunity for resistance, then there could be no power relations.

We selected Foucauldian Discourse Analysis to explore how dementia is constructed by staff in an NHS acute organic assessment and treatment ward. Foucauldian Discourse Analysis is not intended to reveal the ‘true’ nature of psychological phenomena, and as such, this report does not seek to determine the validity of the construct of dementia. Instead the interest is in how people are positioned within discourses of dementia, and with what consequences (Willig, 2008).

(See sections 2.3 and 2.4 in extended paper)

These concepts informed the research questions. The primary aim of this research was to explore: How is dementia constructed by staff in an acute organic assessment and treatment setting? What are the implications of these constructions for those who are receiving care?

Secondary aims of the research included: What gives certain discourses more momentum, and why are other discourses lesser developed? How are categories constituted in these discourses? What truth effects are created in these discourses? What discursive strategies are employed to demonstrate that decisions regarding care are justified? Are there any benefits or limitations of the dominant discourses?

Method

Ethical approval was granted from the local NHS Trust and the Faculty of Medicine & Health Sciences Research Ethics Committee at the host University.

Participants

A purposive strategy was used to sample discourse. In this study discourses are understood in a Foucauldian sense, as bodies of knowledge, or groups of signs and practices (Foucault, 1967). The data consists of five audio recordings of multidisciplinary staff meetings which were held on an NHS acute organic assessment and treatment ward. The discourse was sampled from what was referred to by the team as the ‘multidisciplinary meeting’ or ‘MDT meeting’ and is part of standard practice in this setting. These meetings were scheduled on a weekly basis and were attended by a variety of professionals who had some form of input into the care of patients on the ward. The aims of the meeting include discussion of new admissions to the ward, clarification of care plans, review of medication and/or diagnoses, sharing of results from physical or psychometric testing, discussion of risks or safeguarding concerns, and consideration of plans for patient discharge. The ward operates within a broader context where issues of mental capacity, consent, deprivation of liberty safeguards (DoLS), and NHS targets regarding efficiency are also relevant.

The five meetings recorded for this study took place over a period of eight weeks. As stipulated by ethical agreements, researchers were unable to access the data without patient identifying information first being redacted. Each audio recording was edited by an undergraduate psychology student who was completing a placement on the ward as part of their studies. Once all patient identifying information had been removed from each recording, the audio file was reviewed by the researcher on the study site to check that patient anonymity had been maintained, and after this was confirmed the file was securely transferred away from the study site.

Information sheets were sent to potential participants a minimum of 24 hours before consenting to participate. Fifteen professionals consented to taking part in the study. Variability is considered a strength in discursive work, and it was hoped that recruiting participants who worked in different roles would allow a variety of discourses and subject positions to be identified, which was considered fitting with the research aims (Parker, 2002). The sample included professionals in a variety of roles, inclusive of Consultant Psychiatrist, Junior Doctor, Pharmacist, Occupational Therapist, Staff Nurse, Clinical Lead (Nursing), Student Nurse, Consultant Clinical Psychologist, Trainee Clinical Psychologist, and undergraduate psychology student. Some participants were recorded in more than one meeting.

Due to the small sample size, demographic information that the participants provided is reported across the sample, rather than individually. This is to reduce the risk of participants being identified. The sample consisted of 7 males and 8 females. The age of the participants ranged from 20 years old to 51 years, with a mean age of 36 years. The range of experience working in care settings was from one year to 30 years, with a mean average of 14 years. Participants worked a mean average of 34 hours per week, with a range of 8 hours to 40 hours a week. Lastly, participants spent a mean average of 14 hours a week in direct contact with patients on the ward, with a range of 2 to 20 hours each week.

In the extracts below, we use pseudonyms. We did not provide details of the speaker's profession to prevent identification of the participant, which from a small sample, is a risk. The sample size is consistent with other published discursive studies and consistent with focus group studies (e.g. Georgaca & Avidivi, 2011; O'Key, 2014), and allowed data sufficiency to be reached.

Naturally occurring talk

In discursive work, naturally occurring talk is frequently preferred over interviews (Potter & Hepburn, 2005). The meetings were held as part of regular clinical practice and were recorded on a digital voice recorder without the researchers being present. This format was used to minimise the researcher influence, and to help capture data that was as naturalistic as possible. However, we acknowledge that participants' awareness of being audio-recorded may have reduced how naturalistic the talk was.

Transcription & Analysis

The analysis sought to identify the constructions of dementia that were drawn upon by staff, and how decisions about patients' care were made. From a Foucaudian perspective this meant focussing on discursive resources in the text, and considering their social, cultural and historical construction, as well as implications for subjectivity and practice (Arribas-Ayllon & Walkerdine, 2008). The range of subject positions and objects that were created through the talk was also considered (Harre & Van Langenhove, 1999). The conversations were transcribed in full, following an abbreviated form of the Jeffersonian transcription system (Rapley, 2007). Analysis consisted of an iterative process that involved several close readings of the transcripts, whilst paying attention to patterns of language that were used (Parker, 2002; Willig, 2008). The anonymised transcripts were also discussed with the co-authors in a series of data coding sessions.

Quality issues

This study adopted a social constructionist epistemology. The analysis aimed to meet the quality criteria outlined by Madill, Jordan and Shirley (2000) for discursive psychological research. These criteria refer to internal coherence, deviant case analysis, trustworthiness of analysis and openness to reader evaluation.

(See section 2.9.5 in extended paper)

Analysis

(See extended analysis section of extended paper for further discussion of all four discourses)

Severity and (in)stability discourse

Speakers constructed dementia on a spectrum of severity. Within this discourse each individual patient's dementia symptoms could be categorised as being more or less severe, but there was the potential for this to change. The potential for fluctuation in severity was described through the construction of dementia as an inherently unstable condition. In the following example, the team had been discussing a dilemma about where the patient would be discharged to.

Sam: It's [dementia] so changeable.

Mike: Yes.

Sam: Actually really understanding, particularly (.) with her, and does she understand that if she's living on her own, and if she's (.), if she can't make up her mind, then we have to question her capacity and then move in her best interest? She will say, yes::, today, and tomorrow she'll say, no. So:: does she really understand why she's saying yes or why she's saying no?

In this extract, the patient being unable to make up their mind was considered problematic and hypothesised as being part of their dementia. The problem was constructed as reflecting an instable inner state within the patient, rather than being explicable through reference to their context. In this case, a consequence of constructing the dementia as an unstable intrinsic force did not appear beneficial for the patient's sense of identity and agency. The patient's 'capacity' to make decisions was called into question, putting them at risk of having their decision-making ability eroded, as it would be put into the hands of the professionals. If a patient's actions are considered part of their illness, they then become removed from the range of normalcy, and from being understood within their context. The patient's dilemma risks becoming decontextualized if it becomes solely tied to their dementia. Concluding that a patient's actions stem from their illness can also rule out other explanations and discourage further exploration of their difficulties, and limit the patient's input into decisions about their care. In the extract the professionals are articulating *their* difficulty making an assessment of the patient ('understanding' her), which parallels the patient's difficulty in making a decision ('making up her mind'). However, despite this commonality, the patient is positioned as being 'unstable', which then invites the staff team to take up the corresponding 'stable' position. Decision-making power is then transferred to the seemingly stable staff team. This practice is justified by drawing on a discourse of ethical and professional responsibility ('moving in her best interest') which positions the staff team as protectors of the patient.

There were also instances when fluctuations in a patient's presentation were considered a sign of improvement. Instability was related to severity of dementia, in that less severe dementia fluctuated more often, and severe dementia was a more stable state. This relationship was constructed in a way that described dementia having more of a 'grip' on the person and they were 'past the point of no return' if their symptoms were considered particularly severe. Conversely, if dementia was changeable then the patient was considered to have moments of 'lucidity', in which they were less (or sometimes un-)affected by dementia. This construction links to common discourses around the 'fight' against dementia (Zeilig, 2013). When dementia fluctuates and a patient is considered to show glimmers of their 'real self' this can be understood as showing signs of resistance against the dementia (McParland, Kelly & Innes, 2017). Alternatively, if severe dementia is linked with stability, their fight is considered lost. The 'severely ill' patient can become subsumed by the dementia and the person/the dementia are spoken about as one, as more symptoms become tied to their diagnosis. This links to narratives about people with dementia 'no longer being themselves' (Bryden, 2005).

Progressive illness discourse

This discourse constructs dementia as a biological condition that would eventually progress and become untreatable. This construction was presented through a medicalised discourse, in which 'deterioration' is inevitable. Within this discourse, speakers also constructed dementia being a 'real illness', likened to 'brain damage'. This discourse positioned patients as clinical objects (Foucault, 2006) who were viewed as being at the mercy of their biology or 'the dementia'. A consequence of this discourse is that a 'really ill' patient's symptoms and actions can be seen as being controlled by their illness, and taking away personal control from the patient. Although using a medicalised model could help make sense of a person's presentation, and open up access to care on the ward, there is a cost to this for the patient, as their agency and autonomy is compromised. The patient becomes positioned as a passive repository for their illness, and personal responsibility for their actions is removed. In the next extract, a member of staff discusses their reasoning behind prescribing a patient a benzodiazepine, a medication used to reduce symptoms of anxiety.

Jo: The only thing he's on is Lorazepam because=I was concerned he would get a bit agitated (.) because he kept saying, I want to go home. And then at one point asking (.), said he was going to call the police, because I told him, well=actually, you're under a section, you are legally, we are allowed:: to detain you, because he=said, you can't detain me.

Anna: Yes:, he got angry hhh

Jo: Yes, yes. That=was the only reason I put the Lorazepam on (.), otherwise he's been very settled in himself.

Here Jo draws on discourses around legislation which could serve to legitimise the restrictions that were being imposed on the patient. Discourses around what is 'legal' can help to externalise the decision, thus distancing the staff from the moral dilemma of detaining or medicating a patient against their will. This legal discourse positions the staff as morally defensible and inoculated of stake. However, for the patient, once they had been positioned as a clinical object, it becomes difficult for them to claim status as a social subject at the same time.

When people with dementia are positioned as patients within a biomedical discourse, their symptoms and their bodies become objects of interest to healthcare professionals, that may be exposed, observed and invaded in the process of treatments which are part of the practice of medicine and its institutions (Parker, 1992). For patients who are constructed as being 'really ill', the care that they receive can consist of a sequence of interventions where one medication is tried and tested, and if it fails then another one is offered. This leads staff on a quest to find the 'right medication', which may result in unhelpful side-effects, or failure to identify negative side-effects of specific medications were frequently referred to throughout the data, highlighting how the powerful medicalised discourse was often contested and negotiated by the team, which is seen in the next extract.

Jane: And::, you know, it seemed to, you=know, he seemed quite absorbed(.), but <u>now</u>, you know, as I say (.), you don't know whether it's the medication, <u>do</u> you? And he is on a lot, isn't he?

Mike: Yes.

Jane: And you do wonder about (.2), how they interact with whatever else, I don't know whether he's on any physical meds, but-

Mike: I just (.2), you know, some people have a paradoxical response to sedation, don't they?

Jane: Yes.

If medical intervention was considered to have been ineffective, discourses around dementia being caused by forces outside of the staff team's control were sometimes drawn upon, as dementia was constructed as a condition that would always, inevitably progress. Through this discourse the patient becomes more firmly rooted in their position of a clinical object, as they could be considered 'too unwell' to hope for any improvement, and further options for intervention became shut down. In the following extract, Mike concludes a discussion where the team had expressed feeling 'stuck' with how to best help a patient who did not appear to be responding to pharmacological interventions.

Mike: Just as a, I don't want to sound negative, but it just has the inevitability of a (.), we're going to keep him until we break him, type scenario, doesn't it? Until he (.2), for whatever=the mechanism is, until his behaviour changes. So whether that's::: (.) level of sedation, progression of illness. So he may be one of those people that we keep whilst his illness progresses (.), sadly (.2), erm, until his management needs change.

In this extract Mike refers to the trajectory of progressive illness, and how the end point is that the patient becomes mentally "broken", or beyond repair. Discourses of an illness with inevitable progression could function as discursive tool to unburden the professionals from the moral responsibility of trying to solve the problem that is presented by the patient/their symptoms. Constructing dementia as a 'real illness' reflects the idea of a spectrum of severity, but also reflects a notion that some patients are more *authentically* ill than others. Not all patients were described as 'really ill', however these were not necessarily patients considered to have 'less severe' dementia. Instead, there were some patients who 'needed to go' (i.e. be discharged back home), after it was decided that they did not 'fit' within the remit of the ward. In this extract, Sam presents an argument for why a patient needs to be discharged, as their difficulties were not considered part of an ‘organic’ problem.

Sam: He’s so (.) it wasn’t paranoia. I don’t know that that is kind of (.3), attention seeking is not the word:, but I think he likes it here now.

Lydia: Yes:. He does seek a=lot of reassurance from the staff but again (.), he likes that, having conversations.

This discourse links to assumptions and rules about how a person with dementia should present or behave. There is a suggestion that some patients display inappropriate or unexpected symptoms, which calls their diagnosis into question. Foucault (1985) made claims about discourses producing moral codes that construct what is right and wrong, or what is true and false. Within the professional discourse there may be an unspoken moral code about how a patient with dementia should act, and this has implications for their ability to access certain care. For example, if a patient’s difficulties were not considered to be related to an ‘organic’ origin, then their needs are rendered illegitimate and they risk being rejected by the team and excluded from the care of the team. Patients are therefore required to demonstrate the ‘right’ symptoms, in order to warrant care on the ward.

Loss of insight discourse

In addition to the loss of agency and decision-making ability, dementia was constructed as something that could take away a person’s ‘insight’. Staff frequently discussed how a patient’s ideas about their difficulties differed from how they viewed things. The idea of illness insight involves the expectation that patients subscribe to the staff’s definition of the illness, and the professionals are then tasked with persuading patients that their symptoms could be alleviated by the interventions that they could offer. Below Anna describes the difficulties she has experienced when trying to change a patient’s perspective or persuade them to comply with the care that they are being offered.

Anna: Sometimes: he'll be really compliant (.), just happy:, settled (.2), but once he's got=in his head that he's got a job to do, it's so: difficult to <u>change</u> that.

For the patient it became problematic when they did not accept the explanation of their difficulties that was offered by the staff team, or if they did not cooperate with the care plan that was provided. A disagreement between the two positions was often installed in the patient as a "lack of insight". Problems occurred not just if the patient had a different reality, but also when the patient didn't want to acknowledge or accept, or take responsibility for the different reality. Having the 'right' insight was constructed as leading towards a more positive outcome for the patient, as they would then be aligned with the more stable, insightful staff team. However, this expectation presents a significant challenge for a patient who is immersed in a system that is dominated by discourses around illness residing within them. In order for the patient to gain status as a social subject, they are required to achieve an internal split – between the clinical object, with an inner, unstable illness; and the subject, who can reflect and take responsibility. The clinical object has its own life and agency, while the subject can reflect and understand what is happening. Below, Mike describes how a patient had accepted their diagnosis, and had used this to explain the confusion that they had been experiencing.

Mike: In=no uncertain terms and said (.), it's all nonsense. And he'd taken that on board (.3) but in doing that, he'd, obviously (.2), had to come to <u>terms</u> with the fact that he was that disturbed.

This extract demonstrates how accepting a dementia diagnosis could allow the patient to be able to access care from the staff team, as they become aligned in their view of the problem. However it could also cause patients to become fearful of their illness and what this means for them and their future. The next passage details a discussion where Sam touches upon an ambivalence that the patient experiences with the construction of diagnostic identities.

Sam : 22nd (.1), I can't find about this (.5), OK, so is he having fluctuation and his cognition paranoia is still there underlying. I have a feeling he finds it very,

very difficult or (.2) reluctant to disclose everything he's experiencing, why, that he may get stuck here for longer.

Mike: But I think he's (.) beginning to [be more open with people around him].

For the patient there was a risk associated with having 'gained insight' and accepted a dementia diagnosis. The patient is required to manage the existential threats around loss, physical and mental deterioration, and death, which could cause them to become further distressed. The discourse around 'insight' contrasts with the progressive illness discourse because the notion of insight-to-be-gained reinstalls agency and responsibility to the patient. For the patient, the antidote to their symptoms involves finding a part of themselves that has been preserved (or in some cases, finding a new part of themselves that is acceptable to the team), so that they can become more than just their diagnosis.

Hope in hopelessness discourse

The previous three discourses represent how dementia was constructed by the staff who were providing care, and the subject positions that could be taken up. The following discourse demonstrates the implications for care that is offered, when dementia is constructed in this way. A hopelessness narrative permeated staff talk when they discussed difficulties with a 'lack of progress' or faced a deterioration in a patient's symptoms. Hopelessness was reflected in talk about incurability, and further compounded by staff acknowledging where interventions had been ineffective or unhelpful. The team were required to confront the limitations of their role and a failure to 'do something'. A moral code within the staff team's professional discourse was that they were expected to be actively intervening.

Kerry: We're, literally, not doing anything for him anymore. He's (.2) kind=of just bed and board (.3) hh.

However, within the hopelessness, new hope could be found as a space opened up for care that was no longer seeking to 'change' or cure the patient. Talk of hopelessness served to release staff from the position they occupied where they were treating (attempting to change) clinical objects, and instead, they were able to get in touch with patients as social subjects. Sam and Anna refer to this in the extract below, following a discussion where it was stated that the team had exhausted all options for medical intervention.

Sam: He was (.), yes, lovely, we had a chat (.), but you've got to speak to his stance, you=know, he (.), you've got to walk with him, hold his hands. He told me he's always been hands on. I told him (.) he needs some rest. He said, no, no, I've always been on the go. And then he invited me to a cup of tea and I said, no:, thank you (.), I just have to go and see some people.

Anna: He's still got that, where he can (.3), say if you say about breakfast time, and he wants you to have breakfast with him (.), he's still got those sort=of skills.

In this extract, the patient's 'social skills' were exposed when Sam allowed himself to be guided by the patient in an interaction where power appears to be shared. The patient becomes positioned as a collaborator in their own care, instead of being a recipient whose dementia diagnosis rendered them incapable of having meaningful input. Therefore, for the professionals recognising or acknowledging incurability of dementia was seen to create opportunities for innovative care solutions that appeared to focus more on the patient's present experience rather than their future outlook.

Talk that highlights hope within hopelessness may be that staff's way of resolving the conflict between opposing discourses. Although this discourse could function to unburden the professionals of their moral duty to intervene/change patients, this contrasts with constructions of patients being on an inevitable illness trajectory, and whose status as social subjects has been compromised. For the team there appeared to be an inherent struggle between discourses around cure, and those around care. In the exchange below, Mike offers a suggestion of how to ‘help’ the patient after pharmacological options have not appeared to have any benefit.

Jo: I see his card (.), we’ve increased his haloperidol and it’s not making any difference.

Jane: hhh. No (.5), there’s just no change.

Jo: Is <u>anything</u> helping at all?

Jane: It doesn’t look like it. [It doesn’t seem like it]

Mike: [There is but it’s] whether it’s practically <u>deliverable</u> or not on time, and that’s (.), if he’s, if he’s offered the opportunity to engage in specific tasks that are safer to be engaged in (.), then you can get some containment.

Mike appears hesitant here, which could reflect how discourses around care (‘containment’) are less powerful or less acceptable than those around cure (‘change’). However, by positioning himself as tentative, Mike effectively resists the dominant discourse, and is able to build a more acceptable and plausible account, which disrupts the flow of the powerful medicalised narrative. Through this negotiation, the concept of care is re-interpreted and transformed, and new positions and opportunities are opened up for both the professionals and patients.

Discussion

The analysis offers a reading of staff talk where diverse constructions of dementia were drawn upon including: dementia as an unstable, internal condition that can fluctuate in severity, a biological illness that will ultimately worsen, and something that can take away a person’s ‘insight’. The variability and ambiguity of these discourses highlights complexity in the construction of dementia. Participants had to navigate contradictory discourses which were sometimes drawn on simultaneously, implying that although the discourses are powerful, they were also contested and negotiated by staff in a dynamic and active manner.

Participants deployed different rhetorical strategies to justify and legitimise the decisions that they made around care. Discursive devices such as stake inoculation helped staff to manage issues of accountability and professional credibility (Potter & Wetherell, 1987). Framing constructions within a biomedical discourse allowed staff to take up the powerful position of experts, whose actions were morally sound as they also adopted a role of protectors of patients. Constructing dementia as a real illness entitled patients to access care from the team, if they were considered to reflect the ‘appropriate’ symptoms for dementia. However, because dementia was constructed as an unstable, inner state that could cause a person to lose their ‘insight’, this set patients apart as deviant in some form, and outside the norms of society. This had the result of distancing patients from the staff team, and they could become caught up in a battle where professionals were driven to ‘change’ the patient through the use of controlling interventions (Foucault, 2006).

