Effects and Quality of Stroke Rehabilitation of BAR Phase D

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Bibliography

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ABSTRACT

Background Stroke is a major public health problem of enormous epidemiological significance. Each year, approximately 200.000 people in Germany suffer a stroke. Stroke is the third leading cause of death and the most common cause of acquired disabilities in adults. About one fourth of stroke survivors

report severe limitations in activities of daily living three months after acute stroke. The most common post-stroke conditions are motor and cognitive dysfunctions as well as affective problems. Stroke rehabilitation plays a crucial role in coping with stroke sequelae. The large number of strokes and the often debilitating consequences raise the question to what extent participation can be increased by medical rehabilitation.

Methods A prospective, multicenter survey study was conducted in six neurological inpatient rehabilitation centers. Recruitment focused on patients with recent acute stroke and disease severity corresponding to BAR phase D. Patients completed questionnaires at three points of measurement: at the beginning and at the end of the inpatient rehabilitation and after four months. Primary outcome was participation, secondary outcomes included several parameters of subjective well-being. Furthermore, utilization of aftercare and satisfaction with the rehabilitation program were measured.

Results At the beginning of the rehabilitation, patients experienced severe limitations in participation and reduced subjective well-being. At the end of inpatient rehabilitation, significant improvements of small effect sizes for subjective well-being and medium effect sizes for participation were achieved. After four months, effects had decreased, yet improvements compared to baseline were still noticeable. Patient ratings of the rehabilitation program and the outcomes achieved were consistently positive. Two thirds of the patients were advised to make use of aftercare offerings and most patients (83 %) participated in an aftercare program of any kind.

Conclusions The results of this study support the notion that stroke rehabilitation has significant and sustainable effects. Participation in particular seems to improve through medical rehabilitation. Partly decreased effects after four months raise the question of adequate aftercare.

Introduction

Stroke is a major public health problem of enormous epidemiological significance. According to the Erlangen Stroke Registry, in Germany 196 000 persons experience first stroke and 66 000 recurrent stroke each year [1]. With approximately 8 %, stroke is still the third leading cause of death in Germany, following heart disease and cancer. However, a continuous decline in stroke mortality has been observed in recent years. At the same time, stroke is the leading cause

of acquired disability in adults. About one quarter of stroke survivors is affected by severe limitations in their activities of daily living three months after the acute stroke [1] and even after several years more than 65 % of stroke patients have not returned to pre-stroke levels of activity and participation [2].

The most common post-stroke conditions are disturbances in sensorimotor, cognitive und emotional-affective functioning. Motor impairments as well disorders of language and speech usu-

ally dominate the clinical picture [3]. In addition, approximately 15 % of stroke patients experience at least mild cognitive dysfunction after the cerebrovascular accident [4] and not less than one third of patients develops symptoms of depression [5], which turns out to be a long-term problem. Pursuant to German social law, core target of medical rehabilitation after stroke is the restoration of social participation. Especially in phase D of the BAR phase model, maximum increase in the abilities to participate in daily life, at the workplace and in recreational activities is the key target of rehabilitation in patients with maintained or restored independence [6]. The large number of those affected and the often debilitating consequences of stroke raise the question to what extent participation can be increased by medical rehabilitation.

Quality assurance in medical rehabilitation has steadily increased in significance in recent years [7]. Despite differentiated indication-specific patient surveys, the results of quality assurance analyses are frequently too general and do not produce rehabilitation-specific insights for individual conditions, such as stroke. The patient surveys of the German Pension Insurance Association (DRV Bund) [8] focus on patient satisfaction with rehabilitation programs, changes in individual symptoms and the question of fitness for work. In addition, the overall number of patients in neurological rehabilitation is very low and data of patients diagnosed with stroke are not analyzed separately.

A study by Weber et al. [9] specifically designed to assess the impact of various types of treatment on the course of stroke patient rehabilitation used pension insurance fund data but could only draw general conclusion and primarily highlighted the need for further studies addressing all levels of the International Classification of Functioning, Disability and Health (ICF). They also address another key problem of studies evaluating the success of rehabilitation programs after stroke: Frequently, the focus is on outcome parameters beyond the subjective increase in participation reported by patients, such as functional independence and mortality. Likewise, for the comparison of various systems of stroke management and stroke rehabilitation usually criteria such as mortality rates, need for nursing care and medical treatment are evaluated [10, 11]. However, the important questions of social integration, quality of life and participation typically remain unanswered.

