Data supplement to Feast et al. Behavioural and psychological symptoms in dementia and the challenges for family carers: systematic review. Br J Psychiatry, doi: 10.1192/bjp.bp.114.153684

Supplement DS1: Search strategy

Searches of studies published between 1980 and April 2012 were carried out through PsycINFO, CINAHL EBSCO (Cumulative Index to Nursing and Allied Health), Medline, EMBASE and Web of Science (including Science Citation Index – Expanded (SCI-EXPANDED), Conference Proceedings Citation Index – Science (CPCI-S), Social Science Citation Index (SSCI), and Conference Proceedings Citation Index – Social Science & Humanities (CPCI-SSH).

1. dementia exp/
2. Alzheimer's disease exp/
3. 1 OR 2
4. behavioural and psychological symptoms.mp
5. behavior disorders/
6. BPSD.mp.
7. behavior problems exp/
8. challenging behaviour.mp.
9. 4 OR 5 OR 6 OR 7 OR 8
10. elder care/
11. home care exp/
12. outpatient treatment exp/
13. significant others/
14. caregivers exp/
15. family exp/
16. caregiver.mp.
17. 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16
18. caregiver burden/
19. stress/
20. chronic stress exp/
21. physiological stress exp/
22. psychological stress exp/
23. social stress exp/
24. stress reaction exp/
25. crises exp/
26. distress exp/
27. family crises/
28. 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26
29. 3 AND 9 AND 17 AND 28

Supplement DS2: Meta-ethnographic procedure

A summary of the meta-ethnographic procedure is outlined below:

- First-order construct (carers' interpretation of experience): for the results sections where qualitative data of carers' views and accounts were present, these were extracted. For studies with quantitative data, carers' responses to standardised questionnaires about BPSD were extracted.

- Second-order construct (the authors' interpretation of carers' views of their experience): for studies with qualitative data each was examined for the authors' interpretation of their findings; for quantitative studies the authors' interpretation of their results and their conclusions were used.

- First- and second-order constructs were combined to derive conceptual groupings for each study. Shared conceptual groups were clustered into themes and then into theme categories across studies.

- Third-order construct (reviewers' interpretations of authors' interpretations of carers' experiences): key themes and concepts within theme categories using interpretations of summaries of carer experience were grouped using reciprocal (similarities between conceptual groups) and/or refutational (differences between conceptual groups) synthesis.[6]

- Line of argument [6,7]: construction of an interpretation based on an iterative process involving checking and cross-checking by the reviewers of the identified third-order constructs, to reveal individual 'hidden meanings' in each study, thus identifying a whole meaning of care experience from a set of parts.

A fuller description of each stage with greater explanation is given below:

Extracted data were tabulated, with direct or paraphrased quotes from qualitative data used to preserve the original meaning of the first-order constructs. Summaries of carers' responses to questionnaire items within quantitative data were carefully extracted in the context of participant characteristics and settings in order to collect first-order constructs. Following extraction of the first- and second-order constructs, we listed conceptual groupings for each study, to facilitate the process of exploration, juxtaposition, and comparison.[6] At this stage data extracted from both qualitative and quantitative studies were clustered in the form of themes, and were no longer distinguishable in terms of study design, enabling the synthesis of different types of data. The process of translating studies into one

another by creating themes describes the idea that each author is using their own interpretive language but not further conceptual development. Two authors (AF and NM) independently performed reciprocal and refutational analyses to summarise shared themes across studies. Relationships between conceptual groups, themes and theme categories were organised and illustrated using conceptual maps. Similar, overarching themes were grouped into theme categories, and interpretative third-order constructs (further conceptual development through views and interpretations of the synthesis team) were iteratively identified. These were cross-checked and refined by two authors (GC and EM-C).

Finally, the synthesis team (all authors) developed a 'line-of-argument' synthesis of the third-order constructs[7] to depict the most appropriate understanding of the reasons for variation in family carer responses to BPSD. The 'line-of-argument' is an interpretation of the relationship between themes which further emphasises a key concept that may be hidden within individual studies, to discover the whole from a set of parts. [6] This higher level interpretative synthesis is explanatory in nature, thus providing scope for developing new insights. In this case our aim was to improve understandings of why there is wide variation in carer responses to BPSD.

