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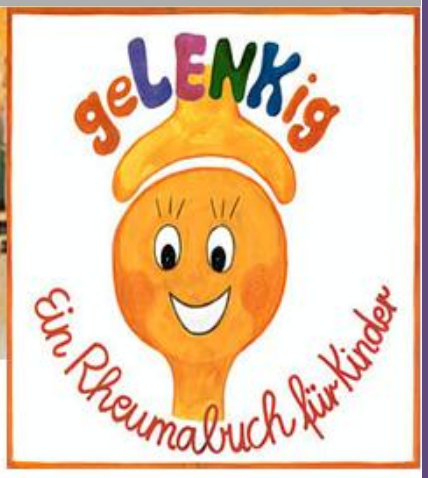
INVOLVEMENT OF YOUNG PATIENTS SUFFERING FROM JUVENILE IDIOPATHIC ARTHRITIS IN DECISION-MAKING PROCESSES REFERRING TO THEIR DISEASE



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Contents

Samenvatting

Titel: Participatie van jonge patiënten met juvenile idiopatische arthritis (JIA) bij beslissingen ten opzichte van hun ziekte.

Doel: Deze studie bestudeert de waarnemingen en preferenties van jonge patiënten met juvenile idiopathische arthritis en mogelijke beïnvloedende factoren (leeftijd, geslacht, hevigheid van de ziekte, vaardigheden in shared decision-making (SDM)) ten opzichte van participatie bij medische beslissingen om de beslissingsproces in de pediatrisch medische zorg te verbeteren.

Methode: 58 patiënten van de pediatrisch rheumatologische afdeling van de St. Josef-Stift Sendenhorst werden gevraagd (52 participeerden) om een vragenlijst in te vullen. Deze vragenlijst bestaat uit vragen over demografische gegevens en aanpassingen van bestaande versies van de Controle Preference Scale (CPS), de Decision-Making Involvement Scale (DMIS), de Perceived Efficacy in Patient-Physician Interactions (PEPPI) scale en de Childhood Health Assessment Questionnaire (CHAQ).

Resultaten: Wat patiënten prefereren en ervaren blijkt niet sterk van elkaar te verschillen. Dit komt overeen met het feit dat 85% van de ondervraagde patiënten tevreden of erg tevreden is met de manier waarop beslissingen worden genomen. Verder werden er geen significante verschillen gevonden met betrekking tot de vier mogelijk beïnvloedende factoren. De p-waarden van een X^2 test gaan van 0.087 tot 0.861. De resultaten voor communicatie met ouders was gemiddeld 2.85 (SD=0.64) en met de reumatoloog 2.78 (SD=0.63) op een schaal van 0 tot 4. Met een one-way ANOVA een correlatie tussen de resultaten van de PEPPI en alle subschalen van de DMIS werd gevonden met $3.299 \leq F \leq 18.172$ (df=1) en $p<0.045$. Dus, hoe hoger de vaardigheden in shared decision-making hoe meer participatie in decision-making (DM).

Conclusie: Hoewel er kleine verschillen bestaan tussen de groepen van leeftijd, geslacht, hevigheid van ziekte en vaardigheden in shared decision-making is de algemene tevredenheid onder de jonge patiënten met juvenile idiopathic arthritis erg hoog. De mate van participatie wordt in vergelijking onder de vier mogelijk beïnvloedende factoren voornamelijk bepaald door de vaardigheden in shared decision-making.

Abstract

Title: Involvement of young patients suffering from juvenile idiopathic arthritis (JIA) in decision-making processes referring to their disease.

Objective: This study examines the perceptions and preferences of young patients with juvenile idiopathic arthritis and possible influencing factors (age, gender, severity of disease, skills in shared decision-making (SDM)) referring to the involvement in medical decision-making (DM) to improve the process of decision-making in pediatric medical care.

Method: 58 patients of the pediatric rheumatology section of the St. Josef-Stift Sendenhorst were invited (52 took part) to complete a questionnaire. This questionnaire consists of demographic questions and adaptations of existing versions of the Control Preference Scale (CPS), the Decision-Making Involvement Scale (DMIS), the Perceived Efficacy in Patient-Physician Interactions (PEPPI) scale and the Childhood Health Assessment Questionnaire (CHAQ).

Results: Patients' preference and perception do not seem to differ significantly. This is consistent with the fact that 85% of the questioned patients are satisfied or very satisfied with the way of decision-making. Furthermore no significant differences were found referring to the four possibly influencing factors. The p-values of a X^2 test range from 0.087 to 0.861. The results for communication with parents was 2.85 (SD=0.064) on average and with 2.78 (SD=0.63) the rheumatologist on a scale from 0 to 4. With a one-way ANOVA a relationship between the results of the PEPPI and all subscales of the DMIS was found with $3.299 \leq F \leq 18.172$ (df=1) and $p<0.045$. So the better the skills in shared decision-making, the more involvement.

Conclusion: Although small differences were found between the groups of age, gender, severity of disease and skills in shared decision-making, the overall satisfaction of the young patients is very high. The amount of participation in comparison of the four possibly influencing factors is mainly determined by skills in shared decision-making.

Introduction

Juvenile idiopathic arthritis

Arthritis is a dysfunction of the body's immune system. The immune system of a patient is overactive and acts against body's own tissues, which leads to swelling and/or stiffness of the joints and fevers during an active phase of the disease (Guell, 2007; Tong, Jones, Craig, & Singh-Grewal, 2012). Referring to rheumatism or arthritis people mostly think of elderly people suffering from this disease (Guell, 2007). In reality young patients are also diagnosed with arthritis. Juvenile idiopathic arthritis is a collective name for seven categories of arthritis. It is diagnosed when the symptoms emerge before the age of 16 and persist for at least six weeks and the etiology has to be unknown (Ravelli & Martini, 2007).

Juvenile idiopathic arthritis is the most present chronically inflammable rheumatic disease in infancy with an incidence of 10 out of 100.000 children (Ganser, 2012). The prevalence in girls is higher than among boys: 60% of the children diagnosed with juvenile idiopathic arthritis are girls (Östlie, Dale, & Möller, 2007). In 50% of cases, the disease persists throughout adulthood (Davidson, 2000).

Besides the physical symptoms juvenile idiopathic arthritis brings difficulties on the social and psychological domain (Guell, 2007; Tong, et al., 2012). Inflamed joints transform normal activities like walking or writing into difficult ones, which can affect a patient's everyday life to an enormous extent (Guell, 2007). In addition, patients are responsible for the intake of their medicine at the right time and their blood has to be controlled on a regular basis. The patients might often be more controlled by their parents, because they are worried and want to protect their children from their illness. Furthermore juvenile idiopathic arthritis patients have to be much more organized and responsible. They have to organize their normal life and all the visits at the clinic or their rheumatologist. As they are often hindered to take part in normal activities at school or in their free time they have to think about alternatives early (Guell, 2007). They often depend on another person's help and may be discriminated by unknowing others (Tong, et al., 2012). Another great problem is that the main symptom of juvenile idiopathic arthritis is pain, which cannot be seen or experienced by others, which leads to difficulties in understanding patients' problems (Guell, 2007; Stinson et al., 2008; Tong, et al., 2012).

Treatment

Treatment of juvenile idiopathic arthritis is aimed at controlling the disease because a cure is still not available (Ravelli & Martini, 2007). The main part of the treatment focuses on medication. In general there are three main groups of medication against the symptoms of juvenile idiopathic arthritis. The first group consists of the non-steroidal anti-inflammatory drugs (NSAIDs) like Naproxen, Ibuprofen or Indometacin. Treating children with juvenile idiopathic arthritis usually starts with these drugs. They have a rapid effect on local inflammations and are well-tolerated (Ravelli & Martini, 2007). The second group includes basis anti-rheumatics or Disease Modifying Antirheumatic Drugs (DMARDs), such as cortisone supplements. In 2003, the oral intake of small doses of cortisone formed the main medication in combination with intra-articular injections in acute phases of the disease (Woo, 2003). Glucocorticoids are hormones which are naturally produced in the body. They are dumped in case of inflammation because they suppress the activity of different compounds of the human immune system (Martini, 2009). The other substances, such as Methotrexate, Sulfasalazine, Azathioptine and Cyclosporin A are long-term drugs which reduce the reaction attendance of the immune system (Woo, 2003). The third and newest group of medication against juvenile idiopathic arthritis are the so called “biologicals” or “biological DMARDs”. These substances also influence the immune system but they are more specific than the basis rheumatics because they focus on one specific inflammation compound (Woo, 2003).

For patients with rheumatic diseases, choosing for a specific treatment is a complicated decision. The patients have to consider which medication is the best to choose, which adverse effects can be tolerated and also what alternative treatments are available etc. One patient out of the population of the study by Goodacre (2004) stated that he made a decision for a specific treatment to beware the quality of life. Another patient said “It is all toxic, no matter how good or how much it helps there is always a price for it.” (Goodacre, 2004). All anti-rheumatics have significant adverse effects (Woo, 2003), causing patients’ reluctance. In 2004, 29 participants (28-71 years) of the study performed by Goodacre (2004) were diagnosed with rheumatoid arthritis. Using in-depth interviews, activity diaries and focus groups the study revealed that all participants thought that the intake of medication should be minimized. This was because of their adverse effects and also because especially long-term medication was associated with ‘reliance’ and ‘dependence’ (Goodacre, 2004). Yet, in most cases the disease cannot be controlled without medication. Reluctance and misunderstandings about DMARDs were also found by Mahmud et al. (1995), who conducted

a study among 100 patients (mean age 61 years) with rheumatoid arthritis and/or osteoarthritis investigating patient's knowledge. They found that around 66% of patients did not have sufficient knowledge about the main adverse effects of their medication. Another study by Berry, Bradlow & Bersellini (2004) among 81 patients (between 18 and 81 years) with rheumatoid arthritis and other painful musculoskeletal conditions revealed that the main risk patients perceive are the adverse effects of their medical treatment. This indicates that all patients with rheumatoid arthritis or other chronic diseases have difficult decisions to make, referring to their medical treatment. And most of them are not prepared enough to make these decisions (Stinson, et al., 2008).

One can easily imagine that this process of decision-making could be even more difficult in pediatrics. A study by Stinson et al. 2008 among 36 adolescents (13-17 years) about the needs of adolescents to self-manage their disease showed that young patients have different worries referring to adverse effects than adults. One is the gain in weight while taking cortisone. Another one is that young patients are still in the process of learning to self-manage their disease and often do not have full knowledge (Stinson, et al., 2008) since the interaction mainly occurs between the patients' parents and the physician (Beresford & Sloper, 2003). Obviously the decision-making process in medical care is complicated and differs with the age of the patient.