If everyday abilities and participation are selected as key parameters of stroke rehabilitation, the patient's subjective perception becomes a key element of evaluation. In this regard, only limited data specific to stroke are available. The studies of Bölsche et al. evaluated these categories and arrived at the conclusion that the greatest gains were made in functional independence and everyday abilities. With regard to quality of life and general health status, moderate improvements were observed [12–14].

Gerdes, Baum et al. [15] found similar results in their study on outcome quality in 3 neurological rehabilitation facilities. They collected data of 700 patients, using both patient and physician questionnaires due to the wide range of neuropsychological impairments. In this very inhomogeneous study population, the physician-documented effects in the somatic domain were very strong with regard to improvements, while they were noticeably weaker for patient-perceived impairments in areas of daily living [15]. This example shows that improvements in somatic parameters are not

necessarily associated with an improvement in patient-perceived health and quality of life.

In a pilot study, Pöpl et al. used the IMET index to measure participation [16]. For the indication Neurology in an outpatient setting, slight improvements in participation status were identified at the 4-month follow-up and the suitability of IMET as a tool to document participation was proven. Against the backdrop of a lack of studies evaluating changes relevant to daily life and participation after stroke rehabilitation, the aim of this study was to close this gap in our understanding of stroke rehabilitation.

Material and Methods

Study design

We conducted a prospective multicenter observational study in 6 rehabilitation facilities. Data from patients in neurological rehabilitation were collected at 3 time points: at the start and end of the rehabilitation program and at month 4 after completion. Rehabilitation patients after acute cerebrovascular events (subarachnoid hemorrhage, ischemic and hemorrhagic strokes) with a severity of BAR phase D of neurological rehabilitation at baseline were included in this study. Rehabilitation patients who experienced recurrent stroke during phase D rehabilitation, in whom continuation of phase D rehabilitation treatment was not possible due to complications, and those older than 66 years were excluded from this study. After obtaining informed consent, consecutive patients were included in the study.

Instruments

We used a 6-page questionnaire which the participants completed in the rehabilitation facility at the start (T0) and end (T1) of their in-patient stay; the follow-up questionnaires were mailed by the rehabilitation facility to the rehabilitation patients at month 4 after end of rehabilitation and completed at home. The questionnaire was composed of several validated individual instruments. The primary endpoint was participation (IMET [17]) as this is a central objective of rehabilitation in patients with stroke. Secondary endpoints were general symptoms (SCL-90R [18]), catastrophizing cognitions (FSS [19]), functional impairments in daily life (FFbH-R [20]), performance in various aspects of life (numeric rating scales), the risk of losing employment (SPE scale [21]), recommendation and utilization of aftercare offerings, and satisfaction with rehabilitation program. Sociodemographic data [22] were collected as moderator variables and to characterize the patient population.

Statistical analysis

Descriptive statistics and correlation analyses (chi-square test, Student's T test, variance analyses with repeated measurements) were calculated. In addition, intra-group effect sizes were calculated, with the differences in means standardized based on the pooled standard deviations [23]. The effect sizes were interpreted as described by Cohen [24] ($d > 0.2$ small, $d > 0.5$ medium and $d > 0.8$ large effect). We used the SPSS Statistics software suite, version 22.0, for analysis. Significance level was set at $p < 0.05$.

Ethics, collaborations and financial support

The ethics committee of the Faculty of Medicine of the University of Lübeck expressed no professional ethics, medical/scientific and professional law concerns against the conduct of the study and approved the study in its meeting of March 12, 2015 (file no. 15-024). The following rehabilitation facilities participated in this study: Diana-Klinik Bad Bevensen, Klinik am Rosengarten Bad Oeyenhausen, Neurologische Rehabilitationsklinik Bad Bramstedt, RehaCentrum Hamburg, Median Rehazentrum Gyhum, and Zentrum für Rehabilitation Jesteburg. This study was financially supported by vffr (Verein zur Förderung der Rehabilitationsforschung in Hamburg, Mecklenburg-Vorpommern und Schleswig-Holstein e.V.) (project no. 197).

