Sykepleiedrevet overgangspoliklinikk for pasienter med barneleddgikt

Bakgrunn

Overgang fra barn til voksen

Som et resultat av utviklingen innen medisinsk teknologi og behandling har det blitt en betydelig økning i antall unge mennesker med kronisk sykdom og/eller funksjonshemninger som overlever inn i voksen alder (Christie & Viner, 2009).

Økningen i antall unge med kroniske tilstander har ført til at det er satt fokus på overgangen fra barndom til voksent liv i helsetjenesten. Ungdomstiden er en periode i livet der det skjer store forandringer fysisk, psykisk og sosialt i den enkeltes liv. I tillegg til de "normale" endringene må unge med kroniske tilstander samtidig lære seg å ta ansvar for egen helse. Helsepersonell trenger kompetanse på unges utvikling og helse, slik at vi blir i stand til å bistå de unge gjennom overgangen til voksent liv. Dette innebærer at "transition" ikke bare sees som en administrativ hendelse omkring overføring fra barne-til voksenhelsetjeneste ("transfer"), men som en holistisk prosess med et livsløpsperspektiv (Brooks, Bunn, & Morgan, 2009).
Overgangsomsorg med god kvalitet innebærer at overgangen er en prosess og ikke bare en enkelthendelse, at kommunikasjonen er effektiv, at koordineringen fungerer både tverrfaglig og tverretatlig, og at den unge deltar som en sentral aktør.

Det er et fåtall tjenester som har implementert transition policies som er identifisert og anbefalt av de unge, deres familier, multidisiplinære team og berørt voksenhelsetjeneste, på tross av at det er enighet om de unges grunnleggende behov (Berg-Kelly, 2010; Christie & Viner, 2009).

Juvenil Idiopatisk Artritt (JIA)

JIA er den vanligste revmatologsike sykdommen som debuterer i barneår. Rundt 50 % av pasientene med JIA har en aktiv sykdom i voksen alder (Minden, 2009). Ved St. Olavs Hospital er det i dag praksis at disse pasientene overføres til voksenavdeling ved 18 års alder. Disse pasientene blir satt opp til ordinære kontroller hos revmatolog på voksenavdeling etter overgang fra barneavdeling. Pasienter med JIA har sammensatte behov som er utover det rent medisinske, som fysiske begrensinger, redusert funksjon og sosiale utfordringer (Eyckmans, Hilderson, Westhovens, Wouters, & Moons, 2011; Minden, 2009).

Sykepleierdrevet poliklinikk

Tradisjonelt har sykepleiere hatt en assisterende rolle i forhold til legene ved revmatologisk poliklinikk. De har drevet med undervisning, opplæring og "revmaskoler", men ikke hatt ansvar for håndtering av sykdommen. De siste årene har sykepleiere med videreutdanning i revmatologisk sykepleie hatt legedelegerte oppfølgingskonsultasjoner. Dette er konsultasjoner som tidligere ble gjennomført av leger. Pasientene som blir fulgt opp av sykepleier har ikke behov for hyppigere kontroller enn pasientene fulgt opp av revmatolog.

Det er nå gjennomført en randomisert kontrollert studie for å måle effekten av disse legedelegerte konsultasjonene (Koksvik et al., 2013). De publiserte resultatene viser at pasientene blir trygt og effektivt ivaretatt med den nye organiseringsformen og pasienttilfredsheten er økende. *Spesielt viser studien at oppfølging hos sykepleier gir pasietene en opplevelse av økt kontinuitet og trygghet (Koksvik et al., 2013) noe som er angitt som viktig av både pasienter og helsepersonell i overgangen fra barneavdeling til voksenavdeling.*

Gjennom å individualisere oppfølgingen av disse pasientene ved bruk av sykepleiedrevet overgangspoliklinikk kan man sette pasientene i stand til å ta større ansvar for egen sykdom og

helse, og hjelpe dem til å leve livet på best mulig måte til tross for sin kroniske sykdom. Dette vil igjen redusere behovet for oppfølging fra spesialisthelsetjenesten.

Som en videreføring av legedelegerte sykepleiekonsultasjoner er det nå utviklet et opplæringsprogram for utdanning av sykepleiere i ultralyd. Dette programmet inneholder høyskoleutdanning, hospitering samt internasjonalt anerkjente ultralydkurs. Det er nå tre sykepleiere som vil fullføre dette programmet innen desember 2013. Dette medfører at disse sykepleierne kan gjennomføre komplette kontroller inkludert ultralyd.

Mål

Målet med prosjektet:

- Opprettelse av sykepleiedrevet overgangspoliklinikk for pasienter med barneleddgikt i alderen 18-25 år.

Delmål:

- Gi et effektivt individrettet behandlingtilbud med fokus på kontinuitet i overgangen fra barn til voksen, slik at de unge får mulighet til å ta større ansvar for eget liv og egen helse, og behovet for bistand fra spesialisthelsetjenesten reduseres.

Metodikk/Effektmål

Prosjektet er ikke tenkt gjennomført som en randomisert studie og måling av effekt vil derfor ikke være hovedintensjon med prosjektet. Måling av compliance hos denne pasientgruppen vil gjennomføres før og etter prosjektperiode. Dette måles med oppmøtefrekvens på polikliniske kontroller satt etter avdelingens prosedyre for oppfølging av denne pasientgruppen.

Framdrift

Hovedaktiviteten i prosjektet vil være opprettelse av en sykepleiedrevet overgangspoliklinikk for pasienter med barneleddgikt i alderen 18-25 år.

