

Compliance with health regimens of adolescents with epilepsy

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The purpose of this paper was to describe the compliance of adolescents with epilepsy and some factors connected to it. Altogether 300 individuals with epilepsy aged 13–17 years were randomly selected from the Finnish Social Insurance Institution's register. Every fifth person on the list was included in the sample. Seventy-seven per cent ($n = 232$) of the selected adolescents with epilepsy returned a questionnaire sent to them relating to compliance. The data were analysed using the SPSS software. Twenty-two per cent of the adolescents with epilepsy felt that they complied fully with their suggested health regimens, while 44% placed themselves in the category of 'satisfactory compliance', and the remaining 34% reported poor compliance. Compliance with their recommended life-style was poorest, while the highest degree of compliance was recorded for medication. Background variables, such as the duration of the disease, exercise, smoking, alcohol-intake and the number of seizures, were statistically significantly related to compliance ($P < 0.001$). Good motivation, a strong sense of normality, experience of results, subjective outcome, energy and will-power, support from parents, physicians and nurses, and a positive attitude towards to the disease and its treatment, no threat to social and emotional well-being and no fears of complications and no fear of seizures explained good compliance ($P < 0.001$).

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INTRODUCTION

Adolescents with a chronic illness are forced to consider the limitations resulting from their illness¹. One important aspect of an adolescent's life is the need to be part of a peer group². The peer group assumes that all of its members behave in the same way and follow the group's rules. If the life-style recommended to adolescents with a chronic disease does not fit that of their peers, it may be difficult for them to feel part of the group. Chronic disease and its treatment place extensive behavioural demands on adolescents. The demands invade nearly every aspect of their lives, including school, eating, sports, work, travel and dating². Hence, problems related to caring for oneself are common among chronically ill adolescents. Lack of compliance is a major problem. A number of studies (for example references 3–5) have demonstrated that approximately 50% of adolescents with long-term conditions fail to comply with their care recommendations. It is a common belief that adolescents with epilepsy show good compliance with their medication because neglect of medical treatment may cause

epileptic seizures.

Compliance of adolescents in a chronic disease, such as asthma or diabetes, has been studied from a wide range of perspectives, including medical, nursing, psychology, and sociology. Compliance of adolescents in epilepsy has been studied less extensively. Most of these studies particularly focused on compliance problems concerning self-medication. According to a study conducted by Buck⁶, the experience of those in the study, including teenagers, was that the side-effects of medication were related to poor compliance. Day⁷ and Jarvie⁸ argued that knowledge is essential for compliance with medication among patients with epilepsy. Patients with good compliance know the name, dosage schedule and indications for their medication. However, another study suggests that many patients have misconceptions regarding the goal of the treatment and the consequences of missing a prescribed drug dose⁹. Client knowledge may be more limited in view of the common side-effects, the food and fluid intake requirements and the interactions between anti-convulsant and other medications^{7,10}. Non-compliance with medication often in-

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creases the risk of further seizures. Neufeld¹¹ found that adolescents who do not comply with taking their medication had more seizures than those that do comply. Seizures in themselves may cause notable anxiety in adolescents with epilepsy.

Earlier studies have indicated some factors which are associated with the compliance of adolescents with epilepsy. Several studies indicate that compliance with medical treatment can be improved by establishing good relationships between the client and the health care staff (for example references 12 and 13). These studies stress the importance of enabling patients to see their doctors regularly and to talk about epilepsy and living with it^{6,12}. The support of parents and other family members and friends is also considered crucial to the compliance of adolescents with epilepsy⁹. While the parents continue to play the role of primary care-givers, friends and peers provide emotional support by accepting their ill friend with his or her physical limitations^{14,15}. Social dependence has been shown to be more common among adolescents with diabetes and epilepsy than among healthy peers^{12,16,17}. It is also unclear how large a role the stigma of epilepsy may have on adolescents' compliance. According to Buck⁶, patients reported feelings of stigma connected with poor compliance. According to the stigma theory, epilepsy is a culturally devalued condition. Once this negative label has been applied to a person with seizures, the person bears the brunt of societal reactions that lower his or her self-esteem. Cross-cultural studies of epileptic patients emphasize the occurrence of psychological and social problems¹⁸. A current finding indicates that the stigma felt by people with epilepsy was more profound in some countries than in others¹⁹.

