

## Patient education: perspective of adolescents with a chronic disease

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### Summary

- The purpose of this study was to describe patient education from the perspective of adolescents.
- Data were collected by interviewing adolescents who had asthma, epilepsy, juvenile rheumatoid arthritis, and insulin-dependent diabetes mellitus. The sample consisted of 40 Finnish adolescents aged between 13 and 17 years. The interview data were analysed with methods of content analysis.
- From the perspective of adolescents with a chronic disease, patient education can be divided into the following categories: routine programmes, problematic planning issues, atmosphere of patient education session and written patient education material. Some features of ideal patient education also emerged.
- In a routine programme, patient education was based on the professional knowledge of the physicians and nurses rather than the needs of the adolescents. It was provided at a time that was good for the nurses or physicians. The level of education was not compatible with each developmental level of the adolescent.
- Problematic planning issues included a poorly outlined plan of education and a lack of systematic and continuous education.
- Educational communication consisted of dialogue between the adolescent and the educator. An encouraging atmosphere developed when the educators motivated the adolescents, respected them and their opinions and encouraged them to express their feelings, to ask questions and to relate experiences. Also, it was important that the adolescents' opinions were respected.
- In ideal patient education, the sessions had been planned well beforehand based on the adolescents' needs and written patient education material. Ideal patient education helped adolescents to acquire skills to take care of themselves and provided information on how to adjust to different situations and problems.

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- The results provided useful insight into patient education and served to raise awareness of the problems and difficulties experienced by adolescents with a chronic disease.

*Keywords:* adolescent, chronic disease, patient education.

## Introduction

Patient education is considered to be a crucial part of the optimal care of patients with a chronic disease. According to some studies, patient education has been found to improve the patients' quality of life (Klein *et al.*, 2001), their compliance with health regimens (Coates & Ryan, 1996; Klein *et al.*, 2001) and their coping with the chronic disease. Nevertheless, the increasingly short inpatient periods have reduced the time available for patient education and made it more problematic to provide such education because of the shortness of visits. Arguably, adolescents are unable to take responsibility for their self care if they do not have adequate knowledge and skills as well as the requisite mental readiness. In view of this, patient education has a very important role in supporting adolescents' self care and in their willingness to take responsibility for that care. In addition, adolescents have a special need to be independent. The growth of the sense of independence is a critical aspect of development during adolescence. The presence of a chronic disease, such as asthma, epilepsy, insulin-dependent diabetes mellitus (IDDM) or juvenile rheumatoid arthritis (JRA), may hinder such growth by limiting the degree of freedom allowed by adults and by imposing lifestyle constraints (Graetz *et al.*, 2000; Carson & Voorhees, 2001). However, to attain independence, adolescents must be able to take care of themselves.

There are reports about patient education of adults, but the corresponding education of adolescents has been given less attention by researchers, especially the patient education of adolescents with a chronic disease from their own perspective. The present study focused on adolescents' perspective of patient education. The present study aims to answer the question: What is the patient education of adolescents with a chronic disease like?

## Background literature

A literature review was undertaken to establish what was known about the patient education of adolescents with a chronic disease. It revealed that studies have tended to restrict their focus to preventive health care education, adolescents' sexual issues and HIV infection. Other studies

have concentrated on the patient education of adolescents with cystic fibrosis, trauma or cancer, and only a few studies have focused on the education of adolescents with asthma, epilepsy and diabetes from their own perspective. Additionally, some studies have focused on the strategies of patient education (Worstell, 2000; Plante *et al.*, 2001; Divertie, 2002).