Aktivitet

- Hospitering ved Nasjonal kompetansetjeneste for barne- og ungdomsrevmatologi (NAKBUR) ved Rikshospitalet i en uke (februar 2014). Ved dette oppholdet skal det knyttes kontakter og se på opplegget Helse SørØst har for overføring fra barneavdeling til voksenavdeling

- Hopitering ved Transitional Care Clinic ved The Newcastle upon Tyne Hospital, Storbritannia i en uke (mai 2014). Dette er en overføringsklinikk basert på evidensbasert forskning med fokus på de individuelle behovene pasienten har i denne fasen av livet

- Implementering og organisering av overgangspoliklnikk januar 2014-desember 2014

Etter endt prosjektperiode (januar 2014 til desember 2014) vil sykepleierne være i stand til å gjennomføre komplette kontroller inkludert ultralydundersøkelse av pasienter med barneleddgikt, og kunne gi disse et individrettet og effektivt tilbud i overgangen fra barn til voksen.

Det vil være behov for å implementere og organisere overgangspoliklinikken i daglig drift. I implementeringsfasen vil det være behov for en sykepleier som har ansvaret for organisering og gjennomføringen av konsultasjonene. Når denne implementeringen er over, vil tilbudet være en del av daglig drift.

Prosjektorganisering

St. Olavs Hospital har en Nasjonal kompetansetjeneste for svangerskap og revmatiske sykdommer (NKSR). Det er naturlig at en overgangspoliklinikk er knyttet til denne kompetansetjenesten. Ved NKSR er det ansatt to masterutdannede sykepleiere som i dag gjennomfører legedelegerte sykepleiekonsultasjoner og som i tillegg tar utdanning i ultralyd. Kompetansen er derfor høy nok ved NKSR til at prosjektet kan lykkes i både gjennomføring og implementering.

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Budsjett

Hospitering ved Rikshospitalet i en uke, reise og opphold (2 sykepleiere)	10.000,-
Hopitering ved The Newcastle upon Tyne Hospital, Transitional Care Clinic i en uke, reise og opphold (2 sykepleiere)	20.000,-
Innleie av ekstra sykepleiere ved fravær ved deltakelse kurs og hospitering	20.000,-
Oppstart og organisering av overgangspoliklinikk 100% stilling sykepleier	600.000,-
Totalt	**650.000,-**

Prosjektets betydning

I dag gjennomførers kontroller av pasienter med barneleddgikt av revmatologer i den ordinære revmatolgiske poliklinikken. Fokus på overgangen fra barn til voksen med et individrettet tilbud drevet av sykepleiere, vil kunne føre til økt compliance, mer effektive konsultasjoner som igjen kan øke kapasiteten og redusere køen for polikliniske kontroller ved revmatologisk avdeling.

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Vedlegg:

Vedlegg 1

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ARD Online First, published on February 7, 2013 as 10.1136/annrheumdis-2012-202296

EXTENDED REPORT

Patient satisfaction with nursing consultations in a rheumatology outpatient clinic: a 21-month randomised controlled trial in patients with inflammatory arthritides

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Handling editor Hans WJ Bijlsma

▶ Additional material is published online only. To view please visit the journal online (http://dx.doi.org/10.1136/annrheumdis-2012-202296).

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Received 2 July 2012
Revised 11 January 2013
Accepted 13 January 2013

ABSTRACT

Objective To study the effect of individual nursing consultations in patients treated with disease-modifying antirheumatic drugs (DMARDs) in a rheumatology outpatient setting.

Methods Patients with inflammatory arthritides (IA) who had started with a DMARD regimen 3 months before were randomised to two different follow-up consultation systems: either follow-up by a clinical nurse specialist (CNS) or by a medical doctor (MD) in rheumatology 3, 9 and 21 months after randomisation. The primary outcome was patient satisfaction measured by Leeds Satisfaction Questionnaire (LSQ). Secondary outcomes included coping, disease activity, pain, fatigue, patient's global assessment of disease activity and health related quality of life. Effects at 9 and 21 months were estimated by Least Square means calculated from the final mixed model.

Results Of 68 patients randomised, 65 patients completed assessments at 21 months. Statistically significant improvements in favour of the CNS group were found in all LSQ subscales (all p values <0.001) and in overall satisfaction at 9 months (adjusted mean between-group difference 0.74, 95% CI −0.96 to −0.52) and at 21 months (−0.69, 96% CI −0.87 to −0.50). Disease activity Score 28 joint count (DAS-28) was improved from baseline to 9 months in both groups and improvement was maintained at 21 months, but without any group difference. No statistically significant between-group differences were found in any of the other secondary outcomes.

Conclusions Patients with IA are likely to benefit from nurse consultations in terms of increased satisfaction with care compared with MD consultations and without loss of efficacy in terms of clinical outcomes.

The study is registered as a clinical trial at the ClinicalTrials.gov (NCT00403676).

