

THE UNIVERSITY OF HULL

Physical Touch as a Pathway to Personhood in Dementia Care

being a Thesis submitted for the Degree of
Doctorate in Clinical Psychology
in the University of Hull

by

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Thesis Overview

This thesis portfolio comprises three parts: a systematic literature review, an empirical research paper, and appendices.

In part one, the systematic literature review, empirical literature relating to the use of touch interventions in dementia care is reviewed. The review focuses on the aims of touch interventions, and the outcomes of touch interventions for both the caregiver and the person with dementia. Results from the review are used to discuss the efficacy of touch in dementia care. Recommendations for future research are provided.

Part two, the empirical research paper, explores how societal discourses of dementia are enacted by professional caregivers in two different contexts: before and after training in a communication technique called Intensive Interaction. The results are analysed in terms of their social and political context. The implications of the results for person-centred dementia care, and related to this, Intensive Interaction practice, are discussed.

Part three comprises the appendices, including journal submission guidelines, an epistemological statement for the empirical research paper, and a reflective statement about the overall thesis.

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Part 1. Systematic Literature Review

A systematic review of interventions using touch for people with dementia
and their caregivers.

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This paper is written in the format ready for submission to the journal *Dementia*. Please
see Appendix 1 for the Guideline for Authors.

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Abstract

Aim: The deprivation of physical human touch is prevalent for older adults, especially older adults with a dementia diagnosis. The current review sought to review the aims of empirical research into touch in dementia care, and the outcomes of touch interventions for both the person with dementia and the caregiver.

Method: Four online databases (PsycINFO, MEDLINE, Web of Science and CINAHL Complete) were searched for empirical papers which measured the outcomes of touch interventions in dementia care. Of 680 non-duplicated studies, 17 studies met inclusion criteria.

Results: The majority of studies measured agitated behaviour or ‘behavioural symptoms of dementia’, and aimed to reduce distress. A variety of outcome measures was employed, making results across studies difficult to compare. There were indications that touch may improve mood in some individuals. No studies examined outcomes for both members of the touching dyad, and only two studies explored aspects of the relationship between caregiver and person with dementia. The impact of touch interventions in dementia care is equivocal, and there is high inter-person variability.

Conclusions: The current review could provide no strong conclusions about touch interventions in dementia care, as the research base is narrow in focus and variable in its measurements. In line with person-centred care principles, and to increase the validity of the literature, it is recommended that future research examines quality of life outcomes, and tailors touch interventions to individual needs. The touch-based communication technique Intensive Interaction could also be researched for its efficacy in dementia care, as it addresses a significant research gap about touch and relationships.

Introduction

The importance of touch

To be touched by others is a fundamental human need. In infancy, touch is vital for physical and emotional development (Ardiel & Rankin, 2010); across the lifespan touch is used to bond, to communicate, and to manage and express emotions (Gallace & Spence, 2010). Touch can convey feelings, even between strangers without verbal or visual cues (Hertenstein, Holmes, McCullough, & Keltner, 2009).

Touch also imparts a broader sense of shared humanity and personal worth. It is important in creating a sense of self-identity, belonging, and personhood (Green, 2013). Accordingly, touch has been used as a way to reach out to others, and to foster social connectedness and learning - particularly with those who do not possess formal verbal communication (Hewett, 2007).

Touch in later life

The importance of interpersonal touch does not diminish with age. For older adults, touch can increase self-esteem, wellbeing, and perceived health status of older people ; it can also improve mood (Buschmann, Hollinger-Smith, & Peterson-Kokkas, 1999), and promote relaxation (Harris & Richards, 2010).

However, a deprivation of interpersonal touch can be a problem for older adults, particularly those living in residential care settings. There are different ways of conceptualising 'interpersonal touch', but generally the distinction can be made between necessary touch related to a care or nursing task (e.g. taking pulse, washing and

dressing), and non-necessary touch which is emotional or social in nature (e.g. comforting, showing empathy, communicating). Whilst there is a broad range of terms to describe these categories of touch, the former is often called *instrumental touch* and the latter *affective* or *expressive touch* (Routasalo, 1999).

A review by Routasalo (1999) found that nurses predominantly provide instrumental touch to older people. Likewise, Caris-Verhallen, Kerkstra and Bensing (1999) found that nurses working with older people in care homes spent only 2.2% of their time providing expressive touch, compared to 18.2% of their time giving instrumental touch. Conversely, one study within Routasalo's review found that older adults' touch inclinations towards nurses were mostly expressive (Le May & Redfern, 1987). This suggests that, although older adults have a desire for expressive touch, this need may go unmet within care settings.

A lack of touch may be indicative of relational distance, which may be a means for caregivers to preserve emotional resources in the face of another's suffering (Fredriksson, 1999). In part, this may be due to a lack of research with which to inform practice. Caris-Verhallen et al. (1999) also highlight that many of the methods which are chosen for research into touch in later life do not adequately capture the dyadic nature of interactions between older people and professional caregivers, therefore missing out on a key component of touch: the relationship. Standardised measures of the caregiving relationship are also lacking for people with dementia and family caregivers (Spruytte, Van Audenhove, Lammertyn, & Storms, 2002).

Touch in dementia care

Dementia is described as a condition involving the progressive impairment of cognition - but crucially, and arguably most significantly, dementia is characterised by social isolation and unacknowledged personhood (Kitwood, 1997). Older people with severe cognitive impairments are particularly at risk of having their interpersonal and emotional needs neglected (Hubbard, Tester, & Downs, 2003).

Touch in dementia care also benefits both members of the dyad. For couples living with dementia, ‘embodied exchanges’ (communication through physical interactions) can enhance wellbeing and create a sense of ‘*we-ness*’ (McGovern, 2011). Likewise, Edvardsson, Sandman, and Rasmussen (2003) found that touch deepened relationships and changed professional caregivers’ views of both themselves and the people they cared for. Carers in the study viewed people with dementia as fellow human beings, and saw themselves as empowered, valuable people who could ease other’s suffering. Such changes in perspective can reduce caregiver anxiety, stress and distress (Vernooij-Dassen, Draskovic, McCleery, & Downs, 2011).

Rationale for the current review

A number of literature reviews have been conducted into touch in dementia care. For example, Moyle, Murfield, O’Dwyer, & Van Wyk (2013) assess the effect of massage on agitated behaviours, and several other reviews examine touch as part of psychosocial interventions in dementia care (e.g. Verkaik, van Weert, & Francke, 2005; Hansen, Jørgensen, & Ørtenblad, 2006; Livingston et al., 2014). However, existing reviews have included a range of interventions within their criteria, including massage with use of

aromatherapy oils, and biofield therapies (such as *Reiki* and *Healing Touch*) which primarily focus on the energies of the body and may not include any physical contact (Jain & Mills, 2010).

Additionally, there is to the author's knowledge no review of touch in dementia care which includes caregivers alongside people with dementia. There is therefore a gap for examining the outcomes for both members of the touching dyad.

Research Questions

The current review aims to explore the existing research investigating touch interventions with older people living with dementia and their caregivers. The focus is on touch specifically as an intervention, rather than touch combined with other interventions. The questions to be addressed in the current review are:

- How has touch been operationalised within therapeutic interventions in dementia care?
- What are the physical and psychological outcomes of touch interventions for people living with dementia?
- What are the physical and psychological outcomes of touch interventions for caregivers?

Search Strategy

Databases and search terms

A digital search on the use of touch in dementia was conducted using four online databases: MEDLINE (medical), PsycINFO (psychological), Web of Science

(multidisciplinary) and CINAHL Complete (nursing and allied health professionals). The databases were chosen to gain access to studies from a range of disciplines. Prior to searching, limiters applied were: peer reviewed (for quality), published in English (due to lack of translation facilities), and for MEDLINE 'Human'. No date limiters were implemented; studies up to and including May 2016 were therefore included.

Search terms were developed primarily from a taxonomy of touch in older adult nursing, developed by Bush (2001). This included *massage*, and *caring touch*, *expressive touch*, and *affective touch*. Routasalo (1996) refers to spontaneous emotional touch as *non-necessary touch*, and touch can also be referred to as *tactile stimulation* (Parianen Lesemann, Reuter, & Godde, 2015). These terms were also added.

The final search terms were:

(touch* OR "therapeutic touch*" OR "non-necessary touch*" OR massag* OR "caring touch*" OR "affective touch*" OR "expressive touch*" OR "tactile stim*") **AND**
(dement* OR senil* OR Alzheimer*) **NOT** (touch?screen OR touch?panel OR mice)

The final line of terms was added because studies exploring communication technology for older adults were prevalent in an initial search. The titles and abstracts of resultant studies were scanned for whether they met inclusion/exclusion criteria by the main reviewer (CH). If it was unclear from assessment of title and abstract whether selection criteria were met, papers were read in full, and included or excluded accordingly. The reference lists of included articles were also hand-searched for any relevant studies. Figure 1 illustrates this process.

Inclusion and Exclusion Criteria

The inclusion criteria for the current literature search were as follows:

- Intervention studies reporting the effect(s) of using touch as an intervention with people with dementia, i.e. touch was measured as an outcome. As this was an exploratory review of the relevant literature, the nature of the touch intervention was not specified for the purposes of this review.
- The current study is investigating the effects of touch interventions on older adults with dementia and their caregivers. Participants are older people with dementia (aged 60+ based on United Nations cut-off for 'older adult'; World Health Organisation, 2016), and/or caregivers of older people with dementia.
- If the study includes both older people with dementia *and* carers, the outcome data for both groups is separate.

Studies which combined the data of older people with and without dementia were excluded, as it was not possible to examine outcomes for dementia specifically.

Additionally, as this review focuses exclusively on touch, studies which combined touch with another intervention (e.g. music or scented oils), or used biofield therapies such as *Reiki* or *Healing Touch*, were excluded. Studies were excluded if touch was not the primary intervention (e.g. as part of multi-modal therapies such as sensory rooms, or studies where touch is not the intervention being measured). Papers which were not intervention studies, such literature reviews and descriptions of projects, were also excluded from the search.

Both qualitative and quantitative methodologies were included if they measured the outcome of a touch intervention.

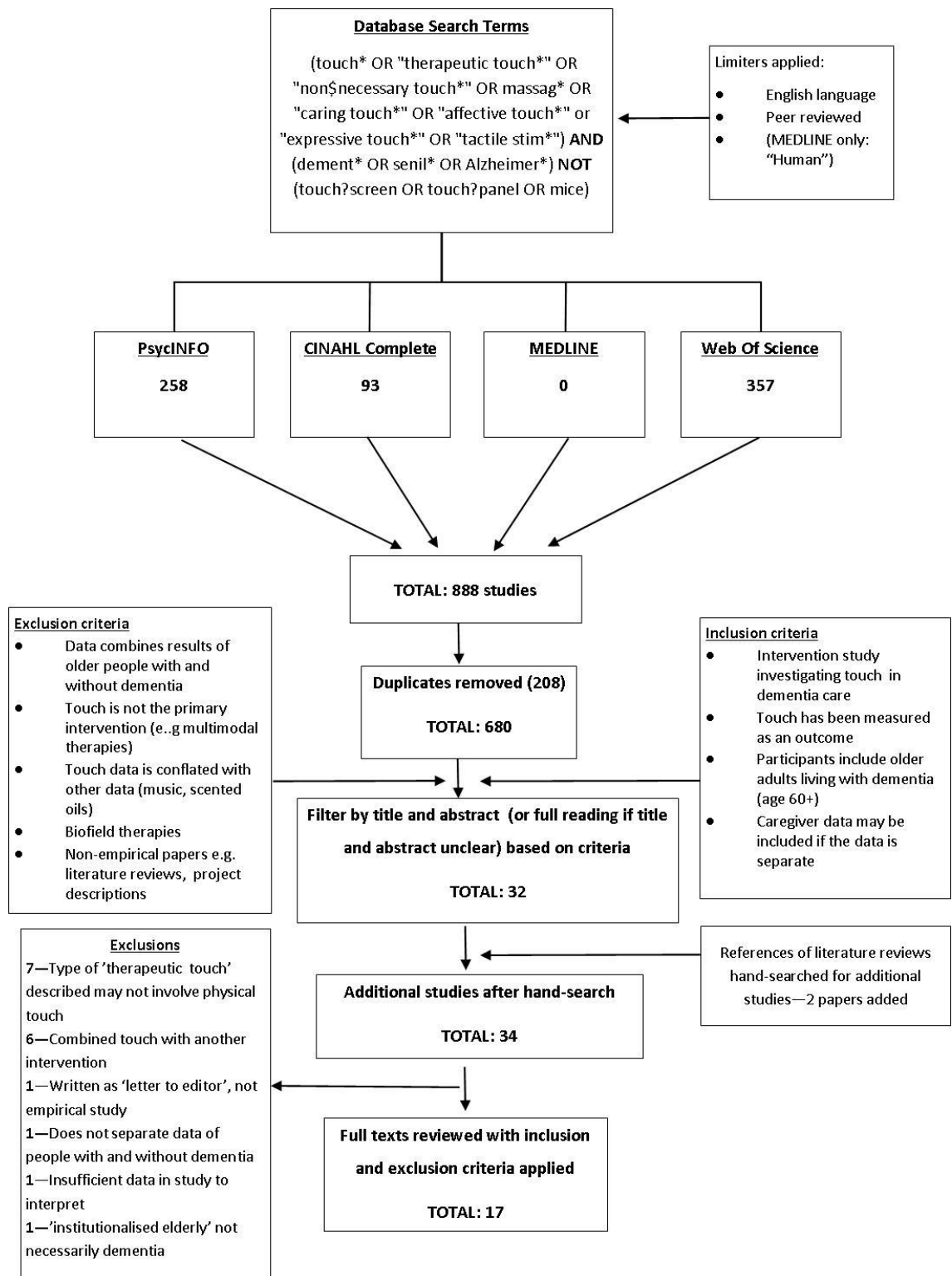


Figure 1. Process diagram for the current literature review.

Quality assessment

Quality assessment allows for the validity of the studies in the review to be considered alongside study results, therefore supporting a more robust analysis. Studies in the current review were not excluded based on quality. This is because previous reviews have identified few studies of high quality – for example Hansen et al. (2006) used strict quality criteria and found only two suitable studies.

An adapted checklist developed by Downs and Black (1998; Appendix 2) was used to assess the quality of quantitative studies in the review. This checklist was developed for both randomised and non-randomised studies in a health care context. It has similar outcomes for studies which are and are not randomised, and high internal reliability (<0.69) and test-retest reliability ($r=0.69-0.90$). The adapted scale has a maximum score of 25.

The current review had one qualitative study. The study used a unique adaptation of content analysis, therefore an atheoretical guideline by the National Institute for Health and Care Excellence (2012; Appendix 3) was employed to assess quality. Aspects of the paper such as theoretical approach, trustworthiness and rigour of analysis were assessed, and the overall study was rated as poor, moderate or good quality.

Results

The current review contained 17 studies, both quantitative (16) and qualitative (1). The quantitative studies contained a variety of outcome measurements, including: standardised scales ($n=16$), researcher-created scales or written record analysis ($n=5$), and physiological measures ($n=7$). A meta-analysis of outcome data was there deemed inappropriate, as it is difficult to compare results. Therefore *an interpretive narrative*

synthesis method was selected. This method, of narratively discussing the aggregated literature, can integrate qualitative and quantitative results, and allows for interpretation across the entire dataset (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005).

Characteristics of included studies

The characteristics of the studies in the current review can be found in Table 1.

Sample sizes ranged from 4-111. Moyle et al. (2014b) and Rodriguez-Mansilla et al., (2015) appeared to use the same samples in multiple studies (i.e. Moyle et al., 2014a; Rodríguez-Mansilla et al., 2013), leading to an overall sample size of 481. The majority of participants (where mentioned) were female in every study except Skovdahl, Sörlie & Kihlgren (2007). Scherder, Bouma, & Steen, (1998) did not report gender. Ages of participants ranged from 62 (Remington, 2002) to 101 (Harris, Richards, & Grando, 2012). Reported mean ages were all in the late 70s or early 80s, which implies some consistency across studies. Type of dementia diagnosis was varied, with severity ranging from 'early' to 'severe'. This renders studies difficult to compare, except under the broad umbrella term 'dementia'.

Only one study (Rowe & Alfred, 1999) took place in a community setting. The remainder were in residential settings such as care homes and hospitals. Only Rowe and Alfred included caregivers as the person giving the touch intervention, although no outcomes for the caregivers were reported in their study.

Results of quality assessment

The full assessment can be found in Appendix 3. 24% of the studies (three quantitative and one qualitative) were independently co-rated (EW). Out of a maximum of 25, the highest quality quantitative papers were Moyle et al. (2014a; 2014b), and the lowest quality scored 12 (Moyle et al., 2011), with a median of 16 (IQR= 3.5). Inter-rater agreement was 73%. The main point of disagreement was whether the sample were representative of a) the recruitment population, and b) the initial sample who were invited to participate, with the main author scoring with stricter criteria (Appendix 2). The qualitative study (Skovdahl et al., 2007) was rated as modest quality by both raters.

The strengths of the literature lay in clearly describing the study, its measures, and its outcomes. Skovdahl et al. (2007) used a unique type of content analysis but did not describe the process of analysis. Most quantitative studies (11/16) reported the reliability and validity of measures (e.g. standardised questionnaires, or author-created rating scales); the qualitative study Skovdahl et al. (2007) did not discuss the reliability of measurement. 14 of 16 quantitative studies gave a description of touch enough to replicate the intervention, however Moyle, Johnston, & O'Dwyer (2011) describe a 'standard 5-minute massage' and Brooker, Snape, Johnson, Ward, and Payne (1997) used only the term *massage*. As such, it is difficult to compare these studies to the rest of the literature base.

12 of the 16 quantitative studies used randomised groups or a crossover design as an attempt to increase the validity of the study. However, only half of the studies attempted to blind those measuring the main outcomes of the intervention. The literature was also limited in its descriptions of participants, which makes it difficult to assess the distribution of possible confounders. For example, medication can worsen 'behavioural

symptoms' of dementia (Schneider, Pollock, & Lyness, 1990), but was only mentioned by Remington (2002), Harris et al. (2012), Rodríguez-Mansilla et al. (2013), and Moyle et al. (2014b). Cognitive function/diagnosis was also variable between studies, if reported at all.

It was difficult to assess whether participants in the study were representative of the population from which they were sampled, due to lack of information about participants, dropouts, and lack of information about the settings from which people were recruited. Only six studies reported no dropouts from the original sample. Therefore the reliability of the findings was compromised. The main author did not believe it was possible to determine whether any of the studies in the current review were representative of people who were invited to participate, due to lack of information about those who were invited to participate (and those who declined to participate), and sample attrition.

Table 1. Characteristics of studies which were included in the current literature review. Study locations, if not explicitly stated, were inferred from author's addresses or from other information in the study (such as country-specific policies, or the location of ethics boards).

Authors	Study location (* if inferred)	Interventions	Setting	Study design	Participant N (original sample; completed study)	Female % of sample	Age (mean; SD; range)	Type of dementia
Belgrave (2009)	Florida, United States; ppt's homes, and long-term care facility.	Baseline (no touch), expressive touch, instrumental touch.	Hospice for late-stage Alzheimer's.	Within-participants.	9; 9	100.0	89	Alzheimer's disease.
Brooker, Snape, Johnson, Ward & Payne (1997)	United Kingdom; NHS long stay dementia unit.	Control (sitting in massage room), aromatherapy, massage, aroma-massage.	Continuing care ward.	Within-participants.	4; 4	75.0	80.3; <u>74-91.</u>	Alzheimer's and frontal lobe dementia.
Harris, Richards & Grando (2012)	Southeastern United States; four nursing homes in rural communities.	Control group; slow stroke back massage.	Four rural nursing homes.	Two group between-participants.	Stated as percentages; 6% dropout, 40 participants completed.	80.0	86.2; 6.49; <u>75-101</u>	Diagnosis of dementia from medical records - Alzheimer's disease, Parkinson's dementia; vascular, mixed & 'otherwise not specified' dementia.

Authors	Study location (* if inferred)	Interventions	Setting	Study design	Participant N (original sample; completed study)	Female % of sample	Age (mean; SD; range)	Type of dementia
Hicks-Moore & Robinson (2008)	New Brunswick, Canada; special care units in three nursing homes across two cities.	Control group; hand massage, favourite music, massage & music.	Special Care Units in nursing homes.	Within-participants.	56; 41	78	84.5; 6.0; <u>67-92</u>	'Primary diagnosis of dementia'.
Moyle, Johnston & O'Dwyer (2011)	Queensland, Australia; residential care facility.	Baseline, foot massage.	Residential facility.	Within-participants.	27; 22	77.2	84.7; 6.1	Diagnosis of dementia or met criteria for probable dementia.
Moyle et al. (2014a)	Queensland, Australia; five long-term care facilities.	Control (quiet presence), foot massage.	Five long-term care settings.	Within-participants.	55; 53	66.0	86.5; 7.13; <u>74-103</u>	Diagnosis of dementia or met criteria for probable Alzheimer's.
Moyle et al. (2014b)	Queensland, Australia; five long-term care facilities.	Control (quiet presence), foot massage.	Five long-term care facilities.	Within-participants.	53; 53	66.0	86.5; 7.13; <u>74-103</u> .	Moderate to late-stage dementia.

Authors	Study location (* if inferred)	Interventions	Setting	Study design	Participant N (original sample; completed study)	Female % of sample	Age (mean; SD; range)	Type of dementia
Quell, Skovdahl, Kihlgren & Lökk (2008)	Sweden; four wards of a dementia care facility.	Control group; tactile stimulation.	Dementia care facility.	Two-group between-participants.	42; 23	Control: 72.3 Stim: 75	Control: 85.5; <u>75-97</u> Stim: 83.5; <u>63-92</u>	Various dementias according to ICD-10 (World Health Organisation, 1993) – vascular, Alzheimer’s, unspecified – early to severe.
Remington (2002)	United States*; four long term residential care facilities.	Control group (no intervention); calming music; hand massage; music & massage.	Nursing home.	Four group between-participants.	68; 68	87.0	82.4; <u>62-99</u>	Medical records indicate Alzheimer’s disease, multi-infarct dementia, or senile dementia.
Rodríguez- Mansilla et al. (2013)	Extremadura, Spain; three residential care facilities.	Control group (care as usual); ear acupressure; massage therapy.	Residential homes.	Three-group between participants.	120; 111	77.4	Ctrl: 81.9; 5.9 Massage: 85.8; 4.9 Acupressure: 85.4; 5.9	Alzheimer’s disease, vascular dementia, or mixed dementia – based on DSM-IV (American Psychiatric Association, 2000) at least one year prior to study.

