



Shared decision-making aid for juvenile idiopathic arthritis: moving from informative patient education to interactive critical thinking

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Abstract

Objectives To develop and evaluate an illustrated, stand-alone, interactive evidence-based shared decision making (SDM) aid for JIA children; its ability to produce positive perceived involvement of JIA patients in their own management and its impact on their adherence to therapy, school absenteeism and treatment outcomes.

Methods The SDM aid was developed to offer information about the disease, risks and benefits of treatment. A multidisciplinary team defined SDM criteria based on international standards (IPDAS). Eight categories emerged as highly important for SDM. Each category was supported by simple illustrations in an interactive style. At the end of each category, the child is asked to make a decision in view of the information given. Ninety-four JIA children were provided with the tool, in a randomised controlled study, in comparison to a control group of 95 JIA patients treated according to standard protocols.

Results A total of 97.5% of the study children reported comprehensibility of more than 90%. The patients' adherence to therapy was significantly ($p < 0.01$) higher in the SDM group, whereas stopping DMARDs for intolerability was significantly higher in the control group at 12 months of treatment. There was a significant improvement in the patient-reported outcomes in the SDM group, and absence from school was significantly higher in the control group ($p < 0.01$).

Conclusions The developed SDM aid offered the children evidence-based information about the pros and cons of treatment options and improved their understanding of the disease and their ability to make an informed decision that is reflected on their adherence to therapy and better treatment outcomes.

Key Points

- This work represents the second generation of shared decision-making tools.
- The developed tool adopts an interactive style and enhances critical thinking, giving the patients the facility of making their own decision regarding their management.
- The work gives an example of core domain set of outcomes which can be used for shared decision-making interventions.

Keywords Adherence · Arthritis · Interactive thinking · JIA · Shared decision making

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Introduction

Clinical decisions in standard practice are often multifaceted, challenging and, whenever possible, should be patient-centred, with the treatment verdicts tailored to the individual patient's requirements [1]. The recent increase in therapeutic options for inflammatory arthritis has added to the complexity of the treatment decision-making process. Shared decision-making (SDM) is an emerging best practice approach in both behavioural and physical health that aims to help people, in treatment and recovery, have informed, meaningful, and collaborative discussions with their treating doctors about their health care services. SDM can simply be described as “when health professionals and patients work together” [2]. This puts the patients at the centre of decisions made about their own treatment and care. Consequently, SDM strengthens the collaboration between the treating clinicians and their patients by encouraging positive dialogue and discussion, which, in turn, is expected to reflect positively on the patients' management outcomes and disease control [3].

SDM in children living with inflammatory arthritis represents a unique challenge. Juvenile idiopathic arthritis (JIA) is the commonest form of joint inflammation affecting children and adolescents, continuing into adult life in 30% of the patients. Caring for children with JIA passes into 2 phases. In the first phase, childhood period, when parents/caregivers are the ones to look after the child, keep the hospital appointments and handle the prescribed medication. They also have a vested interest in the treatment-related decisions and bring different personal values or preferences into the equation [4, 5]. In several instances, many parents are left with unanswered queries, information needs, long-lasting concerns and worry about treatment adverse effects, suggesting the need for improved clinician-parent communication [6, 7]. The second is the adolescence phase during which JIA patients often wish to have an active and independent role in the decision-making process regarding their disease management [8]. Such desire to be involved in their own medical management may further complicate matters, particularly if their preferences differ from their parents' views [9–11]. Therefore, it is vital to have the capacity to facilitate children and adolescents empowerment to become engaged and informed medical decision makers.

SDM is often implemented through the use of decision aids. Most of the available aids are in the form of information leaflets [12, 13] or multi-step cards [14] without a true engagement in the decision-making process, hence, represents a passive way of patient education. Furthermore, in a large systematic review [15] of decision aids, which included 115 randomised controlled trials, results revealed that few of these studies, conducted in a family practice setting, included children, making it difficult to generalise these study outcomes to standard paediatrics practice [16]. This highlighted that there is room and need for a second generation of SDM aids able to

fill this gap and endorse an active role for the patients' in their own management.

The aim of this study was to develop an illustrated and interactive evidence-based SDM aid for JIA children and assess its impact on the treatment options, ability to enhance clinical response, adherence to therapy and patient-perceived involvement in decision making carried out based on the hypothesis that patient decision aids will be more effective than treatment decisions made based on standard formats.

Methods

Driven by the Cochrane review [17] of patient decision aids and the International Patient Decision Aids framework (IPDAS) [18], which identifies SDM tool as evidence-based tools designed to help people engage in deliberative treatment-related decision making by providing information on the options and outcomes relevant to health status, this project included an overall three-phase SDM aid development. The *first phase* is the development of the SDM tool and review by expert multidisciplinary faculty composed of decision experts, patient representatives, policymakers and JIA children (face validity). The *second phase* was a pilot testing of the tool acceptability. The *third phase* involved an evaluation of the SDM tool and its impact on the patients' adherence to therapy as well as reported outcomes.

The third phase was a randomised controlled clinical trial carried out in 4 centres over the years 2016–2018. Local ethical and methodological protocols (Ain Shams University, Cairo, Egypt) for approval of the study were followed (approval number: 17585). All patients or their parents/caregivers who participated in the study signed an informed consent to participate in the work and publish the material according to the declaration of Helsinki.

