

Patient and Caregiver Perspectives of Quality of Life in Dementia

An Investigation of the Relationship to Behavioural and Psychological Symptoms in Dementia

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Key Words

Quality of life · Dementia, behavioural and psychological symptoms · Alzheimer's disease · Antecedents, behaviour and consequences · Patient report · Carer report

Abstract

Background/Aims: Behavioural and psychological symptoms have a high prevalence amongst patients with dementia and can be a significant source of distress to both patients and carers. The present study explored the relationships between quality of life and behavioural and psychological symptoms in dementia (BPSD) from both patient and carer perspectives. Contextual factors surrounding the occurrence of BPSD were explored. **Methods:** Forty-six patients and 116 carers completed questionnaire measures of BPSD and quality of life. **Results:** BPSD were negatively associated with both patient and carer ratings of patient quality of life. The symptoms related to lower quality of life differed between patient and carer ratings: depression and irritability were found to predict lower carer ratings of quality of life,

whilst delusions and apathy indicated lower patient ratings. Carers were found to be poor at identifying antecedents and consequences of BPSD. **Conclusions:** The presence of BPSD is associated with lower quality of life in dementia. Interventions designed to improve the quality of life for patients should focus on the BPSD specifically associated with the patient's rating of quality of life. Information regarding the role of contextual factors in behaviour management should be made available to carers. Copyright © 2008 S. Karger AG, Basel

Introduction

Behavioural and psychological symptoms in dementia (BPSD) represent a heterogeneous group of non-cognitive symptoms and behaviours. In 1999, the International Psychogeriatric Association Consensus Group defined BPSD as: 'Symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in patients with dementia' [1]. The lifetime risk of such symp-

toms in dementia has been cited as high as 90% [2, 3]. The symptoms commonly include agitation, anxiety, depression, apathy, delusions, sleep and appetite disturbance, elation, irritability, disinhibition and hallucinations. BPSD constitute an important component of dementia being as problematic as cognitive symptoms [4].

The nature and stability of BPSD has been subject to debate [5, 6]. Rather than being a unitary concept, recent findings suggest that BPSD occur in clusters or syndromes [7, 8]. Each cluster is thought to have a different prevalence, time course, biological correlate and psychosocial disturbance [9, 10]. Prominent clusters identified in factor-analytic studies include depression, psychomotor agitation, aggression, apathy and psychosis [4, 7–9, 11].

BPSD are a common cause of distress for people with dementia as well as for their carers [12, 13]. Symptoms such as apathy, aggression and mood change are particularly associated with carer burden [14–16], often more so than cognitive problems [17]. Reductions in both patient and carer quality of life (QOL) have been related to the presence of BPSD [16, 18, 19]. Depression, in particular, has consistently been found to be associated with lower QOL in dementia patients [18, 20, 21].

However, the nature of the relationships between BPSD and QOL has yet to be fully discerned. Most work on QOL in dementia has relied on 'proxy' interviews with carers [22]. Few studies have explored the patients' own perception of their QOL. Carer judgements of patient QOL have been used because of the assumption that cognitive impairment prevents dementia patients from making a reliable statement about their QOL. However, research has demonstrated that patients with a Mini-Mental State Examination (MMSE) score as low as 10 can make reliable judgements about their QOL [23, 24]. Studies that have assessed both carer and patient perceptions of QOL have shown them to differ substantially [25, 26]. Formal and informal caregivers along with medical professionals have been found to underestimate patient QOL [27, 28].

Improving patient QOL has become a target for interventions in dementia. In order to provide effective interventions, the relationships between BPSD and QOL must be fully explored. Given the reported disparity in patient/carer QOL judgements, designing interventions around carer reports may not be effective in improving QOL from the patient's perspective. The identification of BPSD strongly associated with lower patient QOL will allow interventions to be targeted to areas of greatest need.

Furthermore, the contextual factors surrounding the occurrence of BPSD must be examined. Social and envi-

ronmental influences, along with biological and psychological ones, are thought to play a significant role in the development and maintenance of BPSD [9, 29]. However, relatively little emphasis has been placed on these to date [30–32]. The ABC (antecedents, behaviour and consequences) approach to the assessment of behaviour provides a structured method for recording and assessing contextual factors involved in the occurrence of behavioural problems [33]. It allows the environmental and social factors present before the onset of a behavioural problem, the behaviour itself and the consequences of the behaviour to be recorded [34]. Once the patterns of ABC are identified, changes can be made to environmental antecedents and/or consequences to reduce the occurrence of a behaviour. Identifying common contextual factors involved in the onset of behavioural symptoms provides potential avenues for the development of interventions to reduce the occurrence of BPSD. One way of determining these common factors is through large-scale ABC analysis.

Aims and Objectives

The primary aim of the present study was to investigate the relationships between BPSD and patient QOL as rated both by carers and the patient themselves. The secondary aim was to explore the contextual aspects of BPSD.