Discourse has the power to construct as well as constrain what can be said, felt, or done by individuals, and as such, these discourses offer ways of being and experiencing for people with dementia, and those who care for them (Willig, 2008). Implications for the consequent positionings available to patients were therefore considered. Discourses of patients with dementia fluctuated between constructions of passive objects and recipients of care, and more active subjects who had much more personal agency. Although some patients were constructed as being actively involved in their care, other patients were constructed as having surrendered to their biological fate. Patients categorised as active in their care were not necessarily individuals considered to have ‘insight’, instead, the active position was achieved through being more aligned with the professional team. Alternatively, patients who were less ‘compliant’ represented a force that the staff had to struggle against and tame, and by rejecting the help that was being offered, they posed a threat to the clinical insightfulness and expert power of the professionals.

Foucauldian Discourse Analysis (FDA) studies are also concerned with the availability of discourses within a culture, and therefore these discourses of dementia only make sense in a particular historical, institutional, political and ideological context. The final discourse of finding hope in hopelessness could be reflective of a current ‘living well with dementia’ discourse. This discourse emphasises supporting a patient’s remaining strengths as well as recognising enduring personhood (Department of Health, 2009; Dupuis et al., 2012), and over the past decade has been inscribed within UK policy directives (DoH 2009, 2012) as well as worldwide dementia policy influencers (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016). The living well discourse can be contextualised within a broader ‘ageing well’ policy landscape which emphasises individuals taking responsibility for their health (Walker & Maltby, 2012). These discourses disrupt the historical institutional order where people with dementia were positioned as being beyond cure and hope, and instead their personhood and capacity for self-expression is promoted (Sabat & Harre, 1994; Sabat, Johnson, Swarbrick & Keady, 2011) However, this study has highlighted that there are challenges to the ‘living well’ discourse within acute organic care settings, which could present barriers to the implementation of care practices based on this framework. This study also recognises how staff working in this context are caught between conflicting narratives about what constitutes care, and may be guided in their actions by an unspoken professional moral code.

An FDA approach recognises both dominant and resistant discourses within the discursive context of dementia, including the constructions described above. e.g. dementia as a disease (Ballenger, 2006; Milne, 2010), and dementia takes away insight (Aquilina & Hughes, 2004; Behuniak, 2011). This analysis has demonstrated that the assessment and treatment process on acute organic wards is far from a straightforward process, and the official discourses of dementia and how they are made sense of by multidisciplinary staff are in fact flexible and contested. Contradictions and ambiguity in talk are considered to be important clues about the contextual and functional features of the discursive world of patients with dementia, and those who care for them. These features are not seen as problems to be solved as would be assumed in positivist research (Potter & Wetherell, 1987). The results highlight how a space can be opened up within the dominant discourse, through the staffs' resistance of discourses around cure and change, and instead drawing on alternative resources and creating innovative care practices that allow power to be shared.

On a methodological level this study presents the first exploration of healthcare professionals' discourses of dementia in this setting, using naturally occurring talk and an FDA framework. This research fills a gap in the current literature, and adds to the argument that dementia needs to be understood as both contextual and diachronic (Berrios, 1987). Discursive studies can add value to existing studies on dementia, by drawing attention to the social and historical context to existing 'knowledge' of dementia, and considering the impact on the individuals with dementia diagnoses, and those who care for them. Healthcare professionals who care for people with dementia may benefit from considering the powerful sway of wider cultural and political narratives in which they are inscribed.

Limitations

The use of an FDA approach is not without limitations. Although the data consisted of naturally occurring talk, participants may have been mindful of being recorded, thus impacting on how openly they spoke. Participants may have been conscious of how they were perceived when constructing their accounts, particularly because the data was collected in a formal, professional context. It is possible that staff consider some talk as being less acceptable, leading them to censor themselves, and leaving some discourses unspoken. Also, due to the way that data was collected, other naturally occurring talk will have been missed, such as informal consultation, and discussions between staff members outside of the meeting, where other ad hoc decisions about care are likely to be made. However, this study deliberately focused on capturing the more 'formal' decisions that are made about care, and therefore 'professional' talk was especially relevant to the research question. It could have been beneficial to supplement the naturalistic data with interviews with staff, in order to further explore the constructions, which could have added richness to the data. However, naturalistic data is considered more suited to DA studies (Potter & Hepburn, 2005).

Researcher bias inevitably comes into the analysis of the talk. However, this is not epistemologically problematic, and quality criteria outlined by Madill et al. (2000) were considered in the write-up. Finally, this was a social constructionist study and therefore relies on the assumption that language is constitutive of experience and action, but these select discussions between staff with only be a fraction of what is spoken in this context (Burr, 2015). Therefore, the study does not make the claim that this can inform us about what ‘really’ happens in practice.

Word count: 6854

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EXTENDED PAPER

1.1 Section Introduction

The central interest of this thesis is healthcare professionals' constructions of dementia and the effects on care that is offered to patients on an acute organic assessment ward in a National Health Service (NHS) facility. In order to provide a context to the study, it is necessary to begin by situating it within a wider picture and to review the literature that has influenced the construct of dementia. I will start by introducing the relevance of the topic, as well as the history of the evolving understanding of dementia and then review the relevance to care practices.

1.2 Dementia symptoms and diagnosis

Dementia is a condition that has been linked to changes in the structure and chemical composition of the brain, leading to the death of brain tissue. Dementia is associated with a cluster of symptoms including memory impairment, reduced concentration, difficulties with planning and organizing, communication difficulties and motor dysfunction (American Psychiatric Association, 2013). In addition, emotional changes include low mood, irritability, anger and anxiety. Behavioural symptoms are linked to the progression of dementia, and include repetitiveness, aggression and wandering due to disorientation (Alzheimer's Society, 2014). There are a number of theories about the underlying causes of dementia, although these are not well understood (Berrios, 1987). Even in medical and scientific fields, uncertainties remain about establishing organic facts regarding the pathology of dementia (Gubrium, 1986; Sabat & Harre, 1994). Research has consistently demonstrated a lack of a clear relationship between brain pathology and its clinical expression (Snowden et al., 2003), and it has been noted that many people with a diagnosis of dementia experience impairment in excess of what is predicted based on findings of neurological impairment (Brody, Kleban, Lawton, & Silverman, 1971a). This highlights a complex interplay of other influences on a person’s symptoms (Brody, et al, 1971; Katzman et al., 1989; Snowdon et al, 2003), although it is not to deny the existence of an underlying biological illness.

Dementia is a degenerative condition for which there is no current cure (World Health Organisation, 2016). Once diagnosed, a person with dementia is expected to live for three to nine years, however this varies depending on the subtype of dementia as well as individual characteristics (Brodaty, Seeher, & Gibson, 2012). Different subtypes of dementia have different preliminary symptoms and courses of progression. Currently, the DSM-V and ICD-10 provide slightly varied definitions of dementias and Neurocognitive Disorders (NCD), although both use similar sub-categories to separate the most common ‘types’ of dementia/NCD. According to the Alzheimer’s Society (2014), dementia/NCD of the Alzheimer’s type accounts for 60-80% of cases. Other types of dementia include Vascular Dementia/NCD, Dementia/NCD with Lewy Bodies, Frontotemporal Dementia/NCD, Huntingtons’s disease and Wernicke-Korsakoff syndrome. Despite proposed differences between the categories, there is a substantial degree of commonality between cases. In cases where individuals display a combination of symptoms across sub-categories, they are likely to be given a diagnosis of a ‘mixed dementia’. In fact, almost half of cases of dementia/NCD of the Alzheimer’s type typically involve ‘other’ dementias, often vascular dementia ((Agüero-Torres, Kivipelto, & von Strauss, 2006; Alzheimer’s Society, 2014).

Over recent years there has been a policy-driven shift towards identifying and diagnosing dementia at the earliest possible opportunity. This stems from suggestions that early diagnosis can reduce feelings of anxiety and uncertainty (Dubois, Padovani, Scheltens, Rossi & Dell’agnello, 2015), improve quality of life and relationships (Werner, Karnieli-Miller, & Eidelman, 2013), and support adaptation (de Vugt & Verhey, 2013). In the UK the Prime Minister’s Challenge on Dementia (DoH 2012, 2016) and The Alzheimer’s Society (2014) set targets for increasing rates of dementia diagnoses. Statistics from NHS England in 2016 state that 67.2% of people affected had received a formal diagnosis of dementia (DoH, 2016), and the Alzheimer’s Society has continued to campaign for diagnostic rates to reach 75% (Alzheimer’s Society, 2014). However, diagnosing dementia, or the specific subtype of dementia is not a straightforward process. In order to receive a diagnosis, one symptom must be an impairment in memory, in addition to one of the following: language disturbance, impairment in motor function, difficulties with orientation, or problems with planning and sequencing. There must be a significant decline from previous levels of functioning, and the symptoms should also cause a significant impairment in social and/or occupational functioning (APA, 2013). Due to the increased drive for early diagnosis, many people do not meet the second diagnostic criteria of functional impairment, and therefore diagnoses may be given before people meet both criteria. An additional complexity arises when for some people, dementia first manifests itself as psychological symptoms such as low mood or personality changes, before the characteristic memory impairments. This highlights the complexity of assessing, diagnosing and treating people diagnosed with dementia. With the diagnosis of dementia being a difficult task, and pressures to improve diagnostic rates, there is the risk of misdiagnosis. Given that a label of dementia can lead to social, relational and psychological difficulties for diagnosed individuals, making sense of, and critical reflection on this construct is of great social importance.

1.2 Prevalence and economic impact of dementia

Worldwide, at least 35.6 million people have a diagnosis of dementia (World Alzheimer's Report, 2011). Dementia is significantly more common in people over the age of 65 (Alzheimer's Society, 2014). Due to advances in healthcare, the global population is ageing, and among the 'oldest old' cohort (those above the age of 80), numbers of people diagnosed with dementia are expected to double every 20 years (WHO, 2012). Although dementia occurs mainly in older people, it is not a natural consequence of ageing, as is commonly assumed (Kite & Johnson, 1988; Stein, Blanchard-Fields, & Hertzog, 2002)

Dementia is a financially costly condition, with the estimated annual cost of dementia per person being £25,472 (Albenese et al., 2007). Total costs have been estimated at £17.03 billion in 2005/2006, although other reports suggest the figure is closer to £23 billion (Alzheimer's Society, 2012). When compared to the cost of other health conditions, dementia costs the UK four times as much as coronary heart disease and stroke, and twice as much as cancer (Luengo-Fernandez et al., 2010). Despite this, there is a vast discrepancy in the amount of funding dedicated to research into dementia, when weighed against the amount of funding channeled into research for these other conditions.

1.3 The evolution of conceptualisations of dementia

Throughout history there have been multiple meanings of dementia, and it has been reported that as far back as 2000 BC the ancient Egyptians documented the concept. Plato also described a state of ‘madness’ in old age which is thought to reflect dementia. However, it was not until 1797 that the phenomenon was given a name. The term dementia was coined by a French psychiatrist Philippe Pinel, and derived from Latin, the word literally translates to ‘out of one’s mind’ (Berrios, 1987). During the 18th century, dementia was a term applied to people with intellectual deficits acquired at any age. Later the term became reserved for people with a loss of cognitive ability. In 1835 the label ‘senile dementia’ was introduced by Dr James Cowles Prichard in his book A Treatise on Insanity. This term was said to describe a syndrome characterised by ‘forgetfulness of recent impressions, while the memory retains a comparatively firm hold of ideas laid up in the recesses from times long past’ (Boller & Forbes, 1998).

In 1901 Dr Alois Alzheimer wrote a case study of Frau Auguste D, a patient in a German asylum who reportedly presented with “reduced comprehension and memory, as well as aphasia, disorientation, unpredictable behaviour, paranoia, auditory hallucinations and pronounced psychosocial impairment” (Maurer, Volk, & Gerbaldo, 1997, p1546-2547). In 1907 the term ‘Alzheimer’s disease’ was established when, after Auguste D’s death, Alzheimer completed a post-mortem report and hypothesized that neurofibrillary tangles and neuritic plaques around the patient’s brain were the cause of their memory problems. No details of their psychosocial history were included, which would have helped contextualise the patient’s presentation (Cheston & Bender, 1999; Kitwood, 1997; McKhann et al., 1984). Because of this omission, the biomedical explanation set the context for understanding dementia over the following century (Cheston & Bender, 1999). In the West, research into dementia gained momentum in the 1980s, with a significant emphasis on the neurobiologic processes of the condition (Bond, 1992). In Western society, the last 50 years have seen a gradual shift in understandings of dementia. Up until the early 1970s symptoms associated with dementia were categorized by age, for example, Alzheimer's disease was categorized as a 'pre-senile dementia' as opposed to the already categorized 'senile dementia' (Fox, 1989; Holstein, 1997; Lyman, 1989) has documented the historical move to eliminate the demarcation between these two originally separate diagnoses.

Today, research into dementia continues to be dominated by the medical field, and efforts continue to be made to link biological findings with the presentation of undesirable symptoms (Finnema, Dröes, Ribbe, & van Tilburg, 2000). However, the search for a cure has so far been met with limited success. Criticisms of the medical model of dementia, and the emergence of evidence highlighting the importance of factors beyond neuropathology, made way for the construction of a number of alternative theories of dementia (Snowden et al., 2003). More holistic biopsychosocial approaches began to acknowledge individual factors relating to the person as well as their social context accounting for the development and progression of dementia (Downs, Clare, & Anderson, 2008). The models described below are not an exhaustive list of sociocultural theories of dementia, but instead are presented in order to present alternative examples to the medical model, and highlight to readers alternatives to the dominant medical discourse.

Baltes and Baltes proposed a developmental model in which ageing is viewed as an adaptive process of selective optimization (Baltes & Baltes, 1990). The model is based on the premise that individuals can age 'successfully' in a process 'involving selection, optimization and compensation' but how these components are realized is dependent on personal and societal circumstances that individuals face as they age. The Adaptation Coping model was developed by Droës (1991, cited in Spector & Orrell, 2010) and describes a number of cognitive, emotional and social adaptive tasks through which individuals with dementia strive to maintain equilibrium. Kitwood's dialectical model (Kitwood, 1993) proposed that dementia could be understood as an interrelationship between neurological deterioration and psychological factors such as personality, biography, social psychology and physical health. Kitwood's work led to the development of a person-centred approach to care (Kitwood, 1997a & 1997b) which emphasises the need to recognise and respect people as unique individuals, within the context of the wider social environment. Kitwood (1997) was concerned with understanding the subjective world of the person with dementia, which he claimed that the medical model neglected. The Biopsychosocial (BPS) model of dementia (Spector & Orrell, 2010) was built on existing biopsychosocial models (e.g. Kitwood, 1997) to provide a framework through which a theoretical understanding of the nature of dementia can be applied to practice. The BPS model also takes into account both positive and negative factors in ageing. The model suggests that recognizing individual biological and psychosocial factors that may be amenable to change is crucial in maximising an individual's potential and minimising their level of excess disability (Brody, Kleban, Lawton, & Silverman, 1971b). The model indicates that in both biological and psychosocial domains there are both fixed and tractable factors. Fixed factors include age and past life events and are not amenable to change. Tractable factors such as environment or mood, however, may be amenable to change. By breaking down contributing factors in this way, the model supports the view of dementia as a process where change, adaptation and improvement are possible. This is intended to help instill hope in care staff, by supporting the idea that improvement is possible, whilst at the same time acknowledging the impact of factors beyond staff control.

The perception of biological and psychological aspects of dementia and their explanation imply the use of explanatory models specific to societal or cultural environments. It should be acknowledged that this study is grounded in a Western perspective and draws on Western literature. There is currently a lack of published research on the experiences of people living with dementia in non-Western cultures (Mazaheri, Eriksson, et al., 2013) or studies on representations of dementia in non-Western countries. However, although the literature is limited, it has been noted that some communities and cultures throughout the world understand dementia in different ways. For example, in a study with an Natuve American population, the hallucinatory symptoms associated with a dementia presentation were positively valued. Rather than pathologically defined, these symptoms were viewed as communications with "the other side" (Pollitt, 1996). In the same study, it was discussed how in Japan the condition is associated with frailty and there are beliefs that remaining physically active is a preventable measure in dementia. Despite these different ways of constructing dementia, it has been suggested that 'the core experience of people with dementia is to some extent universal 'despite differences in cultural or political contexts and with different religious beliefs or confessions' (Mazaheri, et al., 2013).

1.4 Dementia and psychology

Over the past 20 years a number of psychological approaches for understanding dementia have been proposed. Psychological theories draw upon behavioural, cognitive-behavioural and psychodynamic ideas, and can be considered alongside medical explanations of dementia, to produce a more comprehensive biopsychosocial understanding of the condition.

Behavioural theories of dementia suggest that if a person cannot rely on adaptive communication and problem-solving skills, they will signal their needs through the display of problematic behaviours such as 'aggression' or 'wandering' (Cohen-Mansfield, 2008; James, 2011; Moniz-Cook, Stokes, & Agar, 2003; Stokes, 2001). These behaviours are often experienced as challenging to the people around them, and can elicit negative responses, which further distress the person with dementia (James, 2011). Functional Analyses are often used to try and determine the function of the behavior and underlying unmet need. This analysis informs the design of individualized interventions to meet the patient's needs and improve wellbeing, with the aim of reducing 'challenging behaviour' (Gallagher-Thompson, Gray, Dupart, Jimenez, & Thompson, 2008; Haupt, Karger, & Jänner, 2000). The National Institute for Health and Care Excellence (NICE) recommends behavioural interventions as the first-line option for treating 'behavioural and psychological symptoms of dementia' (NICE, 2006; Bannerjee, 2009). Although reviews of behavioural interventions have helped to develop an empirical evidence base (Moniz Cook et al., 2012), when a range of different interventions are employed, in order to meet individual needs, it can make it difficult to assess the actual contribution of behavioral interventions.

Cognitive-behavioural models offer an explanation of how, when a person begins to notice a deterioration in ability, skills or memory, their perception of incompetence can contribute to psychological distress, as well as influence coping behaviours (Egan, Laidlaw, & Starkstein, 2015; Laidlaw, 2003). Cognitive responses include increased attention to mistakes, and making negative predictions about the future or the judgement of other people. This is said to lead to behavioural avoidance which can lead to loss of skills, feelings of worthlessness and social isolation (Laidlaw, 2003). Cognitive behavioural interventions for people with dementia are aimed at supporting the individual to function at more optimal levels for longer, and include techniques such as problem-solving around memory difficulties, increasing meaningful activity, and cognitive-restructuring negative beliefs (Scholey & Woods, 2003). Cognitive behavioural formulations also emphasise understanding the person in context, and attending to their close relationships, as well as the internalization of cultural beliefs about aging and dementia (Laidlaw, 2003). This approach has been shown to reduce negative affect in people with dementia (Kraus et al., 2008; Orgeta, Qazi, Spector, & Orrell, 2015; Scholey & Woods, 2003), and has also been applied in group settings to help reduce caregiver distress (Gallagher-Thompson et al., 2008)

Psychodynamic ideas have been used to understand behavioral and emotional changes in dementia in terms of psychological defences. Defence mechanisms such as denial, projection and withdrawal are suggested to be ways of managing anxiety and shame that is triggered by a loss of independence and ability (Evans, 2008; Soloman & Szwabo, 1992). Whilst defending from painful emotions, these strategies can take on the appearance of more severe cognitive difficulties (Evans, 2008). In addition, psychodynamic theories take into account a person's early life experiences and suggest that memories from the past can merge with the present (Sadavoy, 1991). Early attachment-seeking behaviours such as reassurance-seeking may be observed as a person with dementia becomes increasingly vulnerable and dependent on others (Evans, 2008). Psychodynamic interventions promote the development of safe, containing therapeutic relationships to support the person with dementia to resolve earlier conflicts, improve coping responses, and support acceptance (Brierley et al., 2003; Soloman & Szwabo, 1992). Support for psychodynamic therapies in dementia is shown in case vignettes (Kasl-Godley & Gatz, 2000), and support for the use of an attachment perspective for formulating and caring for people with dementia is evidenced in a review of eighteen studies (Nelis, Clare, & Whitaker, 2014). Although the review indicated that attachment security had implications for the health of the person with dementia, the study contained inconsistent measurements of attachment styles which were not validated for dementia populations.