Authors	Study location (* if inferred)	Interventions	Setting	Study design	Participant N (original sample; completed study)	Female % of sample	Age (mean; SD; range)	Type of dementia
Rodríguez-Mansilla et al. (2015)	Extremadura, Spain; residential care facilities.	Control group (care as usual); ear acupressure; massage therapy.	Residential homes.	Three-group between participants.	120; 111	77.4	<u>67-91</u>	Has met DSM-IV (American Psychiatric Association, 2000) criteria for dementia for at least 1 year; moderate to severe according to MMSE (Folstein, Folstein & McHugh, 1975).
Rowe & Alfred (1999)	Texas, United States; person's home.	Baseline (no massage), back massage.	Community setting.	Within-participants.	28; 18	Older adult: 55.6 Carer: 78.6	Older adult: <u>76.77; 68-90</u> Carer: <u>69.23; 54-82</u> .	Diagnosed with physician as 'probable AD'.
Scherder, Bouma & Steen (1998)	Netherlands* ; residential home.	Control group (placebo electro-stimulation); tactile stimulation.	Residential home.	Two-group between participants.	16; 16	Unstated	85.7; <u>78-92</u>	NINCDS-ADRDA (McKhann et al., 1984) criteria for clinical diagnosis of 'probable Alzheimer's'.
Skovdahl, Sörlie & Kihlgren (2007)	Sweden*; four specialist units of a residential home.	Tactile stimulation.	Nursing home.	Qualitative case studies of caregiver experience.	5; 5	20	81.6; 7.92; <u>73-93</u>	Alzheimer's; vascular dementia; 'dementia without any further specification'.

Authors	Study location (* if inferred)	Interventions	Setting	Study design	Participant N (original sample; completed study)	Female % of sample	Age (mean; SD; range)	Type of dementia
Snyder, Egan & Burns (1995a)	United States*; three Alzheimer's care units.	Control (physical presence), hand massage.	Three Alzheimer care units.	Within-participants.	36; 26	61.5	78.7; <u>60-97</u>	Unspecified; Haycox Dementia Scale (Haycox, 1984) scores 13-36 (mean of 25.9).
Snyder, Egan & Burns (1995b)	United States*; one Alzheimer's care unit.	Control (staff presence); hand massage; therapeutic touch.	Alzheimer care unit.	Within-participants.	18; 17	70.6	77.7; <u>66-90</u>	Unstated (Alzheimer's?).
Suzuki et al. (2010)	Japan*; hospital specialist dementia ward.	Control group (care as usual); tactile massage.	Hospital, specialist dementia ward.	Two-group between participants (matched pairs).	40; 28	71.4	Control: 88.00; 6.63 Massage: 88.71; 7.28	Alzheimer's (12 per group), cerebrovascular (2 per group); diagnosed using DSM-IV (American Psychiatric Association, 2000).

How have touch interventions in dementia been operationalised?

A summary of the operationalisation of touch in the current review can be found in Table 2. Touch as a therapeutic intervention in dementia care has primarily been used to reduce behaviours which disturb others. However, Skovdahl, et al. (2007) and Belgrave (2009) explored the relationship between the person with dementia and the caregiver.

The remainder of this section focuses on how touch has been defined, and the nature of the relationship between the person with dementia and the caregiver.

How has 'touch' been defined?

Touch interventions in the current review were primarily massage-based, the exceptions being Belgrave (2009) who examined expressive and instrumental touches as part of music therapy, and Snyder et al. (1995b), who described therapeutic touch as holding a hand and placing hands on a person's back.

Touch was primarily operationalised as a single event measured by duration (for example a massage). However, Belgrave (2009) considered the intervention as a series of individual touches. None of the studies actively discussed the reasoning for choosing duration (or otherwise) as a way of quantifying the touch intervention. This calls into question how comparable even similar-sounding touch interventions such as 'massage' can be.

Similarly, the length of the touch intervention was highly variable, both in terms of the duration of the study and in terms of the duration of the touch intervention. Studies ranged from 28 weeks (Skovdahl et al., 2007) to a single touching event (Remington,

2002). Where specified, touch duration was pre-defined in all studies except Skovdahl et al. (2007), in which duration was fully determined by the person with dementia.

Overall the literature defined the touch intervention primarily in terms of its physical aspects, rather than its emotional and relational aspects. Only three studies explicitly articulated the sense or feeling required to deliver the touch intervention. Skovdahl et al. (2007) operationalised touch as “to convey attention, communication and close contact” (p. 163), Quell et al. (2008) note “closeness and respect by being sensitive and compassionate” (p. 123), and Belgrave (2009) states that expressive touch is “nurturing or caring” (p. 136).

Table 2. Operationalisation of the touch interventions in the current literature review. The table examines only the length of the touch intervention, rather than the duration of the entire study, to make the operationalisation of the touch intervention clear.

Authors	Touch intervention	Description of touch intervention	Duration of intervention	Touch provider	Measures	Results of study
Belgrave (2009)	Expressive and instrumental touch.	Expressive touch “conveys feelings of support, comfort and care”. Instrumental touch “is used to assist an individual in completing a task”.	3 sessions with expressive touch and 3 sessions with instrumental touch, counterbalanced with 3 sessions of baseline over 9 days.	Music therapist.	Blind-rated videos of rapport. Behaviour state classification system for people with disabilities ¹ .	Instrumental touch (overall) had a significant positive impact on time spent in alert state; expressive did not. First session of expressive touch had significantly higher alertness than baseline - no other significant results for individual sessions. Perceived rapport significantly higher in both touch conditions, compared to control group.
Brooker, Snape, Johnson, Ward & Payne (1997)	Massage.	Hand and lower arm massage using unscented base oil.	8-12 sessions total including four conditions (baseline, aroma, massage, aroma-massage), over a three month period.	Care home staff.	Idiosyncratic agitation scales developed & piloted over three weeks.	Marked between-participant variability. One of four participants had statistically significant decrease in ‘disturbed behaviour’, for aromatherapy and massage separately. Two participants showed reduced ‘disturbed behaviour’ in all treatment conditions, Two participants had an increase in ‘disturbed behaviour’ (one for all treatment conditions, one for massage and aroma separately).

¹ Guess et al. (1988)

Authors	Touch intervention	Description of touch intervention	Duration of intervention	Touch provider	Measures	Results of study
Harris, Richards & Grando (2012)	Slow stroke back massage.	Long, slow, gliding, repetitive strokes from the sacral to cervical regions of the spine.	Once an evening for 48 hours; follow up 48 hours later.	First author of the paper (qualified nurse).	Actigraphy (amount of sleep); written records of sleep.	No significant results on any of the sleep measures used in the study. Significant difference in severity of dementia as measured by MMSE ² between experimental and control group (as a confounding variable).
Hicks-Moore & Robinson (2008)	Hand massage.	Slow strokes, light pressure, and an even rhythm applied to the entire hand including the back, palm, fingers, and thumb.	Length of study unclear; measurements taken 10 mins before intervention, immediately after, 1hr later.	Research assistant.	CMAI ³ (agitated behaviour).	No treatment effect, however all groups (including control group) showed a significant reduction in 'verbal agitation' and 'physical non-aggression' over time.
Moyle et al. (2011)	Foot massage	Standard 5-minute massage.	Once a day for 14 days.	Trained massage therapists.	CMAI ⁴ (agitated behaviour), RMBPC ⁵ (memory behaviour problems).	Significant improvement (i.e. reduction) in overall CMAI and RMBPC scores; follow-up scores were sig. lower than baseline (i.e. fewer problems).

² Mini Mental State Exam; Folstein, Folstein & McHugh (1975)

³ Cohen-Mansfield Agitation Inventory; Cohen-Mansfield (1991)

⁴ Cohen-Mansfield Agitation Inventory - Short Form; Werner, Cohen-Mansfield, Koroknay & Braun (1994)

⁵ Revised Memory and Behaviour Problems Checklist; Teri et al. (1992)

Authors	Touch intervention	Description of touch intervention	Duration of intervention	Touch provider	Measures	Results of study
Moyle et al. (2014a)	Foot massage.	A light-pressure massage with long, gliding, rhythmical strokes and flexion, extension, and rotation of the toes, foot, and ankle.	5 days a week for three weeks.	Trained massage therapists.	Heart rate and blood pressure.	Initial within-participants design yielded significant ‘carry over’ effects; data analysed as between-groups (control and massage). Massage group had non-significant reduction in heart rate compared to control. Control & massage group both had significant reduction in blood pressure over the three-week study.
Moyle et al. (2014b)	Foot massage.	Light pressure massage with long, gliding, rhythmical strokes and flexion, extension and rotation of the toes, foot and ankle.	5 days a week for three weeks.	Trained massage therapists.	CMAI ⁴ (anxiety); OERS ⁶ (observed emotions)	None reported; agitation increased (non-significantly) in both groups and this increase was significantly greater in the control group. The increase was predominantly in ‘verbal agitation’. Trend towards increased alertness in massage group; trend towards decreased alertness in control group.
Quell, Skovdahl, Kihlgren & Lökk (2008)	Tactile stimulation.	Touch massage aimed at reaching receptors just under the epidermis. Aims to convey attention, communication, closeness and respect.	Minimum of once per week for 28 weeks.	Care home staff.	Prolactin (stress-related hormone) levels.	No significant change in prolactin. Participants with more severe dementia had significantly higher stress levels than those with early/moderate dementia.

⁶ Observed Emotion Rating Scale; Lawton, Van Haltsma & Klapper (1996)

Authors	Touch intervention	Description of touch intervention	Duration of intervention	Touch provider	Measures	Results of study
Remington (2002)	Hand massage.	Slow strokes, even rhythm and light pressure to the back of the hand, palm and fingers.	Once.	Unclear.	CMAI ³ (agitated behaviours).	All conditions (music, massage, and both) showed less overall agitation and physically non-aggressive behaviours, compared to control group at: post-intervention, after 10mins, and after 1 hour. No additive effect of combining interventions. No significant effect of treatments on physical agitation or verbal agitation. Hand massage non-significantly reduced verbal agitation more than other interventions; after 1 hour any intervention was (non-significantly) more effective than no intervention in verbal agitation.
Rodríguez-Mansilla et al. (2013)	Massage.	Relaxing massage; superficial effleurage and deep kneading.	5 x week for three months.	Physiotherapist.	Author-designed questionnaire with four elements: 'behaviour alterations', sleep disturbances, eating, 'participation in therapy'.	In the third month, ear acupressure and massage led to significant improvements in all four criteria in the questionnaire (no significant difference between treatments). After two months follow-up: neither treatment group demonstrated significant difference in sleep or 'behaviour alterations' compared to control; 'participation in therapy' and eating remained significantly better in treatment groups compared to control. At follow-up, the only significant difference between treatment groups was improved eating with acupressure.

Authors	Touch intervention	Description of touch intervention	Duration of intervention	Touch provider	Measures	Results of study
Rodríguez-Mansilla et al. (2015)	Massage.	Relaxing massage; superficial effleurage and deep kneading.	5x week for three months.	Qualified physiotherapist.	DOLOPLUS2 (pain) ⁷ ; CSDD (depression) ⁸ ; Campbell scale (anxiety) ⁹ .	Massage and ear acupressure significantly improved all measures compared to control. Massage was significantly less effective than ear acupressure for pain, until after 1 month post-treatment where there was no longer a significant difference.
Rowe & Alfred (1999)	Slow stroke back massage.	Rhythmical, relaxed strokes primarily on each client's neck and shoulders.	At 'onset of agitation' over 3 weeks.	Family caregiver.	ABRSSG ¹⁰ (agitated behaviour); BSRS ¹¹ (symptoms of psychological distress).	Most frequent exhibited behaviours were vocalisation, 'manual manipulation', pacing/walking/wandering and searching. 'Agitated behaviour' significantly more present during high-activity times (e.g. eating, dressing). Massage therapy had no significant effect on outcome measures; there was a trend in reduction for all 'behaviours' except vocalisation.

⁷ Hølen, Saltvedt & Fayers (2005)

⁸ Cornell Scale for Depression in Dementia; Alexopoulos, Abrams, Young & Shamoian (1998)

⁹ The references provided do not lead to a 'Campbell scale'

¹⁰ Agitated Behavior Rating Scale Scoring Guide; Bliwise et al. (1990)

¹¹ Brief Symptom Rating Scale; Rabins (1994)

Authors	Touch intervention	Description of touch intervention	Duration of intervention	Touch provider	Measures	Results of study
Scherder, Bouma & Steen (1998)	Tactile stimulation.	Tactile stimulation by massage; brushing, rubbing and kneading.	Once per day, 5 days a week, for a 6 week period.	Unclear.	BOP ¹² (mood and general functioning); author-designed behaviour inventory.	Significant BOP improvement on ‘need of help’ and ‘physical invalidity’ subscales with tactile stimulation; positive trend for ‘mental invalidity’ and ‘inactivity’ subscales. No significant changes in control group. Tactile stimulation had significant improvement on behaviour inventory overall, and its subscales of ‘depression’ and ‘mood’, compared to control group. No significant differences in behaviour inventory were found at 6-week follow up.
Skovdahl, Sörlie & Kihlgren (2007)	Tactile stimulation.	Stroking the skin softly, only reaching down to the tactile receptors. Aims to convey attention, communication and close contact achieved by touch.	28 week study, at onset of agitation (in practice, approx weekly).	Care home staff.	Written records of tactile stimulation intervention, by staff.	Qualitative analysis – idiosyncratic responses from older adults; staff felt closer to residents and had improved relationships. The time, the person’s readiness and the place of massage were important. Varied responses between participants and within (dependent on mood). Massage seemed less effective when individuals were very anxious.

¹² Beoordelingsschaal voor Oudere Patiënten; Van der Kam, Mol & Wimmers (1971)

Authors	Touch intervention	Description of touch intervention	Duration of intervention	Touch provider	Measures	Results of study
Snyder, Egan & Burns (1995a)	Hand massage.	Protocol provided for back of hand, palm of hand and fingers - variety of strokes.	Twice per day (morning and afternoon) for 10 days.	Care home staff.	Idiosyncratic checklist of agitation behaviours (Behaviour 1 & Behaviour 2).	Significant overall decrease in 'Behaviour 1' (including grabbing, yelling, hitting, trying to get to another place), only in the morning after massage. No difference in Behaviour 2 ('physical resistance' and 'sentence repeating behaviours'). Agitation increased in male participants with massage, and decreased in female participants (unclear whether this was statistically significant).
Snyder, Egan & Burns (1995b)	Hand massage.	Protocols provided. Includes a variety of strokes	10 minutes per day for 10 days.	Members of research team (nurses).	Pulse rate, Relaxation Checklist ¹³ ; idiosync-ratic 'target agitation behaviour'.	Massage group had significantly decreased pulse, degreased 'anxious behaviours' & increased relaxation behaviours, after the first 5 days and second 5 days of the study. No significant changes for control group. 'Therapeutic touch' group had significantly fewer 'anxious behaviours' after second 5 days of study. No significant changes in target behaviours across any group.

¹³ Luiselli, Steinman, Marholin & Steinman (1982)

Authors	Touch intervention	Description of touch intervention	Duration of intervention	Touch provider	Measures	Results of study
Suzuki et al. (2010)	A soft tissue massage that includes both touch and massage.	A series of slow massage strokes applied with firm pressure, mainly using the flat of the hand and fingers.	5x week for 6 weeks.	Ward nurses, and nurse researchers	MMSE ² (cognitive function); GBS ¹⁴ (general functioning); Behave-AD ¹⁵ (symptoms of dementia); salivary CgA (stress).	Intervention group: reduction in CgA & aggressiveness subscale only of Behave-AD. Control: decline on emotional/intellectual function of GDS.

¹⁴ Gottfries-Bråne-Steen Scale; Gottfries, Bråne & Steen (1982)

¹⁵ Behavior Pathology in Alzheimer's Disease Rating Scale; Reisberg, Borenstein, Salob & Ferris (1987)

What is the nature of the relationship between the caregiver and person with dementia?

A range of individuals provided the touch interventions. Only one study asked family caregivers to be participants (Rowe & Alfred, 1999), and it did not measure caregiver outcomes. Two studies did not clearly explain who provided the touch intervention (Scherder et al., 1998; Remington, 2002). Only 5/17 studies in this review appeared to use interventions delivered by individuals likely to be familiar to the person with dementia (i.e. care staff and family). Moyle et al. (2014b) noted that their non-significant results may have been due to people with dementia not knowing the person delivering the intervention very well.

The nature of the relationship between the person with dementia and the person delivering the intervention was rarely defined in detail. For example, Belgrave (2009) focused on a music therapist as caregiver, but it is not clear whether participants knew the music therapist. Considering that this study measures rapport between music therapist and person with dementia, it is surprising that the pre-existing relationship was not described. Only one study considered the impact on the dyadic relationship as an outcome (Skovdahl et al., 2007). In this study, caregivers referred to a 'closer closeness' with residents (p. 165), more positive interactions, enjoyable moments together, and warmer relationships. However, Skovdahl and colleagues have not provided extracts or examples from the data, or a full account of the process by which the data were analysed. This makes it difficult for the reader to understand how the relationship-based outcomes of the touch intervention relate to other, more practical aspects of the intervention (e.g. length of massage).

The qualitative data from Skovdahl et al. (2007) suggest that the touch intervention is not merely a task for the benefit of the person with dementia, but a process which

enriches relationships and provides caregivers with a different way of ‘being’ with a person with dementia. It can also have a positive impact on the caregiver. However, in the context of the rest of the literature base, it is unclear whether the qualitative reports from Skovdahl and colleagues were a function of the type of caregiver chosen (people who knew the person well), or the touching itself. Given the lack of literature exploring the caregiver’s response (both family and professional), the literature base cannot answer that question.

What are the outcomes for the person with dementia?

This section has been separated into three outcomes: physical, psychological, and cognitive. Touch as a therapeutic outcome in dementia care has primarily aimed to reduce behaviours which disturb others. Skovdahl, Sörlie & Kihlgren (2007) and Belgrave (2009) were the only studies which focused on the relationship between the person with dementia and the caregiver.

Physical

Whilst behaviour can be considered a ‘physical’ activity, here ‘physical outcomes’ refers to changes in the body of the person with dementia. Six studies included physiological measures including pulse, blood pressure, stress-related hormones, and sleep (Harris et al., 2012; Moyle et al., 2014a; Suzuki et al., 2010; Quell et al., 2008; Snyder et al., 1995b; Rodríguez-Mansilla et al., 2013). Only three studies found a significant change of touch relative to the control group/baseline, for pulse reduction (Snyder et al., 1995b), sleep, (Rodríguez-Mansilla et al., 2013), and salivary stress-related hormones (Suzuki et al., 2010). Notably, Snyder et al., (1995b) and Suzuki et al. (2010) were the only two non-randomised studies to measure physiological outcomes,

and the outcomes for Rodríguez-Mansilla et al. (2013) were not present at two-month follow up.

However, Rodríguez-Mansilla et al. (2013) did find a significant improvement in eating after three months of touching intervention. This effect was still evident after the two month follow-up, however 'eating' is not specified (e.g. type of food, volume or frequency of eating, participation in mealtimes). Touch may have some significance in improving eating, however it is impossible to determine the nature of this effect.

Rodríguez-Mansilla et al. (2015) measured pain using a standardised observer scale, and found that there was a significant improvement across a three-month study compared to controls, however at one months' follow up this effect had been lost. There was no information on the type of pain being considered (i.e. deep massage on a painful back would be counter-intuitive), or rationale for choosing to measure pain.

As such, this review demonstrates limited evidence for the physical outcomes of touch for people with dementia. However, these physical outcomes have been primarily physiological measures of stress. There may be, then, a need to explore other physical measures such as self reported health status, and self-reported or observed physical relaxation.

Psychological

Psychological outcomes for the person with dementia were primarily assessed with observer measures of 'agitated behaviour' or similar (14/17; six studies employed idiosyncratic scales and nine studies employed standardised scales). Five of these studies did not discuss the reliability or validity of the measures (Rodríguez-Mansilla et

al., 2015; Scherder et al., 1998; Suzuki et al., 2010; Skovdahl et al., 2007; Moyle et al., 2011), which reduces the ability of the literature base to clearly illuminate the psychological outcomes of touch.

The outcome measures which were employed, whilst having some similarities, are not necessarily comparable across the literature. For example, the scales used included measures of physical and verbal aggression, anxiety, 'wandering', mood, confusion, memory problems, and 'target' or 'problem' behaviours. An attempt has been made here to separate different psychological factors, with the acknowledgement that many of the scales overlap.

1. Anxiety and agitation

Based on published scales, agitation/anxiety significantly reduced in four studies (Remington, 2002; Moyle, 2011; Rodríguez-Mansilla et al., 2014; Snyder, 1995b). Moyle et al. (2014b) found an *increase* in anxiety for intervention and control groups, although this effect was significantly mediated by the touch intervention. Three studies found no significant treatment effect (Rowe & Alfred, 1999; Moyle et al., 2014b; Hicks-Moore & Robinson, 2008).

Idiosyncratic scales yielded variable results. Brooker et al. (1997) found a significant difference in only one out of four participants, and Snyder et al. (1995a) found a decrease only in the mornings for 'Behaviour 1', which included 'grabbing, screaming/yelling, hitting/punching, and trying to get to another place'. However no explanation was given as to how these behaviour categories were created. Snyder et al. (1995b) found significant results for reducing idiosyncratic agitation behaviours. As such, the variability between studies is present both in personalised and published

observer measurement scales. Rodríguez-Mansilla et al. (2013) found a significant improvement in 'behaviour alterations' compared to control after three months' intervention, however this did not last to the two-month follow-up.

Skovdahl et al.'s (2007) qualitative study offers a possible explanatory mechanism for the diverse literature base. The outcome of touch in their study dependent upon someone's mood, needs and wishes at the time. It may be that whether or not touch reduces agitation is primarily dependent upon the individual with dementia, and the relationship between the individual and caregiver.

2. Aggression

Aggression was not measured directly by any study, but was included in scales of 'agitation', 'disturbed behaviour' and 'symptoms of dementia'. However there were some specific outcomes - Suzuki et al. (2010) found a significant reduction in the physical aggressiveness subscale of the BEHAVE-AD (Reisberg et al., 1987), without an overall reduction in the scale. Overall, the literature base has not conceptually separated 'aggression' from feeling anxious.

3. Alertness

One study (Belgrave, 2009) focussed on time spent in an alert state, namely in the context of a music therapy session. Touching interventions significantly increased alertness, with instrumental touch the most effective overall. This may be because, contextually, instrumental touch (i.e. showing people how to use instruments) was more appropriate to the situation than expressive touch. Rodríguez-Mansilla et al. (2013) noted significantly increased 'participation in therapy' with massage, which may indicate alertness. However, the authors do not specify 'participation', or the meaning

of ‘therapy’, which does not appear relate to the massage as it was a criterion during the no-massage follow-up. The effect of increased ‘participation in therapy’ was present two months post-intervention.

4. Low mood

Two studies specifically assessed mood (Rodríguez-Mansilla et al., 2015; Moyle et al., 2014b), and both found significant results for touch on improving low mood. Scherder, Bouma & Steen (1998) found significantly improved behaviour inventory subscales of ‘depression’ and ‘mood’. Possibly related to this, they also found significant reductions in the ‘need of help’ and ‘physical invalidity’ subscales of the BOP (Van der Kam, Mol & Wimmer, 1971). Suzuki et al. (2010) found that an ‘emotional functioning’ subscale of the BEHAVE-AD (Reisberg et al., 1987) worsened in the control group, whereas this was not the case for the touch intervention. Skovdahl et al. (2007) referred to emotions of enjoyment and warmth from participants, although on occasions anxiety and restlessness meant that the touch intervention was not implemented. The literature seems to suggest that touch interventions can improve low mood.

Cognitive

Two studies reported an effect of the intervention on cognition. Suzuki et al. (2010) found that whilst the cognition of the control group significantly declined over 6 weeks, this was not the case for the intervention group . Moyle et al., (2011) found a significant improvement in a checklist measuring memory and ‘behaviour problems’, which was retained at two-week follow-up. This may link to Belgrave’s (2009) results that touch can improve alertness, although the study combined data from ‘inactive’ alertness such as vocalisations and active orientation, with ‘active’ alertness such as engagement.