Decision-making in medical care

There are three main models of decision-making in medical care. One of them is the "paternalistic model", which states that the physician makes the medical decision based on his/her knowledge. Another model is the "informed decision-making model". In case of this model the patient should be informed well to be able to make a decision on his/her own. The third model is a kind of a combination of the first two models. It is called "shared decision-making". In this model both the patient and physician provide relevant information and their preferences. Thus, the decision is made in cooperation (Knopf, Hornung, Slap, DeVellis, & Britto, 2008). There is no official definition of shared decision-making but Charles et al. (1997) tried to identify some characteristics. These are as follows (Charles, 1997):

- Shared decision-making involves at least two participants – the physician and patient
- Both parties (physicians and patients) take steps to participate in the process of treatment decision-making

- Information sharing is a prerequisite to shared decision-making
- A treatment decision is made and both parties agree to the decision

Shared decision-making usually takes place between the concerned person and the physician. Several studies show significant advantages of shared decision-making. In a study by Mahler et al. (1990), patients who had a coronary-bypass operation and perceived more control and behavioral involvement, experienced less emotional distress before and after the surgery. This was associated with an earlier hospital discharge. In general they found that if the patients took an active role in their medical care their health outcomes were influenced positively. Similar to these findings Brody et al. (1989) showed that a more active role of the patients is associated with increased satisfaction, greater improvement of the health situation, greater disease control, a better quality of life, and a better relationship with their physician.

In rheumatology, patients want to receive more information about their disease and the available alternatives of action, such as different medications (Neame, Hammond, & Deighton, 2005; Schildmann, Grunke, Kalden, & Vollmann, 2008). Referring to Östlie et al. (2007) and Stinson et al. (2008) especially younger patients express a great need for information in order to develop autonomy in decision-making. As Martin et al. (2008) mentioned, several studies concluded that supporting the patients' autonomy has a positive influence on their motivation and their health behavior. This especially applies for medication adherence. According to these findings the paternalistic model does not seem to be an optimal way of decision-making in medical care.

The disadvantage of the informed decision-making model is that not all adolescent patients with chronic illnesses prefer to make decisions on their own (Knopf, et al., 2008). Another problem is that physicians sometimes provide more information about the treatment alternative they prefer for their patients. "Finally, it could be argued that an autonomous decision is not one that is based on descriptive information only, but is one that has been made also in the light of interpretation and value judgments of other persons." (Schildmann, et al., 2008). According to these findings, shared decision-making seems to be the best option to gather a decision which will be accepted by all participating parties.

Until today little attention was paid to the actual conditions of decision-making in pediatric medical care. Often parents are the link between the physician and the adolescent patient, which increases the complexity of the process of decision-making (Stinson, et al.,

2008). It is known that there is a significant difference if the concerned person is a child/adolescent or an adult person.

Since especially younger adults (>18) who are diagnosed with rheumatoid arthritis have a greater need for information, adolescent patients presumingly also have a great need for information in medical decision-making (Neame, et al., 2005). They also prefer a more active way of behavior in decision-making (Knopf, et al., 2008). In case of young patients (<18) a third party also has to be considered. As legal guardians the parents officially have the right and the responsibility to make decisions concerning the treatment of their child. So shared decision-making in pediatric medical care becomes more complicated. In many cases, parents of chronically ill young patients prefer less involvement of their child than the child itself (Knopf, et al., 2008). Regarding this, young patients are often excluded from the interaction between their parents and their physician (Beresford & Sloper, 2003).

To develop autonomy and responsibility for life with a chronic disease it is important to be involved in decision-making processes concerning the disease, especially for young patients (Östlie, et al., 2007). Early involvement prepares the patients for the future when they will have to cope with their illness without their parents. In addition, participation in decision-making is helpful when young patients undergo painful procedures during the treatment (Runeson, Hallström, Elander, & Hermerén, 2002).

Parents of patients with juvenile idiopathic arthritis act very different referring to the participation of their children in medical decision-making. Some accept a great degree of participation of their child and others want to protect their “poor little child” by excluding it from any process of decision-making. But the patients themselves also have different preferences depending on the relation between them and their parents (Östlie, et al., 2007). The physicians of a study by Guell (2007) about children living with juvenile idiopathic arthritis stated that it is important to teach the parents of patients to let their children participate in the decision-making processes regarding their disease. Treatment of chronically ill children can only be really successful with autonomous participation of the patients themselves in decision-making and therefore they have to be taken seriously (Guell, 2007; Runeson, et al., 2002).

Several studies showed that the desired degree of participation varies among patients (Knopf, et al., 2008; Neame, et al., 2005) and it is already known that the expectations and

desires of patients referring to the medical decision-making process differ depending on age, gender and level of education (Neame, et al., 2005).

Studies about patient satisfaction and preferences in decision-making in medical care are almost exclusively performed among adults (Neame, et al., 2005; Shaw, Southwood, & McDonagh, 2007). Focusing on shared decision-making in pediatric care it becomes more difficult because of the involvement of three parties with different preferences and desires (Charles, 1997). Therefore, the majority of the existing literature referring to shared decision-making in medical care also focuses on adults. Furthermore it is still fact in pediatric care that the communication between the physician and the patient's parents receives the most attention (Beresford & Sloper, 2003). Until today there is still controversy about the issue at what age a child is identified as "competent". It can be stated that most children are competent enough to take part in decision-making processes at some level (King, 1989). Overall, the method of shared decision-making provides the best conditions in order to make decisions in favor of the patient. But the preferences of all three parties concerned have to be considered in each single case.

Aim of the study

This study examines the perceptions and preferences of young patients with juvenile idiopathic arthritis referring to medical decision-making. Special attention was paid to the involvement of three participating parties in all decision-making processes in pediatric medical care. Thus, the first research question is as follows:

1) What role do children with arthritis prefer and perceive in medical decision-making?

It is hypothesized that there is a difference between the preferences and the perceptions of young patients referring to the decision-making process in their medical care. Through the second research question this study determined the actual conditions under which medical decisions are made in the pediatric medical care:

2) How does the decision-making actually takes place?

Additionally this study examines the different factors age, gender, severity of disease and skills of shared decision-making in correlation to their preferences and perceptions in medical decision-making. Hypothetically these factors may have an impact on the preferred and perceived role of young patients. This leads to the third research questions of the study:

3) Which factors can predict the preferred and perceived role?
    - Age
    - Gender
    - Severity of disease
    - Skills of shared decision-making

If the preferred role children and adolescents would like to play in the decision-making process differs from the perceived role and the actual conditions it could be helpful to change the process for more satisfaction among the patients themselves. And if we managed to increase our knowledge how the patients would like to be involved in the process and which factors are the influencing ones, the process of decision-making in medical care could be improved for young patients. The first research question aimed to examine these differences. If physicians and parents know to what extent the patient wants to be involved they may act accordingly to this. As mentioned before, the treatment of children or adolescents with a chronic illness is only successful if they are taken seriously and as autonomous persons with a right to take part in important decisions which affect their disease (Guell, 2007; Runeson, et al., 2002).

Materials & Methods

Participants

Participants were young patients with arthritis. All patients were in treatment at the St. Josef-Stift Sendenhorst, a clinic for rheumatology in Germany. The clinic has one of the two greatest sections for children and adolescents diagnosed with arthritis in the country. Inclusion criteria for participation were a diagnosis of juvenile idiopathic arthritis, achieving treatment at the pediatric and youth rheumatology section of the clinic and an age of nine years or older because completing the questionnaire required a certain level of reading and comprehension skills. In total, 52 patients were included while 58 had been invited to take part in this study (response rate: 89.66%).

Procedure

During a period of about five weeks (25.10.-30.11.2012) all patients of the pediatric and youth rheumatology section of the St. Josef-Stift Sendenhorst meeting the inclusion criteria, were invited to complete the questionnaire. Since, most of the patients were under the age of 18, informed consent had to be received from the parents. During the childrens' hospital stay parents lived in an facility nearby so they could be contacted personally. Other parents were contacted when they visited their children or at the day of discharge. All parents who were contacted agreed with their child's participation.

For the study patients were recruited in different ways. Patients older than 13 years were invited after a seminar called "occupational orientation", which took place every Monday. At the end of every seminar, the researcher presented the study and invited the patients to take part on one of the following days. For patients younger than 13 years there was a relaxation session, provided by the psychologist of the clinic every Monday afternoon. These sessions were used to inform and invite younger patients to participate in the study. Patients who did not take part in one of these two group sessions but met the inclusion criteria were contacted directly and were invited personally.

The questioning took place in a room provided by the clinic, close to the pediatric and youth rheumatology section. The patients came alone or in small groups of two to four. Before starting the questionnaire, the researcher explained that all data would be treated anonymously and that the participation could be terminated at any time. Furthermore they received an explanation of the goal of the study. After the introduction, participants of 14 years or older completed the questionnaire on their own while the researcher was around to

answer any possible questions. While supporting the younger participants (<13 years) the researcher took care not to influence them in any way but just help to understand the questions.

To include more patients than only the in-patients, the researcher also visited the out-patient clinic of the youth rheumatology and proposed to those meeting the inclusion criteria to complete the questionnaire during their waiting period. In these cases the parents were present and could be asked for their agreement directly. All parents agreed with their childrens' participation. After completing the questionnaire (which took about 25 to 30 minutes) each participant received a little piece of chocolate as a thank-you gift.

Instruments

The questionnaire included different validated instruments. Each of the seven scales will be described in the following section. A complete version of the applied questionnaire can be found in the appendix. The questionnaire is written in German because the survey was carried out in Germany. Since most originals of the scales used to construct this scale are in English and it was difficult to receive the German versions, the method of 'back translation' was used to validate the German translation. Applying this method, the original questionnaire is translated into the desired language which is translated back into the original language. This translation is then compared with the original to assess the quality of the translation (Harkness, 1998).

Demographics

With the first scale, consisting of seven questions, patient characteristics were collected. The variables included age, gender, education, the precise diagnosis of juvenile idiopathic arthritis and the age at which the diagnosis was made.

Control Preference Scale

Preferred involvement in the decision-making process about medication was measured with two modified versions of the Control Preference Scale (CPS) (Garfield, Smith, Francis, & Chalmers, 2007). Garfield et al. (2007) conducted an investigation on the dependent variable "Preferences for involvement in the decision-making about medicines." As they mentioned, the CPS had been validated in two previous studies among cancer patients.

The original scale used by Garfield et al. (2007) consisted of three items (questions about who should make a decision regarding the patient's medication) with a five-point

answer scale. The possibilities to answer were as follows: 1) You alone 2) Mostly you 3) Doctor (or other healthcare professional) and you equally 4) Mostly the doctor (or other healthcare professional) 5) Doctor (or other healthcare professional) alone.

To compare the preferences and the perceptions of young patients with juvenile idiopathic arthritis facing decisions about their medicine, two versions of the CPS were designed. For both versions, the CPS was translated into German applying 'back translation' (Harkness, 1998). The answer possibilities given were adapted in order to fit the model of shared decision-making in pediatric care, where the patient itself, the parents and the physician are concerned in the process. The participants could choose one out of seven options of who should make a certain decision [1) You alone 2) Your parents alone 3) You together with your parents 4) You together with your parents and your doctor 5) You and your doctor together 6) Your parents and your doctor together 7) Your doctor alone]. Furthermore each of the answering possibilities were combined with a little picture combination to support the participant's comprehension. To simplify the comparison between perceived and preferred role the answers indicating the involvement of the patient were taken together in the analysis as well as these not indicating a patients' involvement. Answers were coded into "involved" [1) You alone 3) You together with your parents 4) You together with your parents and your doctor 5) You and your doctor together] and "not involved" [2) Your parents alone 6) Your parents and your doctor together 7) Your doctor alone].

