“I think I've come to find it normal”

A qualitative study into the experiences of nursing staff with neuropsychiatric symptoms of people with Huntington's disease living in a nursing home

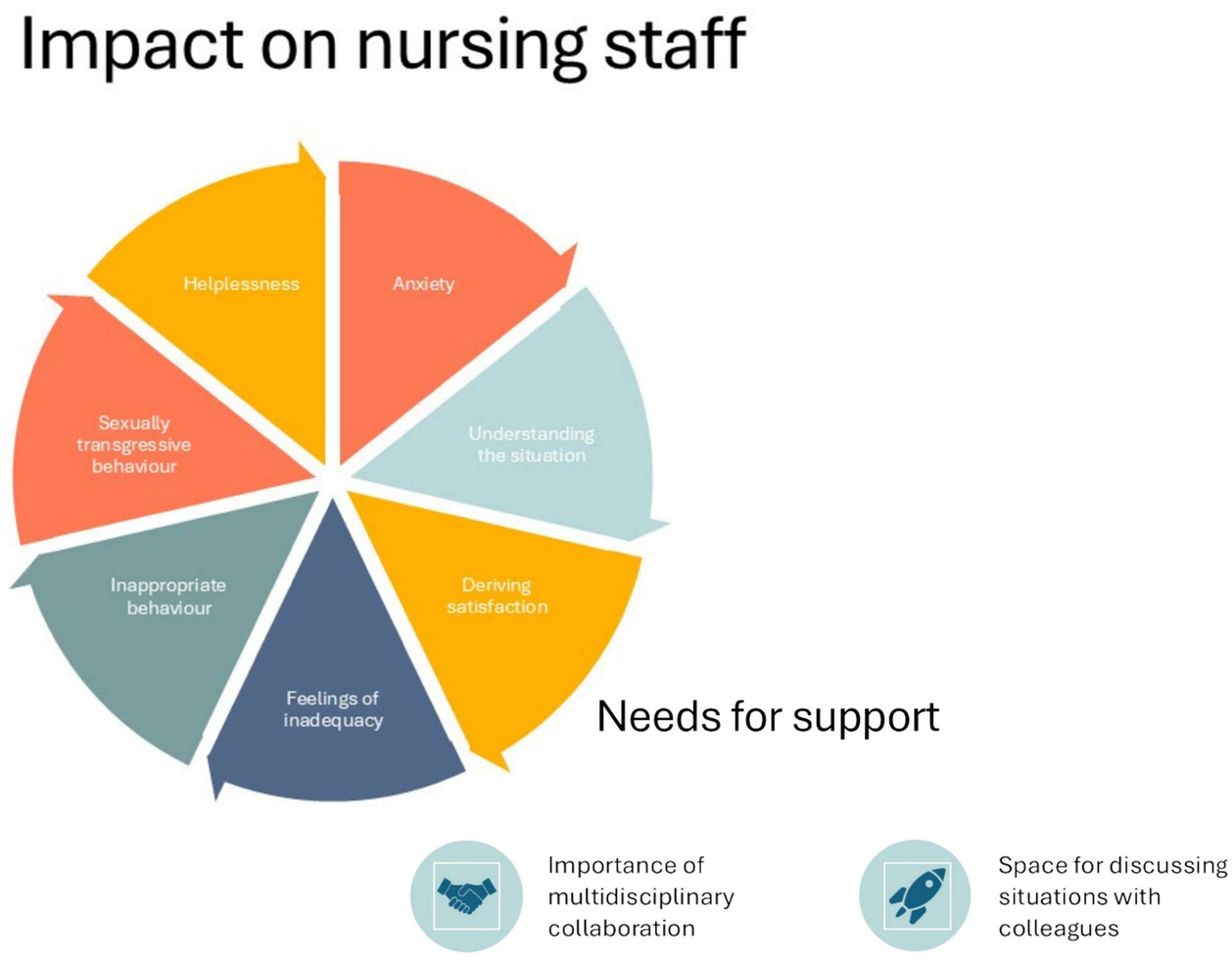
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Introduction:
Neuropsychiatric symptoms are experienced by partners of patients with Huntington's disease (HD) as more distressing than somatic symptoms (Vervoort & van Zuuren, 2021). However, it is unknown how nursing staff, who often care for HD patients in a late stage of the disease, experience these neuropsychiatric symptoms.

Aims
To gain insight in the impact of neuropsychiatric symptoms on nursing staff and to explore their need for support to cope with these symptoms.

Methods
A qualitative descriptive research design was used. Data collection took place between March and May 2024, using semi-structured interviews with eleven female respondents. A topic list was used during the interviews, which was adjusted through an iterative process based on the previously collected data. Interviews were recorded with an audio recorder so that they could be transcribed verbatim and correctly. The data was analyzed using a thematic analysis, by (inductively) coding in three phases, searching for themes and subthemes.



Results
Nursing staff was confronted on a daily basis with neuropsychiatric symptoms in HD patients. All of them experienced at least one serious incident during their working experience. The research also showed that nursing staff are confronted with, among other things, aggression, disinhibited behavior and (sexual) inappropriate behavior. As a result, they experienced feelings of powerlessness, fear and the feeling of inadequacy in caring for people with HD. Nevertheless, all respondents also showed understanding for the neuropsychiatric symptoms, and they experienced neuropsychiatric symptoms as a challenge and experienced their work as satisfactory.

> “When someone calls you names, the first time you think 'oh man', but when someone does it more often, you start to see it as normal, instead of addressing someone about that behavior.”
>
> “Huntington really happens to you. So then you really can't do anything about it, that's why I tolerate more I think.”

Discussion
This research highlights the need for specific support and training for healthcare workers dealing with neuropsychiatric symptoms in people with Huntington's disease. Caregivers often experience helplessness and confront inappropriate behavior but also find satisfaction in their work. The research emphasizes the importance of multidisciplinary collaboration and specialized knowledge. The findings point to the necessity of better supporting nursing staff to improve their wellbeing and the quality of care provided.

Conclusion
This study showed the importance of a multidisciplinary focus on understanding the impact of neuropsychiatric symptoms for nursing staff. Support, for nursing staff dealing with neuropsychiatric symptoms requires a diverse approach; such as the importance of making (transgressive) behavior a topic of discussion or opportunities to reflect on a situation or one's own actions.

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