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The influence of attachment style and relationship quality on quality of life and psychological distress in carers of people with epileptic and non-epileptic seizures

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Conflicts of interest

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Highlights

- Carers for people with seizure disorders (epilepsy and psychogenic non-epileptic seizures) experience high levels of depression and anxiety.
- Mental wellbeing in this group correlates with relationship conflict, and with both patient and carer avoidant and anxious attachment styles.
- These associations differ between carers for people with epilepsy and for those with psychogenic non-epileptic seizures.

Keywords

Epilepsy; psychogenic non-epileptic seizures; attachment; relationships; depression; anxiety; carer wellbeing

Abstract

Background: Seizure disorders affect not only the individual living with seizures, but also those caring for them. Carer-patient relationships may be influenced by, and have an influence on, some aspects of living with seizure disorders – with potentially different interactions seen in epilepsy and psychogenic non-epileptic seizures (PNES).

Objectives: We study the influence of patient and carer attachment style and relationship quality on carer wellbeing and psychological distress, and explore whether these associations differ between carers for people with epilepsy and for those with PNES.

Methods: Consecutive adult patients with epilepsy (N = 66) and PNES (N = 16) and their primary informal carers completed questionnaires about relationship quality, attachment style, and psychopathological symptom burden. We use correlation analysis to identify associations between relationship quality, attachment style, and carer depression, anxiety, and wellbeing; and to explore differences in these associations between carers for people with epilepsy and for those with PNES.

Results: Overall, 25.3% of carers for people with epilepsy or PNES had scores above the clinical cutoff for depression and 39.6% for anxiety; significantly more carers for people with PNES reported clinically significant depression (47.1% vs. 20.0%) but there was no difference in anxiety rates likely to be of clinical relevance. Correlations differed significantly between carers for people with epilepsy and for those with PNES in terms of patient quality of life and carer anxiety ($r_E = -0.577$, $r_{PNES} =$ -0.025); seizure severity and carer depression ($r_E = 0.248$, $r_{PNES} = -0.333$) and mental wellbeing ($r_E =$ -0.356, $r_{PNES} = 0.264$); patient depression and carer anxiety ($r_E = 0.387$, $r_{PNES} = -0.266$); and patient anxious attachment and carer anxiety ($r_E = 0.382$, $r_{PNES} = 0.155$).

Significance: Clinically evident levels of psychological distress are prevalent amongst carers for people with epilepsy and PNES. Clinical and relationship variables affect carer quality of life differently depending on whether care is provided for individuals with epilepsy or PNES.

Introduction

Seizure disorders do not only affect the individual living with seizures, but also their family and friends.^{1–4} This can arise through the assumption of a caring role. Carers make a vital contribution to the management of chronic illnesses; in the United Kingdom the economic value of unpaid care has been estimated to be roughly equivalent to the budget of the National Health Service.⁵ However, there is also an effect on carers' wellbeing, with many carers reporting that they have experienced worsening mental health as a result of caring.⁶ Seizure disorders are unpredictable and paroxysmal, resulting in highly variable levels of care need. When such care needs arise, they may require

specialist skills and experience, such as the administration of emergency medication or identifying whether a seizure requires urgent medical attention. Seizures may not only cause distress or embarrassment to patients, but also to carers.⁷ Caring for patients with seizures has social implications (e.g. driving regulations). Research suggests that carer quality of life (QoL) is worse for carers for people with seizures than for carers providing support to people with other chronic neurological conditions.^{8,9} Understanding the needs of carers of people with seizures is complicated by the heterogeneous nature of seizure disorders. There are potentially important differences in the functioning of families living with epilepsy (an enduring predisposition to abnormal excessive or synchronous neuronal activity in the brain)¹⁰ or those with Psychogenic Nonepileptic seizures (PNES, episodic disturbances of normal functioning and reduced self-control thought to represent a stimulus response shaped by a range of psychological mechanisms).^{11–13}

The small but growing literature on the health and wellbeing of carers of people with seizure disorders has identified a range of potential influencing factors. Characteristics of the seizure disorder itself (e.g. severity) may affect carer wellbeing,⁷ though the evidence is conflicting. ^{8,14,15} However, its contribution appears less important than psychological and social factors¹⁶ such as practical support,^{12,14,17} coping strategies,⁹ level of carer education¹⁸ or employment.¹⁹ There is conflicting evidence of the effects of patient QoL and mental health on carers.^{9,15,18} There is, to our knowledge, little quantitative research directly addressing the extent to which the carer-patient relationship affects carer wellbeing. However, relationship problems have been found to affect the wellbeing and psychological symptom burden of people with seizure disorders.^{4,20,21} Qualitative research involving carers of people living with epilepsy, meanwhile, has consistently highlighted concerns about carers' QoL and its effect on the functioning of close social support networks (especially families).^{1,3}