To find out about the young patients' preferences, the "CPS-Preferred" (Cronbach's $\alpha = 0.707$) was designed. This short scale consisted of three items. These items were the translated ones of the CPS used by Garfield et al. (2007), with the adapted answer possibilities described above. The second modified version of the CPS, the "CPS-Perceived" (Cronbach's $\alpha = 0.874$), was used to investigate the circumstances for shared decision-making that the patients actually perceive. In total this scale consisted of seven items. The three main questions were redrafted so that they referred to the last decision the patient had to make. The answer possibilities for these questions remained the same as in the CPS-Preferred version. Taken into account that such a decision possibly did not occur previously, this was asked before each main question. If this question was answered "No," the patient had to skip the following question. The last item referred to the patients' general satisfaction considering decision-making in their medical care. The answer possibilities for this item ranged from "I am absolutely satisfied" to "I am not satisfied at all" on a five-point scale.

Decision-Making Involvement Scale

In order to receive a more objective insight into the actual conditions of the shared decision-making processes, two versions of the Decision-Making Involvement Scale (DMIS) were used. They were adapted on the basis of the version used by Miller and Harris (2011). In both versions which were used in this study the statements, on which the participant had to react, were drafted from the patients' perspective. One version took into account the patients' involvement referring to the parents (Cronbach's $\alpha = 0.906$), the second version referring to the physician (Cronbach's $\alpha = 0.910$). Both versions contained 30 items with the answering possibilities "No", "A little bit", "Yes" and "Absolutely" for each. The items 2, 7, 13, 18, 22, 25, 30 were filler items to avoid socially desirable answering, and were not included in the analysis. The other items were assigned to one of four subgroups of items. These subgroups were "Child express" (items: 21, 23, 29), "Child seek" (items: 24, 26, 27, 28), "Parent/Physician express" (items: 8, 10, 11, 12, 20), "Parent/Physician seek" (items: 14, 15, 16, 17, 19) and "Joint/Options" (items: 1, 3, 4, 5, 6, 9). The internal consistency of the subgroups of both DMIS scales ranged from 0.577 to 0.814 with values for Cronbach's α under 0.6 for only two subgroups. To interpret results, the means of the scores from each subgroup were calculated. A higher score indicated a greater involvement of the patient in the decision-making process.

Perceived Efficacy in Patient-Physician Interaction

The Perceived Efficacy in Patient-Physician Interaction (PEPPI) (ten Klooster et al., 2012) was applied to measure the patients' competence to obtain medical information from the physician and to comprehend what he/she provided. The original version contained 10 items. The version applied for this study also contained these ten items translated, following the back translation procedure (Harkness, 1998), from the Dutch version into German. The applied version showed a high reliability index (Cronbach's $\alpha = 0.93$). To fit the comprehension level of the younger patients each of the items began with "I think that…". For each item the patients had five possibilities to answer ranging from "I do absolutely not agree" to "I absolutely agree".

The greater the accordance of the patient with the statement of each item, the higher the score for this item. For the analysis the scores of each item were summed up, higher scores indicating a greater competence in obtaining and comprehension of medical information.

Childhood Health Assessment Questionnaire

The Childhood Health Assessment Questionnaire (CHAQ) is an instrument developed to investigate the physical function of children with arthritis (Huber, 2001). The original version of the CHAQ is a parent or self-report questionnaire. In this study it was used as a self-report questionnaire to receive insight into the patients' perceptions. The used questionnaire included 30 items measuring the physical function of the patients in the following eight domains: dressing and grooming, arising, eating, walking, hygiene, reach, grip and activities. The overall Cronbach's α for all eight domains was 0.968, once more indicating a high reliability index. The answering possibilities ranged from "I am able to do this without any difficulty" (score 0) to "I am unable to do this" (score 3). In case the child was not able to carry out the action mentioned in the item because of any other reason than the illness, this was a fourth answering possibility.

The highest score of each domain formed the final score for this domain. Four additional items asked for any aids the patients may need in their daily life. If a patient needed help from another person or any aid, the score in the respective domain was at least 2. The average score of the eight domains formed the final score of the CHAQ. "0" accounted for "no or minimal physical dysfunction" where as "3" indicated "very severe physical dysfunction" (Huber, 2001). Additionally, the CHAQ contained two visual analogue scales (ranging from 0 to 100) to assess the pain level and the level of overall well-being (Foeldvari, 2001).

Reliability

To control the reliability of the questionnaire Cronbach's α was calculated for each subscale (Table 1). The values for Cronbach's α ranged from 0.573 to 0.971, for the translated version of the CHAQ, with only one value under 0.6 for the subscale "arising" (α = 0.573). The first part of the CPS regarding the patients' preferences achieved 0.577 and the second part (regarding the patient's perceptions in decision-making) achieved 0.748 (this score was estimated only with the items about decision-making the other items were irrelevant for the analysis since they only asked if such a decision had previously been made). The PEPPI-scale indicated a Cronbach's α of 0.920. Similar to this score the two DMIS (the one for patient-parent and the other one for patient-physician interaction) achieved 0.922 and 0.904.

Table 1: Scale Statistics

Scale / Subscale	Chronbach's α	# items	min	max	range
Physical impairment: Childhood Health Assessment Questionnaire					
CHAQ	0.968	30	0	3	(0-3)
Dressing & Grooming	0.804	4	0	2	(0-3)
Arising	0.573	2	0	2	(0-3)
Eating	0.703	3	0	3	(0-3)
Walking	0.655	2	0	2	(0-3)
Hygiene	0.858	5	0	2	(0-3)
Reach	0.811	4	0	3	(0-3)
Grip	0.971	5	0	3	(0-3)
Activities	0.842	5	0	3	(0-3)
Personal factor: Perceived Efficacy in Patient-Physician Interaction					
PEPPI	0.928	10	1	5	(1-5)
Control preferences and perceptions					
CPS-Preferred	0.707	3	0	1	(0-1)
CPS-Perceived	0.874	3	0	1	(0-1)
Conditions for involvement: Decision-Making Involvement Scale					
DMIS – Parents	0.906	30	1	4	(1-4)
Child express	0.743	3	1	4	(1-4)
Child seek	0.770	4	1	4	(1-4)
Parent express	0.769	5	1	4	(1-4)
Parent seek	0.814	5	1	4	(1-4)
Joint / Options	0.577	6	2	4	(1-4)
DMIS – Physician	0.910	30	1	4	(1-4)
Child express	0.599	3	1	4	(1-4)
Child seek	0.755	4	1	4	(1-4)
Physician express	0.733	5	1	4	(1-4)
Physician seek	0.761	5	1	4	(1-4)
Joint / Options	0.681	6	2	4	(1-4)

Data-analysis

Statistical evaluation was carried out using IBM SPSS Statistics Data Editor 20. The reliability of the different instruments was investigated with a simple reliability analysis. To describe means and frequencies of the demographic data and the disease related characteristics, descriptive statistics were used. To calculate the amount of participation, the recoded scores (1 = involved, 0 = not involved) of the CPS-Perceived were subtracted from the recoded scores of the CPS-Preferred (concordance). To check whether a correlation between the concordance of the CPS scales and the possibly influencing factors existed, a

Pearson X^2 test was made. To indicate smaller, not significant differences, crosstabs were used to present the results of the CPS scales in relation to the possibly influencing factors age, gender, severity of disease (CHAQ) and skills in shared decision-making (PEPPI). The mean scores and standard deviations on the subscales of the DMIS were also estimated by using descriptive statistics (frequencies). A one-way ANOVA for the two DMIS scales by age, gender, severity of disease (CHAQ) and skills in shared decision-making (PEPPI) was used to check for a relationship between the results of the DMIS and one or more of the four possibly influencing factors.

The tables which can be found in the appendix emerged once more by using descriptive statistics.

Results

Population characteristics

Tables 2 and 3 present the questioned characteristics of the study's population. Mean age of the patients was 13.98 years with a standard deviation of 2.524 years. Overall, the population is a heterogeneous group in various aspects. The age of participants ranges from 9 to 20 years, spreading widely. Furthermore the population included in- and out-patients, male and female patients and different diagnoses of juvenile idiopathic arthritis.

Table 2: Demographics (n=52)

Characteristic	mean	SD	n	%
Setting				
out-patients			18	34.6
in-patients			34	65.4
Age, mean ± SD	14.0	2.5		
Age group				
9-13 years			23	44.2
14-20 years			29	55.8
Sex				
Male			16	30.8
Female			36	69.2
Sibblings, mean ± SD	1.2	1.1		
Education				
Grundschule			1	1.9
Hauptschule			4	7.7
Realschule			15	28.8
Gymnasium			18	34.6
Other			14	26.9

Most patients were suffering from polyarthritis with a negative rheumatism factor, or they stated that they suffered from another form of arthritis, not mentioned as an answer possibility. Actually, 13 participants had no idea of their precise diagnosis. In most cases they chose the answer possibility "Another, namely: …" and wrote "rheuma" or "juvenile idiopathic arthritis". This could be interpreted as an indication that the patients are not really involved in the medical considerations referring to their illness. More than half of the patients stated that they never went to see their rheumatologist alone. One out of 4 said that he/she take somebody in most cases. This also indicates that in the majority of cases, a third person besides the physician and the patient is involved in the processes of illness management.

Table 3: Disease related characteristics (n=52)

Characteristic	mean	SD	n	%
Diagnose age	8.8	5.0		
Years since diagnose	5.2	4.3		
Diagnose				
Systemic juvenile idiopathic arthritis			4	7.7
Polyarthritis (RF pos)			5	9.6
Polyarthritis (RF neg)			14	26.9
Enthesitis related arthritis			2	3.8
Psoriatic arthritis			2	3.8
Other			12	23.1
No knowledge of precise diagnosis			13	25
Companion				
Yes, always.			31	59.6
Yes, usually.			13	25
Sometimes.			6	11.5
Rarely.			2	3.8
No, never.			-	-

Findings about the preferred and perceived involvement

The amount of participation in the three decisions considered in the CPS scales is presented in Table 4. The table shows the results in general, without consideration of differences between different groups. As you can see, there was a difference between the patients' preference and perception regarding their medical decision-making. In accordance with the initial hypothesis the patients who were not involved as much as wanted mostly experienced insufficient involvement (12%-20%). The majority of the children was involved as much as they wanted to be (78%-88%). A more detailed table of the frequencies and percentages per answer for each decision of the CPS-Preferred and the CPS-Perceived can be found in the appendix (Table A).

