

## Previous Experiences with Epilepsy and Effectiveness of Information to Change Public Perception of Epilepsy

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**Summary:** Differences with regard to the effectiveness of health information and attitude change are suggested between people with direct, behavioral experiences with a health topic and people with indirect, nonbehavioral experiences. The effects of three different methods of health education about epilepsy, frequently used in health education practice, are assessed in a pretest posttest design with control groups, controlling for experiences with epilepsy. Subjects were 132 students from teacher-training colleges. After all treatments, attitudes, and knowledge about epilepsy were changed in a positive

way. Treatments were found to be equally effective. Before treatment, direct behavioral experiences were related to knowledge and a more positive attitude towards epilepsy. After treatment, subjects with direct behavioral experiences with epilepsy showed less change of attitude and knowledge as compared with subjects with indirect experiences. Direct experiences appear to restrain the processing of new information and attitude change. **Key Words:** Epilepsy—Health education—Experience—Attitudes—Knowledge.

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No doubt the epileptic seizure or "grand mal" is the most noticeable aspect of epilepsy. Most people associate epilepsy with these rather dramatic, unexpected, and often frightening experiences. With adequate medication, however, most patients are able to control their seizures sufficiently and to live normal lives as others do. Certain personality traits are frequently attributed to persons with epilepsy or they are thought of as being retarded (Bagley, 1972). From a Dutch nationwide survey (NSS, 1980), it can be concluded that 16% of the respondents have the opinion that epilepsy is some form of insanity; 10% object to epileptic patients being part of the labor force. The Dutch survey was an equivalent of the public opinion polls that have been held in the United States every 5 years since 1949 (Caveness and Gallup, 1980; Caveness et al., 1974). In the last two decades, similar surveys have been conducted in parts of Europe as well; in Germany (Hauck, 1968; Diehl and Hauck, 1975; Finke, 1979), in England (Office of Health Economics,

1971) and in Finland (Iivanainen et al., 1980). Indications of misunderstandings about epilepsy can be found in all countries mentioned here (Gutteling et al., 1981).

Wrong ideas about epilepsy influence the functioning of persons with epilepsy, either directly or indirectly (De Boer, 1984; Hoppener et al., 1984). How can these misunderstandings be reduced or eliminated? Health education is usually seen as a possible way to increase the knowledge of the public and to alter wrong ideas. Since World War II, numerous health education methods and programs have been developed and some have been evaluated. The following studies deserve mention.

In the study by Sands and Zalkind (1972), employers living in an American town were exposed to an intensive multimedia health educational campaign on epilepsy aimed at changing their attitudes. Mass media such as local broadcasting, newspapers, flyers and movies informed the public on the campaign. At the same time, lectures and various discussion meetings were organized. The employers received information encouraging them to hire people with epilepsy. After the 1-year campaign, no significant attitude changes were found. Matovu (1974) studied the effects of two educa-

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tional strategies in Uganda, namely a direct approach in which interpersonal communication was stressed by lectures, discussions, and personal contact with the health educator, and an indirect approach in which written material was distributed. For 3 months, villagers and secondary school children were exposed to these approaches. Measures were used before and after distribution to assess the possible changes in knowledge and attitudes of the participants. Both villagers and pupils showed a significant increase in knowledge and a significant attitude change. The direct approach was superior to the indirect approach in both village and school groups. Rose et al. (1955) studied the effects of the film "Seizure." Students who saw the film developed a more positive attitude toward epilepsy than control group students who did not see it. Subjects who were interested in paramedical and social professions had the most favorable attitudes both before and after viewing the film however, although the attitudes of these subjects hardly changed.

In general, it is difficult to derive any single conclusion with regard to the efficacy of the methods used in the research examples mentioned. We believe that this holds for many evaluative research studies in the field of health education, because in a number of cases, both informational content and method of health education are manipulated simultaneously. If only one method is used, e.g., film (Rose et al., 1955) one must ask whether possible effects must be ascribed to method or to content. A problem with the study of Sands and Zalkind is that the informational content of the health education activities may not have been causally related to the variables selected as the criterion of persuasion, e.g., general knowledge or attitude. For adequate interpretation, such a link between informational content and criterion variables is essential.