Results

Patients and dropout

The survey was conducted between December 2015 and June 2017. Altogether 390 rehabilitation patients after acute stroke participated in this study. The mean interval between cerebrovascular accident and start of rehabilitation was 3 months. At the end of rehabilitation and at the time of follow-up, the numbers of cases were 365 and 259, respectively. The complete datasets of 259 rehabilitation patients were included in the analysis; detailed information of the subject flow is provided in ► Fig. 1.

A non-responder analysis was preformed to estimate the risk of bias. We found significant differences between the rehabilitation patients who no longer participated in the study at the time of follow-up (N = 106) and the remaining rehabilitation patients (N = 259) with regard to gender and age. Significantly more male patients dropped out from the study and the non-responders were 2 years younger on average (52.1 vs. 54.3 years). No other differences in sociodemographic characteristics and in primary and secondary endpoints were found (► Table 1).

Patient population

One third of the total patient population was female and the average age was 54 years. Almost two thirds were married and 70 % of patients lived in a common household with their partner. The majority of the surveyed patients were working full-time or part-time and the most common educational achievement was a German intermediate secondary school-leaving certificate ("Realschulabschluss"). Incapacity for work during the last 12 months was 18 days on average and one third of the respondents intended to submit a pension application. ► Table 2 summarizes the sociodemographic characteristics of the study population.

The majority of patients (86 %) undergoing the rehabilitation program had stroke as their primary diagnosis; only in a small proportion of cases subarachnoid hemorrhage or hemorrhagic stroke were the primary diagnoses. Most patients were admitted to the rehabilitation facility from Phase A (77 %), 35 patients from Phase C (23 %) and only one Patient from Phase B. The mean length of stay in the rehabilitation facility was 31 days (SD19.3).

Baseline status at the start of rehabilitation

On admittance to the rehabilitation facility, patients presented was largely intact everyday functioning. The mean baseline Barthel index was 96.4 (SD 8.31) and 91 % had a Barthel index of more than 85 points. Almost one third of patients reported their general health as very good or good (30.3 %) and more than one third were satisfied with their health status (35.5 %). The remaining patients considered their state of health as not so good or poor. With regard to participation, the primary endpoint of this study, patients showed considerable impairments; both in the individual areas of participation and in total participation, the values of the rehabilitation patients surveyed were significantly above the values reported for the general population and those of patients undergoing rehabilitation for other indications [27]. In the other subjective-health scales, impairments were rather moderate to mild. With regard to their performance, the rehabilitation patients reported significant impairments in all aspects of life, with performance losses of 50 % (cf. ► Table 3).

Subjective prognosis of capacity to work

The majority of the respondents who were still working thought that they will be able to continue working until retirement age (73 %), while a little over a third regarded their capacity to work as being permanently at risk. Almost one quarter was thinking about submitting a pension application. Accordingly, 28 % of patients were in the two groups with the highest risk scores (cf. ► Table 4).

Treatments during rehabilitation

Most rehabilitation patients received sports therapy and exercise therapy, neuropsychological therapy and occupational therapy. In addition, physiotherapy and relaxation techniques played an important role. Patients rated the therapies generally positive, with a mean score of 4.32 on a scale of 1 "very bad" to 5 "very good" (► Fig. 2).

Altogether, 86 % of rehabilitation patients reported to have received the right therapies for their condition; 81 % rated the extent of treatment as sufficient. Rehabilitation patients reported physiotherapy, neuropsychological therapy and occupational therapy as the most beneficial treatments.

► **Table 1** Drop-out analysis.