Table 4: Amount of participation (n = 52)

	too much (-1)		as wanted (0)		too little (+1)		n
	n	%	n	%	n	%	
Decision 1: Change of medicine.	1	2	35	78	9	20	45
Decision 2: Change of dosage.	-	-	37	88	5	12	42
Decision 3: Stopping with medicine.	1	3	31	84	5	13	37

* Differences in number of patients is caused by the fact that not all patients could give an answer to all questions of the CPS-Perceived because they may not have had to make such a decision yet.

To review whether there was a correlation between the amount of participation and the four possibly influencing factors, a Pearson X^2 test was implemented. The results are presented in Table 5. No significant correlation was found, most likely due to the small sample size.

Table 5: Pearson X^2 test for the concordance of the CPS – Preferred and the CPS – Perceived in relation to age, gender, severity of disease and skills in shared decision-making.

	Age group		**Gender**		**Severity of disease (CHAQ)**		**Skills in SDM (PEPPI)**	
	X^2	p	X^2	p	X^2	p	X^2	p
Concordance Decision 1: Change of medicine.	1.347	0.510	2.720	0.257	11.048	0.087	2.493	0.646
Concordance Decision 2: Change of dosage	0.499	0.480	0.560	0.454	1.220	0.748	0.299	0.861
Concordance Decision 3: Stopping with medicine.	0.830	0.660	2.329	0.312	7.250	0.298	3.779	0.437

* no significant value

However, revising these results more precisely, some differences could be noticed.

Comparing the two age groups 9-13 years and 14-20 years referring to the preferences and perceptions in decision-making also revealed some differences. Most patients would like to be involved in decisions referring to the treatment of their illness. Comparing the results, the desired involvement in the younger age group was less than in the older age group. Nearly all patients of the older age group wanted to be involved in decision-making. Fewer patients really perceived the desired involvement in both age groups.

Table 6: Distribution of age by preference for and perception of participation in decision-making (prefers to be involved vs. not to be involved) (n=52)

	Preferred					**Perceived**				
	Age 9-13		Age 14-20			Age 9-13		Age 14-20		
	n	%	n	%		n	%	n	%	
Decision 1: Change of medicine.										
involved	19	82.6	29	100	n = 48	13	59.1	20	87.0	n = 33
not involved	4	17.4	0	0	n = 4	9	40.9	3	13.0	n = 12
Decision 2: Change of dosage.										
involved	18	78.3	28	96.6	n = 46	11	57.9	21	91.3	n = 32
not involved	5	21.7	1	3.4	n = 6	8	42.1	2	8.7	n = 10
Decision 3: Stopping with medicine.										
involved	17	73.9	29	100	n = 46	13	65.0	16	94.1	n = 29
not involved	6	26.1	0	0	n = 6	7	35.0	1	5.9	n = 8

Comparing male and female patients, the female patients showed a higher desire to be involved in the decision-making processes than their male counterparts. Looking at the involvement the patients actually perceived in decision-making, the female patients were more involved than the male patients.

Table 7: Distribution of gender by preference for and perception of participation in decision-making (prefers to be involved vs. not to be involved) (n=52)

	Preferred					**Perceived**				
	Male		Female			Male		female		
	n	%	n	%		n	%	n	%	
Decision 1: Change of medicine.										
involved	14	87.5	34	94.9	n = 48	9	64.3	24	77.4	n = 33
not involved	2	12.5	2	5.6	n = 4	5	35.7	7	22.6	n = 12
Decision 2: Change of dosage.										
involved	13	81.3	33	91.7	n = 46	6	54.5	26	83.9	n = 32
not involved	3	18.7	3	8.3	n = 6	5	45.5	5	16.1	n = 10
Decision 3: Stopping with medicine.										
involved	12	75.0	34	94.47	n = 46	10	76.9	19	79.2	n = 29
not involved	4	25.0	2	5.6	n = 6	3	23.1	5	20.8	n = 8

At all levels of severity of disease the majority of patients preferred to be involved in the decision-making process. Only two of the questioned patients provided a level of 2-3 on the CHAQ, so there was no real difference between “involved” and “not involved” on the CPS-Preferred. The results are similar to those of the CPS-Perceived, but especially the patients with a relatively low level on the CHAQ for severity of disease (0.1-1) seemed to perceive less involvement than they preferred.

Table 8: Distribution of illness related factor (CHAQ) by preference for participation in decision-making (prefers to be involved vs. not to be involved) (n=52)

		Preferred							
		CHAQ 0		CHAQ 0.1-1		CHAQ 1.1-2		CHAQ 2.1-3	
		n	%	n	%	n	%	n	%
Decision 1: Change of medicine.									
involved	n = 47	6	85.7	29	93.5	10	90.9	2	100
not involved	n = 4	1	14.3	2	6.5	1	9.1	0	0
Decision 2: Change of dosage.									
involved	n = 45	7	100	27	87.1	10	90.9	1	50
not involved	n = 6	0	0	4	12.9	1	9.1	1	50
Decision 3: Stopping with medicine.									
involved	n = 45	6	85.7	27	87.1	11	100	1	50
not involved	n = 6	1	14.3	4	12.9	0	0	1	50

Table 9: Distribution of illness related factor (CHAQ) by perception of participation in decision-making (prefers to be involved vs. not to be involved) (n=52)

		Perceived							
		CHAQ 0		CHAQ 0.1-1		CHAQ 1.1-2		CHAQ 2.1-3	
		n	%	n	%	n	%	n	%
Decision 1: Change of medicine.									
involved	n = 33	5	100	18	66.7	9	90.0	1	50
not involved	n = 11	0	0	9	33.3	1	10.0	1	50
Decision 2: Change of dosage.									
involved	n = 32	5	100	19	73.1	7	87.5	1	50
not involved	n = 9	0	0	7	26.9	1	12.5	1	50
Decision 3: Stopping with medicine.									
involved	n = 29	5	83.3	16	76.2	8	88.9	0	0
not involved	n = 8	1	16.7	5	23.8	1	11.1	1	100

The patients who scored very low on the PEPPI (0-20) did not seem to prefer involvement in decision-making but there were only two patients with such a low level of skills in shared decision-making. Moderate (21-40) and high (41-50) levels of skills in shared decision-making indicated a higher percentage of patients who wanted to be involved. Similar results were found in the comparison between the CPS-Perceived and the level of skills in shared decision-making.

Table 10: Distribution of person related factor (PEPPI) by preference for participation in decision-making (prefers to be involved vs. not to be involved) (n=52)

		Preferred					
		PEPPI 0-20		PEPPI 21-40		PEPPI 41-50	
		n	%	n	%	n	%
Decision 1: Change of medicine.							
involved	n = 33	0	0	22	85.7	26	96.3
not involved	n = 11	2	100	1	4.3	1	3.7
Decision 2: Change of dosage.							
involved	n = 32	0	0	20	87.0	26	96.3
not involved	n = 9	2	100	3	13.0	1	3.7
Decision 3: Stopping with medicine.							
involved	n = 29	1	50	20	87.0	25	92.6
not involved	n = 8	1	50	3	13.0	2	7.4

Table 11: Distribution of person related factor (PEPPI) by perception of participation in decision-making (prefers to be involved vs. not to be involved) (n=52)

		Perceived					
		PEPPI 0-20		PEPPI 21-40		PEPPI 41-50	
		n	%	n	%	n	%
Decision 1: Change of medicine.							
involved	n = 33	0	0	14	73.7	19	79.2
not involved	n = 11	2	100	5	26.3	5	20.8
Decision 2: Change of dosage.							
involved	n = 32	0	0	11	64.7	21	87.5
not involved	n = 9	1	100	6	35.3	3	12.5
Decision 3: Stopping with medicine.							
involved	n = 29	0	0	13	86.7	16	80.0
not involved	n = 8	2	100	2	13.3	4	20.0

Findings about the actual conditions of involvement

The actual patients' involvement was not exclusively measured with the CPS-Perceived since this means a subjective estimation. The DMIS was used to determine the actual conditions under which medical decisions are made. The overall results of the two subscales for involvement in communication with parents and with the rheumatologist are listed in table 12. Tables B and C in the appendix present all items with the answers in percentages of both subscales of the DMIS to apply a more detailed view.

Table 12: Subscales DMIS with mean and SD for involvement by parents and rheumatologist.

		Involvement by parents		**Involvement by rheumatologist**	
	Range	M	SD	M	SD
Child express	(0-4)	2.80	0.68	2.36	0.71
Child seek	(0-4)	2.70	0.71	2.86	0.71
Parent/Rheumatologist express	(0-4)	2.95	0.62	3.03	0.53
Parent/Rheumatologist seek	(0-4)	3.06	0.65	2.85	0.68
Joint/Options	(0-4)	2.72	0.54	2.81	0.53
Mean	(0-4)	2.85	0.64	2.78	0.63

All scores presented a moderate level of involvement in the upper half of the range (2.63-3.06) The scores on the subscales "child express" and "child seek" are slightly lower than for "parent/rheumatologist express" and "parent/rheumatologist seek" but are not statistically

significant. Furthermore, no significant difference could be found between the two scales DMIS-Parent and DMIS-Physician. This indicated that the children and adolescents did not seem to distinguish between their parents and their physician/rheumatologist in communication regarding their illness.

Table 13: One-way ANOVA for the two DMIS scales by age, gender, severity of disease and skills of shared decision-making.

	age		**gender**		**CHAQ**		**PEPPI**	
	F(df)	p	F(df)	p	F(df)	p	F(df)	p
Decision-Making Involvement Scale - Parent								
Total	0.267(1)	0.608	0.007(1)	0.934	0.961(1)	0.419	**10.845(1)**	**0.000**
Child express	1.003(1)	0.321	0.912(1)	0.344	0.337(1)	0.799	**17.611(1)**	**0.000**
Child seek	0.025(1)	0.876	1.128(1)	0.293	1.789(1)	0.162	**3.299(1)**	**0.045**
Parent express	0.711(1)	0.403	0.070(1)	0.792	0.260(1)	0.854	**7.723(1)**	**0.001**
Parent seek	0.257(1)	0.614	0.330(1)	0.568	1.429(1)	0.246	**12.162(1)**	**0.000**
Joint/Option	0.191(1)	0.664	0.144(1)	0.706	0.492(1)	0.690	**5.798(1)**	**0.005**
Decision-Making Involvement Scale - Parent								
Total	0.799(1)	0.376	1.802(1)	0.186	1.262(1)	0.299	**13.877(1)**	**0.000**
Child express	0.188(1)	0.666	0.364(1)	0.549	0.490(1)	0.691	**6.545(1)**	**0.003**
Child seek	0.995(1)	0.323	2.553(1)	0.117	2.534(1)	0.068	**6.137(1)**	**0.004**
Rheumatologist express	1.423(1)	0.239	1.122(1)	0.295	0.880(1)	0.459	**18.172(1)**	**0.000**
Rheumatologist seek	0.391(1)	0.534	0.905(1)	0.346	0.926(1)	0.436	**12.275(1)**	**0.000**
Joint/Option	3.155(1)	0.082	3.014(1)	0.089	1.462(1)	0.237	**14.010(1)**	**0.000**

* values in bold print are significant.

