The Impact of Aneurysmal Subarachnoid Hemorrhage on Functional Outcome

Catherine J. Kirkness, Jo Marie Thompson, Barbara A. Ricker, Ann Buzaitis, David W. Newell, Sureyya Dikmen, Pamela H. Mitchell

bstract: Despite advances in the management of A aneurysmal subarachnoid hemorrhage (SAH), a significant percentage of survivors are left with persistent cognitive, behavioral, and emotional changes that affect their day-to-day lives. This article describes outcome at 3 months after aneurysmal SAH in 61 patients, using the Extended Glasgow Outcome Scale (GOSE) and the Functional Status Examination (FSE). The GOSE provides a measure of overall functional outcome but does not address the specifics of functional limitations. The FSE, in addition to identifying functional limitations, provides insight into factors contributing to them and the extent to which SAH survivors perceive them as affecting their day-today activities. The findings of this study demonstrate that SAH survivors have considerable limitations in functional status in almost all areas of daily living at 3 months following SAH. The limitations were attributed to a variety of physical, cognitive, and emotional factors, and they were reported to be moderately to severely bothersome in almost half of the individuals. The findings highlight the need for appropriate rehabilitation, education, and support for SAH survivors and their families to enhance coping and improve quality of life, given the substantial and persistent impact of SAH.

Sudden aneurysmal subarachnoid hemorrhage (SAH) strikes with an annual incidence of 6–11 per 100,000 Americans (Broderick, Brott, Tomsick, Miller, & Huster, 1993; Brown, Whisnant, Sicks, O'Fallon, & Wiebers, 1996; Longstreth, Nelson, Koepsell, & van Belle, 1993). The mortality rate continues to approach 50% even with modern, refined neurosurgical intervention and aggressive management of complications. As many as half of survivors remain functionally dependent, and a growing body of literature demonstrates that, despite the absence of gross neurologic deficits, a high percentage of those whose recovery is classified as *good* experience debilitating emotional, behavioral, and cognitive symptoms.

Meaningful assessment of outcome following aneurysmal SAH therefore must go beyond physical functioning to address cognitive and emotional functioning as well as the overall effect of deficits on quality of life for survivors and their families.

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This article describes the functional outcome of survivors at 3 months after an aneurysmal SAH using the Extended Glasgow Outcome Scale (GOSE) (Wilson, Pettigrew, & Teasdale, 1998) and the Functional Status Examination (FSE) (Dikmen, Machamer, Miller, Doctor, & Temkin, 2001).

Background

Healthcare providers traditionally have measured broad outcomes after SAH, including residual neurological impairments (usually motor and language) and independence in activities of daily living. There is now greater recognition of the need to use more sensitive measures to fully capture the impairment experienced by SAH survivors, including measures that address neuropsychologic outcome, personality, behavioral changes, and quality of life. In 1981, Artiola i Fortuny reported a discrepancy between numbers of patients classified as full recovery and numbers actually returning to pre-SAH activity level (Artiola i Fortuny & Prieto-Valiente, 1981). A sentinel work by Ljunggren, Sonesson, Saveland, and Brandt (1985) hypothesized the existence of a post-SAH diffuse encephalopathy that is similar to posttraumatic encephalopathy. The syndrome may be responsible for the subtle emotional, behavioral, and cognitive changes seen in many SAH patients who have no neurologic deficits detectable by using traditional measures of outcome.

Subsequent studies supported the disturbing finding that 30%–83% of patients previously classified as having a good recovery actually were suffering from debilitating neuropsychologic impairments or emotional difficulties

Questions or comments about this article may be directed to: Catherine J. Kirkness, PhD RN CNN(C), Biobehavioral Nursing and Health Systems, University of Washington, Box 357266, Seattle, WA 981957266. She is a research assistant professor at the University of Washington, Seattle.

Jo Marie Thompson, BSN RN, is a research assistant in Biobehavioral Nursing and Health Systems at the University of Washington.

Barbara A. Ricker, MPH RN, is a research nurse in Biobehavioral Nursing and Health Systems at the University of Washington.

Ann Buzaitis, MN ARNP, is a research nurse in Biobehavioral Nursing and Health Systems at the University of Washington.

David W. Newell, MD, is a professor in the Department of Neurological Surgery, Harborview Medical Center, at the University of Washington.

Sureyya Dikmen, PhD, is a professor in the Department of Rehabilitation Medicine at the University of Washington.