INTRODUCTION

Inflammatory arthritides (IA), such as rheumatoid arthritis (RA), ankylosing spondylitis (AS), psoriatic arthritis (PsA) and juvenile idiopathic arthritis (JIA), may have major impact on patients' physical and psychological health, social functioning and work ability with fluctuations over time.[1–7]

New recommendations for management of RA, AS and PsA stress that patients should have rapid access to specialised rheumatology care in order to get an early diagnosis and receive targeted treatment. Furthermore, the treatment should be based on shared decisions between patients and clinicians and maximise long term health related quality of life (HRQOL) through tight monitoring and control.[8–10] To meet these recommendations, several rheumatology departments have undergone changes in the way their service is organised. In some countries, including Norway, clinical nurse specialists (CNSs) have been trained to undertake more advanced and extended roles, such as assessing disease activity, monitoring patients on disease-modifying antirheumatic drugs (DMARDs) and recommending adjustments of drug treatment.[11–13] Moreover, educating patients to better manage their disease and symptoms, providing telephone advice lines, making referrals to other health professionals and psychosocial counselling are commonly addressed by the CNSs.[14–16] The recently published The European League Against Rheumatism (EULAR) recommendations for the role of the nurse in the management of IA, emphasise that the competencies and skills of the nurse should be optimised to further improve patient care.[14] The effectiveness of nurse-led rheumatology care versus usual care was examined in a recent systematic review.[17] Significant effects in favour of nurse-led care were seen in HRQOL, patient knowledge and fatigue. Effects on disease activity and functional status did not differ significantly between nurse-led care and rheumatologist care or multidisciplinary care in patients with RA. Because only four studies were included in this review, more randomised controlled trials (RCTs) are needed to further investigate the effects of nurse-led care.

Patient satisfaction is assumed to be an important indicator of quality of care.[18] Satisfaction with care is found to improve adherence to treatment, functional status, overall well-being and future health related behaviours in various chronic diseases.[19 20] Patient satisfaction is one of the outcomes that has been found to be modifiable in previous studies of nurse-led care in rheumatology.[21]

The primary aim of this study was to investigate the effects of individual nursing consultations compared with rheumatologist consultations on patient satisfaction in a rheumatology outpatient clinic. Moreover, we wanted to investigate if there were any comparative differences in effects on disease

To cite: Koksvik HS, Hagen KB, Rødevand E, *et al. Ann Rheum Dis* Published Online First: [*please include* Day Month Year] doi:10.1136/annrheumdis-2012-202296

activity, disease related symptoms, HRQOL and coping strategies. We hypothesised that patient satisfaction would be equal or higher in patients who were followed up by a CNS compared with patients who were followed up by a medical doctor (MD) and that there would be no differences between the two groups in other outcomes.

METHODS

Study design

In this RCT, patient consultations by a CNS were compared with consultations by an MD in rheumatology. The study was conducted at St. Olavs Hospital in Trondheim, Norway, and was nested within an ongoing Norwegian prospective multicentre longitudinal observational study (the NOR-DMARD).[22] IA patients who start on a DMARD and give their informed consent are included in the NOR-DMARD and assessed before initiation of treatment, at 3, 6 and 12 months follow-up and yearly thereafter. Patients were randomised in the RCT at the 3-month follow-up in NOR-DMARD, which then served as the baseline in the RCT. Follow-up visits in the RCT were after 3, 9 and 21 months (figure 1).

Patients

Inclusion criteria in the NOR-DMARD-register are age >18 years, confirmed IA diagnosis, that is, RA, AS, PsA, JIA or undifferentiated polyarthritis. Between February and October 2006, a senior rheumatologist assessed all patients at their second NOR-DMARD visit for eligibility to the present RCT. The second 3-month NOR-DMARD visit was chosen as baseline in the RCT as the chief rheumatologist could assess if the patient had responded to the DMARD therapy. Exclusion criteria were unwillingness to be followed up by a CNS, change of DMARD, uncontrolled disease activity as determined by the rheumatologist or unstable concomitant disease. Patients received oral and written information about the RCT and gave informed consent before inclusion.

Interventions

The nursing consultations were provided by two CNSs. Each of them had more than 10 years of clinical experience in rheumatology. Additionally, they had undertaken advanced education; one of them had completed a Masters degree including a clinical rheumatology study and the other had completed a rheumatology specialist postgraduate University course (60 ECTS). The patients met the same nurse at each visit. The nurses' disease assessments were described in a thematic check list and included disease activity (joint examination, laboratory tests and patient's global assessment (PGA)), comorbidity, medication use, functional and psychosocial status. Moreover, the nurses provided education and counselling addressing self-management strategies

