

“Feasibility and first clinical effects of a *live* self management program for young adolescents with a rheumatic disease”.

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Abstract

Title: Feasibility and first clinical effects of a *live* self management program for young adolescents with a rheumatic disease.

Objective: The primary objective of this study is to determine the feasibility of the newly developed live self management program, in order to improve and adjust the program if necessary and implement the program in daily practice. Secondary aim is to assess the first clinical effects of the 'live' self management program in young adolescents which completed the program.

Method: Ten young adolescent patients voluntarily took part in the live self management program and accompanying study. All four peer-leaders took part in the feasibility part of this study. Data was collected on demographics, feasibility, self efficacy, self management and quality of life, at baseline and 10 day follow-up.

Results: Feasibility of the program was highly agreed on by both young adolescents participating in the program as by the peer-leaders giving the program. There were recommendations on sports and exercise activities and on the content of the healthy nutrition topic. At follow-up self efficacy had improved with statistical significance ($P = 0.024$), self management showed improvement on several domains, but only emotional well being on a statistical significant level ($P = 0.024$). In quality of life measurement no significant changes were show on the Dutch HAQ-DI. Diaries on pain, fatigue, global health and disease activity showed improvement, though not significantly.

Conclusion: The live self management program seems to be a suitable intervention for young adolescents with a rheumatic disease, to work on their self management skills, and thus, improving those skills, for beneficial effects on carrying out treatment and daily living, in addition to the usual care. Furthermore, the live self management program seems to improve self efficacy in young adolescents with a rheumatic disease.

Keywords: self efficacy, self management, young adolescents, feasibility, clinical effects.

Samenvatting

Titel: Haalbaarheid en eerste klinische effecten van een live zelfmanagement training voor jongeren met een reumatische aandoening.

Doel: Het primaire doel van deze studie is het vaststellen van de haalbaarheid van de live zelfmanagement training, om de training te verbeteren en aan te passen waar nodig en te kunnen implementeren in de dagelijkse klinische praktijk. Secundair doel is om inzicht te krijgen verkrijgen in de eerste klinische effecten van de 'live' zelfmanagement training bij jongeren met een reumatische aandoeningen in de doelgroep 16-25 jaar.

Methode: Tien jongeren namen vrijwillig deel aan de live zelfmanagement training en het bijbehorende onderzoek. Alle vier de expert patiënt trainers namen deel aan het haalbaarheidsdeel van het onderzoek. Data werd verzameld ten aanzien van demografische kenmerken, zelfeffectiviteit, zelfmanagement en kwaliteit van leven, voorafgaand aan de training en tien dagen na de training.

Resultaten: Zowel de deelnemers van de training als de expert patiënt trainers waren het zeer eens met de haalbaarheid van de training. Er werden aanbevelingen gedaan ten aanzien van sport en oefeningen en de inhoud van de module gezonde voeding. Tien dagen na het programma was de zelfeffectiviteit significant ($P = 0.024$) verbeterd ten opzichte van voor het programma, zelfmanagement liet verbetering zien op verschillende domeinen, maar alleen emotionele gezondheid op een significant ($P = 0.024$) niveau. Bij het meten van kwaliteit van leven werden geen veranderingen waargenomen bij de Nederlandse HAQ-DI. Dagboeken voor pijn, vermoeidheid, algemene gezondheid en ziekte activiteit lieten verbetering zien, echter niet significant.

Conclusie: De live zelfmanagement training lijkt een toepasselijke interventie voor jongeren met een reumatische aandoening om aan hun zelfmanagement vaardigheden te kunnen werken. Waardoor deze verbeteren en een voordelig effect hebben op de uitvoer van behandeling en in het dagelijks leven, als aanvulling op de gebruikelijke zorg. Daarnaast lijkt de live zelfmanagement training zelfeffectiviteit bij jongeren met een reumatische aandoening te verbeteren.

Sleutelwoorden: zelfeffectiviteit, zelfmanagement, jongeren, haalbaarheid, klinische effecten.

Introduction

In the western world the reported incidence of Juvenile Idiopathic Arthritis (JIA) varies from 1 to 22 cases per 100,000 children, with a prevalence of 8 to 150 cases per 100,000 [1]. Chronic arthritis in children is defined arbitrarily as arthritis onset earlier than age 16 years and persisting for at least 6 weeks where other causes of arthritis have been excluded [1,2].