The work for this project was carried out by the Behavioural Problems Special Interest Group, part of the European Alzheimer's Disease Consortium (EADC). This is a network of European centres of excellence working in the field of Alzheimer's disease.

Methodology

Design

The study was based on a cross-sectional survey of a consecutive series of patients with Alzheimer's disease, mixed dementia or vascular dementia and their carers recruited from usual clinical practice. All assessments were performed during 1 session at the clinic or patient's home. The results were transmitted electronically to the University of Manchester, which acted as the study coordinating centre. Appropriate ethical permission was sought in each country.

Sample

Seven European centres (Toulouse, Nice, Lausanne, Paris, Manchester, Swindon and Thessaloniki) recruited a minimum of 20 patients attending Old-Age Psychiatry Services. One hundred and sixty-seven patients (63 males and 104 females) were recruit-

ed. In order to obtain a naturalistic sample, only limited inclusion criteria were specified. These consisted of: ICD 10 diagnosis of dementia or, in the absence of a specific aetiology, an MMSE score of 24 or below, plus a carer in regular contact with the patient and informed consent. Participants who did not meet the inclusion criteria or did not have a full data set were excluded from the analysis.

Measures

The following domains were assessed by patient and carer report: QOL, apathy, behavioural and psychological symptoms, carer distress and cognition.

Apathy. The Apathy Inventory [35] evaluates patient and carer perceptions of patient apathy on 3 visual analogue scales: emotional blunting, lack of interest and lack of initiative.

QOL. The quality of life in Alzheimer's disease measure (QOL-AD) [23] is designed to assess both patient and carer reports of patient QOL in dementia. Thirteen life domains are rated on a 4-point scale (poor, fair, good, excellent).

BPSD. The Neuropsychiatric Inventory (NPI) [36] is designed to assess the frequency and severity of neuropsychiatric disturbances in patients with dementia including: delusions, hallucinations, agitation, dysphoria, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behaviour, nighttime behaviour disturbances, and appetite and eating abnormalities. The NPI is a structured interview designed to be performed with the patient's carer. The EADC behavioural problems group also identified several common forms of BPSD not included in the NPI. These were: shouting, misidentification, cursing, sexual disinhibition, hoarding, mirror sign (failure to recognize self in a mirror) and change in personality. These were rated for frequency, severity and distress using the same scales as the NPI Caregiver Distress Scale (NPI-D).

Cognition. The MMSE [37] is a brief assessment of global cognition in dementia scored out of 30. Scores of 24 and below are indicative of a dementia syndrome. In the present study, the ranges of severity used were: mild (23–30), moderate (11–22) and severe (0–10).

Contextual Factors. The BPSD questionnaire was designed by the EADC Behavioural Problems Special Interest Group in order to investigate contextual factors surrounding BPSD. Carers were asked open-ended questions concerning the occurrence of BPSD based on the ABC approach. The questions included: triggers for the behaviour, when and where it occurs, who perceives the behaviour to be problematic and what consequences it has.

Results

Statistical Analysis

A power calculation was not undertaken due to the exploratory nature of the study. Parametric tests were used for normally distributed data and non-parametric tests for non-normal distribution. Data with a skewness or kurtosis statistic of $>\pm 1$ were assumed to be non-normally distributed. All data analysis was performed using SPSS 13.0.

Table 1. Sample characteristics (n = 46)

	Range	Mean	Standard deviation
Age, years	52–95	74.80	8.36
MMSE	6–29	16.5	6.79
QOL-AD carer	14–47	30.80	7.21
QOL-AD patient	21–51	35.13	6.42

Demographics

Of the total sample, 116 carers and 46 patients gave a QOL-AD rating. The MMSE scores of these 46 patients ranged from 6 to 29. Three of them were classified as severely cognitively impaired (MMSE 0–10), 22 moderately impaired (MMSE 11–22) and 21 had mild impairment (MMSE 23–30). Table 1 shows the sample characteristics.

Patient QOL Ratings

Two-tailed Spearman's correlations were performed to assess the relationships between BPSD, apathy, age, duration of illness and cognition and patients' QOL scores as shown in table 2. No significant differences were found between the male and female ratings of QOL using independent-samples t tests ($t = 1.022$, d.f. = 44, $p = 0.313$, lower CI = -1.912 , upper CI = 5.843).

Two significant relationships were found between patient ratings of QOL and BPSD using 2-tailed Spearman's correlations. Associations were found between patient rating of QOL and delusions ($\rho = -0.340$, $p = 0.021$) and lack of interest on the patient apathy rating scale ($\rho = -0.495$, $p = 0.000$). A total of 31 comparisons were made. Applying the Bonferroni correction for multiple comparisons (only correlations significant at 0.001 should be accepted), the correlation between lack of interest and QOL remains significant.

Forty-six of the 167 patients rated their QOL. They were compared with those not assessing QOL on a range of measures. A number of significant differences were found between the 2 groups as shown in table 3 using independent-samples t tests and Mann-Whitney U tests.