Phase I: development of the decision support tool

Driven by the Ottawa Decision Support Framework [19], the information, content and format of the SDM aid were developed via (a) systematic review of the available evidence and literature analysis in MEDLINE. Studies were included if they were published in the English language, reported primary data collected, had participants who were 16 years of age or younger and reported an outcome. Studies were determined to evaluate SDM if the term shared decision-making was used to describe the study, or if other terms were used to describe patient/caregiver participation with their health care providers in medical decision making; (b) expert multidisciplinary faculty input; (c) evaluation of the JIA patients' needs (identified through semi-structured individual patients/parents interview). Related themes were highlighted and grouped together under the domains they were intended to measure and

organised by conceptual categories and (d) input from all key informants. Information was gathered to draft the first version of the tool. Eight categories emerged as highly important for SDM: (1) What is arthritis? (2) Why do we treat arthritis? (3) What are my targets? (4) What are the available treatment options? (5) What are my chances of improvement? (6) How soon will the medications kick in and how to take them? (7) What are the potential side effects? and (8) For how long shall I take the medication? The construction of the draft was based on the following components identified according to the IPDAS collaboration quality checklist [20, 21] framework and the guiding principles of the Ottawa Decision Framework [18]: (1) Information about options and outcomes [22], (2) presentation of outcome probabilities, (3) values clarification, (4) coaching or guidance [23], (5) delivery of the SDM aid for participants and (6) revision of the SDM aid draft (Table 1).

Based on the fact that visual aids can improve understanding of health risks and treatment options [24], visual aids (Fig. 1) have been used whenever it would make the content easier to understand and facilitate independent decision-making. Table 1 summarises the visual aids used.

Phase 2: SDM acceptability assessment

The purpose of pilot testing was to ensure that the SDM aid was (1) clearly formatted, i.e. no queries had been asked by children or their caregivers, (2) acceptable to patients, i.e. no statements were found by the respondents to be offensive or embarrassing and (3) feasible for the children to complete (i.e. completion with ease and time-efficient). Forty JIA children diagnosed according to ILAR classification of JIA [25] were included in this part of the study. They represented 3 phases of the disease process: 30% early in the disease course < 2 years, 40% disease duration 2–5 years and 30% disease duration > 5 years. They were of different age groups, with variable disease activity measures. Twenty children were under the age of 12 years

old and the other 20 were above 12 years. All the JIA children were starting medical treatment either anti-inflammatory medication, conventional or biologic DMARD. The sample size of the patients included in this testing was based on Hertzog [26], suggesting a range of 20–40 participants to allow for sufficient variability in acceptability assessment of an intervention. Time taken per patient for this process was in the range of 25–30 min. The SDM aid draft was amended in view of these pilot testing outcomes.

Phase 3: validity and outcome measures

The purpose of this phase was to field test the SDM tool in the standard clinical setting adopting a blinded-randomised controlled approach.

Randomisation

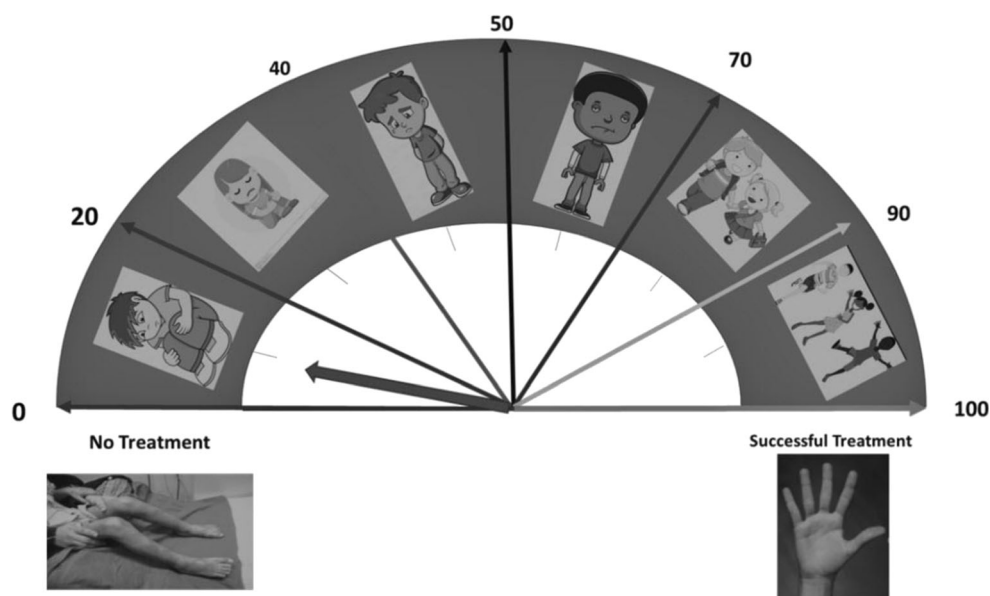
All patients suffering from JIA who attended the rheumatology clinics were assessed for eligibility. JIA children, diagnosed according to agreed published diagnostic criteria [25] who were due to start or switch to or from conventional or biologic DMARD, were included in this phase. Patients enrolled were allocated into two strata to be represented as study and control groups. Allocation concealment was adopted until intervention assignment. Patients were classified into two groups (groups I and II) regardless of their final allocation in relation to intervention. Different personnel were involved in the implementation of randomisation. Assessing eligibility and enrolment of patients were performed by one of the authors who was not involved in the process of random allocation. Participants were not aware of their allocation either in the study or the control group as well as the physician in charge of enrolment. Figure 2 shows a flow diagram displaying the way participants were enrolled in the study. The patients were monitored for 12 months.

