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Effects of a self-care promoting problem-based learning program in people with rheumatic diseases: a randomised controlled study

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Conflict of interest

No conflict of interest has been declared by the authors.

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Author contributions

SA, SB, BA, BF and PT were responsible for the study conception and design. SA and PT supported the tutors. SA performed the data collection. SA, SB, BA, BF and PT performed the data analysis. SA was responsible for drafting of the manuscript. SB, BA, BF and PT made critical revisions to the manuscript. SA obtained the funding. SB provided administrative, technical or material support. SB, BA, BF and PT supervised the study.

Abstract

Aim.

To evaluate the effects of a self-care promoting problem-based learning program for people with rheumatic diseases in terms of health-related quality of life, empowerment and self-care ability.

Background.

Individuals with rheumatoid arthritis express a great need for education and support in adapting to the disease but the average qualities of studies about patient education interventions are not high. There is no evidence of long term benefits of patient education.

Design.

Randomised controlled trial.

Methods.

A randomised controlled design was selected with test at baseline, 1-week and 6-month post-interventions after completed the 1-year program. The tests consisted of validity and reliability tested instruments. The participants were randomly assigned in spring 2009 to either the experimental group (n=54) or the control group (n=148). The program was running alongside the standard care the participants received at a rheumatology unit. Parametric and nonparametric tests were used in the analyses.

Results.

The participants in the experimental group had statistically significant stronger empowerment after participation in the self-care promoting problem-based learning program compared with

the control group, at the 6-month post-intervention. Approximately two-thirds of the participants in the experimental group stated they had implemented lifestyle changes due to the program.

Conclusion.

The self-care promoting problem-based learning program enabled people with rheumatic diseases to improve their empowerment compared with the control group. It is important to continue to develop problem-based learning in patient education to find the very best way to use this pedagogical method in rheumatology care.

Keywords:

Empowerment, nursing, patient education, problem-based learning, rheumatic diseases, self-care

Trial registration.

This study was registered at <http://clinicaltrials.gov> with the identifier number NCT00803491.

SUMMARY STATEMENT

What is already known about this topic

- Individuals with rheumatoid arthritis express a great need for education, support and assistance in adapting to the disease.
- In patient education problem-based learning has shown to be a useful way to give participants a better understanding and motivation to influence their own behaviour to better health.
- The average qualities of studies about patient education interventions in people with rheumatoid arthritis are not very high and they have small and short-term effects.

What this paper adds

- The self-care promoting problem-based learning program enabled the participants with rheumatic diseases to statistically significantly improve their empowerment compared with the control group.
- The participants in the experimental group statistically significantly improved their fatigue and waking during the night while the control group deteriorated in feeling rested after sleep.
- The participants in the experimental group stated they had implemented lifestyle changes they had not done without the self-promoting problem-based learning program.

Implications for practice and/or policy

- The findings confirm that problem-based learning is a pedagogical method that can be used in patient education in rheumatology care.

- It is important to continue to develop problem-based learning but also other pedagogical methods in patient education in rheumatology care, to find programs with evidence of long term benefits.
- There is also a need to improve and develop instruments that could assess health factors in the evaluation of interventions such as a patient education programs.

INTRODUCTION

There are over 150 rheumatic diseases in the world with a great variation in terms of severity and complexity (WHO 2008). The various rheumatic diseases differ in cause, course and treatment, as well as most of the diseases attack the musculoskeletal system but also often other organic systems (Hill 2006, Schmidt *et al.* 2003). It is a common factor for people with rheumatic diseases such as fibromyalgia (Hoffman & Dukes 2008, Tander *et al.* 2008), systemic lupus erythematosus (SLE) (Almehed *et al.* 2010, Kulczycka *et al.* 2010) and rheumatoid arthritis (RA) (Uhlig *et al.* 2007, West & Wållberg-Jonsson 2009) to estimate the health-related quality of life (HRQL) low. Pain, sleep disturbances and fatigue are some of the most important influencing factors on the HRQL for people with fibromyalgia (Arnold *et al.* 2008), SLE (McElhone *et al.* 2006) and RA (Wirnsberger *et al.* 1999). The possibilities to remove the pain, the sleep disturbance and the fatigue have so far been very limited and the possibilities have instead been to try to find ways to alleviate these problems (Hill 2006).

BACKGROUND

Empowerment is a concept often used in health care. World Health Organization describes empowerment in health promotion work as a process where the individuals receives more control over decisions and actions that affect their own life and health (WHO 1998).

Empowerment is a perspective which emphasizes the individuals' own internal power which may be affected by symptoms from chronic diseases but also by different external factors such as social support (Leino-Kilpi *et al.* 1999). An empowerment approach involves helping a person to learn to think critically and to make informed decisions about self-care (Anderson & Funnell 2010). In rheumatology care empowerment is a central concept because of the importance for the patients to maintain independence (Hill 2006) and to be motivated and trained to take care of themselves and their chronic diseases (Anderson & Funnell 2010, Hill

2003). The individuals' ability to find appropriate self-care depends on how strong belief they have in their own abilities (Holloway & Watson 2002, Lorig *et al.* 2004).

Individuals with RA express a great need for education, support and assistance in adapting to the disease (Sierakowska *et al.* 2005). The goal of patient education is that the individuals must participate actively in their care and have knowledge and skills to manage their self-care in the best way (Hansen-Berg 2001). Group teaching is a great way to teach the ability to problem solving and self-care (Hill 2003). Problem-based learning (PBL) is an example of a pedagogical method for group teaching (Maudsley 1999, Schmidt 1983). The basic ideas behind PBL are that the individuals have to investigate an approach to learning, take self-responsibility for learning, find functional knowledge, think critical and find a way to lifelong learning and self-evolution. The learning is based on relevant real-situations to desired learning outcomes, which are analysed and discussed (Rideout 2001, Silén 2004). The purpose of using problems in PBL is to stimulate learning of information and concepts but also to teach a method of approaching and an attitude towards problem solving (Schwartz *et al.* 2001).

