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Educational needs of stroke survivors and their family members, as perceived by themselves and by health professionals

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Abstract

This study identified informational needs of stroke survivors and their family members as perceived by themselves and by health professionals. The source of information, and the desired source for future information were also explored. Green's Precede-Proceed model was used as a theoretical framework. In the study 35 stroke survivors, 39 family members and 43 health professionals participated. The results show that stroke survivors and family members indicated to desire the most information regarding reducing the chance of a new stroke. Stroke survivors rated as the major gaps of information: reducing the chance of a new stroke and coping with stress. Family members rated as the major gaps of information: sources to apply for help; strategies to perform activities of daily living, and reducing the chance of a new stroke. Stroke survivors and their family members expressed as the most desired source of information the doctor in the hospital. Health professionals expressed a high level of concern about the amount of information stroke survivors and family members receive; they expressed a substantial need for information about all topics for both groups, which should be provided by several sources. Some needs are recognized, but in most cases not met. Family members of stroke survivors who suffered more than one stroke seem to have received more information – and to desire less. Both highly educated stroke survivors and family members indicate to have received less information and desire more information than lower educated respondents.

Keywords: Stroke; Educational needs; Source of information; Perceptions; Precede-Proceed framework

1. Introduction

Stroke is the third leading cause of death in western society, after heart disease and cancer, and the most important cause of permanent handicaps [1,2]. Especially for the elderly, strokes are a major source of disability leading to institutionalization [1]. Significant resources are spent on treatment, aid, service and other support for stroke survivors. For example, in the United States, there are 400 000 new incidents of

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stroke a year, resulting in 14 billion dollars spent on caring for stroke patients [3]. Despite the seriousness of the disease, many stroke survivors and their family members are poorly informed about the nature of the disease, recovery and treatment [4–6], and the availability of social services [7]. Although much research has been aimed at physical disabilities, the prevalence of stroke disabilities, other than physical limitations and depression, remains vaguely defined [8].

The purpose of this study was to identify the educational needs of stroke survivors and their family members (significant others), as perceived by themselves and by health professionals. Similarities and differences were explored. In addition, the sources of the received information in the past and the preferences for educational materials in the future were identified.

Several studies have focused on the needs of stroke survivors and their family members. McLean et al. [7] showed the high need for personal-emotional advice. Furthermore 75% of all care-givers ($N = 20$) said that they needed some assistance with physical care. Only 20% received the help they required and most of the respondents were unaware of different aids that are available. Hanger and Mulley [9] stated that almost 25% of the people calling Stroke Association Advice Centre ($N = 1397$) had wanted more information about the nature of stroke. Other common inquiries concerned help at home, speech difficulties, information about patient organizations, rehabilitation, personality changes and depression. Other studies showed that the majority of their sample felt uninformed, concerned and frustrated [10] and experienced a general lack of advice and a lack of interest from the general practitioner in particular [7].

There is little doubt about the contribution families make to the rehabilitation process, the stroke survivor's coping with the event [11] and the community reintegration [12]. Glass et al. [13] report the positive impact of social support on recovery of functional status following stroke. As stroke is a recurrent disease with the risk increasing to 5 times after the initial stroke, the family's education and participation is of utmost importance [14]. Families may facilitate or prevent the achievement of rehabilitation goals by their reaction to the disability and to the patient.

Family members themselves are reported to face problems of social isolation, behaviour problems, financial difficulties and loss of sleep [15–17]. They indicate disturbance in the stroke survivor's communication as the most stressful issue [18]. Treatment should aim at reducing care-giver's depression, minimizing family dysfunction, and increasing the family's knowledge about stroke care [19].

Until now, no studies focused on the comparative perceptions of stroke survivors, their family members and health professionals in relation to stroke. Similar studies in other fields are contradictory: from a recent study into the needs of cardiac patients it appeared that both patients and their spouses identified the need for information as the most important need. However, spouses had the highest need for information about the patient's feelings, for time off for themselves, for talking with the patient about concerns, and for receiving information about the expected psychological recovery. Patients on the other hand needed information about their condition, they wanted honest explanations, and they wanted to talk with a health professional [20]. A study about different perceptions in epilepsy care revealed that although patients, nurses and physicians similarly ranked major general areas of learning needs, differences were found between patients and health care providers in the ranking of individual learning needs. Both patients and spouses expressed this need, which in most cases, was not shared with nurses and physicians [21]. A study of Lauer et al. [22], studying the educational needs of patients with cancer, revealed significant differences between nurses' and patients' perceptions. Finally, a study of patients who had a myocardial infarction showed that physicians, nurses and patients generally agreed upon which areas should be included in educational programs [23]. All three groups rated as the most important topics: 'knowing the signs and symptoms of a heart attack (1)', 'knowing personal risk factors (2) and how to modify or change them (3)' and 'knowing the names, dosages, and side effects of medications (4)'.

