

# Supporting Adults with PWS

How do Professional Caregivers in Aotearoa/New Zealand Address the Ethical and Practical Dilemmas?

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New Zealand Psychologist and former paid caregiver whose background is in supporting people with disabilities and challenging behaviour, and in training caregivers.

In that role, I was impressed by the unique challenges facing those who support people with PWS. I wanted to know the best ways to provide professional development and training to these caregivers.



## Two Research Questions ...

- What is it like to be one of these caregivers?
- How do they address the ethical and practical problems they face?

# The Central Dilemma Facing Paid Caregivers

Supporting someone who has PWS generally requires caregivers to control that person's access to food.

However ....

The promotion of service users' independence and legal rights are core values for all disability support agencies within Aotearoa/New Zealand.

# The Central Dilemma: In other words ....

Caregivers' duty-of-care verses our duty to promote independence, or ....

Paternalism versus respect for civil rights. Safety versus autonomy.

In practice, this ethical dilemma is made much more complex by the determination and creativity of many people with PWS in relation to food.

# 3 Studies

- Study 1: A brief scoping study: Interviewing caregivers in workplace based focus groups.
- Study 2: An attempt at a nationwide population survey.
- Study 3: In depth interviews with 11 professional caregivers.

## Study 3: Caregivers' Central Narrative.

One basic story emerged very strongly in every interview:

Caregivers defined their role in terms of the **challenges** it presented. They described their **responses** to those challenges, and the **goals** they were trying to achieve in choosing those responses.

# Challenges:

Unrelenting yet always changing.

Arise from multiple sources.

- Managing access to food only one of these: 'the easiest challenge'.
- Various aspects of service users' behaviour was the most common theme.



# Challenges behaviours described ...

Various forms of 'foraging'

Non-food related behaviours

- Behaviours of inflexibility and excess
- Interpersonal conflict
- 'Relationship dissonance'

# Other sources of challenge

- Responsibility without power.
- Vulnerability to criticism.
- Isolation.

# A counter-narrative!

- It's a Great Job!
- Every interview featured smiles, laughter and stories.

# Caregivers' Responses to Challenge

## Authoritarianism

Caregivers' all prioritised client safety and made 'substitute decisions'.

A 'benevolent conspiracy'. The importance of consistency among caregivers.

Caregivers strongly valued the wellbeing of the group, as well as that of the person with PWS.

# Caregivers' Responses to Challenge

## Creativity

- The promotion of safe autonomy
- The inevitability of risk.
- Exercise

# Caregivers' Practical Wisdom

Caregivers also emphasised:

- Empathy/fairness
- The importance of managing service users' anxiety.
- Perceived autonomy versus real choices.
- Consistency among caregivers.

# Caregivers' Goals

Safety remains paramount, although space remains for other priorities.

# Caregivers' Goals

## 'The Search for a Liveable Life'

As found in a previous study (Van Hooren et al., 2002) caregivers sought outcomes that yielded benefits for the group, not just for the person with PWS alone.



# Conclusions

Even when they love their work, caregivers define it in terms of challenge to which they have to respond.

These challenges arise from multiple sources but many centre of behaviour of service users.

The central dilemma, 'safety versus autonomy', has been resolved firmly in favour of safety.

# Conclusions

Some degree of risk is regarded as inevitable, it must be managed and tolerated because it cannot be entirely eliminated.

Caregivers seemed to use their work stories to describe the solutions to complex problems.

Caregivers often seem to focus on supporting the group, not just individuals.