

P30: Agitation in Alzheimer's Dementia: Conceptual Framework to Demonstrate the Burden of Illness

Authors: George T. Grossberg, MD, Xue Han, Brian Talon, Emily Boller, MPH, Wenjie Zhang, Sam Keeping

Introduction: Agitation in Alzheimer's dementia (AAD) confers significant humanistic and economic burden; however, factors, and relationships between them, which drive the extent of this burden are poorly understood. The Objectives of this study was to review and gather evidence on the burden of AAD in order to develop a conceptual framework capturing its effects on patients, their families, clinicians (i.e., care teams), and society, which can then be used to guide further research into how the burden of AAD might be reduced.

Methods: Evidence on the burden of AAD was identified via a targeted literature review. Data were classified into societal, patient/family/care team, and mitigating factors. A conceptual framework (i.e., a visual representation of variables and associations between them) was developed to map the relationships between factors and illustrate the precedents and downstream effects of agitated behaviors on patient and caregiver outcomes, including healthcare resource utilization (HCRU), costs, and admission to long term care (LTC).

Results: Agitated behaviors were found to directly impact caregiving demands in terms of the number of hours required to care for patients. Similarly, levels of caregiver stress (i.e., total caregiver burden, personal strain, role strain, and guilt) were found to be associated with the frequency and intensity of AAD. Burden also extended to care teams via increased HCRU (i.e., pharmacy, outpatient, inpatient, and emergency room visits), and consequently costs, relative to non-agitated patients. Indirectly, through caregiving demands, agitation also affected the rate of placement in formal care and LTC, both of which are associated with incremental costs. Evidence also indicated that mitigating factors such as pharmacological treatment could impact the frequency and intensity of agitated behaviors, potentially affecting downstream HCRU and costs. Limited evidence exists on the optimal means of employing such strategies to limit caregiver demands and stress.

Conclusions: This study demonstrated the complex interplay of factors which drive the burden of AAD and the need which exists for novel ways to improve outcomes for those impacted by the disease. Better insight into the mechanism by which agitated behaviors influence caregiver demands and stress could help improve mitigation strategies both within family units and the larger health system.

P31: Direct and indirect costs of dementia in Brazil

Authors: Fabiana A.F. Da Mata, Ari Alex Ramos, Laiss Bertola, PhD, Thais Suarez, Specialist, Cleusa Pinheiro Ferri, Haliton Alves de Oliveira Junior

Objectives: This study aims to estimate the direct and indirect costs related to dementia in Brazil.

Methods: This study is part of the ReNaDe (National Report on Dementia) project, a domiciliary survey conducted with 140 dyads of people with dementia and their caregivers in 17 municipalities in Brazil. We used the cost of illness study Methods to estimate costs. We collected data from the ReNaDe interviews and national records and presented estimates from societal and SUS perspectives. Our total costs encompassed direct medical costs (hospitalizations, outpatient visits, and others) and indirect costs (for instance, the monetary value of informal caregiving hours) (Table 1). We did not consider direct social costs, given limited or in-existent information about cost and services utilization by people with dementia in Brazil. We used the replacement approach to estimate indirect costs.

Results: The monthly cost of dementia per individual increases with the syndrome's progression (Table 2). Indirect costs, primarily associated with informal care provided by family or friends, constitute at least 73% of total expenses, irrespective of dementia stage and adopted perspective. For Brazil in 2019, dementia's total annual cost stood at US\$18 billion, with indirect costs comprising 78%.

Conclusions: The average expenses per individual escalate with the advancement of dementia in Brazil. The pronounced prevalence of indirect costs accentuates the pivotal role that family caregivers assume in dementia care. Moreover, estimating the direct and indirect costs related to dementia, considering the reality of Brazil in its geographical diversity, is essential to understanding the reality of health resource allocation and, therefore, (re)direct resources to meet better the needs of people with dementia and their families.

P32: Association between pain behaviors and sleep impairment among people living with cognitive impairment

Authors: Alison R. Anderson¹, Fanghong Dong², Charisse Madlock-Brown¹, Miranda V. McPhillips³, Nancy A. Hodgson³

¹ College of Nursing, The University of Iowa, Iowa City, IA 52242, U.S.A.

² School of Medicine, Washington University, St. Louis, MO, 63110, U.S.A

³ School of Nursing, University of Pennsylvania, Philadelphia, PA 19104, U.S.A.

Objectives: To examine pain behaviors and sleep impairment by sex, race/ethnicity, education, and cognition in people living with cognitive impairment (PLwCI).

Methods: Participants (N = 210) in the Healthy Patterns Study, aimed at improving sleep-wake disorders in PLwCI, were included for analysis and were comprised of Black: 135 (64%), Hispanic/Latino: 41(19.5%), white: 34(16%), and primarily female: 140 (67%) individuals. The primary independent variable was PROMIS Pain Behavior 7a. Outcome variables were PROMIS Sleep-Related Impairment 8a, Pittsburgh Sleep Quality Index (PSQI), and actigraphy. Higher scores indicate worse symptoms. Descriptive analysis used t-tests, Mann-Whitney U-tests, and Chi-square tests based on data distribution and variable type. Multiple regression models explored pain behaviors and sleep quality, adjusting for age, gender, education, race, and Clinical Dementia Rating (CDR). Data analysis was conducted using R (v3.5.1).

Results: Descriptive analysis showed those with a high school education had higher pain behaviors than those with some college ($p = 0.00703$) and individuals with CDR of ≥ 1 had higher pain behaviors than those with CDR of 0.5 ($p < 0.001$). For PROMIS Sleep, males had higher scores than females ($p = 0.00307$), those with CDR of ≥ 1 had higher scores than those with CDR of 0.5 ($p < 0.001$), and there were race/ethnicity differences ($p < 0.001$) with Hispanics having higher scores. Individuals with less education had higher PSQI scores ($p = 0.0277$). For Objectives sleep (actigraphy), total sleep time differed by race/ethnicity ($p = 0.0173$), with Blacks having slightly shorter sleep. Those with CDR of 0.5 had shorter total sleep time than those with CDR of ≥ 1 ($p = 0.0114$). Regression analysis showed PROMIS pain score was associated with PROMIS Sleep score ($\beta = 0.30$; SE = 0.06, $p < 0.001$), indicating that every unit increase in PROMIS pain score increased PROMIS Sleep score by 0.30. PROMIS pain score was also associated with PSQI ($\beta = 1.04$; SE = 0.28, $p < 0.001$), indicating that every unit increase in PROMIS pain score raises PSQI score by 1.04.

Conclusions: This study identified pain behaviors and sleep quality differences by sex, race/ethnicity, education, and cognition, with worse sleep associated with more pain behaviors. This interplay of demographics, pain behaviors, and sleep emphasizes the need for tailored interventions in PLwCI.