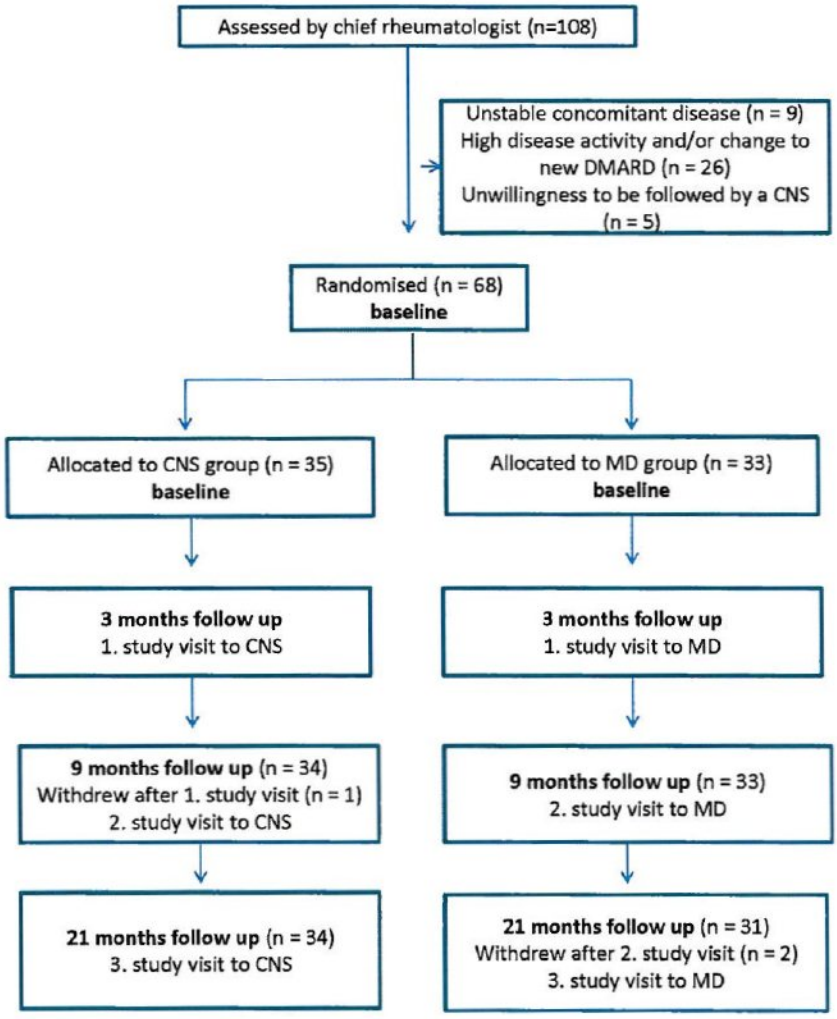

Figure 1 Flow chart of participants. CNS, clinical nurse specialist; DMARD, disease-modifying antirheumatic drug; MD, medical doctor.

that were tailored to the individual patient's needs. The CNSs had open access to a rheumatologist for medical advice, assistance with articular injections and prescription of medications.

Six different MDs undertook the control group consultations, four of them were rheumatologists and two were in their last year of specialist training. Each patient could meet different MDs during the study period. The MD arm of this RCT reflects treatment as usual in Norwegian outpatient clinics.

The CNSs and MDs managed the patients according to their usual practice. Each consultation lasted for 30 min including time for administration and documentation.

Primary outcome

The primary outcome measure was patient satisfaction assessed by the Leeds Satisfaction Questionnaire (LSQ), which is designed to measure satisfaction among patients attending a rheumatology outpatient clinic[23] and was completed after the consultation at baseline and after 9 and 21 months in the RCT. Patients indicate their level of agreement with a series of 45 statements by ticking boxes on a 5-point Likert scale from 1 (strongly agree) to 5 (strongly disagree). The questionnaire comprises six subscales: general satisfaction, information, empathy, technical competence, attitude, access and continuity and one overall satisfaction scale. Translation and cross-cultural adaptation of the LSQ into Norwegian was carried out according to the International Quality of Life Assessment Project guidelines and showed satisfactory psychometric properties.[24 25]

Secondary outcomes

Secondary outcomes included coping with rheumatic stressors, disease activity, pain, fatigue, PGA and HRQOL.

Coping was assessed after the consultation at baseline and after 9 and 21 months by the Coping with Rheumatic Stressors questionnaire (CORS),[26] which is IA specific and includes eight coping strategies related to the IA stressors pain, limitations and dependency. The CORS comprises three pain subscales (comforting cognitions, decreasing activities and diverting attention), three coping with limitation subscales (optimism, pacing and creative solution seeking) and two dependency subscales (accepting one's level of dependency and showing consideration). Each item is scored on a 4-point Likert scale (from 1='seldom or never' to 4='very often'), and each subscale is calculated by summing the scores of the individual items. Higher values on the scale indicate more frequent use of this coping strategy.

Disease activity was assessed by the Disease Activity Score 28 joint count (DAS-28) score based on erythrocyte sedimentation rate.[27] Joint pain, fatigue and PGA were assessed by 100 mm Visual Analogue Scales anchored by 0 (no pain/fatigue/symptoms) and 100 (intolerable pain/fatigue/very bad symptoms).

HRQOL was assessed using the Medical Outcome Study Short Form-36 (SF-36).[28] The 36 items in the SF-36 are grouped into eight multi-item scales including physical functioning, physical role limitations, emotional role limitations, bodily pain, social functioning, mental health, vitality and general health perceptions. Each scale is expressed with values from 0 to 100 (0=poorest possible health state, 100=best possible health state). The SF-36 has been translated and validated in Norwegian patients with RA.[29 30] The questionnaires were delivered and collected by a secretary not involved in the study. Joint examination was performed by the respective professional and based on the EULAR handbook of clinical assessment in RA.[31]

Sample size calculations

We used the overall score of the LSQ in a small pilot study with 35 cases for sample size calculation. Based on this study, the SD was estimated to 0.67. With a conservative estimate for minimal clinical important difference (MCID) of half an SD,[32] we defined the MCID of LSQ to 0.5. A minimum of 28 patients in each group would be needed to detect an improvement of 0.5 on LSQ with 80% power (type II error) at the 5% significance level (type I error). We decided to include 68 patients allowing for a maximum of six drop-outs in each group.

Randomisation

The randomisation was carried out using an internet web-based trial service provided by the Norwegian University of Science and Technology. This was a computerised block randomisation with stratification for gender. All persons involved in the study were blinded to the block sizes. The participants were assigned either a follow-up by a CNS (intervention group) or a rheumatologist (control group). After randomisation, patients were given appointments with their respective practitioners for the 3, 9 and 21-month follow-up visits.

