

**OBJECTIVES:** Multiple sclerosis (MS) and Alzheimer's Disease (AD) are chronic and progressive diseases that have the potential to impose a significant burden on both caregivers and the immediate families of patients. Extensive literature has documented MS and AD caregiver burden on physical and mental health; but there are no direct comparisons of MS and AD caregivers. This study examined the extent of MS caregiver burden compared to non-caregivers and caregivers of AD patients. **METHODS:** Data were obtained from the 2009 National Health and Wellness Survey administered online to a US representative adult sample (N=75,000). Respondents reported health status, quality of life, work productivity, healthcare utilization and caregiver status. Multivariable regressions, adjusting for key characteristics (e.g., age, gender, marital status, depression), were conducted to explore differences between MS caregivers (n=215) vs. non-caregivers (n=69,224), as well as MS caregivers vs. AD caregivers (n=1,341). Rate ratios (RR) and regression weights (b) are reported. **RESULTS:** Compared to non-caregivers, MS caregivers had significantly greater activity impairment (RR=1.41; p=0.01) and poorer mental (b=-1.44; p=0.015), physical (b=-1.96; p=0.002), and health utility scores (b=-0.03; p=0.002), along with more traditional healthcare provider visits (RR=1.46; p<0.0001), ER visits (RR=2.16; p<0.0001), and hospitalizations (RR=2.20; p=0.001) after covariate adjustment. Compared to AD caregivers, MS caregivers had greater activity impairment (RR=1.29; p=0.044) and more ER visits (RR=1.60; p=0.017) and hospitalizations (RR=1.92; p=0.008) after covariate adjustment. Work productivity differences were not observed in comparison with either group, potentially due to the small number of employed MS caregivers in the sample (n=126). **CONCLUSIONS:** MS caregivers had significantly more burden compared with non-caregivers. In addition, the results suggest an even greater burden to these individuals than observed among AD caregivers. The results of this analysis of a national survey reveal the hidden toll of those providing care for MS patients and highlights the need to recognize their burden so that appropriate measures can be implemented.

#### PND39

##### MULTIPLE SCLEROSIS PATIENTS REPORT IMPROVEMENTS IN FATIGUE AND COGNITIVE FUNCTIONING AFTER ONE YEAR OF NATALIZUMAB TREATMENT

Stephenson JJ<sup>1</sup>, Agarwal SS<sup>2</sup>, Kern DM<sup>1</sup>, Kamat SA<sup>1</sup>

<sup>1</sup>HealthCore, Inc., Wilmington, DE, USA, <sup>2</sup>Biogen Idec, Wellesley, MA, USA

**OBJECTIVES:** To evaluate changes in patient reported fatigue and cognitive function after one year of natalizumab treatment in multiple sclerosis (MS) patients. **METHODS:** The study population consists of MS patients initiating natalizumab treatment who agreed to participate in a 12 month longitudinal study. Patients reported experiences with natalizumab using validated patient-reported outcome (PRO) measures prior to natalizumab treatment initiation (BL) and after 3<sup>rd</sup>, 6<sup>th</sup> and 12<sup>th</sup> infusion. The current analysis reports change in fatigue and cognition from baseline through the 12<sup>th</sup> natalizumab infusion. Fatigue was measured by the 5-question Modified Fatigue Impact Scale-5 (MFIS-5, score range 0-20) with lower scores indicating lower impact of fatigue on physical, cognitive, and psychosocial functioning; cognitive function was measured by the 6-question Medical Outcomes Study Cognitive Functioning Scale (MOS-Cog Scale, score range 6-36) with higher scores indicating better reasoning skills, memory, concentration, ability to start several actions at one time and ability to react to what is said or done. Regression analysis was used to control for BL covariates such as age, years since MS diagnosis, number of natalizumab infusions received, disability and functional status, number of MS drugs used prior to natalizumab and comorbidity burden. **RESULTS:** Data for 324 patients who completed the BL through 12<sup>th</sup> infusion assessments are reported. The mean age was 46.5 (SD=10.4) and the majority of patients were female (77.8%). The mean number of years since MS diagnosis was 10.16 (SD=8.23). On average, MFIS scores decreased significantly (BL 12.36+2.18; 12<sup>th</sup> infusion score 11.16+2.18, p<0.001) and MOS-Cog scores increased significantly over time (BL 25.12+1.51; 12<sup>th</sup> infusion score 26.19+1.97, p<0.001) after controlling for covariates. **CONCLUSIONS:** MS patients reported improvements in fatigue and overall cognitive function after one year of natalizumab treatment.