Although many new therapeutic options have been developed the past decade, disease remission is often not achieved. The disease and treatment put extensive behavioural demands on children and young adolescents as well as on their parents. These demands invade nearly every aspect of life: physically, mentally and socially. This includes family life and life with friends, attendance to school and/or work, participation in sports and leisure activities [3]. All these, in addition on precisely scheduled daily medication, regular physical exercise and regular visits to the paediatrician or rheumatologist [3].

Children with a rheumatic disease are growing into adulthood as their peers do. For young adolescents with a rheumatic disease, however, the roads towards adulthood are not always identical to those of their healthy peers [4]. The developmental tasks of late adolescence and early adulthood are profound, even in the best of circumstances, and having a rheumatic disease during this period complicates the trajectory [5]. For young adolescents growing into adulthood, one major task is to develop their own identity and independence. Other tasks are the development of peer relationships, focusing on education and vocation, and the development of sexual identity [6].

As young adolescents become more independent they will gradually have to take on the roles of their parents and become responsible for their illness and treatment. Young adolescents usually are unprepared and inexperienced to fulfil these complete different role [4,7]. Therefore young adolescents with a rheumatic disease should be supported in achieving self management and independency to manage those different elements [8]. The behaviour needed to become a good self manager consists of various elements of self management; problem solving, communication skills, decision making, compliance, self monitoring, dealing with physical effects such as pain, stiffness, fatigue and dealing with psychological effects and social problems as a result of rheumatoid arthritis [9-11]. To develop self management behaviour, knowledge about these elements is essential, and can be achieved by different means [12]. Explanation by a health care professional, for example, can enhance the knowledge which will promote self management behaviour in young adolescents. Though, explanation by a health care professional alone does not necessarily lead to better self management behaviour. Whether or not showing (desired) behaviour is in fact largely influenced by self efficacy [12].

The concept of self efficacy was first introduced by Bandura, who indicates that 'self efficacy is the degree to which a person believes that he or she can perform certain behaviours or

skills' [13]. The point here is not whether someone has enough skills to perform the desired behaviour, but whether he or she believes that she or he has sufficient skills. Because of the strong correlation between self efficacy and self management behaviour, it is possible to enhance self management behaviour in young adolescents with a rheumatic disease through promoting self efficacy [14]. Educational and informative programs, such as self management programs, are reliable interventions to promote self efficacy and enhancing self management behaviour [20]. According to Bandura this can be done in four distinctive ways, within the self efficacy concept, through: practice, observing others (modeling), beliefs of others and interpretation of physiological and emotional state [13].

These self management programs are being implemented and used for people with rheumatoid diseases in numerous countries worldwide [15-18]. The first self management programs were being offered as early as the late seventies [15]. Positive effects have been demonstrated in several randomized clinical trials, regarding adults. Where participants showed improvements on pain, physical functioning and trends towards decreases on fatigue and anxiety were noted, also visits to GPs had decreased [16-18,20]. As of yet, there are no studies undertaken regarding self management programs for young adolescents.

In the Netherlands, self management programs have been offered for patients with rheumatic diseases by Taal [21], and the Dutch Rheumatism Patient League, both programs were focusing on adults only.

Recently, a live self management program for young adolescents with a rheumatic disease aged 16-25 years has been developed, by the University Medical Centre Utrecht (UMCU) in partnership with the Dutch Rheumatism Patient League. The program is given in a weekend by peer-leaders and contains different topics or themes (see table 1). The program is based on the earlier developed Dutch self management program for adults, which in turn is based on American self-management course 'The Arthritis Self Management Program' [19]. The peer-leaders are young adolescents with a rheumatic disease, selected through a voluntary assessment and trained to give the program through a train-the-trainer educational program. Development went through several stages, including focus groups with patients, field experts and senior peer-leaders, recording new instruction videos and testing of program content during train-the-trainer weekends.

Problem

The live self management program has been developed to increase self management skills and self management behaviour, according to the previous described self efficacy concepts. However, it is yet unknown what the experience of peer-leaders and young adolescents with the program is, considering its content and accompanying exercises. In other words, before

the program can be broadly implemented the feasibility has to be assessed. Feasibility evaluates the perceived usefulness, perceived ease of use and user acceptance of the program. In addition the clinical effects on self efficacy, self management and quality of life, in young adolescents, after completion of the live self management program, are unknown.

