


Attitudes of Patients and Relatives Toward Disability and Treatment in Malignant MCA Infarction

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Abstract

Background Attitudes among patients and relatives toward the degree of acceptable disability and the importance of aphasia are critical in deciding on decompressive hemicraniectomy (DHC) in malignant middle cerebral artery infarction (MMI). However, most MMI patients are not able to communicate their will. Furthermore, attitudes of healthy individuals and relatives may not correspond to those of stroke patients.

Methods This is a multicenter survey among 355 patients and 199 relatives during treatment for acute minor or moderate severe ischemic stroke in Germany. Questions address the acceptance of disability, importance of aphasia, and the preferred treatment in the hypothetical case of future MMI.

Results mRS scores of 2 or better were considered acceptable by the majority of all respondents (72.9–88.1%). A mRS of 3, 4, and 5 was considered acceptable by 56.0, 24.5, and 6.8%, respectively. Except for a mRS of 1, relatives indicated each grade of disability significantly more often acceptable than patients. Differences regarding acceptable disability and treatment decision were depending on family status, housing situation, need of care, and disability. The presence of aphasia was considered important for treatment decision by both patients (46.5%) and relatives (39.2%). Older respondents more often refrained from DHC ($p < 0.001$).

Conclusion In Germany, there is substantial heterogeneity in patients and relatives regarding acceptable disability, aphasia, and treatment decision in the hypothetical case of MMI. Relatives significantly overestimate the degree of disability that is acceptable to stroke patients. Further studies are warranted to determine whether differences in attitudes impact on the decision to undergo DHC.

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Keywords Decompressive hemicraniectomy · Malignant middle cerebral artery infarction · Outcome · Disability

Introduction

Malignant middle cerebral artery infarction (MMI) is a devastating disease inevitably leading to either death or long-term disability. Early decompressive hemicraniectomy (DHC) within 48 h from symptom onset is the only treatment to reduce mortality and improve functional outcome that has proven effectiveness in randomized controlled trials (RCT) [1–6]. Nevertheless, many survivors are left with moderate or severe disability. This

corresponds to a score of 4 or 5 on the modified Ranking Scale [mRS; a validated and widely used 7-point functional score ranging from 0 (no symptoms) to 6 (death)]. These patients are unable to walk without assistance and are unable to attend to own bodily needs without assistance (mRS 4) or bedridden, incontinent, and requiring constant nursing care and attention (mRS 5) [5, 7]. There is an ongoing scientific debate as to whether these levels of functional outcome may be deemed to be “favorable” or at least “acceptable.” For this reason, some authors suggest not to recommend DHC in selected patients despite recommendations in current guidelines [8–13].

Evaluating outcome and taking treatment decision in severe stroke is difficult because of three reasons. First, the well-known limitations inherent to the mRS and the lack of consensus on the optimal dichotomization cut-point that separates favorable from unfavorable outcome [14–16]. Second, attitudes toward long-term disability are heterogeneous and individual persons may value a particular level of functional outcome entirely different depending on their social, cultural, or ethical background. Third, patients with severe stroke are usually not able to communicate their will in the acute phase of disease. Because of these limitations, several surveys have been conducted among physicians, nurses, healthcare workers, and the general population in recent years to find a consensus on the question of defining acceptable outcome states and treatment decision in MMI [17–21]. The overall impression from these surveys is that only a minority of respondents consider a mRS of 4 favorable. This perception, however, is in contrast to the willingness to undergo DHC in the majority of even severely disabled survivors of MMI: In observational studies and randomized trials, they report a high rate of retrospective consent to DHC and satisfaction with life [22, 23]. These discrepancies may be explained by underestimated coping capacities of severely disabled patients and the “*disability paradox*” (disabled people report greater quality of life compared to when healthy people are asked to imagine similar circumstances) [24–26]. On the other hand, healthy individuals have never experienced a stroke or the perspective and burden of long-term disability. Therefore, it is questionable as to whether healthy individuals are able to provide congruent answers compared to patients on specific questions such as acceptable outcome in MMI. This is of particular interest in MMI, as surrogates usually take the treatment decision.