Table DS1   Characteristics of included studies

Author and date, QA	Main findings	Country setting	Sample *n*, gender, age, ethnicity	Design/analysis	Relationship type
Albinsson & Strang (2003), 77%	Investigating existential concerns of caregivers, these were feelings of responsibility, isolation through loss of communication, anticipatory grief, and role reversal.	Sweden	*n* : PwD: 20, *n:* FC: 20 Female PwD: 65% Female FC: 55% PwD: 72–95 years FC: 42–81 years	Qualitative. In-depth interviews. Data interpreted using a hermeneutic approach. Cross-sectional.	20% Sp
Allegri et al. (2006), 82%	Neuropsychiatric symptoms like delusions, hallucinations, restlessness, anxiety, euphoria, disinhibition, unusual motor behaviour, sleep disturbances, and appetite alterations were the best caregiver burden predictors.	Argentina	*n*: PwD: 82, *n:* FC: 82 Female PwD: 53.6% Female FC:81.5% PwD: 50 - 90 years FC: age range not stated but *M* 59.6 years, SD=14.8	Quantitative. Cross-sectional. Correlation and linear regression.	Sp and NSp
Allen et al. (2009), 100%	An overarching theme of *one day at a time,* reflecting a response to the perception of severe threats in the future, appeared to run throughout the young people's experiences.	England	*n* : PwD: 12 PwD: 51–64 years 0% females FC :13–24 years 58.3% female 75% (9)White 25% (3) Asian	Qualitative. Grounded theory methodology. Cross-sectional.	100% NSp
Almberg et	Comparison of caregivers who have experienced	Canada	*n*: FC: 46	Mixed methods.	Sp and NSp

Table DS1 Characteristics of included studies

Author and date, QA	Main findings	Country setting	Sample *n*, gender, age, ethnicity	Design/analysis	Relationship type
al. (1997), 77%	burnout and those who have not. Emotion-focused coping combined with problem-solving coping strategy was less associated with burnout.		71.7% female FC: average age 68.5 years PwD: 80 - 102 years	Qualitative interviews using thematic analysis and chi-squared analysis. Cross-sectional.	
Bakker et al. (2010), 80%	Exploring the experiences of a caregiver of a patient with early onset dementia. Confronted with many specific issues, one being the strain of dedication to care versus the caregiver's own future perspective.	The Netherlands	*n* : PwD:1 *n* : FC:1 1 female, 1 male PwD: 59 years	Qualitative. A single case study design. Thematic analysis. Cross-sectional.	100% Sp
Bought-wood et al. (2011), 100%	While considerable similarities exist across the experiences and perceptions of caregivers from all 4 culturally diverse communities, there were nevertheless some important distinctions across the different groups. These study findings have significant implications for those working with culturally diverse communities.	Australia	*n* : FC: 121 72.7% female FC: 17 - 90 years Arab, Chinese, Italian & Spanish	Qualitative. Thematic analysis. Cross-sectional.	Not stated
Brækhus et al. (1998), 71%	Even in mildly demented patients, symptoms of caregiver stress are frequent. Supportive strategies such as early diagnosis, information for	Norway	*n*: PwD: 92, FC: 92 PwD: 51% female PwD: *M* age 75.7 years	Quantitative. Factor analysis. Retrospective, cross-	100% Sp