One must also ask whether previous experiences with epilepsy will restrain or stimulate the processing of new information. The study of Rose et al. (1955) points to the former conclusion. Most health educators, however, seem to believe that previous experiences with a certain topic facilitate the acceptance of new information. Thus, experienced people are capable of functioning as intermediary educators or opinion leaders.

Both Fishbein and Ajzen's theory of reasoned action (1975) and the Health Belief Model (cf. Janz and Becker, 1984) stress the importance of experiences in the process of attitude formation. Regan and Fazio (1977) and Fazio and Zanna (1981) state that the kind of experiences determines the consistency between attitudes and behavior. With respect to the influence of experience on the effectiveness

of new information, Fazio and Zanna (1981) suggest that with direct, behavioral experiences, the knowledge one derives from these experiences remains salient. With indirect, nonbehavioral experiences formed mostly from information transfer through some kind of medium (a person, newspaper, or television program) the medium itself and the information it transmits become salient. With respect to health education in general and epilepsy in particular, direct behavioral experiences may occur because people are or have been patients themselves or because they know patients in their immediate surroundings.

Health education is often customized to a large, average public, that usually has no direct experience with the topic. Most likely the information presented in a general health educational message is not linked sufficiently to the specific kind of knowledge possessed by people with direct behavioral experiences about the topic. Therefore, people with direct behavioral experiences can be expected to be less affected by health education than people with indirect experiences.

The following research questions were thus raised:

1. Does health education lead to a short-term and/or long-term increase of knowledge about epilepsy and does it lead to short-term and/or long-term attitude change (effect of content)?
2. Do different health educational methods lead to differences in knowledge and attitude (effect of method)?
3. Do experiences with epilepsy interfere with change of knowledge and attitude?
4. What is the participants' opinion about the health education and which relation exists between the educational methods and this opinion?

## MATERIALS AND METHODS

### Subjects

Subjects were 132 students (42% men, 58% women) from three teacher-training colleges in three medium-sized Dutch cities, ranging in age from 20 to 25 years. All subjects voluntarily participated in the experiment and received a small fee.

This field-experimental study represents a pretest posttest control group design with the independent variable being Health Education Method (brochures, slides, group discussion); this variable is controlled. Three measurements were used: a baseline measurement, a second measurement directly following the information transfer (short-term effect measurement), and a third measurement (long-term

effect measurement) 3 months after the second. One control group ( $n = 27$ ) received information only after the second measurement and served as a short-term control group. Another group of students ( $n = 19$ ) participated only in the baseline and the third measurements and served as the long-term control group.

Short-term health education effects on knowledge were established by subtracting the scores on the baseline measurement from those on the second measurement. Long-term effects were measured by subtracting scores on the baseline from those on the third measurement.

### Procedure

Subjects were visited in their classrooms by the researcher who asked them to complete a questionnaire. About 6 weeks later, the health education took place. For practical reasons, random assignment of individuals to the various experimental or control conditions could not be realized; therefore, classes were assigned at random to control or experimental groups. Immediately after the health education session, the second questionnaire was completed; followed 3 months later by the final measurement.

In general, the questionnaires, which were identical in all treatments for all subjects, were used in each measurement. At the second measurement, questions were added to measure the subject's opinion of the health education. Control group subjects did not receive health information (at least not before they completed this questionnaire) and consequently they were not asked these questions.

At the baseline measurement, no differences were found between the conditions for the variables of knowledge, attitudes, type of previous experiences with epilepsy, and sex. Thus, the randomization was successful, and the various groups were comparable.