One aspect of relationship quality that has received attention in the literature on carer wellbeing is attachment style. 'Attachment' is a term originating from studies of child-caregiver relationships that describes affective bonds formed with significant others.²² People may vary in their attachment styles – for example, they may be predominantly 'avoidant', rejecting care/attention and electing not to seek care or contact from others; or 'anxious', showing a high degree of dependence on other parties in relationships and distress at detachment from them.^{22,23} Research on attachment in the carer-patient relationship in dementia identifies potential contributions of both patient and carer attachment style to carer wellbeing and psychological symptom burden.^{23,24}

Understanding carer-patient relationships from the carer perspective may be of therapeutic importance in the management of seizure disorders. Family dysfunction is considered an important

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predisposing factor to PNES^{4,13,25,26} and may mediate the association between PNES and child abuse.²⁷ The family environment may also affect severity and impact of epilepsy,² and carer psychological symptom burden may worsen patient QoL. For example, depression in carers for children with epilepsy is associated with lower health-related QoL and greater behavioural disturbance in the child.²⁸

The objective of this study is to explore the influence of the carer-patient relationship on the QoL of carers for people with epilepsy (CfE) and carers for people with PNES (CfPNES), , with particular emphasis on relationship quality and attachment style of both carer and patient. Specifically, we aim to establish whether anxious or avoidant attachment styles on the part of patient or carer, poor patient-carer assessments of relationship quality, or markers of patient health and disease severity (such as symptom burden, quality of life, and psychological distress), are associated with poorer health-related quality of life (HRQoL) or increased psychological symptom burden in carers. We also seek to explore whether these associations differ between CfE and CfPNES

Methods

Setting and participants

Patient and carer participants were recruited prospectively from adult patients consecutively attending outpatient seizure clinics between July 2014 and February 2015. All patients were under the care of specialists at Sheffield Teaching Hospitals and Chesterfield Royal Hospital NHS Foundation Trusts in the UK. Ethical review and approval, patient identification, selection, inclusion, exclusion and consent was all performed as reported previously.²⁰ We asked patient participants to identify their main informal carer and sought consent for patient and carer participation separately. We provided both patients and carers with questionnaires at their first clinic appointment after initial approach, with the option to complete questionnaires on the day or to return them by post. Diagnoses of epilepsy or PNES were confirmed by the participants' neurologists. All patients diagnosed with PNES experienced seizures involving impairment of consciousness. Seizure diagnoses were based on all available clinical information. Diagnoses had not been confirmed by video-EEG recording of typical event in all cases. Patients with mixed seizure disorders were excluded from the study.

Questionnaire instruments

Demographic questionnaire

We sought information on age, gender, ethnicity, marital status, and number of household members from both patient and carer participants.

Carer status

We asked carers to self-report the number of hours spent on caring responsibilities daily, whether or not they were the sole carer for the patient, whether they were paid or had received training in caring for people with seizure disorders, and their subjective assessment of the level of risk to the patient from their seizure disorder.

Health-related Quality of Life

We assessed patient HRQoL using the 10-item Quality of Life in Epilepsy (QOLIE-10) questionnaire.²⁹ The QOLIE-10 assesses seven components of HRQoL (seizure worry, general QoL, emotional wellbeing, energy-fatigue, cognitive functioning, medication effects, and social functioning) to give an overall score from 0 (worst possible) to 100 (best possible). QOLIE-10 scores correlate well with those on the larger QOLIE-31 instrument and the questionnaire items show good test-retest reliability.²⁹

We assessed carer HRQoL using the 12-item Short-Form General Health Survey (SF-12), a generic HRQoL instrument developed for the RAND Medical Outcomes Study, which uses 12 Likert-rated items to generate a Physical Component Summary (PCS) and Mental Component Summary (MCS), each scored from 0 (lowest level of HRQoL) to 100 (highest HRQoL).³⁰ The SF-12 reliably reproduces the performance of the larger SF-36 instrument and the PCS and MCS both show excellent internal reliability, test-retest reliability, and construct validity.^{30,31}

Depression and anxiety

We used the nine-item Patient Health Questionnaire $(PHQ-9)^{32}$ to measure severity of depressive symptom burden, and the seven-item Generalised Anxiety Disorder measure $(GAD-7)^{33}$ for anxiety symptoms in both patients (pPHQ-9, pGAD-7) and carers (cPHQ-9, cGAD-7). Both show high internal and test-retest reliability. Conventional thresholds for clinically significant depression and anxiety are represented by scores PHQ-9 \geq 10 and GAD-7 \geq 8 respectively.

