

## Background

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.

## Aim(s)

The aim was to investigate whether relatives of PwDOC received sufficient support on psychological and administrative level and whether provided care is in accordance with their expectations and experiences. In addition, possibilities to involve relatives to the healthcare and decision making process were investigated.

## Methods

Relatives of PwDOC, enrolled in the transmural clinical care pathway in Noorderhart Mariaziekenhuis (acute hospital) and Noorderhart Rehabilitation & MS were contacted by telephone for voluntary participation. Nine out of eleven relatives filled in a questionnaire about education, (para)medical information, satisfaction, interdisciplinary team, etc. Results were used for preparation of three focus groups (FG) that were organized addressing following themes: acute phase (n=3), rehabilitation phase (n=6) and discharge/follow-up (n=3). The study was led by a nurse practitioner and two staff members with active involvement of a rehabilitation physician. FG were video recorded after which transcription verbatim and thematic analysis was performed.

## Results

Nineteen themes were discussed, of which following were retained: education of relatives, (para)medical information to relatives, psycho-emotional support, residence after rehabilitation, end of life/ DNR. Relatives' perception of PwDOC differs from reality. They don't know the meaning and different phases of disorders of consciousness. Further, there's need for more involvement of relatives in the transmural clinical care pathway. Relatives received sufficient psycho-emotional support from different professionals. There's a lack of facilities for housing PwDOC and there are long waiting lists. In addition, support/information about options and possibilities of residences after the rehabilitation program is missed. Although being reluctant/afraid of conversations about end of life/DNR, relatives indicated that talking about it is important and necessary.

## Discussion

Psychological and administrative support are sufficient. Provided care is partly in accordance with expectations and experiences. Therefore the transmural clinical care pathway needs to be adjusted. There's a need for more involvement of relatives during an interdisciplinary team meeting, by a communication notebook, etc. Although the small sample size, study results are valid and reliable because of the small volume population. Because admission of some PwDOC was long time ago, it may be possible that information about the transmural clinical care pathway may have been forgotten due to a recall bias.

## Implications and future perspectives

The next steps are: to inform the interdisciplinary team and relatives about results, adapt the transmural clinical care pathway, form initiatives to optimize communication between the interdisciplinary team and the relatives and form education for relatives.

## References