A social-constructionist perspective provides an alternative model which describes how individuals adapt to their changing social context (Gergen & Kaye, 1992). This idea is presented in the assimilation of problematic voices (APV) model (Stiles, 1991, 2001), which describes the idiosyncratic process of adapting to dementia (Cheston, 2013; Cheston 2014; Lishman, Cheston, & Smithson, 2016). In the early stages of dementia it is suggested that a ‘dominant voice’ protects an individual’s identity by resisting change and pushing difficulties out of awareness. Cheston (2013) suggests that shame can present a barrier to the person’s ability to acknowledge their difficulties and thus adapt. As time passes, a ‘problematic voice’ acknowledges the need for change and the person begins to become more conscious of their difficulties. As part of this conflict, emotional distress is predicted to rise, however, through successful assimilation, the person can integrate the problems into their life and cope with their experiences. The Dementia Voice Group Psychotherapy project involved six, ten week psychotherapy groups based on the APV model, and a qualitative analysis was utilized to measure the outcomes (Cheston, Jones & Gillard, 2004; Watkins, Cheston, Jones, & Gillard, 2006). Out of forty-two people with dementia who originally attended the intervention, nineteen people completed the course. The outcome analysis of those who completed identified how over time, participants were able to process and assimilate their experiences, and move from feelings of shame, to a place of acknowledgment and insight (Cheston et al., 2004; Watkins et al., 2006). However, the considerable drop-out rate of the group should not be dismissed, and raises questions about the acceptability of the therapy and the group format in which it was delivered. Also, as the aim of the intervention was to assist people with processing their experiences, therefore demonstrating effectiveness of the group would not necessarily be reflected when using measures of symptomatic distress, especially for short-term interventions which may not continue to the final stages of change.

1.5 Dementia through a social constructionist lens

In recent years, there has been a shift towards qualitative research, driven by critique of positivism and hypothetico-deductivism, and increasing openness to the idea that observations are individualistic and selective (Chalmers, 1999). Qualitative approaches can provide thick, rich descriptions useful for exploratory research (Willig, 2008). The use of qualitative methods in dementia research is steadily growing. There is now a growing body of literature studying psychosocial dimensions of people diagnosed with dementia (Clare, Goater, & Woods, 2006; Van Dijkhuizen, Clare, & Pearce, 2006; Harman & Clare, 2006; Keady & Nolan, 1995; Van Dijkhuizen et al., 2006; Kontos, 2006; Sabat, 2001; Van Dijkhuizen, Cotrell & Schulz, 1993).

There has been a particular drive towards the development of research methodologies that rest on social constructionist assumptions. Gergen (1985) was one of the first to bring social constructionism to the attention of the psychological academic community. He described social constructionism as being concerned with unveiling the processes by which people come to describe and account for the world in which they live. This epistemological stance assumes that all aspects of human functioning are produced, and reproduced through language, and exist within particular historical and sociocultural contexts (Burr, 1995). Social constructionism takes a critical stance towards taken-for-granted knowledge, and employs a process of deconstruction to analyse and problematise discourses. Deconstruction refers to an exploration of assumptions and statements, and should be distinguished from a critique. In a critique, statements are challenged by working in the same world of assumptions (Spivak, 1990). This thesis is concerned with the social and interpersonal categories that are brought into existence through talking about dementia (Edwards & Potter, 1992). This is not to deny the relevance of the biological aspects of ageing. However, from a social constructionist perspective the issue is not if biological processes are relevant, but the importance is exploring how dementia (and people with dementia) are produced through language.

Discourse analysis (DA) is a methodology that attempts to understand how in language versions of the social world are constructed (Burck, 2005). When language is studied for its discourses, it is studied for its function, both intended and unintended (Wetherell & Potter, 1988). In discourse analysis, language is considered for its social action, whereby involvement in social interactions are managed by speakers through discursive strategies. These discursive activities include justifying, categorising, explaining, attributing, and naming and blaming. Speakers can use language to position themselves in various ways, and different positions entail different degrees of accountability and have multiple functions, for example, distancing the speaker, or authoritatively endow what is said, in order to achieve social or interpersonal objectives (Harper & Thompson, 2011; Willig, 2013).

Rather than attempting to establish ‘correct’ or ‘true’ accounts of a phenomenon, a DA approach examines what is achieved in talk, and what versions of the ‘truth’ are constructed and authenticated in discourse (Potter & Wetherell, 1987; Talja, 1999; Willig, 2008). DA allows for the “multitude of divergent and conflicting voices with which scientists speak” to be set free, as opposed to assuming there is a true version of participants’ beliefs and actions (Gilbert & Mulkay, 1984, p.2). Language is viewed as a mean of constructing, rather than reflecting, reality (Harper & Thompson, 2011). The aforementioned historical and cultural discourses of dementia would correspondingly impact upon the discursive world and position of those who are diagnosed with dementia. This approach was considered helpful in investigating the topic of dementia and dementia care, given the variable ways that this condition has been constructed over time A DA approach allows for variability and sees this as interesting rather than problematic.

A number of diagnostic entities have been explored using DA, including anxiety (Hallam, 1994), ‘personality disorders’ (Swartz & Ismail, 2001; O’Key, 2014), ‘paranoia’ (Harper, 1994) and anorexia nervosa (Hepworth, 1999). DA has also been used to explore how people with a diagnosis of mild cognitive impairment use language, which was analysed to reveal societal views and shared meanings of distress (Pierce, Lamers, & Salisbury, 2016). These studies take a deconstructive approach to the development of the diagnostic categories, to help reveal underlying assumptions and how they are produced and re-produced within certain socio-historical conditions (Georgaca, 2012). DA methodologies have also been utilised to investigate the accounts of healthcare professionals in various contexts, for example, general practitioners’ and nurses’ constructions of men’s health (Seymour-Smith, Wetherell & Phoenix, 2003) and general practitioners’ talk about chronic fatigue syndrome (Horton-Salway, 2001). Adopting a DA approach can help to explore contentious or contested topics, and can help to examine implicit oppositions in people’s talk (Harper, 1994). The methodology has also been applied to medical texts, such as the study by Hamilton and Manias (2006) which de-constructed medical language in patient notes, and research by Johnstone and Frith (2005) which explored constructions in journal articles of patient experiences of electroconvulsive therapy (ECT). These studies have demonstrated how different ideological discourses are taken up or resisted in professional knowledge claims (e.g. the language of medicine or psychiatry). Also, the studies help to highlight how powerful institutional discourses can be used to justify certain treatments (e.g. medication, in Harper, 1999, and Liebert & Gavey, 2009), support professionals’ claims (Johnstone & Frith, 2005), and legitimise controversial practices (e.g. electroconvulsive therapy in Stevens & Harper, 2007).

1.6 Discourses of dementia

Dementia is featuring increasingly in public, professional and academic discourse and there are now numerous available discourses around dementia and dementia care. These include messages about the burden of dementia, dementia afflicting people who have failed to age well, a dementia diagnosis being a tragedy, and the possibility to live well with dementia. Discourses that are tied to governing social institutions such as geriatric psychiatry, neurobiology, medicine and pharmacology have a great deal of power in forming dominant discourses of dementia. Those discourses which are dominant then privilege certain versions of reality, which in turn legitimise the existing social structures and power relations. However, the power of these institutions has started to wane in governing dementia care, as there has been a growth in the power of previously marginalised voices, including from people with a dementia diagnosis.

1.6.1 Burden discourse

Within policy and general discourse, language around the 'burden' of dementia frequently occurs, as do the terms 'crisis' and 'epidemic' (Mandell & Green, 2011). Dementia has been referred to as a 'millennium demon', and there has been a call for a 'crusade' to overcome it (Willey, 2012). These discourses are suggested to reinforce a sense of horror and fear about dementia (Mandell & Green, 2011), or imply that dementia is infectious and can be caught (Zeilig, 2013). Zeilig (2013) suggests that this discourse evokes a sense of calamity, and that dramatic language has the power to terrify us and make us feel powerless. This adds momentum to discourses around 'battling' dementia, underneath which there is an assumption that this is something that can be 'won'. The burden discourse has also been linked to care of people with dementia, and the financial implications associated with care (Knapp & Prince, 2007).

1.6.2 Failure discourse

Old age is associated with dementia, partly because the risk of dementia increases with age, but also because it continues to be misunderstood by many as being part of the ageing process (Zeilig, 2013). The concept of 'successful ageing’ (Havighurst, 1961; Rowe & Kahn, 1998) emphasises personal agency and control, and places value on independence and the importance of avoiding dependence. In the context of the successful ageing paradigm, people with dementia, particularly if they are dependent on care, have failed the living well test. Van Dyk (2014) suggests that people diagnosed with dementia become marginalized and stereotyped as a result of the discourse around ‘failing to age well’. This discourse therefore has implications for social inclusion because to be both older and ‘mentally ill’ is to be doubly marginalised, and positions people at the edge of mainstream society. This language does more than acknowledge that people are living with a condition, it goes on to label the person with a dementia diagnosis as ‘other’ (Goffman 1963, Hughes et al. 2006, Kitwood 1997), as they are set apart as abnormal or deviant in some form. Socially, people diagnosed with dementia then become positioned as being dependent bodies who require management and care (Innes, 2002; Sabat, 2001), or worse as ‘empty shells’ (Bryden, 2005) who are enduring ‘a living death’ (Behuniak, 2011). Zeilig (2013) suggests that the term dementia itself has become a metaphor for wider social ills, and likens this to the way that the psychiatric term ‘schizophrenia’ has become a metaphor for some social and cultural trends. Public Health guidance has acknowledged the stigma attached to this discourse, and emphasized the importance of challenging the marginalisation of people with dementia (DoH, 2009; World Health Organisation & Alzheimer’s Disease International, 2012). Despite this, it has been highlighted that discourses of dementia that suggest themes of zombies (Behuniak, 2010), animalism (Mc Parland, 2014) and social death (Sweeting & Gilhooly, 2008) continue to be perpetuated. This contributes further to the fear of being diagnosed with dementia, and treating those with the condition as though ‘they are no longer people’ (Baars, Dohmen, Grenier, & Phillipson, 2014).

1.6.3 Tragedy discourse

The biomedical approach to treating dementia has been suggested to fuel what has become known as the ‘tragedy’ discourse. The tragedy discourse is perpetuated when understandings of dementia focus explicitly on loss of function, decline and death (Mc Parland, Kelly & Innes, 2017). Baars and

Phillipson (2014) argue that ‘processes of socialisation often carry cultural messages of familiarity versus strangeness that imply practices of inclusion and rejection’ (2014: 16). In the context of dementia, this rejection sometimes becomes complete when individuals move into formal care settings, representing a transition from one world to another. At their most impaired or frail, people with dementia are no longer considered to be bound by the same rules of ‘our world’ and nor are their human rights respected to the same extent as people without dementia (Graham, 2004; Kelly and Innes, 2013), which further reinforces the narrative of dementia as a ‘tragedy’. The tragedy discourse is also represented in the stereotyping language that is used about dementia, or to describe someone with a dementia diagnosis, as well as in stories about caring for people with dementia (Behuniak 2011; Fontana and Smith 1989; Gillies 2011), and appears frequently in the media (Bartlett and O’Connor 2010; Johnstone 2013; Van Gorp and Vercruysse 2012).

Bavidge (2006) has challenged society’s views on life, death and dying and questioned why the cognitive impairment and decline in independence that is associated with ageing is judged as pathological. Bavidge (2006) compares this to views of cognitive impairment and dependence in early life, where a child who does not speak, but watches the world go by and responds to sound, touch and smell, is regarded with joy, and valued simply because they are present. However, a person with dementia is judged as no longer contributing to society, is not valued equally, and seen to represent a tragedy.

1.6.4 Living well

In recent years there has been a shift away from discourses of dementia as a ‘tragedy’ and ‘social death’, to a ‘living well’ discourse (DoH, 2009). This reflects a challenge to previous negative discourse, by promoting positive ongoing life experiences (Dupuis et al., 2012a), and social inclusion by drawing on the previously absent narratives from people with dementia (Scottish Dementia Working Group, 2016; Swaffer, 2011; Taylor, 2008).The living well discourse has been supported by organisational campaigns such as the Alzheimer Society Canada (2013), Alzheimer Society Ireland (2015), Department of Health

(2012), which aim to reduce the stigma associated with dementia. Despite the developments of the living well discourse in academia and policy, it has yet to have a significant impact on public discourse (Bartlett and O’Connor 2010; Bruens 2014).

The living well discourse has been critiqued by Mc Parland et al. (2017), who argue that efforts to normalise people with dementia risk further excluding the most vulnerable or affected by the condition. They suggest that this discourse risks division amongst people with a dementia diagnosis, by categorising those who are living successfully, and those who are no longer able to maintain society’s expectations of living well.

1.7 Dementia care

Person-centred care (Kitwood, 1997) is the model of care followed in the NHS in dementia care settings (Brooker, 2003). This framework represents a philosophy that was developed out of a resistance to the dominant medical model of care. Kitwood (1997a) criticised the medical model for neglecting the subjective experiences of people with dementia and undermining ‘personhood’. Kitwood (1997) proposed that certain interactions between staff and residents in care settings impair the personhood of people with dementia, and contribute to the development of dementia He developed a list of 17 “personal detractions” (p.40), including ignoring, mocking, blaming, disparaging, and invalidating. It was suggested staff rarely do so with malicious intent, but that that when negative interactions go unchallenged they become an interwoven part of care culture. Kitwood’s (1997) seminal work on personhood is said to have led to a shift in the way dementia was viewed, giving greater consideration to an individual’s needs, interests and strengths. Kitwood’s philosophy for person-centered care was built upon with suggestions for the application to care services. For example, Brooker (2003) made an argument for the creation of a positive social environment for people with dementia, and McCormack (2004) emphasizes the need for choice and partnership in care decision-making. Current national guidance and policies for acute older adult care settings outline recommendations for the implementation of person-centred care, such as supporting shared decision making, improved training for professionals, and improving information giving. (DoH, 2001; NICE, 2006).

Kitwood’s (1997) ideas have been criticized by Davis (2004) for being idealistic, and the lack of empirical evidence for the application of his theories. Davis (2004) suggests that Kitwood did not appreciate the challenges involved in caring for people with dementia, and that his philosophy could lead to feelings of guilt and despair in caregivers who might struggle to maintain personhood for dementia sufferers. Higgs and Gilleard (2015) point out that under Kitwood’s person-centred care approach, personhood becomes a status attributed to patients by other people. If personhood is a status bestowed, rather than something actively shaped by the person with a dementia diagnosis, then their agency becomes lacking (Baldwin & Capstick, 2007). Dening and Milne (2011) also caution that improvements in care are difficult to make if philosophies like person-centered care are not well understood.

1.8 Constructions of dementia and their relevance to care

According to DA researchers, when language is used over time, it gradually becomes institutionalised into accepted patterns of discourse, which shape our activities and practices, social relationships, and organisations. As outlined, the development of knowledge about dementia has been far from consensual, and there remains uncertainty and a lack of agreement about underlying pathology or approaches to treatment. It is against this backdrop that this project considers discourses of dementia on an acute assessment and treatment ward, and the implications for the people who are receiving care. This project takes the perspective that dementia is a construct and that beliefs about dementia are not directly acquired from experience, but are constituted through complex processes of communication and interaction that are situated in broader historical, cultural, social and political contexts (Foucault, 2006).

Although national guidance and policies emphasise the importance of attending to individual circumstances in order to provide person-centred care, it is probable that healthcare professionals will draw upon multiple discourses of dementia, and that this will influence the care that is provided. Multidisciplinary staff work within a system where there are competing discourses about dementia, and they have to balance medical/physical, social and psychological needs. This will impact on how the patient is understood, and therefore how they are cared for (in other words, how they are 'categorised'). All of this occurring in the context of the NHS results in further strains on the system and introduces an additional narrative regarding 'cost' and 'beds' when considering care, which reflects current discourses around 'efficiency' in the health service.

In dementia care settings healthcare professionals occupy powerful 'expert' positions. Part of their role is to interpret symptoms that a patient presents with, and make clinical judgements on whether they are 'natural' or 'pathological', which in turn influences the care that is offered. Kontos (2005) also studied the delivery of care and support for people with dementia, and demonstrated that conceptual understandings of dementia have a very real impact on the lived experience of people with a dementia diagnosis (Kontos & Naglie, 2009). On acute organic assessment and treatment wards, staff are also tasked with describing and interpreting patients' symptoms and attempting to determine if their difficulties can be attributed to changes in brain structure, or if they are environmental, relational or psychological. The position taken up by healthcare professionals with regard to dementia will inevitably guide and inform their clinical reasoning, and approach to decision-making about care.

Some of the most distressing facets of dementia are the 'behavioural and psychological symptoms in dementia', which in medical settings are often referred to as BPSD (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). Examples of BPSD that are commonly referred to include anxiety, depression, 'wandering', 'restlessness', and 'dishinhibition'. More severe BPSD are associated with reduced quality of life (Cerejeira et al., 2012). There is an emerging body of literature looking at the interactive processes that often occur in dementia care settings (James, 2011). Cognitive deficits and behavioural symptoms associated with dementia can result in communication difficulties for patients- both in expression and comprehension. These difficulties can impact on staff not being able to understand the needs of those they care for, and this lack of understanding has been seen to cause other behavioural symptoms such as disengagement, social withdrawal, and verbal or physical aggression (Algase et al., 1996). These ‘distressed behaviours’ often lead to high staff turnover, burnout and increasing costs (Donaldson, Tarrier, & Burns, 1997), and can interfere with the quality of care given to patients (Balestreri, Grossberg, & Grossberg, 2000).

Also, when described in terms of symptoms, or ‘BPSD’ it has been argued that a patient’s underlying needs can remain unmet as this labelling can overlook the unmet need from which the behaviour stems (James, 2011). Language that labels risks taking away someone’s identity, overlooking their life story, strengths and preferences. Adopting diagnostic short-hands might be unintentionally dismissive, but nevertheless can still be damaging. People have multiple identities which intersect with each other, however, diagnostic language which labels people can overlook this.

Kontos and Martin (2013) suggest that the current body of literature on dementia care fails to address the interrelationship between care staff and social structures. Their study explored how agency and structure are intertwined, and how the relationship between them enables or constrains dementia care. The findings suggest that care decisions are the outcome of a discordant interrelationship between professionals’ ‘deliberations and legislative and organisational care mandates’ and that staff often respond to the need to provide individualised care by rule-breaking.

1.9 Framing the research theoretically

Foucault attempted to contextualize and historicize notions of truth, knowledge, rationality and reason that were found within society at different periods in time, and to highlight how these relate to the construction of individual identities (Danaher, 2002). According to Foucault, what people could ‘know’ was always allowed/limited by the context in which they were situated. Foucault emphasized how that which constituted truth was not inevitable, but instead liable to change across different cultures and historical periods. Therefore history could easily have been different.

Foucault's 'archeology of knowledge' exposes the historical origins of powerful discourses and societal institutions (Foucault, 1972). Foucault's use of the term archaeology relates to uncovering discursive formations or events that have constituted and shaped types of knowledge. Foucault suggested that knowledge is produced as a result of the struggle between institutions, and that this becomes presented as the 'truth'. Foucault argued that individuals are constrained by institutional power as to what they can and cannot say; "in every society the production of discourse is at once controlled, selected, organised and redistributed by a certain number of procedures" (Foucault, 1972). FDA views discourses as constructing and reinforcing 'truths', and attempts to explore how certain claims are made, and the possible benefits and limitations of these (Wiilig, 2008).

In his work 'The Order of Things', Foucault explored the history of ideas in Western Europe and claimed that it represented a set of conceptions (or 'epistemes') that were organized around a particular view of the world and how it is ordered (Gutting, 1989). Foucault proposed that the episteme in which we live (or what is to be considered 'the order of things') determines how we make sense of something at a particular time/in a particular context. An important idea for Foucault was that people in another time/place may have understood things in a very different way to us, and may have made sense of the world in ways that we would struggle to imagine (Foucault, 1972)

Discourses are not simply bodies of knowledge, but also courses of action and frames of reference immersed in social practices (Holstein & Gubrium, 2000). Exposing dominant discourses in acute care settings could raise important questions about what we 'think we know' about dementia (George, 2010) and how this might impact on theory, diagnosis, policy and practice, and both expert and common-sense knowledge. Taking a social constructionist stance can help to consider how local interactional and wider historical and cultural contexts may influence, and in turn be influenced by discourse.

The literature and theories discussed in this introduction have highlighted how discourses of dementia are complex, changing and culturally-bound. The literature also highlights the complexity and conflicting narratives around dementia. However, historically the concept of dementia has been presented in a more straightforward way. This study utilises an FDA framework to deconstruct healthcare professionals' discourses of dementia, and the subject position of the 'dementia patient' in an acute care setting. We sought to explore the ways in which dementia is constructed through talk, as well as the relationship to social structures and institutions. Adopting this approach enables the exploration of the research question whilst also paying attention to the function of healthcare professionals' talk, and the different issues that are attended to when teams are making decisions about care practices.

DA researchers have suggested that 'professional' knowledge is categorised linguistically (Licqurish & Evans, 2015). Holding knowledge in these categories, and how the categories are communicated to patients and other professionals can impact on patient experiences. FDA allows for the exploration of the discursive worlds that people with dementia inhabit, and what the implications may be for subjectivities and ways of being. Use of an FDA methodology acknowledges both dominant and resistant discourses of dementia, and provide additional value to existing perspectives on dementia, by contextualizing and drawing attention to the social and historical markers of dementia.

Methodology

2.1 Section Introduction

In the literature review, the ways in which conceptualisations of dementia have differed across time and contexts was identified. It has been argued that because constructs such as dementia are represented through linguistic labels, which are bound by time and culture and reified through their use, they are thus intrinsically variable. An approach that is sensitive to variability and people's use of language was proposed for this study, and this section will detail the epistemology and methodology that was used. This is followed by an outline of methods employed, the procedure of the study, ethical considerations and a discussion of quality issues in qualitative research.

