Stroke Knowledge Among Stroke Support Group Members

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Background and Purpose—Community stroke education is needed to improve early stroke recognition and reduce delays in the referral of stroke patients. In some regions, stroke support groups have become important promoters of regional stroke education. However, there are no data about the level of stroke knowledge among support group members that support this promotional role.

Methods—We performed a cross-sectional questionnaire survey among 11 German stroke support groups. The questionnaire asked for stroke knowledge and sociodemographic and medical data. Stroke knowledge was excellent if a participant knew (1) at least 2 stroke symptoms (good symptom knowledge) and (2) at least 2 stroke risk factors (good risk factor knowledge), as well as knowing (3) that immediate hospital admission or an emergency call is necessary in case of stroke (good action knowledge).

Results—A total of 133 members (96.2%) of 11 stroke support groups took part in the study. Mean age was 65.3 years (SD 11.2 years). Fifty-four percent of subjects were female, 72.8% were retired, and 69.8% were stroke patients. Of the participants, 80.3% had good symptom knowledge, 64.7% had good risk factor knowledge, and 79.7% had good action knowledge. Stroke knowledge was excellent in 44.0% of subjects. Logistic regression analysis showed that age <70 years and not having had a stroke were significant predictors for excellent stroke knowledge.

Conclusions—Overall, members of stroke support groups are well informed about all aspects of modern stroke care. Because of their knowledge and personal experience, support groups should be viewed as important partners in community stroke education. (Stroke. 2000;31:1230-1233.)

Key Words: health education • knowledge, attitudes, practice • peer groups • self-help groups

Community stroke education is needed to reduce delays in the presentation and referral of stroke patients. In some regions, stroke support groups have become important promoters of stroke educational programs. Because members of these groups, typically stroke patients and their families, have a strong interest in stroke as a health topic, they can be considered to represent laypersons with a high level of stroke knowledge. Although stroke knowledge has been found to be insufficient in acute stroke patients, high-stroke-risk populations, and the general population, there are no data about information status among members of stroke support groups.

Using a cross-sectional questionnaire survey, we asked members of stroke support groups about their knowledge of stroke symptoms, risk factors, and actions required in case of a stroke. Various sociodemographic characteristics were studied as predictors for stroke knowledge.

Subjects and Methods

Study Population and Sampling Strategy
We selected 15 of the 30 stroke support groups from the Northrhine-Westfalian area of Germany listed in an official support group directory of the German Stroke Foundation. We first selected all groups within 60 km driving distance from the university hospital in Muenster (6 groups). Next, we made a random selection of 9 groups from the remaining 24 using a random number generator. All 15 groups were contacted by phone and informed about the survey. Four groups did not participate: 2 groups had a busy schedule for the upcoming months, 1 group with severely aphasic patients felt that a written questionnaire was beyond their abilities; and 1 group could not be reached in 3 separate attempts. The survey was performed at a regular meeting of each support group in the summer of 1998 without any specific previous information about the survey instrument. To establish personal relationships with the groups in the area, members of our investigator team personally visited the groups in the greater Muenster area, while the other groups received verbal (by phone) and written instructions for the survey. Each member was asked to fill out 1 questionnaire with no support other than writing assistance if necessary. The numbers of participants and nonparticipants for each group were recorded.

Survey Instrument
The structured, self-applicable questionnaire addressed stroke knowledge (9 items) and sociodemographic and medical characteristics (13 items). The questionnaire was developed from an instrument used by Kothari and coworkers from the University of Cincinnati to study patients’ stroke knowledge.

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Stroke is available at http://www.strokeaha.org
Questions Assessing Stroke Knowledge
Using open questions, we asked participants to list stroke symptoms, risk factors, and the body part affected in stroke. In closed questions, appropriate actions in case of stroke symptoms and the critical 3-hour time interval were addressed. According to our definition, a participant had excellent stroke knowledge if all of the following 3 criteria were met: (1) participant knew at least 2 stroke symptoms (good symptom knowledge), (2) participant knew at least 2 stroke risk factors (good risk factor knowledge), and (3) participant knew that immediate hospital admission or an emergency call to 911 is necessary in case of stroke (good action knowledge).

Additionally, the following sociodemographic and medical characteristics were assessed: age, sex, current living situation, marital status, education, current or last profession, self-assessment of general health (good, fair, or poor), regularity of physician visits, membership status in the stroke support group (stroke patient, family member of stroke patient, or other), interest in additional stroke education, and preferred information modes. Stroke patients among the group members were asked to describe their current functional status using criteria derived from the modified Rankin scale: independent in daily activities, able to walk but needs support in daily activities, or unable to walk and needs support in daily activities.

Statistical Analysis
Statistical analysis was performed with the SPSS software package (SPSS for Windows version 8.0, SPSS Corporation). Comparisons of categorical data were based on the chi^2 test. If subgroups contained fewer than 10 counts per group, Fisher’s exact test was used for analysis. Logistic regression analysis was used to calculate odds ratios of various sociodemographic indicators for excellent stroke knowledge. Univariate analyses for the following variables were performed: education, professional status, age, sex, physician consulting behavior, self-support group membership status, history of risk factors, and the body part affected in stroke. All variables reaching statistical significance in the univariate analysis were included in the final multivariate logistic regression model.