Systematic program planning, based on an extensive investigation of the needs of stroke survivors and their family members, is essential for the qualities of health educational activities in this field. The PRECEDE model [24,25], the framework used in this project, offers a quantifiable means of conducting an educational program. The PRECEDE model [24] has 8 phases, stressing the social diagnosis, collection of epidemiological data, behavioral and environmental diagnosis, educational and organizational analysis, administrative and policy diagnosis, implementation, process evaluation, impact evaluation, and outcome evaluation. The PRECEDE model has been used many times in research. However, in only 2 studies the framework was used to assess needs and to the further development of an educational program [26,27]. Our study reflected mainly phase 4 (educational and organizational diagnosis) of the PRECEDE model. Information from this study should ideally be used in the perspective of the PRECEDE model. Following the phases of this model this study could contribute to providing information that is relevant to stroke survivors and their family members.

2. Method

2.1. Participants

Questionnaires were distributed to 92 stroke survivors, 102 family members and 82 health professionals. Family members in the sample did not need to be related to stroke survivors in the sample. Subject recruitment was done through 3 major metropolitan hospitals, a rehabilitation center, a center for speech and language disorders, a nursing home and a professional conference on stroke. Reminders were sent 2 weeks after the questionnaire was mailed out, or participants were verbally reminded. The inclusion criteria were: time since onset in between 2 and 60 months, and the ability to complete at least 25% of the questionnaire.

Questionnaires were returned by 44 stroke survivors, 44 family members and 47 health professionals. Nine questionnaires of stroke survivors could not be used: 2 persons were excluded because of poor health, 3 respondents did not meet the inclusion criteria, 1 individual was not able to complete the questionnaire sufficiently, 1 person's diagnosis was unclear and 2 questionnaires were invalid: questionnaires were presumed invalid when less than 25% was completed. Three invalid questionnaires were found within the family members' responses, while 2 of the respondents did not meet the inclusion criteria. Four professionals returned the questionnaires blank because they considered themselves not the right persons to complete it. Therefore, the definite response rate was 38% for stroke survivors, 38% for family members and 52% for health professionals. The overall definite response rate at time of closing of the data input was 42%. Taking into account the average age of the sample, the severity of the disease and the fact that the research was completed in a metropolitan area, this is a satisfactory response.

The average age of the responding stroke survivors was 61 years, varying from 36 to 79. They stayed in the hospital for an average of 84 days. The mean time since their (last) stroke was 18 months and most of them suffered from only 1 insult; 3 survivors suffered from 3 strokes. A vast majority of the stroke survivors were married, white and lived at home. More males than females were present in this sample. Survivors of different education levels were represented in the sample (see Table 1). Besides the distribution of race, these demographics generally correspond with the numbers mentioned in stroke research.

The average age of the family members was 62 years, varying from 36 to 84. Their relative stayed in the hospital for an average of 118 days. The mean time since the (last) stroke of their relative was 16 months. The majority of the family members were related to a stroke survivor who had suffered from 1 stroke, 4 people whose

Table 1
Percentages (and N) of stroke survivors and family members representing different education levels

Education level	Survivors	Family members
Grade school	17.5% (7)	15.4% (6)
High school	32.5% (13)	25.6% (10)
College 1-4 years	15.0% (6)	46.2% (18)
University 5 years and more	35.0% (14)	12.8 (5)

relative suffered from 2 strokes, 3 suffering from 3 strokes and 1 from 7 strokes. The majority of the family members of stroke survivors were married, white and lived at home. A higher percentage were female and the spouse of the stroke survivor. Again, different education levels are represented, although higher educated people dominated the sample (see Table 1).

