VOLUME I

RESEARCH COMPONENT

AGGRESSION IN DEMENTIA: ASSOCIATED FACTORS AND IMPACT ON SPOUSAL RELATIONSHIPS

By

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OVERVIEW

This thesis, in two volumes, forms part of a three year Doctorate in Clinical Psychology at the University of Birmingham. Volume one contains a systematic review, an empirical paper and an executive summary. Paper one is a systematic review of research investigating factors that may contribute to the development of aggression in dementia. There was support for a complex interaction of factors, however, high quality, theory driven research is limited. Paper two is a qualitative study that explores spousal carers' perspectives on aggression in dementia within the context of their relationship. The data was analysed using Interpretative Phenomenological Analysis (IPA). Themes emerging from the data relate to how spousal carers understood, and responded to the aggression. Template Analysis (TA) was used to reveal the interplay between aggression and aspects of relationship continuity. Paper three, is an executive summary that serves as a briefing paper for the public domain.

Volume two contains five clinical practice reports (CPR's). CPR1 presents cognitive and systemic formulations of a woman age 45, with a learning disability and symptoms of anxiety. CPR2 is a single-case experimental design investigating a behavioral assessment and intervention used with a 32 year old male with moderate learning disabilities, anxiety and aggression. CPR3 describes an evaluation of repeat referrals to an Improving Access to Psychological Therapies service. CPR4 presents a case study of a 23 year old female with Chiari Malformation. CPR5 is represented in the form of an abstract outlining the case of a 14 year old girl with obsessive compulsive disorder (OCD).

All identifying details have been changed in the interests of anonymity and confidentiality.

DEDICATION

I dedicate this thesis to my mum, and to all the people who gave me motivation to keep going.

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This has been my Everest, and as with any great adventure I could not have made it alone. There are countless people to thank and I truly appreciate everyone involved in this experience.

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Thank you to my fellow adventurers, our time together has been a life changing, unforgettable experience. I’m honoured to have been on this journey with you all.

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PAPER 1

FACTORS ASSOCIATED WITH AGGRESSION IN DEMENTIA: A SYSTEMATIC LITERATURE REVIEW.

By

Holly Gibbons

ABSTRACT

Background

A wide range of potential contributing factors have been associated with aggression in dementia, such as pain, genetics, pre-morbid personality, communication, and mood. Although earlier reviews have been completed, these were not systematic or comprehensive, and did not review more recent literature. Thus, the present review aimed to determine whether recent empirical research provides robust conclusions as to which factors are likely to predict, predispose or perpetuate aggression in dementia.

Method

Bibliographic databases were systematically searched for journal articles published between 2001 and 2014, reporting on factors associated with aggression in dementia. Abstracts and titles of 959 articles were screened. Exclusion criteria were applied to returned searches, removing articles inappropriate for review. The resulting 63 articles were reviewed and summarised, paying particular attention to each study's methodology and contribution to the evidence base.

Results

The majority of studies were found to be in the medium quality range, whereas only one study was of high quality. Across the evaluated studies a total of 30 factors were associated with aggression in dementia, suggesting a complex interaction of factors contribute to aggression in dementia.

Conclusions

Methodological limitations are highlighted and more high quality, theory driven research is needed in order to address these issues. Overall, there were no findings that overtly contradicted those reported in earlier reviews. Findings support the use of functional, individualised assessment. This information is valuable for the development of interventions and for informing standards of dementia care practice.

Keywords: dementia, Alzheimer’s disease, aggression, aggressive behaviour, review

LIST OF ABBREVIATIONS

Acronym	**Description**
5-HT	Serotonin
AD	Alzheimer's Disease
ADAS-cog	Alzheimer's Disease Assessment Scale cognitive subscale
ADNI	Alzheimer Disease Neuroimaging Initiative
ANOVA	Analysis of Variance
APOE	Apolipoprotein Alleles
BEHAVE-AD	Behavioural Pathology in Alzheimer’s Disease
BI	Burden Interview
CAMDEX	Cambridge Examination for Mental Disorders of the Elderly
CERAD-BRS	CERAD Behavior Rating Scale for Dementia
CGA	Comprehensive Geriatric Assessment
CMAI	Cohen Mansfield Agitation Inventory
CSDD	Cornell Scale for Depression in Dementia
CSF	Cerebral Spinal Fluid
CUSPAD	Columbia University Scale for Psychopathology in Alzheimer’s Disease
DMAS	Dementia Mood Assessment Scale
FAST	Functional Assessment Staging
FTD	Fronto-Temporal Dementia
GDP	Geriatric Depression Scale
GDS	Global deterioration Scale

HDRS	Hamilton Depression Rating Scale
IADL	Instrumental Activities of Daily Living Scale
MBI	Maslach Burnout Inventory
MCI	Mild Cognitive Impairment
MDS	Minimum Data Set
MDS-ABS	Minimum Data Set-Aggressive Behavior Scale
MDS-CPS	Minimum Data Set-Cognitive Performance Scale
MDS-PSS	Minimum Data Set-Pain Severity Scale
MFS	Middelheim Frontality Score
MMSE	Mini Mental State Examination
MOBID	Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale
MRI	Magnetic Resonance Imaging
MScale	Mutuality Scale
MXD	Mixed Type Dementia
NCS	Non-cognitive Symptoms
NEO-FFI	Neuroticism Extroversion Openness Five Factor Inventory
NPI	Neuropsychiatric Inventory
OAS (r-OAS)	Overt Aggression Scale (retrospective)
ODAS	Observable Displays of Affect Scale
PAINAD-C	Pain Assessment in Advanced Dementia Scale
PBE	Present Behavioral Examination
PEASAD	The Pleasant Events and Activities Schedule Alzheimer’s Disease
PGCPIS	Philadelphia Geriatric Centre Pain Intensity Scale
PGDRS	Psychogeriatric Dependency Rating Scale

PRND	Prion Protein
PTSD	Post-Traumatic Stress Disorder
QOL	Quality of Life
RAGE	Rating Scale for Aggressive Behavior in the Elderly
RAID	Rating Anxiety in Dementia
SD	Standard Deviation
VaD	Vascular Dementia
VBS	Verbal Behaviour Scale
WVT	Workplace Violence Tool

INTRODUCTION

Dementia places a range of demands on carers, but some are subjectively experienced as more challenging than others. Among behaviours that could be described as challenging, aggression poses significant risk of harm to individuals with dementia and those around them, and has been associated with increased caregiver burden (Keene et al., 1999). Burden can impact the ability to provide care and is frequently a reason for referral to specialist dementia services (Ballard, O'Brien, James, & Swann, 2001; Gaugler, Yu, Krichbaum, & Wyman, 2009). Ultimately, aggression can accelerate a move to a residential setting (Black & Almeida, 2004; Schulz & Sherwood, 2008). Delaying this outcome is one objective of the national dementia strategy (DOH, 2009).

Aggression prevalence in dementia between 40% and 96% has been reported, with verbal aggression tending to be more common and long lasting (Keene et al., 1999; Kunik et al., 2010b). In a study of dementia clinic outpatients, 17% exhibited physical aggression, whereas 33% exhibited verbal aggression (Aarsland, Cummings, Yenner, & Miller, 1996). In contrast, prevalence of aggression in aged matched peers without dementia may be as low as 3% (Lyketsos, 2000).

In a survey investigating challenges faced by family caregivers, many reported feeling poorly prepared to deal with agitation and aggression and few had received relevant training or advice (Newbronner, Chamberlain, Borthwick, Baxter, & Glendinning, 2013). Professional caregivers report similar concerns; limited training contributes to poor quality care practices such as too much reliance on restraint, pharmacological treatment, and avoidance of care activities (Keene et al., 1999; Gastmans & Milisen, 2006; Whall et al., 1992).

It is important to understand the causes of aggression so that appropriate support and interventions can be developed.

For reference, a summary of theories of aggression, and issues in defining aggression can be found in Appendix 2.

Previous literature reviews

Two review articles, reporting potential contributing factors of aggression in dementia, were identified during development of this review. Significant findings and proposed associations identified in these earlier reviews are outlined in Table 1.1.

Hall and O'Connor (2004) conducted a preliminary literature review, drawing on research conducted between 1995 and 2001. Their aim was to consolidate the body of work reporting on potential causes and correlates, to aid clinicians in the assessment and management of aggression in dementia. They used a non-systematic approach, and no critique of studies involved was provided; however, the review provides a useful synthesis of research at that time. They conclude by acknowledging significant gaps in possible environmental, psychological and physiological correlates and recommend that future research also explore social and demographic factors in relation to individuals with dementia and their care providers.

In their selective review, Cipriani, Vedovello, Nuti, & Di Fiorino (2011) briefly summarised results from 16 studies concerning causes of aggressive behaviour in dementia. While focussed predominantly on neuro-pathology, they concluded that multifactorial approaches were necessary for intervention and future research, as no single cause of aggression was identified nor considered likely. They also acknowledged a need for further research relating to physiological need and drug use, including alcohol and caffeine.

Although Cipriani et al. (2011) published their review ten years later than Hall and O'Connor (2004), they only included five studies that were carried out in subsequent years. Most evidence for both reviews was drawn from the same period. Neither described studies in detail and no quality assessment was applied. The basis upon which studies were included was unclear. Therefore, it is difficult to know whether the findings are robust and representative of existing literature.

Aim

A wide range of potential contributing factors have been associated with aggression in dementia, such as pain, genetics, premorbid personality, communication, and mood, but no systematic review of the literature has been applied to the topic. Such a broad and diverse array of potential influencing factors, represent a barrier to scientific and clinical progress. In general, it is useful to update reviews for purposes of informing current practice and future research. The present systematic review aimed to determine whether recent empirical research provides robust conclusions as to which factors are more likely to predict, predispose or perpetuate aggression in dementia; and, by applying a quality assessment framework, to provide a benchmark against which confidence in findings can be measured.

Table 1.1 Summary of findings from previous literature reviews (Hall & O'Connor, 2004; Cipriani et al., 2011)

- A linear correlation with severity of *cognitive impairment* and *impaired activities of daily living*.
- An association with interpersonal factors including *resistance to personal care*, *quality of care-recipient caregiver relationship, carer burden* and *communication difficulties* (production and comprehension). Misinterpretation of caregiver instructions by the person with dementia were highlighted as a potential precipitating factor.
- An association with *premorbid acts of aggression*
- An association with degeneration in specific *brain regions* and, with *frontotemporal* dementia.
- An association with low levels of *serotonin neurotransmission*.
- Positive correlations with symptoms of *depression, delusions and hallucinations.*
- An association with *gender:* Men were found to be more likely to exhibit verbal, physical and sexual aggression compared to women. However, there was speculation around the possibility that results were skewed by perceptions and tolerance of female aggression.
- *Hearing and vision* impairment may lead to increased frustration and misinterpretations.
- Studies of *environmental* factors indicate there may be an association but findings were mixed.
- *Epileptic activity* causing undirected aggression.
- *Physical health* may be correlated either as a direct reaction to pain or due to severe confusion from infection.
- Investigations of disrupted circadian activity did not find an association with aggression.

METHOD

Search Strategy

Initial searches identified all articles investigating potential causes of aggressive behaviour exhibited by people with dementia. Search criteria were applied to the following databases: PsycINFO, MEDLINE, and EMBASE. Publication dates were restricted to 2002 to April 2015, to ensure selection for recent studies, and avoiding significant overlap with earlier reviews. Search terms were: dementia, Alzheimer*, aggres*, violen* and assault*. An asterisk after a term is a 'wildcard' that enables all terms that begin with the preceding characters to be included in the search. Duplications were removed from results. Limits applied were: peer reviewed journal, English language, human only studies. Selection criteria were then applied in a four step process. A flow diagram outlining search and selection process is displayed in Figure 1.1.

Inclusion Criteria

Papers were included if they met the following criteria; reported empirical data on statistical association between a measure of aggression and at least one other measure; dementia diagnosis of sample must be based on standardised diagnostic criteria (e.g. The Diagnostic and Statistical Manual of Mental Disorders, The International Classification of Diseases).

Exclusion Criteria

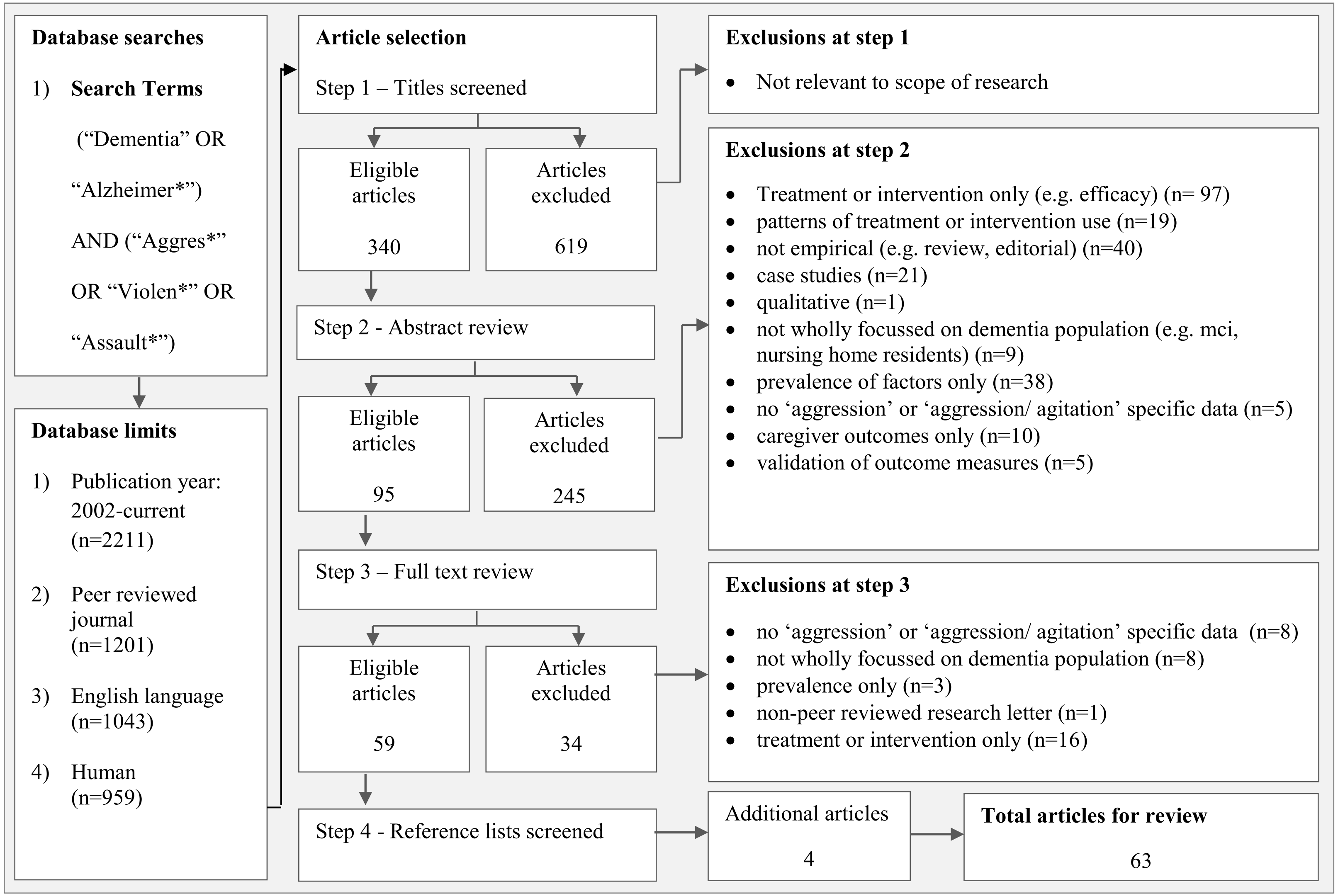
Articles were excluded if they met any of the following criteria; treatment/intervention outcomes or patterns of use only; prevalence rates; no dementia-specific findings; no 'aggression' specific findings; caregiver outcomes only; validation of outcome measures; non-empirical papers; case studies; qualitative studies. Treatment studies were included if direct measurement was made of a potential contributing factor of aggression and the relationship between this and a measure of aggression was statistically analysed.

Selection process

Step 1: Database results were screened to eliminate articles focussed on unrelated topics, and those outside the scope of this review. Titles that appeared relevant to the topic were retained. Step 2: Abstracts of eligible articles were reviewed against inclusion and exclusion criteria. Abstracts with too little information to apply criteria were retained for further inspection. Step 3: Inclusion and exclusion criteria were applied to remaining articles' full text. Step 4: Reference lists of all eligible articles were searched for relevant studies not identified via database enquiry. These articles were included in the final selection.

Following application of selection criteria, there was minimal duplication (n=4) of articles reviewed in earlier reviews (i.e. Hall & O'Conner, 2004; Cipriani et al., 2011) largely due to exclusion of articles published pre-2002.

Figure 1.1 Flow diagram of article search strategy



Quality evaluation

Quality assessment is important for determining potential methodological bias. It allows judgements to be made about the confidence one can place in a study's findings. This is particularly useful when comparing a large number of studies reporting conflicting results. Application of quality criteria is encouraged, but caution is urged regarding how judgements of quality are made in practice, as there is little empirical evidence to support their adequacy (Higgins & Green, 2006).

After consideration of available quality assessment tools, an unpublished quality scale developed by Riley (2014) was selected for this review. It was deemed a good fit due to its suitability for use with correlational research designs, and is adaptable allowing specific issues of interest to be addressed. Each quality indicator is rated numerically against explicit criteria; minimising subjectivity. The framework was adapted to fit the subject under review, including addition of an indicator for definition and measurement of aggression. Full descriptions of applied criteria are outlined in Appendix 3. Nine quality indicators, each with a maximum score of two, were combined to provide an overall score of methodological quality. Descriptive categories were applied to group studies by their quality rating. Scores ranging from 0-6 was rated *low;* 7-12 was rated *medium*; and 13-18 was rated *high*.

For each study, key information was extracted about the method and findings; and the methodology was evaluated against quality criteria. Table 1.2 displays summary information and quality scoring. Summaries focus on aspects relevant to aggression-specific content only. To avoid duplication of factors, studies generated from the same dataset reporting similar findings, were grouped and evaluated as one study, and superscript numbers indicate where details relate to specific studies only. Quality criteria are given in italics with associated score in brackets. The acronym 'NS' denotes a non-significant result.

Table 1.2 Summary of studies included in the review (evaluations in italics)

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Ahn & Horgas, 2013[1] & 2014[2], USA To investigate the effect of pain on disruptive behaviours and whether pain mediates or moderates the relationship between cognitive impairment and aggressive in nursing home residents with dementia	56,577 nursing home residents with a dementia diagnosis aged 65+ (mean 84.37 SD 7.43). *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure: MDS-ABS reliability in the ''acceptable' range. Validity demonstrated.* *Pain measure: MDS-PSS reliability in the 'acceptable' range. Validity demonstrated* *Dementia severity: MDS-CPS reliability in the ''acceptable' range. Validity demonstrated (1)* *Definition of aggression. Measure of aggression frequency (2)*	Cross-sectional *Limited control of potential confounds (1)* *Does not address causal relationship (0)*	*Correlational analysis using logistic[1] regression and hierarchical[2] regression (2)* *Complete data sets required in inclusion criteria (2)*	Residents with more severe pain were more likely to display aggression[1] Frequency of aggression increased with severity of cognitive impairment[2] Pain was associated with more incidents of aggression for those with severe cognitive impairment[2] *Findings supported by one result only (0)*	Pain[1&2] Dementia severity[2] *(9) 'Medium'*
Assal et al., 2004, USA To examine the association of the serotonin promoter, transporter, and receptor genes with neuro-psychiatric symptoms in patients with Alzheimer's disease.	96 individuals with a diagnosis of Alzheimer's recruited via the Alzheimer's disease research centre. (age: mean 76.7 SD 7.4). *Convenience sampling (0)* *Power calculation reported at between 61% - 88% for detecting a medium effect size* (2)	*Aggression measure: NPI reliability in the 'good' range. Validity demonstrated* *Genotyping: polymerase chain reaction (2)* *No definition of aggression. Measure of aggression/agitation severity and frequency (0)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using one-way ANOVA and Bonferroni correction (2)* *Missing data for one participant (1)*	Of the four variants genotyped (5-HT2CR, 5-HTTPR, 5-HTT, & 5-HT2A) the 5-HT2A receptor polymorphism only was found to be significantly associated with aggression *Findings supported by one result only (0)*	Genotype *(9) 'Medium'*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Ball et al, 2009, USA To evaluate the potential of increased aggression in patients with dementia who had a pre-existing diagnosis of post-traumatic stress disorder (PTSD)	215 veteran out-patients with a recent dementia diagnosis. Of these 10 with a PTSD diagnosis. Aged 60+ (mean 76 SD 6.2). *Convenience sample (0)* *Sample size below minimum for achieving adequate power (0)*	*Aggression measure: CMAI reliability in the 'acceptable' range. Validity demonstrated (1)* *Definition of aggression. Specific measure of aggression frequency (2)*	Longitudinal *Limited control of potential confounds (1)* *Does not address causal relationship (0)*	*Descriptive statistics reported (0)* *No report on missing data (0)*	There was no association of increased risk of aggression for those with a PTSD diagnosis *Findings supported by one result only (0)*	PTSD^{NS} *(4) 'Low'*
Ball et al., 2010, USA To examine the quality of caregiver/ care-recipient relationship and its effect on psychosocial variables in dementia.	171 veteran out-patients with a recent diagnosis of dementia aged 60+ (mean 76 SD 6.04). *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure: CMAI reliability in the 'acceptable' range. Validity demonstrated.* *Relationship quality: Mutuality Scale reliability in the 'excellent' range. Validity demonstrated (1)* *No definition of aggression. Measure of aggression frequency (1)*	Longitudinal *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational* using auto-regressive linear model (2) *Missing data identified. Unclear if addressed statistically (0)*	There was no relationship between total mutuality scores and aggression. *Findings supported by one result only (0)*	Caregiver – care-recipient relationship^{NS} *(7) 'Medium'*
Bandyopadhyay et al., 2014, India To compare the neuro-psychiatric profile of individuals with a diagnosis of AD and VaD.	100 neurology outpatients with a diagnosis of AD (n=50) and VaD (n=50) aged 48-81 (mean 65.76 SD 11.68) *Convenience sampling (0)* *Sample size below minimum for achieving adequate power (0)*	*Aggression Measure: NPI reliability in the 'good' range. Validity demonstrated (2)* *No definition of aggression. Measure of aggression/agitation severity and frequency (0)*	Cross-sectional Limited control of potential confounds (1) *Does not address causal relationship (0)*	*Group comparison using Chi-Square (2)* *No report on missing data (0)*	The frequency of agitation and aggression was greater for those with VaD compared with AD and greater for those with large vessel VaD compared with small vessel VaD. *Findings supported by one result only (0)*	Type of dementia *(5) 'Low'*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Beck et al., 2011, USA To examine personal and environmental factors of aggressive and non-aggressive problematic vocalizations.	138 residents with a diagnosis of dementia, recruited from 17 nursing homes. Aged 65+ (mean 85.3 SD 7.0) *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Verbal Aggression Measure: VBS reliability in the 'good' range. Validity demonstrated.* *Personality: NEO-FFI reliability ranging from 'good' to 'excellent'. Validity demonstrated.* *Physiological needs: Observation with 'excellent' reliability achieved.* *Sleep quality: Actigraphy.* *Dementia severity: MMSE reliability in the 'good' range. Validity demonstrated.* *Affect: ODAS reliability in the 'excellent' range. Validity demonstrated (1)* *No definition of aggression. Measure of aggression (1)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using logistic regression (2)* *6 participant data sets excluded due to missing data (2)*	Negative and positive affect, past agreeableness, and general health were significantly associated with aggressive problematic vocalizations. Women were twice as likely to have aggressive problematic vocalizations. An increase in age, by 5-year increments, decreased likelihood of aggressive problematic vocalizations. *Findings supported by one result only (0)*	Affect Gender Premorbid personality Age Physical Health Dementia severity^{NS} Sleep disturbance^{NS} Physiological need^{NS} Education^{NS} Ethnicity^{NS} Environment^{NS} *(9) 'Medium'*