The group who rated their QOL had higher MMSE scores, were more disinhibited, had fewer hallucinations, had more sleep and appetite disturbances and were less verbally abusive than the patients who did not evaluate their QOL. The subjects who rated their QOL were significantly older than those who did not. After applying the Bonferroni correction, the only remaining significant difference was in MMSE scores. A box plot of MMSE scores is shown in figure 1.

Table 2. Correlations between BPSD and carer and patient ratings of patient QOL

	Carer correlation coefficient (n = 116)	Patient correlation coefficient (n = 46)		Carer correlation coefficient (n = 116)	Patient correlation coefficient (n = 46)
Age	0.000	-0.056	<i>Apathy Inventory</i>		
Illness duration	-0.067	0.027	Emotional blunting (carer)	-0.512***	0.191
Time spent with carer	-0.289**	0.034	Lack of initiative (carer)	-0.410***	-0.123
MMSE	0.311**	0.087	Lack of interest (carer)	-0.517***	-0.166
<i>NPI</i>			Apathy Inventory total (carer)	-0.528***	-0.082
Delusions	-0.408***	-0.340*	Emotional blunting (patient)	-0.233	0.041
Hallucinations	-0.291**	0.103	Lack of initiative (patient)	-0.312*	-0.095
Agitation	-0.346***	-0.096	Lack of interest (patient)	-0.199	-0.495***
Depression	-0.416***	0.085	Apathy Inventory total (patient)	-0.304*	-0.277
Anxiety	-0.158	-0.080	<i>NPI-D</i>		
Elation	-0.070	-0.076	Delusions distress	-0.384***	-
Apathy	-0.416***	-0.069	Hallucinations	-0.286**	-
Disinhibition	-0.151	-0.152	Agitation distress	-0.325***	-
Irritability	-0.336***	-0.035	Depression	-0.277**	-
Motor	-0.140	0.007	Anxiety	-0.224*	-
Sleep disturbance	-0.303**	-0.065	Elation	0.134	-
Appetite disturbance	-0.085	0.098	Apathy distress	-0.414***	-
Total NPI score	-0.598***	-0.090	Disinhibition	-0.109	-
<i>BPSD</i>			Irritability distress	-0.332***	-
Shouting or screaming	-0.225*	-0.206	Motor	-0.122	-
Misidentification	-0.207*	-0.202	Sleep disturbance distress	-0.365***	-
Cursing	0.009	-0.103	Appetite disturbance	-0.140	-
Sexual disinhibition	-0.129	-0.150	Total NPI distress score	-0.547***	-
Hoarding	-0.191*	0.176	<i>BPSD distress</i>		
Mirror sign	-0.204*	0.161	Shouting or screaming	-0.203*	-
Change in personality	-0.204*	-0.054	Misidentification	-0.195*	-
			Cursing	-0.013	-
			Sexual disinhibition	-0.230*	-
			Hoarding	-0.180	-
			Mirror sign	-0.242**	-
			Change in personality	-0.257**	-

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.0009$ (significant after Bonferroni correction applied).

Carer QOL Ratings

Two-tailed Spearman's correlations were performed to assess the relationships between BPSD, apathy, age, duration of illness, time spent with carers, cognition and carer ratings of QOL. A total of 52 comparisons were made. Applying the Bonferroni correction, 16 relationships were found to be significant at 0.0009 as shown in table 2. NPI and apathy scores showed high negative correlations with carer ratings of patient QOL as demonstrated in figure 2.

Variables significantly associated with QOL were entered into a multiple regression analysis using the enter method to determine the strongest predictors of carer

ratings of QOL. A significant model emerged ($F_{16, 92} = 5.979$, $p = 0.000$). Depression, irritability, apathy and carer distress at irritability all significantly predicted carer QOL ratings as shown in table 4.

Comparison of Patient and Carer Rating of QOL

A comparison of patient and carer ratings of QOL was performed using a paired-samples t test, which revealed that the carers rated patient QOL significantly lower than the patients themselves did ($t = -2.416$, d.f. = 44, $p = 0.020$, lower CI = -5.299, upper CI = -0.479).

A QOL difference score was computed by subtracting the patient QOL score from the carer QOL score. A nega-