Statistical analysis

Analyses were carried out using both intention to treat and per protocol methods as advocated in the extended CONSORT guidelines.[33] Results are described as intention to treat as they did not differ from per protocol. Treatment effects (mean differences in outcomes between the two groups at 9 and 21 months) were estimated with mixed models repeated measures Analysis Of Variance (ANOVA). This model includes the interaction of treatment and time (ie, 9 and 21 months) and allows adjustment for individual baseline scores. For each outcome measure, we also adjusted for education, disease duration, gender and age. The final model included assessments of interaction and confounding (change in estimate of at least 25%), but none were found. The model assumptions were assessed using marginal and conditional studentised external residuals. We used the Cook's d to assess the influence on the parameter estimates, as well as the DFFits to assess the influence on the predicted and fitted values. Additionally, within group changes were calculated by paired sample t tests.

The statistician was blinded to group allocation while performing the analyses. The analyses were performed using SPSS V.18.

RESULTS

Patient characteristics

From a total of 108 patients assessed by the chief rheumatologist at the RCT baseline, 68 were randomised, 35 assigned CNS consultations and 33 assigned MD consultations (figure 1). Demographic and disease characteristics were well balanced between the two groups (table 1). The patients had low disease activity (mean DAS-28=3.0).

One patient from the CNS group and two from the rheumatologist group withdrew from the study after the first and the second visit, respectively. The flow of participants through the RCT is illustrated in figure 1. No adverse events were reported throughout the study.

Primary outcome

The overall satisfaction with care (LSQ overall score) was relatively high in both groups before randomisation, mean scores

Table 1 Baseline characteristics of 68 patients randomised for follow-up by a clinical nurse specialist (CNS) or a medical doctor (MD)

	All patients (n=68)	CNS group (n=35)	MD group (n=33)	p Values*
Demographic variables				
Age, years	50 (12.9)	49 (13.3)	51 (12.6)	0.75
Female	46 (68)	25 (71)	21 (64)	0.61
Educational level				0.52
Compulsory school	13 (19)	5 (15)	8 (24)	
High school	36 (53)	19 (54)	17 (52)	
College/university	19 (28)	11 (31)	8 (24)	
Diagnoses				0.21
Rheumatoid arthritis	36 (53)	19 (54)	17 (52)	
Psoriatic arthritis	6 (9)	6 (17)	0 (0)	
Juvenile idiopathic arthritis	5 (7)	1 (3)	4 (11)	
Ankylosing spondylitis	10 (15)	4 (11)	6 (18)	
Undifferentiated polyarthritis	11 (16)	5 (14)	6 (18)	
Disease variables				
Disease duration, years	8 (11)	8 (8)	9 (13)	0.66
DAS-28	2.97 (0.91)	3.05 (0.94)	2.87 (0.79)	0.41
Patient's Global Disease Activity (0–100, 0=no activity)	28.1 (20.3)	25.5 (21.6)	30.8 (19.0)	0.29
Symptoms and function				
Fatigue (0–100, 0=no fatigue)	34.7 (29.2)	29.9 (29.7)	39.6 (28.2)	0.18
Joint pain (0–100, 0=no pain)	25.5 (20.7)	23.6 (20.2)	27.4 (21.3)	0.46
MHAQ (0–3, 0=good function)	0.35 (0.38)	0.34 (0.35)	0.37 (0.41)	0.61
Medication				0.41
Methotrexate	37 (54)	18 (51)	19 (58)	
TNF-inhibitor	8 (12)	5 (15)	3 (9)	
Methotrexate+TNF-inhibitor	17 (25)	11 (31)	6 (18)	
Hydroxycloroquine	1 (2)	0	1 (3)	
Leflunomide	2 (3)	0	2 (6)	
Sulphasalazine	3 (4)	1 (3)	2 (6)	

Values are reported as number and proportions, or mean values and SD.
*Difference between groups (independent samples t test for means and χ^2 for proportions).
DAS-28, Disease Activity Score 28 joint count; MHAQ, Modified Health Assessment Questionnaire; TNF, tumour necrosis factor.

(CI) were 3.96 (3.8 to 4.2) in the CNS group and 4.08 (3.9 to 4.2) in the MD group.

Significant between-group differences in all LSQ subscales in favour of the CNS group were observed at the 9- and 21-month follow-up (table 2). Within-group scores showed that patients in the CNS group had increased their satisfaction in all subscales from baseline to 21 months (all p values <0.05). The MD group showed reduced satisfaction in the subscales 'provision of information' and 'access and continuity of care' (p values <0.01). At 21-month follow-up, differences between the groups in subscale scores ranged from 0.38 (technical competence) to 1.12 (access and continuity of care). With an MCID of 0.5 these group differences seem to be clinically relevant.

Secondary outcomes

No significant between-group effects were found in CORS (see online supplementary table 4).

Disease activity was improved from baseline to 9 months in both groups and improvement was maintained at 21 months (mean DAS-28<2.6, which is defined as remission[34]) (table 3). The improvement was slightly higher in the CNS group than in the control group at the 9-month follow-up (between-group difference 0.45, p=0.03), but no significant between-group difference was seen after 21 months. At 9 months, there was a tendency towards lower scores in PGA and joint pain in the CNS group than in the MD group (p=0.05 and 0.06, respectively). Although there was a tendency towards a larger reduction in HRQOL in the domains of vitality, bodily pain, physical function and role emotional in the MD group than in the CNS group from baseline to 21 months, no significant between-group differences were found in any domains (p values ranged from 0.18 to 0.87) (table 3).

DISCUSSION

The overall patient satisfaction increased significantly in patients who were followed up by a CNS compared with patients who were followed up by an MD. No significant differences were found between the two groups in any secondary outcomes at 9- and 21-month follow-up, although there was a tendency towards decreased PGA and joint pain in the CNS group at 9 months.