The aim of this study was twofold: to investigate the attitudes of mild-to-moderate severe affected stroke patients regarding long-term disability and treatment preferences in the supposed case of MMI in order to approximate the attitudes of MMI patients and to compare their attitudes with those of relatives.

Methods

Design

This is a multicenter survey among consecutive patients with acute minor or moderate severe ischemic stroke admitted to a stroke unit in Germany and relatives (convenience sampling). Relatives were defined as associated persons who were visiting the patients in ward and who indicated a close relationship with the patients. The patients and one relative each were issued with the questionnaire at one time during the acute hospital stay. The questionnaire had to be answered by the participants themselves without major support through others. Therefore, severely affected stroke patients could not participate in the survey. The survey was conducted at 9 stroke units. Data collection was completely anonymous. The Ethics Committee of the Charité—University Hospital Berlin, Germany (EA4/127/10), approved the survey.

Development of Questionnaire

An interdisciplinary team of medical sociologists, clinical epidemiologists, neurosurgeons, neurologists, and intensive care physicians experienced in the treatment of patients with MMI developed the questionnaire. The questionnaire consisted of 14 closed questions (Tables 1, 2) and gave information about therapeutic options and outcome in MMI as well as a definition of the mRS according to Vahedi et al. [5] and van Swieten et al. [7], respectively. Patients and relatives were asked to answer the questions based on what they personally considered acceptable and important with respect to degree and mode of disability and treatment modality in the hypothetical case of future MMI. “Still acceptable” outcome was defined as the particular degree of disability with which the respondents could still imagine leading their lives on the basis of their current knowledge. “No longer acceptable” outcome was defined as the highest degree of disability with which the respondents could no longer imagine leading their lives on the basis of their current knowledge. The questionnaire could be answered within approximately 15 min and was pre-tested in 50 participants with respect to length, order, and clarity of questions.

Outcome Measures

The main outcome measures were (1) the degree of disability (determined by the mRS) that the participants consider as being still acceptable for themselves versus being no longer acceptable, (2) the importance of the side of the infarction (dominant vs. non-dominant hemisphere

Table 1 Characteristics of the study population ($n = 554$)

Characteristics	Patient value ($n = 355$)	Relatives value ($n = 199$)
Age, years, median (IQR)	67 (56–75)	56 (45–70)
Age category, years, n (%)		
<45	24 (6.8)	48 (24.6)
45–54	53 (15.1)	40 (20.5)
55–64	75 (21.4)	38 (19.5)
65–74	104 (29.6)	43 (22.1)
≥75	95 (27.1)	26 (13.3)
Not available	4 (1.1)	4 (2.0)
Female sex, n (%)	149 (42.0)	131 (65.8)
Family status, n (%)		
Married	185 (52.1)	126 (63.3)
Single	42 (11.8)	42 (21.1)
Divorced	50 (14.1)	15 (7.5)
Widowed	65 (18.3)	7 (3.5)
No comment	13 (3.7)	9 (4.5)
Housing situation of the patient n (%)		
Living alone	114 (32.1)	42 (21.1)
Living with partner	202 (56.9)	117 (58.8)
Living with relative	15 (4.2)	32 (16.1)
Living in nursing home	14 (3.9)	5 (2.5)
No comment	10 (2.8)	3 (1.5)
Time since stroke, days, n (%)		
0–3	168 (47.3)	82 (32.8)
4–7	86 (24.2)	60 (30.2)
>7	46 (13.0)	26 (13.1)
No comment	55 (15.5)	31 (15.6)
Subjective complete recovery, n (%)		
Yes	134 (37.7)	69 (34.7)
No	204 (57.5)	115 (57.8)
No comment	17 (4.8)	15 (7.5)
Need of care directly after stroke, n (%)		
Yes	128 (36.1)	86 (43.2)
No	219 (61.7)	109 (54.8)
No comment	8 (2.3)	4 (2.0)
Change of housing situation after the stroke, n (%)		
Yes	16 (4.5)	14 (7.0)
No	285 (80.3)	145 (72.9)
Uncertain	45 (12.7)	37 (18.6)
No comment	9 (2.5)	3 (1.5)
Self-evaluated disability, mRS		
Mean, SD	1.49 (\pm 1.38)	1.73 (\pm 1.53)
Median, IQR	1 (0–2)	1 (0–3)
Self-evaluated disability, mRS, n (%)		
0	95 (26.8)	49 (24.6)
1	110 (31.0)	49 (24.6)
2	54 (15.2)	32 (16.1)
3	41 (11.5)	25 (12.6)
4	31 (8.7)	21 (10.6)
5	8 (2.3)	10 (5.0)
No comment	16 (4.5)	13 (6.5)