2.2 Epistemology: Social constructionism

Epistemology is the philosophy of knowledge; it is concerned with questions such as “how can I go about gathering knowledge about the world?” and “how do I know what I know?” (Harper, 1995). This study focused on the construction of knowledge and therefore it is relevant to outline my own epistemological position. I acknowledge my skepticism of universal knowledge claims held by realists (Harper, 1995), and assumptions that there is an objective ‘reality’ which researchers can come to know through the use of traditional empirical methods. This study adopts a social constructionist perspective, claiming that language is not a tool to discover mental states as proposed in cognitive psychology but instead operates as a social action which manages and creates reality (Elliott, Fischer, & Rennie, 1999).

Within a social constructionist stance, it is acknowledged that multiple possible accounts of ‘the nature of things/the world’ are available, and these are viewed as constructions and understood in terms of their functional nature in different contexts. As such participants’ ’talk’ was not seen as a window into their personal thoughts or feelings, but instead their accounts were viewed as serving a range of functions – both interpersonal and societal (Harper, 1995). This research aimed to situate the data within its wider context, therefore FDA was considered the most appropriate framework (Potter & Wetherell, 1987; Sacks, Schegloff, & Jefferson, 1974)

Reflective of the FDA approach, reality and identity were viewed as constructed and maintained through systems of meaning (i.e. language and social practices; Georgaca & Avdi, 2011) From this perspective, ‘truths’ of reality were not sought, and instead the aim was to offer one of many possible interpretations (Taylor, 2001). Participants’ talk was seen as operating in a productive way to construct particular phenomena, position the subject, and subsequently to open up or close down opportunities for action and implicate subjectivity. Additionally, participants’ talk is considered to be context-dependent, and open to influence from the researchers’ own constructions and cultural systems of meaning (Gilbert & Mulkay, 1984),

2.3 Methodology: Discourse Analysis

Discourse analysis (DA) is an umbrella term for a number of different frameworks including, but not limited to: Foucauldian Discourse Analysis (FDA), Feminist Discourse Analysis, Critical Discourse Analysis (CDA) and Discursive Psychology (DP). These methodologies developed through a critique of the ideas of cognitivism and the assumption that people’s language reflects their underlying thoughts and feelings (Willig, 2008). Within DA, language is viewed as a device used to manage social interactions and construct social realities, and the methodology allows questions to be asked about the actions that are performed, or limited, by the use of language. Discourse analysis is also concerned with what is gained, and what might be lost by certain constructions (Potter & Wetherell, 1987).

2.4 Foucauldian Discourse Analysis

Foucault popularized discourse analysis by exposing links between textual sources and powerful social institutions, highlighting concerns about domination and subordination. According to Foucault, discourse can be seen as a mediating lens that brings the world into focus by enabling people to differentiate the validity of statements, and ‘truths’ about the world. Foucault explained how statements accepted as ‘true’ were always historically variable, and come to exist, and be dominant through social relationships, technology and power. Foucault claimed that discourses systematically create and then reproduce social institutions (Holloway, 1997), and that certain dominant discourses serve to regulate and control people (Seale, 1998).

Discourses in this approach are defined as a ‘set of statements that construct objects and an array of subject positions’ (Parker, 1992), or in other words, ‘a body of knowledge'. This is a broad understanding of the term, in comparison to other definitions, such as that adopted within Conversation Analysis where discourse refers to 'language', meaning a linguistic system and where analysis focuses on functional aspects of speech. FDA focuses on the constructive nature of descriptions, rather than being concerned with the possible entities behind descriptions (Horton-Salway, 2001). Concepts of discourse, power and knowledge are central to FDA, as well as consideration of the historical context within which the interactions takes place (Edley, 2001). This means that within talk, people utilise a repertoire of terms which have been provided by history and culture. Language is then said to offer a way of constructing an 'object' however, some constructions are more available than others (Edley, 2001). FDA looks at the ways in which a topic has been constructed within a culture and point in time, and Foucault used 'archaeology' and 'genealogy' to perform a historical analysis of the development of specific forms of knowledge. In Foucauldian terms, 'archaelogy' refers to the analysis of knowledge, and 'genealogical' work focuses on issues of power and its relation to discourse and knowledge (Potter & Wetherell, 1987).

Within a Foucauldian approach, discourses are viewed as productive of the 'objects' of which they speak, as well as in terms of power (Arribas-Ayllon & Walkerdine, 2008). Foucault suggested that power is constituted through discourse, and that power is implicated in the construction of knowledge, and what 'counts' as knowledge. Certain discourses are more powerful and have more authority than others, therefore this study also pays attention to the social context in which knowledge and power is constructed and maintained. FDA can offer insights into how particular knowledge becomes dominant and taken-for-granted, whilst simultaneously silencing alternative interpretations of the world. FDA is also interested in analysing this process of normalisation, and questions whose interests are served or limited by different discursive formulations.

This study assumes that discourse is constructed, situated, and action-oriented (Edwards & Potter, 2001). These terms are described in more detail below:

2.4.1. Constructed: A central feature of interest is the constructive nature of accounts, rather than what might exist ‘in reality’ beyond the accounts. In relation to conceptualisations of dementia, the approach considers this to be ‘constructed’ rather than representing an exact description of a person’s inner, neurological or psychological state. However, Wittgenstein observes that ‘interpretations by themselves do not determine meaning’ (1967, p.198) and therefore the constructive nature of the study, as well as the ways in which the interpretation of the data is also constructed to achieve particular aims must also be acknowledged.

2.4.2 Situated: Discourse and the context in which it is situated is central to its understanding (Potter & Hepburn, 2005). Discourse can be a function of its setting, therefore the positioning and the interactional framework of the discourse should be considered (Sacks, Schegloff & Jefferson, 1974). Also, given the potential infinite variability of discourse, it is important to consider what might be omitted or “what could have been said” in order to understand its meaning (Potter & Wetherell, 1987).

2.4.3 Action-oriented: This involves analysis of the discursive contexts within which various constructions of the object are placed by asking “what is gained from constructing the object in this particular way?“ (Willig 2003, p.174). This involves recognition of different actions performed by the infinite variety of statements that could be made within a given context (Potter, 1996). Language is considered to be active, and constitutive, and as such, particular functions are served as a result of the construction (Potter & Wetherell, 1987)

Researchers that draw on Foucauldian ideas do not speak of their research ‘findings’ as it is recognized that ‘truth’ is contingent upon the subjectivity of the reader, and the changeability of language (Graham, 2011). The aim of the analysis is not to establish a final ‘truth’, but to question the ‘truths’ that have become taken-for-granted, resulting in a different relationship to those ‘truths’. The critical relationship to truth does not mean that there is no truth – rather it means that truths are always contingent and subject to scrutiny – which can open up powerful possibilities for change.

2.5 Reflexivity

Reflexivity relates to the consideration of the researcher’s identity and the way that the researcher interacts with the world and therefore the data (Taylor, 2001). From a DA perspective, neutrality of the researcher is considered to be impossible, because the research and the researcher cannot be meaningfully separated (Taylor, 2001).

Foucault was critical of the view of the individual being fully self-reflexive, unified and rational. Instead he saw individuals as being, to some degree, regulated and controlled by the structure and discourses within which they exist. The researcher’s identity influences the selection of the topic, the methodology and subsequent analysis, and as such it is important for the researcher to reflect and report upon their personal context and assumptions, as these are acknowledged to be inherent to conclusions drawn. Speer (2002) suggests that attempts to cover up any researcher bias can ‘stifle the very features of the interaction that are theoretically interesting’. As such, the issue of subjectivity was managed through the use of a reflexive diary, ideas from which are presented at the end of the paper.

2.6 Method

Details of the method employed in this study will be outlined in the following sections: recruitment, collection of naturally occurring talk, sample size and participants.

2.6.1 Recruitment

This project was interested in healthcare professionals’ constructions of dementia and the influence of the constructions on their work. Multidisciplinary clinical staff working on an Acute Organic Assessment and Treatment ward were asked to participate.

2.6.2 Naturally occurring talk

Discursive data can come from a variety of sources including written text, images, and talk. When using talk ‘naturalistic’ data is preferred over interviews (Potter & Hepburn, 1995; 2012). It has been argued that interviews produce a particular kind of interaction because participants orient themselves to the interview context. This is said to reveal more about the way in which a participant manages their stake as an interviewee than about the discursive repertoires that they draw on in everyday life (Willig, 2008). This study was interested in the discursive struggle which could arise from group discussions when different positions on care are voiced. Therefore, naturally occurring talk taken from a meeting where care was routinely discussed seemed the most appropriate way of capturing discourses in line with the research aims. Before the start of the meeting the participants were reminded of the research aims, the data collection process and the equipment being used to record the discussion. Prior to completing the consent forms, participants were also asked if they had any questions about the research and whether they had understood the aims of the study.

2.6.3 Sample size

Within DA studies groups can be sampled according to whether they participate within a given discourse; which can highlight ways in which people appeal to external discourses and recognize their influence on the discourse under study (Starks & Brown Trinidad, 2007). It was hoped that recruiting participants from various professional roles would allow the different positions and discourses about dementia to be identified.

The sample size for the study was guided by the methodology as well as practical considerations regarding the project timescale. Within qualitative research, large sample sizes are not needed to generate rich data sets as an individual person can generate hundreds or thousands of concepts (Starks & Brown Trinidad, 2007). As discursive work involves intensive analysis (Willig, 2012) large sample sizes may not add to analytic outcomes but instead render the process of analysis unmanageable (Potter & Wetherell, 1987).

It should be emphasised that DA is interested in discourse and not people, and therefore the aim was to sample discourse. Sample size within FDA studies is not prescriptive and as such strict guidelines on participant numbers were not applicable. However, previous published studies employing discursive approaches have tended to use between five and fifteen participants to generate material for analysis (Cheetham, Holttum, Springham, & Butt, 2018; O'Key, 2014).

2.6.4 Participants

Fifteen participants consented to being audio-recorded for the study. The sample included professionals in a variety of roles, inclusive of Consultant Psychiatrist, Junior Doctor, Pharmacist, Occupational Therapist, Staff Nurse, Clinical Lead (Nursing), Student Nurse, Consultant Clinical Psychologist, Trainee Clinical Psychologist, and undergraduate psychology student. Some participants were recorded in more than one meeting.

Due to the small sample size, demographic information that the participants provided is reported across the sample, rather than individually. This is to reduce the risk of participants being identified. The sample consisted of 7 males and 8 females. The age of the participants ranged from 20 years old to 51 years, with a mean age of 36 years. The range of experience working in care settings was from one year to 30 years, with a mean average of 14 years. Participants worked a mean average of 34 hours per week, with a range of 8 hours to 40 hours a week. Lastly, participants spent a mean average of 14 hours a week in direct contact with patients on the ward, with a range of 2 to 20 hours each week.

2.7 Transcription

Transcription can be considered a preliminary stage in the analysis as it involves decisions and stimulates analytic thinking and can involve repeated readings of sections of the data. Potter (2003) suggests that the process of carefully listening to the data is often when analytical insights are first developed. Therefore, I transcribed a portion of the data myself which allowed me to get to know the data by engaging in a close reading of the text and reflecting on this (Wooffitt, 2005). However, due to practicalities and time constraints it was deemed necessary to utilize an external transcription service to transcribe some of the discussions. Willig (2008) suggests that the process of transcription transforms the data and therefore transcripts can never be an exact representation of what was said. Therefore, I evaluated the quality of these transcriptions against the recordings, to check for accuracy and to allow myself to become familiar with the data.

The recordings of the discussions were transcribed verbatim. Transcriptions can include varying levels of detail, and the amount of detail selected depends on the theory and aims of the research project (Taylor, 2001). Since the aim of the analysis was to explore discourse, a modified, simplified form of Jeffersonian transcription was used (Rapley, 2007; see Appendix C).This system is commonly used in discursive studies as it can be adapted in accordance with the amount of detail required (Wooffitt, 2005). Full Jeffersonian transcription could present a challenge to the readability of the material, and for the research questions asked in this study it was considered unnecessary to transcribe the finer details of talk. Pseudonyms were ascribed to participants, patients and any other professionals that were referred to in the talk.

2.8 Coding

Foucault has been reported to have disliked prescription (Graham, 2011), stating ‘I take care not to dictate how things should be’ (Foucault, 1994). Therefore, there are no specific guidelines to follow for a researcher to ‘do’ an FDA. However, Willig (2008; 2012) offers a six-stage model of what she names ‘Foucauldian Discourse Analysis’ and these guidelines for analysis were drawn upon for the present study. The method described by Willig (2008; 2012) pays attention to the immediate interactional context as well as wider discourses and can be seen as fitting closely with Alvesson and Karreman's (2000) description of a 'middle range' approach. Transcripts were analysed in a number of stages.

2.8.1 Preliminary Coding: Following transcription, several close readings of the data were carried out, then an initial coding was performed. Coding involves organising and categorizing the text to identify patterns in language use (Taylor, 2001). This preliminary coding phase involved eliminating any material not relating to the research questions (Potter & Wetherell, 1987), and identifying a corpus of extracts deemed relevant to the research question (Georgaca & Avdi, 2012). As the data consisted of naturally occurring talk, this presented a challenge to deciding which material related to the research question, as participants were not asked directly to talk about dementia. Instead the conversations were held in the context of dementia care, therefore some of the talk might have initially appeared irrelevant or not specific to dementia e.g. conversations about mealtimes, food intake, vaccinations, number of visits from family. However, this data was still included and coded as it was considered to relate to the care that patients received, and also appeared frequently across the data. For these reasons only a small proportion of the data was eliminated in the preliminary coding stage. The data that was considered irrelevant to the research questions and project aims, included conversations about difficulties staff had experienced contacting care homes due to problems with phone lines, and where to locate various forms on the local intranet.

Manual coding was favoured over the use of word-processing, allowing the text to be scrutinized more thoroughly through becoming immersed in the text. The nature of the analysis in FDA is relatively open-ended as well as being circular. The researcher is required to look out for patterns in the data, whilst still being unsure of what these will look like or what the relevance of the patterns might be (Taylor, 2001). Conducting the analysis involves going over data again and again, by listening to recordings, or reading transcripts, and noting features of interest. By thoroughly getting to know the data, I was primarily able to get a sense of what the discussions were about, and secondly able to establish where dementia entered the discussion. This meant identifying instances, ways and means that dementia was spoken of, at which points, and to identify the objects of the discourse.

2.8.2 Secondary Coding: Analysis of discourse is an iterative process and involves going over the data repeatedly (Taylor, 2001). Notes were made about the constructions of dementia and other relevant observations. Transcripts were read through another time, while adding an increased level of detail into the coding. Following these stages, some emerging patterns and conflicting patterns could be paid attention to. This step involved organising the data into discrete coding categories, by re-reading the chunks of text to 'get a feel for them'. As possible patterns emerged, they were noted, but searching for patterns still continued, until there were a range of possibilities to explore further. The first passage read became the first member of the first category. Subsequent passages were read in the same way, and evaluated in relation to the first and considered in terms of whether it was similar or said something new. If the text could not be placed into an existing category, a new one was created, and each category was labelled indicating the content. I followed Potter and Wetherells's (1987) principle of inclusivity so if any passages of text had similar features to two coding categories, they were placed in both categories. This process was repeated until as much data as possible had been coded (see Appendix F).

The secondary coding stage produced a number of categories (see Appendix G). Inter-relationships between discourses could then be considered, as often themes can be interrelated (Taylor, 2001). This was taken to supervision for discussion (see Appendix H for supervision notes), during which I was also able to look for absences and silences, or what is not spoken about, or present that might have been expected. Due to the intense and in-depth analysis which is required in FDA studies, it is often necessary to focus on some categories at the expense of others, and leave unfinished avenues for later exploration (Taylor, 2001). Supervision discussions allowed me to focus on specific areas for analysis, ensuring that these were closely related to the project aims.

2.9 Analysis

The study aimed to investigate ways in which dementia was constructed in participants' talk, the discourses drawn upon, whether tensions and inconsistencies were present and how these were managed, and how actions related to these topics were accounted for and how participants positioned themselves and others within accounts. Potter and Wetherell (1987) suggest that the first phase of analysis should involve searching for systematic patterns in the data, which may be patterns of similarity or difference. Variation is identified as the most important principle in guiding analysis (Potter & Wetherell, 1987; Wooffitt, 2005). During analysis it was important that I remained open and flexible, so that categories were allowed to emerge from the text, instead of being imposed upon the data (Willig, 1998). Throughout the analysis I asked myself; "why am I reading the text in this way? What is being assumed?" and "what discursive features produce this reading?".

Willig's (2008) six stages of FDA were used as a framework for analysis, as outlined below. Willig's steps are designed to facilitate analysis rather than offer a formulaic or restrictive approach. These steps were applied to the coded material to produce the final discourses.

1. Discursive Constructions: This stage considers how discursive objects are constructed. The first task was to identify the 'discursive object' in the discourse e.g. how staff construct and talk about concepts of dementia both explicitly and implicitly. This involved highlighting all the incidences within the text that referred to dementia and the patients diagnosed with a dementia.

2. Discourses: This second stage examines the varying discourses. This involves highlighting the differences between constructions of objects, and locating the constructions within the wider discourse. This involved locating the different constructions of dementia, from biological, to psychological. From a Foucauldian point of view, discourses facilitate and limit, enabling and constraining what can be said, by whom, where and when (Parker, 1992). Since

discourses make available ways of seeing/being, they are strongly implicated in the exercise of power.

3. Action Orientation: This involves an examination of the discursive contexts in which these constructions are being used, and considering what the function or purpose might be of constructing dementia in certain ways. This stage involves asking questions about how discourses are used to construct, and how this may shape actual experiences in the social world. Consideration is given to what might be gained by the construction, and what the function may be.

4. Positionings: The fourth stage examines the ‘positionings’ of the ‘subjects’ described within talk. Discourses are viewed as constructing ‘subjects’ as well as objects, and these different positions offer discursive locations from which it is possible to speak/act. When subject positions are taken up, they have implications for subjectivity and experience. e.g. The subject position of ‘the patient’ within medical discourses can locate the individual as a passive recipient of care. This stage of analysis requires exploration of the subject positions which are offered through the particular constructions of discursive objects and the wider discourses on which they draw.

5. Practice: This stage concerns the relationship between discourse and practice. Discursive constructions and subject positions are considered to open up or shut down opportunities for action. As a result, certain practices can become legitimate within certain discourses. The connection between the constructions of dementia and the ability to perform or not perform certain acts of care was examined. Dominant discourses may exclude or marginalize, although this may be resisted as alternative constructions are always possible, and counter-discourses can and do emerge. Therefore, analysis also explores what can be said, and looks to highlight spaces in which new statements are created.

6. Subjectivity: This sixth stage considers the relationship between discourse and how people think/feel (subjectivity). This part of the analysis traces the outcomes of adopting various subject positions by drawing links between

discursive constructions and personal experiences. This stage in the analysis considered the possible subjective experience of particular subject positions within the construction. The concept is contentious within discursive approaches, and Edwards and Potter (1992) reject the notion of subjectivity and other cognitive constructs about the internal world. The notion of subjectivity is highly interpretive and requires more speculation and so this study drew primarily on stages one to five of Willig's (2008) guidelines.

FDA also takes a historical perspective and explores the ways that discourses have changed over time (Rose, 1999), and how certain discourses came to be established, which is known as archaeology (Kendall & Wickham, 1999). This was considered as a final stage in the analysis.

2.9.1 Ethical considerations

The study received ethical approval from the Faculty of Medicine & Health Sciences Research Ethics Committee at the host University. Approval was also granted by the Clinical Effectiveness meeting in the NHS Trust where the study was carried out.

2.9.2 Gaining informed consent

Crabtree and Miller (1999) have observed that the process of obtaining informed consent can be difficult and complex. Securing an individual's consent can be considered only the first stage in this process, as inevitably this leads to further issues such as whether this allows the researcher the right to use the data in any way they see fit.

Before signing the Informed Consent Form, participants were asked if they had any questions about the research, and whether the aims of the study had been clearly communicated. The Consent Form explained the voluntary nature of participation, the right to withdraw. It was also explained that direct quotes may be used in the study report and potential future publications would be anonymised. Consent was required from all members of staff who were scheduled to be present at the meeting. If one person did not wish to be recorded it would not be possible to redact their contributions due to the way in which the data was collected. Therefore there were some potential social pressures to consenting. However, as the meetings were part of standard practice on the ward, it was considered that this reduced any pressure to participate in the study. Also, it was stressed that if a member of the team did not wish to participate, an alternative group meeting could be identified as a source of data thereby reducing the pressure on any individuals.

2.9.3 Preserving confidentiality and anonymity

As previously stated, when gaining consent to participate in the study I assured participants that their anonymity would be protected. Anonymity of the patients being discussed was also protected as any patient-identifying information was redacted from the recording before I was able to access the recordings.