There was a tendency towards decreased satisfaction in the MD group in 'provision of information' and 'access and continuity of care' at 21-month follow-up, whereas the CNS group showed increased satisfaction in all LSQ subscales. Patient education is one of the primary tasks of the rheumatology nurse.[14] CNSs have cited patient education and the provision of information as one of the most important aspects of their role, assuming that information empowers patients and enables them to make informed decisions and take control of their illness.[35 36] Studies have shown that nurse-led care provides more effective patient education which is directly associated with higher satisfaction.[11 37 38] This is also reflected in the recently published EULAR recommendations for the role of the

Table 2 Difference between MD and CNS group at 9 and 21 months for the primary outcome

	MD group	CNS group	Effect of intervention (95% CI)	p Value*
Leeds satisfaction questionnaire (1–5, 1=lowest score)				
General satisfaction				
Baseline	3.95 (3.70 to 4.20)	3.91 (3.70 to 4.13)		
9 months	3.96 (3.71 to 4.21)	4.32 (4.05 to 4.60)	−0.36 (−0.72 to −0.00)	0.05
21 months	4.06 (3.82 to 4.30)	4.63 (4.47 to 4.81)	−0.57 (−0.86 to −0.27)	<0.001
Provision of information				
Baseline	4.02 (3.85 to 4.19)	4.00 (3.81 to 4.18)		
9 months	3.76 (3.55 to 3.97)	4.32 (4.17 to 4.45)	−0.06 (−0.83 to −0.37)	<0.001
21 months	3.81 (3.59 to 4.03)	4.40 (4.25 to 4.54)	−0.60 (−0.82 to −0.38)	<0.001
Empathy				
Baseline	3.84 (3.64 to 4.05)	3.95 (3.74 to 4.15)		
9 months	3.62 (3.41 to 3.83)	4.45 (4.30 to 4.60)	−0.79 (−1.03 to −0.55)	<0.001
21 months	3.83 (3.62 to 4.03)	4.57 (4.44 to 4.70)	−0.72 (−0.95 to −0.49)	<0.001
Technical competence				
Baseline	4.63 (4.47 to 4.78)	4.55 (4.40 to 4.70)		
9 months	4.16 (3.90 to 4.42)	4.85 (4.74 to 4.95)	−0.67 (−0.93 to −0.40)	<0.001
21 months	4.49 (4.31 to 4.68)	4.87 (4.79 to 4.95)	−0.38 (−0.57 to −0.19)	<0.001
Attitude to the patient				
Baseline	3.95 (3.69 to 4.21)	4.13 (3.92 to 4.35)		
9 months	3.85 (3.56 to 4.14)	4.77 (4.60 to 4.93)	−0.91 (−1.23 to −0.59)	<0.001
21 months	4.05 (3.83 to 4.27)	4.84 (4.72 to 4.96)	−0.79 (−1.03 to −0.54)	<0.001
Access and continuity with care				
Baseline	4.09 (3.84 to 4.35)	4.20 (3.96 to 4.43)		
9 months	3.38 (3.12 to 3.64)	4.28 (4.10 to 4.45)	−0.89 (−1.19 to −0.60)	<0.001
21 months	3.40 (3.18 to 3.62)	4.52 (4.33 to 4.71)	−1.08 (−1.36 to −0.82)	<0.001
Overall score				
Baseline	4.08 (3.94 to 4.23)	3.96 (3.76 to 4.15)		
9 months	3.81 (3.59 to 4.02)	4.50 (4.38 to 4.61)	−0.74 (−0.96 to −0.52)	<0.001
21 months	3.95 (3.80 to 4.11)	4.64 (4.53 to 4.75)	−0.69 (−0.87 to −0.50)	<0.001

Mean (95% CI) scores.
*p Values estimated with mixed models linear repeated measures analysis with adjustment for baseline mean value, as well as for time, gender, age, disease duration and education.
CNS, clinical nurse specialist; MD, medical doctor.

nurse in management of IA,[14] which state that 'patients should have access to a nurse for education to improve knowledge of IA and its management throughout the course of their disease'. Increased knowledge of the disease process, treatment strategies and self-management strategies has been found in patients who are educated during nursing consultations.[11 39 40]

Only two CNSs undertook the nursing consultations, whereas rheumatologist consultations were performed by six MDs. This difference reflects the general practice in most rheumatology outpatient clinics in Norway and may possibly explain the differences between the groups in satisfaction with 'access and continuity of care'. Patients prefer to meet the same clinicians at each visit.[21 23 41 42] Nurses tend to be more accessible to the patients and continuity of care provides the opportunity to establish a confidential relationship.[14] Patients with IA appreciate that the nurses often have longer consultation time.[43] However, in this study the consultation time was equal; both groups were assigned 30-min consultations.

Empathy is particularly important in patients with IA.[36 44] Satisfaction with 'empathy' increased in the CNS group during the study period, whereas it remained unchanged in the MD group. Previous studies have shown that patients appreciate the communicational skills of the CNSs.[45 46] Holistic care and patient-centred information are found to contribute to patient satisfaction.[38] A previous qualitative focus group study with IA patients from three rheumatology outpatient clinics in Norway has highlighted that the nursing consultations contributed to increased accessibility, security and a holistic approach in rheumatology care. Moreover, the nurses ensured that the patient perspectives of living with a rheumatic disease were met.[47]

Coping with rheumatic stressors remained unchanged both between and within the groups during the 21-month follow-up (see online supplementary table 4). These results may reflect that the nursing consultations do not include training of specific coping strategies. The CORS may not have been the best measure to capture what is addressed in the individual consultations.