Attachment style

We assessed anxious and avoidant attachment styles using the short-form 29-item Attachment Style Questionnaire (ASQ),³⁴ for both patients (pASQ) and carers (cASQ). Each of the 29 items is rated on a six-point scale to generate continuous scores for avoidant (16 items) and anxious (13 items) attachment subscales, with overall avoidant and anxious attachment scores calculated as the mean response across all questions corresponding to each scale, ranging from 1 (low avoidance/anxiety) to 6 (high avoidance/anxiety). The ASQ is a parsimonious measure of general adult attachment, with both subscales showing good internal reliability.³⁵

Relationship quality

We explored carer-patient relationship quality using the Quality of Relationships Inventory (QRI)³⁶ from both carer (cQRI) and patient (pQRI) perspectives. This 25-item measure yields subscales with high internal reliability for relationship conflict, support, and depth, with each item rated on a four-point scale and subscale scores calculated as mean responses to each item loading onto the subscale, with scores ranging from 1 (low conflict/support/depth) to 4 (high conflict/support/depth).

Statistical analysis

To examine differences between CfE and CfPNES on demographic, carer status, psychopathology, quality of life and relationship and attachment variables we performed independent samples *t*-tests, χ^2 tests or Fisher's exact tests as appropriate. Patient descriptive results are given elsewhere.²⁰ The distribution of most variables deviates significantly from normality, so to assess association of patient and carer characteristics with carer psychopathology and HRQoL we calculated Spearman correlation coefficients (*t*-tests for binary variables) for CfE and CfPNES (Table 2). As the recommended procedure for testing for equality of Spearman correlation coefficients, we tested for differences in correlations between CfE and CfPNES via Fisher's *z*-transformation (treating Spearman coefficients as Pearson coefficients).³⁷ Given the exploratory nature of this study, we use an uncorrected α =0.05 to define statistical significance.

We performed all statistical analysis in IBM SPSS Statistics for Windows, v24.0 (Armonk, NY: IBM Corp).

Results

Descriptive analyses

We recruited a total of 23 patients with PNES and 72 with epilepsy. Of these, 16 and 66 respectively identified a main carer who consented to participate and completed all questionnaires. We present comparisons between CfE and CfPNES groups in Table 1. CfE were older than CfPNES (mean 57.48 years v 44.18 years, t(81) = 4.62, p<0.001) but all other differences between the two carer groups were non-significant. 25.3% of carers had scores above the clinical cut-off for depression (PHQ-9≥10), and 39.6% for anxiety (GAD-7≥8). CfPNES were significantly more likely than CfE to report PHQ-9 scores above the cut-off for depression (20.0% v 47.1%, p = 0.03 [2-sided Fisher's exact test]). Rates for anxiety did not differ significantly between CfE and CfPNES.

Correlation analyses

Table 2 shows correlation coefficients for all comparisons for CfE and CfPNES, and highlights both statistically significant correlations separately for CfE and CfPNES, and those for which correlations were significantly different between CfE and CfPNES.

Carers for people with epilepsy

Carer anxiety: Carer depression (cPHQ-9), mental wellbeing (SF12-MHS), anxious attachment (cASQ-anxious), carer assessment of relationship conflict (cQRI-conflict), patient HRQoL (QOLIE-10), patient anxious (pASQ-anxious) and avoidant (pASQ-avoidant) attachment, and patient anxiety (pGAD-7) and depression (pPHQ-9) all significant correlated with carer anxiety (cGAD-7) in CfE.

Carer depression: Carer anxiety (cGAD-7), mental wellbeing, avoidant (cASQ-avoidant) and anxious attachment style, and patient HRQoL, anxious and avoidant attachment, anxiety and depression all significantly correlated with carer depression in CfE.

Carer mental wellbeing: Carer anxiety, depression, anxious and avoidant attachment, and relationship conflict, and patient HRQoL, anxiety, depression, and anxious and avoidant attachment, as well as number of seizures and seizure severity (LSSS), all significantly correlated with carer mental wellbeing in CfE.

Carer physical wellbeing: Patient assessment of depth of carer relationship correlated with carer physical wellbeing in CfE.

Carers for people with PNES

Carer anxiety: The only significant correlations with carer anxiety in CfPNES were carer depression, mental wellbeing, and anxious attachment style.

Carer depression: Hours of care provided per day, carer anxiety, mental wellbeing, and anxious attachment style were significantly correlated with depression in CfPNES.

Carer mental wellbeing: Carer anxiety, depression, anxious attachment, assessment of relationship support (cQRI-support), and patient HRQoL significantly correlated with carer mental wellbeing in CfPNES.

Carer physical wellbeing: Duration of the seizure disorder (years) and patient assessment of relationship support (pQRI-support) correlated significantly with carer physical wellbeing in CfPNES.