Quell et al. (2008) found that, when separating the sample into lower and higher cognitive function, the lower-functioning group experienced significantly higher levels of stress. This raises important questions for why stress may be increased in persons with lower cognitive functioning – potentially this is due to lack of contact and increased loneliness (Hubbard et al., 2003). Methodologically, it suggests that level of dementia could be an important confounder in studies measuring stress.

Adverse effects of touch

Some studies documented adverse effects from the touch intervention. Snyder et al. (1995) noted that touch increased agitation in men, however they did not collect data on the gender of nursing staff delivering the intervention. Brooker et al. (1997) found that massage increased idiosyncratic ‘disturbed behaviour’ in two participants (50% of sample); Harris et al. (2012) referred to two percent of participants being unable to tolerate the sleep-monitoring wristwatch; Skovdahl et al. (2007) stated that one of their five participants would on occasion “express that she found the stimulation disturbing” (p. 165), at which point the intervention was stopped. There is limited information across the current review as to why people chose to discontinue participation. However, the meaning of touch differs between individuals, depending on the relationship, touch location, and context (Hollinger & Buschmann, 1993). Skovdahl et al. (2007) also note how different people prefer different bodily areas of tactile stimulation. This links in to the finding that the adverse effects of touch in the current review are not consistent across samples, but rather, seem to be individual to the person.

What are the outcomes for the caregiver?

Physical

No studies included in the review measured physical outcomes for caregivers.

Psychological

No studies measured the psychological outcomes for the caregiver specifically. Skovdahl and colleagues (2007) note that caregivers described tactile stimulation as a “positive tool that enabled them to be close and to spend time with their residents” (p. 168). One caregiver stated that she found delivering tactile stimulation relaxing, and another referred to delivering the intervention as enjoyable. Belgrave (2009) measured rapport between the person with dementia and caregiver, and found significant improvements with touch. However, the data were collected from independently rated videos - the ratings may have been compromised by the fact that touch is generally a sign of rapport to the external viewer.

Conclusions and implications for clinical practice

The aim of this systematic review was to consider how researchers have investigated touch as an intervention in dementia, how touch has been operationalised, and what the outcomes of the interventions have been for the person with dementia and the caregiver. The first two questions have been answered relatively robustly from this review. Touch has predominantly been used to decrease undesirable behaviour states in people with dementia – particularly agitation and aggression. Touch has also been used to reduce stress and promote wellbeing, for example improving sleep and mood

The impact of touch on people living with dementia and caregivers is less clear, as there is a lack of data. Touch interventions in the current review demonstrated equivocal impact on longer-term physiological stress and ‘agitated behaviours’, although there were some short-term improvements in low mood. This mirrors reviews with more ‘broad’ definitions of touch interventions in dementia care (e.g. Hansen et al., 2006). Several of the studies also demonstrated high variability within individual participants (Brooker et al., 1997; Skovdahl et al., 2007; Snyder et al. 1995b). The corresponding implication for clinical practice is to approach touch interventions in a person-centred, tailored way, as no standardised approach can be recommended. Additionally, people with more severe dementia expressed higher stress levels (Quell et al., 2008) – therefore it is clinically important to ensure that the emotional needs of people with severe dementia are being adequately addressed, as this group can be more isolated than less impaired peers.

Whilst the literature base is sporadic, there are clear indications that touch can have a profound impact for some people with dementia, as long as their wishes are at the heart of the intervention (Skovdahl et al., 2007). The dominant model of delivering touch interventions in the current review was to specify a particular time and duration for all participants. Despite the fact that the criteria for the current review did not specify whether a touch intervention must be formal, such as a massage, or more ‘informal’ such as touch within social interactions, only one study investigated informal touch (Belgrave, 2009). These points raise ethical issues about research into touch interventions. Using formal interventions could imply that touch must be a special *event*, rather than a natural part of everyday interaction. Additionally, formal interventions also require extra time and resources compared to the informal approach of integrating touch into interactions. This may link into the ‘professionalism’ of dementia care (Bond,

1992), whereby instrumental doing-to tasks are promoted compared to less formal, more interpersonal approaches care.

Person-centeredness in dementia care involves treating people as individuals, valuing people with dementia and their carers, facilitating a positive social environment, and looking at the world from the perspective of people with dementia (Brooker, 2003), and there is increasing acknowledgement that approaches in dementia care should be person-centred (Edvardsson, Winblad, & Sandman, 2008). There are also methodological problems with standardised approaches, which may erase nuance from the data and therefore miss the effectiveness of the intervention. This could partly account for the variable results in the current review.

For caregivers, providing touch can be relaxing, and facilitate rapport and closeness with people with dementia. This highlights the importance of recognising the emotional impact of providing touch in clinical practice. However, there is a paucity of research exploring caregivers' perspectives. Only one study in this review asked the caregiver to provide their views on what it is like to provide touch to a person with dementia (Skovdahl et al., 2007). No studies measured the outcomes of family caregivers, and only one study took place in the community. This is surprising considering that the World Health Organisation's (2015) *Call for Action* frames dementia as a social issue which includes community, caregivers and family alongside actions for people with dementia as individuals. Additionally, Alzheimer's International's (2015) *World Alzheimer Report 2015* highlights the need to evaluate ways to support people with dementia and their carers in the community. In the current review Moyle et al. (2014b), and Quell et al. (2008) also note the ethical importance of caregivers with whom the person is familiar, yet this was rarely reported in the literature.

Most of the studies utilised observer measures of behaviours related to unhappiness in the person with dementia (e.g. ‘agitation’, ‘behavioural symptoms’, ‘depression’). This is despite moves in other areas of research to collaborate with people with dementia as part of the research process (Hanson, Magnusson, Nolan, & Nolan, 2006), and the consistent finding that proxy measures don’t agree with self-reported quality of life in people with dementia (Vogel, Mortensen, Hasselbalch, Andersen, & Waldemar, 2006). No studies in the current review used an outcome measure for quality of life or wellbeing, which brings into question the relevance of the findings for people with dementia. Additionally, no studies investigated the relationship between both members of the touching dyad.

The practice of objectifying touch interventions, for example using published behaviour or mood scales, may miss elements of touch such as playfulness and spontaneity. However, a research base is developing for a relationship-orientated touch intervention which can be applied to dementia care. *Adaptive Interaction* (Ellis & Astell, 2008; Astell & Ellis, 2006) involves ‘being with’ a person with cognitive impairment, by mirroring the person’s language repertoire (e.g. vocalisations, rocking), and focussing not on outcome, but on enjoyment and togetherness. It is based on a communications approach created for people with severe intellectual disabilities, called *Intensive Interaction* (Nind, 1996). Zeedyk, Caldwell, & Davies (2009) note that this approach can be used irrespective of clinical diagnosis. Adaptive/Intensive Interaction addresses some gaps in the current literature base by being relational, playful, and person-centred. It adds equality to the interaction, as it is not a ‘doing-to’ therapy but a mutual experience (Barber, 2007).

The Adaptive/Intensive Interaction approach does not empirically separate touch from other sensory elements such as vocalisations, and movement. It cannot be used, therefore, to investigate touch alone. Instead, the approach is orientated towards the relationship, which lends it well to empirically investigating the wholeness of the touch experience that is missing from the empirical literature (e.g. fun, closeness, enjoyment, playfulness, connection). This can be analysed in a variety of ways through video tapes, for example measuring amount of eye contact, smiling, joint attention and joint interactions (Kellett, 2000, 2005). Intensive Interaction literature also provides scales which could be adapted to dementia care, for example the Pre-Verbal Communication Schedule (Kiernan and Reid, 1987). It is a touch intervention with the potential to be effective as part of good clinical practice, and it is worthy of further research.

Critical evaluation

The current review has some limitations due to the deliberately narrow definition of touch.. It may not be fully representative of how touch is used in practice, whereby touch may be combined with other interventions (e.g. sensory rooms). However, many of the excluded studies (e.g. massage with vocalisation, Kim & Buschmann, 1999; massage with scented oil, Lee & Lee, 2013) have similar characteristics to the studies in this review (i.e. aim to reduce unwanted behaviours in the person with dementia and/or reduce distress). It is also of note that despite the aims of the touch interventions being relatively homogenous, the current narrowly-defined review found a large variation in outcome measures used for touch intervention studies.

The exclusion of energy-based touch therapies may have biased the review towards Westernised touch. It is possible that touch therapies which focus on shared energies

lend themselves better to investigating the relationship. Additionally, such therapies may focus more on wellbeing rather than disturbing behaviours. A similar literature review examining the aims and rationale of biotherapies may address this gap in knowledge.

The quality of the literature base has affected the robustness of the current review. Characteristics of the settings from which participants were recruited, and the demographics of patients lost to follow-up, were rarely reported in the current review (see Appendix 3). This makes it difficult to assess the representativeness of the groups who completed the studies. There was also a wide range of quality assessment scores ranging from 48% of the maximum score (Moyle et al., 2011; Synder et al., 1995a), to 84% of the maximum score (Moyle et al., 2014a; Moyle et al., 2014b). In part, this may be due to the fact that there was no unifying psychological theory to underpin the operationalisation of touch interventions in the current review.

Three studies based their research on Hall and Buckwalter's (1987) Progressively Lowered Stress Threshold Model (Remington, 2002; Synder et al., 1995a; Snyder et al., 1995b). This model suggests that 'agitated behaviours' in a person with dementia are the result of internal and external stressors interacting with a reduced ability to manage these stressors. Rowe and Alfred (1999) used the Theoretical Model for Aggression in the Cognitively Impaired, adapted by Ryden, Bossenmaier & McLachlan (1991). This model suggests that aggression, manifested in various ways, is caused by innate tendencies (learned responses, genes) interacting with the environment. These two models were not used to explain specific choices for operationalising touch, but to justify the use of a touch intervention. Additionally, neither model is primarily person-centred (unlike, for example, the VIPS model; Brooker, 2003). The remaining 13

studies referenced previous literature on physiological and/or and psychological benefits to touch, without selecting a particular psychological model as the basis for the study. As such, lack of a comprehensive conceptual framework may have compromised the quality of the studies in this review.

Summary and suggestions for future research

The current review investigated the rationale behind touch interventions in dementia care, and outcomes on people with dementia and caregivers. It was identified that there is a need to conduct more empirical research beyond objectified and/or standardised measures of ‘disturbed behaviour’ and dementia ‘symptoms’, which can dehumanise the person with dementia and therefore sideline the dyadic touching partner. Additionally, the variable nature of the touch interventions may be due in part to a lack of consistent theory to underpin the use of touch interventions (and, by proxy, the nature of such interventions).

Future research may benefit from considering the social context of touch (e.g. exploring differences between touch in family and formal caregivers), individualising the time and frequency of touch interventions, and focussing on increasing quality of life rather than reducing undesirable ‘behaviours’. Particularly, increasing the use of self-report measures for people with dementia would demonstrate a valuing of the person with dementia and their perspective, in line with person-centred principles. There is also a need to value families, and diversify research into touch interventions beyond professional care settings.

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Part Two: Empirical Research

Intensive Interaction and Discourses of Personhood: A Focus Group Study
with Dementia Caregivers

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Please see Appendix 4 for the Guideline for Authors.

Abstract

Aim: Societal discourses of dementia tend to be medical and dehumanising, whereas the communication technique Intensive Interaction offers discourses of personhood. The current study aimed to explore how paid caregivers of people with dementia enacted societal discourses of dementia with and without the context of Intensive Interaction.

Method: An Intensive Interaction training day was offered to staff from two care homes. Two focus groups, centred on dementia care, were held: one before training and one after (n=5). Transcripts were analysed with Critical Discourse Analysis, an approach which relates discourses to social power structures with the aim of reducing inequality.

Results: Before the training, carers accessed medical discourses of loss, non-communication, and lack of personhood. 'Being with' people with dementia was framed as separate to work. After training, Intensive Interaction discourses offered options for honouring personhood and interpreting nonverbal communication. Intensive Interaction allowed a reframing of 'being with' people with dementia as 'doing work'. Family caregivers were largely absent from discourse. Care home hierarchies, and the discursive industrialisation of care, were barriers towards honouring personhood.

Conclusions: Staff need to be empowered and supported to enact person-centred care in the current model of 'doing-to' care. Intensive Interaction offers a discourse for staff to do this, however support from management is required. More research is needed to identify ways to involve families in residential care for dementia, and to explore the effects of using Intensive Interaction in practice. Current policy and subsequent research agendas also need to be more inclusive of person-centred approaches to dementia care.

Introduction

“This new use of language
the mumblings and ramblings
(that others think are meaningless
unhooked together sentences of drivel)
contains answers I have looked for
throughout our twenty-five
year-old marriage bed.”

- Helfgott (2009; p. 203), of her husband Abe.

The medicalisation of dementia

Dementia is often considered to be a medical problem. It is framed as a globally burdensome disease, which primarily affects older adults and is characterised by loss of cognitive and physical function (Ferri et al., 2006). There is no consensus as to what constitutes a ‘disease’, except that diseases are abnormalities in the physical body which must be diagnosed by medical experts (Tikkinen et al., 2012; Wikman, Marklund & Alexanderson, 2005). A disease should, however, have a diagnostic taxonomy that clearly differentiates those with and without the disease (Harding and Palfrey, 1997).

Despite the modern conceptualisation of ‘dementia’, across history the term has referred to a range of reversible and irreversible “apparent disorders of the mind” (Harding and Palfrey, 1997; p. 97). The most common diagnosis of dementia, ‘Alzheimer’s disease’,

was first referred to as a disease by psychiatrist Emil Kraepelin - despite a consensus at the time that there was insufficient evidence for this, and disagreement from Alzheimer himself (Berrios, 1990). It is also unlikely that the Alzheimer's original findings, based on a 51-year old woman, were similar to what is known as Alzheimer's disease today (Maurer, Volk & Gerbaldo, 1997).

Neuropathologic studies have also demonstrated that there is no clear link between the assumed brain pathology and outward signs of dementia such as loss of everyday function (Snowdon, 2003). 'Pure' dementia is uncommon (Agüero-Torres, Kivipelto & von Strauss, 2006), and the term 'dementia' does not have a consistent taxonomy, particularly when considering more recent conceptualisations of vascular and fronto-temporal dementia (Sachdev, 2000). As such, there is insufficient evidence to claim that dementia is a 'disease', i.e. a clearly definable physical abnormality situated in the body (Kitwood, 1990; 1997).

Within this medicalised 'disease' model, dementia is seen to threaten civilised society. It is framed as a tsunami, an epidemic, a plague, or as all out war (Zeilig, 2013; Lane, McLachlan & Philip, 2013). People with dementia are considered socially dead, reduced a non-person or zombie as their brain shuts down (Hughes, Louw & Sabat, 2006; Gilhooly, Sweeting, Whittick & McKee, 1994; Behuniak, 2011). As such, loved ones may grieve while the person is still alive (Holley & Mast, 2009), and there are even debates about euthanasia for people with a dementia diagnosis (Hertogh, de Boer, Dries & Eefsting, 2007). Due to the lack of scientific evidence to support the disease model, these conceptualisations can be considered a result of objectifying, depersonalising medical discourses (Kitwood, 1997; Killick & Allan, 2001; Bender, 2014).

Discourse can broadly be considered as ‘language in use’ (Cameron, 2001). This includes all elements of how people use text, speech, pictures and other symbols to make meaning (e.g. grammar, metaphor, font, lexical choice, emphasis, tone, pauses, turn-taking and volume). Discourse, in this first sense, is something that people ‘do’. However, discourses can also be thought of as relatively stable, abstract structures which define the limits of how people make meaning (Jørgensen & Phillips, 2002). For example, the discourse of the courtroom is formal, clear and concise. This is very different to nursery discourse, where simple and informal language is used, often in the form of song.

The way that an individual chooses to ‘do’ their discourse will either support or challenge the overarching discourse structure, and likewise the overarching discourse structure will limit a person’s options for discourse. This is known as a *dialectical relationship* (Fairclough, 2001). Fairclough also refers to frameworks of related discourses (usually attached to a particular social institution like education or the market) as *orders of discourse*. Orders of discourse set the limits of how people think and what they do within certain institutions or situations. They are often demonstrated in what is taken to be ‘common sense’ or ‘natural’. Therefore, dementia currently fits into a medical order of discourse.

Discourses of dementia do not exist in isolation from how people feel (George, 2010) or what people do. Mitchell, Dupuis and Kontos (2013) suggest that the medicalisation of dementia is a form of violence across “image, language, and action in all aspects of our contemporary world” (p. 12). They argue that these concepts (image, language and action) are interlinked (Fig 1.), and therefore on-the-ground practices such as the

excessive ‘medication’ of older people living with dementia (Vetrano et al., 2011) can be changed by altering the discourses used to conceptualise dementia.

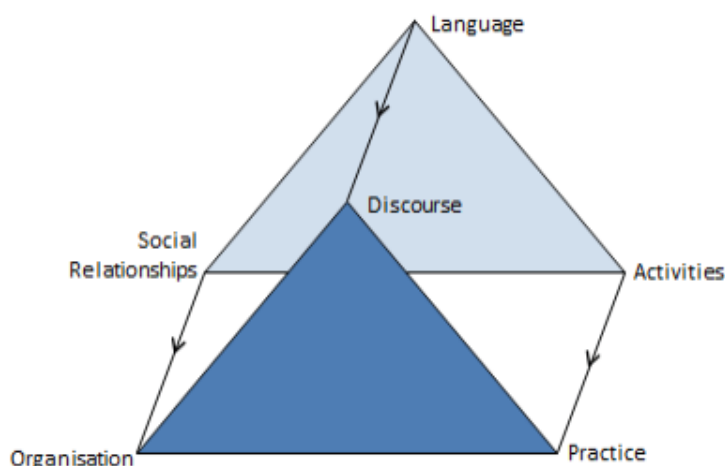


Figure 1. A model of how discourses of dementia link to social practices (Mitchell et al. 2013).

Medically, ‘experts’ have dominance in diagnosing and ‘treating’ dementia (Bond, 1992). However, there is no medical ‘cure’ (Wilson, 2008), and in this absence of a cure no hope. Instead, medical treatments rely mainly on drug intervention for ‘symptoms’ (Taft, Fazio, Seman & Stansell, 1997). This sidelines relationships and creates dynamics of helplessness and dependence (Lyman, 1989). Crucially, this hopeless picture is not supported by people with dementia themselves (de Boer et al., 2007). Advocacy movements contest the passive patient’s role: people with dementia want to be valued contributors to society, be socially connected, and be able to make choices for themselves (Dementia Action Alliance, 2010).

Think differently, work differently

Medical discourses of dementia, whilst dominant in society, do not completely preclude personhood-centred approaches to dementia care. For example, validation therapy is an empathy-based approach which centres the person as a unique and valuable human being (Feil, 1993). Validation involves accepting a person for who they are and within their current reality, such as reflecting a person's feelings rather than orientation to 'facts'. However, validation still presumes the final stage of dementia is "vegetation", or a type of withdrawal akin to becoming the "living dead" (Feil, 1991, p. 112). Additionally, this approach is considered to be a one-way therapy in which the person with dementia is validated by another – as such, it lacks a reciprocal relationship.

Intensive Interaction is an alternative way of communicating, which was originally developed for people without verbal speech. It is a dyadic form of 'being-with' a person who does not use formal verbal language, based on infant-caregiver interactions (Nind & Hewett, 1994). Intensive Interaction engages primarily with play, touch, humour, and games (Caldwell, 2006a, 2006b, 2007), and specifically uses these terms in its discourse. Techniques within the approach include mirroring, empathy, spontaneity, attentiveness, and use of sounds and the body. As such, Intensive Interaction has similarities with validation approaches in dementia care, but crucially it is not deemed to be a therapy and its fundamental principles are based on forming a reciprocal relationship. Additionally, unlike validation approaches which assume an end-state of loss, Intensive Interaction always assumes that the interaction partner is a fellow, equal human being with the ability to meaningfully connect and engage. Therefore, it is inclusive of all people with dementia.

Intensive Interaction, then, provides a discourse of common humanity, whereby the interaction can have a powerful impact on both parties. Caldwell (2007) suggests that Intensive Interaction is a journey from “I” to “we” (what Kitwood, 1997, would call *I-Thou* relating in dementia care). The approach has the capacity to allow staff to ‘reach’ people who were previously considered unreachable, and to actively improve the quality of life of both parties through empathetic interaction (Barber, 2007). This may be particularly important in demanding settings such as dementia care, where staff stress levels and burnout are correlated with empathy (Åström, Nilsson, Norberg, Sandman & Winblad, 1991). There is also a small literature base advocating and developing on the use of Intensive Interaction within dementia care, where the technique has been demonstrated to increase communication and build fulfilling relationships (Harris & Wolverson, 2014; Ellis & Astell 2008; Astell & Ellis, 2006).

Analysing the role of dementia discourses in practice

One way to consider how dementia discourses influence practice (and vice versa) is through Critical Discourse Analysis. There are numerous theoretical models of Critical Discourse Analysis, but commonalities between them include (Wodak & Meyer, 2009):

- Actively seeking to address social inequality;
- Adopting a critical approach, which seeks to understand the links between discourse, social practice and power;
- Considering discourse as a social phenomena, not just as language and grammar;
- Analysing texts in context (‘text’ being the communicative event under analysis, e.g. leaflet, conversation, speech);

- Assuming that discourses are ideological, i.e. they influence the relatively stable, socio-political belief structures and values of a society.

Therefore, Critical Discourse Analysis can be used to enhance Mitchell et al.'s (2013) model of discourse (Fig. 1), by exploring the *ways* in which dementia discourses are used, and examining how these discourses support current care practices. Importantly, Critical Discourse Analysis focuses on the creation of power dynamics and social identities through discourse. In this case, the approach can explore the identities and power differentials created by the label dementia, and its impact upon personhood.

Fairclough (Chouliaraki & Fairclough, 1999) provide a model for conducting a Critical Discourse Analysis within a *dialectical-relational approach*. This approach assumes that the use of 'symbols' to make sense of the world (e.g. language, body language, pictures) overlaps with other parts of social life such as power, belief systems and institutions. This means that one must analyse discourse and other elements of social life (such as the structure of institutions, what people do) in relationship with each other. A fuller description of Critical Discourse Analysis, and a more detailed background to Fairclough's model, can be found in Appendices 6 and 7.

Rationale for the current study

Thus far, it has been argued that medical discourses of dementia are dehumanising and disempowering. The communication technique Intensive Interaction uses alternative discourses, which centralise personhood and reciprocity. Mitchell et al. (2013) suggest that this is important because discourses of dementia have an effect on practice and relationships in dementia care (Fig. 1) – that is, (de)humanising discourses foster (de)humanising practice. However, Mitchell and colleague's model does not suggest

how discourse is linked to practice. Critical Discourse Analysis provides a framework to analyse the nature of the relationship between discourse and practice.

The current study therefore sought to address the social problem of depersonalisation in dementia care, using Critical Discourse Analysis. The first aim was to explore how medicalised societal discourses of dementia are enacted within the discourse of paid carers. The second aim was to explore how medical discourses of dementia are enacted by paid caregivers after training in Intensive Interaction. The third aim was to use these exploratory analyses to identify possible solutions to the problem of dehumanisation.

