Modern Interdisciplinary and Interhospital Acute Stroke Therapy—What Patients Think About It and What They Really Understand

Hannah Pressler, *,[a] Arno Reich, PD Dr. med,*,[a] Jörg Bernhard Schulz, Prof. Dr. med,* Omid Nikoubashman, Prof. Dr. med,† Klaus Willmes, Prof. Dr. rer nat.,* Pardes Habib, MD,* and Jan-Philipp Bach, PD Dr. med.*

Background: Access to reperfusion therapies in patients with large vessel occluding acute ischemic stroke demands process reorganization and optimization. Neurovascular networks are being built up to provide 24/7 endovascular stroke therapy service. In times of an increasingly complex stroke rescue chain little is known about patients' and their relatives' treatment awareness. *Methods:* All patients, who received any kind of acute reperfusion treatment between January and August 2017 in the university hospital Aachen, and their proxies, were included in the survey. Patients were either primarily or secondarily transferred. *Results:* For all questions regarding stroke treatment patients and their caregivers provided concurring answers. 40% of both patients and caregivers did not understand the treatment that was performed. Finally, patients who perceived on their own that stroke detection was delayed had significantly longer onset to door times than patients who did not have this impression. *Conclusions:* This study showed that patients' and proxies' answers correlated significantly. In case of patients' unavailability extrapolation of treatment satisfaction from answers by proxies might be permitted. High percentages of patients and caregivers do not understand relevant information, possibly due to limits of communication in an emergency setting or deficits in communication during the hospital stay. More emphasis should be laid on providing further information during the hospital stay.

Key Words: Acute ischemic stroke (AIS)—neurovascular network (NVN)—endovascular stroke treatment (EST)−patient satisfaction

Introduction

Stroke is the third-leading cause of death and the most common cause of disability in adulthood[1]. Specific treatment for acute ischemic stroke includes systemic thrombolysis with recombinant tissue Plasminogen Activator (rtPA) (IVRTPA) and/or endovascular thrombectomy with second-generation devices. In 2016, 5 prospective, randomized, open-labeled, blinded endpoint designed clinical trials[2-6] demonstrated superiority of endovascular thrombectomy in large vessel occlusions in the anterior circulation compared to standard care. In addition, the recently published DAWN study highlights the fact that some patients with longer symptom duration also benefit from endovascular treatment.[7]. Because of these positive results regarding applicability and generalizability in clinical practice,[8,9] it appeared even more important to establish a regional network of acute stroke care centers that provide patients eligible for endovascular therapy with direct access to this therapy. In 2011, the German Stroke Society established criteria for the "neurovascular network," which comprise supra-regional medical care as well as the close

From the *Department of Neurology, Medical Clinic, RWTH Aachen University, Aachen, Germany; and †Department of Neuroradiology, Medical Clinic, RWTH Aachen University, Aachen, Germany.

Received March 14, 2018; revision received May 7, 2018; accepted May 22, 2018.

Grant support: No grant support.

Disclosure of Conflict of Interest: All authors declare that there is no conflict of interest.

Address correspondence to Jan-Philipp Bach, MD, Department of Neurology, RWTH Aachen, Pauwelsstrasse 30, Aachen 52074, Germany. E-mail: jbach@ukaachen.de

[a]Contributed equally.

1052-3057/$ - see front matter

https://doi.org/10.1016/j.jstrokecerebrovasdis.2018.05.029

cooperation between neurological departments and emergency services.[10]

Previous studies demonstrated that both patient characteristics as well as services provided and the organizational structures had an important impact on patient's satisfaction with acute stroke care.[11-13] Previous investigations showed that stroke patients at large are pleased with inpatient care.[11] Compared to their relatives, they were more satisfied, particularly regarding the information they received and the services provided from social workers.[14] However, it has not been studied sufficiently how extended therapy options such as endovascular stroke therapy (EST) and a new network structure affect the patients' satisfaction. In addition, there are no reports whether caregivers are sufficiently suited as proxies. Our first aim was to analyze whether patient and family members´answers showed good agreement. We further investigated patients 'and their relatives' understanding of the performed procedures.