Although compliance and factors associated with it have been studied, very little is known about the factors associated with the compliance of adolescents with epilepsy. The purpose of this paper is to describe the compliance of adolescents with epilepsy and some factors connected to it. The results of the study can be used to plan and implement the care of adolescents with epilepsy. Answers were sought to the following questions: 1. To what extent do adolescents with epilepsy comply with health regimens? 2. What factors are connected with the compliance of adolescents with epilepsy?

There is no generally accepted definition of compliance. In the study reported in this paper, compliance was defined as an active, intentional and responsible process in which adolescents with epilepsy work to maintain their health in collaboration with health care providers.

MATERIALS AND METHODS

Sample

In Finland, all patients with chronic illness are registered with the Social Insurance Institution for reimbursement of the cost of treatment and care. Therefore, adolescents with epilepsy all over the country were readily available on that register. At the time of data collection, there were 1732 adolescents (aged 13–17 years) with epilepsy in Finland registered with the Social Insurance Institution. The criteria for sample selection were that the disease had been diagnosed more than 1 year ago and the adolescent was aged 13–17 years. Age selection was based on the expectation that by the age of 13, self-care responsibilities had been assumed by the adolescents. Altogether 300 individuals were randomly selected from the Finnish Social Insurance Institution's register. Every fifth person on the list was included in the sample.

Data collection

The data were collected by using a questionnaire based on a theoretical model of compliance of adolescents with diabetes¹⁴ and a literature review concerning the compliance of adolescents with chronic diseases, such as asthma, diabetes, epilepsy and juvenile rheumatoid arthritis. The content of the questionnaire was initially developed for adolescents with diabetes, but has later been adjusted to be applicable to adolescents with asthma, juvenile rheumatoid arthritis and epilepsy. This version of questionnaire was tested among adolescents with epilepsy ($n = 10$) and clinical experts ($n = 2$) to confirm the content validity of the questionnaire. The questionnaire consisted of 58 items on the following topics: compliance with health regimens, sense of normality, support from nurses, physicians, friends, and parents, energy and will-power, motivation, impact of care and treatment, attitude, fear of complications, fear of seizures and subjective outcomes. The topic of compliance measures the self-care behaviour of adolescents with epilepsy, the collaboration shown by health care staff, and the responsibility and activity shown in care.

Twelve questions pertained to the background variables. The questionnaire was formatted using five-point Likert scales from definite agreement through indecision to definite disagreement. Cronbach's alpha value of the questionnaire for adolescents with epilepsy was 0.94.

The questionnaires were sent to the adolescents selected from the Social Insurance Institution's register and the subjects then returned them directly to the researcher. Only 47% ($n = 140$) of the subjects re-

turned the questionnaire after the first request, while 77% ($n = 232$) did so after the second request. Six parents of the adolescents called the researcher to tell her that their adolescents were mentally handicapped and therefore unable to respond.

The subjects were informed in a letter attached to the questionnaire that their answers would be used for research purposes, that their identity would not be revealed at any stage, and that the researcher would consider the information confidential. The voluntary nature of participation was also emphasized.

Data analysis

The data were analysed using the SPSS (Statistical Package for Social Sciences) for the Windows software package. Sum variables were formatted from the items concerning compliance (12 items), sense of normality (10 items), subjective outcome (three items), attitude (three items), support from parents (four items), nurses (three items) and physicians (three items), and threat to physical (three items), social (five items) and emotional (four items) well-being. Here are a few examples of the items which have been used to construct the sum variables. The following items are an example of the contents of the sum variable for compliance: 'I carry out my medical treatment according to the instructions given by my doctor or nurse, I do not carry out the medical treatment as instructed because the medicine causes side-effects, I write down information about my epileptic seizures according to the instructions given by my doctor or nurse, I take responsibility for my own care, I follow regularly the life-style recommended to me, I visit my doctor or nurse regularly according to the instructions and the doctor cooperates with me to plan my treatment to suit my life situation.'

The following items are an example of the content of the sum variable for sense of normality: 'Taking care of my epilepsy according to the instructions is a natural part of my daily routine, prevents me from living a normal life like the others, limits my everyday life, or limits my independence.' Collaboration with nurses and physician was elicited by the following items: 'Pays attention to my life situation and problems when planning my treatment, is interested in my epilepsy rather than me, orders how I should act and encourages me to take care of myself.' Each of these items was formatted separately with regard to the actions of nurses and doctors. The following examples illustrate the items used to measure subjective outcomes: 'Taking care of my epilepsy according to the instructions makes me feel good, and taking care of my epilepsy according to the instructions lets me stay healthy.'