The average age of the health professionals ($N = 43$) was 41 years. The sample contains a relatively high number of nurses ($N = 11$), physiotherapists ($N = 10$) and social workers ($N = 9$), but none of the 5 family physicians responded.

2.2. The questionnaires

The researcher developed a new questionnaire for stroke survivors, their family members and the health professionals, since no existing instruments were found to be appropriate to reach the goals of this study. Prior to implementation of the questionnaire, they were circulated among project staff, stroke health care professionals and health education specialists for content validity. Suggestions were incorporated into the new versions. The questionnaire was pilot tested with 12 subjects. This information was used for the development of the final questionnaire. No information is available about criterion validity, construct validity and reliability. Questions were asked about the amount of information the stroke survivors and/or their family members had received and wished to have received since the stroke, on relevant topics (23 topics in total).

The response options were scaled at an ordinal level: 'none', 'some' or 'a lot'. Three possibilities for answers were chosen as this seemed to be the maximum amount still clear to the participants, taking into account the severity of the disease, the average age of the population and the number of questions asked. No 'non-applicable' category was enclosed so that participants could not use this as a loop-hole if they did not exactly remember or know what to choose. Participants were instructed to circle the answer that came closest to their experience. Differences between the questionnaire for survivors, family members and health professionals were highly limited to increase the possibility of comparing results of the 3 groups.

3. Results

3.1. Overall amount of information

Table 2 shows the opinions of stroke survivors, family members and health professionals regarding the overall amount of information received by stroke survivors and family members, since the stroke. Almost none of the respondents received too much information. However, nearly one-third of the stroke survivors received a considerable amount of information. The percentages of respondents that received the right amount of information is relatively low. Most of the stroke survivors and family members received some information. Health professionals believe that, in general, stroke survivors and family members would have received too little information. No pronounced differences in the perception of the overall amount of received information between education levels or number of strokes could be observed.

3.2. The received and desired information

In Tables 3-6, the highest and lowest needs for information are presented.

Stroke survivors (Table 3) were moderately informed. Sixty-five percent of the stroke survivors received little or no information about how the stroke may affect sexual activity; 60.5% received no information about bladder problems.

Table 2
Percentages of the overall amount of information received by stroke survivors and family members, perceived by themselves and by health professionals

Amount of information	Survivors	Family members	Health professionals about survivors	Health professionals about family members
Too little information	12.2%	12.8%	42.9%	41.9%
Some information	36.6%	48.7%	35.7%	34.9%
Just the right amount of information	17.1%	15.4%	7.1%	7.0%
Considerable information	31.7%	23.1%	14.3%	16.3%
Too much information	2.4%	0%	0%	0%

Table 3
The highest rated items (and percentages) in received and desired information of stroke survivors

Received no information about:	Received a lot of information about:	Desire no information about:	Desire a lot of information about:
how a stroke may affect sexual activity (65.0%)	diagnosis (50.0%)	what is going to happen when I leave the hospital (35.5%)	reducing the chance of a new stroke (84.4%)
bladder problems (60.5%)	what is being done for the stroke survivor (37.5%)	changes in touch (34.4%)	risk factors for stroke (75.0%)
changes in touch (52.8%)	risk factors (37.5%)	how a stroke may affect sexual activity (32.3%)	causes of stroke (71.9%)
problems with vision (51.2%)	causes of stroke (35.9%)	problems with vision (32.2%)	diagnosis (67.6%)
coping with stress (42.1%)	talking difficulties and walking difficulties (32.5%)	problems with concentration (31.3%)	what is done for the stroke survivor, walking difficulties and rehabilitation process (61.3%)

More than half of the respondents indicated to have received no information about problems with vision (51.2%) and changes in touch (52.8%). Survivors received relatively much information about the diagnosis; 50% indicated to have received a lot of information about this topic; 84.4% of the stroke survivors desired a lot of information about the ways to prevent a new stroke. The risk factors of stroke were rated secondly; 75.0% desired a lot of information. Other high-rated topics are the risk causes of stroke (71.9%) and the diagnosis (67.6%). Most stroke survivors received some information about most topics. They desired little information about what is going to happen when they leave the hospital, changes in touch, sexual activity, problems with vision and problems with concentration. Comparing the received and desired information of stroke survivors, the highest need for information seems to be on reducing the chance of a new stroke and coping with stress.