Yoos & McMullen (1999) note that one opportunity for nurses to educate patients and families is available during acute care visits, particularly visits to emergency units. Nevertheless, as in many long-term medical conditions, treatment and care are based on self care and adolescents are encouraged to assume responsibility for self care (Cane & Richardson, 1997; Lemanek *et al.*, 2001). Divertie (2002) suggests that, after providing patient education during the acute visits, more comprehensive instructions should be provided during the follow-up visit with the primary provider, which should ideally be scheduled for the day following the acute care visit. Worstell (2000) argues that not all the patient's educational needs can be met during the brief medical visits. The most effective patient educational programme is the one tailored to meet the patient's individual needs (Bradbury & Jenkinson, 1998; Divertie, 2002). At many hospitals, patient education is provided in groups. According to Plante *et al.* (2001), group interventions for adolescents have been developed to increase their knowledge of the illness, to enhance their psychological adaptation, and to minimize physical symptoms and side-effects.

All patients should have a written patient education plan and the plan should be updated at every visit as necessary. According to Hoskins *et al.* (2001), the patient's understanding and compliance with the plan should also be checked at every visit. While we might assume that nurse practitioners routinely provide comprehensive patient education to their asthma patients and families, a recent study showed that, out of 122 nurse practitioners studied, only 20% provided written asthma treatment plans, and only 61% checked compliance with medications at each visit (Hoskins *et al.*, 2001). The approaches that have improved compliance include providing the patient with clear, written instructions and simple schedules and ensuring frequent contacts with health professionals (Ferri *et al.*, 1998; Lemanek *et al.*, 2001). However, while a

management plan is essential, it is important to limit the written material to a manageable amount for each patient (Ott & Hardic, 1995). All handouts should be concise and written at the patient's reading level and language. According to Rankin & Stallings (1996), printed health education material, such as patient information handouts, booklets, pamphlets and information sheets, are among the most common and most extensively used teaching tools.

Communication between the educator and the patient is important. Worstell (2000) argues that communication must be enhanced to address the patient's cultural and lifestyle practices, including environmental exposure. This will require a change in clinicians' patient education skills (Graetz *et al.*, 2000). At the beginning of the teaching session, the topics to be discussed should be outlined in easily understood terms. Medical terminology should be avoided, and nurses should always speak at the patient's level of understanding (Ott & Hardic, 1995; Llahana *et al.*, 2001). Individuals are most likely to remember the first and last thing they are told during a teaching session. In light of this fact, it is important to repeat the key teaching points at the end of the visit (Divertie, 2002). Worstell (2000) argues that, even after patient education, a large number of asthma patients do not fully understand what 'control of asthma' really means and what treatments are available. They underestimate the severity of their condition and overestimate how well their asthma is being controlled.

## Methodology

The qualitative research approach was used to study patients' education from the perspective of adolescents with chronic disease.

## Sample

The data were collected from the Finnish Social Insurance Institution register. In Finland, all patients with a chronic disease are registered by the Social Insurance Institution for reimbursement of the cost of treatment and care. Adolescents with a chronic disease were most readily contactable via that register. At the time of data collection, there were 8671 adolescents (aged 13–17 years) with asthma, epilepsy, IDDM or JRA in Finland. Altogether 1200 individuals were selected from the Finnish Social Insurance Institution's register (Kyngäs, 2000). The criteria for sample selection were that the disease had been diagnosed more than 1 year previously and the adolescent was aged 13–17 years. Every fifteenth person on the list of adolescents with asthma, every fifth

adolescent with IDDM, every fifth adolescent with epilepsy and every second adolescent with JRA were included in the sample. The questionnaire was returned by 1061 adolescents. A letter, where anonymity was assured, was enclosed with the questionnaire to invite the responding adolescents to participate in an interview on their care and everyday life with a chronic disease. The respondents willing to participate in the interview were asked to send their address to the researcher. A total of 264 adolescents volunteered to participate in the interview. Their names were listed in an alphabetical order, and every third name was picked from the list. The interview sample thus consisted of 88 adolescents with a chronic disease. The selected adolescents were contacted to confirm their participation in the interview. Eighty-four adolescents were reached. Every second adolescent ( $n = 40$ ) was interviewed, so that final sample for this study consisted of 40 adolescents aged 13–17 years. Nine of them had diabetes, 11 had JRA, 12 had asthma and eight had epilepsy. The series comprised 60% females and 40% males. Of all the subjects, 28% were 13–14 years old and 35% were 16–17 years old. Eight of them (20%) had the disease for <3 years and 40% for over 8 years (Table 1).