Some limitations need to be addressed. First, it was not possible to blind participants and practitioners, which may have influenced the results in either direction. However, everyone involved were blinded to the randomisation procedure. The treatment allocation was not known before the patient was entered into the study. Only five of 108 patients were not willing to be followed by a CNS. Based on these considerations, the risk for selection bias is considered as low. Multiple measurements may increase the risk of a type I error, but with p values <0.001 we consider this risk to be low.

Disease activity was assessed with DAS-28 for all IAs. It is well accepted that DAS-28 can be used in PsA in addition to RA. However, since this study was not powered for subgroup analyses we chose to use DAS-28 also in patients with AS, even if this is suboptimal, in particular in patients without peripheral arthritis.

Table 3 Differences between MD and CNS groups at 9 and 21 months for secondary outcomes

	MD group	CNS group	Effect of intervention (95% CI)	p Value*
DAS-28				
Baseline	2.87 (2.59 to 3.15)	3.05 (2.72 to 3.37)		
9 months	2.59 (2.28 to 2.88)	2.20 (1.92 to 2.48)	0.45 (0.06 to 0.84)	0.03
21 months	2.58 (2.32 to 2.84)	2.35 (2.00 to 2.71)	0.31 (−0.12 to 0.75)	0.15
Fatigue (VAS, 0–100, 0=no fatigue)				
Baseline	39.6 (29.5 to 49.6)	29.9 (19.6 to 40.3)		
9 months	35.2 (24.6 to 45.7)	32.3 (22.0 to 42.5)	4.0 (−15.8 to 7.8)	0.50
21 months	40.3 (29.2 to 51.3)	32.9 (23.5 to 42.4)	0.3 (−11.8 to 12.3)	0.97
PGA (VAS, 0–100, 0=no activity)				
Baseline	30.8 (24.0 to 37.5)	25.5 (17.9 to 33.0)		
9 months	36.0 (25.7 to 46.4)	21.2 (14.5 to 27.9)	11.0 (−0.03 to 22.0)	0.05
21 months	36.9 (26.1 to 47.8)	25.3 (16.7 to 33.8)	7.6 (−5.2 to 20.4)	0.24
Joint pain (VAS, 0–100, 0=no pain)				
Baseline	27.4 (19.8 to 34.9)	23.6 (16.5 to 30.6)		
9 months	32.4 (22.3 to 42.5)	18.6 (11.7 to 25.6)	10.9 (−0.7 to 22.4)	0.06
21 months	35.8 (25.7 to 45.8)	22.8 (14.9 to 30.7)	10.0 (−1.3 to 21.3)	0.08
SF-36 (0–100, 0=poorest health)				
Mental health				
Baseline	75.1 (69.5 to 80.7)	80.1 (74.7 to 85.5)		
9 months	73.9 (67.5 to 80.2)	82.0 (77.3 to 86.7)	−6.7 (−13.5 to 0.1)	0.05
21 months	75.6 (69.5 to 81.7)	77.8 (71.2 to 84.5)	−0.6 (−8.5 to 7.2)	0.87
Vitality				
Baseline	66.7 (58.0 to 75.3)	65.7 (56.5 to 74.9)		
9 months	50.3 (42.1 to 58.5)	55.6 (47.8 to 63.4)	−5.5 (−15.7 to 4.8)	0.29
21 months	45.5 (38.3 to 52.7)	49.3 (41.3 to 57.2)	−3.8 (−13.4 to 5.8)	0.43
Bodily pain				
Baseline	57.9 (50.2 to 65.4)	59.6 (53.0 to 66.1)		
9 months	52.7 (44.9 to 60.6)	60.7 (53.7 to 67.6)	−6.2 (−15.6 to 3.2)	0.20
21 months	47.9 (40.2 to 55.6)	55.5 (48.1 to 62.9)	−5.8 (−15.6 to 4.0)	0.24
General health				
Baseline	56.5 (53.5 to 60.4)	60.6 (56.0 to 65.2)		
9 months	54.0 (46.5 to 61.6)	63.9 (57.1 to 70.6)	−8.4 (−18.9 to 2.0)	0.11
21 months	53.5 (45.6 to 61.4)	62.3 (54.7 to 69.8)	−7.9 (−19.5 to 3.7)	0.18
Social function				
Baseline	49.2 (47.0 to 51.4)	48.9 (44.7 to 53.1)		
9 months	75.8 (66.3 to 85.3)	87.1 (80.6 to 93.7)	−11.5 (−22.7 to −0.3)	0.05
21 months	76.6 (67.1 to 86.1)	83.5 (73.7 to 93.2)	−6.1 (−19.4 to 7.3)	0.37
Physical function				
Baseline	66.7 (58.0 to 75.3)	65.7 (56.5 to 74.9)		
9 months	65.8 (55.2 to 76.2)	69.7 (61.2 to 78.2)	−3.9 (−11.2 to 3.4)	0.29
21 months	62.6 (53.2 to 71.9)	65.2 (55.7 to 74.6)	−2.1 (−10.6 to 6.5)	0.63
Role physical				
Baseline	43.9 (28.3 to 59.6)	48.5 (34.3 to 62.8)		
9 months	53.1 (37.1 to 69.1)	41.2 (27.5 to 54.9)	7.7 (−8.2 to 23.6)	0.34
21 months	62.1 (47.0 to 77.2)	46.3 (32.1 to 60.6)	9.7 (−8.3 to 27.7)	0.29
Role emotional				
Baseline	70.7 (56.6 to 84.8)	77.5 (65.7 to 89.2)		
9 months	63.5 (47.9 to 79.2)	79.4 (66.9 to 91.9)	10.7 (−4.7 to 26.2)	0.17
21 months	66.7 (51.2 to 82.1)	77.5 (63.8 to 91.1)	4.6 (−13.8 to 23.0)	0.62