Patient education with PBL has shown to be a useful way to give patients a better understanding and motivation to influence their own behaviour to better health (Tingström *et al.* 2005, Tingström *et al.* 2002). At a 12 month follow-up, after a problem-based patient education, patients with RA had easier to manage pain and other problems with the disease, compared with the control group (Lindroth *et al.* 1997). Women with fibromyalgia and other non-malignant pain strengthened their internal resources after participation in problem-based rehabilitation (Medin *et al.* 2003). Besides these studies there are few studies in rheumatology care where the used pedagogical method of learning is described. The average qualities of

studies about patient education interventions in people with RA are not very high and they show small and short-term effects on disability, the individuals' global assessment and psychological status. There is no evidence of long term benefits of the patient education (Riemsma *et al.* 2009). It has also been shown that there are methodologically limitations in patient education interventions in rheumatology care, such as insufficient relevant outcomes and lack of consensus for outcomes (Iversen *et al.* 2010).

THE STUDY

Aim

The aim of the study was to evaluate the effects of a self-care promoting PBL-program for people with rheumatic diseases in terms of HRQL, empowerment and self-care ability.

Design

A randomised controlled design was selected with test at baseline, 1-week and 6-month post-interventions after the completed 1-year PBL-program for people with rheumatic diseases who had chronic musculoskeletal pain, sleep disturbances and/or fatigue.

Participants

The inclusions criteria were that the participants had 1 or more diagnoses of rheumatic diseases for more than a year, had musculoskeletal pain, sleep disturbances and/or fatigue during the last three months, understood and spoke Swedish and wanted to participate in the PBL-program. A screening questionnaire with four questions (whether to participate in the PBL-program, having had musculoskeletal pain, sleep disturbances and fatigue during the last three months) and a cover letter were sent to 800 individuals registered at a rheumatology unit in the southwest of Sweden. The baseline questionnaire and an informed consent were then

sent to the participants who met the inclusion criteria. In case of no answer from the participants after three weeks, at any of the mailing of the questionnaires, a reminder was done with a telephone call from the first author.

To enable the individuals who met the inclusion criteria and had completed the baseline questionnaire (n=202) to get the same opportunity to join the PBL-program, a randomisation to either the experimental group or the control group was done. A note with the letter E or C was placed in a sealed envelope. These envelopes were then mixed and put in a box. When the researchers received a completed baseline questionnaire an envelope was picked from the box. The participants were randomly assigned to either the experimental group (n=54) or to the control group (n=148). The participants were informed of group belongings and additional information about the study by a phone call. There were 51 participants in the experimental group who began in the 1-year PBL-program and 38 participants (75%) remained at the 1-week post-intervention but also at the 6-month post-intervention. The dropout were due to medical reasons, difficulties to get away from work, economic reasons, disliked the group dynamics or the pedagogical approach. In the control group there were 131 participants (89%) at the 1-week post-intervention. At the 6-month post-intervention there were 124 (84%) in the control group (Figure 1).

The power calculation with a 25% possible of dropouts showed that 54 individuals in the experimental group and 148 individuals in the control group would be enough. The power calculation was based on values of the SF-36 vitality scale from another study (Arvidsson *et al.* 2011a) and a power of more than 80% at a two-tailed test, a significance level of 5% and an assumption that the minimum difference between the groups was 10 points and the maximum standard deviation was of 20 points. Valuation of the clinical relevance of mean

changes in SF-36 is ongoing (Ware 2007) and there is no definition of a minimal clinically important difference (MCID) in the SF-36 subscales in individuals with rheumatic diseases. However, the MCID for the SF-36 subscales have shown to be between 2.0-7.8 points in osteoarthritis. Effects below the MCID may be detectable as clinically meaningless (Angst *et al.* 2001).

At the screening to the study there were 598 individuals who did not fulfil the inclusions criteria, of whom 225 (38%) were men and 373 (62%) were women. Their age was between 17-83 years with a mean age of 54 years (SD 14.3). There were 389 voluntary explanations from the individuals not participating in the study. They were, for instance, the work situation (n=93, 24%), not having musculoskeletal pain, sleep disturbances and/or fatigue (n=89, 23%), residing too far from the hospital and with no economic compensation (n=54, 14%), having the inclusion problems but not wanting to participate (n=47, 12%), only problems with pain (n=31, 8%) or feeling too weak (n=23, 6%).

Intervention

The 1-year self-care promoting PBL-program was run alongside the usual standard care all participants in this study received at a rheumatology unit. The standard care depended on, for instance, the participants' diagnosis and the severity of the disease but also what treatment the participant preferred. The participants in the experimental group were divided consecutively into 7 tutorial groups of 7 or 8 participants and 1 tutor. Each tutorial group met for 1 ½ hours, 10 times in a 1-year period.

As guidance in preparing the content of the curriculum for the PBL-program were proposals and comments from 6 other individuals with rheumatic diseases who participated in a focus-

group interview but also results from other studies were used (Arvidsson *et al.* 2008, Arvidsson *et al.* 2011a, Tingström *et al.* 2002, Tingström *et al.* 2005). The results from a study (Arvidsson *et al.* 2011b) also confirmed the results about the important starting points from the focus-group interview. Following starting points which were linked to self-care when people with rheumatic diseases had chronic musculoskeletal pain, sleep disturbances and fatigue were determined in the curriculum: self-awareness and self-confidence, relationships to other, stress and relaxation, physical activity and rest, medicines and herbal remedies, tobacco and alcohol and food and drink. Each tutorial group could also discuss further areas they considered as important. The objective with the curriculum was that the participants in the experimental group would get an opportunity to find approaches to self-care and to be able to handle the chronic musculoskeletal pain, sleep disturbances and fatigue and thereby improving their HRQL and the belief in their own ability.