Table 3. Group differences between patients with and without a QOL rating

	QOL score (n = 46)	No QOL score (n = 121)	Statistic (U/t)	p values
Mean age, years	78 (58–95)	75 (52–90)	1,763.00	0.029*
Mean MMSE \pm SD	20.80 \pm 5.40	14.57 \pm 6.70	t (107) = 5.98	0.000***
<i>NPI</i>				
Delusions	0.00 (0–12)	0.00 (0–9)	2,662.00	0.582
Hallucinations	0.00 (0–1)	0.00 (0–4)	2,432.00	0.032*
Agitation	0.00 (0–9)	0.00 (0–12)	2,435.00	0.164
Depression	1.00 (0–9)	0.00 (0–6)	2,471.00	0.243
Anxiety	0.00 (0–8)	0.00 (0–8)	2,607.00	0.480
Apathy	1.00 (0–12)	2.00 (0–12)	2,462.00	0.233
Elation	0.00 (0–6)	0.00 (0–12)	2,746.00	0.825
Irritability	1.00 (0–8)	0.00 (0–12)	2,655.50	0.614
Abberant motor activity	0.00 (0–8)	0.00 (0–12)	2,716.50	0.775
Disinhibition	0.00 (0–12)	0.00 (0–12)	1,933.50	0.047*
Sleep disturbances	0.00 (0–12)	0.00 (0–12)	1,853.00	0.015*
Appetite disturbances	0.00 (0–12)	0.00 (0–12)	1,753.00	0.003***
NPI total score	13.00 (0–60)	14.00 (0–49)	2,423.50	0.197
<i>BPSD</i>				
Shouting or screaming	0.00 (0–3)	0.00 (0–12)	2,010.00	0.010**
Misidentification	0.00 (0–12)	0.00 (0–9)	2,591.50	0.400
Sexual disinhibition	0.00 (01)	0.00 (0)	2,587.50	0.549
Hoarding	0.00 (0–12)	0.00 (0–12)	2,588.50	0.369
Mirror sign	0.00 (0–3)	0.00 (0–9)	2,573.50	0.142
Change in personality	0.00 (0–12)	0.00 (0–4)	2,663.00	0.864
Apathy Inventory (carer)	8.00 (0–36)	4.00 (0–36)	1,889.50	0.748
Apathy Inventory (patient)	1.00 (0–21)	0.00 (0–15)	653.00	0.135

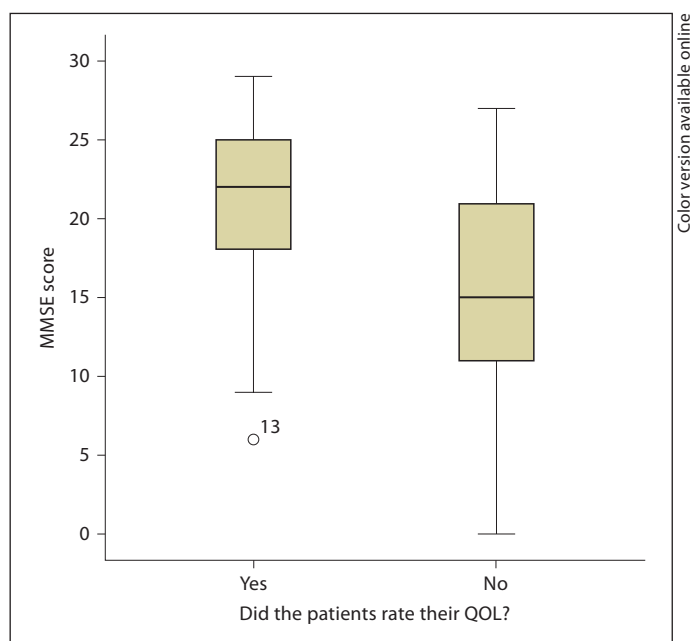
Medians and ranges are given for non-normally distributed data, and means and SD for normally distributed data. * p < 0.05, ** p < 0.01, *** p < 0.002 (significant after Bonferroni correction has been applied).

tive difference score indicates that the patients rated their QOL higher than their carer. The QOL difference scores are plotted in figure 3. Each point represents a patient-carer pair. Out of 45 pairs, 28 patients scored higher than their carer, whilst only 17 carers scored higher than the patient.

Investigation of Contextual Factors

The carers were asked a series of open-ended questions designed to investigate the contextual aspects of the most problematic BPSD displayed by the patient. In order to analyze the data, the responses were grouped into common factors. An overview of the qualitative information gathered is given below.

Fig. 1. Box plot of MMSE scores for patients who rated their QOL and those who did not. Patient 13 had an outlier result.