Comparison of correlations between carer groups

There were several significant differences in correlation coefficients between CfE and CfPNES. Of particular note, several measures of patient HRQoL, psychopathology, and seizure severity showed correlations with carer wellbeing and psychological symptom burden in opposite directions between CfE and CfPNES: seizure severity and carer depression ($r_E = 0.248 \text{ v} r_{PNES} = -0.333$; p = 0.049); seizure severity and carer mental HRQoL ($r_E = -0.356 \text{ v} r_{PNES} = 0.264$; p = 0.034); and patient depression and carer anxiety ($r_E = 0.387 \text{ v} r_{PNES} = -0.266$; p = 0.025). However, it should be noted that while the correlations for the CfPNES group were opposite to predictions, they were all non-significant.

Patient HRQoL and carer anxiety also correlated in CfE, but not CfPNES ($r_E = -0.577 \text{ v} r_{PNES} = -0.025$; p = 0.043).

There was also a significant difference in the correlations between patient anxious attachment and carer anxiety ($r_{\rm E} = 0.382 \text{ v} r_{\rm PNES} = 0.155$; p = 0.007).

Discussion

Our results add weight to the assertion that the emotional and health effects of seizure disorders do not remain confined to individuals experiencing seizures, but instead extend through interpersonal relationships to others around them. They suggest that while some of these effects are felt by CfE and CfPNES alike, in other respects diagnosis importantly interacts with these relationships. We therefore discuss the implications of our results for CfE and CfPNES separately, then the salient differences between groups.

Epilepsy

We found that the feature most strongly correlated with carer wellbeing in this study was the HRQoL of the patient. The association between patient HRQoL and carer depression and anxiety is consistent with van Andel *et al.*'s earlier research,⁹ and replicates findings in caregivers for people with other chronic conditions.³⁸ As with previous research, while we found that severity of the seizure disorder (LSSS and seizure frequency) did correlate with poorer carer mental wellbeing, those correlations were not as strong as those with psychological and relationship variables.^{7,8,14–16} Although the strongest correlations were observed between patient and carer psychological variables, indicating that patient distress may have the strongest effects on carer psychopathology and wellbeing, the correlations demonstrated with relationship variables and attachment suggest these factors are also relevant to carers.

PNES

The feature most strongly correlated with carer wellbeing in CfPNES was the presence of an anxious attachment style in carers. This association is, to our knowledge, a novel finding in carers of patients with seizure disorders. Similar effects of attachment style on psychological symptom burden have previously been found in carers for people with dementia,²³ where they were found to be mediated to a significant extent by dysfunctional coping strategies. Families of people with PNES tend to use a different set of coping strategies than families of people with epilepsy,^{13,39} and family dysfunction including insecure attachment is thought to be implicated in the aetiology of PNES.^{4,25,27} In general, there were fewer significant correlations between carer psychopathology and wellbeing and our predictor variables in CfPNES than in CfE. This may represent the smaller sample size of CfPNES; alternatively, patient-carer relationships in the CfPNES may have been more heterogeneous than those in the CfE group, making associations between our variables of interest less apparent across all CfPNES.

Comparison

Our analysis of the difference in correlations between CfE and CfPNES highlights some further discrepancies that may merit further exploration and shed light on the influence of the carer-patient relationship on carers' wellbeing. There were significant disparities across a range of correlational variables. Of particular interest, several measures of patient seizure burden and wellbeing had different directions of correlation with carer QoL and psychological symptom burden in CfE and CfPNES. For example: seizure severity correlated positively with depressive symptoms and low mental HRQoL in CfE, but positively in CfPNES; patient depressive symptoms correlated positively with carer anxiety in CfE but negatively in CfPNES. While the results of such analyses must be read with caution due to the small sample of CfPNES (some of the correlations in the CfPNES group consequently falling short of our defined threshold for statistical significance), these results suggest that some CfPNES may experience the patient's care needs as an active source of mental wellbeing, perhaps through helping to shape their perception of self in a caring role or through a sense of jointly fighting adversity (for instance related to deficient health service provisions for patients with PNES). Qualitative research suggests that the caring role can be a source of carer wellbeing and help to shape and define the caregiver's identity.^{3,40,41} While this process may be constructive, it also opens the possibility that such 'carer gain' could prove to be a perpetuating factor in PNES and a potential target for relationship-focussed therapeutic interventions.

Given that ours was a cross-sectional study and that we can therefore not infer the direction of the relationship between different variables, our data are also consistent with the interpretation that the severity of PNES could deteriorate as the HRQoL of the carer improves. It has been hypothesised

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that (at least some) PNES may function to communicate distress and elicit care.⁴² In carer-patient relationships in which this was the case, attempts by a CfPNES to encourage more independence from the patient (for instance by spending less time with them or providing less support) could feel quite threatening to the patient, and cause an increase of somatic expressions of distress, for instance in the form of PNES.