### Experimental manipulations

Health education methods used by the Dutch Federation Against Epilepsy include written material in the form of leaflets and audio-visual material, used in lectures and group-centered educational activities. Based primarily on these materials and on theoretical notions (Van Den Ban, 1981), the following three educational methods were used:

1. Leaflet method. The participants received a leaflet with information about epilepsy.
2. Audio-visual method. The participants watched an audio-visual consisting of 20 color slides with accompanying text.
3. Group discussion method. Following a brief

instruction from the health educator, the participants watched the audio-visual and then took part in a group discussion about epilepsy. Feedback between participant and health educator was possible.

To avoid content and method confusion, methods were manipulated independent of content. In all three experimental methods, exactly the same information was given; only the method of education was varied—from a relatively simple leaflet to a more complex and intensive group discussion with audio-visual support. The education was given by members of the Dutch Federation Against Epilepsy. For standardization purposes, these educators were trained some time before the experiment started. The experimental procedure guaranteed that every individual health educator participated in all three experimental treatments.

### Control measures

In the baseline measurement, subjects were asked about their previous experiences with epilepsy. Based on the results of these questions, each experimental group could be subdivided into three groups of approximately the same size: (a) a group with almost no direct behavioral experiences with epilepsy, consisting of individuals who had only heard or read something about epilepsy; (b) a group with a moderate level of behavioral experiences, consisting of students who knew somebody with epilepsy personally or who had themselves witnessed one or more epileptic seizures, (c) a group that had the most behavioral experiences with epilepsy, consisting of students who both knew an epileptic and had witnessed one or more seizures.

### Dependent measures

Knowledge about epilepsy was measured by 12 multiple-choice questions about epilepsy and mental illness, the limitations for epileptic patients, the taking of medicine, the incidence and origins of epilepsy, the danger of seizures to one's health, epilepsy and brain activity, the consultation of a physician when a seizure occurs, and epilepsy and risks in traffic. A high score represented a high amount of knowledge.

Attitudes were measured with questions designed by Caveness and co-workers (1980) about willingness to socialize with persons with epilepsy, persons with epilepsy having jobs like other people, epilepsy as a mental illness, the danger of epileptic seizures while driving, and the effect of taking medicine on driving. For these questions, an index was calculated. A high score on this index represented a favorable attitude toward epilepsy.

Directly following the health education, the subjects of the experimental groups were asked to evaluate the health education on involvement with epilepsy; health education efficacy; the health educator (reliability, credibility, competence); the need for information about epilepsy; and the information itself (reliable, credible, clear, meaningful).

## RESULTS

### Effects on Knowledge

Analysis of variance showed that the short and long-term main effects of educational methods were significant as compared with the control group ( $F = 45.34$ ,  $df = 3/112$ ,  $p < 0.001$ , and  $F = 5.29$ ,  $df = 3/104$ ,  $p < 0.01$ , respectively). Thus, health education increased knowledge about epilepsy. The difference between the separate experimental groups versus the control group were also significant.

Table 1 shows the results of the analysis of variance for the differences in knowledge about epilepsy between experimental conditions with regard to the factors of educational method and level of experience with epilepsy. No significant short- or long-term differences in effect were found; therefore, the superiority of one method over another could not be established.

Significant short- and long-term main effects were found for level of experience with epilepsy. Further analysis revealed that directly following the health education, the group having no behavioral experiences had a significantly higher level of knowledge than the group with the most behavioral experiences ( $F = 7.6$ ,  $df = 1/56$ ,  $p < 0.008$ ; average knowledge 11.03 and 10.30, respectively). The level of knowledge of the group with a moderate level of behavioral experiences in between (average knowledge 10.52). The baseline data show, however, that the group with the most behavioral experiences had more prior knowledge than the group with no behavioral experiences, whereas the middle group had a middle position at the baseline as well ( $F = 10.38$ ,  $df = 2/83$ ,  $p < 0.001$ : average knowledge for the group with most

behavioral experiences 7.57, middle group 5.76, group with no behavioral experiences 5.24).