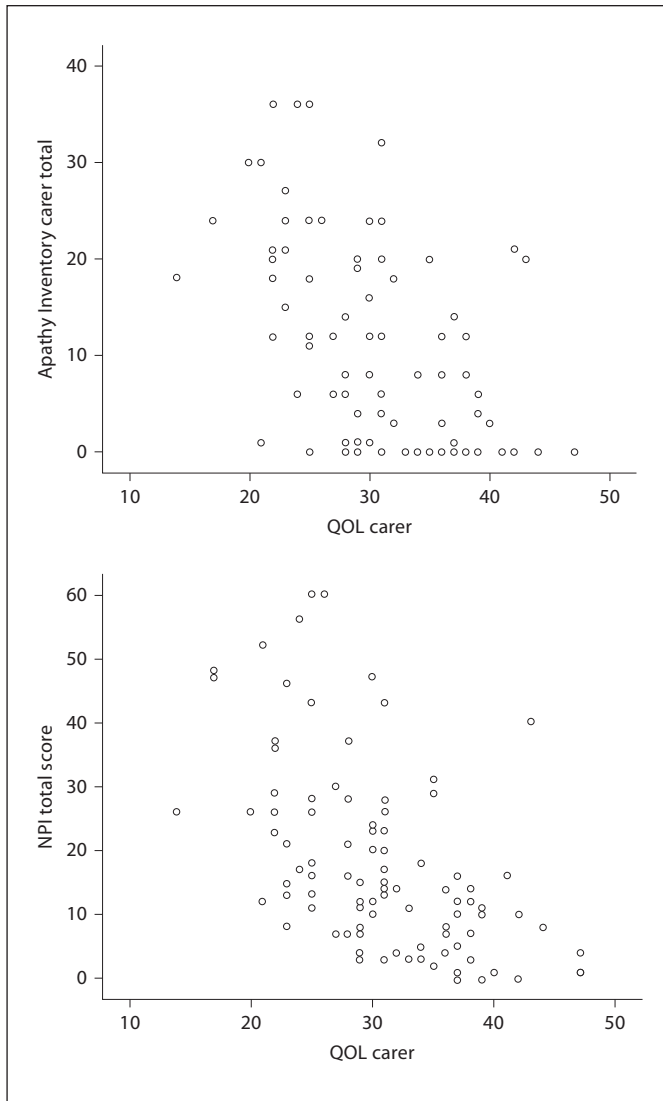


Fig. 2. Scatter plots of NPI and Apathy Inventory scores and carer ratings of patient QOL.

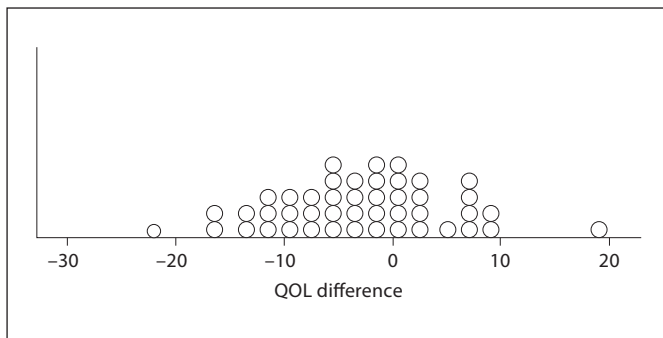


Fig. 3. Plot of patient and carer QOL difference scores.

Table 4. β Weights and significance levels of predictors of carer ratings of patient QOL

	Standardized β	Adjusted R^2
		0.45
Delusions	-0.01	
Agitation	-0.07	
Depression	-0.27**	
Apathy	-0.09	
Irritability	-0.34**	
NPI total score	-0.07	
Emotional blunting (carer)	5.09*	
Lack of initiative (carer)	6.86*	
Lack of interest (carer)	6.64*	
Apathy Inventory total score (carer)	-15.69*	
Delusions distress	-0.60	
Agitation distress	-0.05	
Apathy distress	-0.96	
Irritability distress	2.58*	
Sleep distress	-1.52	
NPI-D total score	-0.085	

* $p < 0.05$, ** $p < 0.01$.

Problematic Behaviours. The carers identified apathy as the most problematic behaviour (23.6%), followed by disturbance of sleep and anxiety. Elation, misidentification and appetite disturbances were the least commonly cited behaviours. Interestingly, 33% of the behaviours considered as most problematic were not those most frequently rated on the NPI.

When the Behaviour Is a Problem. Whilst 48.6% of the carers were unable to indicate what time of day the behaviours were a problem, 17.4% identified it to be in the morning, 14.6% of the carers reported behaviour to be problematic at any time and 9% at night.

Where the Behaviour Is a Problem. Where the behaviour was a problem, this could not be specified by 57.6% of the carers, whilst 29.4% identified it to occur at home.

What Starts the Behaviour. Triggers for the behaviour could not be found by 73.6% of the sample. Eight percent reported problematic behaviour to occur when the patient was tired.

Consequences of the Behaviour. The carers were questioned regarding the consequences of behaviour. The 2 largest groups for whom the behaviour had consequences were, as would be expected, patients (16%) and carers (38.9%). In contrast to the other contextual questions, only 13.9% of the carers were unable to identify who the behaviour had consequences for.

Who Finds the Behaviour a Problem. For the majority of cases the spouse found the behaviour to be problematic (54.4%), followed by the daughter (20.8%) and the son (5.4%). Only in 4.7% of the sample was the behaviour deemed to be a problem to the patient.

Discussion

Quality of Life

The present study set out to investigate patient and carer ratings of patient QOL and their relationship to BPSD. The patients were found to consider their QOL significantly higher than carers did. The observed discrepancy between patient and carer ratings of QOL replicates previous research [16, 38]. Consistent with this finding, the relationships identified between BPSD and QOL differed for patient and carer ratings of QOL. Significant correlations were found between patients' ratings of QOL and frequency of delusions and apathy. Irritability and depression, as measured by the NPI, were the most significant predictors of carer ratings of patient QOL, followed by apathy and carer distress at patient irritability. These are known indicators of disease severity; patients with greater cognitive impairment display more depression, agitation and psychosis [39]. In the present study, lower ratings of QOL made by patients were associated with symptoms such as delusions, which patients are likely to find distressing. Conversely, poor ratings of QOL made by carers were observed for symptoms such as irritability and depression, which carers are likely to find more distressing than patients.