	Participants 175	Drop-outs 51	p value
Sociodemographic characteristics			
Gender, N (%)			<0,01
male	163 (63,9)	82 (78,1)	
female	92 (36,1)	23 (21,9)	
age, years, M (SD)	54.3 (7,9)	51,8 (8,5)	0,010
Education, N (%)			0,799
max. lower secondary school	89 (35,6)	41 (39,0)	
– secondary school, POS	95 (38,0)	39 (37,1)	
general university entrance qualification	66 (26,4)	25 (23,8)	
Working, N (%)	214 (84,3)	81 (76,4)	0,078
Disease-related characteristics			
Admission from phase, N (%)			0,816
A	118 (76,6)	49 (75,4)	
B	1 (0,06)	1 (1,5)	
C	35 (22,7)	15 (23,1)	
Primary diagnosis, N (%)			0,440
cerebral infarction	218 (85,5)	93 (89,4)	
intracerebral hemorrhage	19 (7,5)	4 (3,8)	
subarachnoid hemorrhage	18 (7,1)	7 (6,7)	
Barthel index, M (SD)	96,4 (8,3)	95.1 (11,7)	0,266
Participation, M (SD)	26,9 (21,7)	27,4 (21,6)	0,859
somatic complaints, M (SD)	6,2 (5,2)	5,8 (5,2)	0,987
Functional capacity, M (SD)	81,0 (19,2)	81,2 (19,7)	0,911
Catastrophizing, M (SD)	5,0 (19,2)	5,0 (8,1)	0,947

► **Table 2** Characteristics of the patient population.

Gender	
female N (%)	92 (35,8)
Age in years M (SD)	54,5 (7,1)
Education, N (%)	
lower secondary/no school-leaving certificate	88 (35,2)
intermediate school-leaving certificate/ polytechnic secondary school	95 (38)
technical university entrance qualification/ general university entrance qualification	66 (26,4)
Currently working N (%)	
working full-time or part-time	212 (83,5)
incapacity for work, days M (SD) ¹	18,2 (44,31)
Intention to submit pension request, yes N (%) ¹	50 (24,2)
Living with partner N (%)	112 (69,6)

¹only working rehabilitation patients (N = 211).

From the offered range of health education, training and advice, health-related lectures were most popular among rehabilitation patients, but socio-legal advice and general education events played an important role too (► **Fig. 3**).

Almost 50 % or one third of rehabilitation patients who were still working participated in work-related events. These also received positive ratings, with a mean of 4.0 (5 = “very good”).

Changes in disease-specific parameters after rehabilitation

Everyday functioning was significantly improved immediately after the end of rehabilitation. The mean Barthel index at the end of rehabilitation was 98.8. After rehabilitation, 68 % of rehabilitation patients achieved a Barthel score of 100; in only 6 patients, the score was below 85. For participation and all other measured parameters, positive, statistically significant improvements on the level of small to moderate effect sizes were found (cf. ► **Table 3**).

While for the primary endpoint, participation, significant effects were demonstrated after 4 months, the effects on the other parameters diminished over time, with some returning to baseline levels. Performance could be increased in all measured aspects of life over the period of 4 months (► **Table 3**).

► **Table 3** Changes in subjective health at the end of rehabilitation and after 4 months.

	Measurement time points, M (SD)			SRM ¹		p values ²
	T0	T1	T2	T0-T1	T0-T2	Time
Primary endpoint						
IMET(0-90)	27,21 (21,77)	19,16 (19,75)	21,50 (21,41)	0,53	0,26	<0,01
Secondary endpoints						
Functional capacity (0-100)	81,01 (18,98)	86,24 (16,99)	84,41 (20,06)	0,41	0,20	<0,01
Catastrophizing (0-45)	5,11 (7,74)	3,70 (7,10)	5,56 (8,47)	0,61	- 0,05	<0,01
somatic complaints (0-48)	6,26 (5,22)	4,80 (4,59)	6,32 (5,87)	0,32	- 0,02	<0,01
Performance: everyday life (0-10)	5,9 (3,1)	*	6,7 (2,6)	*	0,44	<0,01
Performance: occupational (0-10)	5,3 (3,6)	*	6,0 (3,4)	*	0,48	<0,01
Performance: leisure time (0-10)	5,2 (3,2)	*	6,8 (2,6)	*	0,18	p = 0,021

¹standardized response mean; ²F tests; * No data collected on this parameter at the end of rehabilitation

► **Table 4** Changes in specific areas of participation.