The results of the one-way ANOVA showed that there were no significant values for the results of the DMIS (sub)scales referring to age, gender and severity of disease. As opposed to this the analysis of variance was significant for the results of the DMIS (sub)scales referring to the results of the PEPPI. Thus it could be concluded that the better the skills of the

patient in shared decision-making, the more involved the patient was in the decision-making process.

Overall satisfaction

The overall satisfaction of the participants seemed to be very good. Nearly 85 % of the population were satisfied or very satisfied with the way of decision-making. No one was very dissatisfied and only 13.5 % had neutral opinions or were not satisfied with the process (Table 14).

Table 14: Overall satisfaction

	I am very satisfied	**I am satisfied**	**Neutral**	**I am dissatisfied**	**I am very dissatisfied**
Frequency	11	33	4	3	0
Percentage	21.2	63.5	7.7	5.8	0.0

Discussion

Main results

The overall satisfaction with the way of medical decision-making was very good among the patients of this study. The patients who were not involved as much as they wanted to be perceived less involvement than they preferred. These findings are similar to the findings by Neame et al. (2005) and Schildmann et al. (2008). They stated that adult patients with rheumatoid arthritis would like to receive more information referring to their disease which could be interpreted as a desire for more involvement. As already mentioned in the introduction many studies showed that decision-making is not optimal in medical care and could be improved (Beresford, 2003; Charles, 1997; Östlie, 2007; Schildmann, 2008; Stinson, 2008). In contrast to this, this study revealed that the majority of the questioned young patients with juvenile idiopathic arthritis was satisfied with the way of decision-making. Nevertheless, improvement is possible and of course desirable but the situation does not seem to be that unsatisfactory as it is constituted in the current literature. So to further improve the decision-making processes more information should be provided by the physicians, since this would support the patients' involvement.

Researching existing literature focusing on chronically ill patients, a greater part of the studies available paid attention to disease-related aspects as patient fears of adverse effects or thoughts about different treatment options etc. (Berry, 2004; Scarpato, Antivalle, Favalli, Nacci, Frigelli, Bartoli, Bazzichi, Minisola & Cerinic, 2010; Schildmann, 2008). Until today only little research is done referring to decision-making and the satisfaction of patients with the processes in their medical care. Especially shared decision-making, which is very important in the pediatric medical care, has received little attention so far (Charles, 1997). This study focused on the actual conditions of decision-making in pediatric medical care and the preferences and satisfaction of the young patients diagnosed with juvenile idiopathic arthritis. Additionally, the four possibly influencing factors age, gender, severity of disease and skills in shared decision-making were examined. Previous studies demonstrated that the factors age and gender could influence the patients' preferences and perceptions of decision-making (Freburger, Callahan, Currey & Anderson, 2003; Östlie, 2007; Stinson, 2008). We showed that younger patients' (9-13 years) desire for involvement is lesser than among older ones (14-20 years). This is in contrast to two previous studies by Östlie et al. (2007) and Stinson et al. (2008) among adolescent patients and young adults (12-27 years) diagnosed

with juvenile idiopathic arthritis. They reported that younger patients wished greater involvement than older patients. A possible explanation for these differences might be the age distribution, since the youngest participants in the study by Stinson et al. (2008) were 12 years old. This might indicate that younger patients – adolescents – have a higher desire in comparison with adult patients but very young patients – children – in turn may not have such a high desire for involvement. The youngest patients of the study by Östlie et al. (2007) were 15 years old. Referring to the results of this study and previous ones the optimal level of young patients' involvement should be determined (among other factors) by age.

The findings by Neame et al. (2005), stating that especially female patients wanted to be involved more in comparison to the male ones could be affirmed in this study, as long as the desire for more knowledge referring to the disease itself and the treatment could be interpreted as a desire for more involvement. Again a provision of more information in order to improve patients' knowledge would support especially the desire of females to be more involved in the decision-making process.

No studies were found referring to "severity of disease" as a possibly influencing factor. In this study the influence which the "severity of disease" may have had on the preferences and perceptions in medical decision-making showed no statistical significance. This might be due to the small sample size of this study. Slight differences were found through a detailed view on the different levels of severity. Thus, further research should focus on "severity of disease" as a possibly influencing factor for preferences in shared decision-making.

Developing autonomy is very important in learning to cope with a chronic illness. Especially younger patients have to develop autonomy to learn to self-manage their disease (Östlie, 2007; Stinson, 2008). A basic requirement for developing autonomy is an effective communication with responsible persons as the physician and parents in pediatric care. Thus, the study examined if a correlation between the self-efficacy of patients to interact with their physician/parents and the actual conditions under which their decisions are made existed. However, the strong correlation between the total scores of the PEPPI and the total scores of the DMIS-Parent and the DMIS-Physician showed that this self-efficacy seems to be a good predictor for the level of involvement of patients in communication with their physician and their parents. This supports the findings by ten Klooster et al. (2012) that the PEPPI-5 is a valid and reliable instrument. The higher the self-efficacy of the patient to communicate with

the physician (and/or parent in case of younger patients) the higher the involvement of the patient. Since the PEPPI seems to reliably predict patients' involvement a determination of the patients' skills in shared decision-making – before starting a decision-making process – could help to find an optimal level of involvement.

The scores of the DMIS showed that the children's seeking and expressing information was lower than for parents or physician. These findings are in line with what Beresford and Sloper (2003) found that most of the communication takes place between parents and physicians excluding the patient itself. But improvement is possible. "Child express" could be increased if physicians and parents would seek for more information from the child. This in turn might encourage the patient to seek for more information. The DMIS supports what was found through the investigation with the CPS but as a more objective instrument it will be helpful in the future to determine the actual conditions under which decision-making takes place at a given moment.

Physicians and parents should pay attention to the factors age, gender, severity of disease and skills in shared decision-making to adjust an optimal level of patients' involvement. Additionally they have to stay alert to identify other factors which possibly play a role in improving shared decision-making.

Strengths and limitations

This study is one of the first quantitative studies investigating decision-making in pediatric rheumatology. Chronically ill patients have to make several important decisions – regarding their disease – during their lives. Espescially young patients with a chronic illness should be supported in self-manage this disease as early as possible. Therefor this study tried to identify influencing factors, actual conditions of decision-making and the preferences and perceptions of young patients. Additionally this study paied attention to the triangle relationship of patient, physician and parents.

The number of participants is too small to talk about a representative study. A reason for that is the short available period of questioning (five weeks) so this study could be seen as a preliminary study to identify directions for future research. Since a certain level of comprehension skills is necessary to complete the questionnaire, patients younger than nine years could not be included. Furthermore completing the questionnaire required a relatively high level of concentration for a period of about 30 minutes which is a challenge for such young children. Nevertheless, patients younger than nine years should also be involved in

further research. The earlier the child participates the better he/she will be able to manage his/her life with a chronic illness later. Thus, further research should focus on developing an instrument to questioning younger patients without challenging them through such demanding questionnaires. In addition the participation in this study was voluntary and started after a presentation of the study by the researcher. Because of this, participants who might have had some problems in decision-making and did not want to talk about this might not have participated. Nevertheless, the overall response rate was very high.

Conclusion

This preliminary study shows that although the young patients suffering from juvenile idiopathic arthritis in general are satisfied with the way of decision-making, the perceptions and preferences are not identical. Thus, there is certainly room for improvement. Factors such as age, gender and severity of disease might have an influence on the perceptions and preferences but especially the strong correlation between the self-efficacy in communicating with the physician/parent and the actual level of involvement presents a direction to further improve the decision-making process in pediatric medical care. A training to improve this self-efficacy might increase the level of involvement.

Future directions

Further investigation with a greater number of participants will be necessary for a representative sample. Maybe some more influencing factors than investigated in this study could be identified and analyzed. Because it is obvious that patients' involvement in pediatric care is not how it should be in order to achieve optimal treatment, an important question for further research would be: How could an optimal level of patient involvement be realized? In practice parents of chronically ill children and their physicians have to pay attention to the preferences of the patient referring to decision-making. Trying to involve the patient itself and analyzing his/her reactions to this could be helpful to provide an adequate level of involvement.

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Appendix I: Tables

Table A: Preferred and perceived involvement in decision-making.

	Preferred		Perceived	
	n	%	n	%
Decision 1: Change of medicine				
Du allein.	1	1.9	3	5.8
Deine Eltern allein.	1	1.9	2	3.8
Du und deine Eltern zusammen.	10	19.2	9	17.3
Du, deine Eltern und dein Arzt zusammen.	36	69.2	21	40.4
Du und dein Arzt zusammen.	1	1.9	-	-
Deine Eltern und dein Arzt zusammen.	2	3.8	8	15.4
Dein Arzt allein.	1	1.9	2	3.8
Decision 2: Change of dosage				
Du allein.	2	3.8	-	-
Deine Eltern allein.	-	-	2	3.8
Du und deine Eltern zusammen.	12	23.1	7	13.5
Du, deine Eltern und dein Arzt zusammen.	26	50.0	18	34.6
Du und dein Arzt zusammen.	6	11.5	7	13.5
Deine Eltern und dein Arzt zusammen.	5	9.6	5	9.6
Dein Arzt allein.	1	1.9	3	5.8
Decision 3: Stopping with medicine				
Du allein.	4	7.7	2	3.8
Deine Eltern allein.	-	-	3	5.8
Du und deine Eltern zusammen.	12	23.1	8	15.4
Du, deine Eltern und dein Arzt zusammen.	26	50.0	17	32.7
Du und dein Arzt zusammen.	4	7.7	1	1.9
Deine Eltern und dein Arzt zusammen.	5	9.6	3	5.8
Dein Arzt allein.	1	1.9	3	5.8

Table B: DMIS-Parent: Answers in percentage.

	Nein	Ein bisschen	Ja	Ja sehr
Child express				
21. Ich habe Ideen vorgeschlagen.	5.8	21.2	61.5	11.5
23. Ich habe meine Meinung geäußert.	7.7	9.6	48.1	34.6
29. Ich habe meinen Eltern Informationen gegeben.	11.5	40.4	32.7	15.4
Child seek				
24. Ich habe meine Eltern nach Informationen gefragt.	17.3	26.9	46.2	9.6
26. Ich habe meine Eltern nach ihrer Meinung und nach ihrem Rat gefragt.	9.6	25.0	42.3	23.1
27. Ich habe Fragen gestellt.	7.7	15.4	63.5	13.5
28. Ich habe meinen Eltern zugehört.	0.0	7.7	65.4	26.9
Parent express				
8. Meine Eltern haben versucht mir etwas beizubringen bezüglich meiner Krankheit	19.2	25.0	38.5	17.3
10. Meine Eltern haben Ideen vorgeschlagen oder mir einen Rat gegeben.	3.8	5.8	53.8	34.6
11. Meine Eltern haben ihre Meinung geäußert.	1.9	7.7	50.0	40.4
12. Meine Eltern haben mir Informationen gegeben.	7.7	19.2	48.1	25.0
20. Meine Eltern haben mir Feedback dazu gegeben wie ich mich um meine Krankheit kümmere.	13.5	15.4	48.1	23.1
Parent seek				
14. Meine Eltern haben mich nach meinen Ideen gefragt was zutun ist.	9.6	23.1	50.0	17.3
15. Meine Eltern haben mich nach meiner Meinung gefragt.	1.9	7.7	55.8	34.6
16. Meine Eltern haben mir gesagt dass meine Meinung wichtig ist.	5.8	13.5	38.5	42.3
17. Meine Eltern haben mir zugehört.	0.0	7.7	46.2	46.2
19. Meine Eltern haben mich nach Informationen gefragt.	21.2	26.9	36.5	15.4
Joint / Option				
1. Wir haben diskutiert.	23.1	42.3	25.0	9.6
3. Wir haben zusammen Ideen gesammelt was zutun ist.	7.7	17.3	57.7	17.3
4. Wir waren uns einig was zutun ist.	17.3	19.2	48.1	15.4
5. Meine Eltern haben mir verschiedene Handlungsmöglichkeiten erklärt.	17.3	23.1	36.5	23.1
6. Meine Eltern waren still während des Gesprächs.	11.5	11.5	46.2	30.8
9. Meine Eltern gaben mir die Möglichkeit eine Entscheidung zu treffen was zutun ist.	1.9	25.0	51.9	21.2

Table C: DMIS-Physician: Answers in percentage.