Objective

The primary objective of this study is to determine the feasibility of the live self management program in order to improve and adjust the program if necessary and implement the program in daily practice. The secondary objective is to gain insight in the first clinical effects of the self management program in young adolescents with a rheumatic disease aged 16 – 25 years after completion of the program.

Research questions

“What is the feasibility of the live self management program offered to young adolescents with a rheumatic disease, according to the peer-leaders and young adolescent participants?”

“What are the first clinical effects of the live self management program, in a pilot group regarding young adolescents with a rheumatic disease, on self efficacy, self management and quality of life?”

Materials and Methods

Design

Overall study design is a prospective, longitudinal quasi-experimental pilot study. This study is quasi experimental, because of the absence of randomisation and a control group. The study is longitudinal, because data is collected at two points in time. The program was administered after baseline data collection and follow up was scheduled 10 days after completion of the program. Feasibility was only assessed after completion of the program, clinical outcomes are assessed before and after completion of the program. Both baseline and follow-up data was collected through self report online questionnaires and text messages.

Intervention

The recently developed live self management program for young adolescents, given in a weekend, consist of the following topics: capabilities and talents, dealing with questions and problems about rheumatism, controlling your life, communicating with your environment and health care providers, setting boundaries, pain and fatigue management, relaxation and

exercising, dealing with relationships (family, friends, mate) and finding important, reliable information. These different topics are spread over the weekend, for details see Table 1. Each topic is supported by instructions given by the peer-leaders and accompanied by; exercises, reflection, feedback, music, presentations, quizzes, questions, games, videos and other visual aids. In these exercises and assignments, the elements of the self-efficacy concept play a major role. For additional information, see appendix I.

-----**Table 1**-----

Population

The study population consists of a convenience sample of young adolescent patients with a diagnosed rheumatic disease in the Netherlands and the peer-leaders, in which the latter group only took part in the feasibility part of this pilot study. The peer-leaders were recruited through the Dutch Rheumatism Patient League and selected after completion of a thorough assessment. The remaining peer-leaders were specially trained through a train-the-trainer course, during two weekends.

The participating young adolescent patients met all of the following criteria: 16 – 25 years of age, diagnosed with a rheumatic disease by their GP, paediatrician or rheumatologist, had access to a computer with internet and were able to complete the online questionnaires, had not participated in a self management program before and are able to read and write Dutch.

Because a convenience sample was used, the sample size of approximately 10-15 participants is suboptimal. To demonstrate intervention efficacy in a single group, a sample in range of 20–25 would be more adequate, but could not be achieved due to time limits [22]. Study participants were recruited through the website www.reumaitgedaagd.nl, they are directed to this website through information on leaflets, posters and the website of the Dutch rheumatism patient league and their youth division.

Descriptive data

The characteristics of the study participants are given through the demographic variables and include: age, sex, marital status, diagnosis, disease duration, current treatment (yes or no), employment status and educational level.

Outcome data

The variables examined in this study are: feasibility, self efficacy, self management and quality of life (physical functioning, pain, fatigue, global health and disease activity) [23].

Feasibility

Feasibility was judged by the young adolescent participating in the program, and the peer-leaders giving the program. The peer-leaders only took part in determining the feasibility of the live self management program.

Feasibility was examined through self administered questionnaires which were developed, based on the Technology Acceptance Model (TAM). This model looks into the following three domains: (1) perceived usefulness, (2) perceived ease of use, and (3) user acceptance [24]. The TAM-based questionnaire will assess if the program is an appropriate intervention to achieve an increase in self management behaviour in young adolescents with a rheumatic disease. And also, the extent to which the program is useable considering program content and form (e.g. exercises, flipcharts and presentations).

Separate TAM questionnaires were developed, by two experts, for participants and peer-leaders. The TAM-Participant which contains four questions about perceived usefulness, with a 5-point Likert scale ranging from 1 (agree) to 5 (disagree). Two questions about perceived ease of use, with a 3-point Likert scale ranging from 1 (good) to 3 (insufficient) and five questions about user acceptance, with dichotomous and continuous scoring options. Questions on perceived ease of use and user acceptance have extra room for comments and recommendations.