	Measurement time points, M (SD)			SRM ¹		p values ²
IMET items (0-10)	T0	T1	T2	T0-T1	T0-T2	Time
Usual activities	1,5 (2,0)	1,1 (2,0)	1,3 (2,1)	0,20	0,08	<0,01
Domestic responsibilities	2,9 (2,7)	2,0 (2,5)	2,1 (2,6)	0,35	0,27	<0,01
Errands	2,9 (3,1)	2,0 (2,7)	1,8 (2,6)	0,36	0,34	<0,01
Daily tasks	4,2 (3,4)	2,9 (3,0)	3,0 (3,1)	0,44	0,36	<0,01
Recreation	3,7 (3,0)	2,3 (2,6)	2,6 (2,7)	0,56	0,36	<0,01
Social activities	2,9 (3,0)	1,7 (2,3)	2,1 (2,7)	0,48	0,24	<0,01
Personal relationships	1,8 (2,5)	1,5 (2,5)	1,9 (2,7)	0,18	-0,01	<0,01
Sexual activities	3,1 (3,2)	2,3 (3,0)	3,0 (3,4)	0,30	-0,01	<0,01
Stress	4,1 (3,2)	3,3 (3,1)	3,6 (3,1)	0,31	0,12	<0,01

¹standardized response mean; ²F tests;

Looking at limitations in participation on the item level over the clinical course, almost all aspects showed a positive course with a slight reduction at month 4 after rehabilitation. The only exception were personal relationships and sexual activities where the limitations at month 4 after rehabilitation exceeded the baseline values (► **Table 4**).

Subjective prognosis of capacity to work at month 4 after rehabilitation

The risk score for subjective prognosis of capacity to work deteriorated slightly between baseline and the time of follow-up. Four months after the end of rehabilitation, 32 % of the rehabilitation patients who were still working were in the two highest risk groups compared with 28 % prior to rehabilitation. The number of rehabilitation patients who thought that they will be able to continue

working until retirement age slightly dropped; at the same time, the number of those who considered their capacity to work as being permanently at risk and of those who thought about submitting a pension application fell slightly. All these differences were not statistically significant. ► **Table 5** shows the frequency of the various items and the total score for subjective prognosis of capacity to work at baseline and at month 4 after rehabilitation.

Most of the patients who had been still working at the start of rehabilitation, returned to their job after rehabilitation (90 %). The 22 rehabilitation patients were no longer working at the time of follow-up, stated that they had lost or given up their jobs or were retired. No relation was found between participation in work-related events during rehabilitation and subjective prognosis of capacity to work at the time of follow-up or job loss.

► **Table 5** Subjective prognosis of capacity to work at baseline and at month 4 after rehabilitation.

	% yes ¹		SPE score	%	
	T0	T2		T0	T2
			0	58,3	57,1
1. Do you think you will be able to continue working until retirement age?	72,5	67,5	1	13,6	11,5
2. Do you think your current state of health will put your capacity to work permanently at risk?	36,7	35,1	2	11,6	16,8
3. Are you currently thinking about submitting a pension application?	24,2	23,6	3	16,6	14,7

¹for patients still working, N = 212

► **Fig. 2** Therapies during rehabilitation.

Recommendations and utilization of rehabilitation aftercare

Almost two third (64 %) of rehabilitation patients stated that they had received an aftercare recommendation. Overall, these aftercare recommendations were perceived as rather helpful. More than half of these rehabilitation patients received a recommendation for physiotherapy (58 %); occupational therapy was recommended in 40 %, MTT in 26 %, and in 29 (11 %) rehabilitation patients speech therapy was recommended. Other aftercare recommendations were in the single-digit range.

With regard to the utilization of aftercare, most patients reported to have participated in some type of aftercare. The extent varied between the different offerings. Half of the rehabilitation patients received individual physiotherapy, on average 19 sessions. Slightly more than one third (35 %) received occupational therapy, on average 16 sessions. MTT was performed in 21 %, on average 24 sessions. The remaining aftercare offerings played a minor role (► **Fig. 2**).

(► **Fig. 4**) The rehabilitation patients who received an aftercare recommendation, but did not utilize it (16 %) mainly reported as reasons lack of motivation, excessively long waiting times or no available offerings. Some did not have the time or felt they were too sick for it.

► **Fig. 3** Health-educational and work-related offerings during rehabilitation.

► **Fig. 4** Utilization of aftercare options.