	Nein	Ein bisschen	Ja	Ja sehr
Child express				
21. Ich habe Ideen vorgeschlagen.	25.0	30.8	34.6	7.7
23. Ich habe meine Meinung geäußert.	9.6	28.8	38.5	21.2
29. Ich habe meinem Rheumatologen Informationen gegeben.	34.6	26.9	28.8	7.7
Child seek				
24. Ich habe meinen Rheumatologen nach Informationen gefragt.	7.7	19.2	51.9	19.2
26. Ich habe meinen Rheumatologen nach seiner Meinung und nach seinem Rat gefragt.	13.5	15.4	46.2	23.1
27. Ich habe Fragen gestellt.	5.8	17.3	53.8	21.2
28. Ich habe meinem Rheumatologen zugehört.	0.0	1.9	55.8	40.4
Parent express				
8. Mein Rheumatologe hat versucht mir etwas beizubringen bezüglich meiner Krankheit	1.9	13.5	53.8	28.8
10. Mein Rheumatologe hat Ideen vorgeschlagen oder mir einen Rat gegeben.	1.9	7.7	61.5	26.9
11. Mein Rheumatologe hat seine Meinung geäußert.	7.7	5.8	53.8	30.8
12. Mein Rheumatologe hat mir Informationen gegeben.	1.9	5.8	63.5	26.9
20. Mein Rheumatologe hat mir Feedback dazu gegeben wie ich mich um meine Krankheit kümmere.	15.4	23.1	46.2	13.5
Parent seek				
14. Mein Rheumatologe hat mich nach meinen Ideen gefragt was zutun ist.	11.5	40.4	34.6	11.5
15. Mein Rheumatologe hat mich nach meiner Meinung gefragt.	9.6	9.6	53.8	25.0
16. Mein Rheumatologe hat mir gesagt dass meine Meinung wichtig ist.	11.5	11.5	53.8	21.2
17. Mein Rheumatologe hat mir zugehört.	1.9	5.8	53.8	36.5
19. Mein Rheumatologe hat mich nach Informationen gefragt.	32.7	15.4	36.5	13.5
Joint / Option				
1. Wir haben diskutiert.	46.2	26.9	21.2	3.8
3. Wir haben zusammen Ideen gesammelt was zutun ist.	11.5	19.2	48.1	19.2
4. Wir waren uns einig was zutun ist.	11.5	25.0	48.1	13.5
5. Mein Rheumatologe hat mir verschiedene Handlungsmöglichkeiten erklärt.	1.9	11.5	51.9	32.7
6. Mein Rheumatologe war still während des Gesprächs.	1.9	3.8	44.2	48.1
9. Mein Rheumatologe gab mir die Möglichkeit eine Entscheidung zu treffen was zutun ist.	5.8	17.3	57.7	17.3

Appendix II: Letters

Written consent of parents

ST. JOSEF-STIFT SENDENHORST

UNIVERSITY OF TWENTE.

Befragung zum Thema „Beteiligung junger Rheumapatienten im Entscheidungsprozess bezüglich ihrer Erkrankung“

Sehr geehrte Eltern,

Mein Name ist Caroline Cordesmeyer und ich bin Studentin der Psychologie an der Universität Twente in Enschede, Niederlande. Im Rahmen meiner Bachelorarbeit im Fachbereich der Gesundheitspsychologie interessiere ich mich dafür, inwiefern besonders junge Rheumapatienten in die Entscheidungsprozesse bezüglich ihrer Erkrankung einbezogen werden.

Am St. Josef-Stift Sendenhorst führe ich diesbezüglich eine Untersuchung durch, welche aus einer Befragung der Patienten auf er Kinder- und Jugendstation der Klinik besteht. Diese Befragung ist von der Geschäftsführung des St. Josef-Stifts, Herrn Strotmeier und dem Chefarzt der Abteilung, Dr. Ganser genehmigt worden. Weiterhin werde ich bei meiner Arbeit durch den Psychologen Herrn Illhardt unterstützt.

Mit dieser Untersuchung möchte ich herausfinden inwiefern die Kinder und Jugendlichen aus ihrer Sicht an wichtigen Entscheidungen die ihre Erkrankung betreffen teilnehmen. Mein Interesse ist auch darauf gerichtet, wie viel Einfluss und Mitentscheidungsrecht die Kinder und Jugendlichen gerne hätten. Außerdem untersuche ich Faktoren wie das Alter, Geschlecht oder aktueller Stand der Gesundheit die möglicherweise Einfluss auf den Entscheidungsprozess haben.

Die Befragung ihres Kindes würde ca. 25-30 Minuten in Anspruch nehmen. Alle Daten werden selbstverständlich streng vertraulich und anonym behandelt. Wenn Sie selbst ein Interesse an den Ergebnissen meiner Untersuchung haben oder weitere Fragen haben können sie mich gern per E-Mail (c.cordesmeyer@student.utwente.nl) kontaktieren.

Mit freundlichen Grüßen,

Caroline Cordesmeyer

Einverständniserklärung

Ich bin damit einverstanden das mein Sohn/meine Tochter _____ an der Befragung zum Thema „Beteiligung junger Rheumapatienten im Entscheidungsprozess bezüglich ihrer Erkrankung“ teilnimmt.

_____	_____
(Name des Erziehungsberechtigten)	*(Datum & Unterschrift)*

Introduction 9-13

Hallo! ☺

Vielen Dank, das Du mitmachst!

Ich habe hier einen Fragebogen, den ich gern mit dir zusammen aufüllen würde. Es geht in diesem Fragebogen darum, wie viel du zusammen mit deinen Eltern und den Ärzten entscheidest, was dein Rheuma betrifft. Das ganze dauert ungefähr 25 bis 30 Minuten.

Du kannst mir jeder Zeit zwischendurch Fragen stellen wenn du welche hast. Wenn du nicht mehr weiter machen möchtest darfst du das auch jeder Zeit sagen und wir hören mit der Befragung auf und du musst auch nicht sagen warum du keine Lust mehr hast.

Alles was du mir hier erzählst bleibt unter uns und ich werde es niemand anderem erzählen. Auch wenn du später noch Fragen hast, kannst du immer zu mir kommen.

Gut! Wenn du willst fangen wir dann nun an.

Introduction 14-20

Hallo! ☺

Vielen Dank, das Du mitmachst!

Ich habe hier einen Fragebogen und würde dich bitten ihn auszufüllen. Es geht in diesem Fragebogen darum, wie viel du zusammen mit deinen Eltern und den Ärzten entscheidest, was dein Rheuma betrifft. Das ganze dauert ungefähr 25 bis 30 Minuten.

Ich bleibe die ganze Zeit in der Nähe und du kannst mir jeder Zeit zwischendurch Fragen stellen wenn du welche hast. Wenn du nicht mehr weiter machen möchtest darfst du jeder Zeit einfach aufhören und du musst auch keinen Grund dafür nennen.

Alles was du hier ankreuzt oder aufschreibst bleibt natürlich anonym.

Auch wenn du später noch Fragen hast, kannst du immer zu mir kommen.

Gut! Wenn du willst kannst du jetzt anfangen.

Appendix III: Questionnaire

Questionnaire

ST. JOSEF-STIFT SENDENHORST
UNIVERSITY OF TWENTE.

Fragebogen zum Thema „Beteiligung junger Rheumapatienten im Entscheidungsprozess bezüglich ihrer Erkrankung“

An dieser Stelle möchte ich dich noch einmal darüber informieren, dass alle Informationen die du hier preis gibst völlig anonym und vertraulich behandelt werden. Dein Arzt oder deine Eltern werden die Ergebnisse deiner Befragung nicht zu sehen bekommen. Und du musst nirgends deinen Namen angeben.

Das Ziel dieser Befragung ist es einen Eindruck zu bekommen wie im Bezug auf deine Erkrankung Entscheidungen getroffen werden.

Die Fragen die du in diesem Fragebogen findest beziehen sich auf verschiedene Bereiche.

Zuerst möchte ich mit den ersten sieben Fragen gern mehr über deine Person erfahren. Als zweites folgen einige Fragen über deine Gesundheit. Im dritten Abschnitt möchte ich gerne erfahren wie du dir Entscheidungsprozesse vorstellst. Anschließend geht es um deine Fähigkeiten die wichtig sind um gute Entscheidungen zu treffen. Anschließend wird danach gefragt wie du, mit deinem Arzt und deinen Eltern zusammen, Entscheidungen bezüglich deiner Krankheit triffst. Zum Schluss kommen noch einige Fragen darüber wie du die Entscheidungsprozesse bezüglich deiner Krankheit wahrnimmst und wie zufrieden du damit bist.

Der Fragebogen besteht insgesamt aus 57 Fragen, die teilweise Unterfragen beinhalten.

Das Bearbeiten dauert ungefähr 25-30 Minuten. Danach bekommst du eine kleine Belohnung.

Bei fast allen Fragen must du einfach bei der zutreffenden Antwort ein Kreuz machen.

Hast du noch Fragen?

Ich bedanke mich jetzt schon für deine Teilnahme! ☺

Fragen zu deiner Person

1) **Wie alt bist Du?** ☐☐

2) **Bist Du ein Mädchen oder ein Junge?** ☐ Mädchen ☐ Junge

3) **Wie viele Geschwister hast Du?** ☐☐

4) **Auf welche Schule gehst Du?**

☐ Grundschule

☐ Hauptschule

☐ Realschule

☐ Gymnasium

☐ Auf eine andere, nämlich _____

5) **Welche Art von Rheuma wurde bei Dir diagnostiziert?**

☐ Systemische juvenile idiopatische Arthritis (Still-Syndrom, Morbus Still)

☐ Polyarthritis, Rheumafaktor positiv

☐ Polyarthritis, Rheumafaktor negativ

☐ Arthritis mit Enthesitis

☐ Psoriasis-Arthritis

☐ Eine andere, nämlich _____

6) **Wie alt warst Du als die Diagnose gestellt wurde?** ☐☐

7) **Nimmst Du jemanden mit wenn Du zu deinem Rheumatologen gehst?**

☐ Ja, immer.