Results

Biographic Data
A total of 133 members of the 11 stroke support groups took part, for a participation rate of 96.2%. Mean age was 65.3 years (SD 11.2 years). Of the participants, 54.2% were women and 72.8% were retired. Nearly seventy percent (69.8%) were stroke patients, and 27.8% were family members. In stroke patients, the time since the stroke event varied between 0 and 22 years. Additional stroke education was of interest to 90.2% of the population. The following educational modes were preferred (several options per person were possible): support group (84.7%), brochure (34.2%), physician (31.5%), television (29.7%), and newspaper (20.0%). The distribution of other sociodemographic and medical variables is listed in Table 1.

Stroke Knowledge
When asked for the body part affected by a stroke, 52.4% listed the brain or head. More than 85% (86.6%) knew that stroke therapy is best started within 3 hours. The average number of stroke symptoms known was 2.7 (SD 1.7); 9.8% did not know any stroke symptom, whereas 9.8% recalled 1, 28.8% recalled 2, 28.0% recalled 3, and 23.5% named 4 or more symptoms. Similarly, the average number of risk factors listed was 2.5 (SD 1.7). No risk factor was recalled by 11.3%, 1 by 24.1%, 2 by 16.5%, 3 by 19.5%, and 4 or more by 28.6%. Approximately 80% had good symptom knowledge, 64.7% had good risk factor knowledge, and 79.7% had good action knowledge. Excellent stroke knowledge was demonstrated by 44.0% of subjects; details are provided in Tables 2 and 3.

With regard to sociodemographic characteristics, patients with excellent stroke knowledge were significantly more likely to be younger (<70 years old), to be in the stroke support group as a family member or volunteer, and not to have had a stroke.

Factors Influencing Stroke Knowledge
Good symptom knowledge was found significantly more frequently among participants <70 years of age (86.3% versus 69.6%, P=0.022), those with a self-reported health status of good or fair (86.8% versus 45.5%, P=0.005), those who had not had a stroke (90.2% versus 75.3%, P=0.037), and those interested in additional stroke education (83.6% versus 58.3%, P=0.049). Good risk factor knowledge was
significantly more likely among those who had not had a stroke (80.5% versus 57.0%, \( P < 0.010 \)), those interested in obtaining additional information from their physician (80.0% versus 57.9%, \( P = 0.032 \)), participants living with their family versus those living alone or in a nursing home (73.3% versus 46.0%, \( P < 0.005 \)), family members or other volunteers versus stroke patients (relatives 82.9%, other members 100%, patients 58.0%; \( P < 0.007 \)), and participants \( \geq 70 \) years of age (74.1% versus 45.7%; \( P < 0.007 \)). Good action knowledge was significantly more likely among participants with a self-reported health status of good or fair (83.2% versus 50.0%, \( P = 0.025 \)).

### Discussion

**Stroke Knowledge Among Stroke Support Groups**

Our study of 11 stroke support groups showed good stroke knowledge in the majority of participants: 80% knew at least 2 stroke symptoms, and 80% knew to seek immediate professional help in case of stroke symptoms; 65% knew 2 or more risk factors. To the best of our knowledge, this is the first study of stroke knowledge among members of stroke support groups. The high information status demonstrated among these laypersons stands out markedly compared with stroke knowledge of the general population. In 2 recent
German studies, we demonstrated that only 52% of persons of working age and 40% of the retired population knew at least 1 stroke symptom. In contrast, 90% of the stroke support group members knew this much. Likewise, only 78% of the working population and 41% of the geriatric population knew that immediate professional help is necessary in case of stroke symptoms, but 80% of the self-support group members did. Similar results can be found when the data are compared with a recent study about stroke knowledge in the general US population. In a representative telephone survey of 2642 inhabitants of the Cincinnati, Ohio, area, Panceri and co-workers showed that only 57% of the general population knew 1 stroke sign, and 68% could name at least 1 stroke risk factor. Because members of stroke support groups showed better knowledge than the German as well as the US general population, our findings cannot be explained by cultural or medical system differences but reflect a difference due to the stroke experience.

**Stroke Knowledge Differs Within Support Groups**

Support groups for patients of various diseases, such as breast cancer and coronary artery disease, have been shown to be important sources for emotional support, disease-related information, and public education. Better coping skills and reduced caregiver burden have been demonstrated among patients and caregivers with better support systems. Traditionally, support groups are organized regionally, as were those in our survey. More recently, Internet-based support groups have arisen. Stroke has been called a disease affecting families; for example, disabilities of patients lead to increased responsibilities with significant role changes for family members of stroke patients or, in 2 cases, stroke care professionals. In contrast to other diseases, strokes often lead to problems of long-term care, rehabilitation efforts, and coping strategies. To keep the instrument short, these aspects were not addressed in our survey.

**Perspectives and Conclusions**

Our survey demonstrates that members of stroke support groups have good knowledge about stroke. These findings support approaches to integrating stroke support groups into regional stroke education programs. Building regional partnerships, clinical stroke experts and stroke support groups should work together to better inform the public about stroke.

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