Thus, the group with most behavioral experiences with epilepsy showed the least increase of knowledge immediately following health education and had less knowledge as compared with the group with no behavioral experiences. Three months after health education, there was still a significant increase in knowledge regarding the baseline measurement and the control group, although the group with no behavioral experiences no longer had more knowledge than the group with the most behavioral experiences.

Directly after health education, a significant interaction effect was found between educational method and level of experience. This effect can be interpreted as follows: there was no difference in the effect of the various educational methods between the group with no behavioral experiences ( $F = .86$ ,  $df = 2/28$ , NS) and the middle group ( $F = .88$ ,  $df = 2/28$ , NS). For the group with the most behavioral experiences, the group discussion method differed significantly from the leaflet method ( $F = 11.03$ ,  $df = 1/13$ ,  $p < 0.006$ ). The difference between the group discussion method and the audio-visual method tended to be significant ( $F = 3.81$ ,  $df = 1/16$ ,  $p < 0.07$ ). There was no difference between leaflet and audiovisual methods. Three months after health education, the interaction effect was not significant; therefore, a (combined) influence of method and level of experience did not exist.

### Effects on attitudes

Analysis of variance for the experimental groups together and the control group showed a significant effect with respect to attitudes about the educational methods directly following education ( $F = 3.48$ ,  $df = 3/112$ ,  $p < 0.02$ ). Three months later, this could not be assessed. Therefore, the participants had a more positive attitude toward epileptic persons only immediately after health education.

Determining differences between experimental methods showed neither significant short- ( $F =$

TABLE 1. Analysis of variance concerning knowledge within the experimental groups with educational methods and experience with epilepsy as factors

Source of variance	Immediately following education			Three months After education		
	F	df	p	F	df	p
Educational method	.56	2	NS	.89	2	NS
Experience with epilepsy	14.93	2	<0.00	9.21	2	<0.00
Interaction: educational method and experience with epilepsy	2.48	4	<0.05	.36	4	NS

1.72,  $df = 2/84$ , NS) nor long-term effects ( $F = 1.27$ ,  $df = 2/84$ , NS). Therefore, with respect to attitude change, the greater effectiveness of one educational method over the other could not be established, as it could not be established for knowledge. Three months after the health education, a significant main effect for level of experience with epilepsy was found ( $F = 4.21$ ,  $df = 2/84$ ,  $p < 0.025$ ); there was, however, no such short-term effect ( $F = 2.02$ ,  $df = 2/84$ , NS).

How can the relationship between attitudes and level of experience be interpreted? Individuals with almost no behavioral experiences with epilepsy appeared to have a less positive attitude toward epileptic persons on the baseline measurement than that of individuals with the most behavioral experiences (average attitude for the group with no behavioral experiences 6.73, for the middle group 6.95, for the group with the most behavioral experiences 8.20). Immediately after health education, the group with the most behavioral experiences still had a more positive attitude than the other group ( $F = 4.43$ ,  $df = 2/83$ ,  $p < 0.025$ ; average attitude for the group with no behavioral experiences 8.07, for the middle group 7.70, and for the group with the most behavioral experiences 8.79). The relative attitude change as compared with the baseline measurement was greatest for the group with no behavioral experiences and least for the group with the most behavioral experiences. The middle group again was midway between the two.

#### The participants' opinion about the education methods

In general, no significant differences were found in the participants' opinions about the health educational methods used. The general opinion varied from fairly good to very good (Table 2). The level of experience with epilepsy did not play a part in the opinion about the various educational methods.

Table 2 indicates that the method of group dis-

cussion and the role of the health educator in the group discussion were judged significantly more positively than were both other methods and their respective health educators. This can be explained in part by the possibility for interaction between the participants and the health educator and between the participants themselves, which more likely led to involvement and satisfaction.