Relatives assessed housing situation of the patient, subjective complete recovery, need of care directly after stroke, change of housing situation after the stroke, and self-evaluated disability for their own patient
IQR Interquartile range, *SD* standard deviation, *mRS* modified Ranking Scale

Table 2 Acceptable disability and treatment decisions ($n = 554$)

Characteristics	Patient value ($n = 355$)	Relatives value ($n = 199$)
Still acceptable outcome, mRS, n (%)		
1	54 (15.2)	12 (6.0)
2	60 (16.9)	20 (10.1)
3	112 (31.5)	60 (30.2)
4	63 (17.7)	52 (26.1)
5	24 (6.8)	6 (15.6)
No comment	42 (11.8)	24 (12.1)
No longer acceptable outcome, mRS, n (%)		
1	8 (2.3)	0 (0.0)
2	12 (3.4)	4 (2.0)
3	31 (8.7)	15 (7.5)
4	112 (31.5)	38 (19.1)
5	126 (35.5)	85 (42.7)
No comment	66 (18.6)	57 (28.6)
Side of stroke important for therapeutic decision, n (%)		
Yes	165 (46.5)	78 (39.2)
No	118 (33.2)	75 (37.7)
No comment	72 (20.3)	46 (23.1)
Therapeutic decision dominant hemisphere, n (%)		
Decompressive hemicraniectomy	121 (34.1)	74 (37.2)
Non-surgical therapy but intensive care treatment	69 (19.4)	32 (16.1)
No therapy	43 (12.1)	30 (15.1)
No comment	122 (34.4)	63 (31.7)
Therapeutic decision non-dominant hemisphere, n (%)		
Decompressive hemicraniectomy	106 (29.9)	77 (38.7)
Non-surgical therapy but intensive care treatment	92 (25.9)	38 (19.1)
No therapy	54 (15.2)	28 (14.1)
No comment	103 (29.0)	56 (28.1)

mRS modified Ranking Scale

affecting the presence of aphasia) regarding treatment decisions of the participants for themselves, and (3) what treatment modality the participants would prefer for themselves in the case of dominant versus non-dominant hemisphere infarction, giving three alternative options, i.e., decompressive hemicraniectomy versus intensive care treatment versus palliative care and possible determinants of decisions (age, sex, marital status, recovery, need of care, and housing situation before and after stroke, and self-evaluated disability).

Statistical Analysis

Descriptive statistics were calculated for all variables, and the Chi-square test or the Mann–Whitney U test was used as appropriate. Univariate analyses were performed for all categorical variables. Adjusted odds ratios were calculated using multivariable logistic regression models with stepwise backward variable selection. Due to the completely

anonymous design pair formation between patients and relatives, diversification of participant within the centers, and sensitivity analysis between attitudes of participants from different hospitals were not possible. Data sets with missing values were not included in the analyses. Missing values (questions) ranged from 42 to 122 of 355 (11.8 and 34.4%, respectively). All tests were two-tailed. Statistical significance was determined at a α -level of 0.05. Statistical analyses were performed using the SPSS 20.0 software package (SPSS Inc, Chicago, IL).