Pamela H. Mitchell, PhD FAAN RN, is the Elizabeth S. Soule Professor and Associate Dean for Research in the University of Washington School of Nursing. She also is a adjunct professor in the Department of Health Services, SPHCM.

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depending on the scope and specificity of the criteria used (Buchanan, Elias, & Goplen, 2000; Deruty, Patet, Mottolese, & Portilla, 1988; Deruty, Pelissou-Guyotat, Mottolese, & Amat, 1994; Dombovy, Drew-Cates, & Serdans, 1998; Fertl et al., 1999; Hackett & Anderson, 2000; Hutter & Gilsbach, 1993; Hutter, Gilsbach, & Kreitschmann, 1995; Ogden, Utley, & Mee, 1997; Ropper & Zervas, 1984; Saveland et al., 1986). Global intelligence most often is intact in Glasgow Outcome Scale (GOS) good recovery subjects. In a high percentage of them, however, speed of information processing is slowed, concentration may be substantially impaired, and both short- and long-term memory are impaired (short-term more than long-term memory).

Recent studies have focused on changes in the behavioral and emotional domains, including social withdrawal or anxiety, disturbing personality changes, increased emotional lability or dependence, unusual sensitivity to noise or disorder, decreased awareness of the needs of others or the extent of deficits, irritability, decreased libido, inability to make decisions, mental and physical fatigue, apathy, and loss of motivation (Buchanan et al., 2000; Hellawell, Taylor, & Pentland, 1999). These factors are subjective and often correlated with decreased quality of life, as reported by both patients and caregivers. One study reported interviews of 28 SAH survivors and their caregivers; 24 of the survivors were classified as good recovery and 4 as moderate disability on the GOS. They were interviewed, on average, 19 months after the SAH. More than half of both the patients and their caregivers met criteria of psychological distress. The study found that 13% of patients and 15% of caregivers had had suicidal ideation in the 7 days before the interview. A disturbing percentage of patients (28%) and caregivers (26%) reported feeling that death would have been preferable to the current burden of illness (Buchanan et al., 2000).

Further study is clearly required. Our study explores the ability of two recently developed tools, the GOSE and the FSE, to describe recovery of individuals following SAH.

Methods

The data presented are preliminary. They are taken from a prospective, randomized, controlled clinical trial examining the effect of a highly visible display of cerebral perfusion pressure on the management of cerebral perfusion pressure and outcome following traumatic brain injury and SAH. The design is descriptive.

Participants

Approval for the study was obtained from the University of Washington Institutional Review Board. Inclusion criteria for participants in this preliminary analysis were the same as those for enrollment in the larger study. They included having suffered aneurysmal SAH, being at least 16 years of age, and having invasive arterial blood pressure and intracranial pressure monitoring devices in place. Exclusion criteria included a Glasgow Coma Scale (GCS) score of 3, with bilateral fixed, dilated pupils, and impending death.

Procedure

A cerebral perfusion pressure display was allocated to individuals admitted to an intensive care unit with SAH within 24 hours of the insertion of invasive arterial blood pressure and intracranial pressure devices. This component was considered a study of medical records data, so the need for consent was waived by the institutional review board. Consent for a follow-up interview was obtained from family members at the time of hospitalization, because most subjects were unable to consent for themselves. When possible, consent was obtained from participants before the follow-up. Demographic data and information on medical condition and management were obtained prospectively from the medical records. Followup interviews were carried out to assess outcome at 3 and 6 months. Only the 3-month data are reported here.

Recent studies have focused on changes in the behavioral and emotional domains.

Follow-up data were obtained by a telephone interview of the patient, if he or she was able to answer questions. As necessary, it was supplemented by an interview of a family member or someone else close to the patient. If the patient was unable to be interviewed, the data were obtained from a family member or someone else who was involved in the patient's care and was aware of his or her level of functioning and care needs.

Nurses were trained to use the structured interview formats for the GOSE and FSE. These interviews involve specific questions requiring a yes or no answer, upon which the scoring is based. Any questions about scoring were clarified through discussion between interviewers. Participants were given the opportunity to explain their answers and provide additional information. The telephone interview took approximately 60 minutes.

The study was conducted at a medical center that admits approximately 100 patients with SAH per year. Patients are managed whenever possible with early surgery to obliterate the aneurysm, administration of nimodipine, and aggressive control of arterial blood pressure, intracranial pressure, and cerebral perfusion pressure. Cerebral blood flow velocity is routinely monitored by transcranial Doppler ultrasonography. Vasospasm is treated by using hypertensive, hypervolemic, hemodilution therapy and balloon angioplasty as indicated.