Active group The developed stand-alone interactive tool was associated with 2 cover letters, one addressed for the parents (for children < 12 years old, it is intended that the tool will be reviewed by the children in the company of their parents) and another one addressed for the children > 12 years. One SDM tool was devoted to conventional DMARDs and another one for biologic DMARDs. A total of 110 JIA children were allocated to this group. Prior to assessment in the clinic, every patient completed a copy of the childhood-patient-reported outcome measures questionnaire (c-PROMs) [27]. To develop both estimates of effect size and variance for larger size randomised control trials, the sample size was selected based on Hertzog's recommendation [24] as well as the Cochrane data [16]. The final version of the SDM aid was made available to the patients in both printed paper as well as electronic

Table 1 Visual aids used in the shared decision-making aid for JIA

Emojis	To make numeric information easier to understand
Illustrated visual aids	To figure out treatment targets and help the children choose their individual desired treatment outcomes
Virtual risk tools	For possibility of having side effects
Visual progressometer	Progress indicator and chances of improvement in response to treatment. The child is asked "If you had a magic wand to improve your condition, what number would you set the indicator at?" Using such a visual aid gives the child some room to customise treatment options.
Therapeutic visual aids	To estimate the chances of developing side effects as well as the rate of halting joint damage and hand deformities when the child takes conventional or biologic

Fig. 1 Progressometer: if you had a magic wand to improve your condition, what number would set the indicator at? You can go anywhere up to 100



pdf format. All the patients had disease activity measured using JADAS-27 [28]. Time allowed per patient for completion of SDM tool was 30 min.

Control group A total of 110 JIA patients, were allocated to this group. Information regarding their treatment options was given using the standard protocols. Information leaflet about the agreed medication was handed to every patient. Each subject had their disease activity measure recorded as well as a blood check for inflammatory markers (ESR and CRP). Prior to assessment in the clinic, JADAS-27 disease activity score was evaluated and recorded.

The tool aimed to be implemented in standard practice to enhance the patients' ability to make a decision regarding their medical management, through changing knowledge, altering patients' informing beliefs about arthritis medications and better interpretation of medical status and enabling the patients to set up their own targets and treatment. Consequently, this should reflect on their disease activity status and functional ability as well as health-related quality of life. The tool was set up to be self-administered. The patients had access to the tool before their clinic visit. There was a specialist nurse, as well as the principal investigator, available in the centre to answer any query that patient/parent might have. The patients in both groups were assessed for:

(a) Its impact on patient-reported outcomes (c-PROMs) and disease activity: All the patients in both the study cohort and control group were managed according to the Treat-to-Target approach [29] aiming at disease remission or low disease activity status [30–33] and were assessed on a 3-month basis for a total period of 12 months. Measures assessed to evaluate the management outcomes included

functional disability, quality of life, stopping medication and absence from school as well as patient self-reported joint tenderness. Patient global assessment and patient motivation were recorded. To avoid information bias, all patients and doctors were instructed not to discuss their study intervention assignment with their treating rheumatologists or other patients. The treating physicians measuring the disease outcomes were not aware of the state of administration of the SDM tool.

- (b) Patient's perceived involvement in SDM: This was assessed using the nine-item Shared Decision-Making Questionnaire (SDM-Q-9). This is a validated tool consisting of nine statements measuring the process of SDM [34]. Response options were provided in the form of a four-point Likert scale ranging from 'strongly disagree' to 'strongly agree' [35]; a response option of 'not sure' was also included [36]. Patients were instructed to select one option that best matched their level of agreement to their perceived involvement in each step of the SDM process. Patients' responses for the SDM-Q-9 questionnaire were collapsed into three categories (agree, disagree and not sure). Parents were asked to complete the questionnaire if the children's age was less than 12 years old.
- (c) Adherence to therapy: Adherence, as defined by Cramer et al. [37], was evaluated using the parameters of compliance and persistence. Compliance was estimated by the medication possession ratio (MPR) and persistence by the time from treatment initiation to discontinuation with no medication refill gap for a period of 30 days or more during the period of interest. MPR was defined as the ratio of actually available doses against the expected doses that the patient should possess over a fixed period of