Author, Publication Year, Country, Aim	**Participants *Recruitment strategy and sample size appropriate?***	**Data collection method *Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design *Control of variables? Causality addressed?***	**Analysis *Appropriate? Any missing data?***	**Main Findings *Robust results?***	**Factors *Overall Quality Rating***
Bidzan et al., 2012, Poland To assess the relationship between aggressive and impulsive behaviours and cognitive function disorders in Alzheimer's disease patients.	31 nursing home residents with a diagnosis of AD. (age: mean 77.10 SD 8.39) *Convenience sampling (0)* *Sample size below minimum for achieving adequate power (0)*	Aggression measures: CMAI *reliability in the 'acceptable' range. Validity demonstrated.* *Dementia severity: ADAS-cog reliability in the 'excellent' range. Validity demonstrated (1)* *No definition of aggression. Measure of aggression frequency (1)*	Longitudinal *Limited control of potential confounding variables (1)* *Does not address causal relationship (0)*	*Group comparison using two sample T-test (2)* *Large amount of data missing in follow-up not addressed statistically (0)*	Verbal aggression intensity significantly increased with the progression of dementia for those with a lower baseline level of dementia. Physical aggression intensity significantly increased with the progression of dementia for those with a higher baseline level of dementia. *Findings supported by one result only (0)*	Dementia severity *(5) 'Low'*
Bostrom et al., 2012, Canada To examine the frequency and associations between aggressive acts experienced by care providers in dementia care.	91 care providers recruited from four dementia care settings (residential n=2, secured unit n=2). *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure: WVT reliability data unavailable. Validity demonstrated (0)* *No definition of aggression. Measure of aggression (0)*	Cross-sectional *Potential confounds not discussed (0)* *Does not address causal relationship (0)*	*Correlational using linear regression (2)* *No report on missing data (0)*	Care providers on secured units experienced significantly more aggressive acts (verbal and physical) compared with those at residential care centres. Caregiver characteristics (e.g. gender, job satisfaction, and years of experience) did not meet significance. *Findings supported by one result only (0)*	Environment Caregiver factors^{NS} *(3) 'Low'*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Cooke et al., 2010, Australia. To investigate the effect of a group music on (and predictors of) agitation and anxiety in older people with dementia.	47 residents of two long-term care facilities, with a diagnosis of dementia. Aged 75-94. *Convenience sample (0)* *Power level of 0.90 and alpha 0.05, to detect an effect size of 0.67 (2)*	*Aggression measure: CMAI reliability in the 'acceptable' range. Validity demonstrated.* *Dementia severity: MMSE reliability in the 'good' range. Validity demonstrated.* *Anxiety measure: RAID reliability and validity in the 'good' range (1)* *No definition of aggression. Measure of aggression frequency (1)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using multiple regression (2)* *Missing data addressed statistically (2)*	Greater cognitive impairment was associated with a higher level of agitation. *Findings supported by one result only (0)*	Dementia severity Anxiety^{NS} Gender^{NS} Environment - Length of time in residence^{NS} *10 'Medium'*
Craig et al., 2004a[1] & 2004b[2], UK To examine associations between A218C tryptophan hydroxylase polymorphism and agitation/aggression in AD[1]. To test the hypothesis that APOE Ɛ4 increases risk of aggression in those with a diagnosis of AD[2].	396-400 memory clinic out-patients with a diagnosis of AD. Aged 55–99 years (mean 78 SD 7.5). *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure: NPI reliability in the 'good' range. Validity demonstrated* *Genomic DNA: extracted from blood leukocytes using the salting-out method (2)* *No definition of aggression. Measure of aggression/agitation severity and frequency (0)*	Cross-sectional *Limited control of potential confounds (1)* *Does not address causal relationship (0)*	*Correlational using logistic regression[1]. Group comparison using chi-square[2] (2)* *No report on missing data (0)*	There was a significant relationship between the tryptophan hydroxylase C-containing genotypes and agitation/aggression for males only. There was no additional risk for those also carrying APOE Ɛ4[1]. There was however, a higher frequency of APOE Ɛ4 alleles found in individuals exhibiting agitation and aggression[2]. *Findings supported by one result only (0)*	Genotype Gender *(6) 'Low'*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
de Jonghe Rouleau et al., 2005, Netherlands To explore phenomenology of self-injurious behaviour in people with a dementia diagnosis.	110 nursing home residents with a diagnosis of AD or 'other' dementia. Aged 67–105 years (mean 83). *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure: OAS reliability in the 'good' range. Validity demonstrated.* Dementia severity: CAMDEX *reliability in the 'good' range. Validity demonstrated.* *Mobility and restraint: Dichotomous clinician assessment (2)* *Definition of self-injurious behaviour. Measure of aggression frequency (2)*	Cross-sectional *Limited control of potential confounds (1)* *Does not address causal relationship (0)*	*Correlational using logistic regression (2)* *No report on missing data (0)*	Residents with self-injurious behaviour were more often immobile or restrained in bed. There was no association between dementia severity and self-injurious behaviour. *Findings supported by one result only (0)*	Care approach Dementia severity^{NS} *(8) 'Medium'*
D'Onofrio et al., 2012, Italy To evaluate the prevalence of NCS in patients with AD and VaD.	302 geriatric hospital inpatients, with a dementia diagnosis, AD (n=115) VaD (n=93). Aged 65 to 98 (mean 79.98 SD 6.54). *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure: NPI reliability in the 'good' range. Validity demonstrated.* Dementia severity: *MMSE,* IADL and CGA *reliability in the 'good' range. Validity demonstrated (2)* *No definition of aggression. Measure of aggression/agitation severity and frequency (0)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using logistic regression (2)* *No report on missing data (0)*	AD patients demonstrated higher frequency of aggression/ agitation compared to VaD patients. Aggression/ agitation in both AD and VaD patients was associated with moderate to severe level of dementia severity. *Findings supported by one result only (0)*	Dementia severity Type of dementia *(7) 'Medium'*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Engelborghs et al., 2006a[1], 2006b[2], 2006c[3], & 2008[4] Belgium To investigate the relationship between: cerebrospinal fluid biomarkers, frontal lobe features, APOE, neurotransmission and NCS.	248-283 memory clinic outpatients with a dementia diagnoses (AD n=170-201, FTD n=25-27, MXD n=28-33, DLB n=18-24). (age: Mean 67.4 – 81.4). 148 control group participants recruited from a general hospital. Aged 17–88 years (mean 54.6 SD 18.2)[1]. *Convenience sampling (0)* *Sample size below minimum for achieving adequate power (0)*	*Aggression measure: Behave-AD reliability in the ‘excellent’ range. Validity demonstrated.* *Neurochemical cerebrospinal fluid: Lumber puncture and commercially available enzyme-linked immunosorbent assay kits*[1&4] *Frontal lobe features: MFS reliability ‘in the ‘good’ range. Validity demonstrated*[2] *(2)* *Genotyping: polymerase chain reaction*[3] *No definition of aggression. Measure of aggression (1)*	Cross-sectional[1,2,&4] and longitudinal[3], plus blinding procedures[1,4] *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using Spearman and Bonferroni (2)* *Missing data excluded pairwise (2)*	A significant negative correlation between CSF Ab42 levels and aggressiveness were found in AD patients. Results for tau and P-tau181 were not significant[1]. Frontal lobe symptoms were associated with increased severity and frequency of agitated and aggressive behaviour[2]. FTD patients with APOE Ɛ4 scored significantly higher for aggression compared to APOE Ɛ2. Those with two APOE Ɛ4 had significantly higher aggression scores compared to those with one APOE Ɛ4[3]. A strong positive correlation was found for increased activity in dopaminergic transmission and aggression in those with FTD who had not received psychotropic medication[4]. *Findings supported by one result only (0)*	CSF Biomarkers[1] Brain region[2] Genotype[3] Type of dementia[1234] Neurotransmission[4] *(9) ‘Medium’*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Etcher et al., 2012, USA To investigate circadian rest-activity system motor control in nursing-home residents with dementia and with/without aggressive behaviour.	96 residents from 9 nursing homes, with a diagnosis of AD (n=90) or VaD (n=6). (age: mean 86.9 SD 76.6). *Convenience sampling (0)* *Sample size below minimum for achieving adequate power (0)*	*Aggression measure:* CMAI *reliability in the 'acceptable' range. Validity demonstrated* *Circadian activity: Actigraphy to measure alterations in motoric changes over a 24hr period (1)* *Definition of aggression. Measure of aggression frequency (2)*	Cross-sectional *Limited range of potential confounds addressed (1)* *Does not address causal relationship (0)*	*Group comparison using ANOVA and post hoc tests (2)* *No report on missing data (0)*	Individuals with AD and aggression exhibited significantly higher levels of regularity and lower levels of complexity with respect to motoric control. *Findings supported by one result only (0)*	Circadian regulation *(6) 'Low'*
Flirski, 2012, Poland To evaluate possible associations between genotypes and NCS.	147 individuals, of which 99 were diagnosed with AD (age: mean 76.63 SD 6.17) and 48 with MCI (age: mean71.02 SD 6.61). *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression Measure: NPI reliability in the 'good' range. Validity demonstrated.* *Genotyping: Using standard method (1)* *No definition of aggression. Measure of aggression/agitation severity and frequency (0)*	Cross-sectional, plus blinding procedures. *Limited range of potential confounds addressed (1)* *Does not address causal relationship (0)*	*Correlational using logistic regression (2)* *No report on missing data (0)*	Carriers of PRND 3'UTR polymorphism had a greater risk of agitation/ aggression in AD. There were no significant associations between any other genetic polymorphisms tested (e.g. APOE Ɛ4, CYP) *Findings supported by one result only (0)*	Genotype *(5) 'Low'*

Author, Publication Year, Country, Aim	**Participants *Recruitment strategy and sample size appropriate?***	**Data collection method *Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design *Control of variables? Causality addressed?***	**Analysis *Appropriate? Any missing data?***	**Main Findings *Robust results?***	**Factors *Overall Quality Rating***
Garcia-Alloza et al., 2004 & 2005, UK To test the hypothesis that disturbances of the serotonergic 5-HT1B/1D and 5-HT6 receptors or that an imbalance between the cholinergic and serotonergic systems contribute to the cognitive impairment and/or NCS in AD.	42 individuals, of which 22 (age: mean 81.06 SD 1.60) were diagnosed with AD and 20 control cases. (age: mean 74.75 SD 2.67) *Convenience Sampling (0)* *Sample size below minimum for achieving adequate power (0)*	*Aggression measure: PBE reliability in the 'acceptable' range. No validity information available.* *Neuro-chemical measure: Assessed using post-mortem tissue: Quality with pH>6.1 considered acceptable. Assays performed using established methods (1)* *No definition of aggression. Measure of aggression (0)*	Cross-sectional, plus blinding procedures. *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using multiple regression (2)* *No report on missing data (0)*	There was a significant relationship between aggression in AD and: the 5-HT6 serotonergic receptors/ enzyme choline acetyltransferase ratio, and a decrease in cholinergic function. *Findings supported by one result only (0)*	Neurotransmission *(5) 'Low'*
Gehrman et al., 2003, USA To examine the relationship between sleep-disordered breathing and agitation in patients with AD.	38 nursing home residents, with a diagnosis of AD. Aged 61 to 95 (mean 82.3). *Convenience sampling (0)* *Sample size below minimum for achieving adequate power (0)*	*Aggression measure:* CMAI *reliability in the 'acceptable' range. Validity demonstrated.* *Sleep quality: Assessed over one night using behavioural observation (1)* *Definition of aggression. Measure of aggression frequency (2)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational (2)* *No missing data (2)*	Aggressive agitation was greater with more severe sleep-disordered breathing. *Findings supported by one result only (0)*	Sleep disturbance *(9) 'Medium'*
Grochmal-Bach et al., 2009, Poland To assess the occurrence of aggressive and impulsive behaviours in FTD and AD.	27 nursing home residents, with a diagnosis of AD (n=19; age: mean 73.95) FTD (n=8; age: mean 63.25). *Convenience Sampling (0)* *Sample size below minimum for achieving adequate power (0)*	Aggression measure: CMAI *reliability in the 'acceptable' range. Validity demonstrated (1)* *No definition of aggression. Measure of aggression frequency (1)*	Cross-sectional *Limited control of potential confounds (1)* *Does not address causal relationship (0)*	*Group comparison using t-test (2)* *No report on missing data (0)*	Significantly more physical aggression in FTD group compared to AD group. *Findings supported by one result only (0)*	Type of dementia *(5) 'Low'*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Hall et al., 2005, Australia To test the hypothesis that oestrogen would reduce circulating testosterone and aggressive behaviour in male patients with advanced dementia.	27 males (controls n=14) with a diagnosis of dementia recruited from inpatient and residential nursing homes. Aged 55-89. *Convenience Sampling (0)* *Sample size below minimum for achieving adequate power (0)*	*Aggression measure: RAGE reliability in the ''good' to 'excellent' range. Validity demonstrated* *Hormones: Assays performed using established methods (2)* *Definition of aggression. Measure of aggression frequency (1)*	Random assignment, plus blinding procedures. *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Group comparison using t-test (2)* *Small amount of missing data (1)*	There was no relationship between increased oestrogen concentration and aggression. There was no significant decrease in testosterone levels. *Findings supported by one result only (0)*	Hormones^{NS} *(8) 'Medium'*
Hamuro et al., 2006, Japan To confirm whether behavioural and psychological symptoms are related to the severity of untreated dementia.	202 untreated outpatients with a diagnosis of Alzheimer disease. (age: mean 81.02 SD 6.08). *Convenience Sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure: Assessed by clinician.* *Dementia severity: FAST reliability in the 'good' range. Validity demonstrated (0)* *No definition of aggression. No specific aggression measure (0)*	Cross-sectional *Potential confounds not discussed (0)* *Does not address causal relationship (0)*	*Group comparison using Chi-square test (2)* *No report on missing data (0)*	Incidents of physical aggression increased in frequency as severity of AD increased. *Findings supported by one result only (0)*	Dementia severity *(3) 'Low'*
Herrmann et al., 2004, Canada To investigate whether central noradrenergic activity is related to physically aggressive behaviours in AD.	15 long-term care residents from two facilities with a diagnosis of AD. (age: mean: 81:5 SD 5:5). *Convenience Sampling (0)* *Sample size below minimum for achieving adequate power (0)*	*Aggression measures:* CMAI *reliability in the 'acceptable' range. Validity demonstrated.* *r-OAS reliability in the 'acceptable' range. Validity demonstrated* *Noradrenergic activity: The clonidine challenge test (1)* *No definition of aggression. Measure of aggression frequency (1)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using multiple regression (2)* *No report on missing data (0)*	Scores of physical aggression were significantly higher for those with a blunted growth hormone response, indicating altered central noradrenergic activity. *Findings supported by one result only (0)*	Neurotransmission *(6) 'Low'*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Holtzer et al., 2003, USA To examine the correlates between cognitive status and psychopathological features in patients with AD.	236 outpatients with a diagnosis of AD at baseline. (age: mean 72.7 SD 9.2). 48 participants remained at 5 year follow-up. *Convenience Sampling (0)* *Sample size below minimum for achieving adequate power (0)*	*Aggression measure: CUSPAD reliability in the ‘’good’ to ‘excellent’ range. Validity demonstrated* *Dementia severity: MMSE reliability in the ’good’ range. Validity demonstrated (2)* *No definition of aggression. Measure of aggression (1)*	Longitudinal *Limited control of potential confounds (1)* *Does not address causal relationship (0)*	*Correlational using Markov analysis (2)* *Large amount of missing data addressed (2)*	Aggression tended to increase as a function of disease course and reduction in cognitive function. *Findings supported by more than one result (2)*	Dementia severity *(10) ‘Medium’*
Husebo et al., 2011[1] & 2014[2], Norway To determine whether a systematic approach to pain treatment can reduce agitation in people with dementia living in nursing homes.	352 residents with a diagnosis of dementia, From 60 nursing homes, control (n=177; age: mean 87 range 67-104), intervention (n=175; age: mean 85 range 65-101). *Randomised cluster sample (2)* *Power calculation reported: 95% power at 5% significance to detect 25% difference in the change (2)*	*Aggression measures: NPI reliability in the ‘good’ range. Validity demonstrated. CMAI reliability in the ‘acceptable’ range. Validity demonstrated.* *Pain measure: MOBID Pain reliability in the ‘good’ range. Validity demonstrated (2)* *Definition of aggression. Measure of aggression/agitation severity and frequency (0)*	Random assignment, plus blinding procedures. *Range of potential confounds addressed (2)* *Causal relationship investigated* (2)	*Group comparison using ANCOVA and linear random intercept model (2)* *Large amount of missing data addressed statistically (2)*	There was a significant association between pain and verbal agitation/aggression in favour of treatment[1]. Findings remained significant for verbal aggression only[2]. *Findings supported by one result only (0)*	Pain *(16) ‘High’*
Kitamura et al., 2012, Japan To clarify whether NCS show gender differences in manifested symptoms and outcomes.	292 inpatients with a diagnosis of dementia. *Convenience Sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure: Behave-AD reliability in the ‘excellent’ range. Validity demonstrated (2)* *Definition of aggression. Measure of aggression (2)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using logistic regression (2)* *No report on missing data (0)*	Men were more likely to exhibit aggression compared to women. *Findings supported by one result only (0)*	Gender *(9) ‘Medium’*

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Ko et al., 2012, Japan To examine experiences of aggressive behaviour exhibited by dementia clients aged toward staff in long-term hospital care.	170 nurses and care staff working on dementia wards. Age 19-67 (mean 36.9 SD 12.3). *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure, and care environment: custom questionnaire. No validity or reliability stated for custom questionnaire.* *Staff Burn-out: MBI reliability in the 'acceptable' range. Validity demonstrated (0)* *No definition of aggression. No specific measure of aggression (0)*	Cross-sectional *Potential confounds not discussed (0)* *Does not address causal relationship (0)*	*Group comparison using Mann-Whitney U-test, Chi-Squared and Fisher's (2)* *Complete data sets required in inclusion criteria (2)*	Those fostering a trusting relationship, spending adequate time and gaining consent were less likely to experience aggression. Those experiencing burnout, working numerous night shifts and being in charge of a larger number of clients were more likely to experience aggression. *Findings supported by one result only (0)*	Care-recipient – caregiver relationship Caregiver-factors *(5) 'Low'*

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Kunik et al., 2010, USA To examine factors predicting the development of aggression.	171 veterans from primary care and geriatric outpatients, with a recent diagnosis of dementia. (age: mean 76 SD 6.2). *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure:* *CMAI reliability in the 'acceptable' range. Validity demonstrated.* *Pain measure: PGCPIS reliability in the 'acceptable' range. Validity demonstrated.* *Depression: HDRS reliability in the ''good' range. Validity demonstrated.* *Psychosis: NPI reliability in the ''good' range. Validity demonstrated.* *Social stimulation: PEASAD reliability in the ''good' range. Validity demonstrated.* *Caregiver burden measure: BI reliability in the ''good' range. Validity demonstrated.* *Quality of relationship: MScale reliability in the 'very good' range. No validity data available (1)* *Definition of aggression. Measure of aggression frequency (2)*	Longitudinal *Range of potential confounds addressed (2)* *Attempts to address causal relationship (1)*	*Correlational using linear regression (2)* *No report on missing data (0)*	Higher levels of caregiver burden, worse pain, depression, increases in delusions, and decline in mutuality were associated with risk of aggression. *Findings supported by one result only (0)*	Caregiver factors Pain Care-recipient – caregiver relationship Depression Delusions Social stimulation^{NS} Hallucinations^{NS} *Gender*^{NS} *Age*^{NS} *Ethnicity*^{NS} *(9) 'Medium'*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Lai et al., 2003[1], 2010[2], & 2011[3], Singapore To measure the serotonergic receptors and hippocampus changes of a cohort of behaviorally assessed AD patients.	24-33 community-based UK Participants with a diagnosis of AD. Aged 64-98 years (mean 81). 14-20 age matched controls[1&3] *Convenience Sampling (0)* *Sample size below minimum for achieving adequate power (0)*	*Aggression measure: PBE reliability in the 'acceptable' range. No validity information available.* *Neuro-chemical and brain region changes using post-mortem tissue. Assessed using established methods (1)* *Definition of aggression. Measure of aggression (2)*	Cross-sectional[1] and longitudinal[2,3], plus blinding procedures[1,2]. *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using multiple regression (2)* *No report on missing data (0)*	Reduced seretonergic (5HT1A) receptor binding densities predicted aggression in a subgroup of AD participants with severe aggression compared to controls and AD participants with mild aggression[1]. serotonin re-uptake sites (5-HTT) were preserved or up-regulated in patients with aggression[2]. Increased tangle load, but no other hippocampal variables (atrophy, cell loss), were associated with increased severity of aggression and presence of chronic aggression[2]. *Findings supported by one result only (0)*	Neurotransmission Brain region *(7) 'Medium'*
Lanctot et al., 2002,USA To test the hypothesis that reduced serotenergic activity is related to aggression in patients with AD.	22 long-term inpatients (aggression n=11, non-aggression =11) with a diagnosis of dementia. (age: mean 82.2 SD 6.4). *Convenience sampling (0)* *Sample size below minimum for achieving adequate power (0)*	*Aggression measures: BEHAVE-AD reliability in the 'excellent' range. Validity demonstrated.* *Serotenergic activity:Fenfluramine challenge test reliability in the 'acceptable' range (2)* *No definition of aggression. Measure of aggression severity and frequency (1)*	Cross-sectional, plus blinding procedures. *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using Spearman's.rank and multiple regression (2)* *Complete data set required in inclusion criteria (2)*	The agitation/ aggression group had an increased response compared to the non-aggressive group indicating serotenergic hyper-responsivity. This response was found to be greater for females with aggression. *Findings supported by one result only (0)*	Neurotransmission *(9) 'Medium'*

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Lanctot et al., 2004,USA To examine the relationship between regional brain perfusion and aggression in dementia.	49 outpatients with a diagnosis of AD. (age: mean: 74 SD 10.7). *Convenience Sampling (0)* *Sample size below minimum for achieving adequate power (0)*	*Aggression measure (plus other variables): Behave-AD reliability in the 'excellent' range. Validity demonstrated.* *Dementia severity: MMSE reliability in the 'good' range. Validity demonstrated.* *Regional blood flow measure: single-photon emission computed tomography (2)* *No definition of aggression. Measure of aggression (1)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using multiple regression (2)* *No report on missing data (0)*	Associations of aggression were decreased blood flow though the hippocampus and amygdala regions, younger age, greater activity disturbance, and less cognitive impairment. *Findings supported by one result only (0)*	Brain region Age Non-aggressive agitation Dementia severity Gender^{NS} Delusions^{NS} Hallucinations^{NS} Anxiety^{NS} Sleep disturbance^{NS} *(7) 'Medium'*
Leonard et al., 2006, USA To determine potentially modifiable resident characteristics that are associated with physical and verbal aggression.	*306045 nursing home residents with a diagnosis of dementia. Aged 60+ (*mean *82.2 SD 6.4)* *Representative sample (1)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure and all other variables derived from the MDS. Reliability in the 'acceptable' range. Validity demonstrated (1)* *Definition of aggression. Measure of aggression frequency (2)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using logistic regression (2)* *Complete data sets required in inclusion criteria (2)*	Presence of depression, delusions, hallucinations and constipation were associated with aggressive behaviour. *Findings supported by one result only (0)*	Depression Delusions Hallucinations Constipation Pain^{NS} Infection^{NS} *(11) 'Medium'*

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Lopez et al., 2003, USA To examine the relationships among common symptoms of AD.	1155 (438 mild, 563 moderate, 154 severe) outpatients with a diagnosis of AD. *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure and all other variables not otherwise specified: CERAD-BRS reliability ranging from 'good' to 'excellent'. Validity demonstrated* *Depression: HDRS reliability in the ''good' range. Validity demonstrated.* *Dementia severity: MMSE reliability in the 'good' range. Validity demonstrated. (2)* *No definition of aggression. Measure of aggression frequency (1)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using logistic regression (2)* *No report on missing data (0)*	Aggression in those with: mild AD was associated with agitation, emotional lability, uncooperativeness; moderate AD was associated with delusions, hallucinations and uncooperativeness; severe AD was associated with agitation, emotional lability, uncooperativeness, delusions, and hallucinations. *Findings supported by one result only (0)*	Dementia severity Care approach Delusions Hallucinations Non-aggressive agitation Emotional lability Gender^{NS} Anxiety^{NS} Sleep disturbance^{NS} Depression^{NS} *(8) 'Medium'*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Majic et al., 2012, Germany To investigate the correlates of dementia associated agitation and depression.	304 nursing home residents with a dementia diagnosis. (age: mean 81.6 SD 10.5) *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure: CMAI reliability in the 'acceptable' range. Validity demonstrated.* *Dementia severity: MMSE reliability in the 'good' range. Validity demonstrated.* *Depression measure: DMAS reliability in the 'acceptable range'. Validity demonstrated (1)* *Definition of aggression. Measure of aggression frequency (2)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Group comparison using factor analysis and chi-square (2)* *No report on missing data (0)*	Physically aggressive and verbally agitated behaviours (in women) increased with dementia level of cognitive impairment and were associated with symptoms of depression. *Findings supported by one result only (0)*	Dementia severity Depression Age^{NS} *(8)'Medium'*
Matthews et al., 2002, UK To investigate the relationships between changes in the noradrenergic system and the presence of and NCS.	46 community-based individuals with a diagnosis of dementia (age: mean 81 SD 1) and 33 elderly controls (age: mean 74 SD 2). Convenience Sampling (0) Sample size below minimum for achieving adequate power (0)	*Aggression measure: PBE reliability in the 'acceptable' range. No validity information available.* *Neuro-chemical and brain region changes using post-mortem tissue. Assessed using established methods (1)* *Definition of aggression. Measure of aggression (2)*	Longitudinal, plus blinding procedures. *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using multiple regression (2)* *No report on missing data (0)*	Neuron loss from the Locus Coeruleus was associated with aggression. There was no association of noradrenergic activity. *Findings supported by one result only (0)*	Brain region Neurotransmission^{NS} (7) 'Medium'
Miu et al., 2014, China To investigate associates of pain in individuals with dementia residing in nursing homes.	309 nursing home residents with a diagnosis of dementia (55 with physical aggression). (age: mean 85 SD 7.5). *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measures: Assessed by care giver.* *Pain measure: PAINAD-C reliability ranging from 'acceptable' to 'good'. Validity demonstrated (0)* *No definition of aggression. No specific measure of aggression (0)*	*Cross-sectional* *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using logistic regression (2)* *No report on missing data (0)*	The presence of physical aggression was independently associated with the prevalence of pain. *Findings supported by one result only (0)*	Pain *(5) 'Low'*