The TAM-Leader questionnaire was developed for the peer-leaders who led the program. The questionnaire is almost the same, except for three questions considering user acceptance, which are different. One major difference is that the peer-leaders should answer the questions in regard to young adolescent fulfilling the program, in retrospect.

Scores on both TAM questionnaires are interpreted per domain, higher scores or higher agreement, indicating a higher perceived usefulness and/or a higher perceived ease of use and/or a higher user acceptance.

Self efficacy

Self efficacy, one's belief in their own capabilities [13], was assessed by the Dutch translation of the 8-item short form Arthritis Self Efficacy Scale [25], the Dutch-ASES. The scale was translated into Dutch by means of repeated forward-backward translation and was checked carefully by two field experts, 12 patients and the developer. The questionnaire consist eight questions were the score covers a possible value range from 1 to 10 for each question. A mean score of the eight questions is calculated, were higher scores indicating more perceived self efficacy [26]. Previous validation of the German ASES (ASES-D), shows internal consistency reliability (cronbach's alpha) of 0.90 [26].

Self management

Self management was assessed by the Dutch translation of the health education impact questionnaire (heiQ) version 3.0 [27,28]. The scale was translated into Dutch by means of repeated forward-backward translation and was checked carefully by two field experts, 12 patients and the developers. The heiQ is a health education impact evaluation questionnaire that consists of 40 questions on 8 different domains: health directed behavior, positive and active engagement in life, emotional well-being, self monitoring and insight, constructive attitudes and approaches, skill and technique acquisition, social integration and support, health service navigation. The scoring for the HeiQ 3.0 is a sum-score per subscale, with higher scores indicating higher self management. The English version of the HeiQ 3.0 shows reliability (cronbach's alpha) of 0.70 – 0.89 on the 8 domains and high construct validity [27].

Quality of life

Physical functioning

The Dutch consensus Health Assessment Questionnaire- Disability Index (HAQ-DI) [29] was used to assess physical functioning. The HAQ-DI has the ability to effectively measure Health Related Quality of Life (HRQoL) longitudinally, which is central to describing the impacts of disease and treatment on normal day life [30,31]. The HAQ-DI contains 20 items that measure physical disabilities over the past week, in 8 categories of daily living: dressing and grooming, rising, eating, walking, hygiene, reach, grip, and activities. Each item of the HAQ DI is scored on a 4-point likert scale ranging from 0 (without any difficulty) to 3 (unable to do). The overall HAQ DI score is calculated by summing and averaging the highest item score of each category. The overall score ranges from 0 to 3, where scores of 0–1 are generally considered to represent mild to moderate disability, 1–2 moderate to severe disability, and 2–3 severe to very severe disability [26,30,31]. The Dutch HAQ-DI has shown good validity and reliability like the original English HAQ-DI (cronbach's alpha) of 0.85 – 0.95 [29].

Pain, fatigue, global health and disease activity

Pain, fatigue, global health and disease activity were measured separately using Numerical Rating Scales (NRS). For NRS measurements, text messaging (SMS) by mobile phone was used. Participants receive four text messages, for two days in a row, at baseline and ten day follow up. The scores cover a possible value range from 1 to 10 for each question, an average score at baseline and at follow-up is calculated. Higher scores indicating more pain and/or fatigue and/or worse global health and/or disease activity. NRS is equally valid as the Visual Analogue Scale (VAS), but preferred above the VAS because they are easier and quicker to score [32]. NRS and VAS scales are well known instruments within the rheumatology, and accepted as an reliable way to measure pain and fatigue [33,34]. A recent

study on using text messaging in data collection shows good test-retest reliability between the data from the two different measurement methods, at one week and one month time intervals [35].

Statistical analysis

Baseline demographic variables were processed using descriptive statistics to describe frequency and means.

Data collected regarding feasibility was processed by descriptive statistics. The information gathered on perceived usefulness, perceived ease of use, and user acceptance by program participants and peer-leaders was described using descriptive statistics.

Non parametrical test was used to asses changes in outcome measures (self efficacy, self management and health status) between baseline and follow-up, after administering the program. The Wilcoxon signed rank test was used, because the sample size did not reach the limit for paired t-test.