At the first meeting focus was on describing and discuss the pedagogical method of PBL, the content of the program, the role of the tutor, how to organise the group work and to set up a cooperation contract. This cooperation contract included, for instance, the importance of respecting each other's knowledge and opinions. Then, to start the learning process, the tutor presented a situation or event (scenarios) and the participants discussed their experiences and raised thoughts. A structured problem-solving process described by Tingström *et al.* (2005) was used to stimulate the participants to dare to be active in the discussions, ask questions, activate prior knowledge and appraise the newly gained knowledge and its application in their own lives (Tingström *et al.* 2005, Tingström *et al.* 2002). The used structured problem-solving process was '1) Scenario, clarify terms and concepts, 2) Brainstorming, 3a) Organise in problem areas, 3b) Scrutinise and evaluate knowledge, 4) Select 1 or more questions, 5) Specify learning needs, 6) Self-studies, 7) Discuss, scrutinize and synthesise newly-acquired

knowledge, 8) Apply newly-acquired knowledge in your own life, 9) Evaluation, 10) Continue problem-solving' (Tingström *et al.* 2005, p. 326).

To clarify the self-directed learning, each participant wrote targets for their learning and self-care activities in a workbook. The tutors gave suggestions about how and where to search for learning materials. The tutorial groups had in addition to the self-directed learning an opportunity to ask a resource person in rheumatology care, such as a physician or a physiotherapist, to come to a meeting and answer specific questions. This was not used but a physician, specialist in chronic musculoskeletal pain, gave a lecture which was based on questions from all the 7 tutorial groups.

Three nurses were trained in PBL and each nurse was tutor for 2 or 3 tutorial groups. The tutors did not have a traditional role of teachers or experts, their role were to support the participants in the problem-solving process. The first author supported the tutors once a month but had also individual meetings when needs were aroused.

Data collection

The baseline data collection took place between January-April 2009. The data in the study were collected at 3 points: baseline, 1-week post-intervention and 6-month post-intervention. The outcome was assessed by validity and reliability tested instruments.

Instruments

The instruments covered the areas: HRQL, empowerment, self-care, SOC, chronic musculoskeletal pain, quality of sleep, fatigue and demographic variables. HRQL was assessed by the Short Form-36 Health Survey (SF-36) in the Swedish standard edition

(Sullivan & Karlsson 1994). The SF-36 gives 8 subscales assessing different aspects of HRQL: Physical Functioning (PF), Role–Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role–Emotional (RE) and Mental Health (MH). The score for each of the 8 subscales ranged from 0 to 100. A higher score indicated better health (Sullivan & Karlsson 1994). Empowerment was assessed by the Swedish Rheumatic Disease Empowerment Scale (SWE-RES-23) which has 5 subscales assessing different aspects of empowerment: subscale 1, Goal achievement and overcoming barriers to goal achievement; subscale 2, Self-knowledge; subscale 3, Managing stress; subscale 4, Assessing dissatisfaction and readiness to change; and subscale 5, Support for caring. The items are scored on a 5 point Likert-scale ranging from strongly disagree (1) to strongly agree (5). A higher value indicated a stronger empowerment (Arvidsson *et al.* 2012). Self-care was assessed by the Appraisal of Self-Care Agency Scale (ASA-A) which assesses self-care ability. The total range of the ASA-A scale is 24 to 120 points. A higher score indicated better self-care ability (Evers 1989, Söderhamn *et al.* 1996a, Söderhamn *et al.* 1996b). Sense of Coherence was assessed by the SOC-questionnaire with 13 questions. These questions measure comprehensibility, manageability and meaningfulness, which show the level of SOC. The total range of the SOC scale is 13 to 91 points. A higher score indicated better SOC (Antonovsky 1993, Antonovsky 1987/2005). Chronic musculoskeletal pain and fatigue were assessed by a visual analogue scale (VAS), 0 to 10. A higher score indicated worse pain or fatigue. Quality of sleep was assessed by 4 questions used in previous studies (Bergman *et al.* 2001, Liljenberg *et al.* 1988, Mallon & Hetta 1997). The demographic variables were sex, age, civil status, education, residence, socioeconomic status (main and current occupation) and rheumatic disease. Socioeconomic status was based on the participant's occupation and classified according to the Swedish socioeconomic classification system, SEI (Statistics 1982). The 18 basic socioeconomic classes were merged to 4 groups: manual workers,

assistant no manual employees, intermediate/higher no manual employees including upper level executives and others. The group 'others' included self-employed, farmers, housewives and students (Bergman *et al.* 2001). The diagnosed rheumatic disease was obtained from medical records.

The participants in the experimental group also completed a questionnaire consisting of 18 questions about the quality of the PBL-program at the 1-week post-intervention. This questionnaire concerned questions about the content of the PBL-program, the problem-solving process, the learning process, the group process and lifestyle changes. Most questions had 5 possible scores ranging from a 'very small degree' to a 'very large degree'.

Ethical considerations

The study was conformed to the principles outlined in the Declaration of Helsinki (WMA 2008) and national codes of ethics in Sweden (CODEX 2010) and was approved by the Regional Ethical Review Board in Lund, Sweden, dnr 560/2008. This study was registered at <http://clinicaltrials.gov> with the identifier number NCT00803491.

Data analysis

The statistical package SPSS for Windows, Release 18.0 was used. The Pearson chi-square test was used to explain the characteristics of the studied population and comparisons between the experimental and the control groups. The independent t-test was used to measure differences between the groups at the same measurement occasion. Paired sample t-test was used to measure the differences in the groups at different measurement occasions. Parametric tests were used as this are usually used in the selected instruments, which may allow for further comparisons with other populations. It was also possible to do parametric tests due to

a population sample of more than 30 participants in each group (Altman 1999). To analyse chronic musculoskeletal pain, fatigue and quality of sleep non-parametric tests were used. Mann Whitney U-test was used to measure differences between the groups at the same measurement occasion. Wilcoxon signed ranks test was used to measure the differences in the same group at different measurement occasions; $p < 0.05$ was considered statistically significant.

