Outcomes for persons with Prader-Willi syndrome in full-time services

Findings from international archival data and future research directions

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The study

• Data supplied by 11 full-time care services from across six countries
  - Denmark, Germany, Ireland, Switzerland, United Kingdom, United States

• At least partial data: n = 193 individuals with PWS
  - In service for 10.26 yrs (range <5 to >40)
  - Average age of entry = 26.67 yrs (range <10 to >50)
Overall BMI reduction

- Data sample: $n = 141$
- Mean BMI reduction: $12.31 \text{ kg/m}^2$
- Statistically significant change:
  - $t(140) = 19.65$, $p < .001$
BMI reduction after one year

- Data sample: $n = 34$
- Mean BMI reduction
  - $4.07 \text{ kg/m}^2$
- Statistically significant change
  - $t(33) = 5.32$, $p < .001$

![Mean BMI graph]

<table>
<thead>
<tr>
<th></th>
<th>At entry</th>
<th>After 1 year</th>
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<tbody>
<tr>
<td></td>
<td>31.47</td>
<td>27.40</td>
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More time, more BMI reduction

- Data sample: $n = 141$
- Bivariate correlation
  - $r = +.272, p = .001$
- Controlling for age
  - $r_p = +.284, p = .001$
- Excluding outlier
  - $r_p = +.267, p = .002$
Overall change in Behaviours of Concern

- Data sample: $n = 41$

- Mean reduction
  - $0.538 \pm 0.576$

- Statistically significant change
  - $t(40) = 5.98, p < .001$
Change in Behaviours of Concern after one year

- Data sample: $n = 39$
- Mean reduction: $0.354 \pm 0.446$
- Statistically significant change:
  - $t(38) = 4.96$, $p < .001$
Predictors of Current BMI

Data sample: $n = 91$

- Staff specialization
- Food security
- Service specialization

$\beta = +0.531$
Predictors of Behaviours of Concern

Data sample: n = 91

- Staff specialization
- Food security
- Service specialization
- Size of service

Reduction in Behaviors of Concern

$\beta = +0.694$
Summary of Findings

- When in residential services, people with PWS
  - (a) lose significant weight, and
  - (b) exhibit significant improvements in behaviours of concern

- These improvements
  - (a) become apparent within one year, and
  - (b) increase over time

- Various service features are associated with improvements:
  - (a) Service specialization, staff specialization, food security & size of service all important
  - (b) Service specialization is especially important for BMI
  - (c) Size of service is especially associated with improvements in behaviours of concern
Future Research Directions?

- Archival data
  (a) Broaden / deepen / greater cultural representation

- Primary data
  (a) Standardised outcome measures
  (b) Voices of persons with PWS
  (c) Voices of families
  (d) Voices of caregiving staff

- Processes vs. Structures
  (a) *Why* are certain service features important?
  (b) *Why* do outcomes improve over time?
FAM-PWS 2024

A Study of Families Living with PWS

Welcome to our study!

We are psychology researchers based in the University of Galway in Ireland. One of us is a parent of a son who has PWS.

Our study will examine the experiences and well-being of families living with Prader-Willi Syndrome.

If you are a parent/guardian of a person who has PWS, then please consider taking part in our study. The study involves a survey that you can complete online in around 20-25 minutes.

Click here to take part.
Thank you!
Danke schön!

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