

Patient-reported outcome measures in subarachnoid hemorrhage

Edith Nobels-Janssen^{1,2}, Philip J van der Wees³, Wim I M Verhagen², Gert P Westert³, Ronald H M A Bartels¹, Jeroen D Boogaarts¹

¹Department of Neurosurgery, Radboud University Medical Center, Nijmegen, The Netherlands, ²Department of Neurology, Canisius Wilhelmina Hospital, Nijmegen, The Netherlands, ³Radboud Institute of Health Sciences, IQ-Healthcare, Radboud University Medical Center, Nijmegen, The Netherlands

Conclusion

Due to the low quality of evidence, the evidence base for selecting a suitable PROM for use in patients with aSAH is insufficient.

Introduction

- Patient reported outcomes (PROs) describe health from a patient's view and are measured with PROMs.
- Clinicians can use PROMs to focus on a patient's individual health goals.
- Currently, PROMs are seldom used in research involving patients with aSAH.

Aim of the review

To provide an overview of the validity and reliability of available PROMs used in patients with aSAH.

Methods

Literature available in PubMed, Cochrane and EMBASE was systematic searched. Search terms: 'subarachnoid hemorrhage', 'PROMs' and 'validation study'.

Data analysis

COSMIN criteria were used for:

- 1) quality assessment of the studies
- 2) quality assessment of the measurement properties.

The GRADE methodology was applied to assess the level of evidence.

Results

- A total of 6967 unique articles was identified.
- Full text review resulted in 9 articles included in this review in which 7 different PROMS were assessed:
 - EuroQoL 5D
 - Health Utility Index
 - modified Rankin Scale structured interview
 - Quality of Life after Brain Injury overall scale
 - Subarachnoid Haemorrhage Outcome tool
 - Stroke-Specific Quality of Life Scale
 - short version of the Stroke-Specific Quality of Life Scale

Questionnaire	PROM development	Structural validity	Internal consistency	Reliability	Criterion validity	Hypotheses testing	Responsiveness
mRS-SI				Very low			
QOLIBRI-OS			Very low				
SAHOT	Very low	Low	Low			Very low	Very low
SS-QoL		Very low	Very low	Very low		Moderate	Very low
SS-QoL short version			Very low		High	Moderate	

Table 1: level of evidence for each PROM

mRS-SI: modified Rankin Scale structured interview; QOLIBRI-OS: Quality of Life after Brain Injury overall scale; SAHOT: Subarachnoid Haemorrhage Outcome Tool; SS-QoL: Stroke-specific Quality of Life Scale;

Discussion

- In none of the PROMs content validity was assessed, that means that it is uncertain whether relevant PROs are measured by these PROMs.
- At least half of the information on measurement properties was not assessed.
- There are limited validation studies for PROMs used in patients with aSAH.
- There are more validation studies for PROMs used in patients with stroke in general, but these are not assessed in this review.

Registry of review protocol: PROSPERO (CRD42018058566)

Nobels-Janssen. Neurology. 2019 Jun 4;92(23):1096-1112. doi: 10.1212/WNL.0000000000007618



Edith Nobels-Janssen
Afdeling neurochirurgie
Radboudumc
Postbus 9101, 6500 HB, Nijmegen
Email: edith.nobels-janssen@radboudumc.nl