

Psychological conditions of caregivers of adult subjects with Prader-Willi syndrome.

A. Guerrini Usubini¹, A. Bondesan, D. Caroli, F. Frigerio, G. Grugni, G. Castelnuovo, A. Sartorio

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Background: Prader-Willi syndrome (PWS) is a rare genetic neurodevelopmental disorder. Individuals with PWS face a range of cognitive, behavioral, and emotional challenges that require comprehensive and lifelong care, posing significant demands on their caregivers. The study is not only aimed to assess the psychological conditions of caregivers of adult subjects with PWS focusing on psychological distress and coping, but also to shed light on a crucial yet often overlooked aspect of healthcare. This study aims to compare the psychological well-being of individuals with PWS and their caregivers, providing valuable insights that can potentially improve the quality of care for these individuals. The sample recruited at the Division of Auxology, IRCCS Istituto Auxologico Italiano, was composed of 30 adult subjects with PWS (11 men and 19 women; mean age \pm SD: 36.4 ± 10.31 years; mean Body Mass Index (BMI): 35.7 ± 8.92 : kg/m²) and their caregivers (10 men and 20 women). To assess the psychological condition of caregivers, the Italian-validated versions of the Depression Anxiety and Stress Scale (DASS-21) and the Coping Orientation to the Problems Experiences (COPE) were used, while to assess the psychological well-being of individuals with PWS and their caregivers, the Italian validated version of the Psychological General Well-Being Index (PGWBI) was used.

Results: depression ($p < 0.001$), stress ($p = 0.050$), and total score ($p = 0.009$) of DASS 21 were higher in the caregivers of subjects with PWS than in the general population. PGWBI scores of caregivers were significantly lower than in individuals with PWS in Positive Well-being ($p < 0.001$), General Health ($p = 0.006$), Vitality ($p = 0.004$), and the total score ($p = 0.006$). The depression subscale of PGWBI was higher in caregivers than in subjects with PWS. Correlations between the subscales of COPE and the total score of PGWBI in caregivers revealed that the Avoidance subscale of COPE had a negative significant correlation with the total score of PGWBI ($p = 0.003$).

Conclusions: our results highlighted several critical insights into the profound emotional and psychological challenges faced by the caregivers of individuals with PWS.

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