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Moran et al., 2005, Ireland To determine the prevalence and correlates of sleep disturbance in a memory clinic population of AD Patients.	224 Individuals with a diagnosis of AD (non-sleep disturbed N=169, sleep disturbed N=55) were recruited via a national referral centre for people with memory difficulties. (age: mean 74.91 SD 7.74) *Convenience Sampling (0)* *Sample size below minimum for achieving adequate power (0)*	*Aggression and Sleep disturbance measure: Behave-AD reliability in the 'excellent' range. Validity demonstrated (2)* *No definition of aggression. Measure of aggression (1)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using logistic regression (2)* *No report on missing data (0)*	Sleep disturbance (repetitive awakenings) was independently associated with agitation/aggression. *Findings supported by one result only (0)*	Sleep disturbance *(7) 'Medium'*
Morgan et al., 2013, USA To examine factors predicting development of aggression in patients with dementia.	171 veterans from primary care and geriatric outpatients, with a recent diagnosis of dementia. (age: mean 75.81 SD 6.19). *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression and agitation measure: CMAI reliability in the 'acceptable' range. Validity demonstrated (1)* *Definition of aggression. Measure of aggression frequency (2)*	Longitudinal *Range of potential confounds addressed (2)* *Attempts to address causal relationship (1)*	*Correlational using latent variable model (2)* *No report on missing data (0)*	Changes in baseline non-aggressive agitation predicted the onset of aggression. *other findings reported in Kunik et al., 2010 *Findings supported by one result only (0)*	Non-aggressive agitation *(9) 'Medium'*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
O'Leary et al., 2005, USA To determine whether conduct problems predict physical aggression against caregivers by dementia patients relates to the level of cognitive impairment.	198 geriatric outpatients with a diagnosis of dementia aged (AD 55%), VaD (14%), MXD (3%), Other (28%) and their caregivers. Mean age 78y. *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression and agitation measure:* CMAI *reliability in the 'acceptable' range. Validity demonstrated.* *Dementia severity: MMSE reliability in the 'good' range. Validity demonstrated.* *Depression: GDP reliability in the 'good' range. Validity demonstrated.* *Premorbid personality: Caregiver interview (0)* *Definition of aggression. Measure of aggression frequency (2)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using Spearman's rank (2)* *No report on missing data (0)*	Physical aggression against a partner was more likely if the patient had a history of conduct disorder, was male, exhibited non-aggressive agitation, or had a moderate level of cognitive impairment. *Findings supported by one result only (0)*	Dementia severity Premorbid conduct disorder Gender Non-aggressive agitation Depression^{NS} Type of dementia^{NS} *(7) 'Medium'*
Orengo et al., 2002, USA. To test the hypotheses that testosterone levels relate to aggression and that aggression is inversely related to oestrogen levels	50 male care home residents aged with a diagnosis of dementia (AD n=31, VaD n=14, MXD n=3, other n=2). (age: mean 76. SD 5) *Convenience sample (0)* *Power level calculated at 80% (2)*	*Aggression measures: OAS reliability in the 'good' range. Validity demonstrated.* *CMAI reliability in the 'acceptable' range. Validity demonstrated.* *Hormones: Assays performed using established methods (1)* *Definition of aggression. Measures of aggression frequency (2)*	Cross-sectional, plus blinding procedures. *Limited control of potential confounds (1)* *Does not address causal relationship (0)*	*Correlation and linear regression (2)* *No report on missing data (0)*	Testosterone was positively correlated and oestrogen was negatively correlated with aggression in men. Testosterone, however accounted for only 21% of variance in aggression. *Findings supported by one result only (0)*	Hormone *(8) 'Medium'*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Pritchard et al., 2007a[1], 2007b[2], 2008a[3], 2008b[4], 2009[5], UK To investigate the role of genetic determinants of NCS in AD.	367-395 individuals with a diagnosis of AD recruited via memory clinics during a clinical trial study (age at baseline: mean 74.4 SD 6.99). *Convenience sample (0)* *Power level reported at 80% to detect effect size of 1.65-2.07(2)*	*Genotyping: polymerase chain reaction.* *Aggression measure: NPI reliability and validity in the 'good' range (2)* *No definition of aggression. Measure of aggression frequency (1)*	*Longitudinal* *Limited control of potential confounds (1)* *Does not address causal relationship (0)*	*Correlational using logistic regression and linear regression (2)* *Missing data addressed statistically (2)*	No significant association with APOE variants (ε2/ ε 3/ ε 4)[1], serotonin transporter gene[2], *5HT2A and 5HT2C[3], dopaminetransporter gene[4], or dopamine receptor genes[5].* *Findings supported by one result only (0)*	Genotype^{NS} *(10) 'Medium'*
Somboontanont et al., 2004, USA To identify immediate antecedants of bathing-related physical assaults against caregivers by residents with AD.	18 nursing care residents with a dementia diagnosis. Aged 65 – 96 (mean 87.1 SD 9) *Convenience sample (0)* *Sample size below minimum for achieving adequate power (0)*	*Aggression and all other variables obtained via observation of video-taped bathing. Inter-rater reliability in the 'good' range (1)* *Definition of aggression. Measure of aggression frequency (2)*	Cross-sectional *Limited control of potential confounds (1)* *Does not address causal relationship (0)*	*Correlational using lag sequential analysis (2)* *No report on missing data (0)*	Physically assaultive behaviour was associated with: confrontational communication, absence of restraint, physical contact, presence of multiple caregivers, and lack of verbal prompt. *Findings supported by one result only (0)*	Care approaches Caregiver factors Environment^{NS} *(6) 'Low'*
Talerico et al., 2002, USA. To examine associations of aggression in older adults with dementia.	405 nursing home residents. (age: mean 84.8 SD 7.19). *Convenience sample (0)* *Power reported at 96% at alpha 0.5 to detect R^2 0.17 (for physical aggression)* *Power reported at 72% at alpha 0.5 to detect R^2 0.11 (for verbal aggression) (2)*	*Aggression and other variables: PGDRS reliability in the 'good' range. Validity demonstrated.* *Depression measure: CSDD reliability ranging from 'good' to 'excellent'. Validity demonstrated (2)* *Definition of aggression. Measure of aggression severity and frequency (2)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using hierarchical regression (2)* *No report on missing data (0)*	Higher levels of physical aggression were associated with depression, impaired communication, use of physical restraint and antipsychotic medication. Higher levels of verbal aggression were associated with impaired communication, severity of disorientation and antipsychotic medication. *Findings supported by one result only (0)*	Depression Communication Care approaches Disorientation Anti-psychotic medication *(10) 'Medium'*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Treiber et al., 2008, USA To examine associations between vascular conditions, APOE ε4, and neuropsychiatric symptoms in AD.	254 individuals with a diagnosis of AD. Aged 68-89 (mean 85.68 SD 6.62). *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure: NPI reliability in the 'good' range. Validity demonstrated.* *Dementia severity measure: CDR reliability in the 'excellent' range. Validity demonstrated.* *Genotyping: Using standard method.* *Vascular conditions: Medical notes and examination (2)* *No definition of aggression. Measure of aggression/agitation severity and frequency (0)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using logistic regression (2)* *No report on missing data (0)*	Hypertension was associated with aggression/agitation. No other vascular conditions were found to be significant (e.g. diabetes, heart attack, stroke). *Findings supported by one result only (0)*	Physical health Age^{NS} Dementia severity^{NS} Genotype^{NS} Education^{NS} *(7) 'Medium'*
Trzepacz et al., 2013, USA To examine the neuroanatomy of agitation and aggression in Alzheimer's disease and MCI.	462 participants recruited via the ADNI program (data available to scientific community). (177 MCI; age: mean 74.4 SD 7.8 range 55–88), 122 MCI-converts to AD; age: mean 74.6 SD 6.9 range 55–89), 163 AD; age: mean 75.3 SD 7.5 range 57–91) *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure: NPI reliability in the 'good' range. Validity demonstrated.* *Dementia severity: MMSE reliability in the 'good' range. Validity demonstrated.* *Neuroanatomy: MRI (2)* *Definition of aggression. Measure of aggression/agitation severity and frequency (0)*	Longitudinal *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlation using Spearman's and mixed effects repeated measures model (2)* *Missing data addressed statistically (2)*	Greater atrophy of frontal, insular, amygdala, cingulate, and hippocampal regions were associated with greater severity of agitation/aggression in the AD and MCI-convert groups. Aggression and agitation increased with increased severity of cognitive impairment. *Findings supported by one result only (0)*	Brain regions Dementia severity *(9) 'Medium'*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Van Der Flier et al., 2007, Netherlands To investigate differences in behavioural symptoms in Alzheimer disease according to APOE.	110 people with a diagnosis of Alzheimer’s from a memory clinic. Ages by group (Ɛ4 negative, mean 71 SD 10; Ɛ4 heterozygous, mean 70 SD 8; Ɛ4 homozygous, mean 69 SD 7). *Convenience sampling (0)* *Sample size below minimum for achieving adequate power (0)*	*Genotyping: Light CyclerAPOE mutation detection method.* *Aggression measure: NPI reliability in the ’good’ range. Validity demonstrated (2)* *No definition of aggression. Frequency and severity of agitation/ aggression measured (0)*	Cross-sectional *Limited control of potential confounds (1)* *Does not address causal relationship (0)*	*Group comparison using one-way ANOVA (2)* *No report on missing data(0)*	Severity of agitation/ aggression was greater for carriers of homozygous APOE Ɛ4 compared to heterozygous and non- carriers. *Findings supported by one result only (0)*	Genotype *(5) ‘Low’*
Vermeiren et al., 2014, Belgium To identify brain region-specific monoaminergic correlates of NCS in AD patients.	*40 individual with a diagnosis of dementia recruited from a memory clinic. Aged 49-96 years (mean: 75.7 SD 11.7).* *Convenience Sampling (0)* *Sample size below minimum for achieving adequate power (0)*	*Aggression measure: Behave-AD reliability in the ‘excellent’ range. Validity demonstrated* *Dementia severity: GDS reliability in the ‘good’ range. Validity demonstrated.* *Brain tissue sampling: Assessed using established methods (2)* *No definition of aggression. Measure of aggression (1)*	Cross-sectional *Limited control of potential confounds (1)* *Does not address causal relationship (0)*	*Correlational using Spearman’s and Bonferroni correction (2)* *Missing data not addressed (0)*	*Hippocampal serotonin levels inversely correlated with agitation/aggression but were positively correlated with dementia severity scores.* *No correlation found for any other monoamines (e.g. dopamine, norepinephrine),* *Findings supported by one result only (0)*	Neurotransmission Brain region Dementia severity 6 ‘Low’

Author, Publication Year, Country, Aim	**Participants *Recruitment strategy and sample size appropriate?***	**Data collection method *Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design *Control of variables? Causality addressed?***	**Analysis *Appropriate? Any missing data?***	**Main Findings *Robust results?***	**Factors *Overall Quality Rating***
Volicer et al., 2009, Netherlands To investigate modifiable factors related to abusive behaviours in nursing home residents with dementia.	929 residents with a dementia diagnosis from 10 residential and 8 nursing homes. Aged 65–102 (mean 84.5 SD 7.0). *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression and all other variables derived from the MDS. Reliability in the 'acceptable' range. Validity demonstrated (1)* *No definition of aggression. Frequency of aggression measured (1)*	Cross-sectional *Limited range of potential confounds addressed (1)* *Does not address causal relationship (0)*	*Correlational using logistic regression (2)* *Complete data sets required in inclusion criteria (2)*	Lack of understanding combined with resistiveness to care and depression were identified as risk factors for verbally and physically abusive behaviour. *Findings supported by one result only (0)*	Depression Communication Care approach Delusions^{NS} Hallucinations^{NS} Pain^{NS} Constipation^{NS} Gender^{NS} Dementia severity^{NS} *(8) 'Medium'*

Author, **Publication Year,** **Country,** **Aim**	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Whall et al., 2008, USA To explore background and proximal factors associated with aggressive Behaviour among nursing home residents with dementia.	107 residents from 9 nursing homes with a diagnosis of AD (n= or VaD. (age: mean 87.1 SD 6.5). *Convenience sampling (0)* *Power calculation reported at 80.5%* (2)	*Aggression measure: CMAI reliability in the 'acceptable' range. Validity demonstrated.* *Dementia severity: MMSE reliability in the 'good' range. Validity demonstrated.* *Sleep quality: Actigraphy.* *Physiological need: Observation with ''excellent' reliability achieved.* *Personality: NEO-FFI reliability in the 'good' range. Validity demonstrated (1)* *Definition of aggression. Frequency of aggression measured (2)*	Cross-sectional, plus blinding procedures. *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using logistic regression (2)* *No report on missing data (0)*	Shower/ bath events was significantly associated with aggression, risk factors increasing the likelihood of aggression were gender, level of cognitive impairment, past non-agreeableness, and a longer night time sleep. *Findings supported by one result only (0)* .	Bathing Premorbid personality Gender Dementia severity Sleep disturbance Physical Health^{NS} Physiological need^{NS} Care approach^{NS} *(9) 'Medium'*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Xing et al, 2012, China To investigate associations between NCS and testosterone in AD patients.	173 outpatients with a diagnosis of AD (male n=86, female n=87), aged 65+. *Convenience Sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure: NPI reliability in the 'good' range. Validity demonstrated.* *Genotype: Restriction enzyme digestion approach.* *Hormones: Assays performed using established methods (2)* *No definition of aggression. Measure of agitation/aggression frequency and severity (1)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using logistic regression (2)* *No report on missing data (0)*	Estradiol (an oestrogen hormone) was negatively correlated with agitation/aggression among male patients, and the testosterone was positively correlated with agitation/aggression among female patients. Female patients with higher levels of estradiol or testosterone and carrying the APOE ε4 allele had higher frequencies of agitation/aggression. *Findings supported by one result only (0)*	Hormones Genotype *(8) 'Medium'*
Zeisel et al., 2003, USA To measure associations between environmental design of AD special care units and incidence of aggression and other factors, among residents.	427 residents across 15 AD special care units. Aged 53 - 102 (M 81.14 SD 7.8). *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure: CMAI reliability in the 'acceptable' range. Validity demonstrated.* *Environmental factors: Assessed by researchers. No reliability reported. (0)* *Definition of aggression. Frequency of aggression measured (1)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using hierarchical linear model (2)* *No missing data (2)*	A higher staff ratio was associated with less verbal aggression only. Male residents and those with a greater likelihood of falls were more likely to exhibit aggression. A more institutional environment positively correlated with verbal aggression. A range of other environmental factors were not found to be significant (e.g. access to gardens, privacy) *Findings supported by one result only (0)*	Environment Caregiver factors Gender *(8) 'Medium'*

Author, Publication Year, Country, Aim	**Participants** ***Recruitment strategy and sample size appropriate?***	**Data collection method** ***Reliability and Validity of measures? Robust definition and measurement of aggression?***	**Design** ***Control of variables? Causality addressed?***	**Analysis** ***Appropriate? Any missing data?***	**Main Findings** ***Robust results?***	**Factors** ***Overall Quality Rating***
Zuidema et al., 2009, Holland. To assess the influence of gender and dementia severity on neuropsychiatric symptoms of dementia.	1319 individuals with a diagnosis of dementia, recruited from 26 nursing homes. Aged 36 – 102 (mean 83 SD 8.1). *Convenience sampling (0)* *Sample size above minimum for achieving adequate power (1)*	*Aggression measure: CMAI reliability in the 'acceptable' range. Validity demonstrated.* *Dementia severity: GDS reliability in the 'good' range. Validity demonstrated (1)* *No definition of aggression. Frequency of aggression measured (1)*	Cross-sectional *Range of potential confounds addressed (2)* *Does not address causal relationship (0)*	*Correlational using logistic regression (2)* *No report on missing data (0)*	Aggression prevalence increased with severity of dementia. Physical aggression was more prevalent in male patients. Verbal aggression was more frequent in female patients. *Findings supported by one result only (0)*	Dementia severity Gender *(7) 'Medium'*

RESULTS

63 articles were selected for evaluation. After combining articles that used the same dataset, there were 50 studies represented in the data extraction table.

Summary of evaluations

Quality

Most studies fell within the medium quality range (n=33), low quality studies made up the next largest group (n=16), leaving the remaining high quality paper (n=1) as a relative outlier.

Location

Studies took place in USA and Canada (n=24); UK and Ireland (n=5); Rest of Europe (n=12); Asia (n=7); and Australia (n=2).

Age

Age reporting was inconsistent, some articles did not state participants' age (n=3), and so no standard format could be maintained in the evaluation summary. No studies investigated early onset dementia exclusively. In cases where younger adults (<65) were included (n=12), they only made up a small proportion of the overall sample.

Setting and sampling

Recruitment settings were primarily residential/nursing care homes (n=20) and community outpatients (n=19). The remainder took place in specialist inpatient units (n=6), or did not clearly indicate the setting (n=5).

One study used random-cluster selection, and one other study obtained a representative sample. All others used convenience sampling (n=48). Of these, two studies employed large sample sizes that had more chance of being representative and generalisable, however, checks were not carried out to confirm this.

Number of participants and statistical power

Statistical power calculations were used infrequently (n=7). In each case, adequate power was achieved. A large proportion of studies (n=25) employed samples sizes above the minimum to detect a medium effect size for correlation/ regression analysis, with alpha set at .05 and power at 80% (see Appendix 3 for details). However, many studies were underpowered (n=18). This presents particular issues for interpretation of non-significant findings.

Study design and control of potential confounds

Cross-sectional design was typically used to address factors relating to aggression (n=39), meaning only the presence or absence of a correlation could be established. Some factors were, however addressed using a longitudinal method (n=11) and random assignment was used in two treatment studies (n=2).

Only two treatment studies met inclusion criteria. Both investigated effects of treating a potential contributing factor on rate of aggression, rather than treating aggression directly.

Only 10 studies reported use of blinding procedures, which involved data collection by researchers or clinicians who were blinded to the study hypothesis.

Control of potential confounds was evaluated in terms of exclusion criteria employed by the study, and in terms of variables that were addressed statistically. Most studies considered a range of potential confounds (n=31), such as co-morbid conditions, medication use, demographics, and level of cognitive impairment. The remaining studies had limited control of variables (n=16) or gave no indication of control for potential confounds (n=3).

Measures and definition of aggression

Few studies made reference to a definition of aggression (n=20); those that did typically referred to a list of example behaviours. Measures of aggression most often applied were the CMAI (n=18), NPI (n=12) and the BEHAVE-AD (n=6). Ten other standardised measures were employed and four studies used a customised measure.

Several studies reported a composite score for agitation/aggression (n=10). Studies that measured aggression independently, tended to record aggression frequency only (n=24), in contrast to measurement of both frequency and severity (n=2). Remaining studies only indicated that aggression was present during the time frame of interest (n=14).

Measurement tools were generally within the "acceptable" range for reliability (see Appendix 3 for descriptive categories), with evidence of validity for use in dementia.

Analysis

Only 16 studies reported on the issue of missing data. Seven of these reported no missing data, and nine reported missing data but did address the issue adequately. Correspondingly, it was unclear whether any data was missing or how it may have been addressed for most studies (n=34).

Most studies made use of appropriate statistical tests (n=49). Regression modelling was typically applied (n=28). However, a substantial amount of variance was unexplained, suggesting involvement of other factors not included in the model.

Synthesis of findings

A total of 36 potential contributing factors were investigated, and 31 had a significant association with aggression. To consider similar and related factors, they are clustered into 10 broad categories. Inevitably some overlap between sections exists. Table 1.3 provides a summary of findings, indicating the extent of support in terms of the number of studies finding a significant relationship, and the number finding no significant relationship. The table also compares findings of the current review with those of the two previous reviews (Hall & O'Connor, 2004; Cipriani et al., 2011).

Table 1.3 Summary of significant and non-significant factors

Category (*Factors*)	Factor dimensions	Studies reporting a significant relationship*				Studies reporting a non-significant relationship*			Predicted findings**
		Quality of study			Total	Quality of study		Total	
		High	Med	Low		Med	Low		
Dementia Severity									
Dementia Severity±			11	3	**14**	4	-	**4**	S
Physical health									
Pain		1	2	1	**4**	2	-	**2**	S
Infection		-	-	-	**-**	1	-	**1**	S
General physical health		-	2	-	**2**	1	-	**1**	S
Constipation		-	1	-	**1**	1	-	**1**	-
Physiological Function									
Sleep disturbance¥		-	3	-	**3**	3	-	**3**	-
Circadian regulation		-	-	1	**1**	-	-	**-**	NS
Physiological need		-	-	-	**-**	2	-	**2**	-
Biomolecules									
Neurotransmission		-	3	3	**6**	1	-	**1**	-
	Altered serotonin activity	-	*(2)*	*(2)*	***(4)***	-	-	**-**	S
	Altered cholinergic activity	-	-	*(1)*	***(1)***	-	-	**-**	-
	Altered dopaminergic activity	-	*(1)*	-	***(1)***	-	-	**-**	-
	Altered noradrenergic activity	-	-	*(1)*	***(1)***	*(1)*	-	***(1)***	-
Hormones		-	2	-	**2**	1	-	**1**	-
	Testosterone	-	*(2)*	-	***(2)***	*(1)*	-	***(1)***	-

Category (*Factors*)	**Factor dimensions**	**Studies reporting a significant relationship***				**Studies reporting a non-significant relationship***			**Predicted findings*** ***
		Quality of study			**Total**	**Quality of study**		**Total**	
		High	**Med**	**Low**		**Med**	**Low**		
	Oestrogen	**-**	*(2)*	-	***(2)***	*(1)*	-	***(1)***	-
CSF biomarkers		**-**	1	-	**1**	1	-	**1**	-
	Ab42	**-**	*(1)*	-	***(1)***	-	-	**-**	-
	Tau	**-**	-	-	**-**	*(1)*	-	***(1)***	-
	P-Tau181	**-**	-	-	**-**	*(1)*	-	***(1)***	-
Neurology									
Type of dementia		**-**	2	2	**4**	1	-	**1**	-
	AD	**-**	*(1)*	-	***(1)***	*(1)*	-	***(1)***	-
	VaD	**-**	-	*(1)*	***(1)***	*(1)*	-	***(1)***	-
	FTD	**-**	*(1)*	*(1)*	***(2)***	*(1)*	-	***(1)***	S
Brain region		**-**	5	1	**6**	-	-	**-**	-
	Hippocampus	**-**	*(3)*	*(1)*	***(4)***	-	-	**-**	S
	Amygdala	**-**	*(2)*	-	***(2)***	-	-	**-**	S
	Frontal lobes	**-**	*(2)*	-	***(2)***	-	-	**-**	S
	Locus Coeruleus	**-**	*(1)*	-	***(1)***	-	-	**-**	-
	Cingulate cortex	**-**	*(1)*	-	***(1)***	-	-	**-**	-
	Insular cortex	**-**	*(1)*	-	***(1)***	-	-	**-**	-
Genotype									
Genotype		**-**	2	2	**4**	3	-	**3**	-
	APOE	**-**	*(2)*	*(2)*	***(4)***	*(3)*	-	***(3)***	-
	5-HT	**-**	*(1)*	-	***(1)***	*(1)*	-	***(1)***	-
	Tryptophan	**-**	-	*(1)*	***(1)***	-	-	**-**	-

Category (*Factors*)	**Factor dimensions**	**Studies reporting a significant relationship***				**Studies reporting a non-significant relationship***			**Predicted findings****
		Quality of study			**Total**	**Quality of study**		**Total**	
		High	**Med**	**Low**		**Med**	**Low**		
	PRND	-	-	*(1)*	***(1)***	-	-	-	-
	Dopamine	-	-	-	-	*(1)*	-	***(1)***	-
Demographics									
Gender		-	7	1	**8**	5	-	**5**	-
	Male	-	*(6)*	*(1)*	***(7)***	*(5)*	-	***(5)***	S
	Female (verbal aggression)	-	*(2)*	-	***(2)***	*(5)*	-	***(5)***	-
Age		-	2	-	**2**	3	-	**3**	-
Education		-	-	-	-	2	-	**2**	-
Ethnicity		-	-	-	-	2	-	**2**	-
Behaviour and mental health									
Depression		-	5	-	**5**	2	-	**2**	S
Anxiety		-	-	-	-	3	-	**3**	-
Affect		-	2	-	**2**	-	-	-	-
Emotional lability		-	2	-	**2**	-	-	-	-
Psychotic Symptoms		-	3	-	**3**	2	-	**2**	-
	Hallucinations	-	*(2)*	-	**(2)**	*(3)*	-	**(3)**	S
	Delusions	-	*(3)*	-	**(3)**	*(2)*	-	**(2)**	S
Non-aggressive agitation		-	4	-	**4**	-	-	-	-
Pre-morbid personality		-	2	-	**2**	-	-	-	-
	Past agreeableness	-	*(1)*	-	**(1)**	-	-	-	-
	Pat non-agreeableness	-	*(1)*	-	**(1)**	-	-	-	-
Pre-morbid conduct disorder		-	1	-	**1**	-	-	-	-

Category (*Factors*)	Factor dimensions	Studies reporting a significant relationship*				Studies reporting a non-significant relationship*			Predicted findings**
		Quality of study			Total	Quality of study		Total	
		High	Med	Low		Med	Low		
Anti-psychotic medication		-	1	-	**1**	-	-	-	-
Disorientation		-	1	-	**1**	-	-	-	-
PTSD		-	-	-	-	-	1	**1**	-
Environment and care activities									
Environment		-	2	1	**3**	2	1	**3**	M
	Institutionalised/ high secure unit	-	*(1)*	*(1)*	**(2)**	-	-	-	-
	Environmental conditions (e.g. temperature, noise, lighting)	-	-	-	-	*(2)*	*(1)*	**(3)**	-
Care events		-	1	-	**1**	2	-	**2**	-
	Bathing	-	*(1)*	-	**(1)**	-	-	-	-
	Other direct care events (e.g. dressing, mealtimes)	-	-	-	-	*(1)*	-	**(1)**	-
	Non-direct care (e.g. time spent in communal space)	-	-	-	-	*(1)*	-	**(1)**	-
Care Approach		-	4	1	**5**	1	-	**1**	-
	Confrontation	-	-	*(1)*	**(1)**	-	-	-	-
	Restraint/ confined	-	*(3)*	-	**(3)**	-	-	-	-
	Resistance	-	*(1)*	-	**(1)**	-	-	-	S
	Caregiver behaviour (e.g. facial expressions, body movements)	-	-	-	-	*(1)*	-	**(1)**	-

Category (*Factors*)	Factor dimensions	Studies reporting a significant relationship*				Studies reporting a non-significant relationship*			Predicted findings**
		Quality of study			Total	Quality of study		Total	
		High	Med	Low		Med	Low		
Interpersonal factors									
Relationship quality		-	1	1	**2**	1	-	**1**	S
Communication		-	2	-	**2**	-	-	-	S
Caregiver factors		-	2	2	**4**	-	1	**1**	-
	Staff ratio	-	*(1)*	*(1)*	***(2)***	-	-	-	-
	Burden	-	*(1)*	-	***(1)***	-	-	-	S
	Burnout	-	-	*(1)*	***(1)***	-	-	-	-
	Characteristics (e.g. gender, years of experience)	-	-	-	-	-	*(1)*	***(1)***	-
Social stimulation		-	-	-	-	1	-	**1**	-

Key

± 11 studies found an increase in dementia severity was associated with an increase in aggression in line with predicted findings, 1 study reported findings in the opposite direction, 2 studies found a non-linear relationship with dementia severity.