More than a quarter of the patients in the study were able to give their views and talk reliably about their perceptions of their QOL. Reliability was assumed if the patient was able to comprehend and respond to the assessment. Although most QOL studies have used 'proxy' interviews with carers, the present evaluation demonstrates that people with dementia can express their perceptions of QOL, consistent with the findings of Godlove-Mozley et al. [24].

A number of implications arise from the results. Firstly, the present study has demonstrated that patients with MMSE scores as low as 6 can provide ratings of QOL. Secondly, the presence of BPSD is associated with poorer QOL as rated by both patients and carers. Stronger relationships were observed between BPSD and QOL than cognition and QOL as measured by the MMSE. The findings suggest that treatments designed to alleviate BPSD may have beneficial effects for patient QOL. Finally, pa-

tient ratings of QOL are not associated with the same factors as carer ratings of patient QOL. While lower QOL ratings were correlated with BPSD in both groups, the specific symptoms differed. When designing interventions to improve patient QOL, it is essential that BPSD related to lower patient ratings of QOL are targeted. Basing interventions on factors linked to carer-rated QOL may have little to no therapeutic benefit for patients.

Limitations

A number of potential limitations of the study must be considered.

Firstly, only 46 of the 167 patients rated their QOL. A number of significant differences were found between those evaluating their QOL and those not doing so, including higher MMSE scores. However, of the 46 patients, 16 were recruited in Manchester, 20 in Swindon and 10 in Lausanne, suggesting that failure to provide a QOL rating was related to the centre, rather than the patient. Details on failure to obtain a patient QOL rating were not recorded, although this pattern of results suggests that a much greater proportion of the total sample were able to give a QOL score than actually did. This observation indicates that differences identified between the group of patients that assessed their QOL and the group that did not are not necessarily related to the ability to give a QOL rating.

Secondly, the study employed a mixed sample. All patients had a diagnosis of dementia (Alzheimer's disease, vascular dementia or mixed dementia) or an MMSE score of 24 or below. It is possible that QOL ratings differ between dementia subtypes. However, previous studies of QOL have employed mixed samples [38, 40]. To our knowledge, no investigations of QOL and dementia subtypes have been undertaken.

Thirdly, clinicians were not asked about their confidence that the patient was able to give a reliable rating of QOL. However, all assessments were conducted in specialist dementia centres across Europe by experienced clinicians. All clinicians were asked to gain a rating of QOL only if they felt the patient could give a reliable report.

Fourthly, due to the large number of comparisons made, the chance of spurious significance occurring is increased. Therefore, some caution must be applied when interpreting findings significant at the 0.05 level. However, when the Bonferroni correction for multiple comparisons was employed, only 1 correlation (delusions and patient QOL) was no longer significant. Further research is recommended to confirm the associations found in the present trial.

Finally, the study was a pilot investigation of the link between BPSD and QOL. A number of variables which could potentially impact on this relationship were not measured in the present study. The influence of medication and socio-economic status on both BPSD and QOL merits further investigation. Future research may benefit from the inclusion of these variables.

Contextual Factors

The qualitative data investigating contextual factors surrounding the occurrence of BPSD represents the first attempt to examine these aspects in a structured way using a large patient population. Whilst the data provide unique insights into the antecedents and consequences of behaviour, a large proportion of the responses were non-specific. It is unclear whether language barriers caused misunderstanding, making answering the questions difficult, or whether the majority of carers were unable to identify antecedents and consequences. The use of more detailed questioning or the provision of sample answers may provide more accurate information in future research.

Alternatively, the large number of non-responses may reflect a low level of knowledge of the ABC approach amongst dementia carers. Carers who are not aware of this method may not have previously analyzed patient behaviour and the contextual factors surrounding it. The ABC approach has been shown to be useful in behaviour management [34, 41]. Providing information about it to carers may help them to identify, and consequently modify, the contextual aspects influencing BPSD.

Despite the many non-responses, the study demonstrated that large-scale ABC analysis is feasible and provides a framework upon which to build future trials. Further research may reveal relationships between specific BPSD and contextual factors.

Conclusion

The present study investigated QOL, its relationship with BPSD and contextual factors surrounding the occurrence of BPSD in patients with dementia. The findings highlight the difference in ratings of patient QOL made by carers and patients, demonstrating the importance of asking patients to assess their own QOL. To our knowledge, the study attempted the first large-scale investigation of the ABC approach to behavioural management. Although a large proportion of non-specific responses were found, the results present an opportunity for future research to refine questioning techniques. Furthermore, the findings suggest that providing information regarding the ABC approach to carers may be beneficial.