☐ Ja, meistens.

☐ Manchmal.

☐ Selten.

☐ Nein, nie.

Childhood Health Assessment Questionnaire

In diesem Abschnitt wollen wir wissen inwiefern Dich deine Krankheit im alltäglichen Funktionieren beeinflusst. Denke an die vergangene Woche und kreuze die Antwort an, welche deine alltäglichen Aktivitäten am besten beschreibt. Bitte nenne nur die Schwierigkeiten die mit deiner Erkrankung zusammenhängen.

	Das bereitet mir…	…überhaupt keine Mühe	…etwas Mühe	… viel Mühe	…kann ich überhaupt nicht	Nicht zu-treffend
	Anziehen & Pflege					
	Bist Du in der Lage…					
8)	**… Dich selbst anzuziehen, inklusiv Schuhe binden und Knöpfe schließen?**	☐	☐	☐	☐	☐
9)	**…Dir deine Haare zu schamponieren?**	☐	☐	☐	☐	☐
10)	**… Dir deine Socken aus zu ziehen?**	☐	☐	☐	☐	☐
11)	**… Dir deine Fingernägel zu schneiden?**	☐	☐	☐	☐	☐
	Erheben					
12)	**… von einem niedrigen Stuhl oder vom Boden aufzustehen?**	☐	☐	☐	☐	☐
13)	**… in dein Bett hinein oder hinaus zu kommen?**	☐	☐	☐	☐	☐
14)	**… dein Fleisch beim Essen selbst zu schneiden?**	☐	☐	☐	☐	☐
15)	**… eine Tasse oder ein Glas zu deinem Mund zu führen?**	☐	☐	☐	☐	☐
16)	**… eine neue Müslipackung zu öffnen?**	☐	☐	☐	☐	☐
	Gehen					
17)	**… draußen auf ebenem Boden zu laufen?**	☐	☐	☐	☐	☐
18)	**… 5 Treppenstufen zu steigen?**	☐	☐	☐	☐	☐

19) Welche Hilfen benutzt Du im Alltag?

☐ Gehstock ☐ Gehwagen ☐ Unterarmgehstützen (Krücken) ☐ Rollstuhl

☐ Geräte die du zum Anziehen benutzt (Knopfhaken, Reißverschlusszug, langer Schuhanzieher).

☐ Spezielle Utensilien zum Schreiben.

☐ Speziellen Stuhl.

☐ Anderes: _____

20) Für welche Bereiche im täglichen Leben brauchst Du Hilfe von einer anderen Person?

☐ Anziehen & Hygiene ☐ Aufstehen ☐ Essen ☐ Gehen

	Das bereitet mir…	…überhaupt keine Mühe	…etwas Mühe	… viel Mühe	…kann ich überhaupt nicht	Nicht zutreffend
	Hygiene					
	Bist Du in der Lage…					
21)	**…Deinen ganzen Körper zu waschen und abzutrocknen?**	☐	☐	☐	☐	☐
22)	**… ein Bad zu nehmen (in die Badewanne hinein und heraus zu kommen?**	☐	☐	☐	☐	☐
23)	**… Dich auf die Toilette zusetzen und wieder aufzustehen?**	☐	☐	☐	☐	☐
24)	**… Dir deine Zähne zu putzen?**	☐	☐	☐	☐	☐
25)	**… Dir deine Haare zu bürsten?**	☐	☐	☐	☐	☐
	Reichweite					
26)	**… ein schweres Objekt wie zum Beispiel ein großes Spiel oder Bücher oberhalb deines Kopfes zu erreichen und herunter zu nehmen?**	☐	☐	☐	☐	☐
27)	**… Dich zu bücken um etwas vom Boden aufzuheben?**	☐	☐	☐	☐	☐
28)	**…Dir einen Pullover über den Kopf zu ziehen?**	☐	☐	☐	☐	☐
29)	**… deinen Kopf zu drehen und über deine Schulter zurück zu sehen?**	☐	☐	☐	☐	☐

	Greifen	…überhaupt keine Mühe	…etwas Mühe	… viel Mühe	…kann ich überhaupt nicht	Nicht zutreffend
30)	**… mit einem Füller oder Bleistift zu schreiben?**	☐	☐	☐	☐	☐
31)	**… Autotüren zu öffnen?**	☐	☐	☐	☐	☐
32)	**… Gefäße zu öffnen die bereits offen waren?**	☐	☐	☐	☐	☐
33)	**… einen Wasserhahn zu öffnen und zu schließen?**	☐	☐	☐	☐	☐
34)	**… eine Tür zu öffnen wenn Du einen Türknopf drehen muss?**	☐	☐	☐	☐	☐
	Aktivitäten					
35)	**… Besorgungen zu machen und einkaufen zu gehen?**	☐	☐	☐	☐	☐
36)	**… in ein Auto, Spielzeugauto oder Schulbus ein- und auszusteigen?**	☐	☐	☐	☐	☐
37)	**… Fahrrad zu fahren oder Dreirad?**	☐	☐	☐	☐	☐
38)	**… im Haushalt zu helfen (Spülen, Müll rausbringen, Gartenarbeit, dein Bett machen, putzen)?**	☐	☐	☐	☐	☐
39)	**… zu rennen und zu spielen?**	☐	☐	☐	☐	☐

40) Welche der folgenden Hilfsmittel brauchst Du für eine der oben genannten Aktivitäten?

☐ Erhöhter Toilettensitz ☐ Stange in der Badewanne ☐ Glasöffner

☐ Badewannensitz ☐ Lange Greifhilfe ☐ Lange Greifhilfe im Bad

41) Für welche Bereiche brauchst Du Hilfe von einer anderen Person?

☐ Hygiene ☐ Greifen und Öffnen von Dingen

☐ Reichweite ☐ Besorgungen und Hausarbeit

Schmerzen

42) Wir wollen außerdem wissen inwiefern Du durch Schmerz (die durch deine Erkrankung verursacht werden) in deinem alltäglichen Leben beeinflusst wirst. Gib an wie viel Schmerzen Du in der letzten Woche hattest, indem Du einen Punkt auf der Linie markierst.

Keine Schmerzen 0 ⟷ 100 Sehr starke Schmerzen

Globale Einschätzung

43) Bedenke alles was durch deine Erkrankung beeinflusst wird. Gib an wie gut es Dir insgesamt geht indem Du einen Punkt auf der Linie markierst.

Sehr gut 0 ⟷ 100 Sehr schlecht

Control Preference Scale - Preferred

Denk an die letzte Entscheidung die Du treffen musstest bezüglich deiner Krankheit.

44) Wenn Du daran denkst Dich auf ein neues Medikament umzustellen, wer sollte hauptsächlich über deine Behandlung entscheiden, wenn der Arzt Dich über die Vor- und Nachteile informiert hat?

☐ Du allein.

☐ Deine Eltern allein.

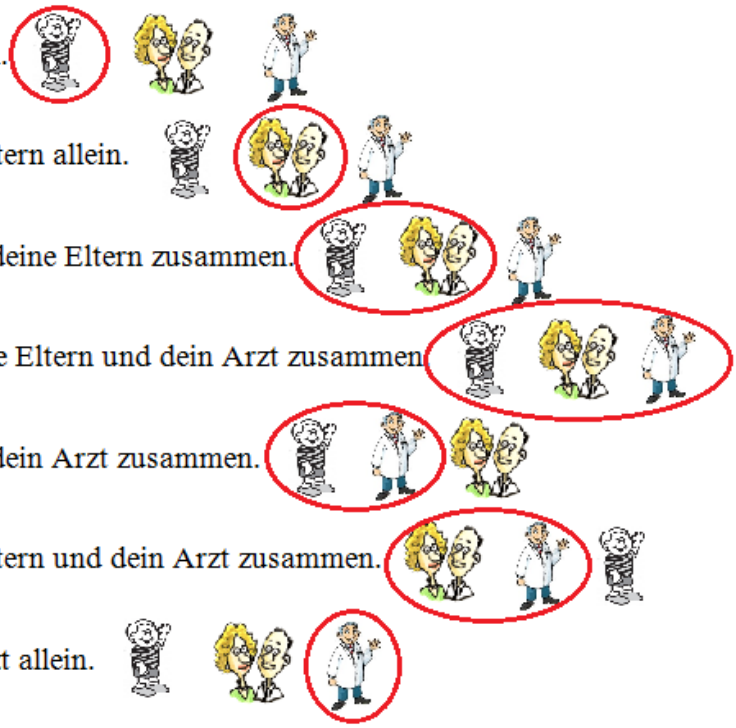
☐ Du und deine Eltern zusammen.

☐ Du, deine Eltern und dein Arzt zusammen

☐ Du und dein Arzt zusammen.

☐ Deine Eltern und dein Arzt zusammen.

☐ Dein Arzt allein.



45) Wenn Du daran denkst die Dosis deines Medikaments zu ändern, wer sollte hauptsächlich die Entscheidung treffen, wenn der Arzt Dich über die Vor- und Nachteile einer Änderung der Dosis informiert hat?

☐ Du allein.

☐ Deine Eltern allein.

☐ Du und deine Eltern zusammen.

☐ Du, deine Eltern und dein Arzt zusammen

☐ Du und dein Arzt zusammen.

☐ Deine Eltern und dein Arzt zusammen.

☐ Dein Arzt allein.

46) Wenn Du daran denkst ein Medikament abzusetzen, wer sollte hauptsächlich die Entscheidung treffen, wenn der Arzt Dich über die Vor- und Nachteile informiert hat?

☐ Du allein. 

☐ Deine Eltern allein. 

☐ Du und deine Eltern zusammen. 

☐ Du, deine Eltern und dein Arzt zusammen 

☐ Du und dein Arzt zusammen. 

☐ Deine Eltern und dein Arzt zusammen. 

☐ Dein Arzt allein. 

47) Wer sollte Deiner Meinung nach hauptsächlich die Entscheidungen treffen über die Behandlung deines Rheumas?

☐ Du. 

☐ Deine Eltern. 

☐ Dein Arzt. 

Perceived Efficacy in Patient–Physician Interactions

48) Gib an inwiefern Du mit den folgenden Aussagen übereinstimmst.