Material and Methods

Patient Recruitment

Patients receiving acute reperfusion therapy (consisting of systemic thrombolysis with rtPA (IVRTPA), EST, or both (bridging)) between January and August 2017 in the University Hospital RWTH Aachen (UKA), Germany, the coordinating center of the Neurovascular Center of the region of Aachen (http://www.schlaganfall-netzwerk-west.de),[9] were included in the study. We included both, patients primarily admitted to the tertiary stroke center as well as patients who were referred from other neurological stroke units. In case of patients with severe aphasia, dysarthria, coma or other reasons preventing answering a structured interview, the questionnaire was completed only with their relatives. In order to see whether this lead to a bias, we included an appropriate analysis.

Data Acquisition

Patients' data were extracted from the medical reports and collected in a local prospective stroke database, which contributed to a series of stroke studies already.[8,15] A summary of these characteristics is provided in supplemental material S1. The ethics board of the Medical Faculty of RWTH Aachen University approved this study (EK 073/17). We used a standardized, structured questionnaire (supplemental material S2). All patients and caregivers provided their consent to participate.

Statistical Analysis

Data are shown with the standard deviation of the mean as error bars. Standard statistical tests (Mann−Whitney U test, Pearson chi-square test, Fisher's exact test) were applied for group comparisons. Cohen's kappa (κ) was used to measure the agreement between patients and the corresponding caregivers for scales with yes/no or categorical alternatives. For ordinal scaled responses, we applied weighted kappa (κ_W) by Cohen[16] to take into account the degree of disagreement. The confidence interval was 95% for all kappa values. For the interpretation of kappa values we used the classification of Altman.[17] P values less than or equal to 0.05 were considered significant. All statistical analyses were performed with SPSS 24 software (IBM, Armonk, NY).

Results

One hundred thirty-nine patients with AIS and 100 caregivers were included in this survey. Figure 1 shows a flow chart of the treatment groups. Baseline characteristics of patients are displayed in supplemental material S1. Among the 139 cases, 115 patients, and 100 caregivers completed the questionnaire. This included 76 pairs of patient and corresponding relative. In 39 cases there was no possibility to ask the relevant family members due to absence (n = 29), rejection (n = 4) or missing surviving family members (n = 7). The most reported reasons for the 24 patients not completing the questionnaire included severe aphasia (n = 8), dysarthria (n = 6), advanced dementia (n = 2), or death in the hospital (n = 8). We used the pairs of patient and relative to first analyze how well their answers agreed. A detailed description of the results for each question is provided in supplemental material S3. In summary, the investigation of inter-rater agreement between patients and caregivers showed good agreement (defined as k = 0.61-0.80)[17] for statements regarding recognition of stroke ($\kappa = 0.65$), speed of patient transport ($\kappa = 0.65$), being informed about therapy ($\kappa = 0.62$), transfer back to the previous clinic ($\kappa_W = 0.61$). Responses relating to informing about transport to the coordinating tertiary stroke center ($\kappa = 0.58$), being informed about chances and risks ($\kappa = 0.42$), participation in therapy decisions ($\kappa = 0.47$) showed moderate accordance between patients and relatives. In order to account for a possible bias due to aphasia, we performed a further subgroup analysis. Out of the 76 matched pairs, 26 suffered from aphasia. For these couples, our detailed analysis showed that for the majority of questions, agreement was better for this subgroup of patients. Only for question 6 (have you understood what treatment you received) and question 11 (do you wish to be transferred back to the hospital you came from), agreement was less good compared to the other couples. Further analysis revealed no difference for sex and age. Type of stroke did not lead to significant differences between groups. Especially, posterior versus anterior circulation did not influence the results. With respect to stroke etiology, differences were negligible as well, especially with respect to the small sample size. Severity of stroke, (severe stroke classified as National Institutes of Health Stroke Scale >11, compared to National Institutes of Health Stroke Scale ≤11) did influence the answer: agreement