¥ 2 studies found reduced sleep was associated with aggression, 1 study reported findings in the opposite direction.

** Figures in brackets indicate total findings for each factor dimensions*

*** Predicted findings based on previous reviews (Hall & O'Connor, 2004; Cipriani et al., 2011): S = significant, NS = non-significant, M = Mixed (some significant and some non-significant).*

Dementia severity

‘Level of cognitive impairment’ (based on a measure of cognition) and ‘dementia severity’ (usually based on a measure of functional and cognitive abilities) are related terms, and were often used interchangeably. For ease of comparison within this review, only the term ‘dementia severity’ has been used.

Dementia severity was frequently investigated and there was good support for an association with aggression. According to eleven studies (8 medium, 3 low quality) aggression had a linear relationship with dementia severity (Ahn & Horgas, 2013, 2014; Bidzan, Bidzan, & Pachalska, 2012; Cooke, Moyle, Shum, Harrison, & Murfield, 2010; Hamuro et al., 2006; Holtzer et al., 2003; Lopez et al., 2003; Majic et al., 2012; Trzepacz et al., 2013; Vermeiren, Van Dam, Aerts, Engelborghs, & De Deyn, 2014; Whall et al., 2008; Zuidema, de Jonghe, Verhey, & Koopmans, 2009). One medium quality study found a relationship in the opposite direction (Lanctot et al., 2004). Two medium quality studies found a non-linear relationship, and only moderate levels of dementia severity were associated with aggression (D'Onofrio et al., 2012; O'Leary, Jyringi, & Sedler., 2005). Four medium quality studies found no association for dementia severity (Beck et al., 2011; de Jonghe-Rouleau, Pot, & de Jonghe, 2005; Treiber et al., 2008; Volicer, Van der Steen, & Frijters, 2009).

These results suggest the likelihood of exhibiting aggression increases with disease progression, although most studies with this finding excluded those with the most severe dementia. So it is possible that aggression could subside at the later stage, when, for some, mobility and communication are further diminished.

Physical Health

A variety of physical health factors were investigated. Pain was most consistently associated with aggression. However, no support was found for an association with general physical health status.

Pain

Four studies (1 high, 2 medium, and 1 low quality) found an association between pain and aggression, but two medium quality studies did not (Ahn & Horgas, 2013, 2014; Husebo, Ballard, Cohen-Mansfield, Seifert, & Aarsland., 2014; Kunik et al, 2010; Leonard, Tinetti, Allore, & Drickamer, 2006; Miu & Chan, 2014; Volicer et al., 2009). In their high quality study, Husebo et al. (2014) found treatment for pain significantly reduced incidents of aggressive behaviour, and following treatment withdrawal, an increase in aggression was noted lending further support to the association. In a follow-up analysis published subsequently, verbal and physical aggression were analysed separately and the effect only remained significant for verbal aggression.

Infection

One medium quality study found active infection increased aggression likelihood (Whall et al., 2008).

General physical health

Two medium quality studies (Beck et al., 2011; Treiber et al., 2008) found poorer general health increased aggression likelihood, but one medium quality study did not (Leonard et al., 2006). In their medium quality study, Treiber et al. (2008) examined associations between vascular conditions and aggression in a community sample diagnosed with AD. Hypertension was associated with aggression, increasing risk threefold.

Constipation

One medium quality study found the presence of constipation measured as a separate dimension from pain, increased likelihood of physical aggression in a representative sample of nursing home residents (Leonard et al., 2006). Another medium quality study found no association (Volicer et al., 2009).

Physiological Function

Findings were mixed for sleep and circadian regulation.

Sleep disturbance

Three medium quality studies found sleep disturbance increased aggression (Gehrman et al., 2003; Moran et al., 2005; Whall et al., 2008). Findings differed in direction of change; reduced sleep quality was associated with increased aggression in two studies (Gehrman et al., 2003; Moran et al., 2005); whereas Whall et al. (2008) reported residents having 30 minutes more sleep on average per night, were more likely to exhibit aggression during personal care. Three medium quality studies, found no evidence to support a relationship between aggression and sleep disturbance (Beck et al., 2011; Lanctot et al, 2004; Lopez et al., 2003).

Circadian Regulation

Circadian regulation helps maintain a normal sleep-wake cycle, and other cyclical biological processes. One low quality study found an association between aggression and altered circadian regulation (Etcher, Whall, Kumar, Devanand, & Yeragani, 2012).

Physiological need

There was no association between aggression and physiological need (e.g. thirst, hunger), according to two medium quality studies (Beck et al., 2011; Whall et al., 2008).

Biomolecules

Hormones and neurotransmitters are chemical messengers integral to regulation of bodily functions, including behaviour. On balance, findings support an association between aggression and variations in biomolecular function.

Neurotransmission

Six studies (3 medium, and 3 low quality) found an association between aggression and neurotransmission (Engelborghs et al., 2008; Garcia-Alloza et al., 2004, 2005; Herrmann, Lanctot, Eryavec, & Khan, 2004; Lai et al., 2003, 2011; Lanctot et al., 2002; Vermeiren et al., 2014). Low serotonin level, in particular, was identified as a risk factor for aggression. Other findings included changes in cholinergic function, increased activity in dopaminergic transmission, and altered noradrenergic activity. One medium quality study found no significant association for neurotransmission (specifically, noradrenergic activity - Matthews et al., 2002).

Hormones

Two medium quality studies investigated effects of sex hormones on aggression in dementia (Orengo, Kunik, Molinari, Wristers, & Yudofsk, 2002; Xing, Qin, Li, Jia, Jia, 2012). Higher levels of testosterone, and lower levels of oestrogen in both males and females were predictive factors of aggression (Orengo et al., 2002; Xing et al., 2012). One medium quality study found increasing oestrogen in males had no impact on behaviour (Hall, Keks, & O'Connor, 2005).

Cerebrospinal fluid biomarkers

Biomarkers can be used to measure risk and progression of certain diseases; several have been investigated for efficacy in differential diagnosis of dementia. One medium quality study found aggression was associated with low levels of cerebrospinal fluid amyloid b42

(CSF Ab42) for individuals with AD (but not FTD, MXD, or DLB). This study noted that a lower CSF Ab42 level was also associated with more severe cognitive impairment (Engelborghs et al., 2006a).

Neurology

While there can be substantial overlap, each type of dementia is associated with specific mechanisms of change occurring in different brain regions. Different parts of the brain are thought to be responsible for particular aspects of cognitive ability and behaviour. Correspondingly, changes in specific brain regions may be reflected in changes in the abilities or behaviour as dementia progresses. The amygdala and hippocampus found in the temporal region, for instance, play key roles in the modulation of memory and emotional behaviour (Vermeiren et al., 2014).

Results in the present review suggest a relationship between neurological change in specific regions and increased risk of aggression. In contrast, type of dementia was a less reliable predictor.

Dementia type

Four studies found an association between type of dementia and increased aggression. However, results were contradictory; one medium quality study found an association for AD but not VaD; one low quality study reported, in contrast, an association for VaD but not AD (Bandyopadhyay et al., 2014; D'Onofrio et al., 2012). Two studies found increased risk of aggression in FTD (1 medium, and 1 low quality) (Engelborghs et al., 2006c; Grochmal-Bach et al., 2009). One medium quality study reported no evidence to support dementia type as a factor in aggression (O'Leary et al., 2005).

Brain region changes

Six studies (5 medium, and 1 low quality) reported findings related to specific brain regions identified via brain imaging or post mortem samples (Engelborghs et al., 2006B; Lai, Chen, Hope, & Esiri., 2010; Lanctot et al., 2004; Matthews et al., 2002; Trzepacz et al., 2013; Vermeiren, Van Dam, Aerts, Engelborghs, & De Deyn, 2014). Changes in the temporal region, particularly the hippocampus and amygdala, were most often implicated as a factor associated with increased severity and frequency of aggression. Other regions found to be associated included the frontal lobes, locus coeruleus, insular and cingulate cortex.

Genotype

The term genotype relates to an individual's genetically inherited identity and, in this context, refers to a particular gene or set of genes that have been studied in order to test for genetic determinants of aggression in dementia. In the present review, findings were inconsistent.

Four studies (2 medium, and 2 low quality) found more frequent incidents of aggression for carriers of APOE Ɛ4 (Craig, Hart, McCool, McIlroy, & Passmore 2004b; Engelborghs et al., 2006c; Van Der Flier et al., 2007; Xing et al, 2012). In one medium quality study the association was only significant for individuals with FTD, and not for other types of dementia (AD, MXD, or DLB) (Engelborghs et al., 2006c). Three medium quality studies found no evidence to support an APOE association with aggression (Flirski, 2012; Pritchard et al., 2007a; Treiber et al., 2008).

Other significant findings relating to genotype were 5-HT2A receptor polymorphism (reported by 1 medium quality study), tryptophan hydroxylase C containing genotype (reported by 1 low quality study), and PRND 3'UTR polymorphism (reported by 1 low quality study) (Assal et al., 2004; Craig, Hart, Carson, McIlroy, & Passmore, 2004A; Flirski, 2012). Pritchard et al., (2007B, 2008A, 2008B, 2009) however, found no role of serotonin- or dopamine-related genes in aggression in dementia.

Demographics

Of all demographic variables investigated, gender was most often studied.

Gender

Six studies (5 medium, and 1 low quality) found aggression, or in one case ‘physical aggression only’, was more likely to be expressed by males (Craig et al., 2004a; Kitamura, Kitamura, Hino, Tanaka, & Kurata, 2012; O'Leary et al., 2005; Whall et al., 2008; Zeisel et al., 2003; Zuidema et al., 2009). Two medium quality studies found an association between female gender and an increased risk for verbal aggression (Beck et al., 2011; Zuidema et al., 2009). There were five studies of medium quality that found no relationship between aggression and gender (Cooke et al., 2010; Kunik et al., 2010; Lanctot et al., 2004; Lopez et al., 2003; Volicer et al., 2009).

Age

Two medium quality studies found an association between age and aggression likelihood. In both cases, younger individuals were at greater risk (Beck et al., 2011; Lanctot et al., 2004). Three medium quality studies reported no significant relationship for age (Kunik et al., 2010; Majic et al., 2012; Treiber et al., 2008).

Education and ethnicity

Years of education and ethnic background were not predictive factors for aggression, according to two medium quality studies (Beck et al., 2011; Treiber et al., 2008).

Behaviour and mental health

Behaviour and mental health was the most extensively investigated overarching category. Although findings were contradictory, it is common for non-cognitive symptoms

(NCS) to occur simultaneously (D’Onofrio et al., 2012). There was some evidence to support the association of depression, affect/ lability, non-aggressive agitation, and premorbid personality and behaviour with aggression, but findings for anxiety and PTSD were not significant. Results were mixed for psychotic symptoms, and limited for anti-psychotic medication and disorientation. Presence of co-morbid symptoms of depression and non-aggressive agitation appeared to represent fairly robust predictive factors.

Depression

Five medium quality studies found comorbid symptoms of depression were associated with aggression (Kunik et al., 2010; Leonard et al., 2006; Majic et al., 2012; Talerico, Evans, & Strumpf, 2002; Volicer et al., 2009). In contrast, two medium quality studies found no such relationship (Lopez et al., 2003; O'Leary et al., 2005).

Anxiety

According to three medium quality studies, there was no evidence to support an association with anxiety (Cooke et al., 2010; Lanctot et al., 2004; Lopez et al., 2003).

Affect and emotional lability

Two medium quality studies found emotional lability, and both positive and negative affect were significant factors, suggesting that demonstrative behaviour in general may be predictive of aggression (Beck et al., 2011; Lopez et al., 2003).

Psychotic symptoms

Three medium quality studies found an association between the presence of delusions and increased likelihood of aggression (Kunik et al., 2010; Leonard et al., 2006; Lopez et al., 2003). But two medium quality studies found no evidence to support this link (Lanctot et al., 2004; Volicer et al., 2009). Results for hallucinations were similar; two medium quality studies found an association between the presence of hallucinations and increased likelihood of aggression (Leonard et al., 2006; Lopez et al., 2003). Three medium quality studies found no evidence to support this link (Kunik et al., 2010; Lanctot et al., 2004; Volicer et al., 2009).

Non-aggressive agitation

Four medium quality studies found a significant correlation between non-aggressive agitation and aggression (Lanctot et al., 2004; Lopez et al., 2003; Morgan et al., 2013; O'Leary et al., 2005).

Premorbid personality

Two medium quality studies found premorbid personality factors (past agreeableness and past non-agreeableness) were associated with aggression (Beck et al., 2011; Whall et al., 2008). The contradictory result of past-agreeableness was specific to verbal aggression (Beck et al., 2011).

Premorbid conduct disorder

One medium quality study found an association between increased aggression and premorbid conduct disorder (O'Leary et al., 2005).

Anti-psychotic medication

One medium quality study found an association between aggression and use of anti-psychotic medication (Talerico et al., 2002).

Disorientation

One medium quality study found an association between disorientation and increased aggression (Talerico et al., 2002).

PTSD

One low quality study found no evidence to support an association between increased aggression and PTSD in a sample of ten veteran outpatients (Ball et al., 2009).

Environment, care events and care approach

Certain environmental stimuli or care activities may represent ‘triggers’ for aggressive behaviour. For instance use of restraint or confrontation is likely to elicit agitation and anger which may provoke aggression.

There was little evidence to support any consistent influence of environmental factors; results for care approaches were more promising. All studies reporting on these factors were carried out in residential settings.

Environment

Two studies (1 medium, and 1 low quality) found an association for environmental factors (Bostrom, Squires, Mitchell, Sales, & Estabrooks, 2012; Zeisel et al., 2003); three other studies (2 medium, and 1 low quality) did not (Beck et al., 2011; Cooke et al., 2010; Somboontanont et al., 2004). Out of the wide array of factors investigated only high secure or ‘institutionalised’ settings increased aggression likelihood.

Care events

One medium quality study found an association between aggression and specific care events. In this study, Whall et al. (2008), observed six different direct and non-direct care events including bathing, mealtimes, dressing, and time spent in communal space; only bathing was found to be significant.

Care approach

Five studies (4 medium, and 1 low quality) found certain care interactions, including use of restraint, confrontation and resistance, were associated with aggression (de Jonghe Rouleau et al., 2005; Lopez et al., 2003; Somboontanont et al., 2004; Talerico et al., 2002; Volicer et al., 2009). One medium quality study found no evidence to support the association (Whall et al., 2008).

Interpersonal factors

Included in this category are themes relating to relationships and interactions between carer and care-recipient. Interpersonal factors appear to be important correlates of aggression in dementia. However, the range of factors investigated did not reveal any consistent contribution. There is a sound theoretical basis for the significance of communication; for example, it is likely that impaired communication increases the chances of the person having unmet needs, and aggression may be used to express need (Talerico et al., 2002). With one exception (community), these studies were carried out in residential settings.

Relationship quality

Two studies investigated relationship quality, with similar results. One low quality study found developing trust and increasing time with care-recipients reduced aggression likelihood (Ko et al., 2012). Correspondingly, a decline in relationship mutuality increased aggression likelihood in one medium quality study (Kunik et al., 2010). One medium quality found no evidence to support relationship quality as a factor in aggression (Ball et al., 2010).

Communication

Two medium quality studies found an association between impaired communication ability and aggression (Talerico et al., 2002; Volicer et al., 2009).

Caregiver factors

Four studies (2 medium and 2 low quality) found an association between aggression and caregiver factors; only staff ratio, burden and burnout were significant (Ko et al., 2012; Kunik et al., 2010; Somboontanont et al., 2004; Zeisel et al., 2003). One low quality study found no significant association between caregiver factors, including demographics and clinical experience *(*Bostrom et al., 2012).

Social stimulation

Social stimulation was not found to be a significant factor, according to one medium quality study (Kunik et al., 2010).

DISCUSSION

Findings

This review provides a comprehensive account of recent investigations into potential contributing factors towards aggression in dementia. Although previous reviews have been undertaken, this was the first to adopt a systematic methodology and to apply quality ratings to studies. A summary of the main findings are presented, along with associated quality information and comparison to earlier reviews.

Methodological quality of studies was largely within the medium range. Only one was found to be of high quality. Around a third of studies were rated low quality, highlighting the importance of drawing on multiple sources of evidence.

The results summary is organized according to frequency of support provided for the factors (criteria outlined in table 1.4). Quality issues are highlighted within this framework. Factors with multiple dimensions are categorised according to the frequency of support for each separate dimension, and therefore may be represented within more than one category.

Table 1.4 Summary of criteria for grouping factors

Category criteria
(1) At least four studies investigated the factor, all the studies reported significant associations between that factor and aggression, and all these associations were in the same direction (i.e. either all negative or all positive).
(2) At least four studies investigated the factor, at least half of these studies reported significant associations all in the same direction, but the remaining studies reported non-significant associations.
(3) At least four studies investigated the factor; some studies reported significant associations in one direction, but others reported significant associations in the opposite direction, and some studies reported non-significant results.
(4) At least four studies investigated the factor, but fewer than half of the studies reported significant associations in the same direction, and the remaining studies reported non-significant associations.
(5) Fewer than four studies investigated the factor, but all reported significant associations in the same direction.
(6) Fewer than four studies investigated the factor, some studies reported significant associations in one direction, but others reported non-significant associations.
(7) Fewer than four studies investigated the factor and none found a significant association.

Category 1

There were three factors that met the criteria for category 1: neurotransmission (serotonin), brain region changes (hippocampus), and non-aggressive agitation. At least four studies investigated each factor, all the studies reported significant associations between the factors and aggression, and all these associations were in the same direction.

The association between aggression and changes occurring in the hippocampus were in line with previous review findings, as was the finding for neurotransmission (serotonin) (Hall & O'Connor, 2004; Cipriani et al., 2011). In contrast, associations between non-aggressive agitation and aggression had not previously been reported.

There are some aspects relating to the evidence for these factors that are important to consider. Associations were consistent, and longitudinal methods were applied by at least one of the studies for each factor. Despite this, the findings were typically from medium and low quality studies with fairly small sample sizes of less than 50 participants (Garcia-Alloza et al., 2004, 2005; Lai et al., 2003, 2011; Lanctot et al., 2002; Lanctot et al., 2004; Trzepacz et al., 2013; Vermeiren et al., 2014). Non-aggressive agitation is one exception; this factor was investigated by medium quality studies, the majority of which had reasonable sample sizes of more than 150 participants (Lanctot et al., 2004; Lopez et al., 2003; Morgan et al., 2013; O'Leary et al., 2005).

Category 2

There were five factors that met the criteria for category 2: pain, genotype (APOE), gender, depression, and psychotic symptoms (delusions). At least four studies investigated each factor, more than half of these studies reported significant associations all in the same direction, but the remaining studies reported non-significant associations.

Findings for each of these factors were in line with expected results, with the exception of genotype which was not examined in the earlier reviews (Hall & O'Connor, 2004; Cipriani et al., 2011).

Quality of the studies was typically within the medium range for both significant and non-significant findings. Pain was the only factor to have evidence derived from a high quality study (Husebo et al., 2011 & 2014). In their first paper, Husebo et al. (2011) reported a linear relationship between pain and aggression, with more severe pain being associated with greater risk of aggression. In their second paper, Husebo et al. (2014) re-analysed their data by separating verbal and physical acts of aggression, and they found the relationship only remained significant for verbal aggression. No other study examining pain reported results based on this distinction, so further research is required before any firm conclusions can be made. There were no details regarding the type of pain experienced, however it is likely that it represents an unmet need.

According to Pritchard et al. (2007a) the evidence presented in relation to genotype and aggression is broadly in keeping with the previous literature reporting on NCS more generally, in that significant findings are not consistently reproduced. They remarked that the mixed body of evidence may relate to the method of analysis selected. In their study any initially significant findings, no longer remained so following correction for multiple testing due to the increased threshold for significance.

Male gender was found to be associated with aggression; however, emerging but limited evidence suggests there may be a divergence between physical and verbal variants. Specifically, according to the two studies that examined this distinction, females were more likely to express aggression verbally whereas males were more likely to exhibit aggression physically (Beck et al., 2011; Zuidema et al., 2009).

There were two studies that examined depression as a factor but found no significant association with aggression; both relied upon self-report by the individuals with dementia (Lopez et al., 2003; O'leary et al., 2005). In contrast, studies reporting that depression increased the likelihood of aggression, relied upon assessments by professional caregivers only (Kunik et al., 2010; Leonard et al., 2006; Majic et al., 2012; Talerico et al., 2002; Volicer et al., 2009). It is worth noting that the assessment of depression in dementia can be limited by co-morbid symptoms of reduced insight and communication difficulties (Lopez et al., 2003). In consideration of these aspects of assessment, it may be that participants were less well able to report on their symptoms of depression leading to the non-significant result.

Category 3

There were two factors that met the criteria for category 3: Dementia severity and sleep disturbance. At least four studies investigated these factors; some studies reported significant associations in one direction, but others reported significant associations in the opposite direction, and some studies reported non-significant results.

A linear relationship between increased aggression and more severe dementia was in line with expected results (Hall & O'Connor, 2004; Cipriani et al., 2011). Furthermore this finding was supported by the majority of studies investigating this factor, most of which were of medium quality, including three that employed longitudinal methodologies (Bidzan et al., 2012; Holtzer et al., 2003; Trzepacz et al., 2013). Overall, however, the relationship between aggression and dementia severity was mixed. This may be due to the wide variety of assessment tools used to measure this factor, however, they were all considered to be at least in the 'good' range of reliability (see Appendix 3 for reliability descriptions). Another consideration is that some individuals with the most severe dementia symptoms may have been excluded from studies due to ethical considerations regarding assessment or due to the increased likelihood of co-morbid conditions occurring with increased age. Exclusion of those with more severe dementia may have weakened the observed relationship between severity and aggression in some studies.

The impact of sleep quality on aggression had not previously been investigated in earlier reviews (Hall & O'Connor, 2004; Cipriani et al., 2011). The mixed findings, reported by medium quality studies, present an unclear picture. It is plausible that the linear relationship in two studies finding an increase in aggression following a period of disturbed sleep (Gehrman et al., 2003; Moran et al., 2005), relates to an increase in levels of irritability which in turn increases the likelihood of aggression. It is less clear why, in one study, slightly more (30 minutes) overall sleep increased aggression (Whall et al., 2008). One explanation, suggested by Whall et al. (2008), was that increased sleep duration was also associated with psychotropic medication use, the effects of which could have influenced the rate of aggressive behaviour in their study.

Category 4

There were two factors that met the criteria for category 4: age and psychotic symptoms (hallucinations). There were at least four studies that investigated each factor but fewer than half of the studies reported significant associations in the same direction, and the remaining studies reported non-significant associations. All studies were of medium quality.

Age had not previously been identified as a factor in earlier reviews (Hall & O'Connor, 2004; Cipriani et al., 2011). When considering the strong evidence for the role of dementia severity it is somewhat paradoxical that, where significant, it was younger age that increased risk for aggression. One explanation may be that physical agility is likely to be greater at a younger age, which in turn could influence the likelihood of physical aggression.

As mentioned, according to earlier reviews psychotic symptoms were expected to have a significant association with aggression (Hall & O'Connor, 2004; Cipriani et al., 2011). In this review, however, when considered separately from delusions, hallucinations appear to be less consistent as a predictive factor for aggression. Correspondingly, in their longitudinal study, Kunik et al (2010) found delusions to be significant but not hallucinations. They suggested that the inconsistent relationship reported in the literature and in their own study, may be due to relatively small numbers of participants developing hallucinations, use of antipsychotic medication, and study exclusion criteria. Indeed, these issues are relevant to the present review as in all studies investigating this factor, prevalence of hallucinations was low and anti-psychotics were typically prescribed to participants from this population (Kunik et al., 2010; Lanctot et al., 2004; Leonard et al., 2006; Lopez et al., 2003; Volicer et al., 2009).

Category 5

There were 17 factors within category 5: infection, circadian function, neurotransmission (cholinergic, and dopaminergic), CSF biomarkers (Ab42), Brain region changes (amygdala, frontal lobes, locus coeruleus, insular and cingulate cortex), genotype (tryptophan, and PRND), affect, emotional lability, pre-morbid personality (past agreeableness, and past non-agreeableness), pre-morbid conduct disorder, anti-psychotic medication, disorientation, environment (institutionalised/ high secure unit), care events (bathing), care approach (confrontation, restraint, and resistance), communication, and caregiver factors (staff ratio, burden, and burnout). Fewer than four studies investigated the factor, but all reported significant associations in the same direction. Although limited in quantity, the evidence for these factors was typically derived from medium quality studies.

Previous reviews identified the following factors as potential contributing factors of aggression in dementia; infection, brain region changes (amygdala, frontal lobes), care approach (restraint), communication, and caregiver factors (burden), whereas in contrast to the present review, circadian disturbance had previously been found to be non-significant (Hall & O’Connor, 2004; Cipriani et al., 2011).

While the specific environmental factors outlined above were significantly associated with aggression, results for environmental factors in this review and in the previous reviews, were mixed overall (Hall & O’Connor, 2004; Cipriani et al., 2011). This is likely due to variations in the aspects of environmental conditions that were investigated (Beck et al., 2011; Bostrom et al., 2012; Cooke et al., 2010; Somboontanont et al., 2004; Zeisel et al., 2003).

In relation to pre-morbid personality and conduct disorder, there are issues of validity regarding measurement. For each, the studies relied upon caregiver testimony and without access to any objective data there is risk of disparity between the caregiver’s knowledge and the actual pre-morbid personality and behaviour (Beck et al., 2011; O'Leary et al., 2005; Whall et al., 2008).