Not all of the significant differences in correlations between the CfPE and CfPNES groups were in different directions (e.g. the associations of carer anxiety with patient HRQoL and patient anxious attachment). In each of these cases, the correlation was stronger in CfE than CfPNES but in both, it pointed in the same direction. As suggested above, this may be an artefact of the small size of the CfPNES group or suggest that CfPNES represent a more heterogeneous population than CfE, showing less uniformity in factors influencing wellbeing.

Our results also serve to confirm various other determinants of carer wellbeing and psychological symptom burden identified previously. Carer wellbeing and psychopathology were not significantly associated with patient diagnosis, consistent with previous evidence that carer QoL does not differ between CfE and CfPNES.¹²

Future directions

Despite suggestions that the connections between attachment and wellbeing in dementia are condition-specific,²⁴ connections between attachment, coping and wellbeing in carers for people with seizure disorders may prove a fruitful avenue for future research, particularly given evidence that dysfunctional coping has a marked influence on wellbeing in CfE.⁹ Future research should also explore the extent to which these associations are affected by patients' diagnoses. The existence of a potential moderating influence of diagnosis is tentatively supported by our correlation analysis, which showed a significant difference in the correlation between patient anxious attachment style and carer anxiety between CfE and CfPNES.

Limitations

Some significant limitations of the study should be borne in mind. Given the exploratory nature of this study we performed only a correlational analysis of associations between variables and make no claims regarding direction of causation. As already mentioned above, small numbers in the CfPNES group limit the extent to which we can explore patients' diagnoses as a moderating factor in the analyses performed; given the theoretical reasons to believe diagnosis might play such a role, this is a notable area for future research. We did not exclude patients from recruitment whose diagnoses had not been 'proven' by video-EEG. While this decision decreases the level of certainty about PNES or epilepsy diagnoses, our study may better reflect clinical reality in less highly specialised services

and make our sample more representative of the total seizure disorder population.⁴³ The possibility of collinearity between some of our independent variables and the dependent variables of interest may also explain some of the observed significant associations. Future work with a larger study sample permitting moderation analysis and formal assessment of collinearity via logistic regression would help to overcome some of these limitations.

Conclusion

We conclude that the carer-patient relationship, in particular attachment style, makes an important contribution to wellbeing in carers for people with seizure disorders, though potentially in different ways for CfE and CfPNES. Given the observed interactions between patients' key interpersonal relationships and the severity and level of disability associated with seizure disorders, our findings highlight the importance of paying attention to carer-patient relationships in these conditions.

References

- Epilepsy Society. Connecting with carers: Carers of people with epilepsy share their needs and experiences. http://www.epilepsysociety.org.uk/sites/default/files/connectingwithcarersJanuary2012.pdf. Published 2012. Accessed August 28, 2013.
- 2. Ellis N, Upton D, Thompson P. Epilepsy and the family: a review of current literature. *Seizure*. 2000;9(1):22-30. doi:10.1053/seiz.1999.0353
- 3. Harden J, Black R, Chin RFM. Families' experiences of living with pediatric epilepsy: A qualitative systematic review. *Epilepsy Behav*. 2016;60:225-237. doi:10.1016/j.yebeh.2016.04.034
- 4. LaFrance WC, Alosco ML, Davis JD, et al. Impact of family functioning on quality of life in patients with psychogenic nonepileptic seizures versus epilepsy. *Epilepsia*. 2011;52(2):292-300. doi:10.1111/j.1528-1167.2010.02765.x
- Webber D, Payne C. Chapter 3: Home produced 'adultcare' services Office for National Statistics. In: *Household Satellite Account Compendium*. London: Office for National Statistics; 2016. https://www.ons.gov.uk/economy/nationalaccounts/satelliteaccounts/compendium/househol

dsatelliteaccounts/2005to2014/chapter3homeproducedadultcareservices#gross-value-addedof-informal-adult-care. Accessed August 13, 2018.