Results

Characteristics of Study Subjects

A total of 675 patients and relatives were issued with the questionnaire at 9 German Stroke Units between May 2011 and May 2012 (Charité—University Hospital Berlin

$n = 416$, University Hospital Munich Technical University $n = 40$, Community Hospital Hans-Susemihl-Krankenhaus Emden $n = 23$, University Hospital Halle $n = 17$, University Hospital Mainz $n = 17$, Community Hospital Katharinenhospital Stuttgart $n = 17$, University Hospital Cologne $n = 10$, University Hospital Frankfurt $n = 8$, Community Hospital HELIOS-Klinikum Meiningen $n = 6$). From these, 554 participants, 355 patients and 199 relatives, answered the questionnaire, while 121 participants returned a blank questionnaire (response rate 82.1%). Relatives indicated that before the index stroke 163 patients (81.9%) did not require constant care, 21 (10.5%) received support by their relatives, 4 (2.0%) received support by an ambulant caregiver, 5 (2.5%) were residents in a nursing home, and 6 (3.0) abstained from voting. Relatives of patients were either spouses ($N = 93$, 46.7%), partners ($N = 22$, 11.1%), parents ($N = 37$, 18.6%), children ($N = 14$, 7.0%), close friends ($N = 11$, 5.5%), or otherwise acquainted persons ($N = 20$, 10.1%); 2 (1.0%) did not indicate their relation. Characteristics of the participants are shown in Table 1.

Attitudes Among Patients and Relatives

Acceptance of Outcome

Most of the patients and relatives regarded a mRS of 1 or 2 as acceptable outcome after malignant MCA infarction (88.1 and 86.0, 72.9 and 82.0%, respectively). Only half of the patients but the majority of relatives considered a mRS of 3 acceptable (56.0 and 71.9%). Less than half of the patients and relatives considered a mRS of 4 acceptable (24.5 and 41.7%), and only a minority of patients and relatives considered a mRS of 5 acceptable (6.8 and 15.6%). Except for a mRS score of 1, differences in attitudes toward acceptable outcome were statistically significant between patients and relatives, with generally higher rates of acceptance in relatives (mRS2: $p = 0.004$, mRS3: $p < 0.001$, mRS4: $p < 0.001$, mRS5: $p = 0.003$). Attitudes toward no longer acceptable outcome reflected those toward acceptable outcome (Table 2; Fig. 1).

Considering the dichotomized degree of disability (mRS 1–3 vs. 4–5), significant differences in attitudes were found between patients and relatives ($p < 0.001$), housing situations before stroke ($p = 0.002$), change of housing situation after stroke ($p = 0.004$), complete recovery after stroke ($p = 0.001$), need for care after stroke ($p < 0.001$), and self-evaluated disability after stroke ($p < 0.001$) (supplemental table I). In multivariate analysis, only relatives ($p < 0.001$) and actual degrees of disability after stroke (with more actual disabilities indicating higher acceptance $p < 0.001$) were significantly associated with considering a mRS of 4–5 as still acceptable (supplemental table IV).

Treatment Decision Depending on the Presence of Aphasia

Less than half of the patients (46.5%) and relatives (39.2%) regarded side of the infarct (dominant vs. non-dominant impacting occurrence of aphasia) as important in their treatment decision ($p = 0.16$) (Table 2; Fig. 2). No differences were found among all subgroups (supplemental table II).

Preferred Treatment

Overall, decompressive hemicraniectomy was the treatment of choice over intensive care treatment or palliative care in both dominant and non-dominant hemispheric MMI (Table 2).