Family members (Table 4) indicated to be less informed than stroke survivors. They received least information about sexual activity; 69.2% received no information about the topic. Other topics about which family members received relatively little information were: changes in touch, spending leisure time, bladder problems, strategies to perform activities of daily living and coping with stress. A relatively high amount of information was received about difficulties with walking, the diagnosis and what is being done for the stroke survivor. Generally, family members desire more information than stroke survivors. The highest amount of information is wished about reducing the chance of a new stroke; 83.3% want to receive a lot of information about this topic. The risk factors, cause and diagnosis of

Table 4
The highest rated items (and percentages) in received and desired information of family members

Received no information about:	Received a lot of information about:	Desire no information about:	Desire a lot of information about:
how a stroke may affect sexual activity (69.2%)	walking difficulties (62.3%)	how a stroke may affect sexual activity (38.9%)	reducing the chance of a new stroke (83.3%)
changes in touch (69.2%)	diagnosis (47.4%)	bladder problems (27.8%)	risk factors for stroke (77.8%)
spending leisure time (60.5%)	what is being done for the stroke survivor (46.2%)	activities of daily living (22.2%)	causes of stroke (77.8%)
bladder problems (60.5%)	risk factors for stroke (43.6%)	problems with vision (20.0%)	what is done for the stroke survivor (77.8%)
activities of daily living (56.4%)	medication (41.0%)	what is going to happen when the stroke survivor leaves the hospital (20.0%)	diagnosis (75.0%)

stroke and what is being done for the stroke survivor are also highly rated items. They express a relatively low need for information about sexual activity and bladder problems. Differences in desired and received information indicate that the highest need for information is about sources to apply for help, coping with stress, strategies to perform activities of daily life and reducing the chance of a new stroke.

Professionals (Table 5 and 6) think that stroke survivors received the least information about how the stroke may affect sexual activity, how to cope with stress and how to spend leisure time. They believe that these topics are the same for family members. Topics about which professionals expect survivors to have received 'a lot' of information are: strategies to perform activities of daily living (46.5%) and medication (37.2%). Health professionals believe that family members received most information about the rehabilitation process and strategies to perform activities of daily living. Professionals think that both stroke survivors and their family members need a lot of information. According to the health professionals, stroke survivors desire a lot of information about reducing the chance of a new stroke, what is being done for them, the rehabilitation process and what is going to happen when they leave the hospital. In the eyes of the professionals, family members wish a lot of information about the same topics that count for the stroke survivors, together with information about medication. The greatest gaps in information of stroke survivors, according to the

Table 5
The highest rated items (and percentages) in received and desired information of stroke survivors as perceived by health professionals

Received no information about:	Received a lot of information about:	Desire no information about:	Desire a lot of information about:
how a stroke may affect sexual activity (59.5%)	activities of daily living (46.5%)	spending leisure time (7.0%)	reducing the chance of a new stroke (95.3%)
how to cope with stress (46.5%)	medication (37.2%)	coping with stress (4.7%)	what is done for the stroke survivor (88.4%)
spending leisure time (44.2%)	walking difficulties (34.9%)	what food to eat (4.7%)	rehabilitation process (88.4%)
effect of stroke on family relationships (34.9%)			what is going to happen when the stroke survivor leaves the hospital (88.4%)
bladder problems (32.6%)			

Table 6
The highest rated items (and percentages) in received and desired information of family members as perceived by health professionals

Received no information about:	Received a lot of information about:	Desire no information about:	Desire a lot of information about:
how a stroke may affect sexual activity (47.6%)	rehabilitation process (34.9%)	how a stroke may affect sexual activity (4.8%)	rehabilitation process (90.5%)
spending leisure time (41.9%)	activities of daily living (34.9%)	changes in touch (4.8%)	reducing the chance of a new stroke (88.1%)
coping with stress (37.2%)	what is going to happen when the stroke survivor leaves the hospital (32.6%)	what food to eat (2.4%)	what is done for the stroke survivor (88.1%)
effect of stroke on family relationships (30.2%)	medication (32.6%)	spending leisure time (2.4%)	medication (85.7%)
changes in touch (30.2%)	walking difficulties and talking difficulties (25.6%)		what is going to happen when the stroke survivor leaves the hospital (85.7%)

health professionals are on reducing the chance of a new stroke, the causes of stroke and the risk factors of stroke. Family members, in the eyes of the professionals, have the largest shortage of information about coping with stress and reducing the chance of a new stroke.