- 6. Carers UK. *State of Caring 2017*. Carers UK; 2017. carersuk.org/stateofcaring. Accessed March 26, 2018.
- 7. Thompson PJ, Upton D. The impact of chronic epilepsy on the family. *Seizure*. 1992;1(1):43-48. doi:10.1016/1059-1311(92)90054-5
- 8. Petruzzi A, Rigamonti A, Finocchiaro CY, et al. Psychological features and quality of life in 50 adult patients with epilepsy and their caregivers from the Lecco epilepsy center, Italy. *Epilepsy Behav*. 2017;71:13-16. doi:10.1016/j.yebeh.2017.03.024

- 9. van Andel J, Westerhuis W, Zijlmans M, Fischer K, Leijten FSS. Coping style and health-related quality of life in caregivers of epilepsy patients. *J Neurol*. 2011;258(10):1788-1794. doi:10.1007/s00415-011-6013-1
- 10. Fisher Robert S., Acevedo Carlos, Arzimanoglou Alexis, et al. ILAE Official Report: A practical clinical definition of epilepsy. *Epilepsia*. 2014;55(4):475-482. doi:10.1111/epi.12550
- 11. Brown RJ, Reuber M. Towards an integrative theory of psychogenic non-epileptic seizures (PNES). *Clin Psychol Rev.* 2016;47:55-70. doi:10.1016/j.cpr.2016.06.003
- 12. Karakis I, Montouris GD, Piperidou C, Luciano MS, Meador KJ, Cole AJ. Patient and caregiver quality of life in psychogenic non-epileptic seizures compared to epileptic seizures. *Seizure Eur J Epilepsy*. 2014;23(1):47-54. doi:10.1016/j.seizure.2013.09.011
- 13. Wood BL, McDaniel S, Burchfiel K, Erba G. Factors distinguishing families of patients with psychogenic seizures from families of patients with epilepsy. *Epilepsia*. 1998;39(4):432-437.
- 14. Mahrer-Imhof R, Jaggi S, Bonomo A, et al. Quality of life in adult patients with epilepsy and their family members. *Seizure*. 2013;22(2):128-135. doi:10.1016/j.seizure.2012.11.012
- 15. Van Andel J, Zijlmans M, Fischer K, Leijten FSS. Quality of life of caregivers of patients with intractable epilepsy. *Epilepsia*. 2009;50(5):1294-1296. doi:10.1111/j.1528-1167.2009.02032.x
- 16. Rawlings GH, Brown I, Reuber M. Predictors of health-related quality of life in patients with epilepsy and psychogenic nonepileptic seizures. *Epilepsy Behav*. 2017;68:153-158. doi:10.1016/j.yebeh.2016.10.035
- 17. Karakis I, Cole AJ, Montouris GD, San Luciano M, Meador KJ, Piperidou C. Caregiver Burden in Epilepsy: Determinants and Impact. Epilepsy Research and Treatment. doi:10.1155/2014/808421
- Gutierrez-Angel AM, Martinez-Juarez IE, Hernandez-Vanegas LE, Crail-Melendez D. Quality of life and level of burden in primary caregivers of patients with epilepsy: Effect of neuropsychiatric comorbidity. *Epilepsy Behav*. 2018;81:12-17. doi:10.1016/j.yebeh.2018.01.034
- 19. Ohaeri JU, Awadalla AW, Farah AA. Quality of life in people with epilepsy and their family caregivers. An Arab experience using the short version of the World Health Organization quality of life instrument. *Saudi Med J.* 2009;30(10):1328-1335.
- 20. Green B, Norman P, Reuber M. Attachment style, relationship quality, and psychological distress in patients with psychogenic non-epileptic seizures versus epilepsy. *Epilepsy Behav*. 2017;66:120-126. doi:10.1016/j.yebeh.2016.10.015
- 21. Jones B, Reuber M, Norman P. Correlates of health-related quality of life in adults with psychogenic nonepileptic seizures: A systematic review. *Epilepsia*. 2015;57(2):171-181. doi:10.1111/epi.13268
- 22. Bowlby J. Attachment and Loss Vol. 1: Attachment. London: Pimlico; 1982.
- 23. Cooper C, Owens C, Katona C, Livingston G. Attachment style and anxiety in carers of people with Alzheimer's disease: results from the LASER-AD study. *Int Psychogeriatr*. 2008;20(3):494-507. doi:10.1017/S104161020700645X

