









2025 INTERNATIONAL CONFERENCE | PHOENIX, AZ

June 24-28, 2025 Spa







Caregivers Working with the Family of the Person with PWS

Brian Hughes and Lynn Garrick







Workshop goals

- Understand the lived experience of families navigating residential care for a person with PWS
- Explore the importance of trust, communication, and shared responsibility between group homes and families
- Learn practical strategies for improving family engagement while maintaining program consistency and safety
- Build empathy and insight through real-life perspectives, research, and guided discussion







- 1. Welcome and Introduction (15 min)
- 2. Costs and Benefits of Family Involvement (30 min)
- 3. Where do Families Fit? Bridging the Gap from Provider to Partner (15 min)
- *Pause -* (5 min)
- 4. Easier Said than Done! What are the Practical Implications? (30 min)
- 5. Learnings (15 min)
- 6. Closing and Key Takeaways (10 min) *United in* H PE 2025 PWS CONFERENCE



Study

Micallef Pulè, K., & Hughes, B. M. (2025).

Anxiety, depression, and stress in parents and siblings of people who have Prader-Willi syndrome: Morbidity prevalence and mitigating factors.

Journal of Intellectual Disability Research, 69, 417-427.

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ORIGINAL ARTICLE OPEN ACCESS

Anxiety, Depression and Stress in Parents and Siblings of People Who Have Prader-Willi Syndrome: Morbidity Prevalence and Mitigating Factors

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Keywords: anxiety | depression | family cohesion | Prader-Willi syndrome | PTSD | PWS families | PWS parents | PWS siblings | social support | stress

ABSTRACT

Background: Individuals with PWS need constant support and/or supervision, which creates a high caregiver burden on their parents and siblings. Previous research has identified adverse stress outcomes in relatively small and country-specific samples. This study's aims were to examine stress outcomes in a large multi-country sample of parents and siblings and to expand upon previous research by incorporating data on psychosocial factors that may mitigate stress outcomes.

Methods: The sample comprised 135 parents of a child with PWS, with additional data for 45 siblings as reported by parents. Participants were recruited from 31 countries, spanning Europe, North and South America, Africa, Asia and Australasia, who participated by completing an online questionnaire that included standardised psychometric measures of depression and anxiety (HADS), life stress (PSS), PTSD symptoms (CATS-C) and family cohesion (FACES II). Outcomes were compared to published population norms, and multiple regression was used to investigate the role of potential exacerbating and mitigating factors. Results: Findings revealed high rates of mental pathologies in both parents and siblings. Parents' scores for depression and anxiety indicated high rates of caseness: 67.4% of parents exhibited 'abnormal' levels of anxiety, while 15.6% exhibited 'borderline abnormal' levels; 34.8% exhibited 'abnormal' levels of depression, with 22.2% exhibiting 'borderline abnormal' levels. Younger parents exhibited higher anxiety than older parents (p=0.007); younger male parents reported higher depression than older male parents (p = 0.029). Parents whose child with PWS lived in the family home exhibited higher depression scores than parents whose child with PWS lived away from home (p=0.035). Family cohesion was inversely associated with parental depression (p < 0.001) and parental anxiety (p = 0.012), even when statistically controlling for age of parent, age of child with PWS and parental education level. Scores for life stress were markedly higher than population norms, with 88.7% of parents exhibiting 'high' or 'moderate' life stress. Parental life stress was significantly correlated with temper outburst severity in their child with PWS (p < 0.001) and with food problem severity (p < 0.001). All siblings exhibited at least one symptom of PTSD, with 28.9% of siblings exhibiting 'clinically relevant' levels of PTSD symptoms. Sibling PTSD symptom levels were significantly associated with temper outburst severity in the child with PWS (p=0.025) but not with ratings of food problem severity (p=0.114). Family cohesion was inversely associated with PTSD symptoms in siblings (p = 0.022).

Conclusions: PWS impacts families negatively, and relatives suffer as a result. The findings of this study confirm that parents and siblings of persons with PWS exhibit clinically notable levels of mental pathology. Strategies to enhance family cohesion should be employed to help diminish adverse outcomes among PWS families.