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Author and date, QA	Main findings	Country setting	Sample *n*, gender, age, ethnicity	Design/analysis	Relationship type
	caregivers, and intervention strategies are discussed.			sectional.	
Bruce et al. (2000), 90%	Most caregivers suffered high levels of stress, mainly due to behaviour disturbances and care needs of the dementia sufferers. Problems with health care agencies were also reported by a majority of the caregivers to be contributors to their distress.	Australia	*n* : FC: 24 FC: 66.6% female FC: 36 - 85 years PwD: 57 - 93 years	Qualitative. Semi-structured interviews of caregivers after an aged care assessment intervention. Thematic analysis, cross-sectional.	75% Sp
Chappell et al. (1996), 76%	Aimlessness, aggressive behaviours, forgetfulness, and restlessness are correlated with heightened feelings of burden.	Canada	*n*: FC: 327 FC: 79% female FC: 26 - 90 years PwD: 65 and above	Quantitative. Multiple regression. Cross-sectional.	Sp and NSp
Gaugler et al. (2011), 77%	Caregivers who did not indicate a care-recipient's dangerous behaviour initially but did so subsequently were more likely to experience increases in burden. Quantitative study to determine the ramifications of temporal change in individual behaviour problems when accounting	USA	*n*: PwD: 4,545 *n*: FC: 4,545 PwD female 39.49% PwD 40 years and above FC: *M* age: 62.7 years 8.14% Black, 87.50% White,	Quantitative. Longitudinal. Mixed effects and Cox proportional hazard modelling.	Sp and NSp

Table DS1 Characteristics of included studies

Author and date, QA	Main findings	Country setting	Sample *n*, gender, age, ethnicity	Design/analysis	Relationship type
	for increases in care burden + time to NHA.		4.07% Hispanic, 0.29% missing		
Gitlin et al. (2010), 81%	Intervention caregivers reported less upset with all problem behaviours (*p*= .001), less negative communication (*p* =5.02), less burden (*p* = .05), and better well-being (*p* = 0.001) than controls. Fewer intervention caregivers had depressive symptoms (53.0%) than control group caregivers (67.8%, *p* = 5.02).	USA	PwD: 52.7 % female *M* age: 82.1 years FC: *n*: 272 FC: 82% female FC : 33 - 93 years 69.9% White 30.1% Other	Quantitative. Longitudinal. Analysis of co-variance, chi-squared.	Sp and NSp
Hepburn et al. (2002), 77%	Results partly confirmed that wife caregivers are more distressed than husbands, but the results also indicated these caregivers were more similar than dissimilar. Identified four distinct patterns for construction of the meaning of the caregiving experience in the caregivers' discourse.	USA	*n* : FC: 132 PwD and FC: not stated *M* age: 73 years FC: 70.5% female 129 (97.7%) White 2 (1.5%) African American 1 (0.8%) Native American	Qualitative. Constant comparative analysis was used to code open-ended interviews with 132 caregivers regarding their experiences in caregiving. Cross-sectional.	100% Sp
Hurt et al. (2008), 88%	BPSD were negatively associated with both patient and caregiver ratings of patient quality of life. The symptoms related to lower quality of life	England, Switzerland, Greece,	*n*: FC: 116, PwD: 46 PwD: range not specified *M* age: 76 years	Mixed methods. Cross-sectional. Correlational.	Sp and NSp

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Author and date, QA	Main findings	Country setting	Sample *n*, gender, age, ethnicity	Design/analysis	Relationship type
	differed between patient and caregiver ratings: depression and irritability were found to predict lower caregiver ratings of quality of life, while delusions and apathy indicated lower patient ratings	France	FC: not specified		
Lim et al. (2008), 75%	Elder's Cognitive Decrement and Activities of Daily Living had a positive indirect impact on caregiver burden through the wandering behaviour of PWDs. Impaired cognitive functioning and decreased ADL in PWD in our study did not have a direct influence on burden experienced by family caregivers.	Korea	*n* : 83, FC: 83 PwD:83 PwD 60–94 years, 55 female, 28 male FC: 20–83 years, 61 female, 22 male Korean	Quantitative. Cross-sectional descriptive.	Sp and NSp
Nagaran-tnam et al. (1998), 83%	The most common behavioural changes were aggression (59%), wandering (27%), delusions (22%), Incontinence (18%). Aggression caused the most distress to the caregiver.	Australia	*n* : PwD: 90, FC: 90 PwD: 54.4% female Male *M* age: 70.8 years Female *M* age: 77 years	Quantitative. Chi-squared. Correlational. Cross-sectional.	None identified
Nygaard et al. (1998), 84%	85% of caregivers felt despair and anger and 75% complained of chronic fatigue. There was a statistically significant correlation between	Norway	*n* :46 PwD, 46 FC PwD:71.7% female. Male *M* age 80.2 years, female *M* age	Quantitative. Analysis of variance. Cross-sectional.	Sp and NSp