- 24. Nelis SM, Clare L, Whitaker CJ. Attachment in people with dementia and their caregivers: A systematic review. *Dementia*. 2014;13(6):747-767. doi:10.1177/1471301213485232
- 25. Brown RJ, Reuber M. Psychological and psychiatric aspects of psychogenic non-epileptic seizures (PNES): A systematic review. *Clin Psychol Rev.* 2016;45:157-182. doi:10.1016/j.cpr.2016.01.003
- 26. Griffith JL, Polles A, Griffith ME. Pseudoseizures, families, and unspeakable dilemmas. *Psychosomatics*. 1998;39(2):144-153. doi:10.1016/S0033-3182(98)71361-1
- 27. Salmon P, Al-marzooqi SM, Baker G, Reilly J. Childhood Family Dysfunction and Associated Abuse in Patients With Nonepileptic Seizures: Towards a Causal Model. *Psychosom Med.* 2003;65(4):695-700. doi:10.1097/01.PSY.0000075976.20244.D8
- 28. Ferro MA, Speechley KN. Depressive symptoms among mothers of children with epilepsy: a review of prevalence, associated factors, and impact on children. *Epilepsia*. 2009;50(11):2344-2354. doi:10.1111/j.1528-1167.2009.02276.x
- 29. Cramer JA, Perrine K, Devinsky O, Meador K. A brief questionnaire to screen for quality of life in epilepsy: the QOLIE-10. *Epilepsia*. 1996;37(6):577-582.
- 30. Ware JE, Gandek B. Overview of the SF-36 Health Survey and the International Quality of Life Assessment (IQOLA) Project. *J Clin Epidemiol*. 1998;51(11):903-912.
- 31. Brazier JE, Harper R, Jones NM, et al. Validating the SF-36 health survey questionnaire: new outcome measure for primary care. *BMJ*. 1992;305(6846):160-164.
- 32. Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. *JAMA*. 1999;282(18):1737-1744.
- Spitzer RL, Kroenke K, Williams JBW, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. *Arch Intern Med*. 2006;166(10):1092-1097. doi:10.1001/archinte.166.10.1092
- 34. Feeney J, Noller P, Hanrahan P. Assessing adult attachment. In: Sperling M, Berman W, eds. *Attachment in Adults: Clinical and Developmental Perspectives*. New York, NY: Guilford Publications; 1994:128-152.
- 35. Karantzas GC, Feeney JA, Wilkinson R. Is less more? Confirmatory factor analysis of the Attachment Style Questionnaires. *J Soc Pers Relatsh*. 2010;27(6):749-780. doi:10.1177/0265407510373756
- 36. Pierce GR, Sarason IG, Sarason BR. General and relationship-based perceptions of social support: Are two constructs better than one? *J Pers Soc Psychol*. 1991;61(6):1028.
- 37. Myers L, Sirois MJ. Spearman Correlation Coefficients, Differences between. In: *Encyclopedia of Statistical Sciences*. American Cancer Society; 2004. doi:10.1002/0471667196.ess5050
- Chung ML, Moser DK, Lennie TA, Rayens MK. The effects of depressive symptoms and anxiety on quality of life in patients with heart failure and their spouses: testing dyadic dynamics using Actor-Partner Interdependence Model. J Psychosom Res. 2009;67(1):29-35. doi:10.1016/j.jpsychores.2009.01.009

- 39. Stanhope N, Goldstein LH, Kuipers E. Expressed emotion in the relatives of people with epileptic or nonepileptic seizures. *Epilepsia*. 2003;44(8):1094-1102.
- 40. Hughes N, Locock L, Ziebland S. Personal identity and the role of 'carer' among relatives and friends of people with multiple sclerosis. *Soc Sci Med*. 2013;96:78-85. doi:10.1016/j.socscimed.2013.07.023
- Epilepsy Society. Connecting with Carers: Carers of People with Epilepsy Share Their Needs and Experiences. The Epilepsy Society; 2012. http://www.epilepsysociety.org.uk/sites/default/files/connectingwithcarersJanuary2012.pdf. Accessed March 26, 2018.
- 42. Robson C, Drew P, Walker T, Reuber M. Catastrophising and normalising in patient's accounts of their seizure experiences. *Seizure*. 2012;21(10):795-801. doi:10.1016/j.seizure.2012.09.007
- 43. McGonigal A, Oto M, Russell AJC, Greene J, Duncan R. Outpatient video EEG recording in the diagnosis of non-epileptic seizures: a randomised controlled trial of simple suggestion techniques. *J Neurol Neurosurg Psychiatry*. 2002;72(4):549-551. doi:10.1136/jnnp.72.4.549