Discussion

Medical assessment of the rehabilitation patients included in our study showed relatively low levels of impairment in everyday functioning at the start of rehabilitation. The average Barthel index of 96 and the large proportion of rehabilitation patients with a score >85 exceeds the values reported by Gerdes et al. [25] by far. However, it has to be taken into account that their patient population included rehabilitation patients of all BAR phases. The high level of independence found in our study does not come as a surprise considering the fact that it is a requirement for phase D rehabilitation. However, as Gerdes et al. [25] also pointed out, it can be expected that in phase D rehabilitation patients strong ceiling effects of the Barthel index influence the results; consequently, actually existing impairments cannot be detected with the Barthel index in this target group.

Therefore, measures of social participation and subjective health are parameters of greater significance. Here, the rehabilitation patients showed high to moderate levels of impairment at baseline. This is in line with the findings reported by Pöpl et al. [16] for patients in phase D and E of neurological rehabilitation and also in line with the scores found by the Schleswig-Holstein Medical Rehabilitation Quality Community (Qualitätsgemeinschaft medizinische Rehabilitation in Schleswig-Holstein, QGmR) for the indication Neurology [26].

With regard to the primary endpoint, participation, the mean score in our patient population was 10 points higher than the normal value in the general population [27]. At the same time, the score is 10 points lower than the one reported by Pöpl et al. [16], but it has to be taken into account that the mean age in their study was 10 years higher than the one in our study. Since limitations in participation show a strong correlation with age [27], this difference in mean age adequately explains the score difference. In the QGmR, rehabilitation patients of the indication Neurology also showed greater limitations in participation [28]. The most severe limitations in participation were reported in the areas of daily tasks, coping with stress, recreation and leisure as well as sexual activity. In various studies on outpatient neurorehabilitation, these were the most affected areas, too [29, 30]. The lowest level of interference was found in the areas of personal relationships and usual activities of daily living.

At the end of rehabilitation, a significant improvement in participation was found which was still detectable 4 months after rehabilitation and can thus be regarded as a sustained effect. A comparable effect was reported by Pöpl et al. [16] for outpatient rehabilitation patients; these findings support the positive effect of stroke rehabilitation on participation. However, the measure of limitations in participation was found slightly increased at the time of follow-up compared with the mean at discharge and was also higher than the normal value established in a healthy population sample. Recently, an international publication highlighted the problem of persistent limitations in participation found in physically recovered stroke patients. Despite the good physical outcome, 52% of patients reported limitations in participation over the long-term course [31]. Against this backdrop, the effect of a sustained improvement in participation is promising, but capable of improvement.

With regard to the secondary endpoints of subjective health it should also be noted that functional impairments in daily life at baseline were almost twice as high as in the general population. This is also in line with other data available [28–16]. By contrast, the levels of general symptoms and catastrophizing cognitions were relatively low and only minimally above or even below the normal value for the general population. At the end of rehabilitation, improvements in these parameters are also noted which remained relatively stable over time for functional impairments and performance in various aspects of life. The effects on general symptoms and catastrophizing cognitions could not be maintained over the follow-up period. In everyday life, rehabilitation patients have to face difficulties on their own and are alone with their worries and fears; it is difficult to permanently implement health-promoting behavior in everyday life. A complicating aspect is that, especially in the patients with stroke, the initial hope that impairments will improve may wane over time.

The subjective prognosis of capacity to work was already positive at the start of rehabilitation, with little change over the follow-up period.

Compared with other rehabilitation indications, the level of rehabilitation aftercare recommendations is relatively high; however, in view of the in some cases debilitating sequelae of stroke even a non-recommendation level of 30% is still too high. Likewise, with regard to utilization of aftercare, gaps are apparent which need to be closed.

Overall, rehabilitation patients were very satisfied with the rehabilitation program. Almost all rehabilitation patients (92%) rated their stay in the rehabilitation facility and the success of rehabilitation in a range from good to excellent. This, in combination with the great health-related benefits of rehabilitation perceived by patients, shows the high relevance of rehabilitation for those affected by stroke.

Limitations

The interpretation of the results is limited by the longitudinal observational study design. Studies without control group do not allow to draw conclusions on the efficacy of stroke rehabilitation. Consequently, there is a need for further studies with a controlled design.

Conclusions

The results of our study involving 6 rehabilitation facilities indicate that rehabilitation has a positive and sustained effect on limitations in participation after stroke. Furthermore, the ratings of the rehabilitation patients suggest that the perceived benefits of neurorehabilitation in stroke patients are high.

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Conflict of Interest

The authors declare no conflict of interest.

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