Method

Design

The study used a focus group design within the context of Intensive Interaction training. Focus group data can be considered more naturally conversational than other qualitative methods such as interviews (Grudens-Schuck, Allen & Larson, 2004). Focus group methodology can encourage greater self-disclosure between participants, and to facilitate this, a homogenous group of participants is recommended (Sharts-Hopko, 2001). This research method fits well with conducting research with paid care staff, who work in teams during their everyday occupation.

Smithson (2000) states that focus group data can be used to gather knowledge about societal discourses on particular issues, and that participants have more flexibility within the researcher's agenda compared to other approaches. Kitzinger (1995) similarly suggests that focus groups are a useful research design for using open-ended questions to discover group norms, and "explore the issues of importance to

[participants], in their own vocabulary, generating their own questions and pursuing their own priorities” (p. 299). As such, this type of study design matches with the principles of Critical Discourse Analysis (making links between local and societal discourse).

Two focus groups were conducted – one before the training, and one after the training. This was to allow for an exploration of group perspectives in two different contexts: before being introduced to Intensive Interaction discourses, and after being introduced to them.

Recruitment

Participants were recruited as a convenience sample from two specialist dementia care homes in the north of England, across July-November 2016. The care homes were part of a non-profit organisation which runs 15 care homes for older adults. The research supervisor for the current project (a practicing Clinical Psychologist) had a prior working relationship with the care home managers, and gained their consent to recruit staff from the homes.

To ensure the Intensive Interaction training was meaningful for the care homes, 12 staff places were negotiated. Ideally, focus groups should have between 5 and 10 participants (Jayasekara, 2012) to ensure that there are enough participants to facilitate discussion, but not so many that individual voices are lost. It was agreed with managers that staff who were interested in the research project would sign up on the day of training.

The chief researcher provided posters (Appendix 8) to advertise the training within the care homes. Managers provided all interested staff with an information sheet about the

research study (Appendix 9), and recruited staff for training. Once 12 staff were recruited, managers provided the chief researcher with a list of attendees. There were no prior relationships between the attendees and the chief researcher.

Participants

All 12 training places were filled, although two staff did not attend due to illness. Of the 10 attendees, five participated in the research (demographics in Table 1; consent form and demographics form in Appendices 10 and 11). All participants were female and identified as White British. It is of interest that no personal carers chose to take part in the research. Only one member of Care Home 2 participated in the focus groups; however, this staff member was an active participant in the focus groups and did not appear inhibited.

Table 1. Demographics of research participants.

Demographic	Carer 1	Carer 2	Carer 3	Carer 4	Carer 5
Care home	1	1	1	2	1
Job title	Domestic	Housekeeper	Activity Coordinator	Activity Coordinator	Handyperson
Age	52	55	34	58	57
Working hours	Full time	Full time	Part time	Part time	Part time
Years in current job	13	22	15	4	4
Years working with dementia	13	22	18	7	14
Type of experience with dementia	Professional	Professional	Professional	Professional	Professional Personal (historical)

Procedure

A full day of Intensive Interaction training was held off the care home site. Four people facilitated the training day – two Intensive Interaction trainers, the chief researcher, and the research supervisor. Figure 2 outlines the structure of the training day.

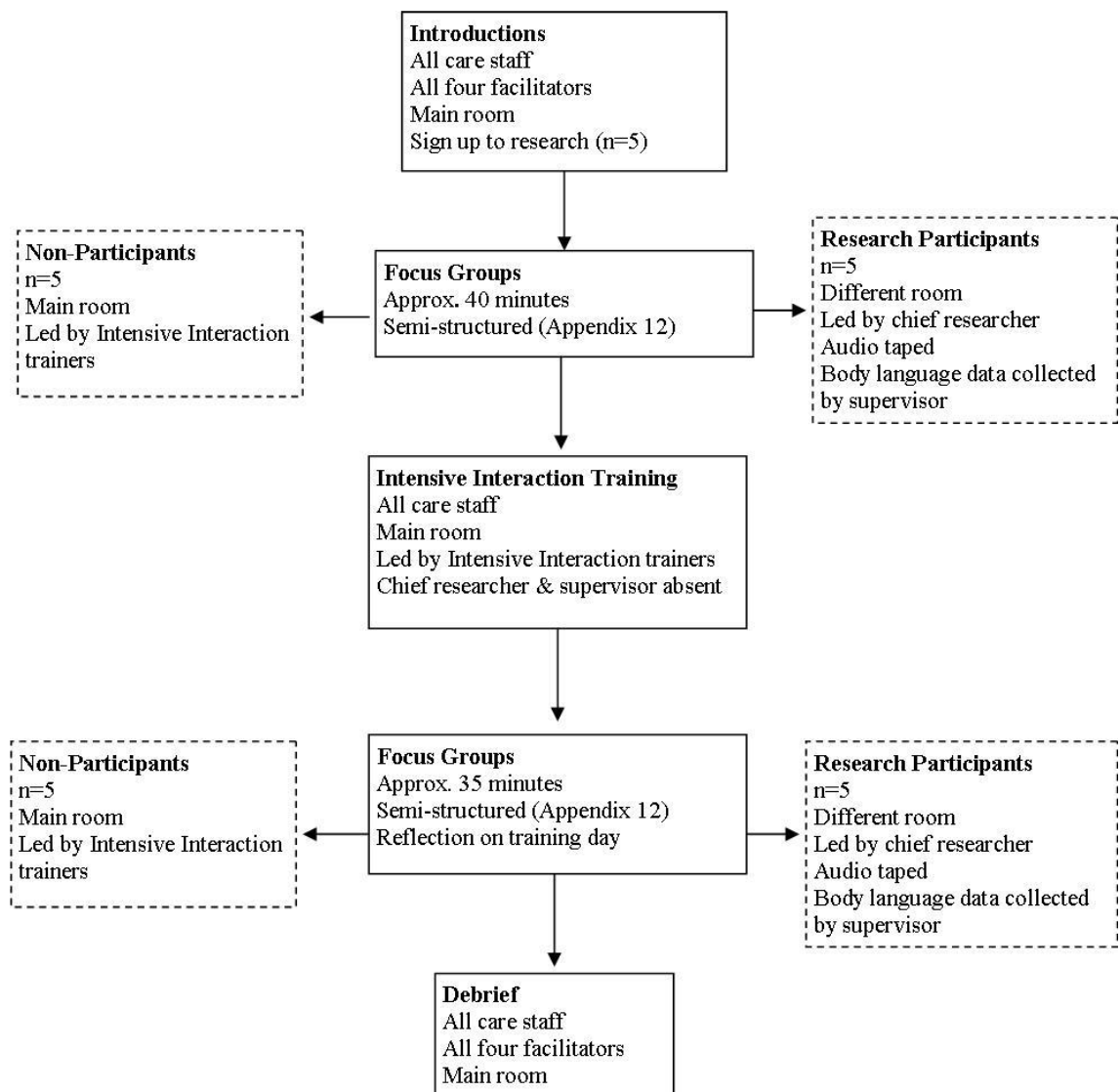


Fig 2. Process diagram for data collection at the Intensive Interaction training day.

During the initial introductions, care home staff were invited to sign up to the research project. The first activity of training was a 40-minute focus group, which was run separately for research participants and non-participants (Fig. 2). The research group, led by the chief researcher, was audio-recorded, and body language data was collected by the research supervisor.

The focus groups were semi-structured, using a guide based upon discourses identified as lacking in the medical model of dementia (Appendix 12). These discourses are: personhood (e.g. “What happens when someone gets dementia?”), communication (e.g. “How do you communicate with people with dementia?”), embodiment (questions about touch), empathy (e.g. “What do you think that is that like for the person?”) and reciprocity (e.g. “Can people with dementia give anything back?”).

After the focus group task, the remainder of training was completed with all staff together, and without the presence of the chief researcher or research supervisor. Training consisted of an overview of Intensive Interaction principles via discussion, video and presentation, considering who might benefit from Intensive Interaction, and a range of practical exercises about using the approach (such as role-playing the dyad of a person without verbal speech and a carer). The training emphasised putting oneself in the shoes of a person without verbal speech, and personal reflection on how staff could incorporate Intensive Interaction into their work.

After training, staff were again separated into research and non-research focus groups. These focus groups lasted 35 minutes and were conducted in the same format as the morning groups (Fig. 2). The same interview guide was used (Appendix 12), with additional reflection upon the training day.

A debrief of the Intensive Interaction training was then held in the main training room, with all staff and all four facilitators.

Ethics Approval

Ethical approval for the current study was obtained from the University of Hull Faculty of Health and Social Care Ethics Committee on 26/06/2015 (Appendix 13).

Data analysis procedure

Methodology for analysis

A Critical Discourse Analysis model provided by Fairclough (Chouliaraki & Fairclough, 1999; Fig. 3) was used to guide the analysis. Although the model is set in stages, the practice of Critical Discourse Analysis is recursive, and the researcher will move back and forth across the stages during the analysis. In the first stage, a social problem is identified (Fig. 3). The ‘social problem’ currently identified is the medicalised discourse of people with dementia, which supports dehumanising practices such as over-medicating and dishonouring people’s personhood.

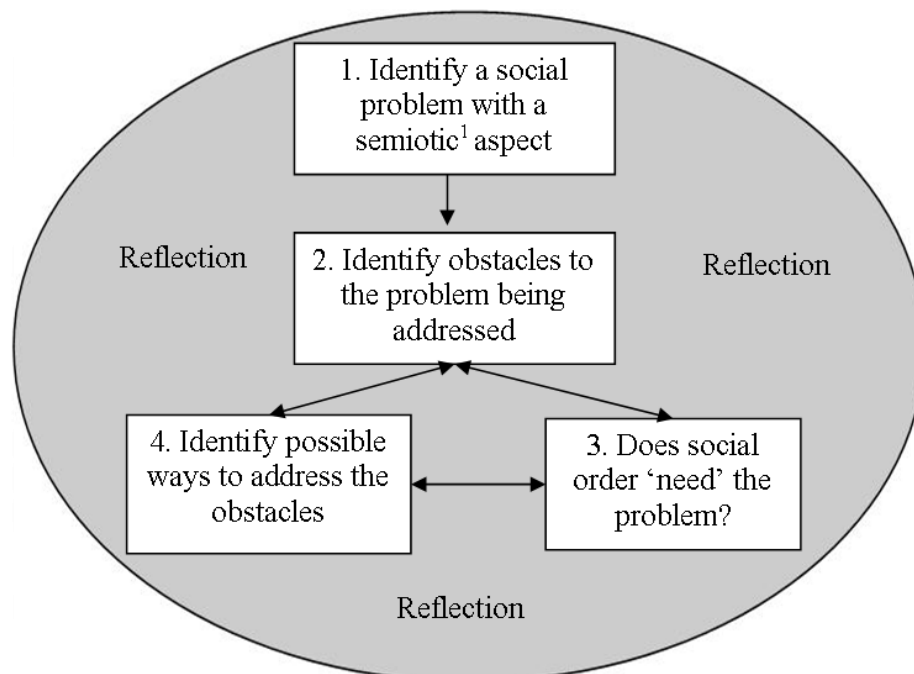
Secondly, obstacles to addressing the social problem are identified through analysing the discourse of a ‘text’ or multiple texts. For example, a discourse analysis of policy might reveal that people with dementia are referred to in terms of problems and ‘symptoms’. This process is the main bulk of the analysis.

The third stage involves analysing where the social problem (the depersonalisation of people with dementia) fits into wider culture, and whether the problem is required to maintain the current social order. For example, the profits from medical dementia care

might support other social structures such as private companies, whose success supports an economic model of privatisation, which in turn supports certain political ideologies.

At the fourth stage of Fairclough's model, the researcher identifies ways of addressing any obstacles which are in the way of social change. For example, Innes (2002) identified that consultation from a range of individuals (practitioners, policy makers, people with dementia and their carers) is required for the effective improvement of service provision.

The final stage is reflection upon the whole process, but in practice reflection should be integrated at all stages and is therefore represented in Figure 1 as background for the entire analysis.



1. 'Semiotic' is to the relationship between a 'sign' (e.g. word, gesture, use of capital letters) and the object/meaning to which it refers.

Figure 3. Fairclough's framework for Critical Discourse Analysis (adapted from Chouliaraki & Fairclough, 1999).

Data collection

Research data were collected with *micro-interlocutor analysis* (Onwuegbuzie, Dickinson, Leech & Zoran, 2009). This method involves an additional researcher taking notes on embodied data (gesture, facial expression) whilst the verbal data is voice recorded. The richness of the focus group (i.e. differing reactions among group members) is therefore maintained for the analysis, and embodied data can be combined with verbal transcripts provide a more robust interpretation (Duggleby, 2005). As noted, research focus groups were led by the chief researcher, with the research supervisor collecting the additional embodied data.

Method of analysis

The texts analysed in the current study were detailed (typed) transcriptions of the audio for each focus group, with corresponding body language data added by hand. The use of multiple sources of data (body language, group dynamics, vocal properties and speech content), or ‘triangulation’ (Potter, 1996), ensures that the researcher’s interpretations are sound (i.e. the researcher’s interpretations should converge with the other sources of data). The researcher’s interpretations in the current study were also triangulated with the initial literature review, which examined the wider social, scientific and political context of dementia discourses.

Post-transcription, the chief researcher undertook several close readings of the texts, with annotations of initial thoughts and impressions added during each reading. This is called ‘familiarisation’ (Rabiee, 2004) and aims to “immerse in the details and get a sense of the interview as a whole before breaking it into parts” (p. 657). Familiarisation supports an understanding of the whole text, and therefore the selection of

representative extracts for analysis. Cameron (2001) also notes that, due to the nature of spoken discourse, it is important to see patterns across the text, rather than picking isolated and decontextualised examples.

After familiarisation, each line of text was coded for themes based on the interview guide (personhood, communication, embodiment, reciprocity, empathy). Extracts which particularly focussed on personhood were selected for in-depth analysis, as personhood is the crucial discourse missing from the medical conceptualisation of dementia. The analysis included aspects of discourse such as grammar, syntax, vocabulary, emphasis, tone, social function, paralanguage (such as ‘mm’), volume, crosstalk, false starts, pauses, and self-corrections. These are presented fully in the results section for transparency.

The extracts selected for presentation in the current study were short extracts which involved multiple participants, to give the reader a sense of group dynamics. They were also extracts which involved the texturing of multiple discourses, as an analysis of how different discourses are ‘worked together’ is crucial to understanding how these discourses can be resisted (Fairclough, 2001). To demonstrate how the extracts are representative of the wider focus group, the results for each focus group are preceded by a brief narrative which summarises the content of the whole text. Additionally, the process of triangulation suggests that the extracts are representative of the wider social and political context.

Fairclough (2003) and Cameron (2001) also note the need to analyse *intertextuality* in Critical Discourse Analysis. Intertextuality is the way that different voices are woven into the text, either through direct quotes and paraphrasing, or by using discourses from multiple social arenas (in the current study, examples might be discourse of the care

home, medical discourse, or managerial discourse). This part of the analysis was conducted by collecting all the direct quotes and paraphrases that were used by focus group participants, and making notes of the societal discourses which were enacted in each line of speech.

Finally, an overall ‘map’ of the discourses from the focus groups was developed (Appendix 14), to illustrate how medical discourse is situated within other discourses, and to facilitate an overall summary of the discourses. This map was used to inform the final part of the analysis – identifying problems which perpetuate the depersonalisation of people with dementia, and suggesting possible solutions.

Results

Each focus group will then be presented separately, with the following data:

1. A summary of the main content;
2. An analysis of intertextuality (representations of different voices within the text);
3. An analysis of discourses of personhood within the text.

Focus Group 1

1. Summary of content

When asked about dementia, carers referred to it as an illness, worse than death, the loss of a person and death itself. However, when asked about one-to-one time and communicating with people, carers spoke about treating people as individuals, and provided anecdotes of interacting differently with different residents. Carers also framed

dementia as being an older person's illness, referring to younger dementia as 'heartbreaking'.

Carers discussed a lack of resources, particularly of time and staff. Job role and hierarchy were considered important factors as to whether someone had the time (and permission) to interact with residents. Communicating and being with people with dementia was framed as an extra from work, and as inactivity (the word 'sit' was used exclusively in reference spending time with residents). People with severe dementia were considered unable to communicate. Family members were thought of as either not understanding dementia, or not wanting to understand.

The longest pause in the focus group was after the question "Can people with dementia give anything back?". Staff referred to positive interactions (a smile, pleasant exchanges, welcoming staff after leave, and joining in activities) as something that people with dementia could give back.

2. Analysis of intertextuality

A full representation how carers incorporated other voices into the focus group can be found in Appendix 15.

Carers generally referred to residents and themselves. Residents were most often considered as a group. Direct speech was usually used as part of storytelling and anecdotes. Anecdotes primarily framed residents as the recipient of an interaction, such as reacting to activities. For carers this was primarily active, such as offering reassurance. Residents' families were almost absent from the text, and quoted either to

support the loss of the person, or in a way that demonstrated that family could not understand dementia.

Direct quotes from residents as a group were often stated in a high-pitched or enthusiastic tone – however, when carers gave direct quotes from individual residents, they attempted to represent that person’s voice and mannerisms. This suggests that individualising a person supports an acknowledgement of personhood, whereas a group of people with dementia are considered in the context of more patronising discourses.

The extract in Table 2 follows a conversation about dementia being an illness in which the person has ‘disappeared’. This extract can be separated into three types of representation: people with dementia and their families, care homes, and dementia itself.

Table 2. Extract from Focus Group 1, demonstrating the use of different voices in the text. Carers are numbered and ‘M’ refers to the main researcher (moderator).

Extract of Intertextuality from Focus Group 1.

The moderator question triggering the discussion was the first question of the focus group: “I just wondered what you thought of dementia(.) like what is dementia(...) to you”. The group has unanimously referred to dementia as an illness, “sad”, “awful”, and then like seeing a person “disappear”.

4: Yeh like like I just said about that chap who(.) who I know [*quieter*] whose wife died last week(.) [*louder*] like(.) he was(.) he was upset (..) but(.) [he said he lost her two and a half
[years ago when she first started with dementia

1: [it’s a blessing, it’s a blessing

2: [years

?: yeh's from group

3: a lot of a lot of people say that(.) a lot of relatives will say I lost my mum or my dad(.) [yeh
(.) yeh] like two years ago when they first come in here [yeh] coz it's not the person is it(.)

4: No, no

1: They say it's on like the same wavelength as(.) cancer don't they(.) dementia it's like your
cells your brain cells [yeh it's-] int it shutting down

Representing people with dementia and families

Carer 4 attempts to frame the *chap* as being (normatively) upset at his wife's death. The use of the friendly word *chap*, the pauses, and the re-emphasis on *was* may mitigate social damage to the husband. Conventionally, one should express unadulterated grief when a spouse dies; here the carer is stating that this was not his main feeling. It belies other potential emotions such as relief, being unburdened, confusion, or as carers later state in this focus group, feeling 'glad for' the person who has died. As such, using indirect speech may be a way to create distance from the words the husband said, to protect him socially. Indirect speech also removes complexity, contradiction and ambivalence.

Carer 3, however, does use direct speech, referring to what relatives say with a first-person phrase. Perhaps when referring to generic 'relatives', it is safer to use direct speech, because it is not a social threat to an individual person or family. After using relatives' voices as the main clause, Carer 3 moves back into her own voice with the conjunction *coz*. The following clause suggests that relatives' experiences are *because* the person no longer exists (i.e. the non-existence of the person was already a fact before families had their say).

Representing care homes

Initially, Carer 4 stated that somebody was lost when they first got *dementia*, but later in the extract Carer 3 suggests that the person was lost upon ‘com[ing] in here’. Therefore, dementia and care homes become synonymous. There is also the implication of agency on the part of the person with dementia, as they ‘come in’ rather than being ‘taken’ or ‘brought’. This is characteristic of Focus Group 1, whereupon in all instances except one, people with dementia are referred to ‘coming in’. The one exception is a man with dementia who once worked in care homes. In that case, the person was referred to with the negative, de-agentic terms ‘landed’ and ‘ended up’ in a care home. In neither focus group is there any positive reference to care homes.

Representing dementia

The extract is textured with medical discourses. ‘They say’ that dementia is like cancer. There is no singular agent, just a sense that this is a normative discourse (socially, the realm of scientists and medical professionals). Carer 1 pauses before the words ‘cancer’ and ‘dementia’, potentially because of the images, discourses and feelings of fear that these concepts stir. There is also use of the pronoun ‘your’, which conveys the sense that dementia could happen to anybody, rather than being something which happens to ‘them’. Dementia is framed brain cells shutting down, using terms which denote it as a common-sense statement (*it’s like* and *int it*). The phrase ‘int it’ may also function as an invitation to bring other carers into the conversation.

3. Discourses of personhood

In the extract below (Table 3), the data can be separated into discourses of personhood related to both people with dementia and carers.

Table 3. Extract from Focus Group 1, representing discourses of personhood. Carers are numbered and 'M' refers to the moderator.

Extract of Personhood from Focus Group 1

The moderator question triggering the discussion was “What do you think one to one would bring(.) Like what would be different?”. Before this, the moderator asked what made Carer 5 ‘brilliant’ as stated by other carers. This led to discussion about one-to-one care, particularly spending time with residents, and then a conversation about sitting with people with dementia through the night so that they do not “go [die] on their own”.

1: Better quality of life

3: You just don't get no time.

1: But when there's only like four to(.) how many?

3: Yeh

M: Mm

2: We have to-

1: You haven't got that time [for each(.) each person they've all got different needs and-

?: [yeh I know when you've just got three-

3: We always say they're human beings [mm] at the end of the day [aren't they do you know cos [yeh]

1: [yeh(.) yeh [it could be us

?: [yeh

3: er yeh(..) [it could be someone's mum someone's dad someone's sister

1: [it could be us one day

4: Well it's like a mother with a child isn't it [yeh] It's like(.) you know

2: Well it's like us as cleaners we don't even have time to sit(.) [no] do we(.) [no] with them(.)
We'd like to

Personhood of people with dementia

The statement about quality of life refers to “better quality of life *for the person with dementia*”. The fact this is not explicitly stated suggests that it is a commonsense ‘fact’. Unlike earlier representations of dementia as equal to death, there is an assumption of a life which can have varying levels of quality. This may have been enabled by the fact that just prior to this extract, carers were talking about the importance of being with people when they die, i.e. by comparison carers now considered a person with dementia to be a living person.

When Carer 1 does use the phrase “each person” she pauses prior to the word *person*. This indicates some unnaturalness in the phrase. It is a local demonstration of societal discourses of dementia which focus on the loss of a person. The conflict between the care role, which requires an acknowledgement that people with dementia *are* people, and the medical model which suggests that loss of normative cognition means loss of the person, is played out in such discrepancies in how carers conceptualise people with dementia in discourse.

Likewise, although Carer 3 states “they’re human beings”, she uses the ‘Other-ing’ word *they* and buffers this with filler statements such as “at the end of the day”, which is also placed in a weak position as a subordinate clause. Additionally, the humanity of people with dementia is referred to as something which staff *say*, rather than a statement of how things *are*. The discourse here represents an attempt to honour the personhood

of people with dementia, however its linguistic properties suggest ambivalence about this.

Interestingly, the acknowledgement that people with dementia are human beings is followed by Carer 1 stating “It could be us”. This discourse of empathy and shared humanity is not taken up by the group, as demonstrated in Carer 3’s reluctance with “err yeh(.)” followed by her distancing herself by stating other relationships such as mum, dad and sister. Carer 1’s repetition is met by even further distance, as Carer 4 changes the noun to “it” and “a mother” as opposed to *someone’s* mother. This discourse of motherhood also infantilises the person with dementia.