Validity and reliability

Most of the instruments in this study demonstrated good validity and reliability, like the SF-36 (Persson *et al.* 1998, Sullivan & Karlsson 1998, Sullivan *et al.* 1995), the ASA-A (Söderhamn *et al.* 1996a, Söderhamn *et al.* 1996b) and the SOC (Eriksson & Lindström 2005, Pallant & Lae 2002, Söderhamn & Holmgren 2004). The SWE-RES-23 has demonstrated acceptable validity and reliability (Arvidsson *et al.* 2012). The reliability was not tested in this study. However, in the selection of instruments the focus was on finding instruments with known good or acceptable validity and reliability to prevent threats.

The internal validity with history and maturation threats were supposed to affect both the randomised groups and were therefore not a typical threat. The threat of the selection of participants was present when comparing groups but the threat was probably small in this study because of the random assignment. The dropout was 25% in the experimental group and there was a risk that only the healthiest and most motivated individuals with rheumatic diseases participated and completed the self-care promoting PBL-program.

The researchers strived to be as objective as possible in the data collections and in the data analyses. All statistical analyses were discussed and judged by all the researchers involved but also with a statistician to prevent a threat to the objectivity.

RESULTS

There was an equal predominance of women in both the experimental group (71%) and in the control group (73%). The mean age was 56.4 years (SD 7.2, 37-68 years) in the experimental group and 55.2 years (SD 13.2, 21-78 years) in the control group. There were more participants in the experimental group who lived in a rural area (Table 1).

HRQL was assessed by the SF-36 8 subscales and there were no statistically significant differences between the experimental group and the control group and these subscales at baseline, 1-week post-intervention and 6-month post-intervention (Table 2). There were changes in the groups at the different measurement occasions. In the experimental group there were statistically significant improvements in 2 SF-36 subscales: VT and SF. The mean improvements for VT were 7.1 points (95% CI -12.9 - -1.3, $p=0.017$) and for SF 9.2 points (95% CI -16.7 - -1.8, $p=0.017$) between 1-week post-intervention and 6-month post-intervention (Table 3). In the control group there were statistically significant improvements in 3 SF-36 subscales: RP, BP and GH. The mean improvements for RP were 10.2 points (95% CI -17.1 - -3.4, $p=0.004$) between baseline and 6-month post-intervention and 12.5 points (95% CI -19.8 - -5.2, $p=0.001$) between 1-week post-intervention and 6-month post-intervention. The mean improvements for BP were 4.4 points (95% CI -8.4 - -0.5, $p=0.027$) and for GH 3.3 points (95% CI -6.1 - -0.7, $p=0.016$) between baseline and 6-month post-intervention and for GH 2.6 points (95% CI -5.1 - -0.1, $p=0.044$) between 1-week post-intervention and 6-month post-intervention (Table 4).

Empowerment was assessed by the SWE-RES-23 total score and its 5 subscales. At the 1-week post-intervention the experimental group scored statistically significant higher means than the control group in the SWE-RES-23 total score (95% CI 0.1 - 0.5, $p=0.005$) and in 3 SWE-RES-23 subscales: subscale 1 (95% CI 0.1 - 0.6, $p=0.001$), subscale 2 (95% CI 0.1 - 0.6, $p=0.017$) and subscale 4 (95% CI 0.1 - 0.5, $p=0.014$). At the 6-month post-intervention the experimental group scored statistically significant higher means than the control group in the SWE-RES-23 total score (95% CI 0.0 - 0.4, $p=0.038$) and in 2 SWE-RES-23 subscales: subscale 2 (95% CI 0.0 - 0.5, $p=0.036$) and subscale 3 (95% CI 0.1 - 0.6, $p=0.004$) (Table 2).

There were changes in the groups at the different measurement occasions. In the experimental group there were statistically significant differences between baseline and 1-week post-intervention in the SWE-RES-23 total score (95% CI -0.5 - -0.1, $p=0.001$), subscale 1 (95% CI -0.5 - -0.1, $p=0.008$), subscale 2 (95% CI -0.6 - -0.2, $p=0.001$), subscale 4 (95% CI -0.4 - -0.1, $p=0.002$) and subscale 5 (95% CI -0.5 - -0.0, $p=0.043$). There were statistically significant differences between baseline and 6-month post-intervention in the SWE-RES-23 total score (95% CI -0.5 - -0.1, $p=0.008$), subscale 2 (95% CI -0.7 - -0.2, $p=0.001$) and subscale 3 (95% CI -0.7 - -0.1, $p=0.009$) (Table 3). In the control group there was a statistically significant difference between baseline and 1-week post-intervention in SWE-RES-23 subscale 3 (95% CI -0.3 - -0.0, $p=0.021$). There were statistically significant differences between baseline and 6-month post-intervention in the SWE-RES-23 total score (95% CI -0.2 - -0.1, $p<0.001$), subscale 1 (95% CI -0.2 - -0.0, $p=0.048$), subscale 2 (95% CI -0.3 - -0.1, $p=0.001$), subscale 3 (95% CI -0.3 - -0.1, $p=0.003$) and subscale 5 (95% CI -0.6 - -0.2, $p<0.001$) (Table 4).

Self-care ability was assessed by the ASA-A and sense of coherence was assessed by the SOC. There were no statistically significant differences between the experimental group and the control group at baseline, 1-week post-intervention and 6-month post-intervention in terms of ASA-A or SOC (Table 2). In the experimental group and the control group there were no statistically significant changes in terms of ASA-A or SOC (Tables 3 and 4).