## Data collection

When the informant's participation in the interview was confirmed by telephone, an appointment for the interview was made at the same time. The adolescents were told that the interviews would concentrate on their everyday life

**Table 1** Background information about participants ( $n = 40$ )

Background information	$n$ (%)
Sex	
Female	24 (60)
Male	16 (40)
Disease	
Asthma	12 (30)
Epilepsy	8 (20)
Diabetes	9 (22)
JRA	11 (28)
Age	
13–14 years	11 (28)
15 years	15 (37)
16–17 years	14 (35)
Duration of disease	
<3 years	8 (20)
3–8 years	16 (40)
>8 years	16 (40)

JRA—juvenile rheumatoid arthritis.

with a chronic disease and consist of open discussion. Most of the interviews were carried out at hospital. The researcher booked a room from the hospital for interviews. Some interviews were carried out at the adolescents' homes and some at the researcher's office. Each interview lasted for 1–2 hours (mean: 1 hour 38 minutes). The interviews dealt with the following topics:

- everyday life with a chronic disease;
- experiences of being a patient at a hospital or visiting an outpatient department for follow-up;
- experiences about patient education and
- social support.

Semi-structured interview guides with a schedule were used to help the interviewer. Questions of the following types were asked: What kind of experiences do you have of being a patient at a hospital? What kind of experiences do you have of patient education? From whom and what kind of social support do you receive? During the interviews, the adolescents were systematically encouraged to give examples and to explain the reasons for their answers. The adolescents discussed readily and openly the issues raised in the interview. All the interviews were transcribed verbatim from the tape-recorded conversation, which resulted in 146 pages of text (A4 size, double-spaced) concerning the informants' experiences of patient education.

### Data analysis

The interview transcripts were analysed using content analysis. Content analysis is a process of analysing documents systematically (Miles & Huberman, 1994). The categories and their contents were derived inductively from the data during the process of analysis. Similar events and incidents were grouped together into categories. Content analysis was continued until all themes were saturated (Miles & Huberman, 1994; Kyngäs & Vanhanen, 1999).

### Ethics

It was emphasized that participation in the study was entirely voluntary. Anonymity was assured and permission for the interviews to be recorded was obtained. The research plan for this study was reviewed and approved by the Board of Ethics of the local Medical Faculty.

### Findings

The participants in this study described patient education in terms of the following categories: routine programme

(including place, time, content and level of patient education), problematic planning issues, atmosphere of patient education sessions and written patient education material. Some features of ideal patient education were also pointed out. Some direct quotes are presented below, followed by the participant's code.

### Routine programme

According to the participants, routine programme meant that patient education was based on the professional knowledge of the physicians and nurses rather than the adolescents' needs. It was carried out at a time that was good for the nurses or physicians. The room for patient education was not necessarily good for that purpose, but the hospital did not have a proper place for patient education. In addition, the adolescents felt that the level of patient education was not compatible with their developmental level:

I do not understand why the nurses and physician did not ask what kind of knowledge or skills I need and base their education on that... (39th participant)

The adolescents felt that the patient education sessions were often kept in a room with a telephone ringing and people coming and going. They presumed that the patient education session was for them and expected to have a quiet place for it. Some of the participants also had their patient education session in the same room where they had had injections or undergone some other painful procedures. That room reminded them about those painful investigations and made it hard for them to concentrate on what they were told. Even when they mentioned that to the nurses, the room was not changed:

I was in a shock during the patient education session because I saw all the needles and instruments on the table. They reminded me of very painful tests.