Personhood of staff

In some ways, suggesting that one-to-one time can only improve quality of life for people with dementia denies the personhood of carers, as carers are trapped in the role of doing-to (I-It relating) rather than being-with (I-Thou relating). Carer 1 in her initial “There’s only four how many?” depersonalises carers by referring to them as a number. Carer 2 in her final statement refers to her hierarchical status of “us as cleaners” – by suggesting *even* cleaners don’t have time to sit (read: spend time with). This statement can be interpreted as a tacit acknowledgement of the perceived low status of the role, and an acceptance of the hierarchy.

Focus Group 2

1. Summary of narrative

Conversation in Focus Group 2 centred on the concept that everybody can communicate. Carers reframed behaviours which they previously would have considered ‘challenging’

(such as residents throwing things, banging on the table) as a form of communication. People's viewpoints had fundamentally shifted, and the word 'never' ("I've never had training", "I never knew") demonstrated this dramatic change. Carers strongly felt that they would change their future care practice by spending more time with residents, and observing people to discern the meaning behind their behaviour. However, carers also acknowledged that care homes can be chaotic, and spoke again about understaffing. These were perceived challenges to spending more time with residents.

Carers felt that Intensive Interaction was difficult to put into words. It may be that because much of the discourse of Intensive Interaction is about the body, and about a *felt sense* of connection, it does not fit into verbal language. Carers referred to going 'into the world' of the person with dementia, and felt that Intensive Interaction would improve relationships. Staff could think of no drawbacks to Intensive Interaction.

Intensive Interaction was seen to legitimise things which carers did already, such as being emotionally affectionate (e.g. use of nicknames and family names such as 'dad'), and being creative in their work (e.g. putting on a nightdress whilst getting residents ready for bed). Carers felt that, without the Intensive Interaction label, managers might frame 'sitting' and conversing with residents as not-working, and mirroring as mimicking people with dementia. There were also concerns about organisational bodies being critical of such approaches (e.g. putting on the nightdress). However, staff felt empowered by having 'Intensive Interaction' to explain what they were doing and why, the label perhaps giving words to an experience which is primarily beyond words.

Carers repeatedly stated that everybody at the care home, in all roles, should be given Intensive Interaction training for the technique to fully work. Particularly, they felt that staff who were higher up in the hierarchy would benefit from training, as they would

then understand why carers were using it. However, Intensive Interaction was considered something to 'do' or 'use', rather than a way of being, and was therefore assimilated into an industrialised discourse of care.

2. Analysis of intertextuality

In the second focus group, carers imagined the voice of nonverbal residents, and attempted to put themselves in the shoes of a resident with dementia both verbally and physically (e.g. banging on the table). Family were almost absent from the discourse except for one indirect comment, and the voice of the 'Other' was more frequent – particularly those higher up the staff hierarchy who might criticise staff. Appendix 16 provides a detailed summary.

Focus Group 2 primarily included the voices of carers and residents intertwined. As such, the analysis of the following extract (Table 4) has not been separated into different sections.

Table 4. Extract from Focus Group 2, demonstrating different voices within the text. Carers are numbered and ‘M’ refers to the main researcher (moderator).

Extract of Intertextuality from Focus Group 2

The moderator question triggering the discussion was “Is this [Intensive Interaction] any different to the kind of touch you’d normally do(.) when you’re at work?”. Staff responded by saying they would not have attempted it due to being thought of as ‘taking the mickey’. Discussion moved onto having never ‘banged back’, but staff stated they now understood that this is a form of communication, and there is a reason.

4: And it’s like attention isn’t it(.) [yehs] you know I don’t want to be here bang bang bang(.) move me(.) [yeh]

3: But if they can’t physically say please I don’t want to sit here I want to go and sit in the lounge where it’s nice and quiet(.) then how else are they going to let you know by banging on the table and throwing cups

1: You see like [resident] he can’t see can he so he shouts doesn’t he(.) he can’t see(.) so he shouts [right okay] so that’s his way of communicating

3: You need a lot of touch with that gentleman as well

1: Yeh he does grab hold of you(.) Once you sit near him and he’s got you he’s amazing isn’t he(.) he is he’s lovely(.) But that’s because he can’t see you and he wants to hear you and he wants to touch you

3: He’s only been in a few days [yeh] we’re only getting to know him aren’t we really but he is he’s lovely

1: And he’ll ask you your name(.) doesn’t he he always asks you your name

Carer 4 uses the word “attention”, which is seen as a reasonable goal, rather than the negatively-connotated action “attention-seeking”. She also creates a direct quote from residents who are unable to communicate in normative verbal language, with “bang(.)

move me”. This demonstrates the empathy of being able to step into someone’s shoes and reach their ‘voice’. Carer 3 supports this, by also creating direct speech for residents who do not have a normative verbal ‘voice’ (“please I don’t want to sit here”). However, the ‘Other-ing’ term *they* is still present in the text.

Interestingly, Carer 4 frames her direct quote in an assertive, potentially demanding tone (“move me”), whereas Carer 3 represents residents as being submissive and overly polite (“please”, “nice and quiet”). Across both focus groups, the most common word used to describe individual residents as people is *lovely*. However, residents are also described across the focus groups using demanding (and potentially infantilising) terms such as *shouts, bangs, wants, grabs, got*, and carers suggesting that they *had to* perform an action (e.g. dance). Therefore, whilst carers make it clear that they enjoy their work, and care about residents, there may be some unacknowledged negative feelings – potentially linked to lack of reciprocity and the way the ‘doing-to’ role *creates* a burden. This has led to a dichotomy of aggressive/demanding versus passive/submissive, which is played out in how resident’s voices are articulated in the text.

The theme of burden/reciprocity continues as Carer 1 states “And he’ll ask your name”, which implies that the resident also cares about the carer. *He’ll* as a contraction for *he will* suggests that this resident is an exception to the rule. The resident is given an indirect voice, which reduces his visibility in the text, and invites greater attention to the fact that he’s asking carers their names. Perhaps the request for names is foregrounded because it represents reciprocity, and an honouring of the *carer’s* personhood.

2. Discourses of Personhood

The example below (Table 5) is chosen because it directly addresses the tension between the medical discourse of dementia and humanising concepts of dementia. The extract follows the moderator question: “Is dementia still the same compared to what you said in the morning group?” – staff had stated that dementia was the same (i.e. an illness) but now they knew how to communicate to make things better.

Table 5. Extract from Focus Group 2, representing discourses of personhood. Carers are numbered and ‘M’ refers to the main researcher (moderator).

Extract of Personhood from Focus Group 2

The moderator question below followed a previous moderator question “[...]what’s dementia(.) Is that still the same [as the morning focus group] do you think”. Staff responded by saying ‘the dementia’ is the same but that now they knew how to ‘communicate to make things better’.

M: And how might things be different?

3: I think it’s about understanding em as well like

2: Like I say if they sit there banging we just say don’t do that we’re not(.) doing it back with them and(.) things like that

?: Mm

2: I mean with noises-

1: We just let em now we know(.) why they’re doing that

2: Like you say [we think oh they’re attention seeking again drama-queening again

1: [cos we’ve always thought oh they must be wet they’re either yeh they’re

Extract of Personhood from Focus Group 2

hungry they're wet(.) now they're doing it(.) we know they're doing it for a reason

3: You automatically [go to the personal care

1: [yeh(.) you go

3: [eating drinking not their emotional needs you know when(.) that possibly -

1: [yep like they've said

2: It's possible that's what it is(.) yeh

Referring to residents communicating in an embodied way (“banging”), Carer 2 states “doing it back with them” whereas Carer 1 states “we just let em ”. This is indicative of two sides of a power dynamic – acting as equals, or acting as one who has the power to stop somebody behaving in a particular way. However, the Other-ing word *they* and *them* is used, without any corresponding reference point (e.g. use of the word *residents*). Likewise, Carer 3’s first statement of the extract uses the word *them*, and suggests that understanding residents is an extra (“as well”). However, this could also be interpreted as Carer 3 trying to join in the conversation, using “as well” to imply a continuation of the discussion.

Carer 2 uses the phrases “attention-seeking” and “drama-queening” to represent people who bang on tables. The fact that “drama queen” becomes a verb suggests that residents literally take on that identity by behaving in a certain way, which also threatens an individual’s personhood. These phrases are also quite adolescent in nature, which elicits discourses of motherhood. Carer 1 also uses the phrase “they’re hungry they’re wet”. This socially places older adults with dementia alongside infants – a direct threat to

personhood. It also exemplifies the social dominance of the ‘woman as mother’ and ‘woman as carer’ role in society. However, the phrase is situated between the ‘before’ (“we’ve always thought”) and the ‘after’ (the “now”), implying that Intensive Interaction is a bridge away from infantilisation.

It is of interest that Carer 1 ends with “now they’re doing it(.) we know they’re doing it for a reason”. She began the sentence by suggesting that people with dementia did things for no reason before the training – i.e. that the caregiver’s perception was also the person’s reality. However, the minor pause and rephrasing with “we know” articulates that the reason for people’s behaviour was always there, it is now simply understood by carers. This arguably represents compassion and empathy.

Carer 3 eventually states that it’s *physical* care which is natural (“automatic”). This automaticity is supported by referral to “the” personal care, i.e. as a thing which already exists. Emotions are placed as entities different to “personal care”, as Carer 3 continues “not their emotional needs you know when(.) that possibly -”. The verbal emphasis on *emotional* underlines its separateness to other kinds of care. There is also some texturing with the passive, medical rhetoric of “needs”, rather than *desires* or *wants*. The filler “you know” after the word *emotional*, followed by a pause, suggests tension between discourses.

This tension may be where the discourse of *care comes naturally* meets medical discourses. In the care home, *natural* (“automatic”) care has become synonymous with medical care, and to consider the emotional reasons for behaviour may threaten both the dominant medical understanding, and one’s identity as a good and natural carer. This hesitancy is mirrored by Carer 2 who likewise follows with “it’s possible”.

Discussion

Perpetuating factors and possible solutions

A crucial part of Critical Discourse Analysis, according to Fairclough (from Chouliaraki & Fairclough, 1999) is to assess whether some aspects of society ‘needs’ a social problem. The social problem identified in the current study is the medicalisation of dementia.

On a social level, the medical model allows distance from emotion. Fostering compassion involves being congruent, empathetic, and open to human vulnerability (Gilbert, 2010). This can be difficult in dementia care, because carers are looking into their own possible future, which can provoke anxiety, and therefore necessitates the denial of difficult emotions (Kitwood, 1990). The medical model also implies that dementia, the most feared medical diagnosis in older age (Betts & Cheston, 2012), can be ‘treated’ – dementia is hopeless, but we may hopefully ‘cure’ it. Perhaps society needs this hope, *because* dementia is considered such a terrifying diagnosis.

However, some hopefulness was present within Intensive Interaction discourse in the current study – hope of being *able* to communicate, make a difference, and improve quality of life. Whilst dementia itself was consistently conceptualised as an illness across both focus groups, the conceptualisation of the *person* was different in an Intensive Interaction context. Therefore, using Intensive Interaction discourses in dementia care may increase hope for positive change (and therefore care staff’s perceived self-efficacy), which could reduce the emotional need to distance from people with dementia. This ties into face-to-face ethics, whereby to be ethical one must truly

‘see’ a person by openly meeting with their face, and connecting to both the ‘Other’s’ distress and one’s own desire to help (Casey, 2006).

The medical model also allows for the person’s problems to be attributed to *them* as an individual. If distress, loneliness, and lack of interesting occupation are framed as an ‘illness’, rather than a legitimate response to one’s circumstances, society does not have to change (Kitwood, 1997). This fits well with an individualistic, industrial model of society, whereby medical and social care institutions are focussed on economic efficiency (von Dietze & Orb, 2000).

For example, the medical discourse of decline and death implies that governmental funding for quality of life improvement is unnecessary (Innes, 2002). Using the singular ‘illness’ model of dementia, and its negative framing, is also a route to gain attention from funders – for example research grants for charities and universities, and social resources from authorities. As such, a greater research focus needs to be placed on non-medical elements of ‘dementia’. However, the UK’s *Prime Minister’s Challenge on Dementia 2020* (Department of Health, 2015) has a research agenda weighted towards genetics, drugs, cures, and ‘comorbidities’ (pp. 46-47). Individual staff might struggle to deliver person-centred care without empowerment from higher in the hierarchy, such as from management or policy (Laschinger, Finegan, Shamian & Wilk, 2001).

Staff in the current study also identified a lack of time to ‘be with’ residents, even if the desire to do so is present. ‘Being with’ was framed as ‘not doing’ within an industrial model. This also impacts residents: staff and family caregivers tend to focus on activities which maintain a resident’s physical ‘doing’, whereas residents find more meaning in activities oriented to social and psychological needs (Harmer & Orrell,

2008). It may be that such activities are easier to see outwardly, and also to clearly document as an ‘activity’ in paperwork.

The recent report *Cutting the Red Tape* (Department for Business, Innovation & Skills, 2016) notes that care homes face a significant burden of bureaucracy from multiple agencies (e.g. Local Authority, Care Quality Commission). The Department of Health (2016) has agreed to investigate this further to reduce bureaucracy in care homes and streamline professional bodies’ involvement. It will be crucial for the government to ensure that this leads to tangible outcomes such as decreased paperwork burden and fewer visits from agencies which detract from frontline care. If not, there may be a role for campaigning (e.g. from charities such as *Age UK* and the *Alzheimer’s Society*, or *Dementia Action Alliance*) to ensure this report is not forgotten.

Families are notably absent from care home discourses. This may be due to a societal professionalism of dementia care (Bond, 1992). This maintains dominant social power structures, whereby informal carers such as family members are at the bottom of the hierarchy (in the current study, framed as not understanding the dementia), and health care professionals and their respective professional bodies are at the top. The absence of family, and rigid role hierarchies within care homes, may not support care but actually limit possibilities. As a solution, White-Chu, Graves, Godfrey, Bonner & Sloane (2009) suggest the creation of ‘flattened hierarchies’ in care homes, which enable more individualised care (within a consumerist lens). They also provide a list of potential discourse terms, such as *determined* instead of *difficult*, and *active* instead of *agitated* – with a view to changing culture by changing discourse. The authors outline reciprocity (everybody’s growth and development is promoted), and relationships being placed as centralised.

However, this still does not address the inclusion of families, who may feel that they lack skills or knowledge, which is reinforced by medical knowledge being privileged (Dunham & Cannon, 2008). Evidence suggests, however, that staff and family partnerships are crucial for good quality dementia care (Robison et al., 2007), and in the current study, staff identified that family could support them to get to know an individual. Therefore, future care practice and policy would benefit from a reduced separation between ‘community care’ and care homes, with families considered experts-by-experience across all elements of care – and both the nursing knowledge of carers *and* personal knowledge of families being considered valuable for a holistic understanding of a person.

Strengths and limitations of study

The biggest strength of this study is its breadth of focus, which places dementia discourses within a local context of care home staff group, but makes links between these local concepts and the wider sociopolitical discourse structures. As such, it acknowledges that whilst carers are in a position of power relative to people with dementia, and that carer attitudes and discourses impact upon care (as in the model by Mitchell et al., 2013), carers themselves are subject to strong societal influences and in many ways are disempowered. Additionally, the current study analysed carer’s language in a holistic way, incorporating pauses, emphasis, body language and group dynamics. In Critical Discourse Analysis terms, this is called ‘triangulation’ and increases the robustness of the analysis. Finally, the current study enhances research about dementia discourses by showing *how* such discourses are enacted and perpetuated on a local level.

However, this project should be considered within its limitations. The results are not intended to represent all caregivers, but to provide an example of how societal discourses can be enacted at a local level. All participants, and the moderator, were Caucasian women. As such, there may be scope for exploring how societal discourses are enacted within more ethnically diverse and mixed-gender settings.

As the current project was not intended to be an intervention study, it cannot be stated that Intensive Interaction has ‘changed’ any discourses. It can only demonstrate how staff used discourses in two different contexts: before and after gaining access to Intensive Interaction discourses. Therefore, the current study makes the invisible perpetuation of medical discourses visible, and provides some clear pointers for future research.

Scope for future research

The current study suggests there is much scope for future research in Intensive Interaction and dementia. This includes, but is not limited to, more studies into the effects of Intensive Interaction on care home residents and carers, how Intensive Interaction discourse is used within the context of a care home, the practicalities of using Intensive Interaction and its impact upon relationships (or burden, stress, health and wellbeing outcomes), and using Intensive Interaction with families.

Linked to this, there is a role for research into the effects of changing care practice. For example, families see themselves as having an important emotional role in nursing care, and trust the expertise of staff – however, these sentiments are not always reciprocated by staff (Ryan & Scullion, 2000). Systematically identifying similarities and differences between staff and families – for example in hopes and concerns for residential care, or

perceptions about the roles of family and professional caregivers – may be a first step towards addressing barriers towards family involvement, and promoting collaborative care. However, there is also a need to research the practicalities of how to overcome barriers at a managerial and organisational level (Haesler, Bauer & Nay, 2007).

Within care homes, ‘being with’ could be promoted as an integral part of ‘doing’ care through training, policy, management, and practice. The current study suggests that Intensive Interaction may be one way to achieve this, as a way of providing a discourse which justifies staff and residents spending time together. As such, research could document the implementation of Intensive Interaction principles across an entire care home – that is, ‘being with’ *is* ‘doing’, and it is everybody’s role irrespective of official designation. There is scope for exploring staff and resident responses to a care home culture based on Intensive Interaction, in addition to exploring the role of management in supporting Intensive Interaction within a home.

The current study identified that the main barrier towards implementing Intensive Interaction was concern over how it might be perceived by managers (mimicking, not doing work). Therefore, to support an Intensive Interaction culture staff should be empowered to form bonds with residents (rather than the rhetoric of the current study, “shouldn’t get attached”). This has been framed by some as “professional love” (Arman & Rehnsfeldt, 2006).

Arman and Rehnsfeldt (2006) suggest that professional love cannot be trained, but it can be unbound in supervision by encouraging staff to identify with those they care for, and focusing on relationships rather than tasks. Research could investigate the practicalities of implementing this style of supervision in care homes. Examples of this

in practice may include removing barriers to touch such as the prioritisation of physical care over emotional wellbeing, and promoting connection between residents and clients.

In conclusion, the suggestions for future research into dementia care are orientated around one basic principle: honouring the personhood of people with dementia. This is with a view to providing person-centred, ethical care – by improving communication, enhancing relationships, and caring from a place of shared humanity.

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Part 3 - Appendices

Appendix 1. Guidelines for Submission to *Dementia*

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11. **Further information**

Dementia publishes original research or original contributions to the existing literature on social research and dementia. The journal acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.

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.

1.1 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. Article types

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

Dementia also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 750-1500 words.

The journal also publishes book reviews.

3. How to submit your manuscript

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

Dementia is hosted on SAGE track a web based online submission and peer review system powered by ScholarOne Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit <http://mc.manuscriptcentral.com/dementia> to login and submit your article online.

IMPORTANT: If you are a new user, you will first need to create an account. Submissions should be made by logging in and selecting the Author Center and the 'Click here to Submit a New Manuscript' option. Follow the instructions on each page, clicking the 'Next' button on each screen to save your work and advance to the next screen. If at any stage you have any questions or require the user guide, please use the '**Online Help**' button at the top right of every screen.

All original papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

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*, Heather Wilkinson, College of Humanities & Social Science, University of Edinburgh, 55-56 George Square, Edinburgh, EH8 9JU, UK. Email: hwilkins@staffmail.ed.ac.uk

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4.1 SAGE Choice and Open Access

If you or your funder wish your article to be freely available online to non subscribers immediately upon publication (gold open access), you can opt for it to be included in SAGE *Choice*, subject to payment of a publication fee. The manuscript submission and peer review procedure is unchanged. On acceptance of your article, you will be asked to let SAGE know directly if you are choosing SAGE *Choice*. To check journal eligibility and the publication fee, please visit [SAGE Choice](#). For more information on open access options and compliance at SAGE, including self author archiving deposits (green open access) visit [SAGE Publishing Policies](#) on our Journal Author Gateway.

5. Declaration of conflicting interests

Within your Journal Contributor's Publishing Agreement you will be required to make a certification with respect to a 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 include any declaration at the end of your manuscript after any acknowledgements and prior to the references, under a heading 'Declaration of Conflicting Interests'. If no declaration is made the following will be printed under this heading in your article: 'None Declared'. Alternatively, you may wish to state that 'The Author(s) declare(s) that there is no conflict of interest'.

When making a declaration the disclosure information must be specific and include any financial relationship that all authors of the article has with any sponsoring organization and the for-profit interests the organization represents, and with any for-profit product discussed or implied in the text of the article.

Any commercial or financial involvements that might represent an appearance of a conflict of interest need to be additionally disclosed in the covering letter accompanying your article to assist the Editor in evaluating whether sufficient disclosure has been made within the Declaration of Conflicting Interests provided in the article.

Please acknowledge the name(s) of any medical writers who contributed to your article. With multiple authors, please indicate whether contributions were equal, or indicate who contributed what to the article.

For more information please visit the [SAGE Journal Author Gateway](#).

6. Other conventions

6.1 Informed consent

Submitted manuscripts should be arranged according to the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals". The full document is available at <http://icmje.org>. When submitting a paper, the author should always make a full statement to the Editor about all submissions and previous reports that might be regarded as redundant or duplicate publication of the same or very similar work.

Ethical considerations: All research on human subjects must have been approved by the appropriate research body in accordance with national requirements and must conform to the principles embodied in the Declaration of Helsinki

(<http://www.wma.net>) as well as to the International Ethical Guidelines for Biomedical Research Involving Human Subjects and the International Guidelines for Ethical Review for Epidemiological Studies (<http://www.cioms.ch>). An appropriate statement about ethical considerations, if applicable, should be included in the methods section of the paper.

6.2 Ethics

When reporting experiments on human subjects, indicate whether the procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional or regional) or with the Declaration of Helsinki 1975, revised Hong Kong 1989. Do not use patients' names, initials or hospital numbers, especially in illustrative material. When reporting experiments on animals, indicate which guideline/law on the care and use of laboratory animals was followed.

7. Acknowledgements

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.

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, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

7.1 Funding Acknowledgement

To comply with the guidance for Research Funders, Authors and Publishers issued by the Research Information Network (RIN), *Dementia* additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit [Funding Acknowledgement](#) on the SAGE Journal Author Gateway for funding acknowledgement guidelines.

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Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please visit our [Frequently Asked Questions](#) on the SAGE Journal Author Gateway.

9. Manuscript style

9.1 File types

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, DOCX, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork [and supplemental files] below.

9.2 Journal Style

Dementia conforms to the SAGE house style. [Click here](#) to review guidelines on SAGE UK House Style.

Lengthy quotations (over 40 words) should be displayed and indented in the text.

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. demented). Language that might be deemed sexist or racist should not be used.

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.

9.3 Reference Style

Dementia adheres to the APA reference style. [Click here](#) to review the guidelines on APA to ensure your manuscript conforms to this reference style.

9.4. Manuscript Preparation

The text should be double-spaced throughout with generous left and right-hand margins. 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. Innovative practice papers should be between 750-1500 words.

9.4.1 Keywords and Abstracts: Helping readers find your article online

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on [How to Help Readers Find Your Article Online](#). The abstract should be 100-150 words, and up to five keywords should be supplied in alphabetical order.