There were no statistically significant differences between the experimental group and the control group at baseline, 1-week post-intervention and 6-month post-intervention in terms of feeling pain the last week, feeling fatigue the last week, not falling asleep at night, waking during the night, not feeling rested after sleep or waking too early. There were changes in the groups at the different measurement occasions. The experimental group scored statistically significant improvement between baseline and 6-month post-intervention in waking during the night ($p=0.046$) and feeling fatigue the last week ($p=0.048$). In the control group there was a statistically significant deterioration between 1-week post-intervention and 6-month post-intervention in feeling rested after sleep ($p=0.048$).

The participants in the experimental group scored that they had belonged to a tutorial group that worked well together in a fairly high degree ($n=15$, 39.5%) or in a sufficient degree ($n=10$, 26.3%). The participants described that they felt involved, felt a community and security in the tutorial group and that it was interesting to exchange experiences and knowledge. They also described that they perceived that all participants in the tutorial groups were not enough active or engaged. The dropouts and absences disrupted the work in the tutorial groups. They scored that they had concrete goals for lifestyle changes during the 1-year PBL-program in a fairly high degree ($n=11$, 28.9%) or in a sufficient degree ($n=15$, 39.5%). The participants had implemented these lifestyle changes in a fairly high degree ($n=8$,

21.1%), in a sufficient degree (n=17, 44.7%) or in a fairly small degree (n=9, 23.7%) during the 1-year PBL-program. Examples of lifestyle changes were: trying to think more positively, thinking of them selves, being more physically active, changing in sleeping habits and food habits, reducing the use of pills and reducing the smoking. The participants in the experimental group scored that they had implemented these lifestyle changes in a very small degree (n=9, 23.7%), in a fairly small degree (n=14, 36.8%) or in a sufficient degree (n=12, 31.6%) without the 1-year PBL-program.

DISCUSSION

The self-care promoting PBL-program effectiveness

This study shows that the participants in the experimental group scored at the 6-month post-intervention increased empowerment after participation in a 1-year self-care promoting PBL-program compared with the control group. The participants in the experimental group scored improved fatigue and less waking during the night and the control group scored deterioration in feeling rested after sleep. The participants in the experimental group stated that they had implemented lifestyle changes which they had not done without the PBL-program.

There were statistically significant differences in empowerment between the experimental group and the control group but there were only small differences in the mean values.

However, we believe that the participation in the PBL-program helped the participants to improve their empowerment and that it also have clinical significance. Especially when three fifths of the participants scored that they had implemented lifestyle changes because of their participation in the PBL-program. These results agreed well with Andersson and Funnell's (2010) description from USA that an empowerment based intervention involving facilitating

and supporting the participants to reflect their experiences could enhance the participants' awareness and consequences of the self-care decisions. Empowerment is a continuous variable and the strength and direction of change shows the intervention's effectiveness.

WHO has determined that there is evidence that empowering initiatives lead to positive health outcomes and that empowerment is a very important public health strategy (WHO 2006). An empowerment approach means that the participant is involved in problem formulations, decisions making and actions. Thus, the health-care professionals have to refrain some of their control and power over for instance the participant's disease and treatment (Tengland 2007). Andersson and Funnell (2010) state that 'Empowerment occurs when health-care professionals' goal are to increase the capacity of patients to think critically and make autonomous, informed decisions. Empowerment also occurs when patients are actually making autonomous, informed decisions about their [...] self-management' (p.277). In rheumatology care empowerment is an approach which has not received much attention. This study confirms that empowerment is an approach which is necessary to study more, especially in patient education.

The result in this study could not show that there were any statistically significant differences in HRQL between the experimental group and the control group, but there were statistically significant improvements over time in both groups but in different subscales. In the experimental group there was an improvement in the subscale VT and it was also confirmed in improved fatigue and less waking during the night. The improvement in the subscale SF can be reflected by the PBL-program that could provide an important sense of community when the participants actively were working together with a problem. They became a group responsible for performing shared goals, which is characterised by cooperation rather than

competition (Boud & Feletti 1997). In the control group there were HRQL improvements in the subscales RP, BP and GH and there are no explanations to why this improvement occurred.

The mean improvements in SF-36 subscales in the groups were 2.6-12.5 points and if these changes are of clinical significance are controversial. There is a suggestion that effects larger than 12 % of the baseline value in SF-36 are assumed to be the MCID (Angst *et al.* 2001). In present study there were >12 % improvements in the subscale VT and SF for the experimental group but only in the subscale RP for the control group. This could prove that the PBL-program had a clinical significance for the participants HRQL.

There were not any statistically significant differences between the experimental group compared with the control group on self-care ability, SOC, pain, quality of sleep or fatigue 6 months after the PBL-program. This can be due to that the 1-year PBL-program does not have this effect or that it takes longer time than 6 months to gain a change. However, two-thirds of the participants in the experimental group stated that they had implemented lifestyle changes in a fairly high or sufficient degree during the 1-year PBL-program. In terms of lifestyle changes have Fontaine *et al.* shown that fewer than two-fifths of the individuals with arthritis in USA who reported that they were meeting the public health recommendations for physical activity (Fontaine *et al.* 2004) which may seem as a low value. The question is how this can be improved. Department of Health in England has shown that the main factors for better self-care in a general population were knowledge and understanding. Health-care professionals, but also family and friends are important sources of information, guidance and support for self-care (Department of Health 2005). This result shows the importance of including, for instance, the family in the next upcoming PBL-program.

In the questionnaire about the quality of the PBL-program the participants in the experimental group described both positive and negative aspects. PBL was a pedagogical method which suited some participants very well but not all. It is difficult to create a patient education program that will fit all participants. Instead we should strive to create and offer the patients several different patient education programs. The most effective patient education must be presented to the right patient, at the right time and in the most appropriate way (Hill 2003).

In England health-care professionals sometimes can experience a feeling of powerlessness and a lack of knowledge in how to improve the health experiences in people with rheumatic diseases (Hill 2006). Self-care and patient education have received increased attention over the last decades but there is a need for more research evidence on strategies and treatments that health-care professionals could use to help people with rheumatic diseases to improve their health.

