

A high care unit for patients with Huntington's Disease with challenging behavior; three perspectives explored

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Patients

- Heard and seen by staff

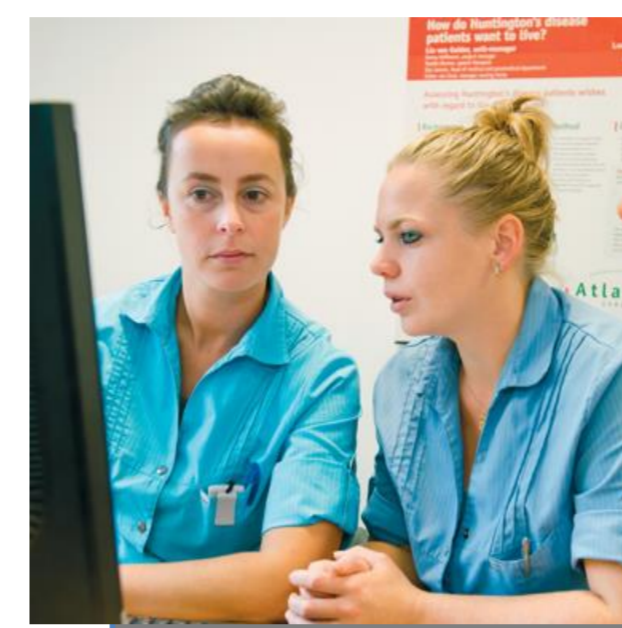
“They take good care of me”



Family caregivers

- Burden ↓
- Trust ↑

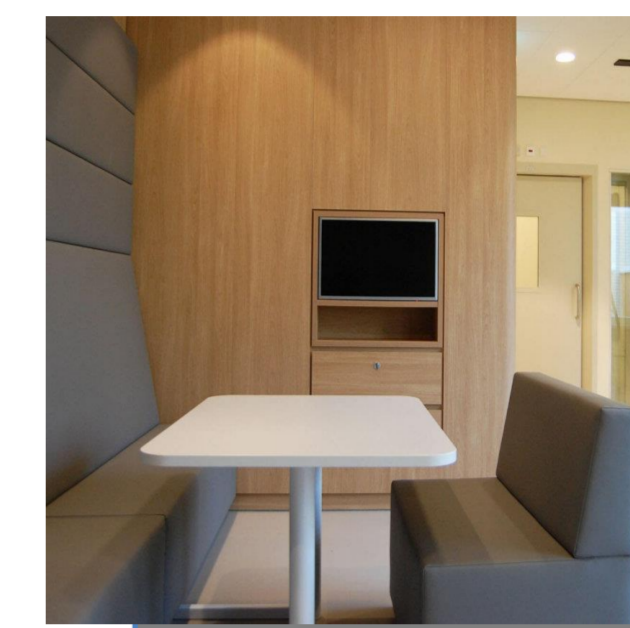
“That gives you peace of mind ... I return home reassured”



Nursing staff

- Stress ↓
- Competence ↑

“I have more self confidence ... and can protect my colleague”



Comfort room

- Hardly used

Possibly due to the provided structure and customized care

Background

Some HD patients show complex behavior such as severe aggression and irritability. They might benefit from a small-scale, structured environment with controlled environmental stimuli. The implications of a newly built high care unit including comfort room are unknown.

Aims

- Insight in the experiences of HD patients, family caregivers and nursing staff with the unit
- Insight in the impact of the unit on family caregiver burden and work stress of the nursing staff over time
- Increasing knowledge about an optimal care approach for HD patients with complex behavior who need long-term care in a skilled nursing facility