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Check for update

Previous research on family caregiving and PWS

| Author | Sample size | Location | Main Analyses |
|------------------------|-----------------------------------|--------------------|---|
| Mazaheri et al. (2013) | 12 mothers + 13 siblings | Fresno, USA | Descriptives; <i>t</i> -tests; qualitative case studies |
| Wong et al. (2021) | 67 'families' (parents) | Taipei, Taiwan | Descriptives; logistic regression |
| Kowal et al. (2022) | 20 caregivers | Lublin, Poland | Qualitative |
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| Present study | 135 parents + 45 siblings | 31 countries | Multivariate regression and ANCOVA |

TABLE 1 Number of parents and siblings represented in the dataset from each country.

| Country | Parents | Siblings |
|-----------|---------|----------|
| Argentina | 1 | |
| Australia | 10 | 3 |
| Austria | 1 | |
| Belgium | 1 | 1 |
| Brazil | 1 | 1 |
| Canada | 2 | 1 |
| Croatia | 1 | |
| Denmark | 5 | 2 |
| Finland | 1 | |
| France | 1 | 1 |
| Germany | 4 | |
| Greece | 1 | 1 |
| Hungary | 3 | 1 |
| India | 12 | 2 |
| Ireland | 19 | 4 |
| Italy | 2 | |
| Malaysia | 1 | |
| Malta | 1 | 1 |

Parental life stress vs. international benchmarks

Population norms for PSS-10 (2020; pre-Covid)



Germany: 12.89



United States: **15.05**



Mexico: 15.81

India: **19.25** ۲

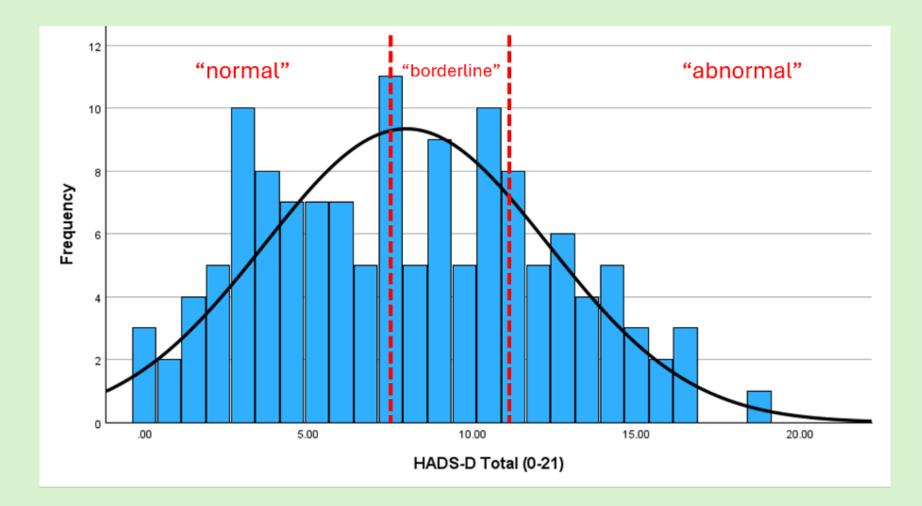
United Kingdom: **19.79**

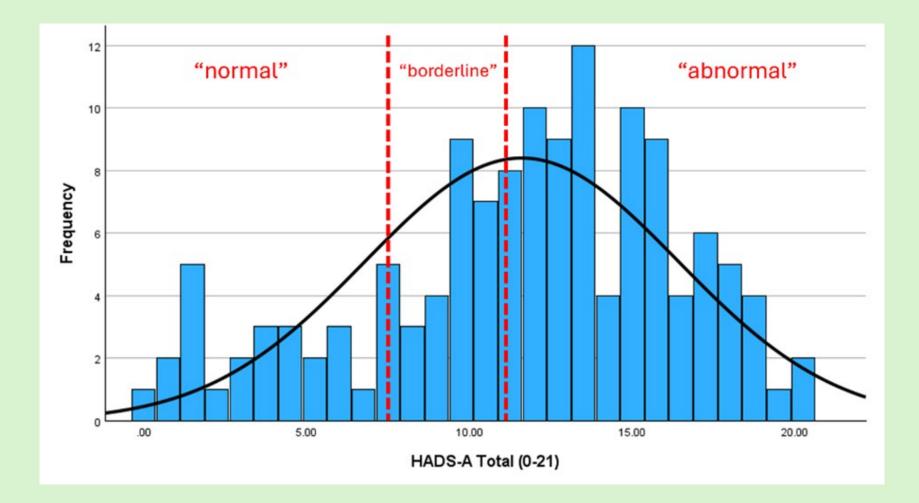
Present sample

Mean: 20.93 (SD = 6.53)