#### DISCUSSION

The study of health education effectiveness is in actuality a study of the goals that health educators try to reach and a determination of how and whether these goals are met. Such a goal might be correct knowledge or a positive attitude. In this study, an increase in knowledge and attitude change were found directly following health education, a long-term increase of knowledge was also found. The superiority of one educational method over the others could not be confirmed; in general, the effects of the various methods did not differ. The conclusion, however, that choice of educational method is relatively unimportant in the case of epilepsy is not warranted. The results indicate that a health educator, aiming at a target group comparable to the one used in this study, could choose the leaflets method. As compared with the audio-visual and the group discussion methods, the leaflet method is a relatively cheap method of information transfer to a large audience. More considerations can be inferred from this study, however. The opinion of the participants was significantly more positive about the group discussion method and the role of the health educator than about both other methods.

Level of experience with epilepsy appears to interfere with the increase of knowledge, because individuals with much behavioral experience with epilepsy and a high level of knowledge at the baseline measurement were influenced to a lesser extent

TABLE 2. *Opinion of subjects in experimental groups about health education and educator immediately after health education*

	Leaflets (n = 31)	Color slides (n = 28)	Group discussion (n = 27)
Involvement	4.86	4.99	5.12
Effectiveness	5.03	4.57	5.23
Evaluation education	4.53 <sup>a</sup>	4.75 <sup>b</sup>	4.90 <sup>c</sup>
Evaluation educator	5.55 <sup>d</sup>	5.83 <sup>e</sup>	6.27 <sup>f</sup>
Need for information	5.93	6.09	6.25
Evaluation information	6.08	6.08	6.47

Min: 1, max: 7.

<sup>a</sup> Versus <sup>c</sup> $F(1/56) = 7.43$ ,  $p < 0.01$ ; <sup>b</sup> Versus <sup>c</sup> $F(1/53) = 1.04$ , NS; <sup>d</sup> Versus <sup>f</sup> $F(1/55) = 10.69$ ,  $p < 0.002$ ; <sup>e</sup> Versus <sup>f</sup> $F(1/53) = 5.73$ ,  $p < 0.02$ .

than individuals who had less behavioral experience with epilepsy and knew less about it. A possible explanation is that the relatively greater knowledge of the former group left little room for an increase in knowledge because they had already reached the maximum level of knowledge. That is not plausible, however, because immediately following the educational sessions the group with no behavioral experiences at all had significantly more knowledge than the individuals with most experiences.

Why did experience with epilepsy interfere with the ability to learn about it? Analysis of the individual questions and answers revealed that individuals with much experience may have had problems with questions about information that could be contradictory to certain experiences in real life. An example of this is the recent medical opinion, given in the information about epilepsy, that epileptic persons must comply for only a relatively short time with certain limitations. Individuals with most behavioral experiences did not change their point of view on this topic, either because the epileptic persons they know must indeed comply with some limitations, or because they still think that limitations are necessary. This supports the idea that experience interferes with the effectiveness of new information.

It did not seem to matter which educational method was used for the groups with little behavioral experience. For the group with most experience, however, the group discussion method was most effective in increasing knowledge. Probably because of the communication between health educator and group members, this method apparently provides the opportunity to correct wrong beliefs about epilepsy. This is consonant with the suggestion of Fishbein et al. (1980), that for health education to be effective, primary beliefs must be changed. For leaflet and audio-visual methods, this communication between health educator and group members is not possible and wrong primary beliefs cannot be altered.

Information transfer is an important aspect of health education—either to provide general information or to raise the level of knowledge on some specific topics. Apparently, the significance of the impact of the kind of experiences found in this study is that the health educator should try to discover the kind of behavioral experiences the audience has had, how salient these experiences are, and what knowledge and attitudes the audience possesses. The content of health education should be adjusted as much as possible to these factors. The effectiveness of the transfer of health information was confirmed in this study to be independent

of the method of education. Direct behavioral experiences can more or less restrain the effects of a general educational message. This means that the people who receive health education should have the opportunity to give feedback to the health educator about their behavioral experiences and their informational needs. The educator should consider this and adjust information to these experiences and needs to maximize the effect of education.