Mean (95% CI) scores.
*p Values estimated with mixed models linear repeated measures analysis and adjusted for the baseline mean value, as well as for gender, age disease and education for secondary outcomes.
CNS, clinical nurse specialist; DAS-28, Disease Activity Score 28 joint count; MD, medical doctor; PGA, patient's global assessment; SF-36, MOS Short Form-36; VAS, Visual Analogue Scale.

We cannot know if patients expected more or less from a nurse than a doctor and thus might be more or less satisfied with the consultations. Patient satisfaction can be a manifestation of gratitude towards the staff or fears of sanctions that will negatively influence their long-term care.[48 49] The patients might have been aware that the principal researcher could be involved in their care after the study was finished, and in some cases, they knew the researcher in her role as a CNS from previous visits. Ideally, the researcher should not have taken part in the nursing consultations as this might affect the external

validity, but as this was a pragmatic real-life study, it was not possible to have another nurse conducting the consultations. In order to illuminate how patients' expectations and attitudes towards care influence their satisfaction, individual qualitative interviews might be used to compliment the findings, which are recommended for future studies.

The generalisability of the findings is limited by several aspects. The study was confined to only one hospital in Norway. The added value of nursing consultations may depend on the skills, competence and experience of both the nurse and the rheumatologist. The study included IA patients with a variety of diagnoses and different levels of disease activity, causing large individual variations, and the study was not powered to investigate subgroup differences. The disease activity was low in both groups, indicating that the patients with higher disease activity might have been excluded from the study. The low disease activity may also be related to initiation of DMARD treatment 3 months before the randomisation. Accordingly, we cannot generalise the results from this study to patients with high disease activity.

The study was adequately powered to answer the primary research question.[33] Moreover, the study results were consistent across similar outcome measures and time points, the results were similarly robust in the adjusted analyses, and the long-term follow-up gives strength to the study.

In conclusion, this study implies that IA patients with low disease activity are likely to benefit from nurse consultations in terms of increased satisfaction with care. Moreover, patients can be monitored safely by CNSs as regards clinical outcomes. The study substantiates the EULAR recommendations for the role of the nurse in the management of chronic inflammatory arthritis[14] and adds support to the role of structured nurse-led management in the outpatient care of IA patients. Further research with respect to which patients would benefit the most from nursing consultations is needed, and guidelines for how they should be managed need to be developed.

Acknowledgements The authors thank CNS Anne Sofie Magnussen at St. Olavs Hospital for participating in the study. The authors owe special thanks to all the patients who made this study possible.

Contributors HSK contributed to the study design, data collection, intervention, analysis and interpretation and writing of the manuscript; HAZ contributed to the study design, data analysis and interpretation and writing of the manuscript; KBH and PM contributed to the data analysis and interpretation and writing of the manuscript; TKK contributed to the study design and interpretation and writing of the manuscript; ER contributed to the intervention and writing of the manuscript.

Funding This research is carried out by funding from the Pahle Legacy, National Resource Center for Rehabilitation in Rheumatology, Diakonhjemmet Hospital, Oslo, St. Olavs Hospital, Trondheim, Norway and Liason Committee Central Norway Regional Health Authority—NTNU. It is hosted by St. Olavs Hospital Trondheim, Norway.

Competing interests TKK and ER have received research grants for the NOR-DMARD registry from Abbott, Amgen, Aventis, BMS, Roche, MSD/Schering-Plough/Centocor, Pfizer/Wyeth, and the Norwegian Directorate for Health and Social Affairs. HSK, HAZ, PM and KBH have no conflicts of interests.

Patient consent Obtained.

Ethics approval Ethical approval was obtained by the National Committee for Research Ethics in Norway.

Provenance and peer review Not commissioned; externally peer reviewed.

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Patient satisfaction with nursing consultations in a rheumatology outpatient clinic: a 21-month randomised controlled trial in patients with inflammatory arthritides

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Ann Rheum Dis published online February 7, 2013
doi: 10.1136/annrheumdis-2012-202296

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Anbefaling prosjektsøknad for sykepleiedrevet overgangspoliklinikk for pasienter med barneleddgikt

Det søkes om midler til et spennende prosjekt med en sykepleiedrevet overgangspoliklinikk for ungdommer med barneleddgikt. Prosjektet vil gi økt kvalitet på behandlingen hos sårbare ungdommer med en kronisk sykdom. Samtidig vil prosjektet føre til en mer effektiv drift, både kostnadsmessig og kvalitetsmessig.

Revmatologisk poliklinikk har store utfordringer med lange ventelister og dette prosjektet vil kunne redusere disse. Etter endt prosjektperiode vil overgangspoliklinikken integreres i driften til Nasjonal Kompetansetjeneste for Svangerskap og revmatiske sykdommer (NKSR).

Prosjektleder har en solid forskningsbakgrunn og prosjektmedarbeiderne har tidligere vist at prosjekter de iverksetter blir fullført og ikke minst implementert etter endt prosjektperiode.

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Med vennlig hilsen

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