All the other sum variables except compliance were formatted in the following way. The sum scores were

calculated and the sum was then divided by the number of variables. The sum variables were then classified into five categories based on the original scales, such as the Likert scale. When this process was completed, the sum variables were assigned into two categories to have fewer categories for cross-tabulation and to calculate the chi-square. The values 1–3 were combined and assigned a value 1, which stands for a negative finding (e.g. weak sense of normality, poor motivation), and the values 4–5 were combined and assigned a value 2, which represents a positive finding (e.g. strong sense of normality, good motivation and support from parents). Compliance was divided into three categories. The sum scores were calculated and found to vary from 12 to 60. They were categorized as follows: a sum score of 12–28 represents poor (code 1), one of 29–44 satisfactory (code 2) and one of 35–60 good compliance (code 3). Frequencies and descriptive statistics were computed for the variables. The relationships between the variables were analysed by cross-tabulation and the significances were tested by the chi-square test.

Subjects

The series comprised 114 females and 118 males of an average of age 14.6 years (SD 1.32). Forty-one per cent of them were 13–14 years old, 20% 15 years old and 39% over 15 years old. Twenty-two per cent had had the disease for less than three years but more than one year, 34% for 3–6 years and 44% for over 6 years (mean duration 6.2 years, SD 35). Twenty-eight per cent smoked regularly, 22% occasionally and 50% never. Twenty-four per cent exercised weekly and 15% never exercised. Twenty per cent drank alcohol every week, 46% did not drink and 34% drank occasionally.

RESULTS

Compliance of adolescents with epilepsy

Only about one-fifth (22%) of the adolescents with epilepsy felt that they complied fully with the health regimens, while 44% placed themselves in the category of satisfactory compliance and the remaining 34% thought they showed poor compliance. Compliance with the recommended life-style was poorest, as only 18% tried to follow the instructions concerning a regular life-style (e.g. regular bed-times and meal times, regular times to take medication), while 40% showed satisfactory compliance with the life-style instructions and 42% showed poor compliance. The second lowest compliance figures were obtained for

home-monitoring (keeping a diary of seizures), with one-third (32%) showing good compliance and 29% poor. The highest degree of compliance was observed for medication and control visits to the hospital. In medication, 37% of the patients ranked in the top category, with only 31% showing poor compliance. Less than half (41%) of the adolescents visited their doctor or nurse regularly, as instructed, and only 11% showed poor compliance with control visits. About half (43%) of the subjects felt that their treatment had been planned together with a physician, and 38% felt that it had been planned together with nurses.

Factors connected to compliance

Table 1 shows the statistically significant ($P < 0.001$) connections between the degree of compliance and the background variables (duration of disease, exercise, smoking, alcohol intake and number of seizures). The adolescents who had had epilepsy for 1–3 years assessed their compliance with health regimens to be better than the adolescents who had had epilepsy for more than three years. Of those who exercised regularly, 51% showed good compliance and 45% satisfactory compliance. Only 9% of those who did not exercise at all showed good compliance. Less than half of those who did not smoke showed good compliance and 36% of those who did not use alcohol showed good compliance. Forty per cent of those who had seizures less often than weekly showed good compliance, whereas 11% of those with daily seizures showed good compliance. Background variables, such as age, family size, family composition (mother, father, stepmother, stepfather, grandparents) and sex, did not have any statistically significant association to compliance.

Table 2 shows the factors with statistically significant ($P < 0.001$) connections with the degree of compliance. About half of the adolescents who showed good motivation, who reported having the energy and will-power to comply with the health regimens, who had a strong sense of normality and who showed a positive attitude towards their disease showed good compliance. None of those with a negative attitude reported having good compliance. Only 3% of those having a weak sense of normality had good compliance. Of the adolescents who felt that the disease constituted no threat to their social well-being, 45% showed good compliance, whereas 63% of those who felt it to be a threat to their social well-being showed poor compliance. The adolescents who felt fears of complications and seizures showed poorer compliance than the adolescents who did not have these fears.

The analysis of individual items indicated that almost half of those receiving support from their parents,

physicians and nurses showed good compliance. More than half (56%) of the subjects felt that their parents were trying to force them to take care of themselves. Sixty per cent of the adolescents reported that physicians are only interested in epilepsy as a disease not in the young people themselves. Also, 60% of the adolescents felt that physicians and nurses give them orders and make decisions concerning their care among themselves instead of negotiating with the adolescents about self-care. About half (51%) of the subjects reported getting support from their friends, and that had a statistically significant connection with compliance.