I asked to go to another room but there was no room for us. Many nurses came into the room to pick up some instruments. That also disturbed me.

I remember nothing about that session... or well, something, the topic was my medication, but nothing more... (24th participant)

According to the informants, the timing of patient education was usually based on the hospital's daily schedule. They felt that there should be no important events close to the education session, as such events may keep their attention on what is going on and interfere with their concentration on the session. The adolescents understood that educators find it very difficult to time the sessions optimally. They appreciated the idea of having a written patient educational plan, which would

include a schedule of patient education sessions and help them to orient themselves appropriately. The adolescents also felt that they needed to know the duration of the teaching session, and that whether 30 minutes is a suitable duration.

According to the informants, the content of patient education has been divided into knowledge, skills and support. Knowledge about the disease, its treatment, self care and the way to handle the problems possibly caused by the disease and its treatment was wanted. Furthermore, the adolescents were interested in the ways of coping with their disease and the experiences of other adolescents with a chronic disease. Interestingly, they were not eager to meet adolescents who had complications or some other problems with their disease and its treatment. That was considered frightening and depressive. Also, learning the skills they would need to take care of themselves was an important part of the patient education. The adolescents felt that the more they know and the more skills they have, the more independently they can live. They also wanted to discuss who is responsible for their care. What is the responsibility of the parents, the health care providers and the adolescents themselves:

...I expected the nurses and physicians to teach me the skills that I need to take care of myself. Also, I expected them to give to me so much knowledge that I could understand my disease and its treatment, and if I had problems, I could solve them. I know that the more skills and knowledge I have, the more independently I can live. I am not dependent on my parents because of my disease... (2nd participant)

The adolescents interviewed needed emotional support and they expected to get it from health care providers as a part of the patient education. According to the adolescents, 'emotional support' meant that the health care providers were ready to listen to the adolescents, to pay attention to their opinions, and to respond to them. The interviewees expected nurses and physicians to be ready to discuss adolescents' feelings and emotional balance. In practice, however, they felt that happened very rarely:

I thought that one part of good patient education would be emotional support. If I have a poor emotional balance, there is no sense in giving me any information or practising some skills. Health care providers should be able to recognize the need for emotional support and to respond to that... I think they recognize this need, but they do not talk about it... maybe they do not have the skills or enough time to handle all patients' feelings... (16th participant)

### Problematic planning issues

The participants felt that patient education planning was poor in two ways: there may be a poorly written plan of patient education or a lack of systematic and continuous patient education. A written plan gave a chance for the adolescents to get familiar with the content and timing of their patient education and sessions, and that was a very important point. Prior information of the education helped them to orient to it, and orientation increased their motivation to learn. In addition, when the adolescents knew the topic of the patient education session, they prepared themselves for it. They read some material beforehand and thought about their personal experiences in that area and questions they would want to ask. Preparatory information had an effect on the patient education session. It changed the doctor/nurse-patient relationship, the atmosphere and the adolescent's motivation. The adolescents adopted an active role and were ready to discuss. They wanted a systematic and well-planned patient educational programme.

Follow-up patient education was also highly valued by the participants. The adolescents really needed new information all the time. They wanted to know about the new methods of investigating their condition, new medication and research results. They hoped that the follow-up patient education would also be scheduled and planned beforehand:

The problem is that I do not get information any more. I have had arthritis for 5 years. When I got the diagnosis, I had very good patient education, but after that nothing... I am interested in new information concerning arthritis and its treatment but nobody says anything to me. Education should be continuous... (34th participant)