2.9.4 Risk of harm

It was considered unlikely that the study would cause distress to participants, particularly given that participation was not any more burdensome than ‘normal’ duties. However, as explained on the information sheet, there was an option to request additional support from the research supervisors, who are qualified health professionals, for participants experiencing distress as a result of participation.

2.9.5 Quality issues

It has been suggested that there are difficulties judging quality or validity in qualitative research as researchers often adopt a perspective that different people have different yet equally valid perspectives on ‘reality’ (Yardley, 2000). As outlined, this study adopted a social constructionist epistemology, thus favouring the existence of multiple interpretations of knowledge, and rejecting the notion of ‘absolute truth’. As such, the application of quantitative measures such as reliability and validity is contradictory to the assumptions underpinning the study, and is therefore meaningless (Reicher, 2000).

However, Madill et al (2000) point out that this does not mean that ”any interpretation is as good as another” (Madill, Jordan & Shirley, 2000 p. 13) and state that it is still important that qualitative research is open to scrutiny, and the credibility of findings is based on more than just the researcher’s authority. A number of criteria have been proposed to help judge the quality of qualitative research (e.g. Henwood & Pidgeon, 1992; Elliott et al., 1999), which are largely based around a clear and logical presentation of analysis, which is grounded in data and takes into account the researcher’s personal biases (Willig, 2008; Yardley, 2000).

The focus in discursive studies is the exploration of an interpretation of discourse and the discursive practices that constitute knowledge (Phillips & Hardy, 2002) and it has been suggested that discursive examinations are best evaluated by assessing the quality of the accounts they produce (Willig, 2008). This study is informed by the evaluation criteria of qualitative research presented by Madill et al. (2000), which are considered appropriate within a constructionist context, and are considered in more depth below. These criteria were held in mind throughout the analytic process, and the reader is also invited to consider these in order to evaluate the quality of this study.

2.9.6 Internal coherence

Internal coherence refers to the evaluation of the degree to which the analysis ‘hangs together’, and avoids any major contradictions. However, due to the idea that dementia is socially constructed, consistency in the ways that healthcare professionals talk about dementia and its effects is not expected. Instead, it is the analytic claims that are made in the study that should be coherent and demonstrate how discursive strategies are employed by healthcare professionals to construct dementia, and impact on the care that is offered. It is acknowledged that as a researcher, my understanding of the data may change through the process of analysis, and as a result I may produce inconsistencies.

This is also acknowledged by Madill et al. (2000), who suggest an alternative criterion for coherence as ‘the absence of abhorrent contradictions’ (p.13). Throughout the analysis, regular contact was maintained with the research supervisors to ensure that interpretations were of a high quality. Transcripts and audio recordings were reviewed and discussed with the research supervisors. Supervision conversations helped to ensure internal coherence and plausibility of the discourses, although this is not the same as inter-rater reliability which would be incompatible with the underlying epistemology of the project.

2.9.7 Deviant case analysis

This quality criterion refers to recommendations that researchers seek out material that challenges their developing theory in order to explain exceptions to the rule, as well as typical examples (Potter & Hepburn, 2005). Deviant case analysis is advocated in order to disconfirm patterns already identified, or to add richness to the level of analysis (Potter, 1996). It is suggested that this process enables the researcher to further demonstrate coherency of the study (Potter & Wetherell, 1987; Potter & Hepburn, 2005). Recruiting healthcare professionals working in various roles and settings was one way of seeking out potentially contrary discourses, which could support or challenge the findings of the study. However, what is considered deviant depends on the emphasis of the researcher and is therefore subjective.

2.9.8 Openness to reader evaluation

It is suggested that readers should be able to make their own evaluation of the analysis through the transparent presentation of the data and analytic process (Madill et al., 2000). This allows readers to either agree with the researcher, or to draw alternative interpretations. In order to aid this, a significant amount of data from the original transcripts is included. Reader evaluation considers if the study contributes to understanding and insights of the phenomena. The validity of discursive research is commonly referred to as the extent to which it demonstrates systematic transparency (Potter & Wetherell, 1987). In an attempt to address this I avoided assuming a ‘neutral’ position as researcher, and disclosed my epistemological position, and underpinning assumptions/biases. The extent to which the analysis was affected by my position was considered throughout the study, and is detailed in the reflexivity section. Reflective of Burr’s (1995) suggestion for increasing the transparency of discursive analysis, methodological processes and the analytic procedure are described in detail. To aid reader evaluation of the findings and to facilitate their own interpretations, extracts from the data are used throughout the analysis to illustrate any presented arguments (Potter & Wetherell, 1987). Large amounts of the original transcripts were included in the write up of this study, with the intention of allowing readers to evaluate the interpretations made. Grounding my interpretations in examples can allow the reader to appraise the fit between the text and the interpretation, and also allow readers to consider possible alternative meanings (Elliot, Fischer & Rennie, 1999). As part of the final stage of analysis, the findings were shared with the research supervisors as a trial of readers’ evaluations (Potter, 1996)

2.9.9 Trustworthiness of analysis

It has been argued that to interpret something is to change it (Willig, 2012), and therefore interpretation is required to be conducted responsibly. Researchers are thus encouraged to consider their own role in meaning-making, and to consider the theoretical, and practical implications of the sense they make of the data. Willig (2012) describes how interpretations are underpinned by assumptions that the researcher has about what is worth paying attention to, as well as their ethical and political commitments. In keeping with the intention to provide trustworthiness, a reflective diary was kept throughout the project. A reflective account is included in this thesis which was informed by entries in the reflective journal. It is hoped that this enables readers to consider the position of the researcher, as well as issues of power between the researcher, participants, and patients whose care was being discussed.

Madill, Jordan and Shirley (2000) acknowledge that the effect of the analyst on research findings can create a problem with credibility in qualitative research. They suggest that the quality of qualitative research should be evaluated against the logic of justification associated with the study's epistemology and through demonstrating internal coherence. In line with Yardley's (2000) recommendations for improving the credibility of qualitative research, my interpretations of the transcripts and the analysis were discussed in detail with my research supervisors. From a discursive stance, this process is viewed as a device to evaluate the extent to which my reading of the data could be followed, not that it could be repeated.

This study adopted a social constructionist stance, assuming that multiple, equally valid interpretations of knowledge are possible, and therefore acknowledging that different people could produce different readings of the data. The analysis is therefore not an attempt to report on an external 'reality', so member-checking, or evaluating the 'accuracy' of the results with the participants, was not considered an appropriate quality criterion.

Extended Analysis and Discussion

3.1 Introduction

In this section, the findings presented in the journal article will be presented first in order to orientate readers and contextualise the discourses that follow. In discursive research it is common practice to present the analysis and discussion alongside each other, and therefore this section is written following this format (e.g., Seymour-Smith, 2008; Stevens & Harper, 2007; Taylor, 2001). In the journal paper, three interconnecting discourses of dementia were described: severity and instability, progressive illness, and loss of insight. An additional discourse of finding hope through hopelessness was also discussed, which related to the practice of dementia care. In this section these four discourses will be expanded on, and I will pay attention to the benefits and limitations of the dominant discourses, as well as drawing attention to subjugated discourses.

Foucault was interested in power relations, and how power can operate in societies to create particular subject positions (Foucault, 1981). The aim of this section is to outline and describe the constructions of dementia, as well as the subject positions that these constructions make available for people with a dementia diagnosis, and the staff who are caring for them. Through these subject positions implications for ways of being and seeing are considered, as well as ideas around power and agency. The findings are drawn from the reading and re-reading of the transcripts, as well as wider research literature. I have sought to increase the quality of this analysis through use of the quality criteria framework provided by Elliot et al. (1999) which is described in the methodology section. However, it is important to clarify that I do not propose that this analysis includes all of the possible stories, or readings of the discourses or positions that are available. My own experiences will have inevitably guided my reading of the data, and therefore this analysis is only one of multiple versions that could be produced. The analysis that I present is also situated in a particular point in time, and if I were to re-read the data in the future, it is probable that I would find different things. In addition, the limitations of the word count for this thesis meant that I have been intentionally selective in what is presented in this section. I hope that the present analysis offers an interesting exploration of healthcare professionals’ talk about dementia, and the implications for people who are identified as needing dementia care.

The discourse of dementia and dementia care, only makes sense in a particular historical, institutional, political and ideological context. When a discourse reaches hegemonic status it becomes seen as ‘natural’/’right’ (and becomes ‘common sense’) because it is deeply rooted in its particular sociohistorical context (Foucault, 1990). FDA takes a historical perspective by exploring the ways in which discourses have changed over time and how this may have shaped historical subjectivities (Rose, 1999). Challenging the assumptions of dominant discourses can provide space for marginalised discourses, and give a voice to alternative perceptions (Speer, 2002). Generating discussion about care practices could also have implications for initiatives to improve practice in dementia care by questioning policies and legislation that may impede care. If taken-for-granted understandings delimit the possibilities for thinking and acting, then unmasking ‘common-sense’ understandings and transforming them into objects for discussion and criticism could open up more opportunities for change (Alvesson & Karreman, 2000).

Descriptions of dementia within the data are complex and multifaceted, although they could be summarized into several topics or ‘macropositions’ (van Dijk, 2009). Similar to other literature on dementia, the biomedical model underpins the dominant discursive construction of dementia. This discourse utilizes constructions of disease and neurological damage, but at the same time carries a personal responsibility to accept care from medical professionals. Foucault described how discipline is a force that operates to control and arrange, and is established through external organisations such as medicine or psychiatry (Foucault, 1977). For Foucault, disciplinary power results from normalization, a process where an ideal norm of conduct is constructed, and from this, people are rewarded if they conform, and punished if they deviate from this ideal. In this analysis, people with a diagnosis of dementia were required to follow a moral code of behavior that involved cooperating with staff and their agenda, but also having self-discipline and self-control.

3.2 Severity and (in)stability discourse

In the journal paper it was discussed how dementia was constructed as an unstable condition, that could vary in severity. One consequence of categorizing dementia in this way was that it became possible to categorise patients into different groups, those who were ‘severely ill’ and those who were less so.

Potter and Wetherell (1987) propose that within talk, accounts are constructed in ways that serve particular interests and perform various functions. It is suggested that these can become more visible when the subject positions taken up are exposed. The positions that are taken up should be considered as part of wider discourses that are available. Therefore, instead of viewing the talk as an indication of the speaker's individual intentions and effects, the institutions and dominant narratives within which they are spoken should also be considered. Foucault suggests that power and 'knowledge' constitute what we are as subjects, as well as what we know as objects (of knowledge). Within FDA, rather than focusing on how one person/group wields power over another, the focus is on the tools, techniques and technologies power relations work 'through and upon individuals' (O'Malley, 1996,189).

Within the talk the 'severely ill' patient often became subsumed by the dementia and the person/the dementia were spoken about as one, as more symptoms become tied to a diagnosis. When a person's actions are considered part of their illness, they become removed from the range of normalcy, and from being understood within their context. If symptoms are attributed to a person's dementia then this can rule out further exploration of the difficulties. This is not to suggest that difficulties or the symptoms displayed are not connected to dementia in some way, but potential problems arise when this excludes other explanations and is seen as the 'truth' about the patient's difficulties. Constructing dementia as a condition that could fluctuate positioned patients as being 'unstable' as too frequent 'change' was pathologized. The healthcare professionals were then invited to take up the corresponding 'stable' position. When staff take up the position as stable, balanced and rational experts, this adds power to their narrative, as it is legitimated by being spoken through an expert voice. A risk with this is that it further diminishes the patient's voice and ability to have input into their own care. When the patient is in the unstable position, this is irreconcilable with the staff team, and could serve to put distance between the staff and the patient, contributing to 'othering' the patient as they are seen as deviant (Bruens, 2014). By positioning themselves as stable, staff were able to present their decisions about care as credible/legitimate and morally sound, and manage issues around stake and accountability.

The staff team were able to utilize practices in an effort to try and reduce the severity of a patient's symptoms, including medication and behavioural interventions. In this way the expert staff team are positioned as having the power to 'reduce' the severity of dementia, or the symptoms that they observe in the patient. In the following extract, the team discuss a patient who had been placed under eye-sight observations as part of their care-plan. This practice distinguishes the patient as being someone who requires continual surveillance in order to manage their symptoms, and is an intervention typically used for controlling or managing so-called 'challenging' behaviours (James, 2011).

Jo: hhh (.) He's still fighting fit.

Jane: Yes:: (.3) no change.

Anna: Last week I'm afraid to say(.), still on eye-sight.

In this exchange, 'fighting fit' is used to describe how the patient has not changed, and following this excerpt the staff continue to talk about the 'lack of progress' they consider the patient to be making. Jo uses irony in describing the patient as 'fighting fit', as rather than literally meaning 'fit and well'. Employing this discursive technique could be a way of bringing lightness to a discussion around what is an otherwise intense and restrictive surveillance intervention. Jane also refers to the stability of the patient's presentation, as there has been 'no change'. However, this is constructed as the patient resisting the staff team, rather than resisting the dementia. Although the patient's dementia has not fluctuated, rather than being a sign of strength or stability, it is problematic for the team as they are locked into a battle (a 'fight').

For Foucault (1977) 'discipline' is a key mechanism by which power operates through and upon people. Foucault's concept of discipline has two meanings which are linked. The first is a set of practices that are enacted upon the body (or a group of bodies), such as segregation and surveillance. The second refers to a body of knowledge that develops from applying these techniques. Central to the concept of disciplinary power is 'normalisation', which is the construction of norms against which 'individual uniqueness can be recognized, characterized and then standardized' (O'Malley, 1996, p.189). Foucault (1981, p.10) defines institutions as the 'crystallisations' of programmes of disciplinary power when it is applied to specific problems. Through this lens, dementia can be viewed as a category, occupied by older people who display particular ‘problematic’ symptoms, who then become socially positioned through the disciplinary forces of power. People with dementia are more likely to be moved into institutions when they display symptoms which are interpreted as ‘severe dementia’, so that their aberrant behaviour can be supervised, contained and managed (and attempts made to ‘normalise’) through caregiving interventions and/or medication (Hyde et al., 2014; May, 1992; Sabat, 2008). Through separating the person from their symptoms, the staff team become distanced from the individual that they are caring for. Battling with the patient’s symptoms could be more morally acceptable than battling with the patient. In the extract Anna also acknowledges that continuing to utilize the practice of ‘eye-sight [observations]’ is not good news for the team, and is possibly something that is practised reluctantly (‘I’m afraid to say’). Staff are then in a conflict themselves as they are bound by the practices that are available to them, but that patients resist, and staff may also wish to resist employing.

Mitchell et al. (2013) note how people with dementia ‘frequently fluctuate’ (p.9), which can be ‘moment to moment, day to day, and week to week’. They note that even in the latest stages of dementia, people have been observed to have moments or times of clarity that cannot be explained by medical science. Therefore, instability could be a good thing because this may offer a space where wellness and connection can be made, which could offer hope for the patient or those caring for them. This is also a contrast to the discourse around people with dementia becoming ‘empty shells’ (Behuniak, 2011). However, the healthcare professionals in this study demonstrated how they can become caught between conflicting narratives of severity and instability.

Within this discourse where there were ‘really ill’ patients, there were also patients categorised as ‘not ill’ or not ‘authentically’ ill. A lack of change in a patient’s symptoms could be a sign of severity, and at other times it was a rationale for discharging the patient, as is seen in following extracts.

Jo: Clinically (.) she’s unchanged (.2) isn’t she basically?

Anna: She is.

Lydia: Yes (.2) she's just in her room day=in (.) day=out. Comes out to get her meals (.) takes them back to her room and brings her plate back to us later.

Anna: Yes.

Lydia: It's just getting her to wash herself (.3) she'll stay in her pyjamas and nightwear.

Jo: If the daughter's saying (.) she's fed up (.) she's going to take her mother home (.) we can't stop.

Anna: Hmm.

Jo: And there is no reason why we should stop her (.3) She needs to go and they need to sort out the accommodation. She doesn't have to be in a hospital to do that.

Anna: No (.) I totally agree, yes.

Jo: The risks are not that high that she cannot go back home. The daughter says she can stay with her (.2) until Sunday.

And a further extract from another similar discussion about discharging a patient:

Anna: Yes, exactly, yes.

Jo: He needs to go:.

Anna: He does, yes.

Jo: Yes.

Anna: There's no change with him (.2) at all.

The team draw on discourses around 'clinical change' as this was presented as an important determinant in whether or not the patient qualified for the 'clinical' care offered by the professionals. A lack of fluctuation (change) was problematised and could build a case for the discharge of a patient. In instances where there is a lack of change, this can pose a threat to the expertise of the staff team, and could exclude the patient from care due to being ‘unresponsive’. In some cases patients were not treatable (i.e. changeable) due to reasons deemed to be connected to ‘non-organic’ aetiology. However what appeared unspoken were the reasons why some patients were categorised as ‘not ill’ instead ‘mildly ill’, given the construct of dementia as a continuum of severity. In the next extract the patient that is being discussed has been labelled as ‘not ill’, and positioned as in need of ‘behaviour management’

Sam: She went into some care home (.2) and=then she came back, I was told.

Ben: OK: yes.

Rachel: She was one of (.) Dr B’s patients. Apparently, last night she was praying loudly.

Ben: She was praying?

Rachel: Loudly at 3 O’clock in the morning. She=said she didn’t like the care home, that’s why she was playing behaviour. That’s the same thing she did in the care home that-

Sam: Is it manipulative behaviour?

Rachel: Yes, it looks like it. It looks like she’s got kind of manipulative behaviour. Because I remember attending her tribunal for the Section 3 before (.2) and she said she didn’t like the care home (.) that’s what she said for her-

Sam: It might be a question of sending her on leave to a place and letting the care home know how to manage if that behaviour appears.

In this extract, ‘manipulation’ is constructed as a tool used by the patient in order to try and grasp some agency and influence over their care. The patient goes on to be referred to as ‘playing the system’, which acknowledges the ‘maze’ that makes up care pathways and has been reflected in past studies (Peel & Harding, 2014). It is implied that the patient is trying to gain access to a certain kind of care, however they are relatively powerless in influencing this (Ringer & Holen, 2016). However, as the patient is constructed as being able to ‘manipulate’ others, their needs become rendered illegitimate and not warranting care from the team as this is constructed as evidence that the patient is ‘not ill enough’.

3.3 Progressive illness discourse

The construction of dementia as a condition that would inevitably progress was embedded within a biomedical discourse. The construction of dementia as a medical illness was not necessarily an unexpected finding however, considering the setting where the discussions took place. The ward was labelled as being for patients with ‘organic’ problems, as opposed to the alternative ward for patients who are considered ‘functional’, so it not unsurprising that this construction underpinned some talk. However it is still of relevance to discuss because of the ways in which the discourse impacted on the care that was offered.

Within this discourse, people who were diagnosed with dementia occupied the subject position of the patient, locating them as recipients of expert care, often whether they wished to received it or not. From a social constructionist stance, it could be argued that a professional’s credibility is associated with the extent to which they subscribe to the narratives attached to professional bodies, which in this context could include the Royal College of Psychiatrists, the Nursing and Midwifery Council, and the Health and Care Professionals Council. By frequently referring to a model of dementia espoused by these professional bodies, this discourse becomes taken for granted and legitimated (‘epistemologised’) while linked to powerful institutional practices (Foucault, 1972). A dominant medicalised narrative can be linked to a tendency to offer pharmacological interventions, or look to biology for an explanation of a patient’s difficulties, as seen in the exchanges below.

Sam: [Because he disengaged] from (.) the previous care package, didn’t he?

Lydia: Yes.

Mike: That was part of the problem::.

Sam: And (.) he's accepting care <u>here</u>?

Mike: <u>Yes</u>, but it's much more structured, isn't it? Much more::, erm (.3) got lots of cues and we=still don't really know whether his stroke was causing him problems that led to his neglect,(.2) self-neglect.

Sam: His <u>memory's</u> still pretty poor.

Lydia: Yes.

Sally: And he'll need a financial assessment as well. So (.2) I think he probably (.) won't manage his finances.

Sam: He hasn't had a chest x-ray, has he?

Ben: No::

Sam: I'll chase.

Richard: So (.) he's the chap who had the (.) bleed, err, quite confused?

Sam:Yes. What do his latest bloods say?

Although in this discussion there is a suggestion about the patient's need for social and functional abilities to be assessed, this comes up against medical tests and the conversation about 'care' appears to get shut down. The more medicalised options (x-rays, blood tests) appear to be privileged over other avenues of inquiry (ability to manage finances), positioning the patient as the focus of an investigation and problem to be solved, as opposed to a person in need of support.