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References

- 1 Finkel S, Burns A: Behavioral and Psychological Symptoms of Dementia (BPSD): a clinical and research update. *IPA Bulletin* 1999;16:2.
- 2 Davis KL, Marin DB, Kane R, Patrick D, Peskind ER, Raskind MA, Puder KL: The Caregiver Activity Survey (CAS) development and validation of a new measure for caregivers of persons with Alzheimer's disease. *Int J Geriatr Psychiatry* 1997;12:978-988.
- 3 Marin DB, Green CR, Schmeidler J, Harvey PD, Lawlor BA, Ryan TM, Aryan M, Davis KL, Mohs RC: Noncognitive disturbances in Alzheimer's disease: frequency, longitudinal course, and relationship to cognitive symptoms. *J Am Geriatr Soc* 1997;45:1331-1338.
- 4 Lawlor B: Managing behavioural and psychological symptoms in dementia. *Br J Psychiatry* 2002;181:463-465.
- 5 Finkel S: Behavioral and psychological signs and symptoms of dementia: implications for research and treatment. *Int Psychogeriatr* 1996;8(suppl 3):215-255.
- 6 McShane R: What are the symptoms of behavioural and psychological symptoms of dementia? *Int Psychogeriatr* 2002;12(suppl 1):147-154.
- 7 Mirakhor A, Craig D, Hart DJ, McLlroy SP, Passmore A: Behavioural and psychological syndromes in Alzheimer's disease. *Int J Geriatr Psychiatry* 2004;19:1035-1039.
- 8 Petrovic M, Hurt C, Collins D, Burns A, Camus V, Liperoti R, Marriot A, Nobili F, Robert P, Tsolaki M, Vellas B, Verhey F, Byrne EJ: Clustering of behavioural and psychological symptoms in dementia: a European Alzheimer's Disease Consortium (EADC) study. *Acta Clin Belg* 2007;62:426-432.
- 9 Robert P, Verhey FR, Byrne EJ, Hurt C, De Deyn PP, Nobili F, Riello R, Rodriguez G, Frisoni GB, Tsolaki M, Kyriazopoulou N, Bullock R, Burns A, Vellas B: Grouping for behavioural and psychological symptoms in dementia: clinical and biological aspects - consensus paper of the European Alzheimer Disease Consortium. *Eur Psychiatry* 2005; 20:490-496.
- 10 Aalten P, Verhey F, Boziki M, Bullock R, Byrne EJ, Camus V, Caputo M, Collins D, De Deyn PP, Elina K, Frisoni GB, Girtler N, Holmes C, Hurt C, Marriot A, Meccoci P, Nobili F, Ousset PJ, Reynish E Salmon E, Tsolaki M, Vellas B, Robert PH: Neuropsychiatric syndromes in dementia: results from the European Alzheimer's Disease Consortium (EADC). I. *Dement Geriatr Cogn Disord* 2007;24:457-463.