Tables

Table 1

	Carers for epilepsy Carers for		Overall (N=83)	
	(<i>N</i> =66)	PNES (<i>N=</i> 17)		
Demographic characteristics				
Age (mean +- SD)	57.5 (10.6)*	44.2 (10.5)*	54.8 (11.8)	
Gender (n, %F)	37 (56.1%)	7 (41.2%)	44 (53.0%)	
Ethnic group (n, %White British)	65 (98.5%)	15 (88.2%)	80 (96.4%)	
Carer status characteristics				
Paid (n, %paid)	12 (22.2%)	2 (13.3%)	14 (16.9%)	
Sole carer? (n, %lone carer)	40 (60.6%)	11 (64.7%)	51 (61.4%)	
Hours of care daily (mean +-SD)	13.3 (9.8)	10.9 (9.2)	12.9 (9.7)	
Level of patient risk (n, %severe)	27 (40.9%)	2 (13.3%)	29 (34.9%)	
Carer Psychopathology and HRQoL				
Depression/cPHQ-9 (mean +-SD)	5.6 (4.9)	8.2 (6.3)	6.1 (5.3)	
Anxiety/cGAD-7 (mean+-SD)	6.2 (5.6)	8.2 (6.0)	6.6 (5.7)	
Physical well-being/SF-12 physical	49.2 (9.9)	48.6 (11.9)	49.1 (10.3)	
(mean+-SD)				
Mental well-being/SF-12 mental	46.2 (11.0)	43.2 (11.2)	45.6 (11.0)	
(mean+-SD)				
Carer relationship quality/cQRI				
Support (mean+-SD)	2.8 (0.9)	3.2 (0.5)	2.9 (0.8)	
Conflict (mean+-SD)	2.9 (0.6)	2.0 (0.5)	2.0 (0.6)	
Depth (mean+-SD)	3.4 (0.6)	3.6 (0.3)	3.4 (0.5)	
Carer attachment style/cASQ				
Avoidant	3.1 (0.8)	3.4 (0.6)	3.2 (0.8)	
Anxious	2.7 (1.0)	2.9 (0.9)	2.7 (1.0)	

Table 1. Sample characteristics for the full sample and for CfE and CfPNES. *Statistically significant difference between CfE and CfPNES; all other differences not significant.

Table 2

	Carer measures of mental health and wellbeing								
Variable	Anxiety		Depression		Physical well-		Mental well-being		
					being		_		
	CfE	CfPNES	CfE	CfPNES	CfE	CfPNES	CfE	CfPNES	
Seizure									
characteristics									
Duration in years	0.039	0.134	-0.050	-0.146	-0.141	-0.601*	-0.049	0.231	
No. seizure/4 weeks	0.174	-0.215	0.176	-0.335	0.198	0.505	-0.347*	-0.011	
Seizure severity	0.173	-0.229	0.248	-0.333	0.168	0.230	- 0.356 *	0.264	
(LSSS)									
Carer									
characteristics									
Hours care per day	0.146	0.425	0.173	.571*	-0.076	0.000	-0.221	-0.363	
Carer									
Psychopathology									
and HRQoL			**	**			**	*	
Anxiety	**	**	0.806**	0.845**	0.115	-0.420	-0.717**	-0.548*	
Depression	0.806**	0.845**			0.081	-0.297	-0.633**	-0.648*	
Physical well-being	0.115	-0.420	0.081	-0.297			-0.162	-0.196	
Mental well-being	-0.717**	-0.548*	-0.633**	-0.648*	-0.162	-0.196			
Carer relationship									
quality									
Support	-0.147	-0.241	-0.005	-0.399	0.051	0.196	0.162	0.498 [*]	
Conflict	0.269*	0.079	0.165	0.270	-0.147	0.071	-0.317*	-0.362	
Depth	-0.171	-0.097	-0.081	-0.002	0.000	0.142	0.217	0.104	
Carer attachment									
style									
Avoidant	0.134	0.328	0.271*	0.278	-0.026	-0.016	-0.327*	-0.037	
Anxious	0.269*	0.616*	0.263*	0.618*	-0.013	-0.011	-0.300*	-0.697**	
Patient									
psychopathology									
and HRQoL	**		**				**	*	
Quality of life	-0.577	-0.025	-0.521	-0.191	0.003	-0.162	0.478	0.646	
Anxiety	0.301	-0.053	0.327	0.249	-0.024	0.224	-0.340	-0.299	
Depression	0.387*	-0.266	0.349*	-0.167	0.072	0.102	-0.432**	-0.022	
Patient relationship									
quality						*			
Support	-0.078	0.050	-0.080	-0.183	-0.123	-0.499*	0.135	0.224	
Conflict	0.222	-0.216	0.212	0.006	-0.072	0.112	-0.168	0.053	
Depth	0.050	0.200	0.163	-0.087	-0.297	-0.372	0.002	0.115	
Patient attachment									
style	**		*				*		
Avoidant	0.422	-0.413	0.335	-0.213	0.087	0.340	-0.366	-0.112	
Anxious	0.382	0.155	0.336 [*]	0.218	0.209	-0.007	-0.457**	-0.203	

Table 2. Summary of correlation analyses for CfE and CfPNES. Significant differences in correlations are marked in **bold**.

For all variables, higher scores indicate higher levels of the relevant variable (e.g. high SF12-MHS =

high mental wellbeing, high GAD-7 = high anxiety, high ASQ-avoidant = highly avoidant attachment style).

*Statistically significant result (p<0.05).

**Robustly significant result (Holm-Bonferroni correction, FWER=0.05).