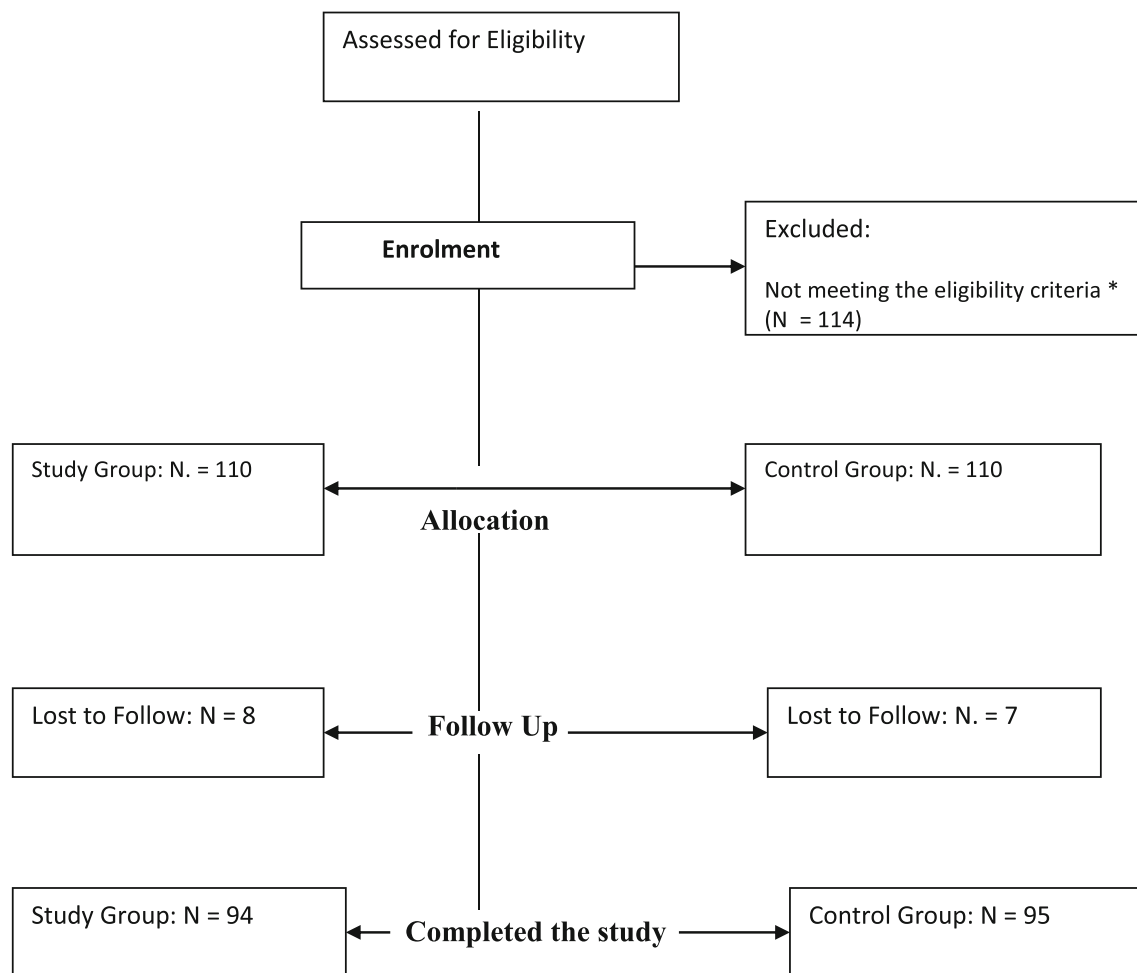


Fig. 2 Flow diagram displaying the way participants were enrolled in the study. *Eligibility criteria: JIA children, < 16 years old, diagnosed according to ILAR classification of JIA [25] who were due to start or switch to or from conventional or biologic DMARD

time. These measures were assessed over a 12-month period and were based on pharmacy data. Reasons for stopping DMARDs were recorded. Study patients were rated as having good compliance if the annual MPR $\geq 80\%$.

- (d) **Schooling:** Parents were asked to indicate the child's educational level (illiterate, primary, middle or high school) and whether or not they were currently attending school. Self-reported absence from school was used to record the number of days over the past 6 months that the child had been absent due to JIA. This was collected and then measured as percentage (number of absent days in relation to total school days).
- (e) **Comprehensibility and usefulness:** The final version of the SDM aid was tested for its usefulness and user-friendliness using visual analogue scale 0–100.

Primary endpoint

The development of a SDM aid promotes and supports informed arthritic children-rheumatologist decision

making about available treatment options and conducts preliminary construct as well as criterion validity testing.

Secondary endpoint

The secondary endpoint is the positive perceived involvement of JIA patients in their own management that would be reflected on treatment outcomes.

Statistical analysis

Data collected was entered into a database for data management and statistical analysis. Categorical variables are expressed as number and percentage, i.e. frequency tables, while quantitative scaled variables are presented as mean and standard deviation. Comparisons were carried out using the Mann-Whitney *U* test and Fisher's exact test where appropriate. Internal consistency was conducted by Cronbach alpha calculation. Alpha error was always set at 0.05. All statistical

manipulation and analyses were performed using the 16th version of SPSS [38]. Criterion validity was assessed by correlation of the SDM score with disease outcomes (functional ability, QoL, c-PROMS).

Results

Patient characteristics are shown in Table 2. Ninety-four JIA patients were included as a study group for the assessment of this SDM aid, whereas 95 JIA patients were included as a control group. On a scale from zero to 100, ‘user-friendliness’ scored a median of 88 (interquartile range [IQR] 73–96), ‘understandability’ 89 (IQR 81–95) and ‘feeling better informed’ 84 (IQR 71–90). The vast majority of patients stated the SDM aid offered additional value in their decision-making and 99% found the figures on possible risks clarifying rather than frightening. Totally, 97.5% of the patients included reported comprehensibility of > 90/100. There was a significant difference ($p < 0.001$) on comparing the number of children/parents who asked to speak to their physician before making a decision regarding their treatment choice (9/94), 9.6% of the active group versus (35/95) 36.8% of the control group.