9.4.2 Corresponding Author Contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

9.4.3 Guidelines for submitting artwork, figures and other graphics

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

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

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This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the article. For more information please refer to SAGE's [Guidelines for Authors on Supplemental Files](#).

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Non-English speaking authors who would like to refine their use of language in their manuscripts might consider using a professional editing service. Visit [English Language Editing Services](#) for further information.

10. After acceptance

10.1 Proofs

We will email a PDF of the proofs to the corresponding author.

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SAGE provides authors with access to a PDF of their final article. For further information please visit <http://www.sagepub.co.uk/authors/journal/reprint.sp>.

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11. Further information

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office at dem.pra@sagepub.com.

Appendix 2. Quality Checklist for Literature Review

Down and Black's (1998) quality checklist was developed for use in healthcare settings. It can be used with randomised and case-controlled samples, making it applicable across a variety of different research methods. Several changes have been made to the original checklist.

Two questions have been removed from the questionnaire. The first was Question 13: *Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?*. Touch interventions can be used anywhere and in any setting. Additionally, due to notions of person-centred dementia care (Brooker, 2003), treatment should be individualised and it is difficult to suggest what interventions the 'majority' of people with dementia receive. That would depend upon the person's needs and desires. Question 14, *Was an attempt made to blind study subjects to the intervention they have received?*, was also removed. A person cannot be 'blinded' to being touched, and it is not possible to provide a placebo touch. This, therefore, did not seem a relevant question to the review.

Two questions were amended. Question 4 states *Are the interventions of interest clearly described?* This was altered slightly to *Is the touch intervention clearly described, such that it could be replicated?* to make it more tailored to the current

review. Question 27 states *Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%? Sample sizes have been calculated to detect a difference of x% and y%. The meaning of this question is unclear, and therefore the question was changed to Was a power analysis calculated to ensure the sample size was able to detect a significant difference?*

All questions were scored 1 (present) or 0 (not present, or unable to determine).

Reporting

1. Is the hypothesis/aim/objective of the study clearly described?
2. Are the main outcomes to be measured clearly described in the Introduction or Methods section?
3. Are the characteristics of the patients in the study clearly described?
4. Is the touch intervention clearly described, such that it could be replicated?
5. Are the distributions of principal confounders in each group of subjects to be compared clearly described?
6. Are the main findings of the study clearly described?
7. Does the study provide estimates of the random variability in the data for the main outcomes?
8. Have all important adverse events that might be an outcome of the [touch] interventions been reported?

9. Have the characteristics of patients lost to follow-up been reported?
10. Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?

External validity

11. Were the subjects asked to participate in the study representative of the entire population from which they were recruited?
12. Where those subjects who were prepared to participate representative of the entire population from which they were recruited?

Internal validity - bias

13. Was an attempt made to blind those measuring the main outcome of the intervention?
14. If any of the results were based on “data dredging”, was that made clear?
15. In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?
16. Were the statistical tests used to assess the main outcomes appropriate?
17. Was compliance with the intervention(s) reliable?
18. Were the main outcome measures to be used accurate (valid and reliable)?

Internal validity – confounding (selection bias)

19. Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?
20. Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?
21. Were study subjects randomised to intervention groups?
22. Was the randomised assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?
23. Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?
24. Were losses of patients to follow up taken into account?

Power

25. Was a power analysis calculated to ensure the sample size was able to detect a significant difference?

Notes on Quality Assessment

When using the checklist, recruitment from the same “recruitment population” was considered to be the same care home, community, or hospital. If participants were recruited from different kinds of ward (e.g. a ward for mild dementia and one for challenging behaviours), they were considered to be part of different populations. If the number of people in the population (e.g. number of residents in the home) was not stated, the question was answered “unable to determine”.

The outcome measures used in the studies were only deemed accurate and valid if the study reported numerical values for reliability and validity.

Regarding dropouts, a dropout rate which could affect the study (and therefore should be taken into account in the analysis) was considered to be over 5% in line with Dettori (2011). Confounding variables between participants included dropouts (if more than 5% of the sample), alongside demographics of gender, age (with mean/median, range, standard deviation as necessary), type of dementia, severity of dementia, and medication. A study did not have to report all of these demographics, but was considered compromised if it only mentioned two or three of them (i.e. less than 50% of the demographic criteria mentioned here).

References

- Brooker, D. (2003). What is person-centred care in dementia?. *Reviews in Clinical Gerontology, 13*(3), 215-222.
- Dettoni, J. R. (2011). Loss to follow up. *Evidence Based Spine Care, 2*(1), 7-10.
- Downs, S. H., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health, 52*(6), 377-384.

Appendix 3. Quality Assessment of Studies

Due to the volume of quantitative studies (16 total), studies have been arranged alphabetically and presented as two tables. Quality assessment of the one qualitative study (Skovdahl, Kihlgren & Sörлие, 1997) can be found in Table 3. Quantitative studies were evaluated by an adapted version of Downs & Black (1998; Appendix 2), and the qualitative guideline by the National Institute for Health and Care Excellence (NICE; 2012) is included in full.

Table 1. Quality assessment of quantitative studies with authors B-R. Co-rated studies (E) are in parentheses.

Criterion	Belgrave (2009)	Brooker et al. (1997)	Harris et al. (2012)	Hicks-Moore & Robinson (2008)	Moyle et al. (2011)	Moyle et al. (2014a)	Moyle et al. (2014b)	Quell et al. (2008)
Aim/hypothesis described clearly	1	1	1	1	1	1 (1)	1	1

Criterion	Belgrave (2009)	Brooker et al. (1997)	Harris et al. (2012)	Hicks-Moore & Robinson (2008)	Moyle et al. (2011)	Moyle et al. (2014a)	Moyle et al. (2014b)	Quell et al. (2008)
Main outcome measures described clearly in Introduction/Method	1	1	1	1	1	1 (1)	1	1
Clearly described patient characteristics	0	1	1	1	1	1 (1)	1	1
Detailed description of touch intervention	1	1	1	1	0	1 (1)	1	1
Confounders between groups clearly discussed	0	1	1	0	1	1 (1)	1	1
Measures used described in enough detail	1	1	1	1	0	0 (1)	1	1
Main findings clearly described	1	1	1	1	1	1 (1)	1	1
Estimates of variability provided	1	0	1	1	1	1 (1)	1	1

Criterion	Belgrave (2009)	Brooker et al. (1997)	Harris et al. (2012)	Hicks-Moore & Robinson (2008)	Moyle et al. (2011)	Moyle et al. (2014a)	Moyle et al. (2014b)	Quell et al. (2008)
Adverse effects of touch have been discussed	1	1	0	1	0	1 (1)	1	1
Characteristics of participants lost to follow up described	0	1	0	0	0	1 (1)	0	1
P-values fully reported	1	0	1	1	0	1 (1)	1	1
Participants representative of recruitment population	0	0	0	0	0	0 (1)	0	1
Participants representative of all who were invited to participate	0	0	0	0	0	0 (0)	0	0
Attempt to blind those measuring main outcomes	1	0	0	0	0	1 (1)	1	1

Criterion	Belgrave (2009)	Brooker et al. (1997)	Harris et al. (2012)	Hicks-Moore & Robinson (2008)	Moyle et al. (2011)	Moyle et al. (2014a)	Moyle et al. (2014b)	Quell et al. (2008)
Any retrospective unplanned analyses made clear	1	1	1	1	1	1 (1)	1	1
Power analysis done for sample size	0	0	0	0	0	1 (1)	1	0
Follow-up period same for all, or accounted for in analysis	1	1	1	1	1	1 (1)	1	1
Appropriate statistical analysis	1	1	1	1	1	1 (1)	1	1
Reliable compliance/consistency for intervention	1	0	1	0	1	1 (1)	0	0
Reliability/validity of outcome measures reported (where applicable)	1	1	1	1	0	1 (1)	1	1

Criterion	Belgrave (2009)	Brooker et al. (1997)	Harris et al. (2012)	Hicks- Moore & Robinson (2008)	Moyle et al. (2011)	Moyle et al. (2014a)	Moyle et al. (2014b)	Quell et al. (2008)
Participants in diff. intervention groups recruited from same population	0	1	0	0	1	0 (1)	0	0
Participants in diff. intervention groups recruited over same period of time	0	0	1	0	1	0 (1)	1	0
Randomised to groups, or crossover design	1	1	1	1	0	1 (1)	1	1
Randomisation hidden until recruitment complete	0	0	0	0	0	1 (1)	1	0
Adequate adjustment for confounders in analysis	0	1	0	0	0	1 (1)	1	0
Losses to follow-up taken into account	1	1	0	0	0	1 (1)	1	0

Criterion	Belgrave (2009)	Brooker et al. (1997)	Harris et al. (2012)	Hicks- Moore & Robinson (2008)	Moyle et al. (2011)	Moyle et al. (2014a)	Moyle et al. (2014b)	Quell et al. (2008)
Total out of 25 (%)	16 (64)	17 (68)	16 (64)	14 (56)	12 (48)	21 (84) E 24 (96)	21 (84)	18 (72)

Table 2. Quality assessment of quantitative studies with authors R-Y. Table 1. Co-rated studies (E) are in parentheses.

Criterion	Remington (2002)	Rodriguez- Mansilla et al. (2013)	Rodriguez- Mansilla et al. (2015)	Rowe & Alfred (1999)	Scherder, Bouma & Steen (1998)	Snyder, Egan & Burns (1995a)	Synder, Egan & Burns (1995b)	Suzuki et al. (2010)
Aim/hypothesis described clearly	1	1	1 (1)	1	1	1 (1)	1	1
Main outcome measures described clearly in Introduction/Method	1	1	1 (1)	1	1	1(0)	1	1
Clearly described patient characteristics	1	1	0 (0)	1	1	1(0)	1	0
Detailed description of touch intervention	1	1	1 (1)	1	1	1(1)	1	1
Confounders between groups clearly discussed	0	1	0 (0)	1	1	0 (0)	1	1
Measures used described in enough detail	1	1	1 (1)	1	1	0 (0)	1	1

Criterion	Remington (2002)	Rodriguez- Mansilla et al. (2013)	Rodriguez- Mansilla et al. (2015)	Rowe & Alfred (1999)	Scherder, Bouma & Steen (1998)	Snyder, Egan & Burns (1995a)	Snyder, Egan & Burns (1995b)	Suziki et al. (2010)
Main findings clearly described	1	1	0 (1)	1	1	1(0)	1	1
Estimates of variability provided	1	0	1 (1)	0	0	1(1)	1	1
Adverse effects of touch have been discussed	1	1	1 (1)	1	1	1 (1)	1	1
Characteristics of participants lost to follow up described	0	0	0 (1)	0	0	0 (1)	0	0
P-values fully reported	1	1	1 (1)	1	0	0 (0)	1	1
Participants representative of recruitment population	0	0	0 (0)	0	0	0 (1)	0	1
Participants representative of all who were invited to participate	0	0	0 (0)	0	0	0 (1)	0	0

Criterion	Remington (2002)	Rodriguez- Mansilla et al. (2013)	Rodriguez- Mansilla et al. (2015)	Rowe & Alfred (1999)	Scherder, Bouma & Steen (1998)	Snyder, Egan & Burns (1995a)	Snyder, Egan & Burns (1995b)	Suziki et al. (2010)
Attempt to blind those measuring main outcomes	1	1	1 (1)	0	1	0 (0)	0	0
Any retrospective unplanned analyses made clear	1	1	1 (1)	1	1	1 (1)	1	1
Power analysis done for sample size	1	0	0 (1)	0	0	0 (1)	0	0
Follow-up period same for all, or accounted for in analysis	1	1	1 (1)	1	1	1 (1)	1	1
Appropriate statistical analysis	1	1	1 (1)	1	1	1 (0)	1	1
Reliable compliance/consistency for intervention	1	1	1 (1)	0	1	1 (1)	0	0
Reliability/validity of outcome measures reported (where applicable)	1	0	0 (1)	1	0	1 (0)	1	0

Criterion	Remington (2002)	Rodriguez- Mansilla et al. (2013)	Rodriguez- Mansilla et al. (2015)	Rowe & Alfred (1999)	Scherder, Bouma & Steen (1998)	Snyder, Egan & Burns (1995a)	Synder, Egan & Burns (1995b)	Suziki et al. (2010)
Participants in diff. intervention groups recruited from same population	0	0	0 (1)	0	1	0 (0)	1	1
Participants in diff. intervention groups recruited over same period of time	0	0	0 (1)	1	0	0 (0)	1	1
Randomised to groups, or crossover design	1	1	1 (1)	0	1	0 (0)	1	0
Randomisation hidden until recruitment complete	0	0	1 (1)	0	0	0 (0)	0	0
Adequate adjustment for confounders in analysis	0	0	0 (0)	0	1	0 (0)	1	0
Losses to follow-up taken into account	0	0	0 (1)	0	0	0 (1)	0	0

Criterion	Remington (2002)	Rodriguez- Mansilla et al. (2013)	Rodriguez- Mansilla et al. (2015)	Rowe & Alfred (1999)	Scherder, Bouma & Steen (1998)	Snyder, Egan & Burns (1995a)	Snyder, Egan & Burns (1995b)	Suziki et al. (2010)
Total out of 25 (%)	17 (68)	15 (60)	14 (56) E 21 (84)	14 (56)	16 (64)	12 (48) E 12 (48)	18 (72)	15 (60)

Table 3. Quality assessment for qualitative study (Skovdahl, Sörli  & Kihlgren, 2007), from NICE (2012) guidelines. Assessment rating underlined. Co-rater’s assessment is marked with an (x).

Quality Analysis Criteria	Assessment	Comments on Assessment
1. Is a qualitative approach appropriate?	<u>Appropriate</u> (x)	Comments: The study aims to consider personal experiences between caregivers and people with dementia.
	Inappropriate	
	Not sure	
2. Is the study clear in what it seeks to do?	<u>Clear</u> (x)	Comments: Purpose and aims are clear, adequate introduction with reference to literature. Content analysis is used in a counter-intuitive way, but this is reflected upon in discussion section. Theory and epistemological approach behind content analysis not discussed- however, study makes it clear the data required is quantitative and qualitative.
	Unclear	
	Mixed	
3. How defensible/ rigorous is the research design/ methodology?	Defensible	Comments: No clear rationale given for choice of sample, and there is no clear rationale given for a qualitative approach except making it clear that <i>experiences</i> were the key data. Content analysis was chosen after data collection, and used in an unusual way – i.e. as a framework for later case descriptions. This is justified, however, questionably rigorous.
	Indefensible (x)	
	<u>Not sure</u>	

Quality Analysis Criteria	Assessment	Comments on Assessment
4. How well was the data collection carried out?	<p>Appropriately</p> <p>Inappropriately</p> <p><u>Not sure/inadequately reported (x)</u></p>	<p>Comments: Example provided of the documentation which caregivers filled in, but not how or when this was filled in. Method of data collection appropriate, tailored to researcher's question.</p>
5. Is the role of the researcher clearly described?	<p>Clearly described</p> <p><u>Unclear</u></p> <p>Not described (x)</p>	<p>Comments: Role of researcher not clearly described (e.g. relationship to caregivers). What was considered 'consent' is explained to participants, but method of explanation not specified, nor how participants were told about the research.</p>
6. Is the context clearly described?	<p>Clear</p> <p><u>Unclear (x)</u></p> <p>Not sure</p>	<p>Comments: Characteristics of participants are explained in detail, nature of the intervention (including emotive aspect) is considered. Bias was not considered, however this study was specifically about caregivers' experiences. Bias in terms of researchers' interpretation of data were not discussed, and the care home setting and carers delivering the intervention were not clearly described.</p>
7. Were the methods reliable?	<p>Reliable</p> <p><u>Unreliable (x)</u></p> <p>Not sure</p>	<p>Comments: Data collected by one method, with no justification for lack of triangulation. No mention of inter-rater reliability, nor how the data were 'abstracted'.</p>

Quality Analysis Criteria	Assessment	Comments on Assessment
8. Is the data analysis sufficiently rigorous?	Rigorous Not rigorous <u>Not sure/not reported (x)</u>	Comments: It is not clear how the data were analysed. There is a brief description of data being divided, summarised and abstracted, but no clear indication of what this means.
9. Is the data 'rich'?	Rich Poor <u>Not sure/not reported (x)</u>	Comments: Participants may have been from different units in the home – differences have not been explored in this study. Summaries of each person with dementia are rich and give a clear picture of the person's experience. Diversity of different caregiver's perspectives has not been reported. Conclusions of the study also consider the context of wider Western culture.
10. Is the analysis reliable?	Reliable Unreliable <u>Not sure/ not reported (x)</u>	Comments: It is not stated how many people coded data, or any indications of assessing the reliability of the analysis. The method is not clearly described. There are no indications of ignoring discrepant results.
11. Are the findings convincing?	Convincing Not convincing <u>Not sure (x)</u>	Comments: Findings are coherent and clearly presented as a narrative of each individual. Reporting style is clear. No extracts from the original data are presented, nor any of the quantitative results (the study mentions dividing positive and negative. Extracts from data are not included.

Quality Analysis Criteria	Assessment	Comments on Assessment
12. Are the findings relevant to the aims of the study?	<u>Relevant</u> (x)	Comments: Both quantitative data (e.g. length and body part of massage), and qualitative data about experiences of caregivers and people with dementia is given.
	Irrelevant	
	Partially relevant	
13. Conclusions	<u>Adequate</u> (x)	Comments: Conclusions are plausible from data, and also coherent. There is adequate discussion of limitations of study regarding the data not being as 'rich' as researchers had hoped; several considerations about what may influence the touch interaction (e.g. gender). This study provides some rich and new data regarding touch in dementia care, particularly about the relationship between caregivers and people with dementia.
	Inadequate	
	Not sure	
14. How clear and coherent is the reporting of ethics?	<u>Appropriate</u> (x)	Comments: There is a thorough discussion about the ethics both of the study and delivering massage, but also about tactile stimulation as a whole. Informed consent is discussed, ethics committee approved, all participants are anonymised.
	Inappropriate	
	Not sure/not reported	
15. As far as can be ascertained from the paper, how well was the study conducted?	++	Comments: A considerate, ethical study which provides valuable insights into the field of touch in dementia. However, the method is not described clearly enough to fully understand how the data were analysed, which makes it difficult to know how reliable the analysis was. This is quite important considering that content analysis was used in a non-traditional way.
	± (x)	
	–	

References

Downs, S. H., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health*, 52(6), 377-384.

National Institute for Health and Care Excellence (2012). *Methods for the development of NICE public health guidance (third edition)*. Obtained from <https://www.nice.org.uk/article/pmg4/chapter/appendix-h-quality-appraisal-checklist-qualitative-studies>.

Appendix 4. Guidelines for Submission to Ageing and Society

Ageing and Society is an interdisciplinary and international journal devoted to the understanding of human ageing and the circumstances of older people in their social and cultural contexts. We invite original contributions that fall within this broad remit and which have empirical, theoretical, methodological or policy relevance. All submissions, regardless of category, are subject to blind peer-review. Authors are reminded of the requirement to avoid ageist and other inappropriate language and to avoid the stereotypical representation of individuals or groups.

All papers must be submitted using Manuscript Central through the Journal's website at: <http://journals.cambridge.org/aso>.

All books for review should be sent to: Stella Allinson, Review Editor's Assistant, Ageing and Society, Faculty of Health and Social Care, The Open University, Walton Hall, Milton Keynes, MK7 6AA, UK.

All submissions must conform to the submission guidelines outlined below. Failure to do so may result in the submission being rejected.

Article categories

Research articles

Research articles must contain between 3,000 and 9,000 words, excluding the abstract and references. Most papers usually have the following sections in sequence: Title page, Abstract (200-300 words), Keywords (three to eight), Main text, Statement of ethical approval as appropriate, Statement of funding, Declaration of contribution of authors, Statement of conflict of interest, Acknowledgements, Notes, References,

Correspondence address for corresponding author. However authors have the flexibility to organise the main text of article into the format that best suits the topic under consideration.

Forum articles

In addition to research papers, the Journal welcomes critical/reflective commentaries on contemporary research, policy, theory or methods relevant to the Journal's readers. These articles reflect a viewpoint of the author and they may form part of an ongoing debate. These articles should contain 2,000-5,000 words. There is no preset organisational structure.

Special issues

Proposals are invited for special issues that fall within the remit of the journal. Ageing & Society especially looks for proposals that show originality and which address topical themes. Proposals which involve authors from a range of disciplines and/or countries are particularly encouraged and the special issue must demonstrate clear added value in advancing an understanding of ageing and later life that is more than the sum of the individual papers.

Proposals should be submitted by the co-ordinating Guest Editors by email to the Editor, Christina Victor: christina.victor@brunel.ac.uk Proposals should be submitted by 28 February each year. For further information see the guidelines for special issue proposals available at:

http://journals.cambridge.org/images/fileUpload/images/A&S_Special_Issue_Proposals.pdf

It is Ageing & Society practice that all papers in special issues are subject to blind peer review, undergoing the same refereeing process as all other submissions, led by the Ageing & Society Editor and co-ordinated by the journal's Editorial Assistant. The final decision whether to publish individual papers submitted as part of a special issues remains with the Editor.

Submission requirements

Exclusive submission to Ageing & Society

- Submission of the article to Ageing & Society is taken to imply that it has not been published elsewhere nor is it being considered for publication elsewhere. Authors will be required to confirm on submission of their article that the manuscript has been submitted solely to this journal and is not published, in press, or submitted elsewhere. Where the submitted manuscript is based on a working paper (or similar draft document published online), the working paper should be acknowledged and the author should include a statement with the submitted manuscript explaining how it differs from the working paper. Articles which are identical to a working paper or similar draft document published online will not be accepted for publication in Ageing & Society.

Appropriateness for Ageing Society

- All submissions must fall within the remit of the journal, as described at the beginning of this document.
- All manuscripts must meet the submission requirements set out in this document, closely following the instructions in the 'Preparation of manuscripts', 'Citation of references' and 'Table and Figures' sections below.
- Authors are requested to bear in mind the multi-disciplinary and international nature of the readership when writing their contribution. Care must be taken to

draw out the implications of the analysis for readers in other fields, other countries, and other disciplines. Papers that report empirical findings must detail the research methodology.

- The stereotypical presentation of individuals or social groupings, including the use of ageist language, must be avoided.

Submission documents

All submissions should include:

- A copy of the complete text of the manuscript, with a title page including the title of the article and the author(s)' names, affiliations and postal and email addresses.
- A copy of the complete text minus the title page, acknowledgements, and any running headers of author names, to allow blinded review.

Named authors

- Papers with more than one author must designate a corresponding author. The corresponding author should be the person with full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish. The corresponding author must confirm that co-authors have read the paper and are aware of its submission. Full contact details for all co-authors should be submitted via Manuscript Central.
- All named authors for an article must have made a substantial contribution to: (a) the conception and design, or analysis and interpretation of data; (b) the drafting of the article or revising it critically for important intellectual content and (c) approval of the version to be published. All these conditions must all be met.

Participation solely in the acquisition of funding or the collection of data does not, of itself, justify authorship.

Peer-review process

- The corresponding author should prepare (a) a complete text and (b) complete text minus the title page, acknowledgements, and any running headers of author names, to allow blinded review. References to previous papers of the authors must not be blinded, neither in the text nor in the list of references.
- Papers are peer-reviewed. Authors may be asked to submit a revised version of the original paper. In any revised submission, we prefer you to indicate these revisions using track changes where appropriate. An accompanying letter from the corresponding author should outline your changes, and comments on advice that you have chosen not to accept. The corresponding author should confirm that co-authors have agreed to any changes made.