Table DS1   Characteristics of included studies

Author and date, QA	Main findings	Country setting	Sample *n*, gender, age, ethnicity	Design/analysis	Relationship type
	caregiver strain and duration of symptoms, degree of dementia and deviation of behaviour. Elderly women caring for their husband and daughters caring for their parents were especially at risk.		81.4 FC: *M* 63.4 age Scandinavian		
Riedijk et al. (2006), 84%	FTD caregivers were more burdened than AD caregivers, and caregivers of patients who were demented for shorter duration had lower health-related quality of life. Caregivers of FTD patients institutionalized after shorter dementia duration were most burdened and affected in their HQoL. Overall, passive coping strategies were associated with increased burden and decreased HQoL.	The Netherlands	*n* : PwD: 153, FC:153 PwD female: 60.1% FC female: 77.1% FC: 32 - 90 years European	Quantitative. Regression analysis, analysis of covariance. Cross-sectional.	Sp and NSp
Riello et al. (2002), 80%	Caregivers of non-delusional patients, compared with the delusional patients' caregivers, reported higher levels of distress because of behavioural disturbances other than delusions. When patients were stratified into 2 groups according to median distress value, 64% of the delusional patients and 33% of the non-delusional patients showed a high	Italy	*n* : PwD: 43, FC: 43 PwD:72.1% Female Age range not stated *M:* 77 years FC not stated European	Quantitative. Correlational, and chi-squared. Cross-sectional.	Not stated

Table DS1 Characteristics of included studies

Author and date, QA	Main findings	Country setting	Sample *n*, gender, age, ethnicity	Design/analysis	Relationship type
	level of caregiver's distress.				
Rinaldi et al. (2005), 76%	Disability, specific behavioural disturbances of the patients as well as caregiver's age, type of relationship and living in the south of Italy were observed to be a major risk factor for burden, distress, depression and anxiety.	Italy	*n* : PwD: 419, FC: 419 PwD: 63% female, 48 - 99 years FC: 72% female, 16 - 89 years. European	Quantitative. Cluster analysis, multiple logistic regression. Cross-sectional	Sp and NSp
Rocca et al. (2010), 76%	Psychotic/behavioural, depressive and minimally symptomatic clusters differed for caregiver burden and lack of insight. Caregivers of the psychotic/behavioural cluster experienced the highest burden. Caregiver burden was influenced by the type of symptoms.	Italy	*n:* PwD:195 PwD: 56.9% female *M* age: 75.4 years FC: not stated European	Quantitative. Cluster analysis, analysis of variance, linear regression. Cross-sectional.	Not stated
Scott et al. (2005), 90%	Seventeen themes were identified for seven questions regarding what caregivers find challenging, the impact, and support: repetitiveness, aggression; emotional, trying diversion, learning curve; diversional techniques, decision making; losses, coping skills, support network, affect; profession intervention/ informal	Northern Ireland	*n:* FC: 13 61.5% female Ages of PwD and FC not given	Qualitative. Cross-sectional. Focus groups Content analysis.	Sp and NSp