Measurements

Outcome was assessed by using the GOSE (Pettigrew, Wilson, & Teasdale, 1998; Wilson et al., 1998) and FSE

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(Dikmen et al., 2001). The GOSE measures global functional outcome, including level of dependence and ability to carry out normal activity. The GOSE extends the widely used GOS by dividing the severe disability, moderate disability, and good recovery categories into upper and lower divisions to produce an 8-point scale (1 = dead, 2 =vegetative, 3 = lower severe disability, 4 = upper severe disability, 5 = lower moderate disability, 6 = upper moderate disability, 7 = lower good recovery, and 8 = upper good recovery). The vegetative category designates inability to obey commands or say any words. Individuals in the severe disability categories are conscious but need frequent help or someone available most of the time. Individuals in the moderate disability categories can be independent outside the home but are unable to return to previous work capacity. Individuals in the good recovery categories are able to work to their previous capacity; they participate at least half as often as before the SAH in social and leisure activities, experience strain in relationships with family and friends less often than weekly, or have physical sequelae such as headache.

The structured interview developed for assigning GOSE scores specifies an ordered set of questions assessing consciousness, independence in and outside of the home, major social roles, and return to normal life (Wilson et al., 1998). Each question covers a key factor relevant to assigning an outcome category and is answered no or yes. Based on the answer, an outcome category is assigned or the next question is asked. The final score is the lowest outcome category assigned to any answer.

Participants are asked how bothersome they find their problems. The choices are not bothersome, mild, moderate, and severe.

The weighted kappa value reflecting agreement between raters using the GOSE is 0.85 (Wilson et al., 1998). The GOSE is significantly correlated with injury severity measures including length of posttraumatic amnesia (Spearman correlation coefficient $[r_s] = -.52$, p < .01), and admission GCS ($r_s = .32$, p < .01) (Wilson, Pettigrew, & Teasdale, 2000). The GOSE also shows a strong correlation with outcome as reflected by the Disability Rating Scale ($r_s = .89$, p < .01), the Beck Depression Inventory ($r_s = -.64$, p < .01), and all scales of the SF-36 ($r_s = .47$ to .71, p < .01; Wilson et al., 2000).

The FSE was developed as a measure to assess functional status changes following traumatic brain injury. It also is applicable to other conditions of acute brain insult, such as SAH (Dikmen et al., 2001). The FSE is based on a structured interview. It evaluates the individual's ability to carry out societal roles and activities and assesses the effect of brain injury on these abilities in terms of maintenance of independent functioning or degree of

alteration in functioning (see Table 4). The measure incorporates three important domains of everyday living, which include 10 categories: the physical domainpersonal care, ambulation, and travel; the social domain-either work or school, home management, leisure and recreation, social integration, and standard of living; the psychologic domain-cognitive and behavioral competency; and financial independence. Items are scored as follows: 0 if there is no change from pre-SAH status; 1 if the individual has difficulty performing the activity but still is independent; 2 if the individual is dependent on others to perform the activity at least some of the time; or 3 if the individual is completely dependent or is unable to perform the activity. Scores from the 10 categories are summed to obtain a total score ranging from 0 to 30. Higher scores reflect poorer functioning. Individuals who have died are assigned a score of 31 so that the scoring reflects the full range of outcomes.

In addition, for each FSE category participants are asked how bothersome they find their problems. The choices are not bothersome, mild, moderate, and severe. They also are asked to assess whether physical, cognitive, or emotional factors are contributing to their problems. If participants have returned to normal functioning in a category, they are asked how long after the injury they returned to normal. Open-ended questions also are used to allow participants to explain their answers.

The FSE demonstrates good test-retest reliability (r_s = 0.80, $p \le .001$). It correlates highly with other functional measures, including the Sickness Impact Profile ($r_s = 0.81$, $p \leq .001$), the SF-36 Physical Component Summary ($r_s =$ -0.68, $p \le .001$), and the GOS ($r_s = -0.84$, $p \le .001$) (Dikmen et al., 2001). The FSE also is correlated with brain injury severity measures including the GCS ($r_s = -0.38$, $p \le .001$), time from injury until consistently following simple commands ($r_s = 0.45$, $p \le .001$), and posttraumatic amnesia (time from injury until memory for day-to-day events is regained) ($r_s = 0.66$, $p \le .001$). The FSE assessments of the patient and the patient's significant other are strongly correlated ($r_s = .80$, $p \le .001$). The FSE demonstrates sensitivity to recovery from 1 to 6 months (Dikmen et al., 2001). FSE scores reflecting greater dependence of the SAH survivor are correlated with greater family burden (in terms of family members' report of needing to give up their own activities) ($r_s = .64$, $p \le .001$) (Dikmen et al.).