In dominant hemispheric stroke, decision toward decompressive hemicraniectomy (and against non-surgical therapy) was more frequently observed in: younger participants (mean age 56 vs. 69 years; age group <45 years 72.9%, 45–54 years 59.2%, 55–64 years 60.5%, 65–74 years 45.1%, >74 years 36.8%; $p < 0.001$); divorced and singles compared to married and widowed (65.4 and 61.4 vs. 50.7 and 39.5%; $p = 0.04$); in cases of complete recovery (60.0 vs. 46.8%; $p = 0.02$), without need of care after stroke (58.0 vs. 45.1%; $p = 0.02$) and minor disability after stroke (mRS0 60.6%, mRS1 53.9%, mRS2 50.0%, mRS3 48.9%, mRS4 48.6%, mRS5 14.3%; $p = 0.04$) (supplemental table III). In multivariate analysis, only respondents who experienced complete recovery after stroke ($p = 0.025$) were significantly more likely to choose DHC, while increasing age was significantly associated with refusing DHC ($p = 0.015$) (supplemental table IV).

In non-dominant hemispheric stroke, decision toward decompressive hemicraniectomy (and against non-surgical therapy) was more frequently observed in: younger participants (mean age 56 vs. 67 years; age group <45 years 73.2%, 45–54 years 55.4%, 55–64 years 46.8%, 65–74 years 41.3%, >74 years 24.7%; $p < 0.001$); relatives versus patients (53.8 vs. 42.1%; $p = 0.03$); and participants living with relatives versus living with a partner, alone, or in a nursing home (62.5, 46.6, 45.3, 15.4%; $p = 0.03$) (supplemental table III). In multivariate analysis, increasing age had a significantly higher likelihood of refusing DHC ($p < 0.001$) (supplemental table IV).

Discussion

Great concern remains about DHC in MMI with respect to whether a higher degree of disability and the presence of aphasia may be desirable clinical outcomes in an otherwise deadly disease. Among patients with acute mild-to-moderate severe stroke and relatives, we found a wide variation

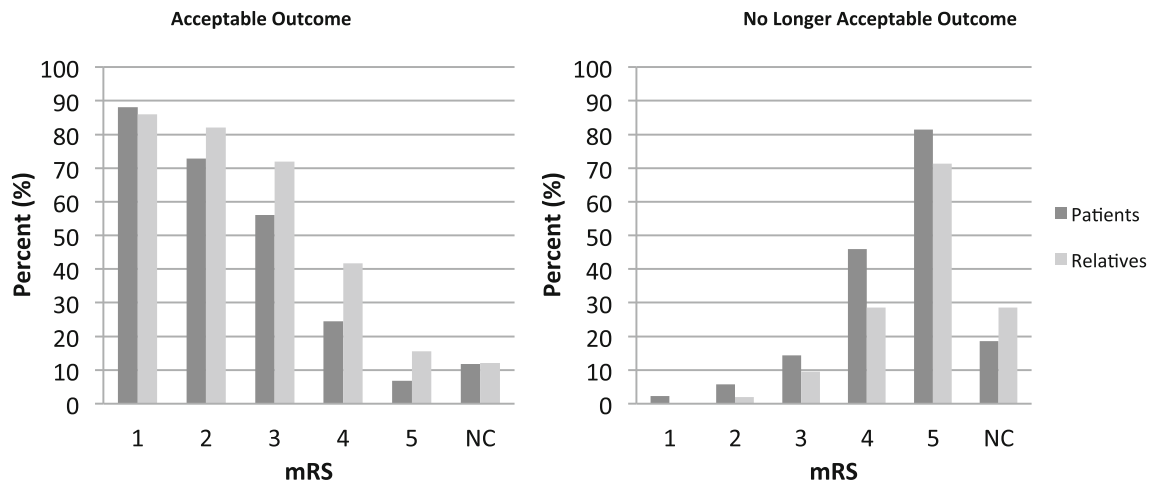
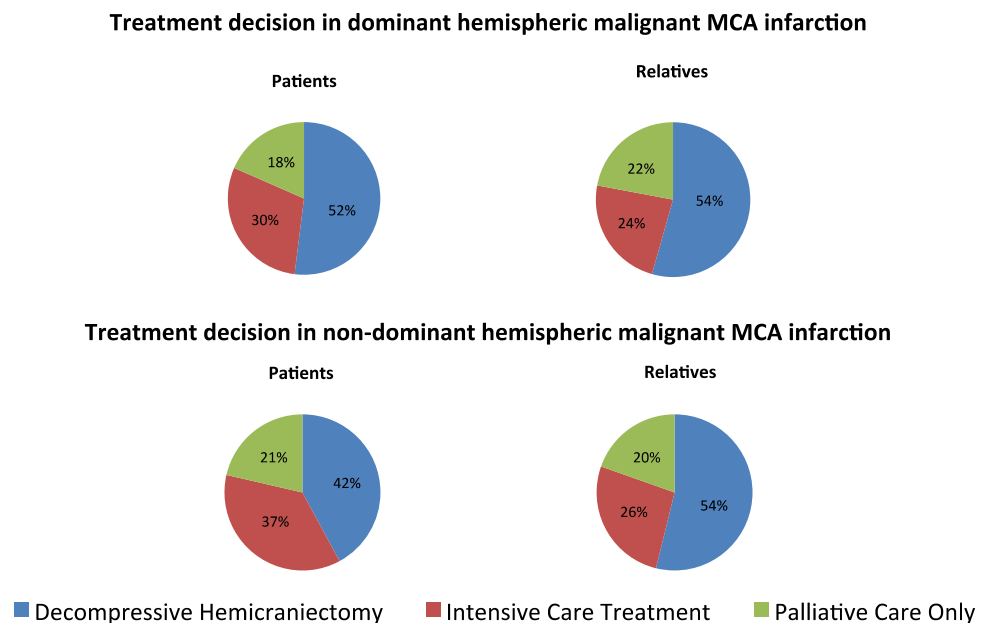