As there are a small number of positive findings for factors in this category, there is not yet adequate evidence to draw any firm conclusions and so more research on these factors is needed.

Category 6

There were seven factors that met criteria for category 6: general physical health, constipation, neurotransmission (noradrenergic), hormones (testosterone, and oestrogen), type of dementia (AD, VaD, and FTD), genotype (5HT), and relationship quality. Fewer than four studies investigated these factors, some studies reported significant associations in one direction, but others reported non-significant associations. Quality of the studies was typically within the medium range for both significant and non-significant findings, with the exception of those finding a significant association for neurotransmission (noradrenergic) and type of dementia (VaD) for which the evidence came from low quality studies; suggesting that evidence for the latter factors is comparatively weaker.

Previous review findings suggested that general physical health, type of dementia (FTD), and relationship quality were found to be significant factors in aggression (Hall & O’Connor, 2004; Cipriani et al., 2011). The mixed findings across more recent investigations into the role of these factors may relate to issues and variations in approach. For instance, in their longitudinal study, Ball et al. (2010) applied a stringent statistical criterion (≤.003) in order to reduce the likelihood of type I error, resulting in a non-significant result for relationship quality. In comparison, the study by Kunik et al. (2010) found the association to be significant (p=.006); this study was also longitudinal, used the same assessment tool for relationship mutuality and employed a similar pool of participants.

The lack of consistent findings for dementia type may relate to difficulties in making valid diagnoses in vivo. None of the studies investigating type of dementia used post mortem samples, despite confirmation of dementia diagnosis requiring post mortem examination (Bandyopadhyay et al., 2014; D'Onofrio et al., 2012; Engelborghs et al., 2006c; Grochmal-Bach et al., 2009; O'Leary et al., 2005).

Category 7

There were twelve factors that met criteria for category 7: physiological need, CSF biomarkers (Tau, and P-Tau181), genotype (dopamine), education, ethnicity, anxiety, PTSD, environment (environmental conditions e.g. temperature, noise, and lighting), care events (direct care excluding bathing, indirect care), care approach (caregiver behaviour e.g. facial expressions, body movements), caregiver factors (characteristics e.g. gender, years of experience) and social stimulation. Fewer than four studies investigated these factors and none found a significant association. All findings were from medium quality studies, with the exception of PTSD, caregiver characteristics, and one study investigating environmental conditions; evidence relating to these factors was from low quality studies.

With the exception of environmental conditions which have been discussed above (see category 5), none of these factors had been investigated in studies covered by the previous reviews (Hall & O'Connor, 2004; Cipriani et al., 2011).

Findings for physiological need are particularly surprising given the importance attached to this in theories concerning NCS (e.g. Cohen-Mansfield, 2000). Both studies investigating this factor used observational methods across several nursing homes to assess a broad array of needs (e.g. thirst, hunger, urinary urge) and reported 'excellent' inter-rater reliability (Beck et al., 2011; Whall et al., 2008). It is difficult, therefore, to point to methodological explanations for a lack of evidence.

In contrast, the lack of supportive evidence for PTSD and anxiety, may to some extent relate to small sample sizes (Ball et al., 2009; Cooke et al., 2010; Lanctot et al., 2004), and in one study, the reliability of anxiety assessment was unclear as no explicit measurement details were provided (Lopez et al., 2003). The lack of supportive evidence for these factors then, does not clearly discount their potential role in aggression in dementia.

Of the 36 potential contributing factors of aggression identified in this review, 20 had not been identified in earlier reviews, and there was only one factor that conflicted with the results; this was circadian disturbance which had previously been reported as non-significant (Hall & O'Connor, 2004; Cipriani et al., 2011).

Indications and patterns of potential methodological weakness are now discussed.

Methodological considerations

Evaluation of the methodological quality provided an overarching view of approaches typically used to investigate associations of aggression in dementia, highlighting areas that may be improved upon as well as areas of strength.

Often studies were very broad in terms of the wide array of possible contributing factors explored in a range of NCS. This approach increases the likelihood of identifying factors that correlate by chance if the alpha level is not adjusted to take account of multiple testing (which not all studies did). This approach also increases the likelihood of non-significant findings by decreasing the power of any multivariate analyses (such as multiple regression). Indeed the amount of inconsistency in results occurring between studies investigating the same factor may be a reflection of this issue. This scattergun approach reflected a lack of theoretically-driven hypotheses underlying the research. A more fruitful approach may be a more theoretically-driven one that is more selective about what factors it investigates.

The reporting of exclusion criteria was typically clear and inclusive. However, recruitment strategies were typically non-random and so it is difficult to be confident in the generalisability of findings. Relatively small sample sizes in some studies decreased the power of the statistical tests, thereby increasing the probability of Type 2 errors (i.e. concluding there was no significant association, when, in reality, there is one). Post-mortem studies, in particular, were limited by small sample sizes, as well as potential effects of post-mortem delay that can lead to poor results (Garcia-Alloza et al., 2005).

There were few studies that employed longitudinal or experimental designs, so the majority of research provides only evidence of an association and does not shed any light on causal relationships. An advantage of cross-sectional studies, however, is that participants are not subject to deliberate exposure to conditions or treatments that may carry some risk or have other ethical implications.

Another issue related to ethical considerations is the risk of harm associated with aggressive behaviour. Presumably, direct intervention would be undertaken in many cases to reduce danger and distress at the time of an aggressive episode. Variation in the receipt and effectiveness of treatment would act as a confounding variable, clouding the association between aggression and the variable under investigation, and decreasing the likelihood of significant findings. Few studies commented on this, so it remains unclear as to how this may have influenced findings.

Several other areas of potential methodological limitation were common among studies. For instance, response bias is likely as few studies adopted blind data collection. Furthermore, as aggression is cited as one of the main reasons for institutionalisation, participants recruited from these settings may have had pre-existing aggression, the onset of which could have been influenced by factors outside of their current environment.

Variability in the definition and measurement of aggression may have influenced findings. Few studies made the distinction between verbal aggression and physical aggression. Some study findings suggest that they may represent different phenomena and should therefore be examined separately (Talerico et al., 2002). Similarly, there was variability in the distinction of aggression from the related construct of agitation, and limited recording of severity and frequency. These represent conceptual issues that may reduce the comparability of studies. Overall measurement of aggression and other psychological and social factors could be improved through use of more robust measures.

Implications for theory and clinical practice

From the evidence presented above it is clear that multiple factors are involved in the occurrence of aggression in dementia, including biological, psychological, social and environmental factors. These factors are likely to interact in different ways across different individuals; therefore, in clinical terms, each case needs to be individually assessed using an approach with the flexibility to address the wide range of variables from these different domains.

Future research

It is imperative that more high quality, theory driven research be undertaken to address the limitations of existing research discussed in this review. There are also some factors that are relatively under-researched and require more extensive investigation.

More theory-driven research is required to enable a more integrated body of research to be established, rather than the current state of affairs in which a range of factors has been identified but the ways in which they interact and relate to one another is unclear. Theory-driven research would also enable studies to focus on a more limited set of variables, thereby avoiding the statistical problems arising from multiple testing and inadequate sample sizes.

Improvements in research quality, including greater use of longitudinal and intervention studies, may shed more light on the causal relationships between these factors and aggression. Better control of potentially confounding variables is also needed, such as controlling for any treatment or intervention for aggression. Better definition and measurement of aggression and potential contributing factors would also increase the validity of findings. Because the causes of aggression are very likely to be multiple and interacting, more sophisticated statistical analyses are required that allow one to determine the effects of one variable while controlling for others, and to determine interactions between variables.

Different research approaches are also worth considering. Promising work by Cohen-Mansfield et al. (2007) investigating non-aggressive agitation, highlighted the benefits of using individualised assessment and intervention as a research approach.

In terms of factors that merit more investigation, few of the reviewed studies targeted their investigations towards precipitating factors within situations where aggression is most likely to occur, such as during intimate care (Keene et al., 1999). Other contributing factors stemming from the immediate environment and care approach have been identified as problematic for other NCS (Kunik et al., 2003). These include crowds, and disruptions to routine, as well as differing care approaches (e.g. the difference between that provided by the family and that provided by paid carers) (Kunik et al., 2003). None, however, were investigated by the studies in this or previous reviews. It may also be useful for future research to investigate whether the significant findings are applicable for individuals with dementia of working age, for whom relationships, responsibilities, and rate of disease progression may be very different, compared to older cohorts and older individuals.

Strengths and weaknesses of this review

The size and scope of this review are among its main strengths. By drawing on a broad body of evidence, it offers a range of relevant information on the topic of aggression in dementia, and the inclusivity provides clinicians and researchers an efficient method of obtaining and updating knowledge. Use of a systematic approach in the search and selection of studies ensured that consistent focus and objectivity were maintained. In addition, this method highlighted substantial gaps in the evidence base, which may assist in the development of future research objectives. Application of a quality framework facilitated comparison of findings, and the degree of confidence that can be placed in each result is informed by the quality ratings ascribed to each study. As much as possible, attempts were made to avoid skewing of the evidence base due to use of the same dataset across several studies. Also, a transparent description of the review methodology was provided for ease of replication.

There are several methodological limitations in the present review. The decision to limit searches to exclude those published before 2002 potentially shifted the balance of evidence; this is not necessarily unhelpful however, as changes in care practices, and more rigorous ethical frameworks (e.g. The American Psychological Society, 2002) could mean that earlier research is, to some extent, out-dated. The quality criteria applied to studies made use of explicit coding in an attempt to avoid subjective ratings of quality as much as possible. It should be noted, however, that no information regarding inter-rater reliability is available. A better method for establishing the relative strength of evidence for the different factors would be to apply a meta-analysis to the findings of studies that passed some minimum standard of quality. Exclusion of qualitative and single case studies, including accounts from the individual with dementia, may have limited the evidence relating to antecedents and other contextual factors. It was decided that application of quality criteria would be inequitable, and the relevance of its quality ratings would be diminished if criteria were extended to include these research designs. Finally, in order to produce a clear and concise synthesis of results, reporting of findings was inevitably oversimplified

Summary

There are multiple factors associated with aggression in dementia and they probably interact in many ways with one another, making investigation complicated and potentially vulnerable to error. This systematic review has found some reasonable evidence for the role of certain contributing factors of aggression in dementia, while the influence of other factors remains unclear or has limited support. Overall, there were no findings that clearly contradicted those reported in earlier reviews. This information is valuable for the development of interventions and for informing standards of dementia care practice that aim to reduce the occurrence of aggression, and, as a consequence, improve well-being for individuals with dementia and their caregivers.

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PAPER 2

Aggression and Continuity in Dementia Caregiving Relationships: A Qualitative Exploration of Spousal Carer Experiences

By

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ABSTRACT

Background

Continuity in relationships is a developing field within dementia care research. Continuity relates to how much the relationship is experienced as the same as it's always been. At the other end of the spectrum is discontinuity. This relates to whether the relationship is experienced as being changed in some fundamental way. There is little evidence about why some perceive continuity but others discontinuity. One possibility is that certain types of change in the person with dementia, such as aggression, may be more challenging to the sense of continuity than others. This research explores how partners of individuals with dementia experience aggression in their relationship, and whether aggression has an impact on their sense of continuity.

Method

Semi-structured interviews were carried out with five spousal carers, whose partner had a dementia diagnosis and had exhibited aggression. Interviews were tape-recorded, and analysed using Interpretative Phenomenological Analysis (IPA).

Results

Three broad themes were identified. These were: Making sense of aggression; The impact of aggression; and coping with aggression. There was development within each of the themes suggesting that understanding and coping evolved over time, for some carers.

Conclusion

Findings in this study indicate that aggression is a challenge to maintaining a sense that the person with dementia is the same, and as a consequence, threatens the ability to maintain a continuous relationship. The associated emotional responses to aggression; bewilderment, anger, hurt, and shame, impacted carers' wellbeing. Finding a way to separate the aggression from their sense of the person was one way to maintain continuity and lesson the negative emotional impact; leading to a more accepting, well- adjusted style of coping.

Keywords: Relationship Continuity, Aggression, Dementia, Carer, Qualitative

INTRODUCTION

Prior research in dementia care has highlighted that development of impairments or changes in aspects of the individual, due to disease progression, can present carers with complex problems; aggressive behaviour has been highlighted as one such source of difficulty (Fischer, Ismail & Scweizer, 2012).

In qualitative studies investigating the impact of dementia symptoms on carers, the ways in which carers perceived ‘problem’ behaviours, were more highly associated with a negative impact on caring than their frequency (Robinson, Adkisson & Weinrich, 2001; Paton, Johnston, Katona & Livingston, 2004). It appears the experience of carer burden and stress may not simply be a case of whether particular symptoms are present. Indeed, while some aspects of dementia are acknowledged as being difficult to manage, some carers find meaning and reward from their caring role (Gillies, 2011). How carers make sense of dementia seems important in understanding the variability of its impact. There is presently, little information about the impact of aggression on those who care for their spouse with dementia, particularly in terms of how aggression impacts the relationship and its impact on care.

An overlapping body of research in dementia care has reported on the transformation of relationships due to the development of dementia. An emerging theme of continuity or lack thereof, relates to perceptions of the relationship and the individual with dementia, prior to and following the onset of dementia. At one end of the continuum, those holding a sense of continuity, may define themselves “in relation to” the cared for individual, in ways that parallel relations prior to the dementia, whereas carers perceiving discontinuity, may focus on evidence highlighting how their relationship and the person have changed (Chesla, Martinson, & Muwaswes, 1994). In qualitative studies, relationship continuity has been associated with carer emotional wellbeing and an ability to adapt to changes, leading to a more positive care experience (Chesla et al.,1994; Murray & Livingston, 1998). Whereas, relationship discontinuity, has been linked to distancing of feelings and a less constructive care experience (Chesla et al.,1994; Walters, Oyebode & Riley, 2010).

A conceptual model of relationship continuity described in Riley et al., (2013) provides a useful framework for understanding how challenges in dementia may change the relationship between the person with dementia and their spouse. Five continuity dimensions are described; 'continuity/discontinuity of person' relates to whether the spouse is seen as the same person they have always been or whether they have changed in some fundamental way; 'continuity/discontinuity of feelings' relates to whether feelings of love and fondness for the person have remained the same or have changed; 'continuity/discontinuity of the relationship' looks directly at the extent to which the relationship is experienced as continuous, discontinuous or transformed; 'continuity/discontinuity of couplehood' looks at whether there is an ongoing sense of being a couple such as through acts of sharing and intimacy or whether there is a sense of being alone; 'loss' relates to the aspects of the person and the relationship that are longed for or grieved (Riley et al., 2013).

Continuity in relationships is a developing field within dementia care research. There is however, little evidence about why some perceive continuity but others discontinuity. One possibility is that certain types of change in the person with dementia, and meanings derived, are more challenging to the sense of continuity than others. Correspondingly responses to change may be influenced by perceptions of continuity or discontinuity. Further research exploring these aspects of caring relationships in dementia may inform ways of promoting continuity. Moving focus away from dementia behaviours, towards relationship constructs, may provide benefits in terms of enhancement of well-being and sustained person-centred care (Walters, Oyebode & Riley (2010).

Aim

This research aims to explore how partners of individuals with dementia experience aggression in their relationship. How does the care-giving partner make sense of the aggression? What impact does aggression have, and how do they cope with it? The interplay between aggression and continuity will also be examined. Is aggression a particular challenge to maintaining a sense of continuity in the relationship?

METHOD

Design and Analysis

As this study was interested in the way carers experience and make sense of aggression in their relationship, Interpretative Phenomenological Analysis (IPA) was selected as the primary method of data analysis. IPA provides a way of looking at experiences in a detailed way and allows exploration of individual differences that may emerge (smith et al., 2009).

Data collection involved semi-structured interviews. An interview guide was available as a general outline of topics, but this did not restrict the use of spontaneous questions and carers were encouraged to tell their own story (Appendix 4). Interviews focussed primarily on the experience of aggression, in terms of how they felt about it, how they understood it, and how they tried to manage it. Changes in the relationship were also investigated. Ethical approval was granted by the National Health Service Research Ethics Committee (Appendix 5).

Interpretative Phenomenological Analysis

IPA was used at the primary analysis and focused on the experience and meaning making of aggression. IPA is a systematic research method developed to examine subjective human experience (Smith, Flowers, & Larkin, 2009). It considers individuals to have unique and expert perspectives on their experiences, and in this study, enables exploration of how dementia and aggression in the relationship may be experienced and understood by the spousal carer. A further advantage of IPA is that a range of theoretical perspectives may be applied in interpretation of the carers' accounts, whilst maintaining awareness of contextual and cultural influences of both participant and researcher (Willig, 2012). Through the process of IPA, themes and connections between themes emerge from the data, these may then be organised and interpreted to convey commonalities as well as distinctions in participant's experiences.

Table 2.1 outlines the steps involved in carrying out IPA, based on the method described by Smith at al., (2009). Analysis outcomes were discussed with the research supervisor to establish agreement on identified themes.

Table 2.1: IPA process (Smith et al., 2009).

Step 1: Reading and re-reading of the transcripts
Step 2: Initial noting involving identification of descriptive, linguistic and conceptual comments.
Step 3: Identifying emergent themes though connections and patterns between initial notes.
Step 4: Searching for connections across emergent themes by looking for interrelationships between emergent themes
Step 5: Moving to the next case and repeating steps 1-4.
Step 6: Looking for patterns across cases.

Template Analysis

Template Analysis (TA) was used as a secondary analysis to establish each participant's position with regard to the pre-existing themes of relationship continuity, based on the dimensions outlined by Riley et al., (2013). This then enabled examination of the connections between relationship continuity, and the experience and understanding of aggression. Unlike IPA, TA allows for inclusion of priori themes that are strongly expected to be relevant in the analysis, and is compatible with a phenomenological approach (King, 2012). Table 2.2 provides a summary of the TA approach applied in this study. Full details of the approach are available online (see King, 2004).

Table 2.2 Template Analysis technique

Steps of TA (King, 2004)	Implementation
Establishing priori themes	Themes were extracted from Riley et al., (2013) A sub-set of the data was read and coded by the researcher and research supervisor to test suitability of priori themes
Developing the template	During reading of the data sub-set, more specific themes (lower-order) were identified and defined under the relevant priori themes (higher order) Inclusion of new themes or adaption of existing themes was not restricted to this stage, and so template development was an on-going process.
Using the template	Transcripts were read thoroughly and all quotations with relevant themes were identified Descriptive quotations and those requiring interpretation were included
Collation	Quotations were organised according to themes
Interpretation	Sections of the text were described and patterns in the data explored

Participants

Five spouses of people with dementia participated in the study. Table 2.3 provides a summary of participant details. The size of the purposive sample was considered appropriate for an IPA approach allowing for in-depth analysis of each case. For inclusion, carers were required to have been the primary carer for their partner for at least 12 months, and to have reported at least three incidents of aggression to service providers since their partner's diagnosis of dementia. Further details of inclusion and exclusion criteria are outlined in Appendix 6. At the time of recruitment, all carers were living at home with their spouse. Ages ranged from 57-79 years (mean: 70 years) Time since dementia diagnosis ranged from 5-10 years (mean: 7 years). Length of relationship ranged from 30-58 years (mean: 48 years). In the interim between recruitment and interview Gladys's husband, Peter, passed away. She conveyed a wish to be included in the study when given the option to withdraw, and careful consideration was taken to ensure no undue distress resulted from the interview. One month prior to interview Betty's husband, Cyril, moved to a residential care home. All were of White British ethnicity. Names have been altered to protect anonymity.

Table 2.3 Summary of participant information

Participant	Participant Pseudonym *(age)*	Spouse Pseudonym	Years married	Years since diagnosis	Acts of aggression	Aggression onset
1	Betty *(74)*	Cyril	55	5	Verbal and physical directed towards partner – no longer current	After onset of dementia symptoms, Pre-diagnosis
2	Maureen *(71)*	Roy	58	10	Verbal directed towards partner and others - current	After diagnosis of dementia
3	Phil *(79)*	Colette	50	6	Verbal directed towards partner and indirect physical (throwing or punching household items) - current	After onset of dementia symptoms, Pre-diagnosis
4	Rita *(57)*	Arthur	30	5	Verbal and physical directed towards partner - current	Early in the relationship. Prior to onset of dementia. Related to undiagnosed anxiety.
5	Gladys *(70)*	Peter	50	8	Verbal and indirect physical (throwing or punching household items) – no longer current	After onset of dementia symptoms, Pre-diagnosis

Procedure

Participating carers were identified and approached in the first instance by two local NHS collaborators from a Carer Support Service and a Community Mental Health Service for older adults. Local collaborators were provided with a recruitment guide outlining the operational definition of aggression and the recruitment criteria to aid appropriate and consistent recruitment (Appendix 6). Additional materials used in the recruitment process were an invitation to participate letter, a form giving consent to be contacted by the Chief Investigator, and a participant information document (Appendices 7,8,9). With consent, potential participating carers were contacted by the researcher to discuss the research in detail and arrange interview appointments if appropriate. Consent to participate was obtained prior to interview (Appendix 10).

All audio-taped interviews took place privately in carers' own homes and lasted between 60 minutes and 180 minutes. Carers were advised that involvement was voluntary and they could take breaks at any time. Information about support in case of distress following the interview was also shared and outlined in the participant information document (Appendix 11).

FINDINGS

Three superordinate themes were drawn out from the data. These were: ‘making sense of aggression’, ‘the impact of aggression’ and ‘coping with aggression’. These are presented in Table 2.4 alongside sub-themes. Although not all carers contributed to all sub-themes, interpretations are made at times, to suggest possible reasons for their absence; it is also not an essential requirement of IPA (Smith, 2003). The final themes were chosen for their relevance to aggression specific content, and their prevalence within the carers’ accounts. The superordinate themes and their sub-themes are discussed in more detail below.

Following the IPA findings, there is a summary of the TA describing where each participant stood in respect of the five dimensions of relationship continuity. A final section then draws together the connection between aggression and relationship continuity.

Table 2.4: Superordinate themes and sub-themes

Superordinate theme	Sub-theme
1) Making sense of aggression	Grappling with uncertainty Towards an understanding of aggression Separating aggression from the person
2) The impact of aggression	Anger Hurt Shame
3) Coping with aggression	Learning to live with aggression Preserving the old self

Super-ordinate theme: making sense of aggression

This theme refers to the carers’ accounts of developing an understanding of the aggression exhibited by their spouse. As they progress from an early to more developed understanding, many similarities within their experiences are evident; despite variations in onset of aggression and knowledge of a dementia diagnosis.

Grappling with uncertainty

All carers described experiencing a state of uncertainty, shock and confusion as a result of the initial acts of aggression. They were unable to make sense of what was happening at this stage, and had many questions that could not be answered readily. Often, aggression first occurred prior to a diagnosis of dementia and was amongst the initial presenting symptoms. In those cases, carers encountered several unfamiliar aspects of behaviour, rather than aggression in isolation, and so it is useful to consider initial responses to aggression within a broad context of change.

Not only was aggression unexpected, it was seemingly in stark contrast to the carers' perception of the person. In Betty's case she felt her relationship with Cyril had been idyllic:

> *I don't know where this aggression come from because he hadn't got a nasty bone in his body. It was… you might not believe this, but it was very rare, very, very rare that we had an upset because we were just so content. You know! Just, we were just one. (P1.12/Betty)*

Exhibiting aggression was so very unlike, Cyril, as a person, that even in the early stages prior to a dementia diagnosis, Betty associated the aggression with a profound change in his thinking, and she could not understand why it was happening.

> *I just didn't know what was going on. I used to think you're going loopy, you're going barmy. You're stupid, you're stupid Cyril. Why say these things? (P1.64 /Betty).*

Phil likened the aggression to a *'tantrum'*, something that was childish, out of control and did not fit with Colette's *'happy go lucky'* nature. He went on to say:

> *Well I couldn't make sense of it to be honest with you. I just didn't know what was wrong (P3.10/Phil)*

Aggression generally did not seem to have an obvious cause or trigger that could account for the change in behaviour. This was true even for Maureen who had some knowledge of Roy's cognitive impairment. She was shocked by the aggression as it was also something she did not recognise in Roy:

> *I suppose when it first started I was quite taken back thinking what's this? Because he's never shown aggression to me and it does alarm you and you think is this going to be a continuation? That he's going to do this. But it was in spasms, you know? A little here, a little there. That's when it started to show up. (P2.96/Maureen)*

Maureen highlighted her uncertainty about how aggression would impact their future, fearing that the aggression was not a one-off occurrence. She mentioned the initial infrequency of aggression, as though it became a feature of their lives more so as a gradual but unpredictable shift. Her use of the term 'a little' also suggests that to some extent she had minimised the aggression early on; as if it was not so bad, because it was not so often.

Gladys reported that aggression was not at all representative of Peter's character:

> *...He was never like that before, no way! He never actually hit me while he was like that. I used to think oh Peter what's wrong with you? What's going on with you? (P5.12/ Gladys)*

She added that Peter hadn't gone as far as being physically aggressive with her, suggesting that she too felt the extent of aggression was an important detail to make clear. Perhaps to some degree this was an attempt to preserve the perception that Peter was not an aggressive man.

Rita talked about her experience of aggression emerging in the relationship many years prior to the onset of dementia in ways that echoed the experiences of other carers:

> *...there was like an internal argument going on all the time. 'Why does this happen?' 'What the hell is going on?' you know? (P4.12/Rita)*

Rita also described Arthur's character as being in opposition to her idea of what it is to be an aggressive person.

> *...the aggression was definitely not because Arthur was a bully or an aggressive person by nature. He's mild mannered, he's you know, kind, he's loving, he's not that person. (P4.20/Rita)*

It is striking that all the carers had similar initial responses. When aggression first emerged it seemed to represent a challenge to the continuity of person; it did not fit with the perception of their spouse; it did not make sense to them based on past behaviour or in relation to events in the here and now. Some minimising of the extent of aggression suggests some early attempts at maintaining continuity.