The participants described dementia as a neurological condition, placing it in the same category as 'brain damage' and 'stroke', and therefore reifying it as an 'illness'. These types of 'physical illness accounts' locate the management of the dementia in the hands of the professionals, and can disqualify non-professional understandings (Foucault, 1972). Being positioned as the patient within a biomedical discourse means that one's body becomes an object of legitimate interest to staff that may be exposed, touched and invaded in the process of treatment, which forms the practice of medicine and its institutions (Parker 1992). Across the talk there were frequent references to biological markers of health and wellbeing (e.g. weight, appetite, sleep) which supported the medicalized discourse and often led to care intervention being directed to the patient's body. These included prescribing medication, but also feeding structures to increase weight, and promoting adherence to 'bedtimes.' These physical markers of the patient's wellbeing could function to help 'normalise' the patient and demonstrate how the staff are able to actively 'do something' to change them.

Jo: Has she lost any (.) weight? Just because (.2) I was wondering if she was wanting-

Jane: Erm: (.5) no (.4) in fact, she gained 1.3 kilograms last week.

Jo: She gained?

Jane: Gained.

Jo: How much?

Jane: 1.3. I mean (.2) when she first came in, according to this, she was 37.6 kilograms.

Anna: That's very light, isn't it?

Jane: And (.) she's now 50.3.

Anna: Wow.

Jo: Yes, that's good.

Jane: So that's=a, quite an increase.

The next extract discusses the norms of sleep:

Sam: I asked him(.) how do you sleep these days? (.2) I don't sleep, I never slept at all, I'm always on the go. I don't know that we're going to be able to change him. It's just him as a person…

Lydia: Yes (.) it is (.) yes (.8) It's like a non-stop motor, isn't=it? It's just going <u>on</u> and <u>on</u> until it gets exhausted. And he gets red and red, and you can see it, he'll fight his sleep. He'll sit down and do this and he's like, no, it looks like he's not letting himself sleep, even though he knows he's tired. He'll say he's tired. Yes, have a sit down, no, he won't. He won't do it until eventually, he genuinely can't fight it anymore and then he'll go and have a good sleep and then it starts again.

Anna: So, and he's not sleeping great either, he didn't sleep last night. He slept really well two nights ago, apparently, he slept the whole night, and then last night he's been up all night and then he's been dozing in this chair this morning. Well he's been asleep when we came on shift in the chair in the lounge. But-

Similar to the previous discourse, the description of a patient's 'symptoms' (of illness) meant that the person with dementia could become lost in the discussions, as 'their problems' were presented in a way that was disconnected from them. This could build a rationale for medical intervention as it is seen as treating 'symptoms' rather than people. In the next extract, Lydia uses extreme case formulation when describing and listing problematic symptoms that the patient has displayed which helps to emphasise how 'unwell' the patient is. Extreme case formulation (Potter, 1996) is used to construct the idea of the patient's illness as unbiased and scientific, and this obscures idiosyncratic or subjective states.

Lydia: Because in the mornings (.) it tends to be handover that he's been quite settled:, pleasant:, and then he just gets <u>worse</u> as the day goes on. I've got a list here that, erm, I need to put together, of things he's done.

Sam: Continues to hit and punch (.2) put staff member once on the 19th, <u>punch</u>, put that staff member on (.2), what do you mean by punch?

Lydia: He continues to hit and punch, I think she meant to put <u>out</u> (.) but she put punch out.

Sam: Put out staff member on the 19th and 22nd. Verbally abusive to staff <u>and</u> patients. Was put in passive holds, which lasted for half an hour, this week. Refused to take medication at times, needs a lot of encouragement. Doesn't like to be interrupted and fiddling with things makes him more aggressive. Urinating on the floors a lot-

Lydia: He does that a=<u>lot.</u>

Sam: PRN used with little effect at times daily. <u>Zero</u> to four hours sleep daily. Verbally and physically aggressive, swearing, grabbing, kicking, punching doors, trying to hit people, moving furniture, even when other people are sitting at tables or on chairs. So:: he's not settled, it's getting <u>worse</u> (.2) I don't know whether that's the dementia getting worse (.) or it's medication making him worse.

Although extreme case formulation is not used to directly build a case for the worsening of the dementia, and Sam speaks tentatively ('I'm not sure'), both of the suggestions for the underlying cause of the behaviours are medicalised (dementia or medication). What is not spoken or acknowledged is the function of these behaviours or the context in which they occurred. The patient becomes objectified rather than their symptoms being considered a product of an interaction or specific circumstance. Subscribing to an 'illness' discourse of dementia was helpful in managing the professional's accountability, professional responsibility and competence, as the problematic symptoms are positioned as residing within the patient. In this way, this discourse overlaps with the 'instability' aspect of the first discourse.

Viewing dementia as a disease has been claimed to enable predictions about the likely speed and nature of deterioration (Holstein & Gubrium, 2000). Dementia is a chronic condition which is often characterised by an 'uncertain course', but drawing on explanations of dementia in terms of progression and stages over time enables those who care to predict and supervise the development of the condition (Innes, 2002). The progressive illness discourse could provide some sort of order and control to something that is often confusing, and can fluctuate as the previous discourse highlights.

This construction also offers a commonly available discourse amongst professionals. However, there is the potential to exclude some professionals, unpaid caregivers and patients from these discussions if they construct dementia in contrasting ways. Foucault referred to a hierarchy of ideas (Foucault, 1972) where some discourses are more powerful than others, which can overshadow or discredit lesser developed ideas. If ‘professional’ discourse excludes ‘non-professional’ speakers, then ‘expert’ speakers hold more power and become less open to challenge. Also, the focus on deficits associated with a deterioration in neurological functioning leads to a pessimistic view of the disease course, which Kitwood (1993) argues has limited the focus of research and treatment for dementia. In the journal paper it was highlighted how the inevitable progression of dementia was likened to the patient becoming ‘broken’ or that the person eventually becomes beyond repair. This echoes ideas of people being ‘as good as dead’ due to dementia (Sweeting & Gilhooly, 2008). The positioning of a ‘broken’ patient is inherently less powerful, which could be why patient voices have often been marginalised or excluded from research under the idea that they would not be able to meaningfully contribute (i.e because they cannot contribute in the ‘right’ way).

The deployment of scientific and medical discourses of dementia constructed the need for expert (determined and decided) interventions to support the patient (Foucault, 1977). However, the discourse of inevitable illness progression released the professionals from continuing to intervene at a certain point, if the symptoms or ‘illness’ is constructed as ‘out of our hands’. One risk of this discourse is that the professionals could discontinue care if there sense that nothing more can be done. Although it could be the case that there are no more medical options of ‘care’ that would be suitable, it is possible that other ways of caring could be identified and implemented, which would be in line with the holistic models of care which are recommended. However these alternatives were unspoken within the talk, suggesting that within this discourse, they were ‘unthinkable’ to the staff team (Deetz, 1992).

The professionals are also positioned in the middle of the conflicting narrative, where there is a moral imperative to intervene by offering care, but they are also made aware that they are fighting a losing battle. Staff and patients are both in less powerful positions because there is the sense that the dementia is an unwieldy force much stronger than them both. One way that staff resolved this conflict was to reinstall the problem within the patient, as seen in Sam's talk below:

Sam: Whether (.) he's one of these people that (.6) You're not changing them

Here is a response by Sam to conclude a conversation about tried and failed interventions. Although this construction could be illustrative of an acceptance of the limits of their professional capabilities, there is also a downside as the patient is put into a category 'one of these people'. This strikes a similarity of constructions of people in mental health settings who are labelled as 'treatment resistant' (O'Key, 2014).

Sometimes patients could not be 'changed' and there was a lack of clarity about whether this was to do with being more severely ill, or because the patient was 'uncompliant' or 'unaccepting' of care. How a patient was categorized could impact on the way in which care practices were presented. In some instances patients had a personal responsibility to accept care, but other times people were 'lost causes'. The boundary between these categories however was unclear and sometimes changed. In this extract that was also discussed in the journal paper, Jo describes the reasoning behind prescribing a patient a benzodiazepine, a medication used to reduce symptoms of anxiety.

Jo: The only thing he's on is Lorazepam because=I was concerned he would get a bit agitated (.) because he kept saying, I want to go home. And then at one point asking (.), said he was going to call the police, because I told him, well=actually, you're under a <u>section</u>, you are <u>legally</u>, we are allowed:: to detain you, because he=said, you <u>can't</u> detain me.

Anna: Yes:, he got <u>angry</u> hhh

Jo: Yes, yes. That=was the only reason I put the Lorazepam on (.), otherwise he's been very settled in himself.

Jo speaks tentatively when describing the 'only' medication used, and backs up this decision by introducing their own subjectivity into the narrative ('I was concerned') (Potter, 1996). There is a wariness in this talk, which could be a reflection on how there is a caution in assigning a person to the 'ill' category, and how this construction is contested.

3.4 Loss of insight discourse

Dementia progression was constructed as something that was eroding different parts of the person, one part of which was a person's 'insight'. Following on from the construction of dementia as an inner instability, patients' indecision or difference in perspective was sometimes pathologized within the talk and constructed as a sign of 'confusion' or a 'lack of insight'. This created an argument for care to be determined by 'expert' category membership (Johnstone and Frith, 2005), and the 'insightful' team.

Incongruity between the awareness of the patient and the professionals was commonly referred to. A 'lack of insight' could isolate the patient from others, particularly from the staff team. There was an accuracy implied in the 'expert' or professional accounts, which is a form of category entitlement (Edwards and Potter, 1992). The lack of insight discourse and the subject positions that can be taken up also link to how active a patient is able to be in their care. The patient is constituted by the prevailing relations of power as an 'un-insighful' clinical object with minimal influence over their care. Through this discourse the patient becomes the subject of interest to the 'experts' as seen in Sam's reaction to meeting a patient at one point in the meeting.

Mike: Yes. It's, I mean it may be a version of truth that he's relating it, if not the truth. So his daughter will probably have a (.), a visit shortly at this moment.

Sam: He could have been here all afternoon, just enthralled and captivated.

The position of the patient who has 'lost insight' feeds into narratives around a loss of power, as it positions the patient as vulnerable to being controlled by the dementia. Through the talk, staff drew on the concept of 'insight' as being something that could fend off dementia, and staff were driven to help patients achieve insight in order to manage their symptoms and gain agency. Staff could then become drawn to trying to persuade or change a patient's perspective, attempting to offer them the benefit of their (expert) insight, with the idea that this could somehow protect the patient.

Anna: You'll say something to him and he'll go, OK, OK, yes, and then carry on what he's doing (.) You'll say, can you stop that? Yes, yes, yes, one minute. And it's the same when you're trying to get his meds in him, he'll say, one minute, one minute. If he's in that zone, it's really difficult to distract him, so difficult.

The assumptions around cognitive impairment being linked to a loss of self have been traced back to the 17th century, when ideas were proposed about the self and the brain being identical in substance (Kontos 2004; Kontos & Naglie, 2009). This ideology laid a foundation for views of the 'modern self', where individuals are considered rational, autonomous, and cognitively determined. Dupuis et al., (2012) suggest that this concept also underpins discourses around dysfunction residing in a specific part of the body, which in the context of dementia is the brain. The result is that people can become divided into insightful or not, which can isolate one group from another. The patient is positioned as a disempowered victim of their failing or faulty brain. This discursive construction can function to reduce the patient's personal agency, as well as emphasising their need for input from expert intervention. The construction of people with dementia as victims is reflected in the discourse of patients 'suffering from dementia' (Mitchell, Dupuis, & Kontos, 2012).

This subject positioning carries a corresponding construction of the cultural and moral imperative to intervene in dementia, as it is considered that ‘they cannot help themselves’. The disempowerment of the patient over their behaviour or symptoms was often tied to an unawareness (‘lack of insight’) of their problem. However, becoming more ‘aware’ also had risks for the patient, as seen in the following excerpts:

Mike: He came to me and said (.) in no uncertain terms and said (.) it’s all nonsense. And he’d taken that on <u>board</u> but in doing that (.2) he’d, obviously, had to come to terms with the fact that he was that disturbed.

Next Jane refers to a similar scenario that she had observed, indicating that this is an easily accessible discourse:

Jane: But I think (.2) on Friday I had a sense that his insight is <u>better</u> than it’s been, and that’s very uncomfortable for him. So (.) erm:: (.) he actually asked to speak to him Friday and said he was struggling because he, you know, he was aware of, erm:, the type of thoughts that he was having and (.) because we talked about how helpful or not it would be to have somebody he could go to in the moment (.) to check out.

Jane is able to draw on two competing ideas around insight when she refers to whether ‘checking things out’ was ‘helpful or not’. This highlights how it was possible for the patient to become distressed by their ‘insight’ and therefore they were positioned as stuck in a bind between two options (insight or not), but there was a downside to both. In this final extract the patient’s awareness of their need for care and reliance on others could produce anxiety. Therefore the consequences of insight were not just a painful awareness of the dementia, but also of their positioning as vulnerable and in the hands of others.

Kit: He expressed he would like, <u>ideally</u>, like to return home. However: (.) is not opposed to go into a care home if this was necessary. He appeared anxious near the end of the assessment (.2) concerned whether his family were stating they did not <u>want</u> him home.

3.5 Hope in hopelessness discourse

Throughout the talk, stories of patients' difficulties appeared to evoke emotions of sadness and hopelessness in the professionals. This linked to the constructions of dementia as inevitably 'breaking' patients, and taking away 'insight', as well as what this meant for the lived experience of patients, as seen in the extract below.

Lydia: He likes company, he's <u>lonely,</u> he says.

Sam: Yes.

Mike: He's very lonely. He says all of his friends have died (.) and he doesn't really have any. I don't know what family-

Lydia: He's=got (.) err: (.) he's got a daughter but he's not in contact with her. Sorry, that was recorded from, I think, his social worker's assessment (.) when you're looking at his paperwork. When I talked to him about his daughters he said (.) erm, oh, yes, I don't see them but they've all got busy lives. I think she (.) one lives (.) but they just don't.

Anna: Oh that's sad.

As discussed in the previous three discourses, staff often took up positions where they were responsible to 'manage', 'do something' for patients. Western concepts of the way that human bodies and minds function are culturally determined. Metaphors of humans functioning like machines that can be fixed when broken are common, and this fits within a rational, technological world-view. When there is a search for a specific aetiology of a disease or dysfunction, this reinforces this view, and patients become fragmented into a collection of separate parts, that can be repaired or altered by different specialists (Mitchell, Dupuis & Kontos, 2012). This physical reductionism then obscures any social and psychological contributors to ill-health, and leads patients and clinicians down a route to try and ‘cure’ the disease (Dubos, 1965). When there is an expectation that something needs ‘to be done’, this can lead to more invasive medical practices (Parker, 1992).

As highlighted in the background section, considerable responsibility is placed on healthcare professionals to promote the personhood of patients, and to ‘deliver’ person-centred care. This is reflected in policy, for example, Objective 13 of the National Dementia Strategy specifies that staff involved with caring for people with dementia need to be equipped with the ‘right attributes and skills’ to provide good quality care (Department of Health, 2009). Such a responsibility implies that the professionals are empowered, and able to operate autonomously creatively, to provide opportunities for choice and engagement with patients. However, this study would suggest otherwise, which is consistent with similar studies in dementia care settings (e.g. Kontos, 2011; Scales, Bailey, Middleton, & Schneider, 2017). These findings suggest that the professionals’ empowerment was not straightforward and automatically granted, instead it was characterised by conflict and negotiation as staff can become caught between conflicting narratives. Despite this, there were occasions when staff were able to actively engage with their subject positioning to generate new, albeit limited, possibilities for action.

In the next extract the staff team discuss the use of ‘observations’, which are a practice involving surveillance of the patient to different extents. The patient in the discussion had been ‘placed’ on continual (‘one-to-one’) observations as an attempt to ‘manage his behaviour’.

Mike: I know, so he <u>needs</u> to be on it (.) but I don’t know if that’s why we’re noticing his way.

Alex: If we bring it down (.) intermittent obs[3], (.2) is that what you’re saying?

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[3] Reference to less intensive patient observations, which would involve observational ‘checks’ at specified time intervals (e.g. every five, ten or fifteen minutes)

Mike: Well I don't, I wouldn't want to suggest that because I don't think it's safe, but then: (.2) at the same time (.) I'm saying, I don't know whether that's having an effect on his behaviour.

Alex: Safe for other people, I'm not sure.

Anna: Because at times he's having to go onto two to one[4]*.*

Mike: I think we're in a double bind, aren't we?

Alex: Yes, because I wouldn't say he should go off it all.

Anna: No:

Mike: When he's on eyesight[5]*, how close are you to him? I mean like if he's (.) in that corner, I can be here.*

Anna: He's on arm's length[6]*, he's on arm's length I believe.*

Jo: Arm's length?

Anna: Yes (.3) but sometimes people sort of stand a little bit further away if he's walking, if he's getting agitated.

Jo: Yes. I mean if there's no one around, you could be in the corner, you don't have to be arm's length.

Anna: No, they don't stay at arm's length (.) if he's in the little lounge and stuff. It's only if he's (.2) I suppose, in the main lounge, wandering up to pictures.

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[4] Refers to two members of staff observing the patient at all times

[5] Refers to the type of observational practice: where the staff member is required to be able to see that patient clearly, but the distance between them is not specified

[6] Refers to closer observations than 'eyesight' as the staff member is required to be within one-arms-length of the patient at all times

*Jo:	Close proximity to other patients.*

Anna: That's when the problem is.

*Jo:	What does his families have to say (.) do they say anything, any comments from them, it's getting worse or?*

Anna: I don't see his family.

Mike: He doesn't have many visitors, as far as I'm aware.

This discussion provides an example of how the staff team operationalize an individualized approach to care, by combining ideas from various perspectives and introducing flexibility into the intervention. In this way, the helpfulness of the intervention was questioned and this made room for a new framework to be drawn upon. There is a resistance of 'official' observational practices as the team were unclear about the details of the care plan ('is he on eye-sight?'), which suggests that this is carried out more flexibly than the 'official' language would suggest. There is a space that opens up for staff to transform this practice into a more person-centred approach once they reject and then reinterpret the operationalization of surveillance methods. Previous studies have suggested that healthcare professionals in dementia care settings can be afraid to care for patients, and are fearful of doing what people want them to do (DeForge, van Wyk, Hall, & Salmoni, 2011) or that staff will break the rules in order to provide what patients want. However, this leaves the staff with a fear of being caught or punished (Kontos et al., 2010). This supports the idea that healthcare professionals in this acute care setting were caught between conflicting narratives about care, and this could also be linked to the suggested 'moral code' of professionals in care.

In the next extract, Mike attempts to un-medicalise the patient by suggesting changes to the pharmacological approach to care.

Mike: What would:: the response for a drug holiday be (3) if it was suggested?

Anna: For=a what?

Mike: A drug holiday (.2) in the nursing team.

Anna: What's that?

Mike: Oh (.2) erm (.2) taking him off stuff.

Anna: Oh (h), oh right (.) OK.

Mike: Do you think people would be (.2) horrified or?

Anna*: I don't know (.4) everyone's discussed that (.) his medication hasn't touched him (.) so I don't know if (.) I=think maybe taking him off Lorazepam (.2) I don't know. (1.5) I think it's sort of, people hope it's going to make a difference when they give it to him. And sometimes, to be fair, it does settle him:. Erm (.2) I don't know.*

However, there is reluctance noted by both Anna and Mike ('do you think people will be horrified?'), which highlights how the unmedicated approach could come up against resistance. Anna draws on the idea of the team's 'hope' that the approach used could 'make a difference'. This could reflect the need of the team to 'do something' actively as part of the moral code of practice. Also, if staff were to stop intervening then they become positioned as deskilled and disempowered. However, although a patient might not always 'recover', this should not mean that there isn't a need to enhance their quality of life. Mike talks about how this can feel uncomfortable for clinicians, but that hope can still be found.

Mike: And (.2) it felt like (.) a bit (.) it=was a painful sort of (.) half an hour I spent with him (.4), but it felt really hopeful because he was then able to (.) he wanted the opportunity to be able to check it out (.2) in the moment and make sure that he wasn't (.2) labouring under that misapprehension.

Extended Discussion

4.1 Summary of findings

This study aimed to ‘excavat(e) our own culture in order to open a free space for innovation and creativity’ (Foucault, 1988, p.163), by discussing the theoretical constructs of Foucault as they relate to dementia and institutional practices of acute dementia care. The analysis was framed within Foucault’s work on power and knowledge, which concerns the productive nature of these forces in shaping ‘realities’, and offers a way of analyzing possibilities and constraints that speakers may face.

This analysis illustrates a number of discourses of dementia that multidisciplinary healthcare professionals draw upon on an acute organic assessment and treatment ward. The analysis highlighted tensions between conflicting discourses drawn upon in this setting, and how these had to be negotiated by staff. Constructions of dementia were diverse and variable and included dementia as an inner instability, dementia as a progressive illness, and a condition that could cause people to lose ‘insight’. The analysis shows that the range of constructions available to healthcare professionals impact on the people that they care for, and their available ways of being and subjectivities. The way that dementia was constructed in talk had implications for power and could either open up opportunities for action, or shut them down. A salient feature of the analysis was the way that participants positioned themselves. Positions adopted such as ‘expert’, ‘protector’ and ‘helper’ of the people with dementia implicitly positioned participants in a position of power, often making decisions on behalf of and in the ‘best interests’ of clients. Discourses of ethical and professional duties were frequently drawn upon to justify their actions. The rhetorical strategies used within the talk to promote the credibility and legitimacy of the staff’s accounts were sometimes at odds with discourses of patient-centredness. Discourses of patients with dementia fluctuated between constructions of passive objects and recipients of care, and more active subjects who had much more personal agency.