Table DS1 Characteristics of included studies

Author and date, QA	Main findings	Country setting	Sample *n*, gender, age, ethnicity	Design/analysis	Relationship type
	support, family; assistive technology, practical support; awareness, education.				
Siriopoulos et al. (1999), 80%	Five major themes emerged from the participants' stories: loss, caregiver burden, coping methods, quality of previous relationship, and effects of AD.	USA	*n* : PwD: 8, FC: 8 PwD: 100% female, 68–90 years FC: 100% male, 64–92 years All eight FCs were White Anglo-Saxon Protestants	Qualitative. Phenomenological method. Cross-sectional.	100% Sp
Tan et al. (2005), 77%	Neuropsychiatric symptoms were positively correlated with caregiver distress. Family caregivers were significantly more distressed than professional caregivers over the delusion, agitation, depression and aberrant motor domains even though the severity of the behavioural disturbances reported were not higher.	Singapore	*n* : PwD: 85, FC: 85 PwD: 54.1% female, 53–97 years FC: Not stated Chinese: 72 Malay:6 Indian: 5 Others: 2	Quantitative. Statistical analysis included chi- multivariate regression analysis. Cross-sectional.	Sp and NSp
De Vugt et al. (2003), 77%	Investigating the relationship between behavioural problems in dementia and changes in marital relationship. Passive behaviour rather than	The Netherlands	*n*: PwD: *n* 53, FC: 53 PwD: 39.6% female PwD *M* age: 71.6 years	Mixed methods. Quantitative and qualitative interviews.	100% Sp

Table DS1 Characteristics of included studies

Author and date, QA	Main findings	Country setting	Sample *n*, gender, age, ethnicity	Design/analysis	Relationship type
	excessive behaviour has most impact on the deterioration of the marital relationship.		FC: 58.5 % female FC *M*: 68.3 years	Regression analysis. Cross-sectional.	
De Vugt et al. (2006), 96%	Patients with FTD had significantly higher levels of agitation, apathy, disinhibition and aberrant motor behaviour than did patients with AD.	The Netherlands	*n* : FC: 74 FC: 58.1 % female, Alz FC *M* age: 71.3 years, Alz PwD *M* age: 71.5 years, FTD FC *M* age: 58.5 years, FTD PwD *M* age: 59.5 years	Quantitative. Mann-Whitney U- test. Cross-sectional.	100% Sp

AD/Alz, Alzheimer's disease; CB, challenging behaviour; FC, family caregiver; FTD, frontotemporal dementia; *M*, mean; NSp, non-spousal; PwD, person with dementia; QA, quality appraisal; Sp, spousal.

Table DS2   Theme category: changes in communication

Themes	First-order constructs	Second-order constructs
Repetitive interactions [29-32]	• 19 out of 24 carers reported constant repetitions as a common source of stress.[29(p 454)] • Repetitiveness was identified as challenging.[30(p 28)] • 'Well, I think it's very stressful and it's the repeating, repeating, and repeating and you expect him to remember something and then he doesn't, and so it doesn't get done or something like that. From that end of it, it is stressful.'[31(p 221)] • Repetitive questioning described as a common problematic behaviour.[32(p 1469)]	
Decline in conversation and isolation [12, 26, 27, 33, 34]	• 'You can't have a discussion anymore, not a real discussion.'[26(p 81)] • 'She has trouble with her speech. I don't know how she's thinking, what she is thinking about. Sometimes she tries to tell me, but it is hard because of her speech.'[26(p 81)] • Communication: 'It is awful to be around a man all day who doesn't communicate. I would rather talk to someone about unimportant or stupid things, than not talk at all'.[27(p 153)] • 'It's an awful illness, because Mom no longer exists even though she's still there . . . not being able to talk with your wife or communicate in any way is the most distressing part of it.'[33(p 230)] • 'You can somehow communicate with a dead person in a grave, and that's better than visiting a living dead person when there are no signs whatsoever of communication.'[33(p 230)]	• As the illness progressed it led to more difficult or challenging behaviour. Behaviours described included lack of communication.[12(p 464)] • The patient can no longer communicate. Interviewees stated that they could no longer establish any verbal or even physical communication with the patients.[33(p 230)] • One husband states that it would be better if his wife were in a grave.[33(p 230)] • Not being able to communicate because of the demented person's memory and language deficits provided a major strain

• 'I try to talk about mutual childhood memories but can't make contact. She doesn't recognize me when I come. She uses a 'language' which I don't understand.'[34(p 687)]	and underlined the loss of a spouse with whom one could enjoy discussion and mutual memories.[34(p 687)]