The application of psychological models in the understanding of adaptive and maladaptive behaviours in people with PWS

Strategies building on individual strengths and reducing behaviours of concern occurring and their persistence over time.

Dr. Norbert Hödebeck-Stuntebeck,
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Understanding Behavior

A good news and a bad news

The good news is: people with PWS are humans like we are

The bad news is: humans (behavior) are very complex to understand

So in the consequence it is a big and very complex task for parents and professional caregivers to understand and handle the behavior of people with PWS!
Understanding Behavior - Psychological approaches and views

Psychological approaches and views:

- System-theory-perspective
- Cognitive Developmental steps of Jean Piaget
- Social-emotional developmental steps of Anton Dosen
- Method of the behavior analysis of the behavior therapy
- Positive Psychologie with the 5 Elements of Martin Seligman
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System-theory-perspective

Person with PWS as the „Identified patient“
System-theory-perspective

- Person with PWS
- Other Professionals
- Parents
- Siblings
- Teachers
- Staff
System-Theory

The importance of the interactions between the stakeholders in the system for understanding the behavior.

Subsystem Family

Subsystem Professionals

Person with PWS

Parents

Siblings

Teachers

Other Professionals

Staff
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Cognitive developmental stages – Jean Piaget

1. Sensorimotor stage (0–2 years)
2. Preoperational stage (2–7 years)
3. Concrete operational stage (7–11 years)
4. Formal operational stage (11 years to adulthood)
2. Stage: Preoperational stage (2–7 years) – characteristics of this stage

- Inappropriate Generalizations
- Egocentrism
- Centering
- Decentering
- Missing Transformations
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Social-emotional developmental age – Anton Dosen

1. Adaptation (0 – 6 months)
2. Socialization (6-18 months)
3. Individuation (1.5-3 years)
4. Identification (3-7 years)
5. Awareness of Reality (7-12 years)
6. Identity (12-18 years)
Understanding Behavior

Fields
1. dealing with your own body
2. dealing with reference persons
3. Dealing with environmental change - object permanence
4. emotion differentiation
5. dealing with peers
6. Handling Material - Activities
7. communication
8. affect regulation
Social-emotional developmental age - profil

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Parts of the behavior analysis

- Life-
- Preceding conditions
- Story (Biography)

- Social conditions
- Behavior in the situation

- Consequences

Development process of the behavior
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Quality of life and well-being for people with PWS

Based on the findings of Positive Psychology (Martin Seligman), it is necessary to examine how the following 5 elements of well-being / quality of life are implemented and consciously experienced and evaluated by the client

- Positive emotion
- Engagement
- Social relationship
- Experiencing meaningfulness
- Self-efficacy experience
Quality of life and well-being for people with PWS

Positive emotion


- Do people with PWS experience their own positive emotions, do they perceive them in themselves?
- What is the extent / the level of the experience of positive emotions in the person with PWS?
Quality of life and well-being for people with PWS

Engagement

Engagement means: An intrinsically motivated action fills the person completely, without being overwhelmed or having an interest in extrinsic rewards (flow).

• Does the person with PWS experience engagement in himself, does he perceive it in himself?
• What is the extent / the level of the experience of engagement in the person with PWS?
Quality of life and well-being for people with PWS

Social relationship

Social relationships means: The realisation of the basic need for social belonging.

• Does the person with PWS experience social relationships, do they perceive them in themselves?
• What is the extent of the experience of social relationships in the person with PWS?
Quality of life and well-being for people with PWS

**Experiencing meaningfulness**

Experiencing meaningfulness means: Being able to classify one's own actions in a superordinate goal, being able to recognise a superordinate goal in one's actions.

- Does the person with PWS experience meaningful action, does he perceive this in himself?
- What is the extent of the experience of meaningful action in the person with PWS?
Quality of life and well-being for people with PWS

**Self-efficacy experience**

Goal achievement - self-efficacy experience means: One's own actions are perceived as (partial) cause for success, for reaching the goal.

- Does the person with PWS experience that he/she achieves his/her goal, that he/she is self-effective?
- What is the extent of the experience of goal achievement and self-efficacy?
Quality of life and well-being for people with PWS

Individual profile

100%

Positive feelings
Engagement
Social relationships
Experiencing meaningfulness
Goal achievement
Quality of life and well-being for people with PWS

Individual Profile - Development

- Positive feelings
- Engagement
- Social relationships
- Experiencing meaningfulness
- Goal achievement
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