Ethical considerations

- Where the paper reports original research, confirmation must be given that ethical guidelines have been met, including adherence to the legal requirements of the study country. For empirical work conducted with human subjects authors must provide evidence that the study was subject to the appropriate level of ethical review (e.g. university, hospital etc.) or provide a statement indicating that it was not required. Authors must state the full name of the body providing the favourable ethical review and reference number as appropriate.

Declaration of funding

- A declaration of sources of funding must be provided if appropriate. Authors must state the full official name of the funding body and grant numbers specified.

Authors must specify what role, if any, their financial sponsors played in the design, execution, analysis and interpretation of data, or writing of the study. If they played no role this should be stated.

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Preparation of manuscripts

All contributions (articles, reviews and all types of review articles) should be typed double-spaced with at least one-inch or two-centimetre margins throughout (including notes and the list of references).

Most research articles usually have the following sections in sequence: Title page, Abstract (200-300 words), Keywords (three to eight), Main text, Statement of ethical approval as appropriate, Statement of funding, Declaration of contribution of authors, Statement of conflict of interest, Acknowledgements, Notes, References, Correspondence address for corresponding author.

The title page should give the title of the article and the author(s)' names, affiliations and postal and email addresses. When composing the title of your article, please give

consideration to how the title would be shortened to appear as a running head in final version of the Journal.

The tables and figures should be presented one to a page in sequence at the end of the paper. Black and white photographs may be submitted where they are integral to the content of the paper. Charges apply for all colour figures that appear in the print version of the Journal (see below for further details).

Authors are asked to follow the current style conventions as closely as possible. Please consult a very recent issue of the journal. In particular, please note the following:

- Use the British variants of English-language spelling, so ‘ageing’, not ‘aging’.
- First level headers are in bold, sentence case and left justified
- Second level headers are in italic (not bold), sentence case and left justified
- Do not number paragraphs or sections. Avoid very short (particularly one sentence) paragraphs.
- Do not use bold text in the text at all. For emphasis, use italic.
- In the main text, the numbers one to ten should be written as words, but for higher numbers the numerals (e.g. 11, 23, 364) should be used.
- All acronyms must be expanded on first use, even EU, USA, UK or UN, for those which are commonplace in one country are not in others.
- Do not use footnotes. Endnotes are permitted for technical and information details (including arrays of test statistics) that distract from the main argument. Endnote superscripts should be placed outside, not inside a punctuation mark (so.3 not4.).
- Write per cent (not %) except in illustrative brackets. Authors, particularly those whose first language is not English, may wish to have their English-language

manuscripts checked by a native speaker before submission. This is optional, but may help to ensure that the academic content of the paper is fully understood by the editor and any reviewers. We list a number of third-party services specialising in language editing and/or translation, and suggest that authors contact as appropriate:

<http://journals.cambridge.org/action/stream?pageId=8728&level=2&menu=Authors&pageId=3608>

Please note that the use of any of these services is voluntary, and at the author's own expense. Use of these services does not guarantee that the manuscript will be accepted for publication, nor does it restrict the author to submitting to a Cambridge published journal.

Citation of references

Contributors may follow either the standard conventions: (a) in-text citation of sources (author/date system); or (b) citations in notes.

(a) *In-text citation*. Give author's surname, date of publication and page references (if any) in parentheses in the body of the text, e.g. (Cole 1992: 251). For references with one to three authors, all authors should be named (Black, Green and Brown 2003). For references with four or more authors, the following form is required: (Brown et al. 2003). Note that all authors must be named in the list of references, and et al. is not permitted in the list. A complete list of references cited, arranged alphabetically by authors' surname, should be typed double-spaced at the end of the article in the form:

Cole, T. 1992. *The Journey of Life: A Cultural History of Aging in America*. Cambridge University Press, Cambridge.

Elder, G.H. and Clipp, E.C. 1988. Wartime losses and social bonding: influences across 40 years in men's lives. *Psychiatry*, 51, 1, 177-98.

Ruth, J.-E. and Oberg, P. 1996. Ways of life: old age in life history perspective. In Birren, J.E., Kenyon, G., Ruth, J.-E., Schroots, J.F.F. and Svensson, T.(eds), *Aging and Biography: Explorations in Adult Development*. Springer, New York, 167-86.

(b) *Citation in notes*. References should be given in notes, numbered consecutively through the typescript with raised numbers, and typed double-spaced at the end of the article. Full publication details in the same format as (a) should be given in the notes when a work is first cited; for second and subsequent citations a short form may be used.

For both styles of reference lists, please particularly note the following:

- Authors are requested to minimise the citation of unpublished working and conference papers (because they are difficult for readers to acquire). Where they are cited, complete details of the title of the conference, the convening organisation, the location and the date of the presentation must be given. Papers that have been submitted to journals but on which no decision has been heard must not be cited.
- Titles of Books and Journals are in Title Case and Italic.
- Titles of papers, articles and book chapters are in sentence case and not italicised.
- Please note carefully that part or issue numbers should be given for journal paper citations, that page ranges for book chapters should always be given and should be condensed, so 335-64 not 335-364, and S221-9 not S221-229.
- Please use (eds) and (ed.) where required (no capitals, full stop after truncated ed. but not compressed eds).

Citation of Internet pages of publications that are available online

Give authors, date, title, publisher (or name of host website) as for a printed publication.

Then follow with ... Available online at ... full Internet address [Accessed date].

Tables and Figures

There should never be more than ten tables and figures in aggregate, and only in exceptional circumstances more than eight. Please do not use Boxes or Appendices. Present all illustrative material as tables or figures. Please indicate in the text where approximately the Table and Figures should appear using the device < Insert Table 1 about here > on its own line. For figures generated by Excel, please send the original file (rather than a 'picture' version) so that the figures can be copy-edited.

Tables and figures should be clearly laid out on separate pages, numbered consecutively, and designed to fit a printed page of 228 x 152 mm (actual text area 184 x 114 mm). Titles should be typed above the body of the table, with an initial capital only for the first word and proper names and italicised or underlined (for italics). Vertical lines should not be used and horizontal lines should be used only at the top and bottom of the table and below column headings. Authors are asked to give particular attention to the title and to column and row labels (they are often poorly selected, incomprehensible or inadequate). All multiple word labels should be in sentence case. Short titles that concentrate on the subject of the table are recommended. Technical or methodological details (such as sample size or type of statistic) should be described in the labels or in table notes. Spurious accuracy should be avoided: most statistics justify or require only one decimal place.

Figures should also be provided on separate pages and numbered consecutively. For each figure, the caption should be below and in sentence case. Separate lists of captions are not required.

Colour figures can be submitted to Ageing & Society, but charges apply for all colour figures that appear in the print version of the journal. At the time of submission, contributors should clearly state whether their figures should appear in colour in the online version only, or whether they should appear in colour online and in the print version. There is no charge for including colour figures in the online version of the Journal but it must be clear that colour is needed to enhance the meaning of the figure, rather than simply being for aesthetic purposes. If you request colour figures in the printed version, you will be contacted by CCCRightslink who are acting on our behalf to collect Author Charges. Please follow their instructions in order to avoid any delay in the publication of your article.

Figures should be provided in the following formats:

- For colour halftones: Tiff or Jpeg format at 300 dpi (dots per inch) at their final printing size.
- For line work or line work/tone: EPS format with any halftone element at 300dpi final printing size.

Proofs and Offprints

Proofs will be sent to the corresponding author as a PDF via email for final proof reading. The proofs should be checked and any corrections returned within 2 days of receipt. The publisher reserves the right to charge authors for excessive correction of non-typographical errors.

Authors will receive a PDF of the published paper and a copy of the Journal, to go to the corresponding author. If offprints are required, these must be purchased at proof stage.

Last updated 4th September 2014.

Appendix 5. Epistemological Statement

The empirical study for this thesis was part of a qualitative paradigm and methodology. Smith (2008) notes that qualitative approaches are often exploratory, and tend to examine meaning-making processes and lived experiences. Reality, therefore, is assumed to be subjective. This can be contrasted with the traditional scientific method, or positivist approach, which adopts a realist stance (there is one 'real' reality) and uses deductive methods to test hypotheses about the world.

According to Ponterotto (2005), epistemology is the relationship between "knower" (participant or object of study) and "would-be knower" (researcher). The current study draws from two philosophies within the qualitative paradigm. The first is constructivism, a form of relativism which assumes that reality is socially constructed, and therefore multiple subjective realities are equally valid. In this view, a researcher co-constructs data with participants and is an integral part of the process. Ponterotto states that a critical approach to data assumes that realities are intertwined with societal power systems and ideologies. Therefore, different subjective viewpoints arise from different value bases, and are enabled (or suppressed) by social power structures. Researchers from a critical approach take an active stance with "proactive values" (p. 129) seeking to address inequalities and emancipate oppressed societal groups – that is, the social inequality is presumed to be a structure which exists beyond the co-constructions of the researcher.

The Critical Discourse Analysis approach utilises both constructivism and critical realism (Jørgensen & Phillips, 2002). This is because discourse (language in use) is considered to have a dialectical relationship with social practices (what people do). For example, discourse constructs social power (constructivism), however discourse also reflects the social relations which exist in society (critical approach). This suggests that some social realities exist outside of an individual's phenomenological experience. Discourse, then, can be considered

both an ideological structure which exists in society (an ‘order of discourse’), but also as a subjectively used phenomena which is dependent upon social context and personal meaning-making.

The researcher in the current study sought to emancipate people with dementia through the discourse of paid caregivers. This is due to a combination of personal and professional experience as a Trainee Clinical Psychologist (see Reflective Statement, Appendix 17). The values base of the researcher, therefore, is of social equality and common humanity. This draws from the critical position. Part of the current project was to examine existing societal discourse structures (the critical approach) and how they are enacted on a local level. Therefore, these discourses are assumed to exist outside of the researcher’s co-created experience with participants. The researcher also developed an interview schedule for the focus groups based on clear ethical values of personhood, such as reciprocity and empathy.

However, the researcher ran the focus groups and co-created a narrative with participants (constructivist position). The topics which were discussed were partly dependent upon the questions asked by the researcher, and it is assumed that participant’s answers in part were influenced by the researcher’s gender (female), race (Caucasian), educational level (doctoral training), in addition to the social setting (participants at a training day, and therefore placed in a position of having less knowledge). Additionally, due to the focus group design participants co-created conversations between themselves.

As such, the analysis of the data had to consider both the discourse structures which exist ‘out there’ in society (the critical approach), and also how the social situation elicited a unique and co-created narrative. Therefore, social positioning within the group was considered alongside other data such as language use. The researcher was an active participant in analysing the data and offering an interpretation (constructivism), however the triangulation of data including words, grammar, body language, pauses, and vocal

emphasis was used to verify the data. That is, the analysis was assumed to be partly socially constructed, and partly reflective of social reality.

References

- Ponterotto, J. G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of Counseling Psychology, 52*(2), 126.
- Jørgensen, M. W., & Phillips, L. J. (2002). *Discourse analysis as theory and method*. London: Sage.
- Smith, J. A. (Ed.). (2008). *Qualitative psychology: A practical guide to research methods*. London: Sage.

Appendix 6. Critical Discourse Analysis Positioning

Discourse analysis as a broad, multi-disciplinary field which can be applied to a range of texts and situations. Methodological selection within discourse analysis is therefore a complex choice. As Alvesson & Kärreman (2000) succinctly summarise, “Discourse [as a term] may mean almost anything” (p. 1127). The authors have responded to the complexity with a grid which articulates the range of positioning within discourse studies (Fig. 1).

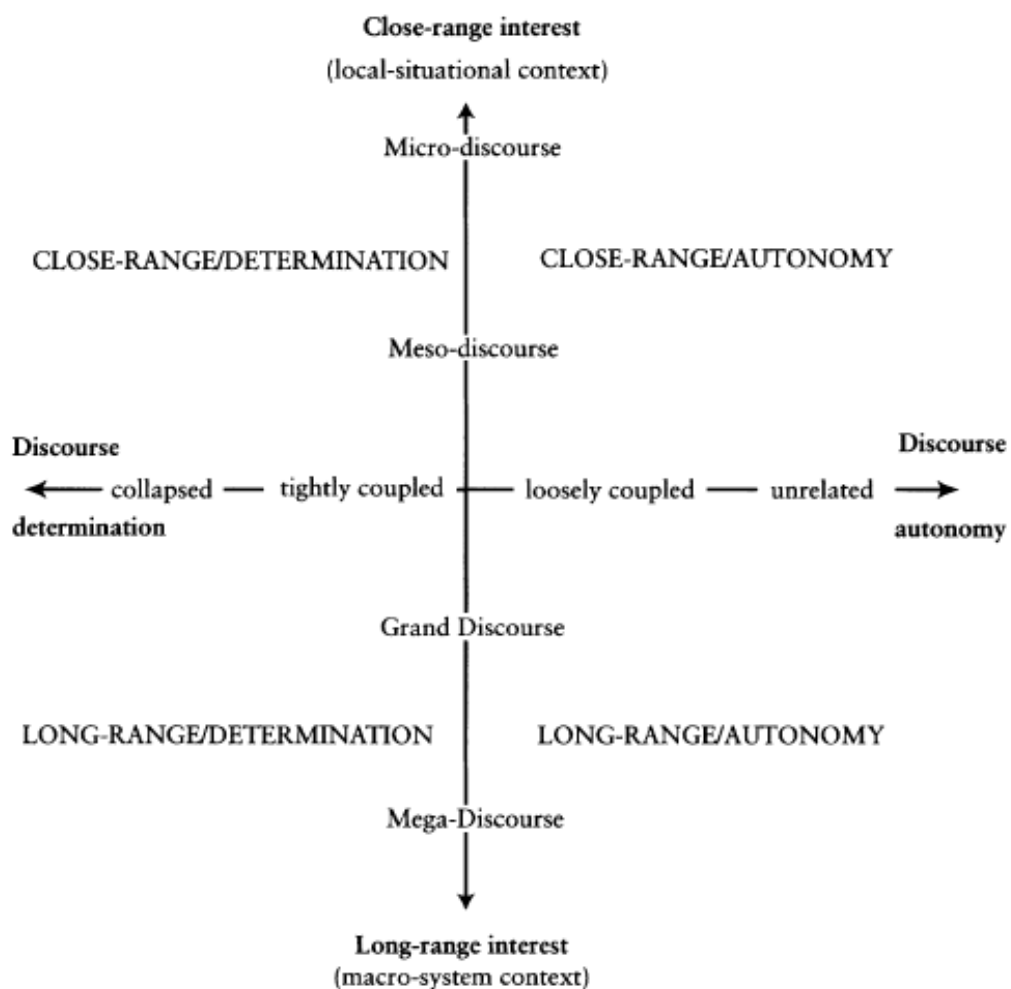


Fig 1. Summary of positions in discourse studies, from Alvesson & Kärreman (2000)

The vertical axis of Figure 1 demonstrates that ‘discourse’ can be considered in a range of shapes and sizes. Some studies may be interested in the local, detailed meanings of a text (micro-discourse). In micro-discourse analysis, a ‘discourse’ examines language choices. This includes grammar, syntax, turn-taking, and rhetoric. An example may be how individuals construe themselves in a particular moment (e.g. with their name, professional title, or nickname). Slightly beyond this, meso-discourse examines the local *context* of a particular ‘text’, such as how and where it was produced, for whom, and why. The meso-level focuses on social power, and what the ‘rules’ are for the production and consumption of text (Behnam & Mahmoudy, 2013).

In Mega-Discourse, Discourses (capitalised to represent their large scale) are considered universal and are examined in a synthesised, standardised way. Meanings are considered the same across usages, and Discourses endure over time. For example a “Discourse of neoliberalism” may include ideas such as *competition*, *growth*, and *productivity*. This Mega-Discourse might be reflected on a small level such as a person referring to ‘producing’ a painting (as opposed to ‘creating’), and would be linked back to a universal neoliberal meaning. Often, Mega-Discourses are ideas which are considered ‘common sense’ in society, and represent overarching rules and norms which are embedded in language generally.

The horizontal axis of Figure 1 represents discourse *determination vs autonomy*. ‘Discourse determination’ suggests that the meaning of ‘discourses’ can be *durable* across time and situations (i.e. demonstrating broader cultural ideas, cognition and how humans make sense of things). In this view, discourse has social/psychological consequences, for example to create meaning, social identity, and power hierarchies, in addition to determining practices (i.e. influencing what people do as well as what they

say). Therefore, language meanings are considered to exist ‘beyond’ the particular moment of discourse.

This contrasts with the right side of the horizontal axis in Figure 1, where discourse is considered transient (i.e. based in the moment with no wider, deeper cultural meanings). In this case, one can consider ‘discourse’ as a linguistic phenomena in its own right (on the diagram referred to as ‘autonomy’). In this view discourse does not constitute people’s identities or social cognition, and is not strongly connect to the overall social world. Therefore, language is a tool that has *particular* meanings within a *particular* interaction, rather than representing anything ‘wider’. It is crucial to have a good understanding of the overall micro-context, to understand the discourse (for example, was this a letter to an employee, a Valentine’s card, a newspaper article?).

The approach of Critical Discourse Analysis (CDA) tends to focus on the deterministic properties of discourse and how this creates identities and social power. Wider discourses are considered to be stable over time and constitutive of people’s social reality (Wodak & Meyer, 2009). CDA also examines what discourses people use, based upon how their identity is constructed. Whilst the focus is on determinism and discourse as creating meaning and identity, CDA accepts that people are autonomous beings who select discourses for their own purposes. However, individuals with more power will have greater access to, and influence over, the discourses that are used in society.

On terms the vertical axis of Figure 1, CDA deliberately seeks to analyse both the micro-discourses and the macro-discourses, in order to make links between them, and reveal how dominant social power is maintained through language and interaction. This involves examining multiple layers of society, from wider webs of text (known as *interdiscursivity*). In essence, CDA looks at *how* the macro levels impact, and are

reproduced, in micro-levels of discourse. Additionally, CDA examines how micro-levels of discourse may reinforce or challenge the macro, with a view to understanding why this is the case. Therefore, CDA aims to work across multiple levels.

References

- Alvesson, M., & Kärreman, D. (2000). Varieties of discourse: On the study of organizations through discourse analysis. *Human Relations*, 53(9), 1125-1149.
- Behnam, B., & Mahmoudy, B. (2013). A Critical Discourse Analysis of the reports issued by the International Atomic Energy Agency (IAEA) Director General on Iran's nuclear program during the last decade. *Theory and Practice in Language Studies*, 3(12), 2196.
- Wodak R. & Meyer, M. (2009). Critical discourse analysis: history, agenda, theory and methodology. In Wodak & Meyer (Eds.), *Methods for critical discourse analysis* (pp. 1-33). London: Sage.

Appendix 7. Fairclough's Model of Critical Discourse Analysis

Critical Discourse Analysis (CDA) is not designed to contribute to a particular theory or discipline. It is designed to support social change and address social inequality (Van Dijk, 1993). As such, Wodak & Meyer (2009) note that there is no 'one' way to approach a discourse analysis, however the common underlying feature is an interest in power and social subjugation, and the linguistic techniques which create and maintain the current power hierarchy. A specific approach to CDA has been selected and adapted for the current project.

Selecting an approach to CDA

This project begins with a social problem, namely the over-medicalisation and dehumanisation of people with dementia. The Dialectical-Relational approach of Norman Fairclough in particular appears to meet the objectives of this project. Firstly, Fairclough takes an explicitly problem-based approach, whereby the first step in the CDA is to identify a social 'wrong' (Fairclough, 2003). The next stage is to identify obstacles to addressing this 'wrong', followed by considering its function in society and identifying ways to rectify the wrong. Wodak and Meyer (2009) articulate the range of other approaches available, but Fairclough provides the only method explicitly beginning with a social problem.

Additionally, Fairclough engages in a micro-analysis of language in order to detect macro-discourses and how these are enacted in the 'micro'. Fairclough's combination of micro-analysis of language, with macro-analyses of language and culture, allows for a broad interpretation of a single text.

Due to the lack of available empirical methods in Foucault's ideas of power, Fairclough developed his own methods based on Foucauldian concepts that power is discursively constructed. However, unlike Foucault, Fairclough suggests that power is a *hegemonic struggle* – that is, a negotiated *process* through social groups in line with Marxist theory, whereby dominant social views benefit the ruling (powerful) classes. In this vein, people can be considered to resist discourses (Jørgensen & Phillips, 2002) and power is never stable but always negotiated. As such, it provides hope for change by deliberately considering resistance. Wherever there is tension between discourses, there is the possibility of change.

People with dementia may lack a common language through which to resist discourses. Carers, however, do have access to language and therefore can discursively resist. As such, this approach fits with using carers as participants.

Epistemologically, Fairclough's approach is somewhere between structuralism and post-structuralism – i.e. discourses reflect real social practices, which can be defined and measured; however discourses are socially constituted and create social practices. A dialectical relationship is assumed. Particularly, Fairclough is interested in *orders of discourse*, or the abstract frameworks of meaning-making which dictate the limits of how people can make sense of the world. The medical order of discourse for dementia will include certain related discourses, and exclude others. Analysing these orders of discourse, and their limits, is a crucial part of the analysis.

As such, Fairclough's method allows for mapping out the different discourses that relate to the medicalisation of dementia. To the author's knowledge, no researchers have comprehensively mapped how concepts such as the medicalisation of dementia interlink with other societal discourses.

References

- Alvesson, M., & Kärreman, D. (2000). Varieties of discourse: On the study of organizations through discourse analysis. *Human Relations*, 53(9), 1125-1149.
- Behnam, B., & Mahmoudy, B. (2013). A critical discourse analysis of the reports issued by the International Atomic Energy Agency (IAEA) Director General on Iran's nuclear program during the last decade. *Theory and Practice in Language Studies*, 3(12), 2196.
- Fairclough, N. (2001). *Language and power*. Harlow, England: Pearson Education Ltd.
- Fairclough, N. (2003). *Analysing discourse: Textual analysis for social research*. New York, NY: Routledge.
- Jørgensen, M. W., & Phillips, L. J. (2002). *Discourse analysis as theory and method*. London: Sage.
- Van Dijk, T. A. (1993). Principles of critical discourse analysis. *Discourse & Society*, 4(2), 249-283.
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Intensive Interaction Training!



Do you spend time with people with dementia?

Do you want to learn a communication technique for people with advanced dementia?

Would you like to take part in a unique research project?

Then Intensive Interaction might be for you!

Intensive Interaction is based on child-caregiver communication. It is effective in reducing challenging behaviours and improving the wellbeing of people who struggle to communicate in formal language.

I am looking for 12 staff to take part in my research project on 12th November 2015. You will get a full day's training on Intensive Interaction at the University of Hull (lunch provided).



We will run two audio-recorded focus groups on the day, to talk about dementia and Intensive Interaction. I will analyse the content of the focus groups for my study. If you are interested, please contact your manager for an information sheet and I will give you a call (either at work or at home, whichever you prefer).

Cheyann Heap, Trainee Clinical Psychologist, University of Hull

Appendix 9. Information Sheet for Participants

“Exploring dementia discourses with Intensive Interaction training: A focus group study with care home staff.”



Dear participant,

Thank you for considering the Intensive Interaction training day and research study. This is part of a Doctorate in Clinical Psychology at the University of Hull, for a Trainee Clinical Psychology (Chey Heap) in the final year of training.