3.3. Influence of education level and suffered stroke

Differences in the overall amount of received information between one or more suffered strokes and different education levels could not be observed. However, some tendencies are seen when the specific topics are compared instead of the overall amount of information. Family members that are related to a stroke survivor with more than one stroke ($N = 8$), indicate to have received some more information than family members of survivors of one stroke. Furthermore, they express a lower desire for information about bladder problems, medication, exercise and leisure time. To identify differences in education level, grade and high school are put into a 'low education level' and college and university into a 'high education level'. 'High educated' stroke survivors generally wish more information. They also indicate to have received less information than 'low educated' stroke survivors. Often, the difference in the desire for information is due to the desire of the highly educated to receive 'a lot' of information, whereas lower educated stroke survivors seem to be satisfied with 'some' information. With 'highly educated' family members the same tendency is observable. The differences between high and lower educated within the family members are even stronger.

3.4. Sources of information

Table 7 presents the sources of received and desired information. The numbers in Table 7 are data percentages representing the percentage of respondents mentioning former and desired sources of information. The most frequently used sources of information for stroke survivors, as perceived by themselves, were talking with the doctor in the hospital, reading pamphlets and talking with a friend or family member. Stroke survivors strongly indicated a preference for talking with the doctor in the hospital than the other sources.

The most frequently used sources of information for family members, as perceived by themselves, were reading pamphlets, talking with the doctor in the hospital and talking with the social worker. Family members also expressed a preference for talking with the doctor in the hospital. Other sources like 'talking with my

Table 7
Percentage of respondents mentioning as sources of received information and wished information for stroke survivors and family members

Source of information	Question 1		Question 2		Question 3		Question 4	
	Survivors	Professionals	Survivors	Professionals	Family members	Professionals	Family members	Professionals
Reading pamphlets	49	42	29	65	72	58	41	79
Reading books about stroke	40	26	17	30	51	40	28	51
Talking with the doctor in the hospital	69	74	69	65	67	84	77	67
Talking with the family doctor	37	35	29	65	39	49	49	61
Talking with the nurse	31	65	20	65	44	58	82	67
Talking with the social worker	37	58	29	63	54	61	31	65
Participating in a social support group	31	35	17	74	36	28	31	74
Watching television or video recorder	31	16	20	47	23	21	10	61
Talking with a friend or family member	49	33	17	26	26	33	15	26
Talking with other professionals	6	19	6	14	8	21	5	9
Contact with other people like them	3	0	0	5	0	0	0	5
Educational program	0	14	0	14	3	9	0	14
Other	6	0	3	2	8	0	3	3

Perceptions of stroke survivors, family members and health professionals.
Question 1: How did stroke survivors receive information after the stroke?
Question 2: In what form should we put information for stroke survivors in the future?
Question 3: How did family members of stroke survivors receive information after the stroke?
Question 4: In what form should we put information for family members of stroke survivors in the future?

family doctor' and 'reading pamphlets' followed at considerable distance.

Health professionals perceived the doctor in the hospital as the most frequently used source, followed by talking with the social worker, reading pamphlets and talking with the nurse for both survivors and family members, but in different order. Professionals expressed that several sources, especially support groups and pamphlets, should be used to inform survivors and family. Apparently, in the opinion of the professionals the social support group has not yet been fully utilized as a possible source of information. It should be noted that health professionals thought that survivors and family consult many more sources than actually is the case.

3.5. Comments

At the end of the questionnaire, participants were asked to write down their suggestions and comments. Both stroke survivors and family members expressed the fact that they had to look for most of the information themselves or had to demand it. Family members added that they were confronted with different approaches and controversial opinions about the care and treatment in different places. The comment made most frequently by health professionals was that the patient (or family member) is often not receptive information, or may forget a part of the information given. As mentioned previously, this might be compatible with the finding that stroke survivors and their family members were selective in their need for information.