The language surrounding dementia has implications for how we see and engage with people diagnosed with dementia. FDA also pays attention to the relationship between discourses and institutions. This means that discourses are not conceptualised as simply ways of speaking or writing, but instead they are bound up with institutional practices too, that is, ways or organizing, regulating and administering social life. Thus whilst discourses reinforce existing social structures, these structures in turn also support and validate the discourses. e.g. people with dementia become ‘patients’ who require medicating, observing/surveillance, normalising or containing which is then reinforced by the institution (Higgs & Gilleard, 2014). Therefore innovative, alternative care practices need to be ‘talked into being’ within the powerful institutions, not just working in opposition.

Foucault describes how the objectification of the subject is constituted through a number of different practices. One mode of objectification relates to dividing practices (Foucault, 1965), which can be both spatial and social. Dividing spatial practices involve physical separation from the social group due to exhibiting difference. Foucault suggests that the actions that occur within dividing practices are justified through science claims and the power that is given to scientific categories. When people becomes socially objectified and categorized, they are given separate social and personal identities. The practice of separating people with dementia into institutions can be considered reflective of this mode of objectification (Higgs & Gilleard, 2014). Foucault (1982) suggests a second mode through which people are turned into objectified subjects. This mode relates to the process of scientific classification, which for Foucault is the practice of making the body an object via a process of diagnostic tests. These actions stem from discourse that is given ‘scientific’ status (Foucault, 1982). Foucault demonstrates how at different points in history, specific scientific ideas about human social behavior were held privileged. Once given this privileged status, certain scientific classifications acted to specify societal norms. It has been argued that the medicalization of dementia has established the condition as an illness, and that this has become a taken-for-granted ‘truth’ (Bartlett & O’Connor, 2007). This study has highlighted the dominance of the medical discourse, despite this contrasting with recommendations for holistic, individualized, person-centred care for people with dementia. The ‘illness’ discourse was also reflected in constructions of dementia as an inner instability, and something that could cause a person to ‘lose insight’. Although these discourses were not directly referring to dementia as a ‘disease’, it could be argued that they are underpinned by similar discourses around pathology existing within individuals.

In this study patients who were constructed as being ‘compliant’ helped to give an illusion of collaboration which could function as being protective of the professionals’ conscience, as care practices undertaken on the ward sometimes involved limiting a patient’s freedom (i.e. through continual observations, or restricting their movements) which could conflict with the moral code of the professionals. The professionals were also able to justify some of their more contested practices by claiming the position of ‘protectors’ of patients. Through the instability, illness and loss of insight discourses staff were able to distinguish themselves as different from patients as they could take up the position of stable, healthy and insightful. Foucault (1965) suggests that labelling others as ‘unreasonable’ and distancing them from those who were considered ‘reasonable’ was detrimental to the communication between the two positions. Foucault was critical of the lack of communication with those who were described as unreasonable. Staff rationality and control was challenged by some patient’s resistance. Therefore in order for power to be shared, it could be useful for healthcare professionals to get in touch with patients at a social and interpersonal level, and consider what makes them similar. By treating patients as clinical objects, person-centred care becomes compromised.

The study showed how the medicalized discourse was able to be resisted and contested by staff, as were the medicalized care practices attached to the discourse. The participants were able to engage with the biomedical narratives in order to highlight the limitations of this discourse, and through acknowledging this, they could make a space where care practices were transformed.

4.2 Implications of the study

Discursive studies emphasise the contextual nature of their findings and that the results should not be viewed as ‘truth’ (Willig, 2008). Therefore, there are challenges to ‘applying’ the findings, when compared to the application to findings from positivist research. Instead of drawing comparisons between the two epistemologies, researchers have suggested that studies should be judged on their usefulness (e.g. Harper, 1999b). On a methodological level, this study represents the first discursive examination of constructions of dementia by multidisciplinary healthcare professionals working in an acute setting. By exploring how professionals construct their accounts as trustworthy and credible, and considering the implications for the care that is provided for people with dementia, the study has raised questions about how staff negotiate and resist contrasting discourses. It is important to acknowledge the pressure and conflict that healthcare professionals can become caught in, and to consider ways to support the workforce in order for caring roles to be sustainable.

Reviewing some of the dominant discourses about dementia can help to reveal the underlying assumptions that infuse the political, social and medical narratives that are told about the condition. Language matters, and when used in certain ways it can limit or shut down opportunities through its power. Language shapes and frames the way that people see the world, as summed up by Davis, Sumara, and Luce-Kapler (2000, p.15) “what is named [is] noticed; what is unnamed is unlikely to be seen”. This study has highlighted a wider diversity of constructions of dementia than might be assumed in a medicalised context. Professionals working in dementia care are therefore encouraged to be reflexively aware of the dominant and limited nature of certain discourses and challenge them, “rather than merely going along with them” (Hare-Mustin, 1994, p.33). Understanding the dominant discourses and what might underlie them is a key way of ensuring that negative attitudes and practices are questioned rather than accepted.

The severity and instability discourse could have implications for other professionals involved in the diagnosis of dementia. Diagnostic tools often rely on the principle that the participant responses represent fairly stable, internal states which are accessible through certain questions (Willig, 2008). The accurate categorizing of conditions via diagnosis is grounded in the assumption that disorders/conditions are empirically testable, have a cut-off between normal/abnormal, and it is possible to distinguish between different categories. The diagnosis of dementia can involve tracking changes in cognition and memory over a period of time. However, the professionals' 'clinical judgement' might be required to help interpret the assessment, yet this shows support for the confusion and contradiction that surrounds discourses of dementia even in professional discourse. The value of DA studies for reflecting on diagnostic categories has been demonstrated in past studies, for example in mental health diagnoses (e.g. Harper, 1995), whose reification is also often taken for granted. This is relevant today considering the range of new diagnostic constructions, following the recent renaming and recategorizing of dementia in the DSM-5 (APA, 2013), and could encourage professionals to think critically about 'taken for granted' knowledge of dementia to which they subscribe. The British Psychological Society (BPS) (2015) published guidelines for clinical psychologists about use of language, which emphasises the need to avoid language that could be alienating to service users. It is important for clinical psychologists to be aware of current discourse analysis findings, so as not to begin working with people with dementia whilst drawing on out-dated or unsubstantiated discourses. Through modelling the use of language which empowers rather than marginalises service users, clinical psychologists can thicken existing spoken discourse, which may influence other professionals that they work alongside. Clinical psychologists are also well positioned to support healthcare professionals and carers to explore their understanding of discourse and the implications of language, through offering education sessions or reflective practice groups.

The language surrounding dementia has implications for how we see and engage with people diagnosed with dementia. Openly exploring the numerous and sometimes conflicting understandings of dementia, and reflecting on the dominant discourses in dementia care could create a space for positive change (Dallos & Vetere, 2003). DA can highlight constraining effects of dominant discourses by deconstructing these, open up the way for more empowering discourses and inform novel interventions (Georgaca & Avdi, 2012). Clinical psychology was not involved in the care of people with dementia until more recently, although psychological factors are becoming increasingly recognized as important in understanding and treating the symptoms of dementia. A range of professions are employed within dementia care settings, in order to meet the broad and complex needs of patients (Mueller, 2017; Department of Health, 2001). An important part of a clinical psychologist's role is working in multidisciplinary teams (Christofides, Johnstone, & Musa, 2012) and it is suggested that clinical psychologists would benefit from paying attention to the language used within the teams, noticing which discourses are privileged and what the implications might be (British Psychological Society, 2015). There is an increasing awareness of the importance of psychological skills involved in delivering holistic, patient centred care. The information produced from this research could help to inform a teaching package delivered by clinical psychologists to other professionals or carers working in dementia care settings.

The diverse roles of clinical psychologists include offering psychological knowledge, formulating psychological processes and supervising staff (Johnstone, 2018). Clinical psychologists are well positioned to facilitate discussion and reflection with co-workers on the construct of dementia, issues of power and agency. Also, support could be offered to staff by helping to explore how professional identities may be bound up with particular values (or unspoken 'codes' of practice), which in turn influence the way that they operate.

4.3 Limitations

Any attempts to generalise these findings should be qualified by the limitations of the study. Although the study aimed to capture naturalistic talk, the knowledge that meetings were being taped recorded meant that the data was generated in a less familiar conversational format. As a result, participants may have drawn upon interpretive repertoires, and adopted subject positions that were not necessarily reflective of their typical behaviour beyond the meeting.

However, it is still suggested that the discursive resources evident in this study are likely to be reproduced in the conduct of participants outside of the study. The concept of ‘naturally occurring talk’ is contentious, as some researchers have argued that any research-prompted data is a contrived artefact. Speer (2002) questions if the concept of naturalistic data is meaningless due to the process of obtaining consent from participants and using recording equipment automatically contaminating the talk. It has been suggested that using semi-structured interviews to gather discourse is one way of identifying more informal discursive resources (Gilbert & Mulkay, 1984), which could have added to the range of discourses in the sample.

Within FDA, discourse is more than just talk, and extra-linguistic communication via body language, facial expression and tone of the speakers could have added more richness to the data. However, accessing this additional detail would have required video-recording of the meetings, utilising more than one camera to capture details from the entire group. This would have introduced greater researcher influence, thus compromising how naturalistic the talk would have been.

The discourses described in this study were only taken from a very specific setting, which only a small proportion of people with dementia will come into contact with. Therefore, the discourses that were revealed may not be relevant to healthcare professionals in other settings, such as memory assessment clinics (where dementia may be diagnosed), or residential (long-term and often end-of-life) care for people with dementia. It should not be assumed that the healthcare professionals from this sample would also construct dementia in the same way when speaking about patients in other services either. The discourses therefore only represent the participants’ constructions of patients with dementia in this particular acute care setting. The small size of the sample and the setting in which the data was collected causes ethical dilemmas about fully situating the sample, as full descriptive information such as age, gender and profession would reduce anonymity.

Finally, Foucault’s philosophies are complex and there are multiple interpretations and readings of his work. In a project with limited scope and word-limit, as well as being a less experienced analyst it is possible to do a disservice to Foucault’s ideas by oversimplifying. This study is also a personal reading, and only one of multiple interpretations, therefore bias is inevitable and unavoidable.

4.4 Future research

In additional discursive work it would be beneficial to deconstruct discourses of dementia in other settings, for example, long-term residential care. Future discursive work could help to explore the construct of ‘care’, and what constitutes care in different contexts. This would build on some of the ideas in this study, such as the notion that there is a ‘moral code’ that influences the work of staff. It would be useful to further deconstruct some of the discourses around needing to ‘do something’ or ‘change’ patients in order to demonstrate care, and trace this over time through Foucault’s ideas of archaeology and genealogy.

It would be useful to investigate the discourses about what kind of care different professional groups can deliver. People who are in the lower paid positions in care work, for example, ‘healthcare assistants’, have been noted to be undervalued and underpaid (World Alzheimer report, 2013; Moniz-Cook, Millington & Silver, 1997). This may limit or subjugate the voices of staff who are less powerful as they are in positions that afford them less ‘expertise’. Nonetheless, staff in these roles provide the majority of ‘direct’ (or ‘hands on’) care. Therefore, inclusion of these staff groups in further studies around care is highly relevant.

It ought to be acknowledged that non-professionals such as family, friends and neighbours make up the majority of care-givers in the community, where approximately two thirds of people with dementia live (Moniz-Cook, Clin, Millington, & Silver, 2007). Discussions about power, personhood and care are undeniably relevant to their experiences and actions as well, although this study has only focussed on paid staff in formal organisational settings. Further discursive research in this area would help to identify which constructions are context-specific, and the additional ways in which dementia is constructed.

The voice of the patient is notably absent in this study. However, throughout the data it was apparent that decisions about care were frequently made in the patient’s absence, rather than in collaboration with patients. It is important to note that people with dementia are increasingly speaking for themselves, and that these once subjugated discourses may now be gaining momentum. Personal accounts from people living with dementia can provide narratives that challenge the persistent association of dementia with decline and ruin, and contribute to new perspectives on what the experience of living with dementia may entail.

4.5 Conclusion

Whilst a ‘cure’ for dementia remains elusive, the logic is that dementia may continue to happen, and care in older age will continue to be needed even beyond the prospect of a cure. What defines our humanity is how we react to these occurrences, and how we allow people outside of societal norms to be cared for. Transformation of dementia care is needed, and is becoming increasingly important as the number of people diagnosed with dementia rises (Mitchell, 2013). Acknowledging the way that power operates through language calls for these issues to be highlighted and critiqued within professional and political domains. Common discourses of dementia as an illness need to continue to be questioned, in order to concentrate focus on the interpersonal and interactional influences in institutions offering care. The ‘official’ discourses around patient-centred care could conceal the power of the professionals, and obscure the dilemmas and tensions apparent when trying to practice in such a way. If issues of power are unspoken, then they risk being unacknowledged in dementia care, potentially leaving people diagnosed with dementia vulnerable to abuses of power.

Reflexive Section

The aim of this section is to outline the continuous decision-making processes that have influenced the contents of this thesis. Writing this section involved a process of describing, explaining and reflecting on various stages of the research. The reflections draw on entries made in a reflective journal, notes made on transcripts and supervision records which were kept throughout the research process. The purpose of this section is to allow my personal and theoretical biases to be explicit, so that readers can evaluate and redefine the claims and counterclaims that are made, as well as potentially increasing resonance with the reader. It is hoped that reflexivity can bolster the quality of this work (Elliot et al., 1999), and add rigour and trustworthiness to the study (Flick, 2006).

From a social constructionist perspective, all knowledge is considered value-laden, and it is unquestioningly influenced by the epistemological and ontological beliefs of the researcher. Therefore, it is important that the relationship between the research and the researcher's theoretical positioning is understood reflexively (Potter & Wetherell, 1987). As part of this, I feel that it is necessary to be transparent about the particular discourse analytic position which my thesis is situated in. This position relates to debates within discursive psychology about the existence of an objective 'reality' outside of discourse, as some postmodern discourse analysts argue 'there is nothing beyond the text' (Edwards and Potter, 1992). However, by taking up an extreme relativist position such as this it has been argued that the material dimension of human lives becomes overlooked (Yardley, 1997). Reflecting on this, I would like to emphasise that for this study, the merit and utility of a DA approach is the consideration of how socio-linguistic aspects of experience relate to material existence.

At different stages of this research I came up against confusion and questions from people about the concept of dementia as a social construction, and asked if this meant that I was questioning the 'existence' of the condition. To me this highlighted how the construct of dementia as a 'disease' or a biological disorder is so culturally embedded, and how it has become a taken-for-granted ‘truth’ that dementia exists and is ‘real’. Foucault (1973) discusses how medical institutions create a certain discourse, that implies that there is no discourse. Instead the knowledge of medicine is presented as factual and impartial. The resistance that I experienced about the notion of dementia as a social construction made these ‘truths’ of medicine even more apparent. Although I found this challenging at times, I also found that it spurred me on in my efforts, as it highlighted the need to challenge the dominant discourse.

When developing this project, I initially found it difficult to be concise about my aims and clearly define the research questions. Having completed an FDA previously, I had experience of utilising the methodology to draw on multiple sources of information as a way of contextualising my findings, and highlighting how knowledge might have come into existence. I was also familiar with how many different questions come into the analysis stage (e.g. ‘truth effects’, the rhetorical and discursive devices used etc). Therefore, when formulating my research aims, I noticed that I was already tending to leap to later stages of the methodology, and gather numerous resources relating to dementia and dementia care. The amount of available information was limitless but this led me down lots of different paths. Although I had been accumulating information that I felt would be helpful when getting to the analysis stages, this resulted in an overly broad aim, as so many pieces of work drew my attention, and it was difficult to focus on the contribution of my own project. In the end I had to be pragmatic about how much I included in my background literature and analysis, due to the scope of the project. One comfort that I drew was that I wanted to do a smaller project justice and do it well, and by looking too broadly I risked alienating readers and others from the project because it could feel unclear and woolly, or lose any nuance. Curbing my enthusiasm to race ahead into my analysis was also important so that I didn’t just produce a ‘reading’ of talk, but instead I was able to go through a rigorous methodological process. In order to do this I had to track back, and drill down into what it was that I was hoping to focus on, and what the intentions of the project were.

Also, when putting together the aim I noticed that I often struggled to verbalise ‘why the project was important’, and the clinical utility of the results. This was perhaps partly due to my passion about the research area because to me it was obvious that ‘of course’ it was important, useful, necessary etc. Reflecting on this helped me to see how embedded my assumptions were. Coming up against different viewpoints and opinions where I had to convince and present an argument for ‘why it was important’ was helpful because it helped me to detach a bit from my own views, and I was exposed to other ways of seeing/understanding dementia.

In the planning stages of the project I had wondered about video-recording the meetings, as a way to add depth to the data through noting non-verbal gestures amongst the talk, such as shrugging or eye-rolling. These gestures and signs could also be considered discourses within an FDA framework, and were details that felt very relevant, particularly because it could help to tell me about what was ‘not said’ or a less acceptable discourse. Not having access to the details meant that I would be drawn to inferring and imagining the non-verbal signs that accompanied the talk, and this would bring in additional bias which could mean straying from the data. However, on balance it was considered that video-recording would risk a greater researcher influence in the discussions as the researcher would be more visibly ‘present’ by having one or two pieces of more obvious equipment in the room, which would have been required to capture the signs of all members of the group.

Also, this study was not concerned with the micro-level of talk, and there was a risk of being perceived as critical, and threatening by focussing on <u>who</u> was saying what. My concern was to do with being considered to be judging individual speakers on their ‘views’ or ‘beliefs’ or ‘competence’, which could have led to participants holding back for fear of scrutiny, or to present a more socially desirable narrative. Instead it was important for me to emphasise that I was interested in capturing what language is available, and what discourses were drawn on, rather than what staff ‘meant’. It felt important to consider the findings in terms of what these mean for the ways that patients are positioned, rather than being blaming or critical of staff. I wished to emphasise this out of compassion, appreciation and respect for the work that staff in dementia care do, but also for methodological reasons. I was conscious that as a researcher I could represent a judgemental gaze (ironically not unlike the one that patients are subject to), and this could give a false representation of the talk that occurs in these meetings. However, even with this awareness I consider the discourse would still be valuable as it could be considered representative of a ‘politically correct’ discourse, or ‘textbook’ professional discourse.

From a Foucauldian viewpoint, the analysis that is presented is itself a discursive construction and thus cannot be evaluated outside of the discursive framework (Willig, 2008). This means that as a researcher I am unable to claim that I have ‘discovered’ knowledge about constructions of dementia. Instead the analyses should been considered in the light of my own reflexive awareness of how they have been co-authored with participants, and the literature drawn upon.

At many points I have struggled with some of the phrasing in this write-up. In particular I have been torn about using the term ‘patient’, and even at one point caught myself using the controversial term ‘sufferer’ of dementia. This could be seen as an indication of how readily available this discourse is. My concerns around the use of the word ‘patient’ meant I was conscious of whether I was subscribing to medicalized language, and reinforcing the biomedical discourse of dementia. As a trainee clinical psychologist it is common to use the phrase ‘service-user’ in clinical work. However, I am aware of the lack of choice some patients had about ‘using’ the service that this study took place in. In the end I settled on the term ‘patient’ as I considered this a more accurate reflection of the positioning of the people admitted to the ward, where they were often ‘done to’ by medical professionals.

I have wondered about the extent to which my preconceptions about what might constitute the dominant discourses has resulted in me seeking confirmatory evidence to support these ideas. My interest in the topic area and motivation for clinical training derive from inspiration from my Grannie, who was diagnosed with Alzheimer’s disease and was cared for in a residential home for the last four years of her life. My personal feelings about the quality of dementia care, and disappointment and frustration about how dementia is commonly portrayed, influenced my desire to work in developing models of care for people with dementia.

The concept of bracketing, or holding back/setting aside my own views is not something considered possible within FDA studies. I felt that this allowed me to be transparent about my biases and attitudes and experiences of dementia care, and acknowledge my cynicism about (some) care practices. I was able to take ownership of this but still be open to be challenged and surprised by the research findings, which was supported through the supervision process. In line with its epistemological assumptions, this study has enabled me to channel my idiosyncratic constructions of the world into the research, and its subjective nature could be viewed as a strength.

Word count: 24473

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APPENDIX A. PARTICIPANT INFORMATION SHEET

The University of Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

Participant Information Sheet

REC ref: 147-1709

Title: **A discourse analysis of constructions of dementia by healthcare professionals working on an Acute Organic Assessment and Treatment Ward**

Name of Researchers: Hannah Matkin, Professor Roshan Das Nair & Dr Nima Moghaddam

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?