Study limitations

A limitation in this study was that the 1-year PBL-program only could be held at the rheumatology unit but also that no economic compensation could be given to the participants for the travels or the need to take times off work. The excluding of individuals not speaking or reading Swedish was also a limitation. Another limitation was that there is a problem in the use of the SF-36 and the SWE-RES-23 that floor and roof effects can reduce the possible change over time in the extreme ends of the scales.

CONCLUSION

This study has shown that a self-care promoting PBL-program enables people with rheumatic diseases who have had the disease for more than a year and had chronic musculoskeletal pain, sleep disturbances and/or fatigue for at least 3 months, to improve their empowerment. The participants also stated that they had implemented lifestyle changes which they had not done without the self-care promoting PBL-program. The results show that it is important to continue to develop PBL in patient education to find the very best way to use this pedagogical method in rheumatology care. There is also a need to improve and develop instruments that could assess outcomes like health factors and lifestyle changes, to evaluate an intervention such as a patient education program.

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Figure 1 Flow chart of the participants in the intervention study with a self-care promoting PBL-program

Table 1 Demographic and clinical characteristics of participants in the intervention study with a self-care promoting PBL-program

Characteristics	Experimental group Baseline n=38	Control group Baseline n=124
Sex		
Male	11 (29 %)	33 (27 %)
Female	27 (71 %)	91 (73 %)
Age		
Mean age (SD)	56.4 (7.2) (37-68 years)	55.2 (13.2) (21-78 years)
Civil status		
Living alone	8 (21 %)	22 (18 %)
Living with somebody	30 (79 %)	102 (82 %)
Education		
Grade school	9 (24 %)	29 (24 %)
Junior secondary school/ Vocational school	9 (24 %)	24 (19 %)
Secondary school	12 (31 %)	40 (32 %)
College/university	8 (21 %)	31 (25 %)
Residence		
Urban	11 (29 %)	61 (49 %)
Rural	27 (71 %)	63 (51 %)
Socioeconomic status, main occupation		
Manual workers	20 (53 %)	60 (48 %)
Assistant no manual employees	4 (10 %)	18 (15 %)
Intermediate/higher employees and upper-level executives	8 (21 %)	36 (29 %)
Others	6 (16 %)	10 (8 %)
Socioeconomic status, current occupation		
Manual workers	10 (26 %)	35 (28 %)
Assistant no manual employees	5 (13 %)	16 (13 %)
Intermediate/higher employees and upper-level executives	6 (16 %)	16 (13 %)
Others	17 (45 %)	57 (46 %)
Rheumatic disease		
Local/general pain	1 (3 %)	6 (5 %)
Osteoarthritis	1 (3 %)	6 (5 %)
Systemic rheumatic disease	5 (13 %)	23 (18 %)
Inf. joint disease	31 (81 %)	89 (72 %)

Table 2 Differences between the experimental group and the control group at baseline, 1-week post-intervention and 6-month post-intervention after a self-care promoting PBL-program.

n=162	Baseline E. group	Baseline C. group	Baseline E. group – C. group		1-week post- intervention E. group	1-week post- intervention C. group	1-week post- intervention E. group – C. group Mean difference (95% CI)		6-month post- intervention E. group	6-month post- intervention C. group	6-month post- intervention E. group – C. group Mean difference (95% CI)	
	Mean (SD)	Mean (SD)	Mean difference (95% CI)	<i>p</i>	Mean (SD)	Mean (SD)		<i>p</i>	Mean (SD)	Mean (SD)		<i>p</i>
PF	55.7 (23.5)	59.2 (23.2)	-3.5 (-12.1-5.0)	0.414	58.8 (25.6)	58.9 (25.3)	-0.1 (-9.3-9.2)	0.991	56.4 (25.9)	60.6 (24.4)	-4.2 (-13.2-4.9)	0.367
RP	45.4 (40.6)	43.6 (41.7)	1.8 (-13.3-17.0)	0.810	55.3 (40.3)	41.3 (41.7)	14.0(-1.2-29.1)	0.071	50.7 (43.3)	53.8 (40.8)	-3.1 (-18.3-12.0)	0.680
BP	41.7 (18.0)	44.0 (20.9)	-2.3 (-9.7-5.1)	0.536	45.0 (21.7)	45.4 (22.1)	-0.4 (-8.4-7.7)	0.923	44.6 (19.7)	48.4 (23.1)	-3.8 (-12.0-4.4)	0.359
GH	48.2 (21.5)	44.3 (21.8)	3.9 (-4.0-11.9)	0.329	50.5 (22.1)	45.0 (20.9)	5.5 (-2.3-13.2)	0.165	52.2 (26.2)	47.6 (22.5)	4.6 (-4.0-13.1)	0.295
VT	40.5 (19.9)	41.2 (24.8)	-0.7 (-9.4-8.0)	0.870	40.0 (24.6)	42.8 (24.4)	-2.8 (-11.7-6.2)	0.541	47.1 (25.6)	44.6 (25.1)	2.5 (-6.7-11.8)	0.586
SF	65.5 (26.2)	69.1 (27.8)	-3.6 (-13.8-6.4)	0.469	64.5 (28.4)	67.2 (30.8)	-2.7 (-13.9-8.3)	0.623	73.7 (28.0)	70.9 (28.1)	2.8 (-7.5-13.1)	0.590
RE	64.0 (38.3)	61.3 (42.4)	2.7 (-12.4-17.9)	0.722	57.9 (42.2)	64.2 (43.8)	-6.3 (-22.3-9.6)	0.431	60.5 (42.3)	66.1 (40.8)	-5.6 (-20.7-9.5)	0.464
MH	70.3 (18.7)	69.8 (22.5)	0.5 (-7.4-8.4)	0.905	65.7 (23.1)	68.8 (24.2)	-3.1 (-11.9-5.7)	0.488	71.8 (20.9)	72.0 (21.3)	-0.2 (-8.0-7.5)	0.951
SWE-RES-23, subscale 1	3.8 (0.7)	3.7 (0.7)	0.1 (-0.1-0.4)	0.229	4.1 (0.6)	3.7 (0.6)	0.4 (0.1-0.6)	0.001*	4.0 (0.6)	3.8 (0.6)	0.2 (-0.0-0.4)	0.059
SWE-RES-23, subscale 2	3.5 (0.8)	3.5 (0.7)	0.0 (-0.2-0.3)	0.913	3.9 (0.6)	3.6 (0.7)	0.3 (0.1-0.6)	0.017*	3.9 (0.6)	3.6 (0.7)	0.3 (0.0-0.5)	0.036*
SWE-RES-23, subscale 3	3.4 (0.7)	3.2 (0.8)	0.2 (-0.1-0.5)	0.169	3.6 (0.8)	3.4 (0.7)	0.2 (-0.1-0.4)	0.179	3.8 (0.6)	3.4 (0.7)	0.4 (0.1-0.6)	0.004*
SWE-RES-23, subscale 4	3.7 (0.6)	3.6 (0.6)	0.1 (-0.2-0.3)	0.650	3.9 (0.7)	3.7 (0.6)	0.2 (0.1-0.5)	0.014*	3.8 (0.6)	3.7 (0.6)	0.1 (-0.1-0.3)	0.538
SWE-RES-23, subscale 5	3.6 (1.0)	3.6 (1.1)	0.0 (-0.4-0.4)	0.910	3.9 (0.9)	3.7 (1.1)	0.2 (-0.2-0.6)	0.295	3.9 (1.1)	3.9 (1.0)	0.0 (-0.4-0.3)	0.680
SWE-RES-23, total score	3.6 (0.6)	3.5 (0.6)	0.1 (-0.1-0.3)	0.344	3.9 (0.5)	3.6 (0.6)	0.3 (0.1-0.5)	0.005*	3.9 (0.5)	3.7 (0.5)	0.2 (0.0-0.4)	0.038*
ASA-A	85.7 (11.7)	86.8 (10.2)	-1.1 (-4.9-2.8)	0.594	87.4 (12.2)	86.7 (10.2)	0.7 (-3.2-4.6)	0.717	87.1 (11.4)	86.3 (10.8)	0.8 (-3.2-4.8)	0.702
SOC	65.9 (11.7)	64.4 (12.8)	1.5 (-3.1-6.1)	0.509	65.2 (11.8)	63.5 (13.1)	1.7 (-3.0-6.3)	0.483	67.6 (11.9)	64.4 (12.6)	3.2 (-1.3-7.8)	0.166