4. Discussion and conclusions

4.1. Study population

The sample of stroke survivors who responded to the questionnaire may have consisted of less severe subjects. Stroke survivors who were unable to write, read or understand English were excluded from the sample. The better the stroke survivor recovered from the stroke, the easier it must have been to complete the questionnaire. The average age of the stroke survivors' sample in this study is somewhat low compared with population values [28,29]. Non-English speaking cultures are underrepresented in the sample. Over 85% of the sample was white, while the research was carried out in a metropolis famous for its multicultural nature. This calls for more attention to non-English speaking cultures, including the development of educational materials. If individuals do not have English as their native language and do not understand the questionnaire, one can expect that they will not comprehend information in English about a difficult subject as stroke.

As the samples of stroke survivors and family members were composed independently, it means that family members of severe stroke survivors do not have to be mispresented. The fact that the demographic variable 'hospital stay' was over 20% higher in the family members' sample than in the stroke survivors' sample, could indicate that family members of more severe stroke survivors joined this sample. Again, the sample of family members was dominated by white people. Individuals who do not have English as their native language were underrepresented in the sample (i.e. only 2.6% of the responding family members were from Asian background). In addition, higher educated persons dominated the family members' sample which supports the idea that the instrument needed a certain degree of comprehension to complete.

The sample of health professionals could have been biased because less committed professionals could also be less interested in completing the questionnaire. Especially in chronic disease, different phases can be discerned [30]. For each individual the length of the phases are different. One can expect that the desire for information also differs per phase. Focusing on different phases instead of a vast period after the stroke onset could be very valuable in future research efforts.

The main limitation of this study was its sampling technique. The study population was selected through a non-probability sampling method. People who agreed to receive a questionnaire, not a random population, were recruited. This implied that conclusions of this survey cannot be generalized to the entire stroke population, family members and professionals, because the participants do not necessarily reflect the general population. The limited sample size endangers the reliability of the results.

4.2. Meaning of the results

The fact that how to reduce the chance of a new stroke is the highest rated item for both family members and stroke survivors is noticeable. Stroke survivors and family members are most concerned with information that will assist them in preventing a new stroke. Subsequently, they consider information that is relevant to their specific situation. Presumable, stroke survivors and family members are primarily concerned with lifesaving activities. When they understand how to prevent the worst thing happening, they start worrying about their 'normal' life; coping with stress, applying for help, strategies to perform activities of daily living, etc. Possibly stroke survivors and family members first go into a phase in which anxiety is prominent and, later on, go into a phase in which their quality of life becomes essential.

Health professionals seemed to be extremely concerned with the limited amount of information received by both stroke survivors and family members. However, health professionals failed to recognize that stroke survivors and family members are selective in their needs for information. Health professionals rated significant needs for information on mainly all topics. Nevertheless, they also indicated in their comments that the survivor and family member are not always receptive to information. In addition, health professionals perceived the needs of survivors and family members as rather similar. The need for information about how to reduce the chance of a new stroke was well recognized by health professionals. However, the results show that this need was not met. Possible causes for this unmet, but well-recognized need are:

- health professionals do not have the required amount of time/money to conduct the right educational activities;
- social desirability of the questionnaire;
- stroke survivors and family members are not receptive to the information given by the health professional as they are overwhelmed by the stroke insult;
- composition of the sample. The doctor in the hospital and the family doctor are prominent sources of desired and received information. However, this group is underrepresented in the sample and it is possible that they would have responded differently to the questionnaire.

The comment made by some professionals that they knew that there was a substantial need for information in advance of this study, could be put in a totally different light. The need for information of stroke survivors and family members seems to be on specific topics, possibly due to the fact that they can only absorb a certain amount of information. For example, where to apply for help is a highly rated item for family members, and not for the stroke survivor. Denial after stroke, which is common, may also work as a barrier for the receptivity of information.

Family members of stroke survivors who suffered more than one stroke seem to have received more information – and to desire less. This seems logical because this group has had more contacts with health professionals than family members that are related to stroke survivors with one stroke. A lower desire for 'self-care' aspects of the disease, such as bladder problems, medication and spending leisure time, suggests that families with more than one suffered stroke are somewhat adapted to some of the consequences of stroke.

Both highly educated stroke survivors and family members indicate to have received less information and desire more information. Possibly people who wish a lot of information are more critical about the amount of information they have received. Anyhow, higher educated people seem to be more receptive to information than lower educated stroke survivors and family members. Health professionals should address this in future educational efforts.

