Nurse-led consultations in patients with rheumatoid arthritis – what, why and how?

Associate Professor, PhD, RN, Jette Primdahl

King Christian X’s Hospital for Rheumatic Diseases, Gråsten, Sygehus Sønderjylland (Hospital of Southern Jutland) and Institute for Regional Health Research, University of Southern Denmark
Where is our hospital situated?

King Christian X’s Hospital for Rheumatic Diseases, Graasten
The next 80 minutes.....

• **What is a nurse-led consultation?**
  – Different types of consultations

• **Why nurse-led consultations?**
  – Evidence for nurses contributions and the nurses role

• **How?**
  – Which patients
  – Preconditions
  – Content, delivery and documentation?
  – Nurses role?
  – Newly diagnosed
  – Screening for cardiovascular risk
Historic development....

• Traditionally patients with rheumatoid arthritis have follow-up by rheumatologists
• In the UK – 25-30 years of experience with nurse consultations
• In Denmark – in 2007 three hospitals had SOME
• 2017 – most hospitals, content and patients vary
• Same development in other specialities
• Due to economy and lack of rheumatologists – or patients needs??
• Sweden?
Nurse-led consultations?

• Nurse-led outpatient follow-up
• Nurse-led telephone consultations
• Nurse-led consultations on newly diagnosed
• Nurse-led screening for comorbidities
• Need supervision and clear responsibilities
Evidence of nurses contributions?

• AMBRA-study, Gråsten, Denmark

• Multi-center study in UK
  (Ndosi et al, 2011)

• Systematic review and meta-analysis comparing nurse-led and phycisian-led follow-up
  (de Thurah et al, submitted)

• EULAR recommendations on the role of the nurse
  (van Eijk-Hustings et al, Ann Rheum Dis, 2012)

➢ Patient experiences
The AMBRA study

• Outpatient treatment of stable patients with Rheumatoid Arthritis
• 2008-2011
• Two hospitals in the southern part of Denmark
Background

- Patients with rheumatoid arthritis (RA) monitored in nursing consultations or shared care are not worse off to patients in traditional medical follow-up

- No documentation of need in medical records for 45% of patients at follow-up by rheumatologist
  (internal audit 2006)

- We expect an unmet demand for rheumatologists in the future
  (Danish National Board of Health 2008)
287 persons with RA
Age > 18 years
Diagnose > 18 months
DAS28-CRP<3.2
HAQ<2.5

AMBRA-course
2X3 hours

Control group (n=97)
Usual care; planned consultations with a senior or junior rheumatologist

Shared care (n=96)
No planned consultations. Access to GP and telephone help-line

Nursing group (n=94)
Planned consultations every three months and telephone help-line
287 persons with RA
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Confidence and satisfaction

How confident are you that if you have problems this system of care will be able to support you?

Not at all confident

Confident

Completely confident

How satisfied are you with the system of care provided for your rheumatoid arthritis?

Not at all satisfied

Satisfied

Completely satisfied

(Kirwan et al Rheumatology, 2003, 42: 422-6)
Confidence 0-2 år

Graphs by group

Confidence

Graphs by group

Confidence

Graphs by group

Confidence

Graphs by group

Confidence

Graphs by group

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Confidence
Satisfaction 0-2 år

Graphs by group

- medical
- shared_care
- nursing

95% CI mean satisfaction
Coefficients from random intercept analysis 0-2 years, Significant values in red

(Primdahl et al, Ann Rheum Dis 2014;73;373-364)
Clinical outcomes 0-2 years

- No difference between the groups in:
  - Disease activity (DAS-28-CRP)
  - Physical ability (HAQ)
  - Fatigue (VAS 0-100)
  - Pain (VAS 0-100)
  - Health related quality of life (SF-12 and EQ-5D)
  - Erosions on X-rays (joint damage 0-2 years)
  - Adverse events
Patient experiences

Being an outpatient with rheumatoid arthritis – a focus group study on patients’ self-efficacy and experiences from participation in a short course and one of three different outpatient settings

Jette Primdahl RN, MHH (PhD Student)¹,³, Lis Wagner Dr, PH (Professor, Research Leader)² and Kim Hørslev-Petersen MD, DM. Sci. (Professor)¹,³

¹King Christian X’s Hospital for Rheumatic Diseases, Graasten, Denmark, ²Research Unit of Nursing, Institute of Clinical Research, Faculty of Health Sciences, University of Southern Denmark, Odense, Denmark and ³Institute for Regional Health Research, Faculty of Health Sciences, University of Southern Denmark, Odense, Denmark

Aim of the study

• To develop an understanding of what is important to the patients based on the participants’ own experiences from participation in one of three different versions of follow-up care for outpatients with RA.
Method

- Qualitative approach inspired by phenomenology
- Focus-group interviews
- Three interviews at each hospital with 4-7 participants – 33 persons in total
- Strategically sampled – all had participated in the study for a year
- All six interviews were recorded, transcribed and analyzed
Three main themes

• Continuity and relationship with health professionals
• A need for others to take control
• Easy access to contact with health professionals – but many barriers
Physician follow-up

- Felt "in safe hands"
- Physicians focused on facts
- Some felt more like a "case" than a person
- Some experienced continuity – some didn’t
- Some experienced interest and care – some didn’t
- Authoritarianism – selected the topics for dialogue
- Many barriers to call
But I think, that I experience myself a bit more like a “case” when I am together with the physicians....