### Atmosphere of patient education sessions

The participants felt that the atmosphere of patients education sessions was either encouraging or depressive. An encouraging atmosphere developed when the educators motivated the adolescents, respected them and their opinions, and encouraged them to express their feelings, to ask questions and to relate experiences. In an atmosphere of that kind, the adolescents were open and felt free to express themselves. That helped them to discuss and to have a feeling that they can be active and contribute to their care. This, in turn, gave them a feeling that they were responsible for their care. That feeling helped them to comply well with their care regimen. Also, if the educator used a kind of language that the adolescents

understood, they found it easier to engage in reciprocal discussion. Some of the terms used by the educators were medical terms that the adolescents were unable to understand. Sometimes they asked the educator to explain the unknown terms, but the explanation was often as difficult as the original term. If the educators' language was too difficult, the adolescents lost their motivation. It was also important that the subjects' opinions were respected. Patient education optimally consisted of dialogue between experts. The adolescents viewed themselves as experts of their lives, whilst the educators were viewed as professional experts:

... sometimes I cannot understand the nurses' and physicians' language. They use their own Latin. If I ask for an explanation, it is as difficult as the original terms. That kind of nurses and physicians do not respect me. They are not talking to me. You can never get good communication with that kind of people... I lose motivation... Some nurses are really skilful. They ask my opinion. They discuss... they are really interested in my life and try give to me knowledge that I really need in my life.  
(22nd participant)

### Written patient education material

According to participants, the written patient education material often consisted of very simple and general information. That simple and general information was useful at the time when the adolescents got their diagnoses, but not after that. Adolescents hoped to have more personalized written patient education material. They felt that the written patient education material should support the oral education given by nurses and physicians and it should be used to prepare them for the patient education sessions. The adolescents also wondered why modern technology (internet, computers) was not used very commonly. There was some information available on the internet, but they felt that information was not updated enough:

... the written patient education material is poor... when I got asthma I got a lot of written patient education material, but I did not understand anything even though it was only one year ago. I was sixteen years old. Now I get a lot of written patient education material, but the information is at such a general level that it does not help me at all. I wonder why they do not make any more personal material, even though that would be very easy with a computer. You could have some basic material there, and I suppose it would be easy to adapt it for me by

making that material to meet precisely my needs ... personally... If I do not find answers in the material, I call the hospital and ask ... (26th participant)

### Ideal patient education

From the perspective of adolescents, 'ideal patient education' meant patient education sessions that had been well-planned beforehand based on the adolescents' needs and written patient education material. They felt that patient education was a continuous process parallel to one's life with a chronic disease. According to the informants, ideal patient education should train them in the skills they need to take care of themselves, give information that can be applied to different situations and solves problems. They also felt that ideal patient education included emotional support for coping with one's feelings. The participants described in more detail the features of good educators than ideal patient education. They had many demands for good educators, pointing out that the educators should be sensitive people who can understand the feelings and capabilities of adolescents. They should be able to create a good atmosphere for the patient education session. They should also have good knowledge and communication skills. The participants also felt that it is necessary to understand well adolescents' developmental phases, their diseases and symptoms and the needs of adolescents for patient education and to plan the patient education sessions accordingly. According to the participants, a good educator can also 'wake up' their motivation and willingness to learn and, maintain a high level of motivation and attention throughout the patient education session. They are also able to sense if something is wrong with the adolescents and are able to modify their plans. The educators should indicate that they are there specifically for the adolescents by not thinking about something else all the time, checking the time, etc. Although the informants set many demands for good patient education, they pointed out that there are many good educators. Sometimes, however, the hospital routine prevented good educators from doing their work as well as they would have been able to do it.

### Discussion

During adolescence, young people learn to take responsibility for and manage their own chronic condition. Advanced knowledge and skills are necessary in the care. To identify issues and to provide appropriate patient education based on adolescents' needs is the most important starting point of patient education and its

planning. Overall, based on the present findings, the crucial problem of patient education appeared to be the lack of individual tailoring. The present findings indicated that patient education largely consists of routines and tends to be based on the professional knowledge of the physicians and nurses rather than the adolescents' needs. That kind of patient education does not serve the adolescents with chronic disease and does not help them to manage their own chronic condition. Bradbury & Jenkinson (1998) and Divertie (2002) argued that the most effective patient educational programme is the one tailored to meet the patient's individual needs. This conclusion receives support from the findings of the present study. From the adolescents' perspective, ideal education is based on their needs. The significance of knowing the adolescent patients and their needs cannot be overemphasized. Patient education programmes should be based on an appraisal of each adolescent's needs rather than rely upon the application of a package suitable for all.