Research shows that Intensive Interaction can reduce challenging behaviours and improve communication with people with learning disabilities. However, use of Intensive Interaction in dementia is relatively new. The purpose of this study is to explore how care home staff think about dementia, and also the use of Intensive Interaction in dementia.

Your manager thought that you might find this training useful, and gave you a flyer. If you want to take part after reading this information sheet, the main researcher (Chey Heap) will give you a phone call to confirm your participation and answer any questions.

This training has space for 12 people who are interested in taking part in the research. Of the 12 people at training, 6 will participate in the research (“first come first serve” as you sign in to the training). Your training will not be affected by whether or not you choose to take part in the research on the day.

Intensive Interaction training will be run by two experienced practitioners, Chrissie Blackburn and Theresa Lambert. It will include discussion, video, information sheets, and use of case studies. You may take part in group exercises to help you understand Intensive Interaction better (e.g. practicing some of the techniques). You will learn some of the theory behind Intensive Interaction, and also plenty of practical tips on when, and how, to use Intensive Interaction. There will be plenty of time to ask questions during training.

In the morning and afternoon, the training will be split in half and two focus groups run (one which will be recorded for research, and one which will not). Chey Heap will run the research focus group, with colleague Emma Wolverson taking notes. Chrissie Blackburn and Theresa Lambert will run the non-recorded focus group.

The morning focus groups will be about your understanding of dementia, particularly advanced dementia, and last for 30-45 minutes. In the afternoon, second

focus groups will be run, again for 30-45 minutes, to reflect on the training day and thoughts on using Intensive Interaction in dementia.

The main benefit of taking part in this research is the Intensive Interaction training, to support your professional development. It also provides a reflection space for you to think about your work, talk to staff from different care homes, and share ideas.

However, dementia can be a difficult to talk about. Please note that you can leave the focus group, or the training, at any time if you are uncomfortable or upset. You also don't have to talk about anything you don't want to.

Straight after training, any audio recordings will be transferred to a password-protected encrypted USB stick. They will transcribe (type up) the recordings, change everybody's real names, and remove identifying data (e.g. if you mention the name of your workplace, this will be removed). They will also type up Emma Wovlerson's notes, then destroy hard copies. All documents will be kept securely on the encrypted USB stick, and your data will remain anonymous.

You can ask for personally identifying data (e.g. the demographics sheet which will be filled in at training) to be destroyed at any point after this study. Otherwise, hard copies of data will be locked in a secure filing cabinet on the University campus.

A final report will be produced, which analyses what was talked about in the focus groups. Short, anonymous quotes might be used in the final report, however you will not be identifiable from these quotes. If you want a copy of this final report once it is written, your manager can provide one, or contact Chey Heap (see below).

Everything you say will be kept confidential, except where there is *significant* malpractice or risk of harm disclosed (e.g. a disclosure of abuse). This would have to be shared with your manager.

After training, your managers are available for support in the workplace. You can also talk to myself or any of the other facilitators of the training if you have questions or problems on the day. The next page has a list of sources of support.

At any time after training, feel to get in touch with Chey to talk about how the day may have affected you. If you have any questions, I can be contacted at c.j.heap@2013.hull.ac.uk, or 07851156466.

Cheyann (Chey) Heap, Trainee Clinical Psychologist

Department of Psychological Health and Wellbeing, University of Hull

Appendix 10. Consent Form for Research

“Exploring dementia discourses with Intensive Interaction training: A focus group study with care home staff.”



Declaration of Consent

I consent to taking part in two recorded focus groups about Intensive Interaction with advanced dementia.

I understand that my data will be kept anonymous, but that short quotes from the groups may be used in future reports.

I know that I have the right to withdraw from the group at any time, and that if I choose not to take part in the group, my Intensive Interaction training is unaffected.

I am aware of sources of support that are available if the group affects me personally, and I have received the contact details of the interviewer should I need further information.

Researcher name:

Date & signature:

Participant name:

Date & signature:

Online support

Dementia UK

<http://www.dementiauk.org/information-support/>

Alzheimer's Society

<http://www.alzheimers.org.uk/>

Caring for a person with dementia

<http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200343>

<http://www.dementiacarer.net>

Age UK (formerly Age Concern and Help the Aged)

<http://www.ageuk.org.uk/>

Telephone numbers

Age UK advice line

0800 169 6565

Yorkshire and Humber branch of Alzheimer's Society Helpline

0114 2768414

Admiral Nursing DIRECT helpline – please note this is NOT a free number

Available 09.15-16.45 every day of the week, plus 18.00-21.00 Weds and Thurs

0845 257 9406

Personal Support

The Samaritans: 08457 90 90 90 (costs up to 4p/min from BT landline)

“Our trained volunteers are able to listen to you any time day or night. We can help you talk through whatever is troubling you, find the answers that are right for you, and offer support. You don't have to give your real name or any personal information if you don't want to.”

MIND Mental Health Charity (open 9am-6pm Mon-Fri except bank holidays)

Info line for a variety of mental health problems, including where to get help, types of mental health problems, and mental health advocacy.

0300 123 3393

Text: 86463

Appendix 11. Demographics Form for Participants

This information will be kept completely confidential. It will be transferred to an encrypted USB stick and the paper copy shredded as soon as possible. This information will not be used to personally identify you.

1. Gender – do you identify as: (please circle or tick)

- Male
- Female
- Other (please specify below if you wish)

2. Age – what is your age?

3. What is your role/job title?

4. How long have you worked with people with dementia, and in what roles?

5. Approximately how long have you been in your current role/job?

6. How would you describe your current employment status? (please circle or tick)

- Full time
- Part time without other employment
- Part time with other employment
- Bank – please circle **set hours** or **zero hour contract**
- Other (please specify)

7. In what capacity do you spend time with people with dementia? (please circle or tick all that apply)

- Professional (at work)
- Past personal (in the past, friends or family members)
- Current personal (at the moment, friends or family members)
- Volunteering/befriending
- Other (please specify below)

8. Ethnic group – which best describes you? (please circle or tick)

- White British
- Other White background
- Black British
- Black African
- Black Caribbean
- Other Black background
- Indian
- Pakistani
- Bangladeshi
- Other Asian background
- Black Caribbean and White
- Black African and White
- Asian and White
- Other Dual Heritage
- Chinese
- Traveller
- Other Ethnic Group
- Prefer not to say

Thank you for taking the time to fill in this demographics sheet

Appendix 12. Interview Guide for Focus Groups

Focus group 1.

Focus group in the morning will be based on the topics which have been identified as missing from dementia discourse. It will be semi-structured, and largely led by the staff's conversation. However, there several themes to be focussed on, with example questions to support the theme.

1. Focus: Personhood.

Questions e.g. “What does the word “dementia” mean to you”, “How do you know if a person has dementia”, “What happens to people when they get dementia”, “How would you describe the relationships you have with people in the care home?”.
How much do you know about the people you work with? Does it matter?”, “How do you manage when people are distressed, or ‘wandering’?”.

2. Focus: Communication.

How do you communicate with people who have dementia? What are the differences between people in earlier dementia vs later dementia? How can you tell what kind of mood someone is in? What sorts of conversations do you have with people with advanced dementia – can you have conversations?

3. Focus: Reciprocity.

Can people with dementia give anything back? (& follow up q's). How do you manage stress at work, and what tends to cause you stress?

4. Focus: Embodiment.

How much touch is involved in dementia care? When might you touch someone and why? How might people with dementia try to touch you, what might that mean? Does someone's dementia make a difference to how you might touch them, if so why?

5. Focus: Empathy.

What do you think it's like for the individual to have dementia? Is that different when someone has *advanced* dementia, if so, how? What is it like for the person when.... (use as follow up, e.g. if staff are talking about activities in the care home).

Focus group 2

Focus group two will largely be based on reflections on the training day, alongside any important topics that came up in the morning group.

However, it will include reflective questions such as:

- How might it feel to do Intensive Interaction with someone?
- How might that person feel?
- Is there anything in the training that has stood out?
- Is there anything new that you have learned, or anything that might change your practice? What do you think about looking at Intensive Interaction for older adults – are there any clear benefits, or drawbacks?

Appendix 13. Ethical Approval Letter

This has been removed for confidentiality.

Appendix 14. Overall Summary of Empirical Data

The data has been summarised in a diagram (Fig. 3). The diagram represents how certain discourses are ‘nested’ within each other in the current study. The primary discourses are of the medical model of dementia and concepts of (lack of) personhood. This provides a framework for discussion about the obstacles to tackling current discourses.

Dementia as a medical problem overlaps with a lack of personhood, and both of these discourses lay the foundation for conceptualisations of people with dementia. Another prevalent discourse is *ageing as decline* (the pale grey circle), which in itself is both a medical and depersonalising concept. However, the discourse of a younger person with dementia did not fit into the ‘ageing as decline’ model, although it was still considered a medical problem. To discuss ‘younger dementia’ getting worse, people were assimilated into ageing discourse (i.e. referred to as looking or acting old).

The two darkest circles (*can't do things* and *hopelessness, inevitable loss*) have a reciprocal influence on each other, but do not overlap. Being unable to do things linked into concepts of infantilisation, people with dementia as a burden and lacking embodiment - that is, the body cannot ‘do’. Infantilisation overlaps with (implied) discourses of women being mothers/carers, which enable an (explicit) discourse of dementia care being natural or ‘automatic’. Hopelessness, however, is related to more to death and societal disease burden. Industrialised notions of care overlap with all of these concepts, in addition to highlighting a lack of resources for adequate care.

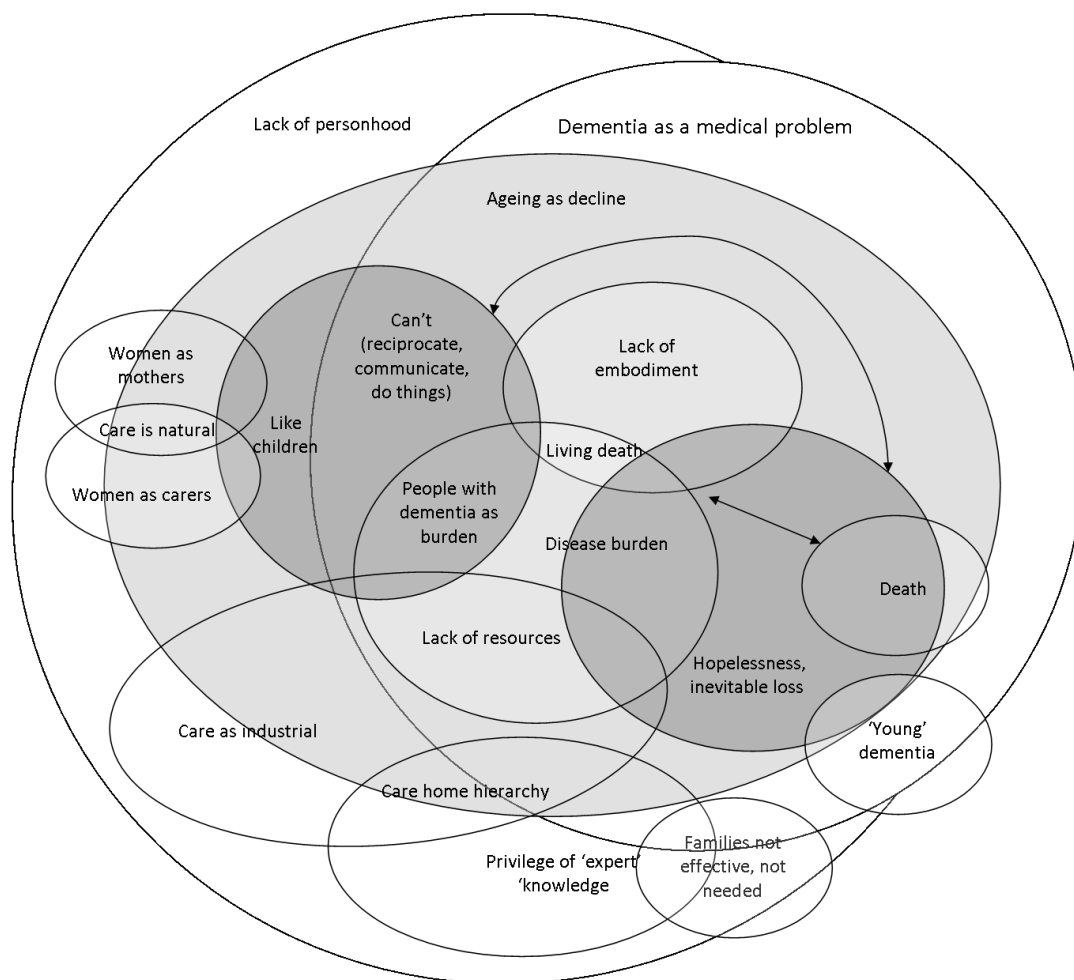


Fig. 3. Summary of the discourses in the overall data, and how they relate to each other.

Societal care discourse is industrial and centres on a) caring for other people's *needs*, and b) being qualified to undertake certain tasks. There are rarely job advertisements asking for carers who enjoy being with people with dementia. Even job roles within care homes are separated based on 'doing' tasks such as cleaning or arranging activities. Therefore, where the privileging of expert knowledge and industrial care overlap, there is the depersonalising discourse of care home hierarchy. Linked into industrial care and dementia as a medical problem, expert knowledge is privileged, and families are considered to be ineffective and unnecessary in care.

Appendix 15. Interdiscursivity in Focus Group 1

Table 1 only considers quotes (either direct or indirect) rather than generic terms such as ‘he shouts’. Although in Intensive Interaction terms, shouting is considered a form of communication, for clarity this is considered to be carers reporting what they perceived as *behaviour*, rather than trying to include the resident’s voice. Additionally, carers using the generic term ‘like you say’ or ‘like I said’, as these are not quotes so much as pointers as to the topic of conversation.

Table 1. Analysis on interdiscursivity in Focus Group 1.

Person	Direct speech		Indirect speech	
	Frequency	Content	Frequency	Content
Individual resident	9	‘Young’ person in home: <ol style="list-style-type: none"> 1. Stating would run away but didn’t want to ‘get’ carer in trouble. 	2	Anecdote, could remember date Resident worked in a home, ‘always said’ he didn’t want to go in one

Person	Direct speech		Indirect speech	
	Frequency	Content	Frequency	Content
		2. Liking club music 3. 'They're all f***ing old in here' Anecdote about hairdresser Anecdote about how to be different with everyone Anecdote about use of nicknames Anecdote about resident using a rota with staff Resident talking to baby doll		
'Residents' (person not specified)	10	Representation of interests compared to younger person Support statement that home is like a prison Reaction to carer returning from leave	1	Telling 'noisy' residents to shut up

Person	Direct speech		Indirect speech	
	Frequency	Content	Frequency	Content
		<p>Reaction to looking at pictures</p> <p>Remembering what 'old' items are for</p> <p>Showing staff what 'old' items do</p> <p>Gasping, upset at newspaper stories</p> <p>Welcoming staff back after leave</p> <p>Giving a reaction, even if that's to decline an activity</p> <p>"Aren't you nice" to staff</p>		

Person	Direct speech		Indirect speech	
	Frequency	Content	Frequency	Content
Carers referring to self	10	<p>Anecdote about residents watching TV</p> <p>Asking resident to 'show' something</p> <p>Anecdote about hairdresser</p> <p>Anecdote about how to be different with everyone</p> <p>Anecdote about use of nicknames</p> <p>Example of 'family doesn't understand', telling staff to stop husband smoking</p> <p>Anecdote about resident using a rota with staff</p> <p>Asking residents what 'old' items do</p> <p>Example of de-escalation/reassurance</p> <p>"Aren't you nice" to resident</p>	4	<p>Anecdote to demonstrate activity (been hovering and said 'let's talk to so-and-so')</p> <p>Tell family staff was present at death</p> <p>State people with dementia are human beings</p> <p>Talking to residents about here-and-now e.g. family, town</p>

Person	Direct speech		Indirect speech	
	Frequency	Content	Frequency	Content
Family, child, spouse	3	<p>Example of ‘family doesn’t understand’, telling staff to stop husband smoking</p> <p>Death as a blessing, person was ‘lost’</p> <p>Example of ‘family doesn’t understand’, shouting at parent</p>	1	Agree ‘the person is lost’
Other / “they”	1	Carer’s daughter: what are you taking a baby basket to work for	1	<p>What ‘they’ call ‘organic’ dementia</p> <p>‘They’ state ‘you’ shouldn’t get attached</p> <p>What ‘they’ call dementia hubs</p>

Appendix 16. Interdiscursivity in Focus Group 2.

Table 1 only considers quotes (either direct or indirect) rather than generic terms such as ‘he shouts’. Although in Intensive Interaction terms, shouting is considered a form of communication, for clarity this is considered to be carers reporting what they perceived as *behaviour*, rather than trying to include the resident’s voice. Additionally, carers using the generic term ‘like you say’ or ‘like I said’, as these are not quotes so much as pointers as to the topic of conversation.

Table 1. Analysis of interdiscursivity in Focus Group 2.

Person	Direct speech		Indirect speech	
	Frequency	Content	Frequency	Content
Individual resident	5	<p>Conversation thinking staff is sister</p> <p>Stating ‘boy bath me’ to short haired carer</p> <p>Saying ‘mash potato’ with carer</p> <p>Anecdote – resident upset, but doesn’t know what is wrong with her</p>	1	Asks ‘your’ name

Person	Direct speech		Indirect speech	
	Frequency	Content	Frequency	Content
‘Residents’ (person not specified)	6	<p>Carer imagining what the resident is ‘saying’:</p> <ol style="list-style-type: none"> 1. I wish I had someone sat with me 2. Someone finally understands me 3. I’ve been banging for years nobody took notice, now they know what I’m on about 4. They know I’m not clicking for sake of it 5. I don’t want to sit here – bang bang – move me <p>Can’t physically say ‘I don’t want to sit here, I want to move’</p>	0	
“Family”, child, spouse	0		1	Wife – it’s fine to call him dad

Person	Direct speech		Indirect speech	
	Frequency	Content	Frequency	Content
Other "they"	/ 5	<p>Manager – you can't call him dad</p> <p>'everybody' responding to staff being 'sister' to resident</p> <p>'They' might say 'you're mimicking'</p> <p>Imagining 'them' saying 'what the heck are they doing' with Intensive Interaction</p> <p>'New ones' stating erroneously that resident is 'in a mood'</p>	9	<p>Discouraging touch</p> <p>Trainers saying carers have probably done Intensive Interaction without realising</p> <p>Trainers talking about Intensive Interaction</p> <p>Trainers saying homes are busy</p> <p>Carer from morning group who mentioned one-to-one</p> <p>'Odd person' who says beach ball is babyish</p> <p>Staff member reassuring training will be alright</p> <p>'They' will tell staff off for taking the mickey</p> <p>Wouldn't have attempted Intensive Interaction activities, 'they' would accuse of taking the mickey</p>

Appendix 17. Reflective Statement

An important starting point for reflection is how I came to research dementia care and Intensive Interaction. My desire to do so begins with my personal experiences of spending much of my childhood in residential care homes for older adults. My older friends and I had a lot of fun, with frequent affectionate physical contact. When I entered clinical practice, I was shocked by the enormity of the literature on medical deficit, and the lack of positive stories. It felt inhumane. As such, my primary desire for this thesis has been to re-centre the person behind the ‘dementia’ label.

For my systematic literature review, I had initially hoped to review Intensive Interaction in dementia care. However, there was not enough literature for a review. This made me wonder, then, what kind of research into touch in dementia care existed, if not Intensive Interaction. I was also curious as to why researchers had chosen touch as an intervention, related to my view that dementia research is a social process (Harding & Palfrey, 1997).

Both my ideas for my systematic literature review and my empirical paper have been a process of honing down grand ideas. Initially, I was going to review all touch interventions in dementia including a range of multi-sensory interventions; for my empirical paper I was also going to provide Intensive Interaction supervision for an 8-week period and analyse tapes of the supervision sessions. It felt difficult for me to narrow down my options at the time, because I was concerned that ‘tighter’ projects would have less of an impact than broader, wide-reaching topics. However, the process of research challenged this belief and I learned that specific ideas with clear aims can be more effective.

Interestingly, this has paralleled my general process of learning in my clinical work of the Doctorate in Clinical Psychology. At the start of my training I was keen to conduct holistic and all-encompassing formulations for clients, always with my gaze on the whole. I found it difficult to focus on one particular problem or aspect of the situation. However, in my final year particularly I have developed the skills to focus on a particular part of the story, whilst holding the ‘bigger picture’ in mind. Similarly, whilst the bigger picture in my thesis is the lack of personhood in dementia care, my systematic literature review focussed on only a part of social interactions (touch), and my empirical paper only focussed on a particular part of the social discourse of dementia (paid caregivers at Intensive Interaction training). As such, through reflecting on my thesis, I have also been able to reflect upon my entire Doctorate.

The process of conducting and writing my research has very much been a joint effort. My thesis has made me reflect how we are all interdependent, and how our social ‘othering’ of people with dementia is also a way of cutting off from that interdependent part of ourselves. I myself have required practical support to design my paper and hone down my ideas, emotional comfort, people to remind me that I have a meeting, and people to treat me compassionately when I *have* forgotten a meeting. None of us exists in isolation, and I have learned to seek help where I need it!

Completing my systematic literature review, at times, felt like an overwhelming task. Whilst the stages of conducting a literature review were simpler than the Critical Discourse Analysis I chose for my empirical paper, there was nevertheless a huge amount of data to filter through. I also engaged in several iterations of the literature review, due to my struggle in narrowing down my research question into ‘pure’ touch interventions. This could have been better avoided if I had begun my literature review

with a clearer question in mind, and in future I would definitely spend more time in creating a precise question before embarking upon the (in my view) more exciting part of doing the review itself. I wonder if, like the carers in my empirical focus groups, I felt that an active ‘doing’ task such as conducting the search was more like ‘real work’ than the thinking task of developing a question. However, it is clear that each part of the search is integral to a good quality final outcome.

Within my empirical paper, planning and conducting the focus groups led a great deal of reflection about my positioning within the group. As a young woman completing a Doctorate in Clinical Psychology, I wondered what the focus groups were like for people who worked in hierarchically-organised care homes. This also led to me feeling self-conscious and keen not to “impose” in the conversation. As such, I felt that I posed questions in a more tentative and rambly way than I had practiced! Before the training day, I conducted a pilot focus group during dementia teaching with my peers at the University, and I would recommend doing so to gain feedback and alleviate nerves. However, I would also encourage people conducting focus groups to have confidence – even if a question isn’t quite “right”, the participants in the focus group will either ask for clarification, or make their own meaning.

I selected the journal *Dementia* for my systematic literature review because my topic was dementia-specific, and the journal also invites social research. I felt that my literature review has a social (relational) focus. I chose to submit my empirical paper to *Ageing and Society*, as the journal has a natural focus on older adults and their context. Additionally, I felt that my empirical paper had implications beyond dementia care, and therefore did not submit to a dementia-specific journal. Both journals have the rigour of being peer-reviewed.

Overall, I feel that the reflection about my thesis primarily based on relationships - perhaps unsurprising considering the subject matter. This includes the relationship between myself and my data, and also relationships between myself, my thesis, and the people who contributed in various ways to the end result.

References

Harding, N., & Palfrey, C. (1997). *The social construction of dementia: Confused professionals?* London: Jessica Kingsley.