1. Introduction

- "Work is at the core of human dignity" - Leila Jahah 2013, 214
- Work positively affects mental well-being and serves five latent functions: time structuring, activity, social contacts, social recognition, and communal participation (Jahah, 2003)
- For people with disabilities, work is crucial for independent living, preventing social isolation, and full societal integration (c.f., 2018)
- People with Prader-Willi syndrome face significant occupational challenges due to employment and considers their specific needs (Ockenes, Sumner & Koel, 2006)

Research question
How can the unique needs of individuals with Prader-Willi syndrome be accommodated in the context of employment?

2. Methods

Qualitative research design: expert interviews
Sample
- Conscious and convenience sampling for heterogeneity
- 6 experts on Prader-Willi syndrome in the workplace context
- 3 employees from different Workshops for Disabled People with varying positions and educational backgrounds
- Dr. Wilhelm Schilling, PhD in Social and Health Pedagogy, heads the PWS specialist service at Regents Wagner Asberg
- Ulrike Urban: Pedagogue with experience in Workshops for individuals with PWS; involved in the "Housing and Employment" working group of the PWSVD
- Rita Bohland-Klein: Psychologist and family therapist at the Prader-Willi syndrome Competence Center of the Kreuznacher Diakonie Foundation

Survey instrument
- Open-ended question guide based on Hellfritsch’s SPSS principle (2014)
- Open-ended questioning for maximum information gain
- Thematic question blocks oriented towards theory
- Pre-test for clarity and effectiveness

Survey/Interview procedure
- Guide sent in advance
- Conducted via Microsoft Teams
- 35-50 minutes on average
- Reflections recorded using keywords
- Transcripts sent for verification

3. Results

Workplace design
- Adaptations should prioritize individual needs and limits
- Create a low-stress work environment that offers orientation
- Assistive devices
- No specific assistive devices needed universally
- Assistive devices particularly suitable for individuals with PWS
- Visual aids, alarm clocks, carrying aids and posture support

Organizational
- Clarity, consistency, and organization in adjustments
- Avoidance of changes due to cognitive inflexibility
- Involvement of the individual in decision-making
- Promotion of a sense of normality by minimizing differences from other employees
- Syndrome-adapted nutritional management
- Eight-hour workday feasible with enough breaks

Daily Routine
- Clear structure with fixed meal and break times, individual variability in the need for additional breaks
- Include activities for balance, rituals, opportunities for movement, and therapy
- Task
- Should align with individual interests and abilities
- Importance of meaningful tasks for motivation
- Begin with easy tasks, gradually increase complexity
- Clear, structured, step-by-step tasks advantageous due to cognitive challenges
- Self-manageable tasks for increased self-efficacy
- Avoid physically demanding tasks due to muscle hypotonia

4. Discussion

- High agreement among experts
- Differences may come from varying professional backgrounds and education
- Most results align with the Caregiver Conference guidelines and information brochures from the Prader-Willi Syndrome Association Australia and the Prader-Willi Syndrome Association USA but extend beyond theirs (2012, n.d., n.d.)
- Recommendations based on experts’ practical experiences suggest potential success
- Limitations: Experts’ ties to disability workshops may have influenced results. Transferability of findings to the primary labor market is uncertain

5. Conclusion

- A variety of recommendations were generated that align closely with existing work
- The large number of recommendations highlights the difficulty in creating a suitable working environment
- Further research is needed to validate the results, particularly concerning the open labor market
- Results can be relevant for further research and practical application to improve employment opportunities for individuals with PWS

Sources