Independent t-test for comparison between groups

**p*<0.05 was considered as statistical significant difference

E.=Experimental

C.=Control

Table 3 Differences in the experimental group at baseline, 1-week post-intervention and 6-month post-intervention after a self-care promoting PBL-program.

n=38	Baseline	1-week post-intervention	6-month post-intervention	Baseline - 1-week post-intervention		Baseline - 6-month post-intervention		1-week post-intervention - 6-month post-intervention	
	Mean (SD)	Mean (SD)	Mean (SD)	Mean difference (95% CI)	<i>p</i>	Mean difference (95% CI)	<i>p</i>	Mean difference (95% CI)	<i>p</i>
PF	55.7 (23.5)	58.8 (25.6)	56.4 (25.9)	3.1 (-7.8-1.4)	0.173	0.7 (-6.0-4.4)	0.761	-2.4 (-2.3-7.1)	0.316
RP	45.4 (40.6)	55.3 (40.3)	50.7 (43.3)	9.9 (-22.9-3.2)	0.133	5.3 (-18.2-7.7)	0.417	-4.6 (-7.8-17.0)	0.455
BP	41.7 (18.0)	45.0 (21.7)	44.6 (19.7)	3.3 (-8.6-2.0)	0.209	2.9 (-7.7-1.7)	0.206	-0.4 (-5.6-6.3)	0.901
GH	48.2 (21.5)	50.5 (22.1)	52.2 (26.2)	2.3 (-6.3-1.7)	0.247	4.0 (-10.1-2.1)	0.193	1.7 (-7.1-3.7)	0.536
VT	40.5 (19.9)	40.0 (24.6)	47.1 (25.6)	-0.5 (-5.1-6.2)	0.852	6.6 (-13.2-0.0)	0.050	7.1 (-12.9- -1.3)	0.017*
SF	65.5 (26.2)	64.5 (28.4)	73.7 (28.0)	-1.0 (-6.4-8.3)	0.787	8.2 (-16.5-0.0)	0.050	9.2 (-16.7- -1.8)	0.017*
RE	64.0 (38.3)	57.9 (42.2)	60.5 (42.3)	-6.1 (-9.9-22.2)	0.444	-3.5 (-11.7-18.7)	0.644	2.6 (-17.3-12.1)	0.719
MH	70.3 (18.7)	65.7 (23.1)	71.8 (20.9)	-4.6 (-1.8-11.1)	0.153	1.5 (-8.1-5.2)	0.656	6.1 (-12.8-0.6)	0.073
SWE-RES-23, subscale 1	3.8 (0.7)	4.1 (0.6)	4.0 (0.6)	0.3 (-0.5- -0.1)	0.008*	0.2 (-0.4-0.1)	0.174	-0.1 (-0.1-0.3)	0.208
SWE-RES-23, subscale 2	3.5 (0.8)	3.9 (0.6)	3.9 (0.6)	0.4 (-0.6- -0.2)	0.001*	0.4 (-0.7- -0.2)	0.001*	0.0 (-0.2-0.2)	0.963
SWE-RES-23, subscale 3	3.4 (0.7)	3.6 (0.8)	3.8 (0.6)	0.2 (-0.4-0.1)	0.307	0.4 (-0.7- -0.1)	0.009*	0.2 (-0.5- -0.0)	0.026*
SWE-RES-23, subscale 4	3.7 (0.6)	3.9 (0.7)	3.8 (0.6)	0.2 (-0.4- -0.1)	0.002*	0.1 (-0.3-0.1)	0.167	-0.1 (-0.1-0.3)	0.160
SWE-RES-23, subscale 5	3.6 (1.0)	3.9 (0.9)	3.9 (1.1)	0.3 (-0.5- -0.0)	0.043*	0.3 (-0.6- 0.1)	0.145	0.0 (-0.3-0.3)	0.925
SWE-RES-23, total score	3.6 (0.6)	3.9 (0.5)	3.9 (0.5)	0.3 (-0.5- -0.1)	0.001*	0.3 (-0.5- -0.1)	0.008*	0.0 (-0.1-0.1)	0.839
ASA-A	85.7 (11.7)	87.4 (12.2)	87.1 (11.4)	1.7 (-3.8-0.4)	0.112	1.4 (-4.2-1.4)	0.315	-0.3 (-2.4-2.9)	0.843
SOC	65.9 (11.7)	65.2 (11.8)	67.6 (11.9)	-0.7 (-2.9-4.4)	0.686	1.7 (-4.5-1.1)	0.226	2.4 (-5.9-0.9)	0.155