	Ich denke, dass…	Ich stimme überhaupt nicht überein	Ich stimme nicht überein	Neutral	Ich stimme überein	Ich stimme vollkommen überein
a.	**… ich meinen Rheumatologen dazu bringen kann mir zuzuhören.**	☐	☐	☐	☐	☐
b.	**… ich weiß welche Fragen ich meinem Rheumatologen stellen will.**	☐	☐	☐	☐	☐
c.	**… ich den Rheumatologen alle meine Fragen beantworten lassen kann.**	☐	☐	☐	☐	☐
d.	**… ich dem Rheumatologen Fragen über meine größten Sorgen stellen kann.**	☐	☐	☐	☐	☐
e.	**… ich die Besuche bei meinem Rheumatologen nutzen kann.**	☐	☐	☐	☐	☐
f.	**… ich dafür sorgen kann, dass mein Rheumatologe meine Beschwerden und Fragen ernst nimmt.**	☐	☐	☐	☐	☐
g.	**… ich verstehe was mein Rheumatologe mir erzählt.**	☐	☐	☐	☐	☐
h.	**… ich dafür sorgen kann, dass mein Rheumatologe etwas gegen meine Beschwerden unternimmt.**	☐	☐	☐	☐	☐
i.	**… ich meinem Rheumatologen meine stärksten Beschwerden gut beschreiben kann.**	☐	☐	☐	☐	☐
j.	**… ich meinen Rheumatologen nach mehr Informationen fragen kann wenn ich nicht verstanden habe was er meint.**	☐	☐	☐	☐	☐

Decision-Making Involvement Scale

Bei den folgenden Fragen geht es darum das Du beschreibst, wie ein Gespräch mit deinen Eltern über deine Krankheit bzw. über eine Entscheidung bezüglich deiner Krankheit abläuft.

49) Stelle Dir eine Situation vor in der Du Dich mit deinen Eltern über deine Erkrankung unterhältst und gib an inwiefern die folgenden Sätze zutreffen.

		Nein	Ein bisschen	Ja	Ja sehr
a.	**Wir haben diskutiert.**	☐	☐	☐	☐
b.	**Wir haben gestritten.**	☐	☐	☐	☐
c.	**Wir haben zusammen Ideen gesammelt was zutun ist.**	☐	☐	☐	☐
d.	**Wir waren uns einig was zutun ist.**	☐	☐	☐	☐
e.	**Meine Eltern haben mir verschiedene Handlungsmöglichkeiten erklärt.**	☐	☐	☐	☐
f.	**Meine Eltern haben mich gefragt ob ich noch Fragen habe.**	☐	☐	☐	☐
g.	**Meine Eltern waren still während des Gesprächs.**	☐	☐	☐	☐
h.	**Meine Eltern haben versucht mir etwas beizubringen bezüglich meiner Krankheit.**	☐	☐	☐	☐
i.	**Meine Eltern gaben mir die Möglichkeit eine Entscheidung zu treffen was zutun ist.**	☐	☐	☐	☐
j.	**Meine Eltern haben Ideen vorgeschlagen oder mir einen Rat gegeben.**	☐	☐	☐	☐
k.	**Meine Eltern haben ihre Meinung geäußert.**	☐	☐	☐	☐
l.	**Meine Eltern haben mir Informationen gegeben.**	☐	☐	☐	☐
m.	**Meine Eltern haben ihre Meinung für sich behalten.**	☐	☐	☐	☐
n.	**Meine Eltern haben mich nach meinen Ideen gefragt was zutun ist.**	☐	☐	☐	☐
o.	**Meine Eltern haben mich nach meiner Meinung gefragt.**	☐	☐	☐	☐

		Nein	Ein bisschen	Ja	Ja sehr
p.	**Meine Eltern haben mir gesagt dass meine Meinung wichtig ist.**	☐	☐	☐	☐
q.	**Meine Eltern haben mir zugehört.**	☐	☐	☐	☐
r.	**Meine Eltern waren abgelenkt während des Gesprächs.**	☐	☐	☐	☐
s.	**Meine Eltern haben mich nach Informationen gefragt.**	☐	☐	☐	☐
t.	**Meine Eltern haben mir Feedback dazu gegeben wie ich mich um meine Krankheit kümmere.**	☐	☐	☐	☐
u.	**Ich habe Ideen vorgeschlagen.**	☐	☐	☐	☐
v.	**Ich war ruhig während des Gesprächs.**	☐	☐	☐	☐
w.	**Ich habe meine Meinung geäußert.**	☐	☐	☐	☐
x.	**Ich habe meine Eltern nach Informationen gefragt.**	☐	☐	☐	☐
y.	**Ich war abgelenkt während des Gesprächs.**	☐	☐	☐	☐
z.	**Ich habe meine Eltern nach ihrer Meinung und nach ihrem Rat gefragt.**	☐	☐	☐	☐
aa.	**Ich habe Fragen gestellt.**	☐	☐	☐	☐
bb.	**Ich habe meinen Eltern zugehört.**	☐	☐	☐	☐
cc.	**Ich habe meinen Eltern Informationen gegeben.**	☐	☐	☐	☐
dd.	**Ich habe meine Meinung geäußert.**	☐	☐	☐	☐

Nun folgen noch einmal die gleichen Fragen, allerdings sollst Du diesmal beschreiben, wie ein Gespräch mit deinem Rheumatologen ober deine Krankheit bzw. eine Entscheidung bezüglich deiner Krankheit, abläuft.

50) Stelle Dir eine Situation vor in der Du Dich mit deinem Rheumatologen über deine Erkrankung unterhältst und gib an inwiefern die folgenden Sätze zutreffen.

		Nein	Ein bisschen	Ja	Ja sehr
a.	**Wir haben diskutiert.**	☐	☐	☐	☐
b.	**Wir haben gestritten.**	☐	☐	☐	☐
c.	**Wir haben zusammen Ideen gesammelt was zutun ist.**	☐	☐	☐	☐
d.	**Wir waren uns einig was zutun ist.**	☐	☐	☐	☐
e.	**Mein Rheumatologe hat mir verschiedene Handlungsmöglichkeiten erklärt.**	☐	☐	☐	☐
f.	**Mein Rheumatologe hat mich gefragt ob ich noch Fragen habe.**	☐	☐	☐	☐
g.	**Mein Rheumatologe war still während des Gesprächs.**	☐	☐	☐	☐
h.	**Mein Rheumatologe hat versucht mir etwas beizubringen bezüglich meiner Krankheit.**	☐	☐	☐	☐
i.	**Mein Rheumatologe gab mir die Möglichkeit eine Entscheidung zu treffen was zutun ist.**	☐	☐	☐	☐
j.	**Mein Rheumatologe hat Ideen vorgeschlagen oder mir einen Rat gegeben.**	☐	☐	☐	☐
k.	**Mein Rheumatologe hat seine Meinung geäußert.**	☐	☐	☐	☐
l.	**Mein Rheumatologe hat mir Informationen gegeben.**	☐	☐	☐	☐
m.	**Mein Rheumatologe hat seine Meinung für sich behalten.**	☐	☐	☐	☐
n.	**Mein Rheumatologe hat mich nach meinen Ideen gefragt was zutun ist.**	☐	☐	☐	☐
o.	**Mein Rheumatologe hat mich nach meiner Meinung gefragt.**	☐	☐	☐	☐

		Nein	Ein bisschen	Ja	Ja sehr
p.	**Mein Rheumatologe hat mir gesagt dass meine Meinung wichtig ist.**	☐	☐	☐	☐
q.	**Mein Rheumatologe hat mir zugehört.**	☐	☐	☐	☐
r.	**Mein Rheumatologe war abgelenkt während des Gesprächs.**	☐	☐	☐	☐
s.	**Mein Rheumatologe hat mich nach Informationen gefragt.**	☐	☐	☐	☐
t.	**Mein Rheumatologe hat mir Feedback dazu gegeben wie ich mich um meine Krankheit kümmere.**	☐	☐	☐	☐
u.	**Ich habe Ideen vorgeschlagen.**	☐	☐	☐	☐
v.	**Ich war ruhig während des Gesprächs.**	☐	☐	☐	☐
w.	**Ich habe meine Meinung geäußert.**	☐	☐	☐	☐
x.	**Ich habe meinen Rheumatologen nach Informationen gefragt.**	☐	☐	☐	☐
y.	**Ich war abgelenkt während des Gesprächs.**	☐	☐	☐	☐
z.	**Ich habe meinen Rheumatologen nach seiner Meinung und nach seinem Rat gefragt.**	☐	☐	☐	☐
aa.	**Ich habe Fragen gestellt.**	☐	☐	☐	☐
bb.	**Ich habe meinem Rheumatologen zugehört.**	☐	☐	☐	☐
cc.	**Ich habe meinem Rheumatologen Informationen gegeben.**	☐	☐	☐	☐
dd.	**Ich habe meine Meinung geäußert.**	☐	☐	☐	☐

Control Preference Scale – Perceived

Denk an die letzte Entscheidung die Du treffen musstest bezüglich deiner Krankheit

51) Musste bei Dir schon mal eine Entscheidung getroffen werden bezüglich der Umstellung auf ein anderes Medikament?

☐ Ja ☐ Nein. (Du kannst die nächste Frage auslassen.)

52) Wenn Du daran denkst als Du auf ein neues Medikament umgestellt wurdest, wer hat hauptsächlich über deine Behandlung entschieden, nachdem der Arzt Dich über die Vor- und Nachteile informiert hat?

☐ Du allein.

☐ Deine Eltern allein.

☐ Du und deine Eltern zusammen.

☐ Du, deine Eltern und dein Arzt zusammen

☐ Du und dein Arzt zusammen.

☐ Deine Eltern und dein Arzt zusammen.

☐ Dein Arzt allein.

53) Musste bei Dir schon mal eine Entscheidung getroffen werden bezüglich einer Änderung der Dosis deines Medikaments?

☐ Ja. ☐ Nein. (Du kannst die nächste Frage auslassen.)

54) Wenn Du daran denkst als das letzte Mal die Dosis deines Medikaments geändert wurde, wer hat hauptsächlich die Entscheidung getroffen, nachdem der Arzt Dich über die Vor- und Nachteile einer Änderung der Dosis informiert hat?

☐ Du allein.

☐ Deine Eltern allein.

☐ Du und deine Eltern zusammen.

☐ Du, deine Eltern und dein Arzt zusammen

☐ Du und dein Arzt zusammen.

☐ Deine Eltern und dein Arzt zusammen.

☐ Dein Arzt allein.

55) Musste bei Dir schon mal eine Entscheidung getroffen werden bezüglich des Absetztens eines Medikaments?

☐ Ja. ☐ Nein. (Dann kannst du die nächste Frage auslassen.)

56) Wenn Du daran denkst als Du das letzte Mal ein Medikament abgesetzt hast, wer hat hauptsächlich die Entscheidung getroffen, nachdem der Arzt Dich über die Vor- und Nachteile informiert hat?

☐ Du allein.

☐ Deine Eltern allein.

☐ Du und deine Eltern zusammen.

☐ Du, deine Eltern und dein Arzt zusammen

☐ Du und dein Arzt zusammen.

☐ Deine Eltern und dein Arzt zusammen.

☐ Dein Arzt allein.

57) Wie zufrieden bist Du ganz allgemein damit, wie Entscheidungen über die Behandlung deines Rheumas getroffen werden?

Ich bin sehr zufrieden	Ich bin zufrieden	Neutral	Ich bin unzufrieden	Ich bin sehr unzufrieden
☐	☐	☐	☐	☐

- Ende -

Vielen Dank für deine Teilnahme! ☺