

People with Prader-Willi syndrome in a work context

A qualitative-explorative study to develop recommendations for considering syndrome-specific characteristics

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1. Introduction

- "Work is at the core of human dignity" - Leila Janah (BSR, 2015, 21:42)
- Work positively affects mental well-being and serves five latent functions: time structuring, activity, social contacts, social recognition, and communal participation (Jahoda, 1983)
- For people with disabilities, work is crucial for independent living, preventing social isolation, and full societal integration (CBF, 2018)
- People with Prader-Willi syndrome face significant challenges in finding suitable employment that considers their specific needs (Dykens, Summar & Roof, 2005)

Research question

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

Aim

Generate recommendations for successful employment relationships.

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. Winfried Schillinger: PhD in Social and Health Pedagogy, heads the PWS specialist service at Regens Wagner Absberg
 - 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

- Semi-structured interview guide based on Helfferich's SPSS principle (2011)
- 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
- Lasted 35-50 minutes on average
- Reflections recorded using keywords
- Transcripts sent for verification

Evaluation

- Transcription followed Dresing and Pehl (2015) guidelines
- Analysis based on Mayring's structured content analysis (2015)
- Deductive and inductive category formation approach
- Definition, anchor examples, and coding rules for clear categorization
- Utilization of MAXQDA software for analysis
- Marking and categorizing of text passages
- Summarizing and structuring the findings of each category

3. Results

Relevant Characteristics

- Individualized manifestations of Prader-Willi syndrome
- Nearly all the characteristics of individuals with Prader-Willi syndrome are relevant in the work context, especially the psychological ones

Employment Options

Sheltered Workshop

- Most suitable option according to experts
- Advantages include promoting individual participation and social integration, as well as addressing special needs

Primary Labor Market

- Experts agree employment is possible but challenging
- Challenges include lack of supportive structure and difficulty accommodating special needs
- Success factors for individuals: absence of significant behavioral problems, good cognitive abilities, adherence to work virtues, adaptability, and self-awareness to express needs.
- Success factors for workplaces: support structures, food security, awareness of PWS among colleagues, stability, and collegiality

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
- Tasks
 - 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

Physical workplace design

- Low-stimulus work environment, minimizing noise
- Sufficient space in the premises and at the workstation
- Food safety
- Availability of a quiet or time-out room
- Tailor ergonomic setup to meet unique needs and comorbidities

Personnel support

- Individual needs assessment
- Support with social behavior to avoid and resolve conflicts
- Assist with medication, health, and food handling
- Support learning new tasks
- Regular reflection sessions for problem-solving and goal setting
- Designated support person essential for guidance and security
- Offer extra support for major issues, including professional help

Requirements for caregivers/contact persons

- Actively and empathetically building relationships
- De-escalation-trained and professional behavior during crises
- Training on understanding PWS and associated challenges
- Clear and respectful communication with context
- Enforce and monitor rules, taking consistent action as needed
- Being able to find a balance between control and freedom
- Empathetic, good social skills, reliable and confident demeanor
- Mentally resilient and team-oriented

Social environment

- Awareness of PWS needed for all, including external contacts
- Understanding and openness are key for a stable environment where individuals with PWS feel comfortable

4. Discussion

Results

- 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 them (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

Methods

- The detailed results section demonstrates the methodology's suitability for answering the research question
- Six quality criteria according to Mayring were largely met
- The use of established methods was a positive aspect.
- Sample Size: Sufficient due to reaching theoretical saturation
- Critique: Including an expert with substantial experience in employing or supporting people with PWS in the open job market would have provided more perspectives and confidence in the results
- Limitations in generalizability indicate that additional research is needed

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 work 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

BSR (2015). BSR Conference 2015: Leila Janah, CEO, Sama Group [Video]. YouTube. Retrieved from: <https://www.youtube.com/watch?v=YkKvF8yo0E&t=1s> (08.01.2024).

CBF (2018). Die Bedeutung von Arbeit für Menschen mit Behinderung. Retrieved from: <https://www.cbf-muenchen.de/club-post-blog/1336-die-bedeutung-von-arbeit-fuer-menschen-mit-behinderung> (08.01.2024).

Dresing, T., & Pehl, T. (2015). Praxisbuch Interview, Transkription & Analyse. Anleitungen und Regelsysteme für qualitativ Forschende (6. ed.). Retrieved from: www.audiotranskription.de/praxisbuch (27.12.2023).

Dykens, E., Summar, K., & Roof, E. (2005). Prader-Willi Syndrom. In S. Goldstein & C.R. Reynolds (eds) Handbook of Neurodevelopmental and Genetic Disorders in Adults (Pp. 439-458). New York: Guilford Press.

Helfferich, C. (2011). Die Qualität qualitativer Daten. Manual für die Durchführung qualitativer Interviews (4. ed.). Wiesbaden: VS Verlag für Sozialwissenschaften. doi:10.1007/978-3-531-92076-4.

Jahoda, M. (1983). Wieviel Arbeit braucht der Mensch?: Arbeit und Arbeitslosigkeit im 20. Jahrhundert. Weinheim, Basel: Beltz.

Mayring, P. (2015). Qualitative Inhaltsanalyse: Grundlagen und Techniken (12. ed.). Weinheim, Basel: Beltz.

Prader-Willi-Syndrome Association Australia (o.J.). A practical guide to supporting people with Prader-Willi Syndrome in the workplace, day program or volunteer setting. Retrieved from: <https://www.pws.org.nz/wp-content/uploads/2018/09/Supported-employment-day-service-guide-PWSA-AU.pdf> (13.12.2023).

Prader-Willi Syndrome Association USA (o.J.). Management of PWS in the Work Setting – A Guide for Employers and Supervisors. Brandon: Prader-Willi Syndrome Association USA. Retrieved from: https://www.pwsausa.org/wp-content/uploads/2022/12/Work-setting-pws_working_proof_blue.doc.pdf (12.12.2023).

Soyer, H., Hödebeck-Stuntebeck, N. (Eds.) (2012): Best-Practice-Leitlinien für Betreuung und Assistenz beim Prader-Willi-Syndrom. Tagungsbericht zu den Internationalen Prader-Willi Syndrom-Konferenzen für „Caregivers“ 2008 und 2009. Absberg, Bad Oeyenhaus: IPWSO.