Towards understanding aggression

Following on from the initial stage of uncertainty, all the carers, with the exception of Betty, describe attempts taken toward developing an understanding of the aggression. They demonstrated a perspective taking approach, where they considered how their spouse experienced the world through the lens of dementia, and how then aggression might manifest as a result.

Maureen examined the content of Roy’s communication and noticed that his thoughts were dominated by fear, as though he felt under constant threat of something bad happening:

> *He doesn’t.... he thinks more bad things now, doesn’t think nice things* […] *There’s always somebody who is gonna stab him, there’s somebody who’s gonna fight with him erm, erm, draws the curtains, draws the blinds “down there’s people looking at us”. Erm, he’s always on... if the news comes on he goes on about the terrorists* […] *I have to turn it off and if there’s any murders it sticks in his head. All the bad things seem to get to Roy now. Whereas there’s no good things, he never says nice things or good things. (P2.50/Maureen)*

By turning her attention to Roy’s own experience, and even keeping a diary of how he had been each day, Maureen identified a pattern of cause (threat) and effect (aggression) that provides a clear and understandable explanation for the aggression. She even extends this interpretation to Roy’s dreams to account for his aggression upon waking.

> *I think he dreams and there is always something on his mind. And I say to him “oh god I wish you could be pleasant and say oh I’m going out for a ride or something, something nice”. But it’s never nice and that’s what makes him aggressive. Because obviously what he’s been dreaming, and he wakes up and he’s in that mood of aggression. Mmm definitely. (P2.78/Maureen)*

Rita reflects on how she began making sense of aggression both early on in the relationship and again following Arthur’s dementia diagnosis. She acknowledges that early in their relationship, before the dementia, the aggression had not ever been fully understood. She had looked back into Arthur's past, hoping that it would reveal the root cause of the aggression; an explanation that could justify his lack of control. The lack of control, in fact, appears important to understand as perhaps the '*inner anger*' in itself is not the most problematic aspect rather it is the inability to control it that poses the significant problem. This could also then provide clues on how to make changes. It seems that finding a way to cope is the driving force behind Rita's attempts to make sense of the aggression:

> *[pre-dementia] I don't think it was ever that clear in my head. Maybe it is now, maybe I can think that now but I don't know that I could have done throughout the marriage. But [pause] what I did think, and I know I thought this that erm, if I helped Arthur, if I made… gave reasons for why he was like he was erm, because I'd done a bit of research, I'd done a bit of learning myself. If I could… if I could explain why then we would get through. […] I felt at the time if we could delve back into Arthur's childhood and why he had these periods of aggression and why he had this inner anger, which he couldn't control. (P4.13/Rita)*

Following Arthur's dementia diagnosis, the aggression was more frequent but transformed in terms of Rita's perception. The knowledge of dementia seems to enable an empathetic view of aggression, perhaps as this finally provided Rita with a reasonable explanation for the aggression in the relationship:

> *Um and at least the violence has now gone to a level that's where you can say it is related to this frustration that he's feeling because of his inability to do the things he wants to be able to do. It must be bloody awful, it must be horrendous. You know, for an intelligent capable person not to be able to turn the shower on. Not to be able to brush his teeth. You know (P4.32/Rita)*

Like Rita, following the diagnosis Gladys and Phil relate aggression to everyday frustrations arising from limitations in their spouses' functioning. They consider how self-awareness in dementia may bring about uncomfortable emotions:

> *He used to get uptight when he couldn't do anything; I think that's what it was really. [...] Cos to think, he could do a lot of things. He put doors up and everything. Now you've got to imagine that person, how do they cope when they can't even do a little bit of painting like. That's one drop aint it? Isn't it? It must be degrading for them. (P5.14/Gladys)*

> *I mean sometimes she'll turn round to me and say "I'm sorry about that earlier on you know what it is, it's my memory". It annoys her because she can't remember things. (P3.22/Phil)*

In their attempts to understand aggression, the carers spent time recollecting aspects of their spouse's character, allowing them to take a person-centred view. They all described aggression as something happening to their spouse rather than something their spouse was doing to them. Perspective taking also seemed to help answer some of the questions regarding aggression posed early on, and this was often aided by the knowledge of a dementia diagnosis. Drawing on aspects of their spouses' past abilities and comparing those with current limitations, identified sources of frustration or distress that represent triggers for aggression.

Separating aggression from the person

This theme relates to the carers' developed understanding of aggression, in which they go beyond cause and effect to give aggression a more individualised meaning. This most often involved a symbolic separation of aggression from the person. The separation occurred in two distinct ways: Either a dual concept of the person was maintained, where the aggressive version was considered to be a separate person; or aggression was seen as an invading entity that takes control of the person making them behave badly.

Anger and aggression do not fit with Maureen's perception of Roy, so she has refrained from integrating this aspect of his personality. Instead she makes a clear distinction between her husband and the person that behaves aggressively. This perhaps alleviates concern that aggression is something '*he's going to do…*', because, to her, it is someone else. In effect, she is maintaining her sense of Roy's continuity:

> *Yes, yes because Roy was a very gentle, erm person. Never showed aggression, never erm, so that's why he's not Roy when there is the aggression and it is Roy when he's gentle. He's nice and he'll smile at me and I think, you know, that's Roy, that's Roy. But when he's angry it's definitely not Roy. No definitely not Roy. (P2.72/Maureen)*

Betty describes the aggression as being something separate from Cyril entirely, taking on a life of its own; as if Cyril undergoes a transition '*like he turns over a page in a book and then he'd go again'*. She thinks of it as a powerful *'gremlin'* that takes over and prevents Cyril from having control. Her characterisation of aggression seems to be the embodiment of all the distasteful, behaviour that Cyril exhibits, and it provides a target for Betty to direct her own negative emotions, whilst allowing her to continue to love and provide care for Cyril.

> *I always said he'd got this Gremlin, it were that horrible Gremlin in his head that was naughty not Cyril. Cos some days he was very, very naughty, very naughty, yeah. (P1.83/Betty)*

> *I used to think I'd love to cut his, the top of his head and get this gremlin out of his head. (P1.19/Betty)*

Rita also talks about aggression as having a character of its own; the *'little devil'*. It is a similar character as before the dementia, suggesting there is continuity of a difficult self. Crucially her relationship to it has been altered since Arthur's diagnosis. She no longer resents it or argues against it:

> *It's still that. Um. It's a slightly more irrational little devil, but it's not as.. because of the Alzheimer's I suppose I am less damning I am less damning, less "you shouldn't do this " So that's a shift that's enabling us to have a… to maintain more of an equilibrium maybe. (P4.3/Rita)*

Phil explained that he sees Colette as a different person more often than not, as a result of aggression:

> *She's not the woman I know. Very occasionally she is but I can't hold a conversation with her now because as I told you she accuses me of making things up you know. (P3.19/Phil)*

> *Well if I try to explain about it "I'm lying", "I'm making it up" she'll just suddenly blow up all of a sudden. (P3.3/Phil)*

There does not seem to be an attempt to separate the aggression from Colette as a person. Instead it is Colette as a whole that has changed. Phil's adapted way of thinking seems to protect him from experiencing the aggression as a personal attack, allowing him to better manage his own emotions and reactions to the aggression as it occurs:

> *Well when she has these now ['I call them brainstorms'] I ignore them. I let her carry on with them but it's worrying. I did take it personally to start but I know*

> *now it's not my Colette put it that way. It's something happening in her head, she's a different person. (P3.39/Phil)*

For Gladys, there were no enduring aspects of Peter's character. She describes him as a very different person compared to who he was before the dementia. The discontinuity however, appears to be due to the wide context of change, rather than aggression alone:

> *I was living with a stranger. He couldn't speak, you couldn't have a conversation with him. He wasn't my husband for about eight years really. (P5.18/Gladys)*

It seems that aggression can pose a significant threat to maintaining continuity of person. For some carers aggression represents a temporary discontinuity of the person – they are no longer themselves when they are aggressive. Perhaps by considering the aggression as a separate unrelated part of their spouses' personhood, they are creating a more personally and socially acceptable reality; and, through exclusion of aggression from their concept of the person, a greater sense of continuity is preserved.

Phil and Gladys responded in a subtly different way to the other carers, there does not seem to be the same attempt to maintain continuity. Instead, they perceive their spouse, now transformed by dementia, as separate from who they had been before the onset of the disease. And so aggression is seen as an integrated part of a different person.

Super-ordinate theme: The impact of aggression

This super-ordinate theme relates to the emotional impact of aggression. Anger, hurt and shame were the emotions most commonly discussed.

Anger

Feelings of anger were reported by Gladys, Phil, Betty and Rita. Anger was often reflected in their responses to their spouse, particularly when aggression first emerged.

Gladys described a strong urge to react to the aggression with aggression:

> *As I said to you I was angry. I could have hit him. I could have strangled him. I really could. I mean the television… with that he could have had an accident. (P5.35/Gladys)*

She managed to contain some of her anger, but still responded in an '*agitated*' way. She associated her feelings of anger to being "*worn out"* by all the challenges she faced since Peter developed dementia.

Phil said that Colette often accuses him of things, and that this often coincides with the aggression. When first confronted with aggression, Phil attempted to physically control it and shake it out of Colette, as if doing so would snap her back to herself:

> *…She used to have these fits and she'd be banging the table with her fists, and before I knew what was causing it, I used to try and restrain her. I used to hold her by the shoulders and shake her, but I don't do that anymore. (P3.29/Phil)*

In this example Phil seems to mirror Colette's behaviour. Overcome by concern, he tried to use physical force to convince her that what she was doing was wrong. This was not unlike her method of banging the table to convince him to admit what, in her mind, he had done wrong. He acknowledged that anger had been present at these times and that he continues to experience frustration as a consequence of the aggression:

> *I used to [feel angry], but understanding more I try to keep it inside you know. I can get a bit frustrated but I let things sort of run their course. (P3.34/Phil)*

Phil keeps his feelings inside now; holding onto his own emotions rather than attempting to make Colette contain hers.

Prior to diagnosis, Betty experienced intense anger due to Cyril's behaviour. She communicated this emotion to him by ignoring him. But Cyril was unable to understand her reaction and so there was no way to jointly resolve the discontent. This represents a significant change to their previously harmonious relationship.

> *I mean as I said we never really fell out but while this first stage of the dementia, when he was so nasty, I used to be so angry. And I used to think, why am I angry? Because he's being stupid; why should he say these things to me? And I'd… I'm not talking, I'm not talking to him, not gonna talk to him because he's so naughty. And then he couldn't understand why I wasn't talking to him. And it wasn't like, until he was diagnosed I thought well this is it. I've got to put up with this. (P1.65/Betty)*

Rita felt as though she had been "*fighting with that little devil*" throughout the relationship. Her anger built up over the years despite attempts to release it verbally:

> *And I wasn't blameless you know, I never used aggression but my words you know, they're good and I was hurtful sometimes so that's just as difficult to deal with isn't it. You know? If you feel that anger inside and I had… and as the years go by I was experiencing more and more anger. (P4.12/Rita)*

Rita takes responsibility for the way she expressed her anger before the dementia, reflecting on it as understandable but not helpful. She suggests that the impact of her 'hurtful words' was equally hard to manage as the aggression from Arthur.

Although Maureen dealt with Roy's anger in an assertive way, her assertiveness was described as a means of preventing harm rather than being fuelled by anger:

> *Yes he's put his fists up to me. He's never hit me, cos I mean, I've jumped out… I said 'if you ever do hit me that'll be the first and the last time Roy', and the last time I thought it's not Roy, he doesn't know, you know. Perhaps I shouldn't say that but I say it just to make him stand back a bit. But he'll raise his fists and he'll come right up to my face and I say 'don't you dare Roy, don't you dare'. But that's when he's really aggressive, and in his face and his attitude to me. (P2.68/Maureen)*

Gladys, Betty and Rita's expression of anger manifests as either verbal or passive aggression, whereas for Phil anger is expressed in a more physical way. To some extent their anger parallels the emotion felt by their spouse. The emotional challenges of living with dementia are shared within the relationship.

Hurt

Phil, Maureen, and Betty describe feelings of hurt in response to accusations made against them by their spouse. These often relate to beliefs of infidelity or deception, which fuel episodes of aggression.

For Phil, accusations are the basis for the majority of aggression exhibited by Colette. She accuses him "*of making things up, of hiding things"* to the point where Phil is blamed for all the difficulties she experiences *"it's me that's caused all this at the moment. I've caused* *all this dementia you know".* This was painful for Phil early on; *"I did take it personally to start".* He seemed to bear the weight of blame when his attempts to challenge or alter Colette's beliefs were unsuccessful; *"Well I've been very nearly in tears over it, very nearly".* The powerlessness in this situation, may also have contributed to the anger and frustration that he also experienced.

Being accused of wrongdoing is hurtful and confusing for Maureen in the immediate moments after Roy exhibits aggression, as it causes her to examine how her actions could bring this about "*you think why does he think that, why's he saying that to me? when I'm in the house all the while with him".* Through the process of separating aggression from Roy as a person, Maureen is able to shift attribution of the event away from her, and let go of the hurt along with it. She describes her resilience as having developed 'thicker skin' that protects her from the emotional impact of aggression:

> *Mmm, hurtful when he first said it you know and then I think to myself 'it's not Roy' so I don't let it hurt me, it doesn't bother me. Whether I've just got hardened to all the different things around me and in the early stages he's gone for me with golf clubs and things like that you know, until they got his medication right. (P2.42/Maureen)*

Betty described the hurt felt by Cyril's accusations as akin to physical pain:

> *I'd be pegging the washing on the line and he'd come and say 'you prostitute'. It was... it used to just cut me in two the things he used to say. (P1.18/Betty)*

Similar to Maureen, Betty had described being able to separate the aggression from Cyril, but only after the event. When confronted with aggression in the moment, hurt was experienced as if it was the old Cyril. It seems that in this instance, maintaining continuity of person may contribute to feelings of hurt. Perhaps switching between the modes ‘Cyril’ and ‘the Gremlin’ is a complex process that is difficult to achieve during heightened emotion. It is only afterwards that she is able to separate them, as a way of coping.

Experiencing hurt due to accusations seems to persist beyond the early stages of aggression, despite their awareness of the dementia and understanding of aggression. For Betty and Maureen it seems that their strategies of separating the aggression from the person are helpful only after the event. By contrast, Phil seems more able to remain detached, perhaps as he no longer considers Colette to be the same person.

Shame

Betty, Gladys and Rita describe the feelings and consequences of shame resulting from the aggression.

Betty could not face the idea of others knowing her husband was directing aggression towards her. Despite her ability to separate the “gremlin” from Cyril, trusting that others would be able to make the same distinction without judgement was perhaps too difficult:

> *No, no I coped myself. To be honest, I was too ashamed. To think that your husband could be aggressive towards you and be so nasty. I used to think I couldn’t tell nobody this and it’s only, erm when people have come, like the CPN has come and he’s been in a mood that they’ve seen it happen. (P1.117/Betty)*

To feel shame in this way suggests that Betty feared the acts of aggression would reveal her to be weak or at fault. So instead she coped with it alone. Shame represented a barrier to support for Betty, and put her more at risk of harm and isolation.

Similarly, Rita describes hiding the aggression prior to the dementia due to concern about the negative perception of others. She did so despite expectations of how she would react in that situation, and the aggression was perpetuated as a consequence:

> *I actually wrote about battered women and did research in what you would do and all. The time I was writing that, I thought if I was ever in that situation I wouldn't hide it, huh! And yet I did. So it was just because there was a lot of stigma attached to it. Much more than there is now. And so because I hid it from everybody, it in a way perpetuated it because we didn't deal with it. (P4.5/Rita)*

Following Arthur's diagnosis of dementia, Rita sought support for her own wellbeing and she was able to be open about the aggression with services. She is no longer driven to maintain appearances, which may also have been influenced by the dementia providing a more socially acceptable explanation.

Gladys seems to feel shame more so on behalf of Peter. She considers how he would have behaved upon witnessing someone being aggressive to their spouse, illustrating the depth of aversion she believed he would have had:

> *I was ashamed really to think my Peter's doing things like that. I was ashamed. If he knew what he was doing he would never have done that, never. If it was the other way around he'd go up and chuff a bloke. But he just wasn't Peter anymore. (P5.23/Gladys)*

This further highlights the challenge aggression posed for Gladys in terms of maintaining continuity of person.

Shame as a consequence of aggression was inherently related to how others would view them as a couple. Fear of this judgement was particularly evident for Betty and Rita, and acted as a significant barrier to disclosure, thereby delaying access to support.

Super-ordinate theme: Coping with aggression

This super-ordinate theme relates to ways the carers coped with aggression, in terms of the emotional impact, and when taking a direct approach to intervene. They reflected on their styles of coping; sometimes they managed well and sometimes not so well.

Preserving the old self

Remembering their spouse as they were before the dementia, allows Maureen and Betty to continue coping. These memories tend to be of the good times and of the characteristics they were most fond of.

Maureen seems to find solace in memories of the way Roy used to be. When the present is at its most difficult, there is a poem written by another caregiver she likes to read. The poem takes the reader on a journey of reflection about a loved one with dementia; it encourages thinking about the person as if still ‘in there’, despite behaving differently, and invites one to see through their eyes:

> *I've got a poem that I've got in the kitchen and I look at it and when I feel 'ooh' [exasperated sound], you know? I look at that poem and I think it's so true that poem is.*
>
> *[Start of poem] Where's the person I always used to know? They are still there in your minds' eye. They may appear to be a little different. They may appear a little shy. Their behaviour may have changed but you should know the reason why. Imagine walking through a fluffy cloud. Do you know where you should go? Your step feels so uncertain; your words just will not flow. Every time you turn around there is nobody that you know. A friendly face appears but to whom does it belong? They tell you who they are but you know they must be wrong. You begin to get frustrated because you know it can't be true. You shout, you bawl, you run away, express your point of view. You need some reassurance, loving arms to hold you tight, to stop the world from coming, to help you with your fright. Take another look at that person, the one you used to know, they really are no different if they could, they'd tell you so. Walk with me? in my fluffy cloud and remember how I used to be. I may have some confusion but remember I'm still there. [End of poem]*
>
> *And I think that does it, that's right that is isn't it? That, that's… and that came from somebody in the carers [network] who wrote it, you know. And when I get to the stage where I think 'ooh' and I look at that and I think it's there in him, it's still sort of there in him you know what I mean? (P2.53/Maureen)*

Maureen actively seeks to connect with the past and seek out aspects of Roy's personality that remain; in this way she preserves continuity of Roy as a person. This seems to help Maureen manage her own distress, and perhaps reinforce her resolve to continue providing care.

Betty takes a similar approach at times of difficulty. She draws on good memories of Cyril to give her the strength to cope:

> *Yeah, yeah if I hadn't of thought back of... when Cyril was being naughty, I always say naughty. erm, and if I hadn't got that [pause], erm, to look back and think how he was, I don't think I would have been able to have coped like I did. Because he was such a lovely, loving caring, caring man. You know? (P1.88/Betty)*

By keeping these important aspects of their shared past in mind, Betty preserves her perception of Cyril as the loving man he has always been. Although a great deal has changed in their lives, the past was good enough to carry them forward together.

By keeping in mind memories of the person as they were, Maureen and Betty are maintaining continuity of their spouses' personality. By connecting with the past they find strength in the present. It seems likely that this may only be useful when good memories are most prevalent.

Learning to live with aggression

This sub-theme looks at how responses to aggression evolved over time. Gains in knowledge and experience described by all carers, often resulted in altered perspectives on aggression, as well as changes in how aggression was managed.

A way of coping shared by Phil, Maureen, Betty and Rita involved removing practical barriers to what the person with dementia was trying to do, and not disagreeing with or contradicting the person. Often this came about after other approaches had been unhelpful, and so this represents a stage of more developed coping that coincides with developments in understanding and in emotional response.

Phil said he attempted to physically "*restrain*" Colette before he knew the aggression was related to dementia. He has since altered his approach as a consequence of having greater understanding. He credits this to support gained from health care services:

> *Erm well, I thought it was a tantrum at the start but now I understand better. It's been explained to me by the nurse and the doctor [...] I mean I don't try to restrain her now. (P3.9/Phil)*

He makes an important connection between his approach and understanding, highlighting how the meaning of aggression can influence coping. Previously aggression was seen as an unreasonable outburst that needed to be contained, but, by gaining awareness of the difficulty Colette may have in controlling aggression, Phil is able to *'let her get on with it and that's it'*. He also talks about learning from the consequences of a previous approach:

> *Well I've learnt to sort of live with it now and say 'yeah alright'. I found that if I disagree with her that's when she gets... but if I agree it calms her down. (P3.15/Phil)*

By behaving as if he agrees with Colette regardless of whether this reflects his true feelings, the aggression is reduced. To do this, Phil has to manage his own emotions and resist the urge to defend against accusations: *"I still get a bit uptight about it but I contain it now"*. In so doing, he effectively removes the resistance that Colette would have otherwise encountered and fought against. There are also times when Phil takes this a step further:

> *She'll have one of these brainstorms and sometimes I have to go out and have a walk around the garden just to let her settle down. (P3.27/Phil)*

By removing himself from the equation entirely he gives Colette space to work through her experience. Phil seems to have gone from ‘hands on’ to ‘hands off’ approach to coping, suggesting there is perhaps scope for further adjustment and coping.

Maureen acknowledges that, for some people, living with aggression would be "*horrendous*" but that she has experienced a gradual shift toward acceptance *"[...] as time goes on you just sort of accept everything that's going on because it's part of the course"*. Moving past uncertainty and hurt experienced early on, she now sees the difficult times as "*just something you've got to ride",* rather than something to control and her approach to coping with aggression reflects this:

> *When his bad mood is on him, I always try to be soft with him. He can be hard with me but I always try to be soft with him, until I think he's not going to accept this so it's best to give him time (P2.99/Maureen)*

Maureen aims to be a soothing influence. She allows rather than challenges the aggression, and is sensitive to when the best approach may be to withdraw all intervention. Even though Maureen describes her approach as having softness, there is strength conveyed in being able to achieve this. She describes herself as *"laid back"* and so it may be that her approach to aggression is aided by a drive to maintain this part of her identity.

Betty had talked about her experience of coping alone because of feelings of shame, and described feeling angry and hurt by the experience of aggression within the relationship early on. She suggests that if she had known aggression could occur as part of dementia, it would have been easier to cope with:

> *I think, yeah like they could have said to me 'Cyril could be… could get aggressive, Cyril could be very hurtful with words, erm, he could be more possessive'. because he was very possessive. I think if they'd have said a few of those little words, erm, I wouldn't have took it so bad as I did. I struggled on my own. [pause] And I'd do it again for him. I'd do it again. Yeah. (P1.118/Betty)*

The knowledge that aggression was part of dementia, and the development in her understanding seemed to aid a shift in Betty's approach towards letting go of the anger she experienced early on and finding ways to communicate with Cyril; albeit at the cost of her own aims and interests. She describes an increasing pressure to "*give in*" to Cyril during disagreements that is "*harder and harder*" to resist:

> *There was a little bit in the garden the one time, and I was putting some plants in the pots, and I came in and the plants were out the pots and I said 'what have you done that for? He always used to say 'I haven't done it' so I put them back in again and I've just said 'now don't get them plants out that pot Cyril cos it's naughty' […] we had a little few words about which pot was what. It was silly, and what does really stick in my mind is, he was adamant that he wanted my pot and I thought I'm not going to give into you and I didn't give into him but he kept on 'that's my pot, that's your pot', but he didn't forget which pot it was. […] Although I couldn't have the pot that I'd done, he left that pot alone. I'd won, but I hadn't won cos he still had that pot, but you know it calmed him down. I always remember that in the garden. (P1.99/Betty)*

In this account Betty encourages Cyril to understand her goal, rather than letting him do what he wants to do. When met with this resistance, Cyril is unable to manage, and aggression emerges. Betty seems driven to compromise by Cyril's distress, rather than willingly removing resistance as an effective strategy.

Rita also experiences the impact of resistance on aggression:

> *So we were in the car driving 40 miles an hour down a hill in a stream of traffic and er, he tried to get out of the car. Um. And of course I was holding onto him and he was really aggressive. (P4.26/Rita)*

Rita held onto Arthur to prevent him from harm, despite the physical aggression that followed. The restriction required to keep Arthur safe was unavoidable but, once out of immediate danger, Rita took the opposite approach:

> *But with the car incident he actually… once I'd gone round the island and he could get out onto the path he did get out, and I let him get out and I kerb crawled. And I just let him walk and followed him. And a bit further down the road we came to a set of shops, I pulled in and got out. I said "shall we go and buy some chocolate?" like a child's diversion tactic and it worked. (P4.28/Rita)*

Rita found a way to support Arthur in achieving what he wanted to do as safely as possible. Once resistance was removed, the aggression subsided long enough for her to introduce another approach that brought them back together towards a mutual goal. In this example Rita keeps Arthur safe at risk to herself. She associates her approach with a method used with children, and this suggests a shift away from her role as wife towards her role as carer.

Arthur's aggression became more prevalent after diagnosis, and for Rita, this change influenced her responses in an unhelpful way: "*So I did go through a period when I was more attacking verbally and that just made things worse*". By reflecting on her coping Rita has since developed a different outlook that highlights the significance of non-resistance, and is reinforced by the idea of not wanting to waste any more time:

> *I probably have learnt that it's better to shut up. But it has taken me a bloody long time [laughing]. […]So I've had to work really hard to put those… to to forgive… it is forgiving. And not blaming because all that does is eat you away and ruin what is left of your lives. And you know, I'm not a spring chicken and I think hang on, you know I don't wanna, I don't wanna live my life like this anymore. Let's just… let's make the most of what we've got. So through all of that shit there's some positivity, there's something coming through. And er. How nice, the sun came through as I said that [laughing]. (P4.31/Rita)*

Rita now sees holding onto blame and anger as destructive, and rather than repeat the past she has worked towards forgiving Arthur in order to make the most of the time they have left. This suggests a transformation of their relationship; one that has been troubled but has a sense of renewed hopefulness. This idea is further supported by Rita drawing attention to the sun appearing from behind a cloud and shining light into the room, as if to say 'this symbolises how things are now in the relationship'.