Results

Sample Description

The sample consisted of 61 patients, aged 27–83 years (M = 54.5 years). Reflecting the higher incidence of aneurysmal SAH in females, 75% of those in the sample were women. The majority of the patients (66%) were married. Table 1 lists other sample characteristics.

For almost half of the patients, the admission GCS score was 13–15. However, for 29% the GCS score was 8

Table 1. Charac

Characteristic Sex

Female Male

Race American Indiar Black Hispanic White

Marital Status
Single
Married
Separated/divor
Widowed
Other
Unknown

Living Situation
Alone
Spouse/significa
Parents/relatives
Other
Unknown

Employment
Unemployed
Employed
Homemaker
Student
Retired
Unknown

Table 2. Initial (Hunt and Hess (

Initial GCS Score 3–8

9–12 13–15

Hunt and Hess Gra

2

3

4

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Table 1. Characteristics of the Sample (N = 61) Characteristic Percentage Number-Female 46 75 Male 15 25 American Indian/Alaskan 7 7 Hispanic 3 ·White 51 84 Marital Status Single 6 10 Married 40 66 Separated/divorced 12 Widowed 5 Other 3 Unknown 3 5 Living Situation 12

41

29

15

67

8

7

15

48

5

2

25

25

Spouse/significant other

Parents/relatives

Other

Unknown

Employment

Unemployed

Homemaker

Employed

Student

Retired

Unknown

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Table 2. Initial Glasgow Coma Scale (GCS) Sc Hunt and Hess Grades (N = 61)	ores and

Initial GCS Score 1 3-8 9-12 13-15	Number 18 15 28	Percentage 29 24 47		
' Hunt and Hess Grade				
1	12	20		
2	14	23		
3	14	23		
4	15	25		
5	6	10		

or less (see Table 2). Approximately equal numbers were classified as Hunt and Hess Grades 1, 2, 3, and 4, with a smaller percentage classified as Grade 5. The cerebral perfusion pressure display was initiated for 90% of the participants within 5 days of the SAH, often postoperatively. For the remaining 10%, the display was initiated within 9 days post-SAH. Surgical clipping of the aneurysm was

performed for 85% of the patients; other aneurysm management included coiling (10%) and wrapping (2%). Fifty-one patients (84%) developed cerebral vasospasm, as evidenced by transcranial Doppler sonography or angiography. This high percentage probably reflects, in part, the daily use of transcranial Doppler sonography to detect vasospasm, including asymptomatic vasospasm that otherwise would have gone undetected. Hypervolemic and hypertensive therapies were instituted based on the degree of vasospasm. Sixteen patients (31%) who had vasospasm underwent cerebral angioplasty.

Fifteen of the patients (25%) died in the hospital. Of the survivors, 14 (30%) were discharged to home; 16 (35%) to a rehabilitation facility; 12 (26%) to a skilled nursing facility; and 4 (9%) to other locations. At the time of discharge from acute care, the GCS scores of the survivors ranged from 5 to 15, with a mean of 13.7 (SD = 1.9). Four patients died between the time of hospital discharge and 3 months post-SAH. Follow-up was carried out for the remaining 42 subjects. The majority of the interviews (64%) were conducted with the SAH survivors themselves.

GOSE and FSE Scores

The mean GOSE score at 3 months after the SAH was 3.3 (SD = 2.0). The GOSE scores ranged from 1 (dead) to 8 (upper good recovery) (see Table 3). No one was in a vegetative state. Among the survivors the largest group was in the lower severe disability category (25%), which reflects inability to look after oneself and a need for frequent help for at least 8 hours a day. A slightly smaller percentage (21%) fell into the lower moderate disability category, which reflects an inability to work or ability to work only in a sheltered workshop or noncompetitive job, although able to function independently inside and outside the home.