Fig. 1 Rates were calculated based on the assumption that considering a certain mRS as acceptable means considering all lower mRS as also acceptable and vice versa for no longer acceptable outcome. *NC* No comment, *mRS* modified Ranking Scale

Fig. 2 Rates of decompressive hemicraniectomy, intensive care treatment, and palliative care only as indicated as preferred therapy in case of malignant middle cerebral artery infarction by patients and relatives. Rates presented differ from Table 2 because missing values were not considered in the *pie charts*



regarding the degree of disability that is considered acceptable and the preferred treatment. This variation was influenced by family status, housing situation, and recovery status. As expected, the majority of patients indicated a mRS of 1 or 2 as acceptable and a mRS of 5 not. A mRS of 3 was regarded acceptable by more than half, and a mRS of 4 by less than half of the participants. Relatives significantly overestimated the degree of acceptable outcome compared to patients. The presence of aphasia was of special concern in a large proportion of respondents.

The disparities regarding acceptable outcome seem to be mainly influenced by the personal experience of disability and dependency. Respondents who indicated higher degrees of self-evaluated disability or were familiar with disability among their relatives were significantly more

likely to accept moderate or severe disability. This finding is in contrast to previous surveys among the general population in Germany, healthcare workers from Australia, and young adults from California: No associations were found between demographic factors, living situation or health status, and the acceptance of disability [17, 19, 20]. These surveys did, however, not specifically ask for disability and dependency among their respondents. Furthermore, subgroups of respondents older than 65 years, living in a nursing home, or indicating poor health status, were too small for reliable analyses. On the other hand, our observation is in line with two observations: the surprisingly high acceptance of disability seen in chronic disabling diseases, such as amyotrophic lateral sclerosis or locked-in syndrome and with the high rates of

retrospective consent to DHC in survivors of MMI [22, 23, 27–29]. The explanation for this phenomenon is probably a dynamic adaptation process that occurs over the time spent in dependency: With every degree of self-experienced disability, the odds ratio to accept moderate or severe disability rises from 1.0 to 7.17 or 6.80 [22, 23].