The most frequently used sources of information by stroke survivors were talking with the doctor in the hospital, reading pamphlets and talking with a friend or family member. Some comments were made by stroke survivors and family members that they still had to look for most of the information themselves and that they had to demand information. This could imply that the doctor in the hospital is the most frequent source of information, but not the most important source of information. On the contrary, the social worker was not the most frequent source, but was mentioned twice as an important source in the comments.

Stroke survivors and family members strongly indicated that they want to talk with the doctor in the hospital rather than all other sources. Apparently, the doctor is still seen as an authority that has the most knowledge of all people. It is also remarkable that talking with professionals was prominent in their wishes. The comment made that they wanted more attention for 'face to face information' supports this finding.

Professionals rated participating in a social support group as a non-utilized source of information while reading pamphlets was rated to be the most desired source for family members, accompanied by several other sources. For stroke survivors they considered that talking to the nurse and social worker are good alternatives. However, the fact that the sample of health professionals contained a high percentage of both nurses and social workers could have biased this finding. The fact that health professionals thought that a social support group should take a more prominent place than it has is interesting. This wish was not expressed by either stroke survivors or family members. However, this does not necessarily imply that this is not a good source of information for the future. As few people attend social support groups, this could be an unknown source of information in the eyes of stroke survivors and family members.

Returning to the Precede-Proceed framework, the most important results are incorporated in the framework. Combining knowledge from literature review and results of this study one can use the framework in Fig. 1 as a start in further health education activities.

4.3. Conclusions

This study showed a need for information on specific topics for stroke survivors and family members. The study points out that health professionals are more concerned about the little amount of information received by stroke survivors and family members, than they are themselves. In addition, health professionals believe the need for information is not very different between the topics. Stroke survivors and family members are selective in their needs.

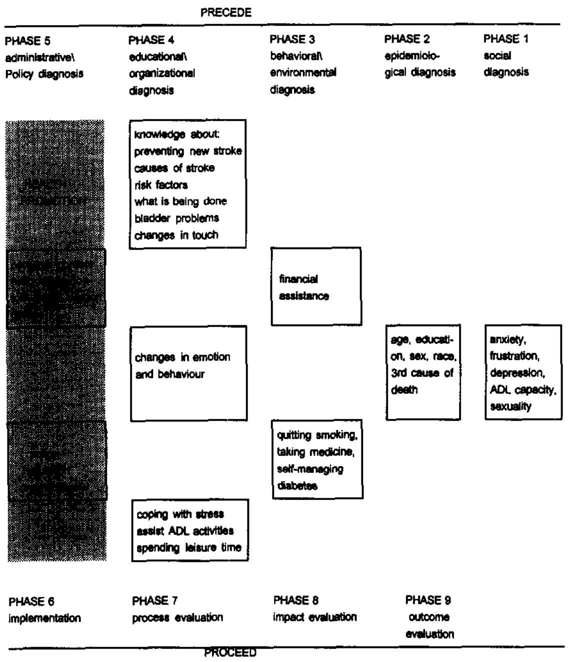

Fig. 1. The Precede-Proceed model applied to the educational needs of stroke survivors and family members.

The study shows that both stroke survivors and family members want to receive information from talking with professionals more frequently, rather than obtaining information from pamphlets and books. The belief of health professionals that support groups could be utilized much better as a source for information in the future is either not subscribed to, or unknown as such by stroke survivors and family members.

More research is needed on the needs of information of stroke survivors and family members. Future research should contain larger and more diverse samples. Other ethnic groups and the more severe stroke survivors should be examined. Although the tool used for this study is still at the development stage, the results are encouraging.

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References

[1] Barnett HJM, Mohr P, Stein BM, Yatsu FM. Stroke: Pathophysiology, Diagnosis and Management. Churchill Livingstone, New York, 1992.
[2] Evans RL, Miller RM. Psychosocial implications and treatment of stroke. Soc Casework 1984; 40(2): 242–247.
[3] U.S. Department of Health and Human Services. Stroke – Hope Through Research. NIH Publication No. 83-2222, 1983.
[4] Anderson R. The unremitting burden on carers. Br Med J 1987; 294: 73–747.
[5] Anderson R. The contribution of informal care to the management of stroke. Int Disabil Stud 1988; 10: 107–112.