Ethical considerations

This study has been approved by the ethical committee of the University Medical Center Utrecht (UMCU), the Netherlands. All patients were informed accordingly, and before any study activities were undertaken, written informed consent was obtained. If patients were under 18 years of age, parents were informed and asked for their informed consent as well.

Results

Participants

Ten young adolescent patients were included for participation in the pilot study and the live self management program, that took place on the 18-20 of March, 2011. After receiving the completed informed consent, and baseline questionnaires, the young adolescents participated in the live self management program. There were no drop-outs during the program. There was one participant lost to follow-up considering data collection.

The mean age of the sample of adolescents was 20.7 years (SD 2.97), and eight were female. Of the ten young adolescents, six had middle and four had higher education. The mean duration of illness was 6.4 years (SD 6.2, range 1-17 years). All young adolescents where treated at a rheumatologist or paediatrician. See table 2.

-----**Table 2**-----

Feasibility

Perceived usefulness

Participants

Seven out of nine participants rated the live self management program as useful, considering: carry out treatment, daily live and additional healthcare. All participants indicated the time investment was considered worth it. See table 3.

Peer-leaders

All peer-leaders rated the live self management program as useful within the perceived usefulness domain, and gave the maximum score. See Table 3.

-----Table 3-----

Perceived ease of use

Participants

The perceived ease of use was judged differently among the participants. Environment, relations and sexuality and communicating with your GP, were rated good by six out of nine participants. Healthy nutrition was scored the worst with two insufficient scorings on content and form. Although overall ratings for content and form were in between good and sufficient, see Table 4a. There were critiques though, issues that returned were: the lack of outdoor activities during the weekend, healthy nutrition was only in general discussed, absence of evaluating the goals, the need for more theoretical interpretation by the peer-leaders. Besides these more negative statements there was also positive feedback: 'very helpful tips and tricks', 'love the mood boards', 'nice video presentations' and 'such a difficult subject like sexuality was also discussed'. From one participant follow-up data was missing on the form of the program. See Table 4b for a complete set of statements.

Peer-leaders

Overall scores on content and form for the live self management program were good, except for content on healthy nutrition, see Table 4a. The peer-leaders had a different approach towards the ease of use domain. They referred more to their preparation and training skills during the weekend. Three of the peer-leaders argued that: 'There should be more physical activities at the start of the program'. Peer-leaders also commented on: 'the video fragment about feeling blue could be adjusted, and be more abstract'. See Table 4b for a complete set of statements.

-----Table 4a-----

-----Table 4b-----

User acceptance

Participants

Concerning user acceptance, all participants indicated that they would recommend the live self management program to other young adolescents with a rheumatic disease. From the young adolescent six out of nine stated that they would participate again in the live self management program, now they know the program content and form.

The participants gave an overall score for the program weekend, rating the whole program with a 7.7 (range 0 - 10) overall.

Peer-leaders

The peer-leaders shared the same opinion considering the recommendation of the program towards other young adolescents with rheumatic disease.

Three of the peer-leaders argued that: 'A preliminary briefing should take place, in order to tune out the different training activities'. Peer-leaders also commented on: 'The lack of an script or a point-by-point program plan'. But, on the other hand all peer-leaders stated: 'Having the freedom of their own interpretation was highly appreciated'.

The peer-leaders also scored the live self management program weekend, they gave the program an 8.4 (range 0 - 10) overall.

Clinical outcomes

The primary outcome variable, self efficacy showed statistical significant improvement ($P = 0.024$), from baseline to follow-up. Of the eight domains in the health education impact questionnaire, one (emotional well-being) improved with statistical significance ($P = 0.024$).

Four domains (positive and active engagement in life, self monitoring and insight, constructive attitudes and approaches, skill and technique acquisition) show slight improvement, although not statistical significant. The other domains did not improve.

On the quality of life scales, the scores by text messages on pain, fatigue, global health and disease activity, showed improvement although not of statistical significance. Two participants returned text messages for only one day, without an obvious stated reason. The Dutch HAQ-DI score did not show a difference between baseline and follow-up measurement. For a detailed description see Table 5.

-----Table 5-----

Discussion

Main findings

The three domains of feasibility that were assessed, indicated that the program was highly appreciated. The differences between the participating young adolescent patients and the peer-leaders, who administered the program, were minor.