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### RÉSUMÉ

Il a été suggéré qu'il existe une différence dans l'efficacité de l'éducation sanitaire et dans les changements d'attitude entre les personnes qui ont eu une expérience directe, comportementale, avec un problème de santé, et les personnes qui n'ont eu qu'une expérience indirecte, non comportementale. Nous avons étudié l'effet de trois méthodes différentes d'éducation sanitaire concernant l'épilepsie, toutes trois d'utilisation courante dans la pratique de l'éducation sanitaire, suivant un protocole comparant la période avant et la période après, avec des groupes de contrôle et une vérification de l'expérience personnelle concernant l'épilepsie. Les sujets furent 132 étudiants suivant une formation d'enseignants. Les trois programmes ont entraîné un changement dans les attitudes et dans les connaissances sur l'épilepsie, avec une efficacité égale pour les trois. Avant le programme, l'existence d'une expérience directe et comportementale se traduit par une meilleure connaissance de l'épilepsie et une attitude plus positive envers l'épilepsie. Après le programme, les sujets qui avaient eu une expérience personnelle de l'épilepsie ont présenté moins de modifications dans leur attitude et dans leurs connaissances par rapport aux sujets sans expérience personnelle. Il semble qu'une expérience directe peut restreindre l'acquisition de nouvelles informations et un changement d'attitude.

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### RESUMEN

Se sugiere la existencia de diferencias en lo que respecta a la eficacia de la información sobre temas de salud y los cambios de actitud entre personas con experiencias directas en su comportamiento con tópicos de salud y las personas con experiencias indirectas no relacionadas con su comportamiento. Los efectos de tres métodos diferentes de educación de salud acerca de la epilepsia, frecuentemente utilizados en la práctica de educación en temas de salud, se han determinado en un diseño pre-test,

post-test con grupos control controlando también las experiencias con epilepsia. Los sujetos fueron 132 estudiantes de unos colegios de formación de maestros. Después de todos los tratamientos las actitudes y conocimiento acerca de la epilepsia cambiaron. Los tratamientos fueron igualmente eficaces. Antes del tratamiento las experiencias directas de comportamiento estaban relacionadas con el conocimiento y con actitud más positiva hacia la epilepsia. Después del tratamiento los sujetos con experiencias directas de comportamiento con epilepsia mostraron menos cambios de actitud y conocimiento comparándolos con los sujetos con experiencias indirectas. Parece ser que las experiencias directas pueden limitar el procesamiento de información nueva y de cambios de actitud.

(A. Portera-Sánchez, *Madrid*)

### ZUSAMMENFASSUNG

Es werden Unterschiede hinsichtlich der Bedeutung von Gesundheitsinformationen und einer veränderten Einstellung zwischen Menschen mit direkter Verhaltenserfahrung mit einem Gesundheitsproblem und Menschen mit indirektem nicht-verhaltensmäßigen Erfahrungen vermutet. Die Wirkung von 3 verschiedenen Methoden der Gesundheitserziehung, die Epilepsie betreffend, die häufig in der Gesundheitserziehungspraxis benutzt werden, werden in einem Design untersucht, das die Vortest- und Nachtestphase, Kontrollgruppen und die kontrollierte Erfahrung mit Epilepsie berücksichtigt. Untersucht wurden 132 Studenten der Lehrerbildungsanstalten. Mit jeder Methode konnten die Einstellung gegenüber und das Wissen über Epilepsie beeinflusst werden. Die Methoden zeigten sich gleichermaßen effektiv. Vor der Behandlung entsprach eine direkte Verhaltenserfahrung dem Wissen und einer positiveren Haltung gegenüber Epilepsie. Nach der Behandlung zeigten Probanden mit direkter gegenüber solchen mit indirekter Verhaltenserfahrung weniger Beeinflussung ihrer Einstellung und ihres Wissens. Es scheint, daß direkte Erfahrungen den Prozeß neuer Information und einer Änderung der Einstellung verhindern können.

(D. Schef, *Heidelberg*)