The perceived level of involvement in treatment decision-making Results of the perceived level of involvement among respondents are summarised in (Table 3). A large proportion of the respondents in the study and control groups agreed that their doctor made it clear that a treatment decision needs to be

made (91.5% vs 88%) and informed them that different treatment options are available (91% vs 86%). However, there has been a significant difference ($p < 0.01$) when questions dealt with the patients’ level of involvement. Seventy per cent of the study group vs 30% of the control group agreed that their doctor wanted to know about their preferred involvement in decision-making. Eighty-eight per cent of the study group respondents agreed that they were involved in the selection of treatment options (vs 38% of the control group), whereas 89% reported that they reached an agreement with their doctor on how to proceed with treatment (vs 41% in the control group).

Adherence to therapy Results of the patients’ reaction toward their illness and its management, by 12 months of therapy, in both the active versus the control group are shown in Table 4. There was a significant main effect in the active group on subjects’ mean displays of adherence to medications. Results of the study revealed that 88.3% of patients in the study group were adherent to their drug therapy in comparison to 70.5% in the control group ($p < 0.01$).

Disease activity and c-PROMs In addition to adherence to therapy, the study group was less likely to stop their medication because of intolerance, more able to cope with their activities of daily living and have less concern about their future ($p < 0.01$). There was a trend towards better disease activity control in the study group (though it did not reach significant difference) in comparison to the control group. Completing the c-PROMs questionnaire was comparable in both groups assessed. 64/94 (68.1%) of the study group and 64/95 (67.4%) of the control group needed help to complete the questionnaire in the first visit, whereas 10/94 (10.6%) and 11/95 (11.6%) of the study and control groups, respectively, required help to complete the questionnaire in the last visit. Seventy-seven per cent of JIA patients were able to attend school while 2% had to stop their schooling and 21% were illiterate because of their illness making it difficult for them to attend the school regularly. School absenteeism was significantly ($p < 0.01$) less in the SDM group, whereas the quality of life measure was significantly ($p < 0.01$) better in the SDM group (Table 4).

Discussion

Critical thinking is the objective analysis of facts to form a judgement. Handling a subject like motivating the patients to be able to make a decision regarding their own management; represents a challenge to developing an interactive SDM tool. The tool is expected to include the rational and unbiased analysis, as well as evaluation of factual evidence regarding why to treat and treatment options. Results of this work revealed that the developed tool was well received by the patients who rated it as highly comprehensible. The tool helped the patients

Table 2 Comparison of age and baseline clinical and laboratory data in study groups

Characteristic	Study group	Control group
Number of patients	94	95
Age range (years)	6.1–15.25	6.25–15.5
Age (years) (mean $\pm$ SD)	12.7 $\pm$ 1.3	12.8 $\pm$ 1.5
Sex (females)	53/94 (57.4%)	54/95 (56.8%)
Disease duration (month $\pm$ SD)	9.7 $\pm$ 2.8	9.6 $\pm$ 3.1
Functional disability: cHAQ (0–3)	1.2 $\pm$ 0.4	1.1 $\pm$ 0.5
Quality of life (0–3)	1.5 $\pm$ 0.5	1.4 $\pm$ 0.6
JASDAS-27 (mean $\pm$ SD)	4.8 $\pm$ 2.8	4.7 $\pm$ 2.9
Prevalence of +ve rheumatoid factor	51.1%	51.6%
JIA subtypes		
Systemic onset	10 (10.6%)	11 (11.6%)
Oligoarticular	23 (24.4%)	24 (25.3)
Polyarticular—rheumatoid factor positive	42 (44.7%)	41% (43.2%)
Polyarticular—rheumatoid factor negative	14 (14.9)	15 (15.8)
Enthesitis-related arthritis	5 (5.3%)	4 (4.2%)

Table 3 Comparison of the respondents' reporting perceived involvement in the share decision-making group (94-JIA patients) versus the control group (95 JIA subjects)

Statement	Agree (%)		Not sure (%)		Disagree (%)	
	Active	Control	Active	Control	Active	Control
My doctor made clear that a decision needs to be made	91.5	88.0	5.5	8.0	3	4
My doctor told me that there are different options for treating my medical condition	91.0	86.0	7.0	11.0	2	4*
My doctor wanted to know exactly how I wanted to be involved in making the decision	70.0*	30.0	5.0	21.0*	25	49*
My doctor precisely explained the advantages and disadvantages of the treatment options	86.0*	43.0	9.0	34.0*	5	23*
My doctor helped me understand all the information	72.0*	36.0	21.0	33.0*	7	31*
My doctor asked me which treatment option I prefer	92.0*	15.0	5.0	44.0*	3	41*
My doctor and I thoroughly weighed the different treatment options	84.0*	24.0	10.0	43.0*	6	32*
My doctor and I selected a treatment option together	88.0*	38.0	7.0	32.0*	5	30*
My doctor and I reached an agreement on how to proceed	89.0*	41.0	6.0	30.0*	5	29*

make good decisions in collaboration with their treating doctors and endorsed embedding best practice in standard day-to-day management. The provision of evidence-based information about options, benefits and risks, together with decision grid, facilitated the active participation of the patients, taking into account their personal values and preferences. This reflected on the children's adherence to therapy, reported outcomes, absence from school and disease activity measures, as well as rates of stopping medications for intolerability. These findings agree with earlier published reports. A Cochrane database systematic review revealed that the use of SDM interventions has been shown to reduce decisional conflict (i.e. patients feeling unsure about their best choice), increase knowledge of treatment options, clarify patients' values, facilitate patient participation in decision-making and reduce overuse of interventions that are not beneficial for the majority [39]. Other studies also endorsed SDM as a best practice in patient-centred care [40], a recognised method to translate comparative effectiveness data into practice [39] and decrease unwarranted variation in

healthcare [41, 42]. No wonder clinical practice guidelines have endorsed SDM for the management of several of the musculo-skeletal conditions such as osteoarthritis, rheumatoid arthritis and psoriatic arthritis, as well as JIA [43–46].