The usefulness of the program was highly agreed on by both participants and peer-leaders. The actual nuances between participants and peer-leaders considering the feasibility of the program was made in the ease of use domain where participants and peer-leaders could go into more detailed comments and recommendations to enhance the self management program. Looking into the different topics of the program, sports and exercise and healthy nutrition had the most 'insufficient' ratings, with the most frequent returned comment: "I missed the outdoor activity". The main comment on healthy nutrition was that it could have been more specific and more in relationship with rheumatic diseases. One important outcome was the need for an outdoor component during the weekend, by both participants and peer-leaders.

The user acceptance, which looked into the willingness to use the program, got positive scorings from both participants and peer-leaders. Most participants of the program stated that they would recommend the program to other young adolescents with a rheumatic disease. So, the participants showed willingness to use the program and see benefits for themselves and others. It is assumed that because of the program being given in one weekend, there were no dropouts during the program itself. Dropout rates seem higher when self management interventions are spread out over time [23, 36-38].

The most important statements that returned in the general comments were the lack of preparation on some topics by the peer-leaders as perceived by the young adolescent participants. Peer-leaders themselves confirmed that in their comments and that will be taken into account for weekends to come. With the comments and recommendations stated by the participating young adolescent patients and by the peer-leaders, the program will be improved and strengthened. The content and form of the program will be improved, by introducing outdoor components to accompanying the sports and exercise topic and the healthy nutrition topic will be specifically focusing on healthy nutrition in rheumatic diseases.

Evidence was found of improved self efficacy in the young adolescent participants of the live self management program. This is consistent with similar peer-led self management programs, regarding adults, that show self efficacy improvement through peer-led self management programs [36-40,42]. One study on a internet based self management program for adolescents showed no changes in self efficacy [41].

Measuring self management through the impact of health education questionnaire showed improvement in accordance to a previous study using the same measurement for self management, were several self management indicators improved also [43].

After attending the live self management program, young adolescent participants showed no changes in scores on quality of life. These results are similar to other studies on self management programs and the effects on quality of life in adults, where quality of life did not improve either after completion of a self management program [36,38-40,42]. One explanation of the lack in improvement on quality of life is that quality of life changes are longitudinally associated especially with disease activity and function [30,31,44]. In a ten day period, the time between baseline and follow-up data collection, the disease activity and function are unlikely to change on a group level. This is confirmed by other studies where quality of life did not change after completion of a self management program [38,40,45].

Limitations

There are several limitations to this study that should be considered in interpreting the findings. First, the sample size is small as this was a pilot study, and the resultant loss in power allowed identifying only medium and large effects, while smaller effects may have been missed. However, the results can be used to improve the program on content and form. Second, this study did not examine durability or maintenance of treatment effects of the program over time, due to time limits. In future studies it will be important to use study designs that allow for examination of maintenance of treatment effects on the long run.

Besides the limitations, this study showed several strengths, for example in data collection, with a near complete follow-up and almost no loss of data. This is probably because of the availability of the questionnaires online, which should prevent missing data, because proceeding in the questionnaires is not allowed with blanks. It remains unclear why one of the participants had missing data on program form, during follow-up data collection, it could be related to computer or internet access problems. Text messaging proved to be a reliable way to collect data, although not all text messages were answered. The reason for not answering text messages remains unknown.

Conclusion

This pilot study provides strong initial support for the feasibility (perceived usefulness, perceived ease of use, and user acceptance) of the live self management program for young adolescents with a rheumatic disease. The live self management program seems to be a suitable intervention for young adolescents with a rheumatic disease, to work on their self management skills, and thus, improving those skills, for beneficial effects on carrying out treatment and daily living, in addition to the usual care.

The live self management program seems to be a strong basis in additional healthcare needs for young adolescents with a rheumatic disease. Furthermore, perhaps of less scientific importance, the participating young adolescents really liked the self management program and enjoyed the weekend with other young adolescent with the same conditions.

Recommendations

Future studies should focus on larger group Randomized Clinical Trials (RCT's), and should look more into the long term effects of the live self management program on young adolescents with a rheumatic disease. Furthermore they should look into the specific population for whom the program is effective.

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Appendix I: The live self management program

The program is given in a weekend, starting on Friday afternoon.