- 11 Frisoni GB, Rozzini L, Gozetti A, Binetti G, Zanetti O, Bianchetti A, Trabucchi M, Cummings JL: Behavioural syndromes in Alzheimer's disease: description and correlates. *Dement Geriatr Cogn Disord* 1999;10:130-138.
- 12 Donaldson C, Tarrier N, Burns A: The impact of the symptoms of dementia on caregivers. *Br J Psychiatry* 1997;170:62-68.
- 13 Tariot PT: Agitation; in Qizilbash N, Schneider LS, Chui H, Tariot P, Brodaty H, Kaye J, Erkinjuntti T (eds): Evidence-Based Dementia Practice. Oxford, Blackwell Publishing, 2002, pp 705-707.
- 14 Donaldson C, Tarrier N, Burns A: Determinants of carer stress in Alzheimer's Disease. *Int J Geriatr Psychiatry* 1998;13:248-256.
- 15 Ballard CG, Neill D, O'Brien J, McKeith I, Ince P, Perry R: Anxiety, depression and psychosis in vascular dementia: prevalence and associations. *J Affect Disord* 2000;59:97-106.
- 16 Burns A: The burden of Alzheimer's disease. *Int J Neuropsychopharmacol* 2000;3:31-38.
- 17 Pruchno RA, Resch NL: Husbands and wives as caregivers: antecedents of depression and burden. *Gerontologist* 1989;29:159-165.
- 18 Matsui T, Nakaaki S, Murata Y, Sato J, Shinagawa Y, Tatsumi H, Furukawa TA: Determinants of the quality of life in Alzheimer's disease patients as assessed by the Japanese version of the Quality of Life - Alzheimer's Disease Scale. *Dement Geriatr Cogn Disord* 2006;21:182-191.
- 19 Banerjee S, Smith SC, Lamping DL, Harwood RH, Foley B, Smith P, Murray J, Prince M, Levin E, Mann A, Knapp M: Quality of life in dementia: more than just cognition - an analysis of associations with quality of life in dementia. *J Neurol Neurosurg Psychiatry* 2006;77:146-148.
- 20 Karlawish JHT, Casarett D, Klocinski J, Clark CM: The relationship between caregivers' global ratings of Alzheimer's disease patients' quality of life, disease severity, and the caregiving experience. *J Am Geriatr Soc* 2001;49:1066-1070.
- 21 Selai CE, Trimble MR, Rossor M, Harvey RJ: Assessing quality of life in dementia: preliminary psychometric testing of the Quality of Life Assessment Schedule (QOLAS). *Neuropsychol Rehabil* 2001;11:219-243.
- 22 Monteiro IM, Auer SR, Boksay I, Reisberg B: New and promising modalities for assessment of behavioural and psychological symptoms of dementia. *Int Psychogeriatr* 2000;12(suppl 1):175-178.
- 23 Logsdon RG, Gibbons LE, McCurry SM, Teri L: Quality of life in Alzheimer's disease: patient and caregiver reports. *J Mental Health Ageing* 1999;5:21-32.
- 24 Godlove-Mozley C, Huxley P, Sutcliffe C, Bagley H, Burns A, Challis D, Cordingley L: 'Not knowing where I am doesn't mean I don't know what I like': cognitive impairment and quality of life responses in elderly people. *Int J Geriatr Psychiatry* 1999;14:776-783.
- 25 Ready RE, Ott BR, Grace J: Patient versus informant perspectives of quality of life in mild cognitive impairment and Alzheimer's disease. *Int J Geriatr Psychiatry* 2004;19:256-265.
- 26 Jönsson L, Andreasen N, Kilander L, Soininen H, Waldemar G, Nygaard H, Winblad B, Jönhagen M, Hallikainen M, Wimo A: Patient- and proxy-reported utility in Alzheimer's disease using the EuroQoL. *Alzheimer Dis Assoc Disord* 2006;20:49-55.
- 27 Sprangers MAG, Aaronson NK: The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease: a review. *J Clin Epidemiol* 1992;45:743-760.
- 28 Karlawish JH, Casarett DJ, James, BD, Tenhave T, Clark CM, Asch DA: Why would caregivers not want to treat their relative's Alzheimer's disease? *J Am Geriatr Soc* 2003; 51:1391-1397.
- 29 International Psychogeriatric Association: Behavioural and Psychological Symptoms of Dementia Educational Pack 2003. Illinois, IPA, 2003.
- 30 McShane R, Gormley N: Assessment and management of behavioural and psychological symptoms of dementia (BPSD); in Cope land J, Abou-Saleh MT, Blazer DT (eds): *Geriatric Psychiatry*. Chichester, Wiley, 2002, pp 241-244.
- 31 Cohen-Mansfield J, Werner P: Longitudinal changes in behavioural problems in old age: a study in an adult day care population. *J Gerontol A Biol Sci Med Sci* 1998;53:M65-M71.
- 32 Awata S: A practical study on the early diagnosis and early care system for the elderly with dementia living in depopulated regions: a network system of public mental health services connected with local general hospital in north-western Miyagi. *Jpn J Geriatr Psychiatry* 1999;10:339-346.
- 33 Mahoney E, Volicer L, Hurley A: *Challenging Behaviors in Dementia*. Baltimore, Health Professional Press, 2000.
- 34 Omelan C: Approach to managing behavioural disturbances in dementia. *Can Fam Physician* 2006;52:191-199.
- 35 Robert PH, Clairnet S, Benoit M: The apathy inventory: assessment of apathy and awareness in Alzheimer's disease, Parkinson's disease and mild cognitive impairment. *Int J Geriatr Psychiatry* 2002;17:1099-1105.
- 36 Cummings J, Mega M, Gray K, Rosenberg-Thompson S, Carusi DA, Gornbein J: The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology* 1994;44:2308-2314.
- 37 Folstein ME, Folstein SE, McHugh PR: 'Mini-Mental State': a practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975;12:189-198.
- 38 Sands L, Ferreira P, Stewart AL, Brod M, Yaffe K: What explains differences between dementia patients' and their caregivers' ratings of patients' quality of life? *Am J Geriatr Psychiatry* 2004;12:272-280.
- 39 Levy ML, Cummings JL, Fairbanks LA, Bravi D, Calvani M, Carta A: Longitudinal assessment of symptoms of depression, agitation, and psychosis in 181 patients with Alzheimer's disease. *Am J Psychiatry* 1996; 153:1438-1443.
- 40 Thorgrimsen L, Selwood A, Spector A, Royan L, de Madariaga Lopez M, Woods RT, Orrell M: Whose quality of life is it anyway? The validity and reliability of the Quality of Life-Alzheimer's Disease (QoL-AD) Scale. *Alzheimer Disease Assoc Disord* 2003;17:201-208.
- 41 Cohen-Mansfield J: Non-pharmacological interventions for inappropriate behaviours in dementia. *Am J Geriatr Psychiatry* 2001;9: 361-381.