[6] Lomer M, McLennan DL. Informing hospital patients and their relatives about stroke. Clin Rehabil 1987; 1: 33–37.

[7] McLean J, Roper-Hall A, Mayer P, Main A. Service needs of stroke survivors and their informal carers: a pilot study. J Adv Nurs 1991: 16: 559–564.

[8] Evans RL, Noonan WC, Bishop DS, Hendricks RD. Caregiver assessment of personal adjustment in a veterans administration medical center outpatient cohort. Stroke 1989; 20(4): 483–487.

[9] Hanger HC, Mulley GP. Questions people ask about stroke. Stroke 1993; 24(4): 536–538.

[10] Evans RL, Held S. Evaluation of family stroke education. Int J Rehabil 1984: 7(1): 47–51.

[11] Evans RL, Haselkorn JK, Hendricks RD, Baldwin D, Bishop DS. An evaluation of the family's role in rehabilitation. Am J Med Rehabil 1992; 71(3): 135–139.

[12] Farzan DT. Reintegration for stroke survivors. Nurs Clin North Am 1991; 26(4): 1037–1047.

[13] Glass TA, Matchar DB, Belyea M, Feussner JR. Impact of social support in first stroke. Stroke 1993; 1: 64–70.

[14] Goldberg G, Berger G. Secondary prevention in stroke: a primary rehabilitation concern. Arch Phys Med Rehabil 1988; 69: 32–40.

[15] Archbold P. Impact of family caring on middle aged offspring. J Gerontol Nurs 1980; 6: 79.

[16] Brocklehurst JC, Morris P, Andrews K, Richards B, Laycock P. Social effects of stroke. Soc Sci Med 1981; 15a: 35–39.

[17] Chaudhuri G. Rehabilitation of stroke patients. Geriatrics 1980; 35: 45–54.

[18] Williams SE, Freer CA. Aphasia: its effect on marital relationships. Arch Phys Med Rehabil; 67: 50–52.

[19] Evans RL, Bishop DS, Haselkorn JK. Factors predicting satisfactory home care after stroke. Arch Phys Med Rehabil 1991; 72; 2: 144–147.

[20] Moser DK, Dracup KA, Marsden C. Needs of recovering cardiac patients and their spouses: compared views. Int J Nurs 1993; 30(2): 105–114.

[21] Dilorio C, Faherty B, Manteuffel B. Learning needs of persons with epilepsy; a comparison of perceptions of persons with epilepsy, nurses and physicians. J Neurosci Nurs 1993; 25(1): 22–29.

[22] Lauer P, Murphy SP, Powers MJ. Learning needs of cancer patients: a comparison of nurse and patient perceptions. Nurs Res 1982; 31: 11–16.

[23] Casey E, O'Connell JK, Price JH. Perceptions of educational needs for patients after myocardial infarction. Patient Educ Couns 1984; 6(2): 77–82.

[24] Green LW, Kreuter MW, Deeds SG, Partridge KB. Health Education Planning; A Diagnostic Approach. Mayfield Publishing Company, USA, 1980.

[25] Green LW, Lewis FM. Measurement and Evaluation in Health Education and Health Promotion. Mayfield Publishing Company, Chapter 10, 1986.

[26] Bailey WC, Richards JM, Manzella BA, Windsor RA, Brooks CM, Soong SJ. Promoting self management in adults with asthma; an overview of the UAB program. Health Educ Q 1987; 14(3): 45–55.

[27] Opdycke RA, Ascione FJ, Shimp LA, Rosen RI. A systematic approach to educating elderly patients about their medications. Patient Educ Couns 1992; 19(1): 43–60.

[28] Kelly-Hayes M. A preventive approach to stroke. Nurs Clin North Am 1991; 26; 4: 931–942.

[29] Modan B, Wagener DK. Some epidemiological aspects of stroke: mortality/morbidity trends, age, sex, race, socioeconomic status. Stroke 1992; 23(9): 1230–1236.

[30] Strauss A, Corbin JM. Shaping a New Health Care System; The Explosion of Chronic Illness as a Catalyst for Change. Jossey-Bass Publishers, San Fransiso-London, 1988.