Day 1: The first part of the program consist of an introduction and establishing the attending participants starting point. During the introduction the background of the program is given and an explanation of self management and the program content and schedule is given. To establish the young adolescent participants starting point, considering self management, an answer to the following question is searched for during the introduction phase: 'Are you a self manager?'. To what extent is the disease coped with by the young adolescent participant, in daily life. This answer is gained by the result of various tasks and exercises, including a questionnaire considering self management behaviour, a knowledge quiz, a video and reactions afterwards. This will lead to an awareness of self management in the participants and what they are willing to do to improve their self management skills.

Day 2: The primary topics on day two are 'my environment', 'pain, fatigue, feeling blue', 'sports and exercising' and 'healthy nutrition'. In 'my environment' an insight is given in feedback and the basic ingredients for an proper conversation. Also an communication style analysis is made by the participants. In 'pain, fatigue, feeling blue' the participants gain insight in phenomenon's like pain, fatigue and emotions regarding their rheumatic disease. 'Sports and exercising' focuses on the importance of these activities considering rheumatic diseases. Participants gain insight in their own exercising behaviour and how to change it positively. In 'healthy nutrition' points out the importance of good and healthy food. All topics are accompanied by different group and individual activities and exercises e.g: presentations, questions, physical tasks, dilemma's and knowledge table.

Day 3: The final day of the program emphasises on the following topics, 'relations and sexuality', 'communication with my GP' and 'Are you in control of your rheumatic disease?' 'relations and sexuality' focuses on al kinds of relations with other people. And considers, communicating, physical contact, sexuality, pregnancy and restrictions. In 'communication with my GP' participants learn how to achieve an shared responsibility for their health with their GP and: "is there room for improvement?". In 'Are you in control of your rheumatic disease?' the participants look back and evaluate their goals and achievements. After this final topic is finished the program end with celebrating achievements.

Appendix 2: Tables

Table 1: The live self management program.	
Day	Activity
(1) Friday	Introduction 'Are you a self manager?'
(2) Saturday	My environment Pain, fatigue, feeling blue Sports and exercise Healthy nutrition
(3) Sunday	Relations and sexuality Communicating with your General Physician (GP) 'Are you in control of your rheumatic disease?' End of program and celebrate achievements

Variable	Live self management training (n=10)
Demographic variables	
Age, mean \pm SD (range)	20.7 \pm 2.97 (17-25)
Female sex, n	8
Education, n	
Lower	0
Middle	6
Higher	4
Married, n	1
Diseases, n	
JIA	3
FM	2
RA	3
Bechterew	1
Immune disease (e.g. MCTD, SLE)	1
Duration of diseases years \pm SD	6.4 \pm 6.2
Treated at Rheumatologist or paediatrician	10

Perceived usefulness concerning	Participants (n = 9)			Peer-leaders (n = 4)		
	agree	neutral	disagree	agree	neutral	disagree
Carry out treatment, n	7	2	0	4	0	0
Daily live, n	7	2	0	4	0	0
Additional healthcare, n	7	2	0	4	0	0
Time investment, n	9	0	0	4	0	0

Table 4a: Perceived ease of use of the live self management program (scores)						
Ease of use concerning	Participants (n = 9)			Peer-leaders (n = 4)		
	good	sufficient	insufficient	good	sufficient	insufficient
Content sections						
Introduction	6	3	0	4	0	0
'Are you a self manager?'	3	5	1	4	0	0
My environment	6	2	1	3	0	1
Pain/fatigue/feeling blue	5	3	1	2	1	1
Sports and exercise	4	4	1	4	0	0
Healthy nutrition	4	3	2	1	3	0
Relations and sexuality	6	3	0	4	0	0
Communicating (GP)	6	3	0	4	0	0
'Are you in control?'	5	4	0	4	0	0
Form sections						
Introduction	6	2	0	4	0	0
'Are you a self manager?'	3	5	0	4	0	0
My environment	3	5	0	4	0	0
Pain/fatigue/feeling blue	5	3	0	2	2	0
Sports and exercise	2	6	0	4	0	0
Healthy nutrition	3	3	2	2	1	1
Relations and sexuality	5	3	0	4	0	0
Communicating (GP)	4	4	0	4	0	0
'Are you in control?'	5	3	0	4	0	0