Interestingly, the acceptability of higher degrees of disability was not reflected by the decision to choose life-saving DHC. On the contrary, respondents who experienced complete recovery and independency after stroke and did refuse to accept higher degrees of disability were significantly more likely to choose DHC as preferred treatment. Vice versa, older respondents indicating higher acceptability for disability were less likely to choose DHC as preferred treatment. This paradox was also found in previous surveys describing similar discrepancies among physicians, healthcare workers, and young adults [19, 20]. A common interpretation of choosing DHC despite the unwillingness to accept higher degrees of disability is that humans lack the ability to estimate risks in uncertain situations and hope for the chance of a good outcome rather than taking into account the true probability [30, 31].

The finding that aphasia is of major concern in a large proportion of respondents has been observed before among physicians and healthy young adults. However, this finding does contrast with studies on DHC in MMI that reported a comparable functional outcome regarding the presence of aphasia [5, 20, 21, 32]. A systemic review on quality of life (QoL) in survivors of MMI provided evidence that there is substantial heterogeneity in QoL results with regard to aphasia. In addition, QoL could often not be obtained in aphasic patients, and sometimes QoL was assessed by proxies only [23]. Therefore, the concerns of healthy respondents regarding aphasia after MMI should be taken seriously until large-scale prospective data on long-term outcome in aphasic survivors of MMI are available.

Previous studies about chronically ill patients found that surrogates were not able to predict patients' wishes regarding medical decisions [33, 34]. In our survey, relatives were consistently more positive than patients. Optimism bias is a well-known phenomenon in surrogates of critically ill patients. Rather than misunderstanding prognostic data and doubt in the accuracy of physicians' prognostications, surrogates tend to overestimate the likelihood of their loved ones to experience favorable outcome. They also feel the need to express optimism in the moment of a poor prognosis and are sometimes captured in linking their wishes to their loved one's outcome [35]. This stresses the need for communication methods on how to inform surrogates of patients with MMI acknowledging optimism bias as a source of discordance regarding prognostication.

Limitations of our study include the possibility of information bias because of missing values and sampling

bias due to convenience sampling. Because severe stroke patients are not able to participate in a survey, our cohort did not include patients with MMI. In contrast, most patients of our cohort did suffer from mild-to-moderate severe stroke. However, the response rate was high and most results were in line with current literature on survivors of MMI. Furthermore, we were not able to pair respondents or correct for center effects due to the completely anonymous design.

Conclusion

In Germany, there is substantial heterogeneity in patients and relatives impressions of what could be an acceptable outcome after MMI. Aphasia is of major concern to a large proportion of respondents regardless of the available data. Further studies are warranted to determine whether differences in attitudes impact on the decision to undergo DHC. Overall, communication methods are needed to avoid optimism bias in surrogate decision making while still guaranteeing appropriate informed consent.

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Author Contributions H.N. analyzed and interpreted the data and drafted the manuscript. M.S. helped in clinical data collection and critical revision of the manuscript for important intellectual content. D.L. contributed to interpretation of data and critical revision of the manuscript for important intellectual content. P.U.H. analyzed and interpreted data and critically revised the manuscript for important intellectual content. E.J. contributed to study concept, design, supervision, and critical revision of the manuscript for important intellectual content.

Compliance with ethical standards

Conflict of interest H.N. received travel grants from Boehringer Ingelheim. P.U.H. received in the recent years research support from the European Union, the Federal Ministry of Education and Research (BMBF) in Germany, the German Stroke Foundation, and the Charité—Universitätsmedizin Berlin. E.J. received research grants from the German Research Foundation (DFG) and from the Federal Ministry of Education and Research (BMBF), and speaker's honoraria and travel grants from Bristol-Myers Squibb, Bayer, and from Boehringer Ingelheim. M.S. and D.L. do not report any disclosures. The study was investigator-driven and not industry-sponsored.

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