Gladys said as a way of managing the aggression she used to "*go on at him*" and "*lose her temper*". She thought this firm approach was effective, but continued to be uncertain that it was the best option:

> *I think so. Yeah! Because, he never said sorry. He never said sorry at all. I have done but Peter… even before he was bad. But I think well should I use the soft approach or the other way; get more agitated with him I just don't know. Don't know. (P5.36/Gladys)*

In particular when faced with the risk of Peter hurting himself, Gladys believed her approach was necessary to prevent aggression from re-occurring *"if I'd have been like that [calm] with him, he'd have done it again"*. There did not however, seem to be a reduction in the aggression "*Well it was going on for 8 or 9 [years] now. Last year he got worse really",* and she continued to seem frustrated by resistance to personal care *"And oh to try and get a nappy on him [exasperated expression]".*

Gladys did not appear to develop her understanding or approach related to aggression, and her experience of anger remained throughout. She maintained a sense of '*Duty'* to care for Peter and wanted him to stay at home as long as possible. It was a move to a residential home, however, that facilitated her learning more about aggression in dementia. This led to regret about the times she directed anger at Peter:

> *I was getting angry with Peter but now it's a bit too late. It is for me, the things they do. If I only knew then, what I know now. I probably wouldn't have been so hard with him. (P5.9/Gladys)*

As Gladys is recently widowed, the information came too late for her to develop a different way of coping.

In these accounts, managing aggression through non-resistance was highlighted as a valuable approach, except where this threatened the safety of those involved. Phil, Maureen, Rita, and Betty developed a non-resistant way of coping, although there were differences in what influenced the development and implementation of this approach. For Phil, receiving information about dementia changed the meaning of aggression. With increased tolerance to anger, he no longer tried to control the aggression through restraint. For Maureen, her observation of the patterns of aggression helped make the aggression more predictable, which encouraged acceptance and resilience allowing her to see the benefits of a non-resistant approach. For Rita, realising that a response fuelled by anger and blame was ineffective and harmful, allowed her to move past these emotions and aided the development of a non-resistant approach. Betty did not see the non-resistant approach as the best course of action nor did she select it willingly. The diagnosis of dementia had left her thinking that aggression was something she must now put up with, so while this seemed to help her experience less anger, she was reluctant to 'give in' to aggression. Instead it was the response she took when the alternative was too difficult. In contrast to the other carers, Gladys' did not reach a more accepting non-resistant approach. Her emotional reaction of anger, and management strategy of attempting to control the aggression remained consistent.

Relationship continuity

This section summarises where each participant stood in respect of the five dimensions of relationship continuity, and provides context for a discussion on connections between relationship continuity and aggression. The hierarchy of themes used for this analysis can be found in Appendix 12. For each participant, there is an example of the analysis displayed in Appendix 13, and for each participant, the number of times a theme occurs within the transcript is also provided. As there were few completely continuous or discontinuous positions, the tally of themes aided the process of determining where each person tended to be on the spectrum of continuity. A summary for reference is provided in Table 2.5.

Table 2.5 Summary of relationship continuity

Participant/ Pseudonym	**Feelings**	**Person**	**Relationship**	**Couplehood**	**Loss**
1 Betty	Same feelings	Different when aggressive	Transformed	Discontinuous (Limited affection and no sharing)	Loss of person and relationship experienced (affection, communication, having no-one to depend on, feeling cared for).
2 Maureen	Same feelings	Different when aggressive	Continuous	Continuous (On-going sharing and some affection)	Loss of person and relationship experienced (companionship, aspects of character communication, affection)
3 Phil	Same feelings (for how they used to be)	Different person	Discontinuous	Discontinuous (Limited affection and sharing)	Loss of person and relationship experienced (companionship, communication sharing activities, aspects of character)
4 Rita	Same feelings	Same/Different Person	Transformed	Continuous (Ongoing affection and some sharing)	Loss of person and relationship experienced (aspects of character, communication, companionship)
5 Gladys	Same feelings (for how they used to be)	Different person	Discontinuous	Not described	Complete loss of person and relationship experienced (all of character, communication, sharing activities and responsibilities)

Rather than a continuation of a marital relationship, Betty and Cyril's relationship was transformed, being defined now by acts of Betty's care and devotion. It had been Cyril who had looked after Betty throughout their relationship until their roles reversed; *"…he wrapped me in cotton wool like I had to wrap him in cotton wool when he was poorly. The role turned"*. Betty was very clear that her love for Cyril was strong and was the same as it had always been. Although, there was a lot of evidence to suggest that she saw Cyril as a different person, this was usually related to the aggression '*It just wasn't Cyril, he was so different'*. She described the change in his character as being like '*turn[ing] a page in a book*' and when he was not aggressive she saw him as '*his old self*'. There was limited affection in the relationship and it seemed to be initiated by Betty only, so there were no real examples of ongoing couplehood. Indeed, Betty described a sense of loss related to aspects of Cyril's character, and for how their relationship used to be.

For Maureen and Roy there was evidence of continuity in their relationship, Maureen said *"I'm still treating him on the whole as my husband"*. She continued to hold the same loving feelings for Roy, despite saying that she had '*about 30%*' of him left. This appeared to be enough for her to have an on-going sense of his personhood, as she tended to see Roy as the same person except when the aggression was around *"He's nice and he'll smile at me and I think, you know, that's Roy, that's Roy. But when he's angry it's definitely not Roy"*. Although affection was limited compared to before the dementia, there was an on-going element of togetherness, and so Maureen perceived a continuous sense of couplehood *"but I still feel as if there's that 50-50 thing going through us"*. There was however, a great deal of loss, particularly in relation to companionship and aspects of Roy's character.

Overall, the current status of Phil and Colette's relationship appears to be discontinuous. Phil said his love for Colette endured *"I still love her of course I do after 50 years you've got to haven't you"*, but this seemed to relate to the person she had been, rather than how he saw her now *"just lately she's not the person I know and love"*. Seeing her now as a different person seems to challenge his feelings of love as well as his experience of affection and sharing "*In the past we were very close, more of a partnership you know, we used to do everything together. Which we still do actually but you know, since she's had this dementia her nature's sort of changed".* He also describes missing aspects of Colette's personality and how the relationship used to be, and her disinterest in particular represented a barrier to maintaining aspects of sharing in activities while aggression impacted their communication. Phil seems to be at a critical point; the relationship is not what it was because Colette aggressively blamed him for the problems she experienced. He described the current status as *"Rocky, it's rocky at that moment to be honest with you but I'm trying to hold things together, trying to explain things to her".*

Rita and Arthur's relationship is transformed and perhaps continuing to transform. There was a brief period of separation; "*I didn't know it was Alzheimer's. And we, we split for a while. So erm, because I couldn't… his personality was changing, I didn't know what to attribute it to",* and their reconciliation was prompted by Arthur's diagnosis; *"I remember the diagnosis… the day. I remember that vividly because I felt relief. And I had him back and the reason I had him back was because he had Alzheimer's".* Since then Rita said that they *"maintain more of an equilibrium"* and are building on a basis of remorse and forgiveness. Although Rita still has loving feelings for Arthur, she acknowledged that at times the strength of love had been tested, and she now sees herself as important in the relationship. There were aspects of Arthur's character that she saw as the same, and some leaning towards him being a different person; *"So his personality it can be there or it can be a different person. That sounds weird".* Rita's sense of couplehood is continuous; she still thinks of her and Arthur as a couple and makes special efforts to maintain the relationship. She does however acknowledge that her role is shifting from wife to carer. The affection they share was described as *'the same'* and something that helped '*balance'* the aggression. Although Rita perceived Arthur's character and the relationship as different, there were few examples that highlighted her experience of loss

For Gladys, there was a discontinuation of the marital relationship following the onset of dementia. She said there was still a relationship but *"it was different"* and she felt as though she was "*looking after a baby really"*. She held feelings of love for the person Peter used to be *"I've always loved him",* but following the onset of dementia he was fundamentally a different person "*He wasn't my husband for about eight years really".* There were no examples of a continuation of their couplehood. For Gladys, there was a complete sense of loss for the person and the relationship *"…it had all gone. To me it had".* This seemed to be connected to her perception of him as childlike starting at the time of diagnosis *"He didn't even know when he was born. So that's when I really seen the child"*, and to not knowing how to cope with the changes in his behaviour and personality *"I didn't know what to do or what to say to him anymore".*

DISCUSSION

This study explored spousal carer's perspectives on aggression in dementia, and considered the interplay between aggression and relationship continuity. Emerging themes relate to how aggression was understood, the impact it had and ways of coping.

Making sense of aggression occurred in three stages. A sense of bewilderment in response to aggression was universal. It did not make sense either in context to what was happening in the moment, or in context to past behaviour. Oyebode, Bradley and Allen (2013), suggest that prior to diagnosis, carers are without a framework to develop their understanding, resulting in a sense of helplessness and frustration. For Rita, Gladys and Phil, the dementia diagnosis was important in moving to the next stage of developing understanding.

Initially, aggression had seemed unexplainable and unpredictable. In response, explanations and ways of predicting aggression were sought. Attempting to see things from the persons' perspective resulted in awareness of emotional distress experienced by the person with dementia. Maureen recognised that Roy was experiencing fear because the types of thoughts he expressed were of 'bad' things that even carried over into his dreams; whereas, Rita, Phil and Gladys recognised signs of frustration, occurring due to emerging limitations in abilities. Use of past knowledge of the person can be helpful in making sense of current behaviours in dementia, but the way this information is used to construct meaning can influence the care experience (Lewis, 1998). This was evident in the final stage involving development of individualised meanings of aggression. For Maureen, Betty and Rita, this involved separating aggression from their sense of the person. They maintained the idea that acts of aggression were not representative of the person. This perspective can be understood in relation to externalisation in narrative theory, in which the person is not viewed as being defined by the problem. Instead a view of the ‘problem being the problem’ is taken (White and Epston, 1990). Language is the main tool used in this approach. For instance, using Betty’s example of describing aggression as a gremlin, she distances the ‘problem’ from Cyril and positions it as a separate entity. In so doing, she keeps the parts of Cyril she finds desirable, current in her perception of him.

In contrast, Phil and Gladys did not externalise the aggression. Instead, aggression became an integrated part of a person they did not recognise, and this had consequences in terms of lasting emotional responses. This response can be understood as a form of unconscious defence due to conflicting emotions. In which the source of distress (spouse) is separated (past from present), so that negative emotions can exist without damaging good memories of the person and relationship (Walters et al., 2010).

Connections between aggression and relationship continuity

All carers described the emergence of aggression as being ‘out of character’, to the extent that it represented a threat to maintaining a sense of personhood. The ways in which carers responded to aggression demonstrate the strength of this threat. Broadly, aggression was either reconciled in order to preserve a sense of continuity, or it contributed to a sense that the person was fundamentally changed.

Betty, Maureen and Rita separated aggression from the person, allowing them to experience their spouse as the being the same (or sometimes the same in Rita’s case), when they behaved more like the person they were perceived to be. The person behaving aggressively was seen as essentially someone else. This helped maintain continuity of feelings, as if, the ‘aggressive other’ was responsible for the initial feelings of anger and hurt, allowing them to carry on loving the person despite the aggression. For Rita this happened much earlier in the relationship, however there were distinct similarities in coping and response. The onset of dementia did shift Rita’s sense of Arthur’s personhood towards discontinuity, and an increase in the aggression contributed to a temporary separation. This was resolved partly through a process of making sense of the aggression as something that was not Arthur – this time it was the dementia.

Continuity of less favourable aspects of character can be troubling for some, particularly for those already struggling with their situation (Gillies, 2011). This seemed to be the case for Rita. She noticed several changes that occurred with the onset of dementia, but it was an increase in aggression that ruptured their relationship temporarily, despite having coped pre-morbidly.

Being able to make sense of, and then separate aggression was an integral part of maintaining continuity of person. The fact that carers separated aggression demonstrates the threat; Betty, Maureen and Rita managed to protect against this threat. This seemed to be more difficult for Phil and Gladys. Both saw the person now as fundamentally different, and aggression was one part of that change. On-going feelings of love seemed to be an echo of the feelings held for who the person once was.

As well as being a threat to continuity of person, for Phil, the aggression was directly connected to discontinuity in the relationship and his sense of couplehood. He said he could no longer have conversations with Colette because of the aggression, as she often became angry and blamed him for her difficulties. He had been able to manage feelings of anger and cope better with the aggression but this did not change his perception of the relationship being rocky.

For Gladys, aggression was an integrated part of a different person. There were no examples of her attempting to overcome discontinuity through separating the aggression or through other means, and the impact of aggression on her emotions went unresolved. Peter was no longer the man she married and this discontinuity indirectly resulted in discontinuity of all relationship continuity dimensions.

The concept of continuity is proposed to be on a continuum rather than ‘completely continuous’ or ’completely discontinuous’ (Kaplan, 2001). In this study, few continuity dimensions were consistently supported. Rita described her experience of Arthur as being both him and not him. Despite this, she held positive views of the now transformed relationship and her commitment to couplehood was strong. Gillies (2011) reported similar findings of inconsistency in carer accounts, reflecting a resistance to integrate changing aspects of their relative for as long as possible. In this study, this seemed to be of benefit, as when faced with challenges such as aggression, it seems very difficult to maintain a continuous relationship without also finding a way to maintain continuity of person.

Coping with aggression

Much like development in understanding, emotional responses and coping approaches evolved over time, for some carers. Similarities in emotional responses were evident in the early stages, when understanding of aggression was being developed. In addition to a sense of bewilderment; anger, hurt and shame were described.

Betty, Maureen, Rita, and to some extent Phil, moved past the negative emotional impact, and associated attempts to control aggression through restraint and verbal hostility, towards a more accepting emotional response and a non-resistant approach. This was more evident for those that maintained a continuous sense of the person (Betty, Maureen, and Rita).

How aggression was understood, was more important in the development of coping, rather than the actual incidents of aggression. The premise that perceptions of aggression have a greater bearing on care outcomes is supported (Robinson et al., 2001).

These findings also offer support to those reported by Walters et al., (2010), who found carers experiencing a sense of continuity in the relationship, were more likely to hold person centred perspectives, suggested by their empathic responses to dementia behaviours, and were better adjusted to the caregiving role. The approach to change adopted by carers experiencing discontinuity, was discussed in terms of a disconnection to protect against emotional distress, and was associated with a less constructive caring experience for both spouses.

Although Phil also developed a non-resistant approach he credited the change in coping to advice given by healthcare practitioners, rather than it evolving as part of an evaluation of trying to control the aggression being ineffective. For Gladys this information came too late. Her approach to coping was guided by her feelings of anger throughout her caregiving experience.

Phil and Gladys had less well adapted modes of coping. It corresponds that their lack of continuity of person/relationship inhibited this development.

Learning to manage with aggression may then, be easier for those maintaining a continuous or transformed sense of the relationship, in terms of a more accepting emotional response and adjustment in coping (non-resistance).

Limitations

Only five carers took part in this study. This was due to difficulty in recruitment, which may relate to a reluctance to disclose aggression in the relationship; this was highlighted by Betty and Rita in this study. Consequently, the experiences described by this small sample must be considered as part of a wider body of research before making any attempts to generalise the findings. Smaller samples are of benefit when using IPA, however, as they allow for greater depth of analysis, as well as case comparison (Smith, 2004).

Carers were all of White-British ethnicity, had been in their relationship for at least three decades, had provided care for their spouse post-diagnosis at home for at least five years, and had already disclosed the aggression to specialist services. Findings are, therefore, unlikely to be representative of couples whose circumstances differ.

Inclusion of only one male spousal carer in the sample restricted identification of gender specific differences. Also, as this study did not specifically differentiate physical and verbal aggression in the analysis, it was not possible to explore any potential variation that may exist in participant's understanding and response to each, as separate phenomena.

There may be alternative explanations for the experiences described. For instance, Gladys was interviewed following Peter's death placing her in a unique position to reflect on her experience. Peter no longer being part of her life may have influenced her account in some way. However, theme development was discussed with the research supervisor to minimise interpretation bias. To promote transparency, supportive quotations were used as much as possible.

Research Implications

This study gave insight into a sensitive topic that has little research. It shows how adjustment and coping with aggression can be aided by externalisation of aggression, promoting a continuous sense of person. Field, Culverwell and Oliver (2015) found promising results using externalisation as a way reducing stigma and promoting communication in a post-diagnostic group for individuals with dementia and their relatives. Teaching externalisation techniques to spousal carers as a relationship-focused intervention may be worth investigating.

Further examination of this topic would be enriched by inclusion of the person with dementia to reveal how carer responses to aggression are experienced.

Use of the conceptual model of relationship continuity (Riley et al., 2013) provided a consistent and robust mode of assessing this issue that was compatible with a qualitative approach. Further use of this model in future research would aid comparability of findings.

Clinical implications

This study has revealed several potential targets for developing relationship-focussed strategies. Carers and the person with dementia should be made aware that aggression may emerge, to help manage expectations and promoting services as stigma-free. This may reduce the experience of shame, removing barriers to seeking support early on. This could also help reduce any associated isolation, or risk from aggression.

Initiating conversations about common emotional experiences, shared by the carer and their spouse, such as anger and frustration, along with advice on managing these difficult emotions, such as through perspective taking and a minimal resistance approach could also be beneficial.

There is an opportunity to increase likelihood of maintaining continuity of person and the relationship, through modelling externalisation of aggression. It is important to also be mindful of allowing those with a genuine sense of loss of the person to hold this perspective guilt free (Davis, 2004).

CONCLUSION

Findings in this study indicate that aggression is a challenge to maintaining continuity of person for spousal carers, and as a consequence, threatens the ability to maintain a continuous relationship. Associated emotional responses to aggression impact carers' wellbeing. Externalisation of aggression and empathy are one way to maintain continuity and lesson the negative emotional impact; leading to a more accepting, well- adjusted style of coping.

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APPENDIX 1

EXECUTIVE SUMMARY

A PUBLIC DOMAIN BRIEFING PAPER

Aggression and Continuity in Dementia Caregiving Relationships: A Qualitative Exploration of Spousal Carer Experiences

Background and Aims

Changes in the person with dementia, can present complex challenges for their carer. Aggression is one such challenge (Fischer, Ismail & Scweizer, 2012).

Continuity in relationships is a developing field within dementia care research. Continuity relates to how much the relationship is experienced as the same as it's always been. At the other end of the spectrum is discontinuity. This relates to whether the relationship is experienced as being changed in some fundamental way (Chesla, Martinson, & Muwaswes, 1994). Relationship continuity has been associated with carer emotional wellbeing and an ability to adapt to changes, leading to a more positive care experience (Chesla et al.,1994; Murray & Livingston, 1998). Whereas, relationship discontinuity, has been linked to distancing of feelings and a less constructive care experience (Chesla et al.,1994; Walters, Oyebode & Riley, 2010).

There is little evidence about why some perceive continuity but others discontinuity. One possibility is that certain types of change in the person with dementia, such as aggression, may be more challenging to the sense of continuity than others.

This research explored how partners of individuals with dementia experience aggression in their relationship, and whether aggression has an impact on their sense of continuity.

Method and participants

Semi-structured interviews were carried out with five spousal carers, whose partner had a dementia diagnosis and had exhibited aggression. Interviews were tape-recorded, and analysed using Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009).

Results

Three broad themes were identified, each with related subthemes. These were: Making sense of aggression (Grappling with uncertainty, Towards an understanding of aggression, Separating aggression from the person); The impact of aggression (Anger, Hurt, Shame); and coping with aggression (Learning to live with aggression, Preserving the old self). There was development within each of the themes suggesting that understanding and coping evolved over time, for some carers.

Discussion

Findings in this study indicate that aggression is a challenge to maintaining a sense that the person with dementia is the same, and as a consequence, threatens the ability to maintain a continuous relationship. The associated emotional responses to aggression; bewilderment, anger, hurt, and shame, impacted carers' wellbeing. Finding a way to separate the aggression from their sense of the person was one way to maintain continuity and lesson the negative emotional impact; leading to a more accepting, well- adjusted style of coping.

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Walters, A. H., Oyebode, J. R., & Riley, G.A. (2010). The dynamics of continuity and discontinuity for women caring for a spouse with dementia. *Dementia, 9*, 169-189. doi: 10.1177/1471301209354027

The full study is reported in:

Gibbons, H. (2016). A*ggression in dementia: associated factors and impact on spousal relationships*. Clin.Psy.D. Volume I. Paper 2. Birmingham: School of Psychology, Birmingham.

APPENDIX 2

Theories of aggression

Issues in defining aggression

Theories of aggression

Several theoretical frameworks can be applied to understanding aggression in dementia. Included among these are; behavioural, neurobiological, and unmet needs approaches. The behavioural model proposes that aggression is triggered and re-enforced by internal and external stimuli, which can be revealed and modified through alteration of behavioural antecedents and consequences (James, 2011). The neurobiological model considers how dementia-related brain changes, such as in the amygdala or frontal lobes, may impact the person's abilities in relation to interpretation and control of behaviour, as well as lowering the threshold for stress tolerance (Geda et al., 2013). The unmet needs perspective understands aggression as a means of communicating needs, or as an expression of frustration at needs remaining unmet, often due to limitations or failed attempts in using more conventional modes of communication (Cohen-Mansfield, 2000). The unmet needs model in particular is cited as well evidenced and helpful for understanding potentially modifiable factors in aggression, as well as NCS of dementia in general (Cohen-Mansfield, 2000, James, 2011).

Issues in defining aggression

No global definition of the term 'aggression' exists, which is problematic when reviewing research in this area, in terms of comparability of studies adopting differing definitions. Some refer to a list of observable acts such as kicking, hitting, scratching and swearing (e.g. Cohen-Mansfield, Marx, & Rosenthal, 1989). This provides consistency of measurement but leaves important contextual factors, such as provocation or self-defence unspecified. At the other end of the spectrum are definitions that give a broad description; for instance, "destructive actions directed toward persons, objects, or self" (Whall et al., 2008). This allows for interpretation of whether an act was experienced as aggressive, but may be unreliable due to individual differences in how behaviours are perceived. Intentionality is another facet sometimes used to differentiate aggression from accidental acts that result in harm. This is difficult to measure given that cognitive impairment can impact the ability to plan and carry out deliberate action.

Agitation is problematic too, as it overlaps with aggression and can have varying definitions. Agitation, in individuals with cognitive impairment, has recently been defined by consensus as an observable behaviour consistent with distress that can involve excessive motor activity, verbal aggression, and physical aggression (Cummings et al., 2015). Agitation may occur without aggression, but it does not necessarily follow that aggression should always be viewed as an 'agitated' behaviour. When reviewing studies that have not separated these constructs in the measurement, analysis and interpretation of findings, it is important to consider the likelihood that findings may be distorted as a result.

APPENDIX 3

Quality Framework

Descriptive Scores

Example reliability categories

Quality Framework for the Evaluation of Quantitative Studies (adapted from Riley, 2014).

1. Potential biases in recruitment? Random sample (2 points) Paper has checked and sample is representative of population on key variables (1 point) Opportunity sample with no check on how representative it is (0 points).
2. Sample size: Power calculation reported and sample size meets requirements of calculation (2); Sample size 82 or larger for correlation studies or 64 or larger in each group for group comparison studies or 34 or larger in each group for matched group studies (1); sample size under 82 for correlation studies, under 64 or 34 for group studies (0) [Figures based on GPower programme - sample size required to detect medium effect size with alpha set at .05 and power at 0.80, two-tailed tests]
3. Reliability* and validity of measures used (including response biases). Measures used have good reliability and validity when used with older adults and individuals with a dementia in the way that they are used in the study (2) Measures have good reliability and validity when used with other populations, but not reported for older adults and individuals with a dementia; or measures have good reliability and validity when used with older adults and individuals with a dementia but there are potentially significant differences between the reliability/validity studies and the study in question (1) Measures have poor reliability and/or validity in some respect (0) [where there is conflicting data or use of multiple measures, scores are based on the weakest measure]
4. Definition and measurement of aggression: Clear working definition of aggression outlined. Frequency and (or) severity of aggressive behaviours measured and reported separately from any related construct (e.g. non-aggressive agitation) (2) Measure of aggression applied and reported separately from any related construct (1) No specific measure of aggression or does not meet scoring criteria in some respect (0)
5. Missing data: No missing data or statistical methods used to address missing data (2) No use of statistical methods to deal with missing data, but amount of data missing is small (1) No report on whether data are missing or not, large amount of missing data and no attempt to deal with it statistically (0)
6. Statistical analysis: Analysis is appropriate for hypotheses (2) Analysis is not appropriate (0)

7. Design: Experimental methodology used (2) Longitudinal design is used in a way that tries to address the causal relationship between variables (1) Method is non-experimental and cross-sectional, or non-experimental and longitudinal but the longitudinal aspect does not shed any light on the causal relationship between variables (0)
8. Confounding variables: Wide range of potentially confounding variables identified and addressed by methodological or statistical means (2) Limited range of potentially confounding variables identified and addressed by methodological or statistical means (1) Potentially confounding variables are not addressed by methodological or statistical means (0)
9. Robustness of findings: Paper reports more than one result supporting the relationship between the relevant variables (including follow-up results) (2) Paper reports only one result supporting the relationship (0)

Overall Descriptive Scores

0 – 6 Low; 7 – 12 Medium; 13 - 18 High

*Example reliability categories

Value of ρ	Cronbach's alpha	Value of K	Categories
-1.0 to -0.7 or 0.7 to 1	$\alpha \geq 0.9$	0.81 - 1.00	Excellent
-0.7 to – 0.5 or 0.5 to 0.7	$0.7 \leq \alpha < 0.9$	0.61 - 0.80	Good
-0.5 to -0.3 or 0.3 to 0.5	$0.6 \leq \alpha < 0.7$	0.41 - 0.60	Acceptable
-0.3 to -0.1 or 0.1 to 0.3	$0.5 \leq \alpha < 0.6$	0.21 - 0.40	Poor
-0.1 to 0.1	$\alpha < 0.5$	< 0.20	Unacceptable

APPENDIX 4

Interview Schedule

Interview Schedule

Title of Project: **Relationships and Coping with Aggression in Dementia**

Interview One: Developing the story of the relationship

Key areas of interest: The relationship prior to and following the development of symptoms of dementia.