This study relied on visual aids to conduct the message to the children, in an interactive stand-alone style, which reflected positively on the treatment outcomes. Traditionally, patients' instructions about treatment options, medication use, side effects and monitoring have been provided in a written format. Unfortunately, optimal learning does not always occur in this manner. Learning theory states that not all students (or patients) learn by reading written information. Visual aids were found as a better option for learning, including pictures, illustrations, and cartoons. In addition, the current media-dominated learning atmosphere makes the use of visual aids or any other visual format more attractive to both children and adults. It has been estimated that 65% of the population are thought to be visual learners—people who retain information better by seeing pictures and videos rather than reading text or hearing information delivered orally [47].

In the era of modern technology, litigious interactions, increase therapeutic options, rapid change in treatment protocols and onsite administrative obligations, the communication between health care providers and patients may be at an all-time low. This study highlights the complexity of patients' participation in SDM and provides a description of how JIA patients perceived their involvement in SDM, their preferences for participation and the factors affecting their contribution in SDM. Results of this work revealed that majority of the patients in the active group perceived that their physicians involved them in SDM. Studies of patient-physician interactions have revealed that a majority of patients have been interrupted by their physicians within the first 18 s after they begin to tell their stories and that many patients never get to tell the most urgent reason for their visit. This situation is potentially tragic since the comprehension of critical information passed from patients to physicians and from physicians to patients is often

Table 4 Patient-reported outcome measures, by 12 months of therapy, in the active vs the control group

Parameter	Study group	Control group
Absence from school (%) [95%CI]	20/94* (21.3%) [13.2–29.4]	32/95 (33.7%) [24.3–43.1]
Functional disability score: cHAQ (0–3) [95% CI]	0.4 ± 0.3* [0.34–0.46]	0.8 ± 0.2 [0.76–0.84]
Quality of life (0–3) [95% CI]	0.5 ± 0.3* [0.44–0.56]	0.9 ± 0.3 [0.87–0.93]
JADAS-27 score [95% CI]	3.1 ± 1.4 [2.82–3.38]	3.6 ± 1.3 [3.34–3.86]
Adherence to medication [95% CI]	83/94* (88.3%) [81.9–94.7]	67/95 (70.5%) [61.5–79.5]
Stopping DMARDs for intolerability [95% CI]	6/94 (6.4%) [4.5–8.3]	18/95* (18.9%) [11.1–26.7]

highly dependent on the quality of mutual communication [48]. On another front, a study carried out a qualitative assessment of the clinicians' current approaches to treatment decision-making in JIA [49]. Results revealed that the clinicians described a decision-making process in which they, rather than the patient, consistently initiated treatment decisions. Initial treatment options presented to the patients/families generally reflected the clinician's preferred treatment approaches, which differed across clinicians. Family members' preferences were seen as more integral in the decision to stop treatment after symptom remission. This highlighted the need to shift this 'clinician-driven trend' to a 'patient-centred approach'.

Challenges to our study were the illiteracy and trying to help the children filling their c-PROMs questionnaires particularly in the first visit or two; after that, there were no problems. Future developments could implement artificial intelligence in the SDM tool. Example is swapping the illustrations and figures by augmented reality models. Other limitations include using one database (MEDLINE) for the systematic review. Also, the results of this study are for the Arabic version of the tool. The English version is assessed in another work.

In conclusion, our findings make a meaningful contribution of SDM in children with JIA given the originality of the interactive shared decision tool. Understanding the current decision-making process in JIA and implementing visual aids play a vital role in developing tools for improving the quality of medical decisions. The adoption of SDM tools leads to improved decision quality, treatment outcomes and adherence to therapy as chosen treatments are consistent with patients' and parents' well-informed preferences.

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Author's contribution All authors contributed in the study methodology, analysis and interpretation of the data and outcomes as well as the manuscript writing, reading and approval of the final version. Prof. Wassif shared in the illustrations selection process and visual aids development. Prof. El Gaafary carried out statistical analysis and reviewed the methodology and results sections. Y. El Miedany developed the figures.

Compliance with ethical standards

Disclosures None.