Paired sample t-test for comparison in the experimental group

**p*<0.05 was considered as statistical significant difference

Table 4 Differences in the control group at baseline, 1-week post-intervention and 6-month post-intervention after a self-care promoting PBL-program.

n=124	Baseline	1-week post-intervention	6-month post-intervention	Baseline - 1-week post-intervention		Baseline - 6-month post-intervention		1-week post-intervention - 6-month post-intervention	
	Mean (SD)	Mean (SD)	Mean (SD)	Mean difference (95% CI)	<i>p</i>	Mean difference (95% CI)	<i>p</i>	Mean difference (95% CI)	<i>p</i>
PF	59.2 (23.2)	58.9 (25.3)	60.6 (24.4)	-0.3 (-2.7-3.4)	0.835	1.4 (-4.3-1.5)	0.340	1.7 (-4.6- 1.1)	0.227
RP	43.6 (41.7)	41.3 (41.7)	53.8 (40.8)	-2.3 (-5.0-9.4)	0.541	10.2 (-17.1- -3.4)	0.004*	12.5 (-19.8- -5.2)	0.001*
BP	44.0 (20.9)	45.4 (22.1)	48.4 (23.1)	1.4 (-5.1- 2.2)	0.446	4.4 (-8.4- -0.5)	0.027*	3.0 (-6.3-0.2)	0.063
GH	44.3 (21.8)	45.0 (20.9)	47.6 (22.5)	0.7 (-3.5-1.9)	0.566	3.3 (-6.1- -0.7)	0.016*	2.6 (-5.1- -0.1)	0.044*
VT	41.2 (24.8)	42.8 (24.4)	44.6 (25.1)	1.6 (-4.7- 1.6)	0.340	3.4 (-6.9- 0.3)	0.071	1.8 (-5.2-1.7)	0.312
SF	69.1 (27.8)	67.2 (30.8)	70.9 (28.1)	-1.9 (-3.3-7.2)	0.472	1.8 (-6.8-3.4)	0.507	3.7 (-8.5-1.2)	0.140
RE	61.3 (42.4)	64.2 (43.8)	66.1 (40.8)	2.9 (-10.6-4.7)	0.445	4.8 (-12.9-3.2)	0.235	1.9 (-9.6-5.9)	0.632
MH	69.8 (22.5)	68.8 (24.2)	72.0 (21.3)	-1.0 (-2.2-4.3)	0.521	2.2 (-5.7-1.3)	0.213	3.2 (-6.9-0.3)	0.075
SWE-RES-23, subscale 1	3.7 (0.7)	3.7 (0.6)	3.8 (0.6)	0.0 (-0.2-0.1)	0.302	0.1 (-0.2- -0.0)	0.048*	0.1 (-0.1-0.0)	0.267
SWE-RES-23, subscale 2	3.5 (0.7)	3.6 (0.7)	3.6 (0.7)	0.1 (-0.2-0.0)	0.066	0.1 (-0.3- -0.1)	0.001*	0.0 (-0.2-0.0)	0.215
SWE-RES-23, subscale 3	3.2 (0.8)	3.4 (0.7)	3.4 (0.7)	0.2 (-0.3- -0.0)	0.021*	0.2 (-0.3- -0.1)	0.003*	0.0 (-0.1-0.1)	0.414
SWE-RES-23, subscale 4	3.6 (0.6)	3.7 (0.6)	3.7 (0.6)	0.1 (-0.2-0.1)	0.512	0.1 (-0.3-0.0)	0.112	0.0 (-0.2-0.1)	0.254
SWE-RES-23, subscale 5	3.6 (1.1)	3.7 (1.1)	3.9 (1.0)	0.1 (-0.3-0.1)	0.326	0.3 (-0.6- -0.2)	<0.001*	0.2 (-0.4- -0.1)	0.001*
SWE-RES-23, total score	3.5 (0.6)	3.6 (0.6)	3.7 (0.5)	0.1 (-0.2-0.0)	0.052	0.2 (-0.2- -0.1)	<0.001*	0.1 (-0.1- -0.0)	0.030*
ASA-A	86.8 (10.2)	86.7 (10.2)	86.3 (10.8)	-0.1 (-1.2-1.3)	0.900	-0.5 (-1.0-1.8)	0.574	-0.4 (-1.0-1.6)	0.630
SOC	64.4 (12.8)	63.5 (13.1)	64.4 (12.6)	-0.9 (-0.6-2.3)	0.252	0.0 (-1.5-1.4)	0.957	0.9 (-2.5-0.7)	0.253

Paired sample t-test for comparison in the control group

**p*<0.05 was considered as statistical significant difference