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Introduction

Caring for individuals with rare diseases can represent a burden and many challenges. Nevertheless, there is a lack of such information regarding Prader Willi syndrome (PWS). Additionally, to our knowledge, there are no reports of comparisons between the main caregivers and other family members. Hence, our aim was to evaluate the psychological impact on PWS caregivers.

Methods

Different evaluation tools and scales were used taking into consideration the impact on caregivers.

The scales used in this cross-sectional study were Zarit (ZCBS) for burden, hospital scale of anxiety and depression, PEDSQL Familiar impact, and WHOQOL-BREF to evaluate the quality of life, and APGAR family questionnaire to analyze family functionality.

Results

Of a total of 65 caregivers of patients with a confirmed diagnosis of PWS evaluated. Regarding these caregivers 46% are mothers (30/65), 31% are fathers (20/65) and the other 23% are other caregivers (15/65) ranging from siblings, guardians or other cohabitants. Their age ranged between 19 and 77 years (mean age 49.9 ± 14.8) and 65% (42/65) of the respondents were female.

Concerning primary caregiver and other caregivers, 46% (36/65) of the respondents are primary caregivers with a mean age of 52.1 ± 11.7 , 89% (32/36) being women.

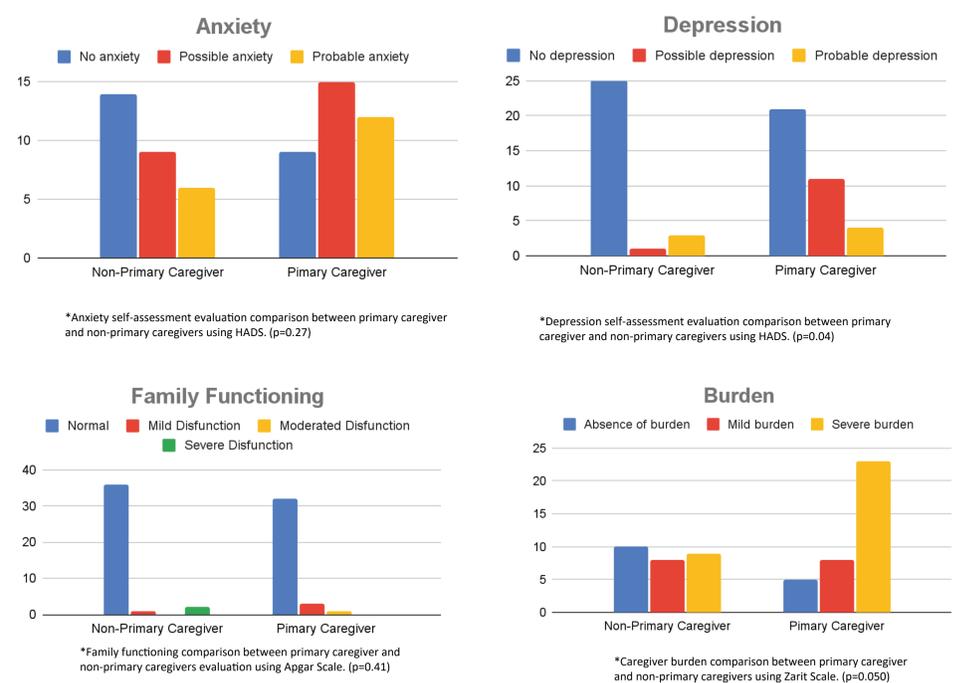
Analyzing the comparison between main caregivers and other family members, we identified worse indicators of quality of life in the main caregivers in both PEDSQL and WHOQOL scale, however were more evident in the psychological dimension of the WHOQOL scale [53.0 ± 17.8 VS. 61.2 ± 12.5 ($p=0.048$)].

Results (cont)

We also observed that 32% of primary caregivers reported high probability of anxiety compared to 19% of non-primary caregivers ($p=0.27$). Concerning depression 40% of primary caregivers related possible or probable case of depression compared to non-primary caregivers 13% ($p=0.04$).

Regarding caregiver burden evaluated using the Zarit scale, 61% of the main caregivers presented high levels of overload compared to 29% of the other relatives ($p=0.005$). Family functioning evaluated using APGAR scale showed a total lower response from primary caregivers but no statistically relevant results were found [25.4 ± 6.7 VS. 26.0 ± 8.2 ($p=0.72$)].

Figures



Conclusions

PWS caregivers can have a profound impact on their life and lead to burnout. Hence it is essential to take care of patients but also keep in mind their Families. For this reason, it is imminent to provide caregivers with adequate guidance for care, but also to escort and attend to these individuals' mental health as well. Building strategies to support these families. This would aid in reducing caregivers' burden.