References

1. El Miedany Y (2014) Adopting patient-centered care in standard practice: PROMs moving toward disease-specific era. *Clin Exp Rheumatol* 32(Suppl 85):S40–S46
2. NICE. Shared decision making. <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>. Accessed on 20 June 2018
3. El Miedany Y, El Gaafary M, Sayed S, Palmer D, Ahmed I (2016) Implementing shared decision making in clinical practice: outcomes of a new shared decision making aid for chronic inflammatory arthritis patients. *J Pat Care* 2:2
4. Lipstein EA, Brinkman WB, Britto MT (2012) What is known about parents' treatment decisions? A narrative review of pediatric decision making. *Med Decis Mak* 32:246–258
5. Lipstein EA, Brinkman WB, Fiks AG, Hendrix KS, Kryworuchko J, Miller VA, Prosser LA, Ungar WJ, Fox D (2015) An emerging field of research: challenges in pediatric decision making. *Med Decis Mak* 35:403–408
6. Lipstein E, Brinkman W, Sage J, Lannon CM, DeWitt EM (2013) Understanding treatment decision making in juvenile idiopathic arthritis: a qualitative assessment. *Pediatr Rheumatol* 11:34–40
7. Lipstein EA, Lovell DJ, Denson LA, Moser DW, Saeed SA, Dodds CM, Britto MT (2012) Parents' information needs in tumor necrosis factor-alpha inhibitor treatment decisions. *J Pediatr Gastroenterol Nutr* 65:244–250
8. Lipstein EA, Muething KA, Dodds CM, Britto MT (2013) "I'm the one taking it": adolescent participation in chronic disease treatment decisions. *J Adolesc Health* 53:253–259
9. Unguru Y, Sill AM, Kamani N (2010) The experiences of children enrolled in pediatric oncology research: implications for assent. *Pediatrics* 125:e876–e883
10. Beresford BA, Sloper P (2003) Chronically ill adolescents' experiences of communicating with doctors: a qualitative study. *J Adolesc Health* 33:172–179
11. Knopf JM, Hornung RW, Slap GB, DeVellis RF, Britto MT (2008) Views of treatment decision making from adolescents with chronic illnesses and their parents: a pilot study. *Health Expect* 11:343–354
12. Arthritis Research UK. <https://www.arthritisresearchuk.org/system/search-results.aspx?keywords=JIA>. Accessed on 20 June 2018
13. West Michigan Rheumatology PLLC. Patient Decision Aids. <http://www.mi-arthritis.com/patient-decision-aids/>. Accessed 20 June 2018
14. DeWitt EM, Lipstein EA, Staun K, Scherer L, Taylor J, Lannon CM, Brinkman W (2014) A178: development of tools to facilitate shared decision making about medications for juvenile idiopathic arthritis—a project of the pediatric rheumatology care and outcomes improvement network. *Arthritis Rheumatol* 66(S3):S232–S233
15. Legare F, Labrecque M, LeBlanc A (2011) Training family physicians in shared decision making for the use of antibiotics for acute respiratory infections: a pilot clustered randomized controlled trial. *Health Expect* 14(suppl 1):96–110
16. Wyatt K, List B, Brinkman W, Lopez G (2015) Shared decision making in pediatrics: a systematic review and meta-analysis. *Acad Pediatr* 15:573–583
17. O'Connor AM, Tugwell P, Wells GA, Elmslie T, Jolly E, Hollingworth G, McPherson R, Bunn H, Graham I, Drake E (1998) A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. *Patient Educ Couns* 33:267–279
18. International Patient Decision Aid Standards Collaboration 2006: Checklist for Judging the Quality of Patient Decision Aids. http://ipdas.ohri.ca/IPDAS_checklist.pdf website. Accessed 20 June 2018
19. Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A et al (2006) International patient decision aids standards (IPDAS) collaboration: developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ* 333:417–423
20. Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M (2011) Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 10:Art. No.: CD001431