Methods

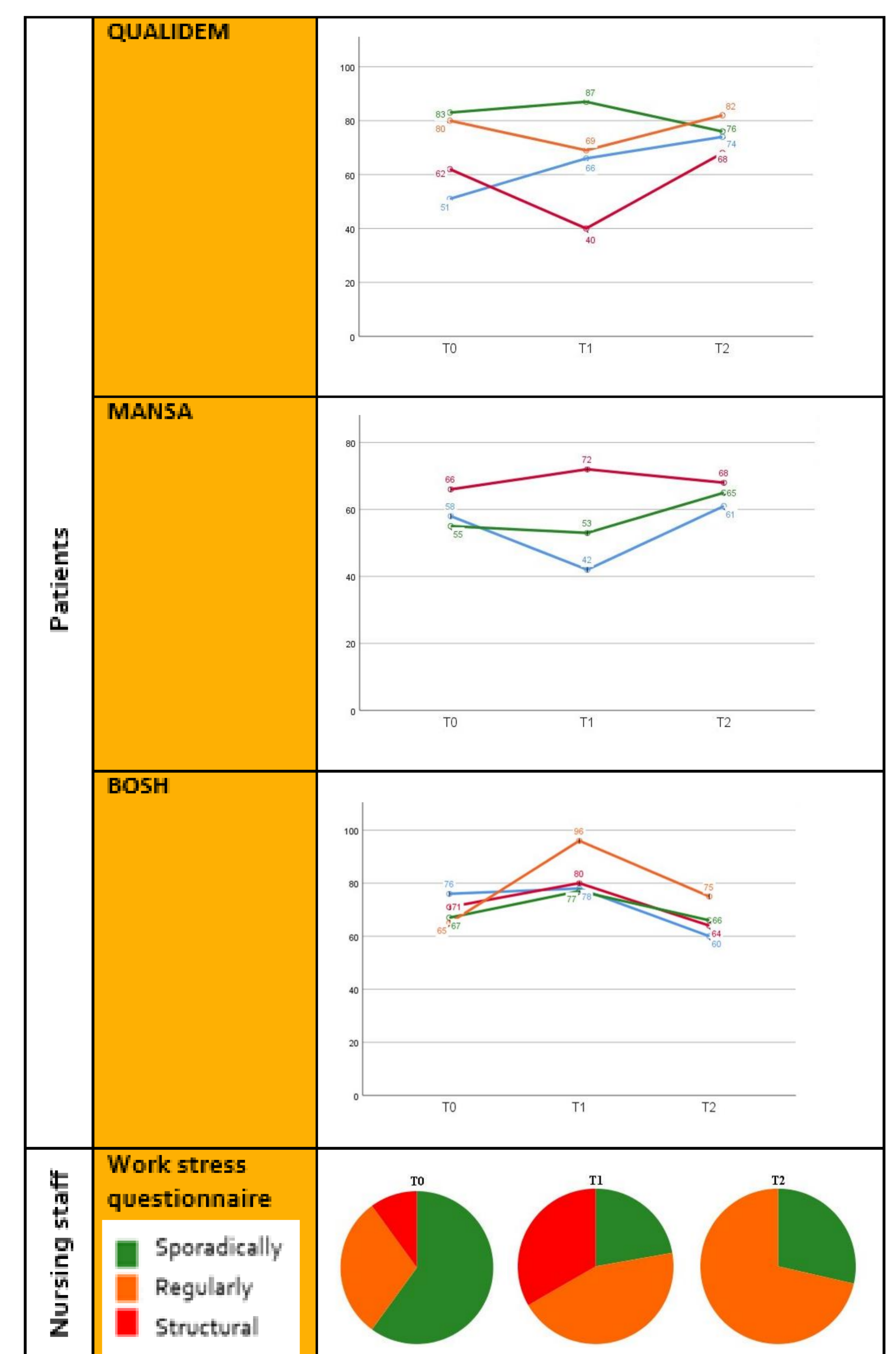
A mixed-method design at baseline, after 6 and 12 months. Using e.g. QUALIDEM, BOSH, MANSA, work stress questionnaire and interviews.

Results

- Patients n=4, family caregivers n=2, nursing staff members n=11
- **Patients** expressed being satisfied living at the unit, no statistically significant changes in QoL, aggression and irritability were found
- **Family caregivers** experienced increased attentive care for their family member and mentioned more peace of mind
- **Nursing staff** reported increased self-confidence and more competence concerning psychiatric disorders

Conclusions

The high care unit was deemed positive by patients, family caregivers and nursing staff. Unexpectedly, the sensory calming comfort room was hardly used probably due to the effect of the provided structure, ambiance and customized care.



QUALIDEM = Quality of Life - Dementia
MANSA = Manchester Short Assessment of Quality of life
BOSH = Behavior Observation Scale Huntington

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