
POSTER ABSTRACT

"Optimizing the transmural clinical care pathway for persons with disorders of consciousness in collaboration with relatives: a qualitative study"

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The current transmural clinical care pathway for the rehabilitation of persons with disorders of consciousness (PwDOC) was developed in collaboration with different healthcare professionals. However, no information was available of persons directly involved in this care pathway.

The aim of this study was to investigate whether relatives of PwDOC received sufficient support on psychological and

administrative level and whether the provided care is in accordance with their expectations and experiences. In addition, possibilities to involve patients and/or their relatives to the healthcare and decision making process were investigated.

The research was carried out at Noorderhart Mariaziekenhuis (acute hospital) and Noorderhart Revalidatie & MS (rehabilitation centre). The transmural clinical care pathway focusses on admission in the acute setting after transfer from an external hospital, the rehabilitation process, discharge and follow-up. Due to the well-known dysfunctions and disabilities present in PwDOC it is difficult to involve the persons themselves. For these reasons, the relatives of PwDOC were involved within this project.

The study was conducted between July 2020 and July 2022. In this period eleven PwDOC were hospitalized. Focus groups were organized to capture the importance of experiences and opinions of relatives of PwDOC. Relatives (n=11) were contacted by telephone and informed about the aim of the study. Participation was voluntary. Nine participants filled in a questionnaire (digital/paper). Hereby, feedback of relatives who were unable or refused to participate at the focus groups was included. Results of the questionnaires were used for preparation of the focus groups. Three focus groups were organized from September to October 2022 addressing the following themes: acute phase (n=3), rehabilitation phase (n=6) and discharge/follow-up (n=3). The questionnaire and focus groups were led by a nurse practitioner, two staff members and with active involvement of a rehabilitation physician. After analyzing the interviews, following themes were retained:

communication, education for relatives about disorders of consciousness, meeting therapists and administrative support.

Based on the preliminary results, it was concluded that relatives received sufficient psychological support during the rehabilitation process. However, there was a need for more administrative guidance during the rehabilitation process. Furthermore, the current working method is not entirely in accordance with the expectations and needs of relatives of PwDOC. The cited themes will be taken into account during the development of the clinical care pathway. Data-analysis are currently ongoing and results will be presented on the poster. Future steps are to inform the interdisciplinary team about the results, organize educational sessions for relatives and form initiatives to optimize communication and administrative support. Additionally, when the PwDOC is unable to participate, the experiences of relatives of PwDOC appear to give important insights in the development of a clinical care pathway.