According to the present findings, the written patient education material given to adolescents did not meet their needs. They wanted to have more personalized written patient education material. One problem with written patient education material is readability. Ott & Hardic (1995) pointed out that patients are often given material written above their reading level. Llahana *et al.* (2001) emphasized that it is important to be aware that the patient education material should be tailored to the cognitive level of the target readers. The present study highlights this same point from the perspective of adolescents. The adolescents presumed that good educators understand their developmental phases and plan the patient education session accordingly. Adolescents react very sensitively to treatment that is not appropriate in view of their developmental level. That challenges the educators to be very familiar with the developmental phases of adolescents and requires them to have special skills.

Based on the present study, adolescents wonder why modern technology is not used more commonly as a method of patient education. There has recently been much discussion about the efficacy of computer-aided patient education programmes, and studies to evaluate their efficacy have been suggested. Many hospitals are planning to use computer-based programmes in the future (Llahana *et al.*, 2001).

The atmosphere of the patient education session was found to be important from the adolescents' perspective. The importance of the educator-adolescent relationship that underpins interactions in the clinical context might be a key. It is an interesting point that the informants

included emotional support as part of patient education. Patient education does not consist of only teaching knowledge and skills. The importance of support by nurses has also been indicated in earlier studies (Bradbury & Jenkinson, 1998; Conway, 1998). According to Roter *et al.* (1988), effective mental and informational support improved compliance. Kyngäs (1999) indicated that 98% of adolescents with asthma who received support from nurses showed good compliance, whereas all of those who did not receive support from nurses had poor compliance.

According to the present findings, adolescents expected the educators to have many skills: to be able to create a good atmosphere for patient education sessions, to have good knowledge, and communication skills and, skills to motivate adolescents to learn. We can ask whether health care providers have such skills. We can naturally assume that, after they have completed their degree, they should have such skills. According to Nordli (2001), nurse specialists may be particularly valuable in supporting and meeting the needs of adolescents. Although the importance of special nurse support is emphasized, reviews of the literature suggest that the role of special nurses as educators has not been studied systematically (Coates & Ryan, 1996; Cane & Richardson, 1997). However, we can expect all health care providers to have the basic skills to provide patient education because, that is part of the daily duties of most of them.

According to the present study, there was not enough well-planned follow-up patient education. Follow-up patient education has been found to significantly facilitate proficiency in chronic disease management. After assessing the adolescent's knowledge about the disease and its treatment, the nurse should make an initial patient educational plan. A teaching record can be utilized to document the completion of the various phases of the plan (Cane & Richardson, 1997; Llahana *et al.*, 2001).

### Implications for nursing

The present study described, among other things, ideal patient education from adolescents' perspective. That had some implications for the development of patient education. As a conclusion, it can be said that patient education should be developed to be more personal and to meet the needs of adolescents rather than be a mere hospital routine programme. Teaching and learning principles, when applied to adolescents, must always consider their developmental and cognitive abilities. Also, written material should be more personal than general information. Further, the language used in the patient education session and the written material should be understandable

to adolescents. Medical terms should be avoided. All hospitals should provide a special room for patient education. In addition to concentrating on knowledge and skill training, patient education should provide emotional support as well. The communication between educators and adolescents should be a two-way communication, and each adolescent should be respected as an expert of her/his life. Written plans about patient education should be provided to adolescents.

The results presented here provide useful insight into patient education and serve to raise awareness of the problems and difficulties experienced by adolescents with a chronic disease.

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