The FSE total scores ranged from 3 to 31, with a mean of 22.4 (SD = 8.1). Greater impairment of functional status is reflected in a higher FSE score. The percentage of individuals scoring codes 0–3 within each FSE category is presented in Table 4. A striking finding is the degree to which individuals experienced significant problems in almost all aspects of daily functioning at 3 months following the SAH. Even in personal care, fewer than 50% reported a full return to their pre-SAH level, and 50% perceived the problems that they were having as moderately or severely bothersome in day-to-day life. The individuals who had returned to normal by 3 months most likely had done so within the first month.

In all FSE categories except personal care and financial independence, fewer than 20% were back to their pre-SAH functional levels at 3 months. In relation to essential home management activities (around or within a few blocks from home), almost half still were completely or partially dependent on others for tasks such as cooking, laundry, shopping, or home maintenance. Travel beyond a short distance from home was severely restricted; 70%

Table 3. Extended Glasgow Outcome Scale (GOSE) Categories at 3 Months Post-SAH (N = 61)

	·			
Number	Percentage			
19	31			
0	0			
15	25			
7	12			
13	21			
3	5			
. 3	5			
1	2			
	19 0 15 7 13 3			

of individuals were either unable to travel outside the home or always dependent on having someone with them when they traveled.

For most (86%), pre-SAH leisure and recreational activities either had been dropped or required having someone accompany them. Social interactions tended to be limited to immediate family members or those with whom the SAH survivor lived, or they had less contact with friends or family.

Most (81%) individuals also identified impairment in cognitive and behavioral functioning that required them to have help in handling affairs or meeting important needs and responsibilities. Commonly reported areas of difficulty were decision making, memory (particularly short-term memory), planning, and problem solving. For approximately half, the impairment required individuals to have supervision in managing their affairs and meeting even basic needs related to health, nutrition, and housing.

In relation to standard of living, 86% had not returned to their pre-SAH level. Most (74%) were cutting into savings or going without extras. Nonetheless, only 62% reported a change in financial status. It is unlikely that the full effect of the SAH on standard of living and financial status was felt within 3 months. Costs were continuing to accrue, and the potential for decreased earning capacity had yet to be fully assessed.

Ability to work was severely affected; 82% had been unable to return to any work activities at 3 months post-SAH. The one person who had been in school pre-SAH had not been able to return.

Approximately half rated the problems they were having in their daily lives as moderately or severely bothersome in almost all areas of functioning (Table 5). Physical factors were reported most frequently as contributing to difficulties, particularly in relation to ability to carry out personal care and home management activities; get around in and outside the home; and resume work, leisure, recreational, and social activities. Fatigue was very frequently identified as a factor. Headache, arm or leg weakness, dizziness, visual difficulties, and impaired balance and coordination also were commonly identified. For almost half, cognitive factors contributed

to problems in most activities; short-term memory impairment was most frequently identified. Emotional difficulties affecting daily functioning were reported by about one-quarter. The effect was pervasive across all areas of functioning. Irritability and withdrawal were common occurrences. A number of individuals also acknowledged feeling depressed.

GOSE and FSE total scores were highly correlated (-0.949, p < .000). As expected, lower GCS score on admission and higher Hunt and Hess grades were predictive of poorer outcome as measured by both the GOSE and FSE.

Discussion

The findings of this study demonstrate that the functional status of SAH survivors at 3 months is significantly affected in all areas of day-to-day living and is related to a variety of physical, cognitive, and emotional difficulties. The institution where the study was carried out is, a major referral center, so it is possible that the sample disproportionately represents severe and complex cases for which relatively poor outcome would be expected. Nonetheless, the findings confirm the substantial effect of SAH on functional outcome at 3 months across a range of SAH severities.

Recovery from SAH can be expected to continue beyond 3 months, so this study is limited in terms of its ability to describe long-term outcome. However, studies involving long-term follow-up (1–14 years) also document strikingly persistent and substantial cognitive difficulties and emotional problems, even in individuals categorized by the GOS as having a good outcome (Bornstein, Weir, Petruk, & Disney, 1987; Buchanan et al., 2000; Deruty et al., 1994; Fertl et al., 1999; Hellawell, Taylor, & Pentland, 1999; Hutter et al., 1995; Lindberg, Angquist, Fodstad, Fugl-Meyer, & Fugl-Meyer, 1992; Ljunggren et al., 1985; Saveland et al., 1986).

Neuropsychologic testing was not carried out as part of this study, although it would provide additional detail regarding cognitive deficits. Nonetheless, the information gained from this study can be used as a basis for further study to develop strategies for teaching and counseling SAH survivors to deal with difficulties experienced in the first months following SAH.