DISCUSSION

The previous findings indicate that 22% show good, 44% satisfactory and 34% poor compliance. Compliance with the life-style recommendations was poorest and that with medication best. Dilorio and Henry²⁰ also found compliance with medication to be good, but that with the other recommended practices, such as safety and life-style behaviours to be poor. Poor patient compliance is one of the major causes of non-responsiveness to antiepileptic drug therapy. One reason for poor compliance with medication is side-effects²¹. Compliance with the life-style recommended to the adolescents was poorest. Chronic illness and daily treatments have negative implications for peer relationships, resulting in functional limitations and frequent interruptions of daily activities. These changes may evoke a feeling of 'being different' and lead to non-compliance. Adolescents prefer their peer group's rules to the recommended health regimens.

Family support is regarded as crucial for the compliance of chronically ill adolescents^{13, 16}. The findings of this study also indicate that support from parents improved compliance. According to LaGreca¹⁵ emotional support from friends is largely oriented towards helping the adolescent to feel accepted. Parental strategies found to be effective include planning of self-care with adolescents, giving regular positive feedback, and providing other rewards to promote compliance. Family members and friends are important people to whom adolescents want to talk^{12, 22}.

Most adolescents felt that life was not easy because of their chronic illness. The adolescents' assigned meanings suggest that chronic illness may pose a threat to well-being²². The present findings support this. Adolescents with epilepsy felt the disease to be a threat to their social and emotional well-being, and this threat was connected to poor compliance. Also, cross-cultural studies of epileptic patients emphasize psychological and social problems¹⁸. Disturbances of emotional well-being, including fear, guilt, shame^{12, 17}

Table 1: Background variables' connections to compliance.

Background variables	Degree of compliance with health regimens								P-value
	Good		Satisfactory		Poor		Total		
	n	(%)	n	(%)	n	(%)	n	(%)	
Duration of disease									0.000
1–3 years	17	(33)	26	(50)	9	(17)	52	(100)	
< 3 > 6 years	11	(14)	38	(50)	28	(36)	77	(100)	
Over 6 years	24	(23)	36	(35)	43	(42)	103	(100)	
Exercise									0.000
Regularly	28	(51)	25	(45)	2	(4)	55	(100)	
Occasionally	21	(15)	65	(46)	56	(39)	142	(100)	
Not at all	3	(9)	10	(29)	22	(62)	35	(100)	
Smoking									0.000
Regularly	2	(3)	23	(35)	41	(62)	66	(100)	
Occasionally	4	(8)	18	(36)	28	(56)	50	(100)	
Not at all	46	(40)	58	(50)	12	(10)	116	(100)	
Alcohol-intake									0.000
Regularly	4	(8)	9	(20)	33	(72)	46	(100)	
Occasionally	10	(12)	30	(38)	40	(50)	80	(100)	
Not at all	38	(36)	61	(57)	7	(7)	106	(100)	
A number of seizures									0.000
Daily	9	(11)	24	(29)	51	(60)	84	(100)	
Weekly	2	(4)	24	(46)	26	(50)	52	(100)	
Rarely than weekly	38	(40)	49	(51)	9	(9)	96	(100)	

depression, and anxiety¹², are quite common among adolescents with chronic conditions compared with healthy peers²³.

Adolescents with epilepsy felt fears of complications and seizures. It has been known that seizures may be a highly anxiety-provoking experience to adolescents¹¹. Also, according to Woodgate²², adolescents worried about their health and the consequences of their chronic disease. Of particular concern was the worry related to developing complications because of the chronic illness. Chigier¹² also argued that the persons with epilepsy live with constant fear of seizures.

Reliability and validity

The questionnaire used for data collection was developed and tested with many sets of data, and the reliability and validity of its final version were shown to be good by the correlation coefficients. Cronbach's alpha was 0.94, which shows good reliability of the instrument. The content validity of the present questionnaire was confirmed by adolescents with epilepsy and clinical practitioners. The 77% response rate gave a total of 232 respondents. Sixty-eight adolescents failed to return the questionnaire, but six of their parents contacted the researcher to explain why they did not return it. It was not possible to evaluate those who failed to return the questionnaire and did not contact the researcher ($n = 62$). Earlier studies^{6,16} suggest that it is difficult for adolescents who show a lack of com-

pliance to take part in research. However, the response rate in this study was high compared with the response rates of survey studies generally, and this may be due to the fact that the questionnaires were mailed from the National Insurance Institution, even though the enclosed letter from the Institution indicated that they were not involved in the study and would not use the questionnaires for any special purposes. On the other hand, an earlier study¹⁴ had a response rate of 89% even though the data were collected through hospitals and by sending the questionnaires to the home addresses of adolescents with diabetes aged 13–17 years.