20.7% "High stress"

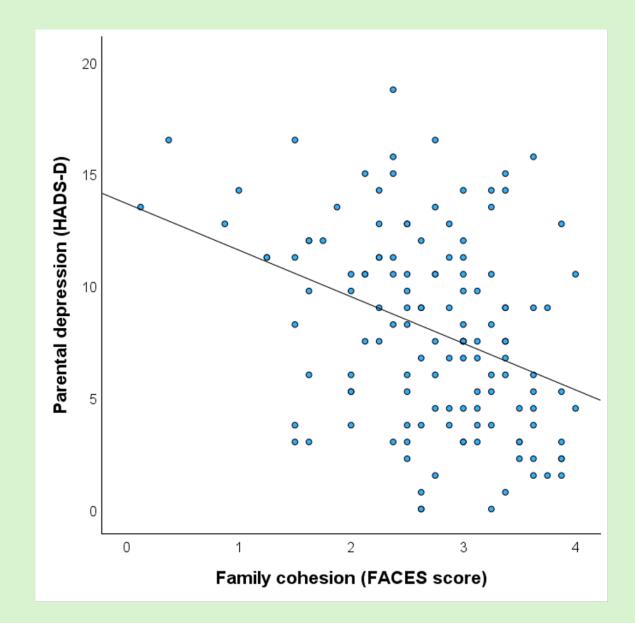
66.7% "Moderate stress"

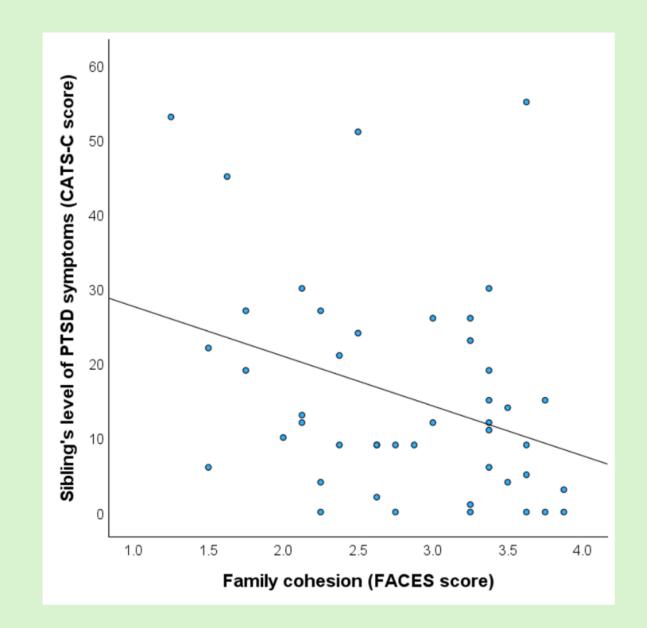




PTSD symptom prevalence in siblings (CATS-C)

- All siblings were reported to exhibit at least some PTSD symptoms
- **28.9%** of siblings (i.e., 13 of 45) had scores indicating 'clinically relevant' levels of PTSD symptoms
- Sibling PTSD symptom levels significantly associated with temper outburst severity but not with food problems severity
- Unaffected by ages or age differences





Highlights

- Clinically notable levels of mental pathology in parents & siblings
- Age inversely associated with anxiety in parents overall, and with depression in male parents
- Family cohesion buffered against parental depression and anxiety, even when controlling for age of parent, age of child, and parental education level
- Sibling PTSD associated with temper outburst severity in the child with PWS, symptoms buffered by family cohesion
- Largest ever study of stress outcomes in PWS families, first international study, first to use mainstream standardised measures of anxiety and depression, first to examine mitigating factors

Thank you!





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Costs and Benefits of Family Involvement

"What are the costs and benefits of ongoing family involvement in care...

- ...for families?
- ...for the individual?
- ...for service providers?

Can family involvement be **counterproductive?**

Where do Families Fit? Bridging the gap from provider to partner

Partners or Recipients

Easier Said than Done! Practical Implications?

1. A parent is upset about a behaviour plan

2. A family wants to bring "off-limits" food on a visit

3. A family is disengaged, distant, uncommunicative

Learnings

Closing and Key Takeaways

THANK YOU!