Awareness of the scope and magnitude of the problems SAH survivors and their families face is increasing. However, few studies acknowledge the importance and relative neglect of thorough rehabilitation services as well as of early education and discussion with survivors and family members regarding expected personality, behavioral, and cognitive changes (Dombovy et al., 1998; Germano et al., 1997; Hutter et al., 1995; Lindberg et al., 1992). Preparation for the scope of the impending life changes may be vital in promoting adjustment, quality of life, and well-being. In the current study, 35% of individuals were

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Category	Code 3 (CompletelyDependent)		Code 2 (Somewhat Dependent)		Code 1 (Independent with Difficulty)		Code 0 (No change From pre-SAH Status)	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Personal care	10	24	2	5	11	26	19	45
Ambulation	9	21	11	26	14	33	8	19
Travel	30	71	7	17	Ź	5	3	7
Work	22	82	2	7	1	4	2	7
School	1	100					_	•
Home management	16	39	18	44	3	7	4	10
Leisure and recreation	19	45	17	41	1	2	5	12
Social integration	7	17	26	62	3	_ 7	6	14
Standard of living			31	74	5	12	6	14
Cognitive and behavioral	20	47	9	21	6	14	7	17
Financial independence	19	45	1	2	6	14	16	38

	"How Bothersome Are Your Difficulties?" (%)						Contributing Factors (%)	
Category	Number	Not Bothersome	Mild,	Moderate	Severe	Physical	Cognitive	Emotional
Personal care	42	55	50	40	10	81	57	29
Ambulation	42	81	47	·26	26	84	29	13
Travel	42	93	55	14	32	68	41	24
Work	27	93	44	22	33	78	57	22
School	1	100	100					
Home management	41	90	45	36	18	79	50	27
Leisure and recreation	42	88	37	27	27	82	50	27
Social integration	42	86	66	17	17	56	44	28
Standard of living	42	86 .	46	32	23	36	29	23
Cognitive and behavioral	42	83	44	50	6		97	23
Financial independence	42	62 -	39	33	28	38	29	17

discharged from acute care to a rehabilitation facility, but a considerably higher proportion were experiencing functional difficulties at 3 months. In addition to acute rehabilitation, ongoing support services and counseling therefore are needed for those who do not enter rehabilitation programs. Further study is necessary to ascertain the specific needs of family members of SAH survivors, assess the adequacy of family preparation and ongoing support, and develop and test interventions to address identified needs.

Physical factors affecting outcome (e.g., weakness, visual difficulties) are easily identified. Clearly it is important to provide teaching and support related to managing these deficits. In addition, it is vital to identify cognitive and emotional problems and to recognize the likelihood that they may have an even stronger long-term effect on the overall functional outcome and quality of life of SAH survivors and their families. Appropriate teaching, resources, and support should be provided.

Summary

This study reports the use of two outcome measures following SAH: the GOSE, a modification of a tool widely used to assess ability to carry out daily activities, and the FSE, a newly developed measure of functional status that encompasses physical, social, and psychologic domains. The GOSE, as a standardized, global measure, allows for assessment of the effect of treatment strategies on outcome but does not provide information on the specific nature of difficulties in daily life. The FSE captures important functional status domains relevant to SAH survivors and shows promise as a measure for evaluating functional status following aneurysmal SAH. In addition to identification of functional status limitations, the FSE provides insight into factors contributing to these limitations as well as the SAH survivor's perceptions of their effect on day-to-day activities.

The GOSE and FSE were not designed to address specific affective or neuropsychologic issues, so they are best used in conjunction with other measures directed at more detailed evaluation of these areas. Screening for SAH-specific impairments should be included as part of a comprehensive assessment of factors contributing to functional status and quality of life in SAH survivors and used as a guide for targeted intervention.

Outcome in this population of SAH survivors, as measured using both the GOSE and the FSE at 3 months, reflects a high degree of limitation in functional status in all aspects of daily life. These findings highlight the need for nurses to be involved in the development and application of appropriate teaching, rehabilitation, and ongoing support for survivors of SAH and their family members, in light of the identified physical, emotional, and cognitive deficits.

Acknowledgment

This research was supported by a grant from the National Institute of Nursing Research (RO1 NR04901-2).

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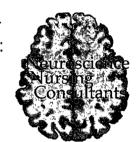
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