#### PND40

##### ASSESSMENT OF PERCEIVED SEVERITY OF DISEASE AND SYMPTOMS, QUALITY OF LIFE, WORK PRODUCTIVITY, AND HEALTH CARE RESOURCE USE IN INDIVIDUALS WITH MULTIPLE SCLEROSIS

Phillips A<sup>1</sup>, Stewart M<sup>2</sup>, Edwards N<sup>3</sup>, Gupta S<sup>4</sup>, Goren A<sup>5</sup>

<sup>1</sup>EMD Serono, Inc., Rockland, MA, USA, <sup>2</sup>Pfizer, Inc., New London, CT, USA, <sup>3</sup>Health Services Consulting Corporation, Boxborough, MA, USA, <sup>4</sup>Kantar Health, Princeton, NJ, USA, <sup>5</sup>Kantar Health, New York, NY, USA

**OBJECTIVES:** There is abundant evidence that individuals with Multiple Sclerosis (MS) have compromised quality of life (QOL) and work productivity, and increased healthcare resource use compared to individuals without MS. The possible association between subjects' self-reported severity of disease and these variables in an MS population has only recently been explored. Patient perceptions of disease have been increasingly recognized as an important factor in healthcare resource use. The objective of this study was to analyze the association between perceived severity of disease (mild, moderate, or severe) and symptoms, quality of life, work productivity, and healthcare resource use in individuals with MS. **METHODS:** Data from respondents reporting an MS diagnosis were obtained from the 2009 National Health and Wellness Survey (NHWS), an Internet-based annual study of the healthcare attitudes and behaviors of a US representative adult sample. The survey included questions about demographics, disease severity, symptoms, quality of life, work productivity, and healthcare resource use. **RESULTS:** In the 2009 NHWS study, 536 reported an MS diagnosis. MS respondents characterized the severity of their disease as follows: mild (n=206; 38.4%), moderate (n=268; 50%); and severe

(n=62; 11.6%). There were no differences in the number of years since diagnosis among the groups but there were significantly more men in the severe group. As perceived severity increased among MS patients (mild, moderate, severe), symptom severity generally increased, QOL decreased (SF-12 Physical Component Score), percent with full-time employment decreased, loss of work productivity and presenteeism increased among those reporting employment and healthcare resource use increased (ER visits and hospitalizations). **CONCLUSIONS:** Generally, those with more severe illness reported greater impairment. However, for many of the variables examined, more significant differences were found between patients who perceive their disease severity as mild and moderate than those patients reporting moderate and severe disease severity.

