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Introduction

We sought to explore the feasibility of the transdisciplinary remote care of subjects with Prader Willi Syndrome (PWS).

Such approach could be a valuable tool for rare diseases since they might promote a more universal access to treatment and care, even beyond the pandemic.

Methods

Data was collected before and during the pandemic onset (2019 and 2020) of patients with PWS and their caregivers.

Different evaluation tools and scales were used taking into consideration the main clinical characteristics of this syndrome and the impact on caregivers.

We assessed the hyperphagia questionnaire (HQ-CT), height, weight, and body mass index (BMI). The Beery-Buktenica developmental test of visual-motor integration (BeeryTM VMI) 6th edition were evaluated, as well as the Zarit scale short form and the hospital anxiety and depression scale (HADS). We also assessed attendance adherence.

Results

- A total of 25 PWS patients were evaluated, as well as 29 of their caregivers.
- The adherence to conventional consultations was lower than virtual consultations (86.1±13.2% vs 96.1±9.7% respectively, $p = 0.001$).
- Anxiety (10.5±3.4 vs. 10.6±4.1, $p = 0.73$) and depression (6.3±3.5 vs. 6.6±4.4, $p = 0.80$) scores were similar. Concerning caregiver burden, using Zarit short form in 13 families, we did not identify significant differences between periods (17.5±7.0, vs. 16.6±6.3, $p = 0.31$).
- Regarding the nutritional profile, we found a trend towards significant BMI reduction (30.1±9.1 kg/m², vs. 28.0±11.7 kg/m², $p = 0.057$), and a nonsignificant reduction in hyperphagia-related behaviors (6.2±4.6 vs. 4.5±2.9, $p = 0.22$).
- Finally, we identified improvements in occupational therapy outcomes including Beery raw (16.7±4.1 vs. 17.4±3.5, $p = 0.08$), visual raw (19.4±3.5 vs. 20.5±3.4, $p = 0.04$), and motor raw (15.9±4.8 vs. 17.5±3.0, $p = 0.027$).

Conclusions

Our findings suggest that remote care of PWS is feasible and is not related to a negative impact in the quality of different fundamental parameters in the treatment of this type of patients.

