COMMENTARY PAPER OF THE MONTH

Progress in BPSD research: analyzing individual BPSD might hold the key to better support caregivers

Behavioral and Psychological Symptoms of Dementia (BPSD) or neuropsychiatric symptoms occur in more or less every person with dementia at some stage during the illness. They often have a significant impact on caregiver well-being and vice versa – caregivers’ response to BPSD can impact on the well-being of the care recipient with dementia (Feast et al., 2016A). The relationship between caregiver and care-recipient factors when it comes to BPSD is complex and more detailed research is needed to be able to progress to more effective interventions and support.

In this month’s “Paper of the Month,” Feast and colleagues (Feast et al., 2016B) present results of a systematic review and meta-analysis of the relationship between BPSD symptoms and caregiver well-being. The authors reviewed the relevant English language literature between 1980 and 2015. This paper advances the field and our knowledge on this important topic as, unlike most previous papers, it focuses on the relationship of individual BPSD and caregiver well-being rather than relying only on symptom clusters or summative BPSD scores. This approach has been recommended in the literature as a next research step needed (Ornstein et al., 2012) to better identify which individual BPSD have the most detrimental impact on caregiver outcomes, such as burden, distress, strain, or stress. Only then will it be possible to develop targeted effective interventions for individual BPSD to improve caregiver well-being.

Forty quantitative papers of high and medium quality, mainly cross-sectional plus two longitudinal studies, met the inclusion criteria. A combined number of 10,978 caregivers of care recipients with dementia from clinic-based and population-based studies had a mean age of 60 years and the majority were female (67%). Sixteen of the forty papers used the Neuropsychiatric Inventory (NPI) and were included in a meta-analysis of mean distress scores. While there was considerable variability in distress ratings for each BPSD symptom between the 16 studies, Feast and colleagues found that the top three distressing BPSD were depression, agitation/aggression, and apathy. The authors conclude that all three of these behaviors are mood-related, which might explain why they have the most negative impact on caregiver well-being. Three of the 16 papers reported correlation data between all 12 mean NPI behaviors and distress. For those three papers, a meta-analysis revealed as top three distressing BPSD irritable behavior, aberrant motor behavior, and delusions. Depression was strongly associated/correlated with distress in both meta-analyses. The authors also report on the 20 papers, which were not suitable for a meta-analysis, comparing them descriptively. This comparison shows for example that differences are observed on what individual BPSD are impacting on caregiver well-being depending on the family relationship (adult–child vs. spousal) between caregiver and care recipient. The reported results and comparisons are complex, as frequently there is heterogeneity between studies.

An interesting question is why there is so much variability reported between studies of moderate to high quality. One reason might be the type of sample and the authors highlight that the two studies with the highest mean distress ratings are both clinic-based. Another relevant factor might be severity of dementia in the care recipients. Furthermore, cultural factors need to be considered as well. While BPSD are common across cultures, the level of dementia and BPSD literacy in the population differs greatly between countries and cultures and this most likely will impact on coping skills and distress levels of caregivers.

While this systematic review was limited to a relative small number of papers and only two meta-analyses could be conducted, the results help to identify crucial knowledge gaps and the need for further targeted studies. Another angle to this topic is the question to what extent the caregiver variability might be responsible for the variability in caregiver distress rather than just the individual BPSD. Longer longitudinal studies investigating both individual BPSD over time as well as caregiver variables should help to address this question. The authors also recommend to use more than one measure of caregiver distress in a study, as different individual BPSD might impact on different specific sub-categories of well-being. Ideally, as in many areas of clinical research, different research groups...
should strive to use similar instruments to enhance the possibilities of good quality meta-analyses. This paper of the month does what is typical for a good paper – advancing knowledge, but also highlighting the enormous amount of research which still needs to be done to attain better care for people with dementia and support for caregivers.

Conflict of interest

Nicola T. Lautenschlager is the current Editor-in-Chief of International Psychogeriatrics. Therefore, this commentary was reviewed by another member of the editorial team.

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References