This study is being conducted as part of a Clinical Psychology doctoral thesis at the University of Nottingham. The study aims to explore staff discussions about caring for patients with dementia on an Assessment Ward. The study is interested in how dementia diagnoses are understood and how decisions about patient care are made. Previous research has considered the challenges that staff face when working with people with dementia, as well as the different factors that influence how decisions are made in care settings.

Why have I been invited?

You are being invited to take part because you are involved in caring for people with dementia as part of your job, and you will have input into the care that is offered. We are inviting between 5 and 25 participants like you to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a Consent Form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

A researcher will come to your place of work to conduct the study. If you do agree to take part we will ask you to sign a Consent Form that states that you have agreed to take part.

You will also be asked to provide some basic information about yourself (e.g., age, gender, job role). This part is optional and you are not under any obligation to provide details you are not comfortable with. We will not ask you to provide your name with these details, therefore the information will be anonymous. The reason we are collecting the information is to provide a background for the study, and to help describe where the information has come from.

If you and other members of staff agree to being involved, a researcher will use an audio-recorder to record a staff meeting where you discuss the care of patients with dementia. We would like to record a meeting that would normally take place on the ward, and that reflects normal practice - such as a Discharge Meeting or a Decision Support Tool Meeting. The researchers will not be present during the meeting.

The meetings will involve discussions about specific patients on the ward, and, in order to keep the identity of patients confidential, we ask for you to only refer to the first name or initials of patients. We also ask that other details such as addresses are not disclosed. If any patient details are spoken about which might identify patients to people outside of the meeting, then please let the researcher know afterwards. The tape recordings will be reviewed before the researcher leaves the hospital and any information which might identify patients will be erased.

The time it will take for the study varies depending on how long your meeting goes on for. We are aiming to record between four and eight meetings in total, over a period of approximately two months. You may be involved in more than one of the meetings.

The conversations that are recorded will be used as part of the project.

Expenses and payments

Participants will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?

We hope that agreeing to participate in the study will not add any additional burden to your normal work duties. We are aiming to record meetings that would be scheduled to happen anyway, and reflect the usual practices of the ward.

The researchers do not anticipate that you will put yourself at any risk by taking part in the study. However, before you decide whether or not you wish to take part, please take time to read this information sheet carefully. It is important for you to understand what the research will involve. You can keep this information sheet.

You are free to refuse to join the study and may withdraw at any time, without having to give a reason. However, as the tape recordings will be anonymous, if you decide to withdraw at a later date we will not be able to destroy your data as it would not be possible to identify which information is yours.

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing, and dignity. This study has been reviewed and given favourable opinion by *[insert details after ethical approval]*

What are the possible benefits of taking part?

We cannot promise the study will help you with any issues you face at work. However, we hope that the information you provide will contribute to a better understanding of your experiences and any challenges face you as a healthcare professional working in dementia care.

What happens when the research study stops?

The data collected will be analysed and written up. If you would like to receive a summary of the study results, please provide contact details for this. Your details will not be linked to any of the data. Once the study has finished you will be contacted with the results.

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 [XXXXXX]*

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.

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.

The recorded discussions from the meetings will be transcribed by the researcher and an external transcription service. The transcription service that is used will be required to sign a confidentiality agreement before being given the recordings. All participants will be assigned a code-name which will keep your identity anonymous. As the researcher will not have observed the meeting, they are also less likely to know who was speaking.

Anything you say will be treated in confidence, and no real names will be mentioned in any reports of the study. Your real name will not be written anywhere except on the Consent Form which will be kept separately and will not be associated with the transcribed conversations. Quotes of what has been said might be used in the write-up of the study, but again you will not be identifiable.

Although what you say in the meetings 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. However, the purpose of the research is not to look for any of these issues.

All 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 will have access to your personal data.

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?

The results of the study will be presented at the department of clinical psychology at the University of Nottingham. We also hope to submit the research for publication in journals of psychology. You and your place of work will not be identified in any publications.

Who is organising and funding the research?

This research is being organised by the University of Nottingham, conducted by Hannah Matkin, a Trainee Clinical Psychologist and is being funded by the University of Nottingham.

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 the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee.

Further information and contact details

If you would like any more information please contact me at:
Yang Fujia Building
Jubilee Campus,
Wollaton Road,
Nottingham,
NG8 1BB
If you have any concerns or complaints you can also contact my project supervisor Professor Roshan das Nair at the same address or by telephone 0115 8468314

APPENDIX B. CONSENT FORM

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Title of Study: **A discourse analysis of constructions of dementia by healthcare professionals working on an Acute Organic Assessment Ward**

REC ref: RGS 17075

Name of Researcher: Hannah Matkin

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet version number 3 dated 22.08.17 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 cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that the conversation from the group meeting will be recorded and that anonymous direct quotes from the meeting may be used in the study reports. I give permission for members of the research team to have access to anonymised transcripts. ☐
4. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities (eg. Research Support Officer, R&D audit) 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. ☐
5. I agree to take part in the above study. ☐

________________________ ________________ ______________________

Name of Participant **Date** **Signature**

_____________________________ ________________ ________________________

Name of Person taking consent Date Signature

2 copies: 1 for participant, 1 for the project notes which will be kept in a secure location.

APPENDIX C. DEMOGRAPHIC INFORMATION SHEET

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

PARTICIPANT DEMOGRAPHICS
(Draft Version 1: 4.8.2017)

Title of Study: A discourse analysis of constructions of dementia by healthcare professionals working on an Acute Organic Assessment Ward

REC ref: RGS 17075

Name of Researcher: Hannah Matkin

Please fill in the following details about yourself.

Please leave out any details that you do not feel comfortable providing. Do not include your name on this form, as the information will be kept anonymous.

Age:

Gender:

Job title:

Number of years working in care settings:

Average number of hours you work per week:

Approximate number of hours per week you spend directly with patients:

APPENDIX D. ETHICAL APPROVAL CONFIRMATION

University of Nottingham
UK | CHINA | MALAYSIA

Email: FMHS-ResearchEthics@nottingham.ac.uk

Faculty of Medicine & Health Sciences
Research Ethics Committee
c/o Faculty PVC Office
School of Medicine Education Centre
B Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham, NG7 2UH

26th October 2017

Ms Hannah Matkin
Trent Doctorate in Clinical Psychology Student
c/o Professor Roshan das Nair
Professor of Clinical Psychology & Neuropsychology
Division of Psychiatry and Applied Psychology
C22, Institute of Mental Health
Jubilee Campus
Nottingham
NG8 1BB

Dear Ms Matkin

Ethics Reference No: 147-1709 **– please always quote** **Sponsor Ref:** RGS 17075	
Study Title: A discourse analysis of constructions of dementia by healthcare professionals working on an acute organic assessment ward	
Short Title: Discourse analysis of constructions of dementia	
Chief Investigator/Supervisor: Professor Roshan das Nair, Professor of Clinical Psychology & Neuropsychology	
Lead Investigators/student: Hannah Matkin, Trent Doctorate in Clinical Psychology Programme, Division of Psychiatry and Applied Psychology.	
Other Key Investigators: Dr Nima Golijani Moghaddam, Research Clinical Psychologist and Tutor Trent DClinPsy Programme, School of Psychology, College of Social Science, University of Lincoln, Dr Danielle De Boos, Assistant Professor and Clinical Tutor, Division of Pscyhiatry and Applied Psychiatry, University of Nottingham	
Type of Study: DClinPsy student project, mixed methods, healthcare professionals	
Proposed Start Date: 10/2017	**Proposed End Date:** 28/02/2018 4 mths
No of Subjects: 16-70	**Age:** 18+years
School: Medicine	

Thank you for submitting the above application which has been considered by the Committee at its meeting on 11 September 2017 and the following documents were received:

Discourse of analysis of constructions of dementia:

- IRAS data set
- Evidence of Insurance, University of Nottingham, July 2017
- Evidence of Sponsorship University of Nottingham dated 23.08.2017
- Protocol version 3.0 date 22.8.2017
- NHS to NHS confirmation of pre-engagement checks
- Participant Information Sheet Draft 3.0 22.8.2017
- Participant demographics, draft version 1: 4.8.2017
- Consent form draft version 1: 4.8.2017

These have been reviewed and are satisfactory and the study has been given a favourable opinion.

APPENDIX E. GUIDELINES FOR AUTHORS FOR ‘DEMENTIA’ JOURNAL

This Journal is a member of the Committee on Publication Ethics.

Please read the guidelines below then visit the Journal’s submission site http://mc.manuscriptcentral.com/dementia to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of Dementia will be reviewed.

There are no fees payable to submit or publish in this journal.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Dementia, please ensure you have read the Aims & Scope.

1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

Dementia also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 2,500-3,000 words. Innovative practice papers should include the words 'Innovative Practice' after the title of their article when submitting to the journal. For further information about innovative practice papers, please refer to the guidelines.

The journal also publishes book reviews.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

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2. Editorial policies

2.1 Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission,
- The reviewer should not have recently collaborated with any of the authors,
- Reviewer nominees from the same institution as any of the authors are not permitted.

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

2.4 Funding

Dementia requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of Dementia to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations here.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

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3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

Dementia and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.1.2 Prior publication

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4. Preparing your manuscript for submission

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dements). Language that might be deemed sexist or racist should not be used. All submissions should avoid the use of insensitive or demeaning language. In particular, authors should use 'dementia-friendly' language in positioning people living with dementia in their article and avoid using pejorative terms such as 'demented' or 'suffering from dementia'. We recommend that authors refer to the Dementia Engagement and Empowerment Project (DEEP) guidance which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information. Alternatively, Alzheimer's Australia sets out guidelines for dementia-friendly language. Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage, please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

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For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

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This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

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4.5 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

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5. Submitting your manuscript

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Visit http://mc.manuscriptcentral.com/dementia to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

Innovative Practice papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Jo Moriarty jo.moriarty@kcl.ac.uk.

Books for review should be sent to: Book Review Editor, Dementia, Caroline Swarbrick University of Manchester, UK caroline.swarbrick@manchester.ac.uk

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a persistent digital identifier that distinguishes researchers from every other researcher and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities ensuring that their work is recognised.

We encourage all authors to add their ORCIDs to their SAGE Track accounts and include their ORCIDs as part of the submission process. If you don’t already have one you can create one here.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

5.3 Permissions

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6. On acceptance and publication

6.1 SAGE Production

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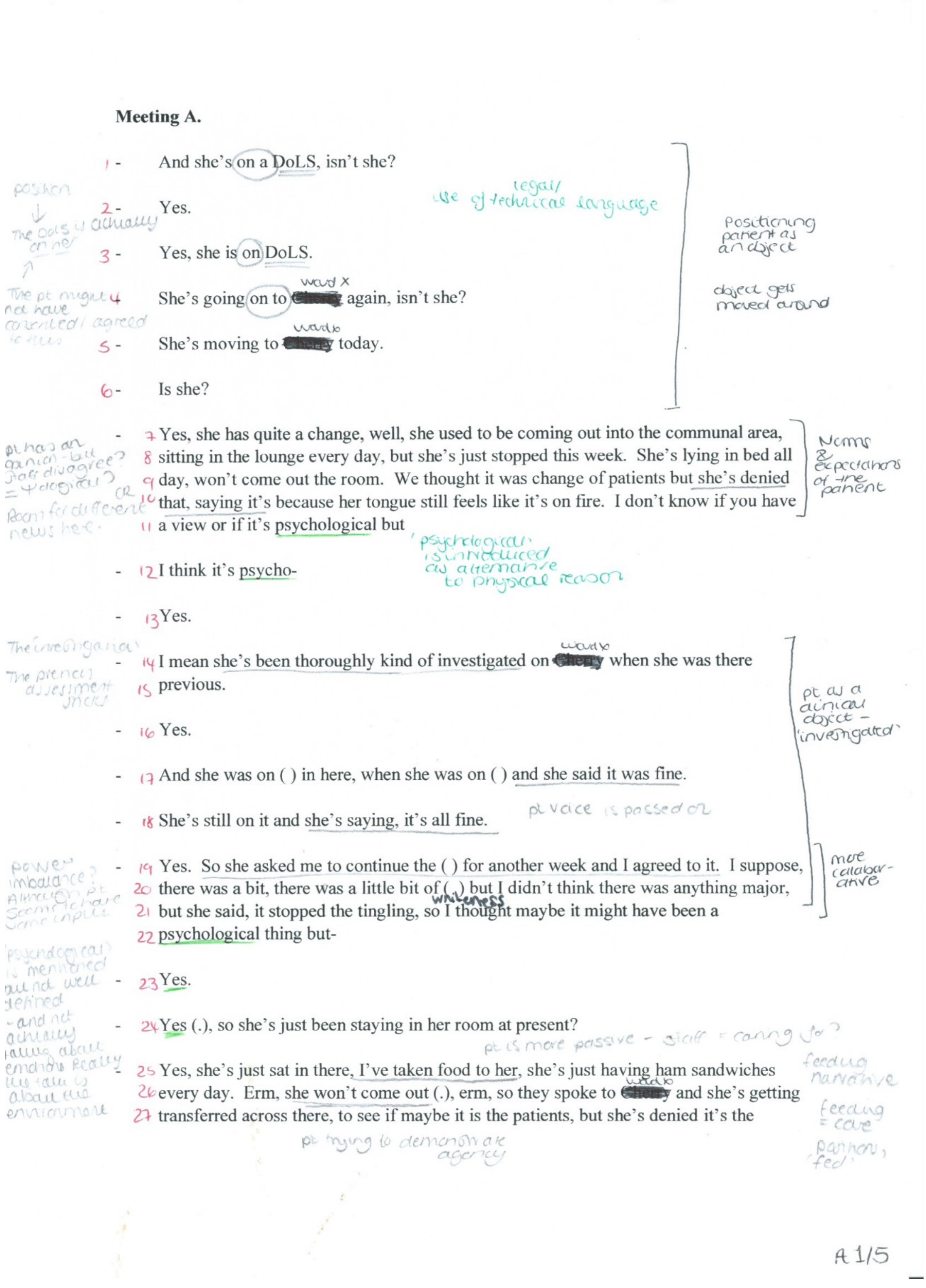
7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Dementia editorial office as follows:

dem.pra@sagepub.com

APPENDIX F. TRANSCRIPT PROCESS NOTES



Meeting A.

- And she's on a DoLS, isn't she?
- Yes.
- Yes, she is on DoLS.
- She's going on to [redacted] again, isn't she?
- She's moving to [redacted] today.
- Is she?

legal/ use of technical language

Positioning patient as an object

object gets moved around

position ↓ The DoLS is actually on her ↑ The pt might not have consented/ agreed to this

ward x

ward b

- Yes, she has quite a change, well, she used to be coming out into the communal area, sitting in the lounge every day, but she's just stopped this week. She's lying in bed all day, won't come out the room. We thought it was change of patients but she's denied that, saying it's because her tongue still feels like it's on fire. I don't know if you have a view or if it's psychological but
- I think it's psycho-
- Yes.

pt has an opinion - but staff disagree? = psychological? OR Room for different views here.

Norms & expectations of the patient

'psychological' is introduced as alternative to physical reason

- I mean she's been thoroughly kind of investigated on [redacted] when she was there previous.
- Yes.
- And she was on ( ) in here, when she was on ( ) and she said it was fine.
- She's still on it and she's saying, it's all fine.

ward b

The 'investigation' The previous assessment sticks

pt as a clinical object - 'investigated'

pt voice is passed on

- Yes. So she asked me to continue the ( ) for another week and I agreed to it. I suppose, there was a bit, there was a little bit of ( ) but I didn't think there was anything major, but she said, it stopped the tingling, so I thought maybe it might have been a psychological thing but-
- Yes.
- Yes (.), so she's just been staying in her room at present?
- Yes, she's just sat in there, I've taken food to her, she's just having ham sandwiches every day. Erm, she won't come out (.), erm, so they spoke to [redacted] and she's getting transferred across there, to see if maybe it is the patients, but she's denied it's the

whiteness

ward b

power imbalance? Although pt seems to have some input

more collaborative

'psychological' is mentioned but not well defined - and not actually talking about emotions. Really the talk is about the environment

pt is more passive - staff = caring for?

feeding narrative

feeding = care

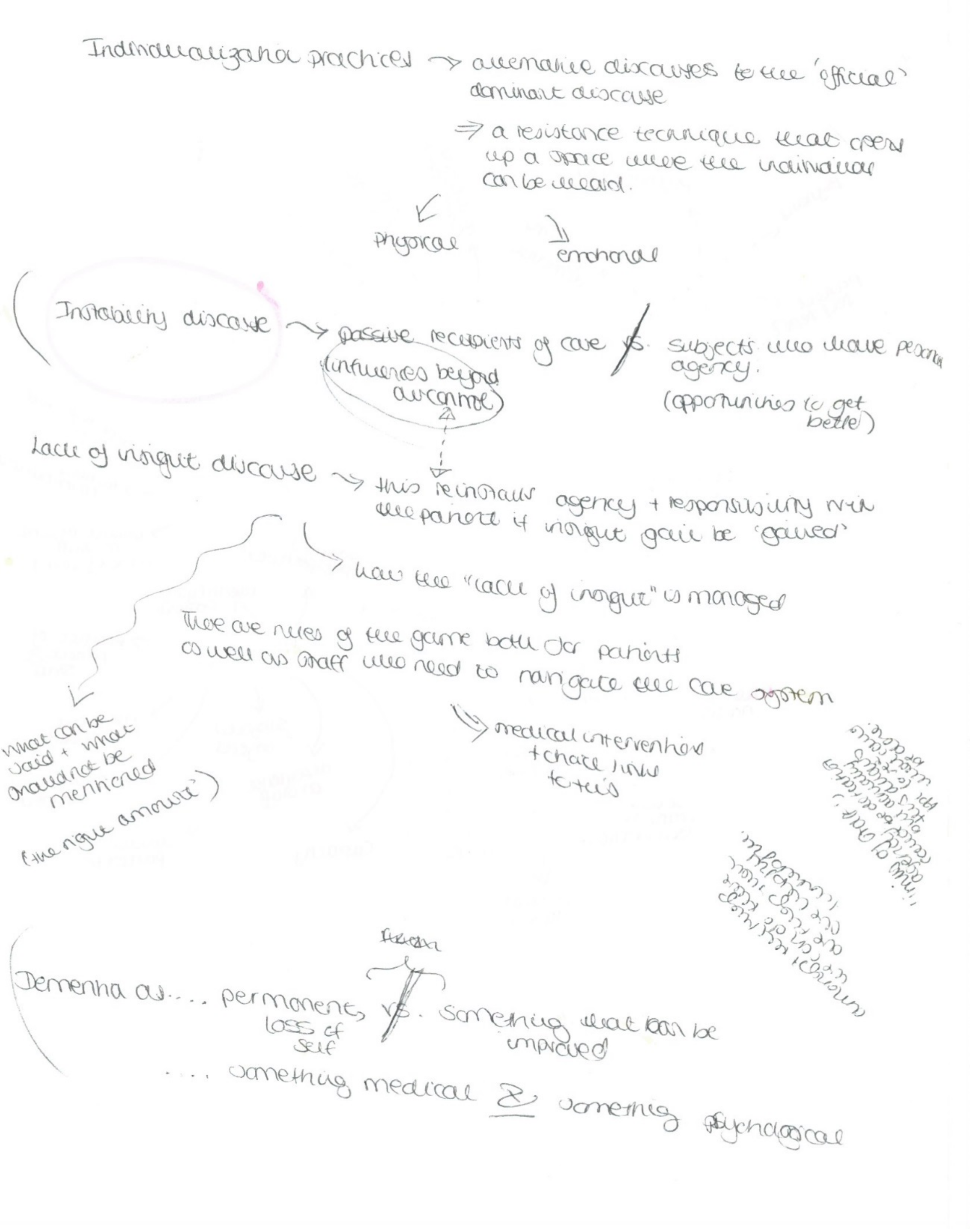
patient, 'fed'

pt trying to demonstrate agency

A 1/5

APPENDIX G. CODING CATEGORIES AND POTENTIAL RELATIONSHIPS

PPENDIX H. SUPERVISION PROCESS NOTES



Individualization practices → alternative discourses to the 'official' dominant discourse

⇒ a resistance technique that opens up a space where the individual can be heard.

physical

emotional

Instability discourse → passive recipients of care vs. subjects who have personal agency.

(influences beyond our control)

(opportunities to get better)

Lack of insight discourse → this reinstates agency + responsibility with the patient if insight can be 'gained'

→ how the "lack of insight" is managed

There are rules of the game both for patients as well as staff who need to navigate the care system

⇒ medical intervention + choice links to this

what can be said + what should not be mentioned

(the 'right' amount)

[illegible]

[illegible]

[illegible]

Dementia as... permanent loss of self vs. something that can be improved

... something medical & something psychological