Implications for care

This paper shows that adolescents with epilepsy show poor compliance. It also indicates the factors connected to compliance with health regimens. To improve compliance, these factors should be given special attention in the care of adolescents. We should find out the factors connected to each adolescent's compliance and try to modify them. It cannot be over-emphasized that educational programmes should be based on an appraisal of each adolescent's needs rather than relying upon the application of a package suitable for all. To adolescents, it is important to feel a sense of normality and also to feel that the disease is not a threat to their social well-being. The question is how well health regimens can be adjusted to adolescents' normal life-styles. The degree of change re-

Table 2: Factors connected to compliance.

Factor	Degree of compliance with health regimens								P-value
	Good		Satisfactory		Poor		Total		
	n	(%)	n	(%)	n	(%)	n	(%)	
Motivation									0.000
Good motivation	48	(39)	56	(45)	20	(16)	124	(100)	
No motivation	4	(4)	44	(41)	60	(55)	108	(100)	
Sense of normality									0.000
Strong	48	(47)	51	(50)	3	(3)	102	(100)	
Weak	4	(3)	39	(30)	87	(67)	130	(100)	
Subjective outcomes									0.000
Positive	51	(35)	66	(46)	27	(19)	144	(100)	
Negative	1	(1)	34	(39)	53	(60)	88	(100)	
Energy and will-power									0.000
Have energy	40	(44)	5	(56)			90	(100)	
No energy	12	(8)	47	(33)	83	(59)	142	(100)	
Support from parents									0.000
Support	49	(42)	66	(57)	1	(1)	116	(100)	
No support	3	(3)	34	(30)	79	(68)	116	(100)	
Support from physicians									0.000
Support	49	(40)	59	(48)	15	(12)	123	(100)	
No support	3	(3)	41	(37)	65	(60)	109	(100)	
Support from nurses									0.000
Support	45	(46)	51	(53)	1	(1)	97	(100)	
No support	7	(5)	49	(36)	79	(59)	135	(100)	
Attitude									0.000
Positive	55	(46)	61	(51)	3	(3)	119	(100)	
Negative			36	(32)	77	(68)	113	(100)	
Threat to social well-being									0.000
No threat	41	(45)	51	(55)			92	(100)	
Threat	11	(8)	41	(29)	88	(63)	140	(100)	
Threat to emotional well-being									0.000
No threat	39	(34)	61	(54)	14	(12)	114	(100)	
Threat	13	(11)	39	(33)	66	(56)	118	(100)	
Fears of complications									0.000
No fears	21	(44)	23	(48)	4	(8)	48	(100)	
Fears	31	(17)	77	(42)	76	(41)	184	(100)	
Fears of seizures									0.000
No fears	27	(46)	23	(39)	9	(15)	59	(100)	
Fears	25	(14)	77	(45)	71	(41)	173	(100)	

quired in life-style may reduce compliance with the therapeutic regimen and, for this reason, it is important to modify health regimens in such a way that they accommodate the adolescents' own life-style. Individualized, tailor-made care planning and personal goal-setting should be emphasized. Adolescents need frequent support, encouragement, and positive feedback as they strive to manage their chronic disease and normal developmental crises. Supportive rather than controlling relationships between adolescents, their parents, and health care staff should be encouraged to improve collaboration in treatment. Parents need to be encouraged to allow adolescents enough physical and emotional freedom even if as a result they temporarily flounder. Health care providers should continuously evaluate the

role of the family and others, especially their effects on compliance, in order to maximize their contributions and to minimize negative impacts.

CONCLUSIONS

Compliance with health regimens of adolescents with epilepsy is poor, especially compliance with recommended life-style. The duration of the disease, exercise, smoking, alcohol-intake and the number of seizures are statistically significantly related to compliance. Good motivation, a strong sense of normality, experience of results, objective outcome, energy and will-power, support from parents, physicians and

nurses, and a positive attitude towards to the disease and treatment, no threat to social and emotional well-being and no fears of complications and no fear of seizures explain good compliance.

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