Table 4b: Perceived ease of use of the live self management program (statements)		
Section	Comments by participants	Comments by peer-leaders
My environment	<p>"I learned a lot during this section, especially through the exercise"</p> <p>"A little bit more personal approach would be nice"</p>	<p>"Very important because young adolescents often have to deal with misunderstanding amongst relatives, friends, colleagues and healthcare providers"</p>
Pain, fatigue, feeling blue	<p>"Insufficient content on this subject, could have gone into more personal detail"</p> <p>"Valuable to listen to other participants coping strategies"</p> <p>"Using the mood boards was a very good idea"</p>	<p>"In this section dealing with loss should be a bigger component"</p> <p>"This section was not prepared as well as it should"</p> <p>"Missed dealing with loss, in this section"</p> <p>"This topic can use another video fragment: explaining feeling blue"</p>
Sports and exercise	<p>"I missed the outdoor activity"</p> <p>"Would have liked more discussion about sport"</p>	<p>"Presentations and video were very good, we lacked in having a actual exercise to make it more concrete"</p>
Healthy nutrition	<p>"Could have been more specific and in relationship with rheumatic diseases"</p>	<p>"The information stand was a good idea but we need something more, a twist"</p>
Relations and sexuality	<p>"I appreciated that a difficult subject like sexuality was also discussed"</p> <p>"It was not all about sexuality but also relationships and the future"</p>	<p>"Important to discuss in a group with young adolescents, this subject is often not accounted for"</p> <p>"The accompanying materials used to talk about this subject are very suited"</p>
Communication with GP	<p>"Already used the practical tips"</p>	<p>"Very important topic"</p>
'Are you in control of your rheumatic disease?'	<p>"Missed some dept into the meaning of being in charge of your rheumatism"</p> <p>"Well thought of: positive gossip!"</p>	<p>"Super, a good end of the weekend"</p> <p>"Great to send yourself a postcard with a memory of the weekend"</p>
General comments	<p>"The peer-leaders seemed less prepared than they should be"</p> <p>"The inexperience showed, but was not bothersome"</p> <p>"Nice to have an introduction to get to know each other"</p> <p>"Missed some time management tips"</p> <p>"The time schedule can be adjusted, the second day was very busy"</p>	<p>"This was a great way to learn young adolescents to manage their rheumatic disease"</p> <p>"Next time there should be a peer-leader briefing before the weekend"</p> <p>"It is important to have an evaluation moment after the weekend with all peer-leaders"</p> <p>"Preparation of peer-leaders is very important, this should have more attention"</p>

Table 5: Clinical outcomes; self efficacy, self management and quality of life			
Variable (min - max)	Baseline N = 10	Follow-up N = 9	P (difference)†
Self efficacy (1-10)	5.34 ± 1.35	6.24 ± 1.49	0.024‡
Self management			
Health directed behavior (4-16)	11.4 ± 2.37	12.0 ± 2.12	0.395
Positive and active engagement in life (5-20)	15.4 ± 2.27	16.11 ± 1.97	0.084
Emotional well-being (6-24)	14.1 ± 3.14	11.11 ± 2.89	0.024‡
Self monitoring and insight (6-24)	17.0 ± 1.94	18.44 ± 1.88	0.203
Constructive attitudes and approaches (5-20)	18.0 ± 4.52	20.22 ± 3.63	0.104
Skill and technique acquisition (4-16)	9.9 ± 1.97	11.56 ± 1.51	0.064
Social integration and support (5-20)	14.3 ± 3.20	15.22 ± 2.33	0.888
Health Service navigation (5-20)	14.4 ± 2.46	15.33 ± 2.12	0.481
Quality of life			
HAQ-DI (0-3)	1.10 ± 0.51	1.17 ± 0.58	0.500
Pain (0-10)	4.42 ± 2.11	5.06 ± 2.05	0.182
Fatigue (0-10)	6.39 ± 1.76	6.11 ± 1.63	0.141
Global health (0-10)	5.75 ± 2.28	6.33 ± 1.62	0.672
Disease activity (0-10)	5.59 ± 1.78	4.72 ± 2.62	0.340

* Values are the mean ± SD unless otherwise indicated.
† From Wilcoxon signed rank test comparing baseline and follow-up data.
‡ Significant $P < 0.05$