#### PND41

##### PARENTING STRESS IN CARING FOR CHILDREN DIAGNOSED WITH NEURO-DEVELOPMENTAL DISORDER

Almogbel YS, Goyal R, Sangsiry S

University of Houston, Houston, TX, USA

**OBJECTIVES:** This study evaluated and examined the relationship between parenting stress in caring for children diagnosed with a neuro-developmental disorder. **METHODS:** A cross-sectional study was conducted by using a self-administered questionnaire distributed through schools that provide services for children with developmental disorder. Parents with children aged 3-18 years and diagnosed with a neuro-developmental disorder were requested to complete the survey. Previously validated scales, the Parenting Stress Index (PSI) and the Columbia Impairment Scale (CIS) were used along with scales to measure parent and child's characteristics. Data was coded and analyzed using SAS v9.2 by performing descriptive and regression analyses. **RESULTS:** A total of 150 surveys were received from 4 schools net response rate (26.5%). The mean parent's age was 45.7(±6.4) years with mothers being higher portion of respondents (84%) and most (90%) were married. Mean PSI reported was 96.9(±23.9) and clinically significant (>85). Higher PSI was attributed to the difficult child (DC) subscale (35.6±10.4) followed by parental distress (PD) subscale (31.8±9.3) and the parent-child dysfunctional interactions (PCDI) subscale (30.2±8.5). Reliability coefficients for the PSI was high (0.91), including the subscales (DC=0.85, PD=0.87, and PCDI=0.8). Mean summary score for CIS was 19.1(±10.7) with a reliability coefficient of 0.9. A multiple regression analysis indicated a positive relationship of PSI with developmental impairment (CIS,  $\beta=1.43$  p<0.0001) after controlling for child's characteristics (age, gender, diagnosis, number of children, child with similar diagnosis, relationship of parent) and parent's characteristics (age, race, education, employment status, income and existing disorder). **CONCLUSIONS:** Children with severe developmental impairment may lead to greater stress for parents. Untreated stress can cause diseases, such as heart diseases and depression. Interventions controlling stress is the key to improving parents' quality of life for those that care for children with neuro-developmental disorders.

#### PND42

##### THE ASSOCIATION BETWEEN PARKINSON'S DISEASE QUESTIONNAIRE (PDQ) SCORES WITH CARER STRAIN AND QUALITY OF LIFE

Jenkinson C<sup>1</sup>, Peters M<sup>2</sup>, Fitzpatrick R<sup>2</sup>, Churchman D<sup>3</sup>

<sup>1</sup>University of Oxford, Health Services Research Unit, Oxford, Oxfordshire, UK, <sup>2</sup>University of Oxford, Oxford, Oxfordshire, UK, <sup>3</sup>Isis Innovation Ltd., Oxford, Oxfordshire, UK

**OBJECTIVES:** The impact of Parkinson's disease (PD) on the quality of life of both patients and their carers has not been well documented. This study describes the health status of both PD patients and caregivers as measured on a generic measure of health status (SF-12), and then explores to what extent patient self-reported health, as measured on the disease-specific Parkinson's Disease Questionnaire (PDQ-39), is associated with carer strain and self-reported quality of life. **METHODS:** A postal survey was carried out of both patients and caregivers through local branches of Parkinson's UK. Questionnaire packs were sent to those on the database with a diagnosis of PD. Patients were asked to give the carer questionnaire to their main caregiver, if they had one. **RESULTS:** Results suggest that PD has substantial adverse effects on both the physical (measured by the Physical Component Summary, PCS) and mental well-being of patients (measured by the Mental Component Summary, MCS) when compared with population norms. Most strikingly PD patients PCS scores fall within the lowest 10% of results, compared with a wider general population sample. While carer physical health was not found to be substantially different from that of the general population, emotional health was severely compromised with a MCS score that places them in the lowest 22% of the population. Regression analysis suggests that the major predictors of carer strain are the PDQ scales of mobility and social support. Carer strain was found to be closely associated with carer mental health. **CONCLUSIONS:** PD impacts on the well being of both patients and caregivers; the data provide evidence that the health status of the patient, in particular their physical health, has a significant impact on the well-being of their caregivers.

#### PND43

##### THE PATIENTSLIKEME® EPILEPSY COMMUNITY: A UNIQUE INSIGHT INTO THE LIVES OF PATIENTS WITH EPILEPSY

de la Loge C<sup>1</sup>, Dimova S<sup>1</sup>, Massagli M<sup>2</sup>, Wicks P<sup>2</sup>

<sup>1</sup>UCB Pharma S.A., Brussels, Belgium, <sup>2</sup>PatientsLikeMe, Cambridge, MA, USA

**OBJECTIVES:** To describe key characteristics of members of the online, USA-based PatientsLikeMe® Epilepsy Community, by comparison with a widely-used USA claims database, PharMetrics®, and to assess the impact of epilepsy on patients' lives using patient-reported data, collected through PatientsLikeMe®. **METHODS:** The PatientsLikeMe® Epilepsy Community allows patients with epilepsy to record