21. Ottawa Personal Decision Guide, 2-page interactive PDF. <http://decisionaid.ohri.ca/decguide.html> website. Accessed 20 June 2018
22. Aletaha D, Neogi T, Silman A, Funovits J, Felson D (2010) 2010 Rheumatoid arthritis classification criteria: an American College of Rheumatology/European League Against Rheumatism collaborative initiative. *Ann Rheum Dis* 69:1580–1588
23. Zeidler H, Amor B (2011) The assessment in Spondyloarthritis International Society (ASAS) classification criteria for peripheral arthritis and for spondyloarthritis in general: the spondyloarthritis concept in progress. *Ann Rheum Dis* 70:1–3
24. Garcia-Retamero R, Cokely ET (2013) Communicating health risks with visual aids. *Curr Dir Psychol Sci* 22:392–399
25. Petty RE, Southwood TR, Manners P et al (2004) International League of Associations for Rheumatology classification of juvenile idiopathic arthritis: second revision Edmonton. *J Rheumatol* 31: 390–392
26. Hertzog M (2008) Considerations in determining sample size for pilot studies. *Res Nurs Health* 31:180–191
27. El Miedany Y, Lotfy H, El Arousy N, Mekawy D, Nasef SI, Hassan W, El Deriny G, Farag Y, Eissa M, Almedany S, El Gaafary M, on behalf of PRINTO Egypt (2018) Facilitating patient centred care: the development of illustrated multidimensional patient reported outcome measure for children with juvenile idiopathic arthritis. *Ann Rheum Dis* 77:502
28. Consolaro A, Ruperto N, Bazso A, Pistorio A, Magni-Manzoni S, Filocamo G, Malattia C, Viola S, Martini A, Ravelli A, Paediatric Rheumatology International Trials Organisation (2009) Development and validation of a composite disease activity score for juvenile idiopathic arthritis. *Arthritis Care Res* 61:658–666
29. Consolaro A, Negro G, Lanni S, Solari N, Martini A, Ravelli A (2012) Toward a treat-to-target approach in the management of juvenile idiopathic arthritis. *Clin Exp Rheumatol* 30(Suppl 73): S157–S162
30. Wallace CA, Ruperto N, Giannini E (2004) Preliminary criteria for clinical remission for select categories of juvenile idiopathic arthritis. *J Rheumatol* 3:22904
31. Magni-Manzoni S, Ruperto N, Pistorio A et al (2008) Development and validation of a preliminary definition of minimal disease activity in patients with juvenile idiopathic arthritis. *Arthritis Rheum* 59: 11207
32. Consolaro A, Ruperto N, Bracciolini G et al (2014) Defining criteria for high disease activity in juvenile idiopathic arthritis based on the juvenile arthritis disease activity score. *Ann Rheum Dis* 73: 13803
33. Consolaro A, Bracciolini G, Ruperto N et al (2012) Remission, minimal disease activity, and acceptable symptom state in juvenile idiopathic arthritis. *Arthritis Rheum* 64:236674
34. Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M (2010) The 9-item shared decision making questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. *Patient Educ Couns* 80:94–99
35. Simon D, Schorr G, Wirtz M (2006) Development and first validation of the shared decision-making questionnaire (SDM-Q). *Patient Educ Couns* 63:319–327
36. Chin Maha H, Muthupalaniappenb L, Chonga W (2016) Perceived involvement and preferences in shared decision-making among patients with hypertension. *Fam Pract* 33:296–301
37. Cramer JA, Roy A, Burrell A, Fairchild CJ, Fuldeore MJ, Ollendorf DA, Wong PK (2008) Medication compliance and persistence: terminology and definitions. *Value Health* 11:44–47
38. SPSS Inc Released 2007. SPSS for windows, version 16.0. Chicago, SPSS Inc
39. Stacey D, Légaré F, Col NF, Bennett CL, Barry MJ, Eden KB et al (2017) Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 1:CD001431
40. Barry M, Edgman-Levitan S (2012) Shared decision making - pinnacle of patient-centered care. *N Engl J Med* 366:780–781
41. O'Connor A, Llewellyn-Thomas H, Flood A (2004) Modifying unwarranted variations in health care: shared decision making using patient decision aids. *Health Aff (Millwood)*. Suppl Variation: VAR63–VAR72. <https://www.ncbi.nlm.nih.gov/pubmed/15471770?dopt=Citation>. Accessed 20 June 2018
42. Brinkman W, Lipstein E, Taylor J, Schoettker P, Naylor K, Jones K et al (2017) Design and implementation of a decision aid for juvenile idiopathic arthritis medication choices. *Pediatr Rheumatol* 15: 48–56
43. Smolen JS, Aletaha D, Bijlsma JW, Breedveld FC, Boumpas D, Burmester G et al (2010) T2T Expert Committee. Treating rheumatoid arthritis to target: recommendations of an international task force. *Ann Rheum Dis* 69:631–637
44. Hochberg M, Altman R, Toupin April K, Benkhalti K, Guyatt G, Maxwell L et al (2012) American College of Rheumatology 2012 recommendations for the use of nonpharmacologic and pharmacologic therapies in osteoarthritis of the hand, hip and knee. *Arthritis Care Res* 64:465–474
45. Smolen JS, Landewé R, Breedveld FC, Buch M, Burmester G, Dougados M, Emery P, Gaujoux-Viala C, Gossec L, Nam J, Ramiro S, Winthrop K, de Wit M, Aletaha D, Betteridge N, Bijlsma J, Boers M, Buttgerit F, Combe B, Cutolo M, Damjanov N, Hazes JMW, Kouloumas M, Kvien TK, Mariette X, Pavelka K, van Riel PLCM, Rubbert-Roth A, Scholte-Voshaar M, Scott DL, Sokka-Isler T, Wong JB, van der Heijde D (2014) EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2013 update. *Ann Rheum Dis* 73:492–509
46. Ravelli A, Consolaro A, Horneff G, Laxer RM, Lovell DJ, Wulffraat NM, Akikusa JD, Al-Mayouf SM, Antón J, Avcin T, Berard RA et al (2018 Jun) Treating juvenile idiopathic arthritis to target: recommendations of an international task force. *Ann Rheum Dis* 77(6):819–828
47. Gossec L, Smolen JS, Ramiro S, de Wit M, Cutolo M, Dougados M, Emery P, Landewé R, Oliver S, Aletaha D, Betteridge N, Braun J, Burmester G, Cañete JD, Damjanov N, FitzGerald O, Haglund E, Helliwell P, Kvien TK, Lories R, Luger T, Maccarone M, Marzo-Ortega H, McGonagle D, McInnes IB, Olivieri I, Pavelka K, Schett G, Sieper J, van den Bosch F, Veale DJ, Wollenhaupt J, Zink A, van der Heijde D (2016) European League Against Rheumatism (EULAR) recommendations for the management of psoriatic arthritis with pharmacological therapies: 2015 update. *Ann Rheum Dis* 75:499–510
48. National assessment of adult learning (NAAL) demographics. https://nces.ed.gov/NAAL/kf_demographics.asp. Accessed 20 June 2018
49. Klamen D, Bindel L (1996) Visual aids for communicating information to patients: an excellent second step. *Acad Emerg Med* 3: 200–201

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