Questions/ prompts:

- What are you like as a couple?
- How was your relationship in the past?
- Choose five adjectives or words that reflect your relationship then?
- How is your relationship since the Dementia diagnosis?
- Choose five adjectives or words that reflect your relationship now?
- Are there any changes in your partner's character that stand out?
- Is there any part of the interview today that you would prefer not to be used?

Interview Two: Understanding the impact of incidents of aggression

Key areas of interest: Recent incidents and impact of aggression on the relationship. Ways of coping.

Questions/ prompts:

- Can you tell me about any recent incidents where your partner became aggressive?
- How did the incident develop?
- What did you think was going on? *Prompt: Why do you think they were being aggressive?*
- What did you do? *Prompt: How did you try to manage it?*
- How did you feel?
- How does this compare to how your partner was before the dementia diagnosis? *Prompt: Is this something completely new?*
- What impact do incidents of this kind have on your relationship? *Prompt: what impact do they have on how you feel about your partner?*
- When your partner has become aggressive, are there any times where you felt you'd handled it particular well? *Prompt: Can you tell me what happened?*
- Can you think of an example of when things have gone badly? *Prompt: What's the impact of that on you and your partner?*
- Is there any part of the interview today that you would prefer not to be used?

APPENDIX 5

Ethical Approval

APPENDIX 6

RECRUITMENT GUIDE

UNIVERSITY OF
BIRMINGHAM

RECRUITMENT GUIDE

Title of Project: **Relationships and Coping with Aggression in Dementia**

Researcher: **Miss Holly Gibbons, Trainee Clinical Psychologist**

I am currently looking for participants to take part in my research looking at the experiences of people caring for their spouse/partner who has dementia. The following information outlines the research inclusion criteria to aid identification of potential participants.
In order to be considered for participation the following criteria must be met.

Participants must:

- be a spouse or partner of an individual who has had a diagnosis of dementia for at least 6 months prior to taking part in the research .
- have been in the relationship for at least two years prior to the dementia diagnosis.
- consider themselves a caregiver for their partner with dementia.
- have informed service providers about incidents of aggression carried out by the person with dementia
- have capacity to give informed consent and reflect meaningfully on their experiences.
- be able to read and speak English to a sufficient level to allow for informed consent and meaningful participation.

The carer can not be considered if any of the following criteria are met.

- Presence of a severe mental health disorder or learning disability in the caregiving spouse or individual with dementia, that predates the dementia diagnosis.
- Where there is a likelihood of high levels of distress being experienced during interview.
- Active safeguarding concerns where a risk to the participant, the individual with dementia or the researcher is present.

* For the purposes of this research the following definition of aggression is to be adopted.

Definition of aggression

Aggression includes acts of physically or verbally threatening behaviour that is directed at people, objects or self. For example:

- Hitting, kicking, pushing, biting; throwing objects
- Verbal insults, swearing, shouting, making threats
- Physically preventing another person from obtaining a desired goal.

APPENDIX 7

PARTICIPANT LETTER OF INVITATION

UNIVERSITY OF
BIRMINGHAM

PARTICIPANT LETTER OF INVITATION

School of Clinical Psychology

Psychology Department
Frankland Building
University of Birmingham
Edgbaston
B15 2TT
Tel: [redacted]

Dear Carer,

My name is Holly Gibbons, I am a Trainee Clinical Psychologist at the University of Birmingham. As part of my training I am conducting research looking at the experiences of people caring for their spouse/partner who has dementia. You have been given this letter to invite you to consider being a participant in this project.

The research aims to explore aspects of spousal relationships that change and aspects that continue to stay the same following the diagnosis of dementia. I am particularly interested in talking to carers who have experienced occasions where their partner has displayed aggression. I think it is important to understand what impact these experiences may have on relationships, and to understand the ways in which carers cope. More knowledge in this area will be helpful for services that provide support in maintaining well-being for couples.

If you were interested in participating, I would arrange to meet you on two occasions to discuss the relationship you have with your spouse/partner, and what effect the aggression has on your relationship. I expect that each discussion would last for about an hour.

If you would like to know more about the research, please complete the attached form and I will contact you to arrange a time to tell you more about the project.

If you have any questions or would prefer to contact me about the research, you can telephone me on the number above or you can e-mail me at [redacted]

Thank you for taking the time to read this letter.
Best wishes.

Holly Gibbons
Trainee Clinical Psychologist

APPENDIX 8

CONSENT TO PASS CONTACT DETAILS TO THE RESEARCHER

UNIVERSITY OF
BIRMINGHAM

CONSENT TO PASS CONTACT DETAILS TO THE RESEARCHER

Title of Project: **Relationships and Coping with Aggression in Dementia**

Researcher: **Miss Holly Gibbons, Trainee Clinical Psychologist**

This form is for recording the contact details of potential research participants who are interested in hearing more about the above research project.

Please initial box

I confirm that I am happy for the researcher to contact me using the address and telephone number below. ☐

Contact Details

Name: .... Date: ....

Telephone Number: ....

Address: ....

....

....

....

The best times to contact me are:

Day of the Week	**Morning**	**Afternoon**	**Evening**
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

Is it safe to leave messages?: YES/NO

APPENDIX 9

PARTICIPANT INFORMATION SHEET

PARTICIPANT INFORMATION SHEET

Title of Project: **Relationships and Coping with Aggression in Dementia**

Researcher: **Miss Holly Gibbons, Trainee Clinical Psychologist**

I am a Trainee Clinical Psychologist at the University of Birmingham. As part of my training I am conducting research looking at the experiences of people caring for their spouse/partner who has dementia. The following information describes the research and may be helpful to you in deciding if you would like to take part.

What is the research about?

This research aims to explore aspects of being in a relationship where one spouse/ partner has a dementia. It is looking at how aggression affects the relationship. I am interested in hearing about how your relationship was in the past and how it has been since your partner developed dementia.

Why have I been invited to take part?

I am inviting individuals who have provided care and support for their partner with dementia for at least six months, and who have experienced aggression from their partner within that time.

Do I have to take part?

It is completely up to you to decide whether or not you take part. If you decide to take part you are still free to change your mind and withdraw at any time without giving a reason. If you decide not to take part or to withdraw from the study, this will not affect the support you or your spouse/partner receive.

What will I be asked to do if I take part?

If you decide to take part, we will arrange to meet twice to talk about your relationship with your spouse/ partner. Although I will ask you some questions about the relationship, I would like to hear about what is meaningful to you and so you will have the freedom to talk about what you want to talk about.

The meetings will last between 60-90 minutes, and if you would like we can take a break at any time during the meeting.

Where will we meet?

It is a good idea for us to meet in a location that is quiet and private. You can choose where we meet from the following options:

- At your own home.
- In the NHS clinic where you currently access carer support services.
- In a suitable local venue of your choice.

What happens if I get upset when we are talking?

While we are talking there may be times when you feel upset, or find it uncomfortable to talk about certain things. You do not have to talk about anything that is too upsetting or that you don't want to talk about. It is absolutely fine to take a break or stop the interview if you feel upset or find a subject difficult.

If you have been particularly upset during the interview, I will advise you to contact your GP or a member of the Carer Support Service. If I am concerned about your well-being, I will discuss this with you first and then contact my supervisor before advising you what to do. There are other sources of support and services outlined at the end of this sheet that may also be helpful.

What will happen as a result of our meeting?

I will make an audio recording of our meetings. I will listen to this and type out an exact record of our conversation. Your real name or the names of anyone else you might mention will not be used. I will use pseudonyms instead. Any other personal information that might identify you will also be excluded from the record I make.

Two weeks after our last meeting I will contact you to ask you if there is any part of what you have said that you do not want me to use in the study. I will delete all or any part of the interview that you request and it will not be used in any part of the study.

The results of the study will be reported in my thesis and will be stored at the University of Birmingham. It will be considered for publication in a journal and may be presented at a conference. These will include quotes from the interviews, however there will be no personal information included that would allow a member of the public to identify you.
I will also write a brief summary of the research findings. I will send a copy of this to you if you would like to see it. This summary will not contain any quotes from the transcripts.

Will my data be confidential?
The information you provide is confidential. The data collected for this study will be stored securely at the University of Birmingham and will only be looked at by the researcher, the researcher's academic supervisor and authorised audit representatives at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data.

Parts of the data may also be made available to the NHS team responsible for your care, but only if what is said in the interview makes me think that you, or someone else, is at significant risk of harm. I will inform you if I decide that I need to do this.

Will I get any benefit from taking part?
There are no direct benefits of taking part. It is hoped that the research will help inform services as to how to better support carers and improve quality of life for both the caring and the cared-for spouse/partner. A summary of the findings will be sent to you if you wish to receive it.

What should I do if I have a complaint or other concern about the way this research has been conducted?
If, after the interview, you have any complaints or concerns, then you can talk to a member of the Carer Support Service whose contact details are given at the end of this leaflet. Alternatively, you can contact my supervisor at the University (Gerry Riley, whose contact details are given at the end of this leaflet).

I'm interested in taking part. What do I do next?

I will telephone you within a day or two of our initial meeting. This will give you time to consider carefully whether you wish to take part. If you do want to take part, let me know when I telephone you and we can arrange a suitable time to meet. If you prefer, you can contact me using the details below.

Contact details

Researcher*:* Holly Gibbons (Trainee Clinical Psychologist)
Email: [redacted]

Supervisor: Gerry Riley (Senior Academic Tutor)
Tel: [redacted]

Thank you for taking the time to read this information

List of Supports and Services

The researcher is not connected with any of these services. They are provided to assist you if you feel that you need extra support. You can also contact your GP, your existing care team for additional support.

Alzheimer's Society
Black Country Office

Part Ground Floor, Castlemill, Burnt Tree, Tipton, West Midlands, DY4 7UF

Tel: 0121 521 3020

E-mail: blackcountryoffice@alzheimers.org.uk

Dementia UK
Head Office
2nd Floor, Resource for London, 356 Holloway Road, London, N7 6PA
Tel: 020 7697 4160
E-mail: info@dementiauk.org

Admiral Nursing DIRECT **helpline**
If you have any questions about dementia or if you need advice and support from an Admiral Nurse please contact the helpline on:
Tel: 0845 257 9406
E-mail: direct@dementiauk.org

Staffordshire Admiral Nurses
(Covers Walsall, Tipton, Bloxwich & Dudley area)
Bupa
Parklands Court Nursing Home, 56 Park Road, Bloxwich, Walsall, West Midlands, WS3 3ST
Tel: 01922 898 094

Dudley Mind - **Carers in Mind**
Mary Stevens Centre, 221 Hagley Road, Oldswinford, Stourbridge, West Midlands, DY8 2JP
Tel: 01384 442938
E-mail: natalie.roswessbruce@dudleymind.org.uk

Service Experience Desk
The Service Experience Desk provides confidential, on-the-spot advice and support in relation to the different services available from Dudley and Walsall Mental Health Partnership NHS Trust. You can contact the Service Experience Desk at:
Dudley and Walsall Mental Health Partnership NHS Trust
2nd Floor
Trafalgar House
Dudley
DY2 8PS
Tel: 0300 555 0535
E-mail: **Sed@dwmh.nhs.uk**

APPENDIX 10

CONSENT FORM

UNIVERSITY OF
BIRMINGHAM

Study Number: ....
Participant Identification Number:......................

CONSENT FORM

Title of Project: **Relationships and Coping with Aggression in Dementia**

Researcher: **Miss Holly Gibbons, Trainee Clinical Psychologist**

Please initial box

1. I confirm that I have understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time during the research interview, without giving any reason. ☐
3. I understand that the research interview will be audio-recorded ☐
4. I understand that following the research interview I will have a two-week period for reflection. The researcher will then contact me at which point I may withdraw my interview entirely or in part, without giving any reason. ☐
5. I understand that the data collected during this study will be looked at by the researcher, the researcher's academic supervisor and authorised audit representatives at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. Parts of the data may also be made available to the NHS team responsible for my care but only if any previously undisclosed issues of risk of harm should be disclosed. ☐
6. I understand that direct quotes from my interview may be published in any write-up of the data, but my name and my spouse/ partner's name, will not be attributed to any such quotes and we will not be identifiable by my comments. ☐
7. I agree to take part in the above study. ☐

.... Name of participant	.... Date	.... Signature
.... Name of researcher	.... Date	.... Signature

APPENDIX 11

Distress Protocol

The following procedure will be followed if a participant indicates they are experiencing a high level of distress or exhibit behaviours such as uncontrolled crying or shaking during the interview.

Stage 1

- Suspend the interview
- Chief Investigator will offer immediate support
- Assess mental status:
    - Tell me what thoughts you are having?
    - Tell me what you are feeling right now?
    - Do you feel safe?
    - Do you feel you are able continue with the interview?

Review

- If participant feels able to carry on, then resume interview
- If participant is unable to carry on, then go to stage 2

Stage 2

- Discontinue interview
- Encourage participant to contact their GP or carer support service for further advice/ support
- Or offer, with participant consent, for the Chief Investigator to do so on their behalf
- Where risk of harm is indicated, the appropriate NHS Trust risk management policy will be adhered to.

Follow-up

- Encourage participant to contact their GP or carer support service should they experience increased distress following the interview
- If participant consents follow up with a courtesy call

APPENDIX 12

Hierarchy of Themes

Hierarchy of themes used in the Template Analysis (TA) and corresponding descriptions of continuity dimensions (adapted from Riley et al, 2013)

HIERARCHY OF THEMES
1. Feelings 1.1. Same feelings 1.2. Different feelings
2. Person 2.1. Same person 2.2. Different person 2.3. Different when aggressive
3. Loss 3.1. Missing aspects of the person 3.2. Missing aspects of the relationship
4. Couplehood 4.1. Sharing 4.2. Affection
5. Relationship continuity 5.1. Relationship continuous 5.2. Relationship discontinuous 5.3. Relationship transformed

APPENDIX 13

Excerpts from Template Analysis

Betty

EXAMPLE QUOTATION	THEME	NUMBER OF REFERENCES
Well we were, we’ve been married 55 years and we’re very, very, happy. You know? and it was just, it’s just so sad what’s happened. I mean I still love him as much, as much as I did then.	1.1. Same feelings	7
Yes it was, like when he was his old self he was lovely.	2.1 Same Person	4
Yes, less and less yeah. Erm but then like when the aggression stopped he was more dormant. Erm he wouldn’t talk and I’d try to make conversation he would just look at me as though I was nothing and then there was times when he would talk but not very often. Once the aggression stopped he went down and down and down.	2.2 Different Person	4
Yeah. So he's sort of being strangled inside. I used to say Cyril just stop it and just think, just think what you're doing, what you're saying. And, and he'd say "what do you mean"? You've just been so nasty to me. "I wouldn't do that to you" and that was like turning the page over in a book.	2.3. Different when aggressive	19
Yeah talking to myself. And even sometimes it’s out loud. You know and I think, oh god, but who can hear me? And I’m talking to him as though he’s, well he’s not there and I’m talking to him as though he was he was not poorly. You know what I mean?	3.1. Missing aspects of the person	6
Like, let’s go down the town and let’s go and do this. And I’m, and I suddenly wake up. There’s nobody there. It’s (pause) it’s so hard, so hard. And he’s so young! He’s only 75. Um. Um. (pause).	3.2. Missing aspects of the relationship	4
	4.1	

	Sharing	
Lovely, lovely. I mean when I go to kiss him and I say 'give me a kiss', eyes are shut, you know, for the kiss. Yeah there's still that, there's still that little bit there. Erm just keep that alive, keep that alive.	4.2. Affection	1
You know, I'd only gotta yawn and he'd say 'sit down, shut your eyes for five minutes'. That's how he was you know and he used to hate to think that I'd got to go do something. He'd say 'let me do that', he wrapped me in cotton wool like I had to wrap him in cotton wool when he was poorly. The role turned.	5.3. Relationship transformed	4

Maureen

EXAMPLE QUOTATION	THEME	NUMBER OF REFERENCES
I do, I can't help but feel… I think, you know if you can think like that you've lost the love for them and er [pause] I haven't lost my love for Roy.	1.1 Same feelings	3
And when I get to the stage where I think aaw and I look at that and I think it's there in him, it's still sort of there in him you know what I mean?	2.1 Same Person	2
Yes, Roy is the old Roy not this Roy I've got now, you know. I've got pictures of me and Roy and I pick them up and that is Roy and that will always be Roy.	2.2 Different Person	3
Yes, yes because Roy was a very gentle, erm person. Never showed aggression, never erm, so that's why he's not Roy when there is the aggression and it is Roy when he's gentle.	2.3. Different when aggressive	9
Erm he's lost a lot of his character, he's lost a lot of character. He doesn't ask for anything or	3.1. Missing aspects of the person	8

anybody. He just sits in a chair you know he's lost, he's lost.		
It's strange it really is strange but as I say you get surprised how many people say "I don't know how you're still doing this for him". [pause] You just feel sometimes that it's a very lonely life. I do sometimes feel lonely when you're sitting in the house at night time, you 've got no one to talk to, you've got no one to put their arm round you, you know. It is… when you've always been such a close couple you find it hard.	3.2. Missing aspects of the relationship	4
I feel as if it's a 50-50 and I know I've lost 30% of Roy, I know that now but I still feel as if there's that 50-50 thing going through us but I just don't know what's going to go first his mental side more so or his physical side.	4.1 Sharing	2
I still tell him 2-3 times a day how much I love him and he tells me how much he loves me and when I put him to bed at night I kiss him and hug him and I tell him 'I love you to bits' and all that and he says "I love you too" he always says "and I love you too" so the love is still there and this morning he's saying "I think you are a lovely person" and sometimes I wonder if he knows exactly who I am, do you know what I mean?	4.2. Affection	1
Yeah well, we've been with each other 58 years. It's a long, long time and you'd be surprised how many people say to me "well I think you've done your lot and I think now it's your time" and "consider putting him into a home" and I sort of steer back and that, you know. I think you haven't got the same relationship as we've got. I don't know how people can find it so easy to say that.	5.1 Relationship continuous	2
Yeah doubling up. I want him to feel loved I think that's the truth of it. I want him to feel loved erm. Cos I do believe they feel it they do feel this	5.3. Relationship transformed	1

erm. As long as I know that I can put my arms around him. When they bring him… all the girls say like “oh you’re so good”… when they bring him down I’ll meet him halfway and put my arms round him and say “oh you smell lovely, oh I really fancy you today” like, you know. And it doesn’t bother him, he just goes and sits himself down, you know. So… I want to know that if Roy does go, if he does pass away, my last words have been how much I love him. So by saying it as much as I can, I want it to be there with him.		

Phil

EXAMPLE QUOTATION	THEME	NUMBER OF REFERENCES
I still love her. I still love her to bits. I mean we’ve been together over 50 years.	1.1 Same feelings	2
Well how can I put it? She’s not the woman I know. Very very occasionally but just lately she’s not the person I know and love.	2.2 Different Person	7
Yeah. When she starts talking about years ago she’s back to the girl I know. But when she starts to talk about what I just described to you she’s a completely different person. I’m the bad guy that’s caused all this. The nurse explained that it’s because I’m with her all day.	2.3. Different when aggressive	1
And also another thing with the wife. She used to sing. She used to get up on stage and sing years ago. She won prizes for singing. She don’t seem to have any interest in anything anymore. She just can’t concentrate.	3.1. Missing aspects of the person	1
Her long term memory is still good. I mean she remembers stuff from years ago before she met me. But she can’t remember something	3.2. Missing aspects of the relationship	4

that happened five minutes ago. We've always been pretty close. We used to enjoy life. I mean have a look [shows photo of wedding party].		
In the past we were very close, more of a partnership you know, we used to do everything together. Which we still do actually but you know, since she's had this dementia her nature's sort of changed.	4.1 Sharing	1
Yeah she'll grab my hand to cross the road and that sort of thing but not as it used to be.	4.2. Affection	1
Rocky, it's rocky at that moment to be honest with you but I'm trying to hold things together. Trying to explain things to her.	5.2. Relationship discontinuous	2

Rita

EXAMPLE QUOTATION	THEME	NUMBER OF REFERENCES
… I still loved him and the love is still there now even though he's changing erm but it's erm [pause] it was it was that strength of love really that was tested at times. So it wasn't that the love dwindled it's the patience went. I wasn't as patient and that in itself wasn't a good thing so	1.1 Same feelings	2
So his personality it can be there…	2.1 Same Person	2
or it can be a different person	2.2 Different Person	2
…I feel complete sadness every day because [pause] I'm mean everybody'd quoted it saying you're losing the person and you are, bit by bit losing them. You notice he can do and another time you think 'oh god he can't do that anymore' you know like making a cup of tea. He can't do that now, you know six months ago he could erm and every day, every day is changing. So you know [pause] that	3.1. Missing aspects of the person	1

frustration is there on a daily basis, that sadness is there on a daily basis and dread.		
We were talking with friends of ours who we said we would go for a weekend away to Florence, we've always wanted to go to Florence so we thought we'd have one of those city breaks once I'd retired, Sandra, the women, is very good at organising these things so I said you do it love. So she said she would but then this evening with them, Arthur was so distressed and so bad and obviously on edge and didn't cope, we cut the night short. Jackie said shall we change where we go. So we're now going to the Lakes, which is fine we'll love that and um she said we'll go to Florence together you and I. And I thought actually that's great because that way I get two holidays instead of one (laughs). But there was a little twinge of sadness because I thought well actually we won't experience this together and I know that was first I'd ever felt that and I know it was the right decision but I know more and more I am going to be doing things alone.	3.2. Missing aspects of the relationship	1
Who you know a whole group of friends who we've been seeing for the whole duration of our marriage. You know, we still get together every month or so and have weekends together.	4.1 Sharing	4
Just a hug and just… Arthur was good at, you know sort of asking how I was and stuff like that when he came home. Erm I think it was [ha] it's hard to remember but I think it was probably when we went out together we held hands a lot you know, still… and we still do actually that hasn't changed. Erm and I think that's one of the reasons why we've made it this far. I do feel that so [pause] because aggression is physical	4.2. Affection	2

as is the opposite which is a hug, a cuddle, or holding hands. I just think that helped the balance a bit. If that hadn't been there I think it would have been even harder. I haven't thought about that before. So I've just thought about that [laughing].		
Erm but hiding that was a big pressure and I didn't realise at the time what it was… how it was draining me. Erm and I subsequently had a break down mmm probably, probably around about the time… actually just before Arthur's diagnosis. Which was five years ago. Erm because things were, you know I didn't know it was Alzheimer's. And we, we split for a while. So erm, because I couldn't… his personality was changing, I didn't know what to attribute it to. That just put extra pressure on. So we did split for about nine months. In that nine months I quite conveniently broke down [laughing]. I'm laughing but it wasn't nice. But I got the right help, fortunately so that was a learning curve again.	5.2. Relationship discontinuous	2
Yeah. It's like that with a lot of things I think I just have to almost engineer things almost to be pleasurable it is almost artificial but it doesn't matter because the end result is better than if you hadn't made the effort. There's a lot of effort, but it's worth it.	5.3. Relationship transformed	9

Gladys

EXAMPLE QUOTATION	THEME	NUMBER OF REFERENCES
I wouldn't say we were close, but we were there for each other. My husband (laugh) how can I say it. He wasn't the best of lovers. He'd be at	1.1 Same feelings	3

the bottom of the list. But to me he was a good husband and a good father. So that was the main thing wasn't it? And as I said I've always loved him. From the age of 14. No other one.		
I was living with a stranger. He couldn't speak, you couldn't have a conversation with him. He wasn't my husband for about eight years really.	2.2 Different Person	8
I mean I miss, I miss him summut horrible but I don't miss what had happened to him.	3.1. Missing aspects of the person	3
I can cope with anybody being like that but with my husband's complaint that was very hard. It's having no conversation that was hard. I just didn't know what to do really.	3.2. Missing aspects of the relationship	1
You're looking after a baby really. Well I think you are.	5.2. Relationship discontinuous	5

APPENDIX 14

Reflexivity

I have several years experience of working with individuals with a dementia diagnosis and their carers, as an assistant clinical psychologist prior to clinical training. I am female, in my 30’s, and I have a close family member who has also worked in older adult healthcare for a large portion of their career. My first experience of dementia was as a young child, when my ederly aunt started to become forgetful and needed more and more support to get by. This role fell to my mother and grandmother.

My experience of working with individuals with dementia and their families, as part of a memory clinic and a specialist psychology service for adults over 65 years of age. Gave me familiarity with the range of experiences that can occur throughout dementia journeys. What particularly stood out for me was that often hopes and plans for retirement had been denied to them by the arrival of dementia, and the road ahead seemed marred by challenges and uncertainty. Hearing their stories of hard work, love and loss struck me profoundly. I recalled one particularly inspiring woman, who despite advice from healthcare practitioners was unrelenting in her determination to keep her husband at home despite the aggression involved. I wondered what had influenced her capacity to cope and how she seemed to have maintained their relationship.

I found the process of interviewing individuals in the study incredibly inspiring. I was moved by their honest accounts and ability to face challenges often with little support. I was surprised at how intense my own emotional response remained while engaging deeply with the material throughout the analysis, which further demonstrated to me the courage of each of the carers in this study.

I was mindful in allowing the data to speak for itself during the process of interpretation. Of course, my interpretations will have been influenced by my clinical psychology training and other experiences of dementia and relationships.

To provide a cohesive account of experiences related to aggression, there were much interesting and valuable data that could not be included within this paper.

While attempts were made to reduce the influence of pre-existing themes of relationship continuity, it is important to acknowledge that I sought to make connections with these themes to address the research aims and so related to them throughout the interpretation where relevant.