(female, 46 years, phys. group)

...when I came to the physician, it was like (straightens up), well, this should just be overcome and then out again (laughing), ehm... the fatigue was not mentioned to him.

(female, 42 years, phys. group)
Nurse-led follow-up

- Valued that they met the same persons
- Knew each other well – confidence and safety
- Sense of interest and care
- Confidence to the nurses knowledge and experience
- Too often for many to come every 3 months
- Easier to call when they know the nurse
- Previous experiences determined expectations to nurses
I would drive far to meet them... I experienced them as interested in "how are your feet"... "oh this bunion is growing big!" – no it is just El Dorado to come here. Previously it was much more... businesslike.. in relation to blodtests and boom, boom, boom... It has been a blessing for me with this nurse.... for me.

(male, 68 years, nurse-led follow-up)
We may be some who are from a time, or are someone who dare to ask more questions when it is a nurse. She is more...I don’t know what to say....I think it has to be something wise, if we should ask the rheumatologist, right?

(Female 65 years, Nurse-led follow-up)
More on patient experiences

- Patients want AHP to listen, empathise and help them to manage their condition, especially the pain
  
  (Ryan et al, 2015)

- Nurse-led consultations led to a sense of security (due to competence and accessibility), familiarity (due to confirmation and sensitivity), and participation (due to exchange of information and involvement)
  
  (Larsson et al 2012)

- Social environment important, nurses experienced as emphatic, knowledgeable and competent, individually based, led to security, trust, hope and confidence
### Cost?

<table>
<thead>
<tr>
<th>Consultations</th>
<th>Physicians</th>
<th>Nurses</th>
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<tbody>
<tr>
<td>Shared care</td>
<td>3,0</td>
<td>2,8</td>
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<td>Nurse-led follow-up</td>
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<td>6,5</td>
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*mean number of consultations in the AMBRA-study*

- Shared care cost 12% and nurse-led follow-up 6% less than physician-led follow-up
- Nurse-led follow-up provides better quality of life than shared care and physician-led follow-up

*(Sørensen et al, Scand J Rheum, 2014)*
Multicenter study UK

- RCT-study – NLC vs. PLC
- 181 patients with RA – 10 centers across UK
- *No exclusion based on DAS-28*
- NLC was more cost-effective with respect to DAS28, but not in relation to Quality of life.
- In all secondary outcomes NLC equalled PLC
- Fatigue, stiffness, HADs - slightly worse in NLC
- Pain and physical function - slightly better in NLC
- NLC had higher ‘general satisfaction’ scores than RLC in week 26 – no difference week 52

(Ndosi et al, 2011)
Systematic review and meta-analysis

- Nurse-led vs. Physician-led follow-up
- 7 studies – 5 RCTs – 723 patients
- No difference in DAS-28 after 1 year
- Slightly better DAS-28 in NLC after 2 years
- No difference in satisfaction after 1 year
- Higher satisfaction in NLC after 2 years

Supports that nurse-led follow-up can achieve similar disease control to as physician-led follow-up for patients with RA with low disease activity or in remission after one year

(de Thurah A, Esbensen BA, Frandsen TF, Ida Roelsgaard I and Primdahl J, submitted)
The next 80 minutes.....

• What is a nurse-led consultation?
  – Different types of consultations

• Why nurse-led consultations?
  – Evidence for nurses contributions and the nurses role

• How?
  – Which patients
  – Preconditions
  – Content, delivery and documentation?
  – Nurses role?
  – Newly diagnosed
  – Screening for cardiovascular risk
Which patients should nurses see?

- Newly diagnosed with inflammatory arthritis?
- Stable patients with inflammatory arthritis?
- Throughout the disease course?
  (van Eijk-Hustings et al, Ann Rheum Dis 2011)

- Other patients with a rheum. disease?

- **Important that the nurses are trained and can provide the type of care the patient need** – and have a rheumatologist to consult and refer to
How? – Preconditions

• Guideline
  – duration, content, process, documentation

• Training
  – joint examinations, communication, evaluation of blood-tests, titration of pharmacological treatment i.e.

• Physical surroundings
  – Privacy, where, equipment needed?

• Cooperation with rheumatologists
  – Supervision, when to refer to rheumatologist, referral to others (podiatrist, occupational therapist, physical therapist etc)
The content in the consultation?

• ”How are you”? Since last visit?
• Assessment of disease activity
• Assessment of blood test – urine test – order new tests?
• Observation and measurements (BP, (temp, weight), HAQ)
• Self-management of symptoms. What did the patient try?
• Education/ information/ support (empowerment)
• Pharmacological treatment, side effects, hand out more
• New appointment – by physician or nurse and when?
• Goals and expectations – patient and family?
• Need for referral to other HPs, GP or rheumatologist?
• Anything else?
Documentation

- In the patients medical file
- Electronic copy is sent to general practitioner
- National quality database - DANBIO
## Danbio - visits

<table>
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<th>Biobank</th>
<th>Diagnosis</th>
<th>N</th>
<th>Äktiv (Op)</th>
<th>Tage siden</th>
<th>Aktiv bio</th>
<th>Aktiv DMARD</th>
<th>Seneste retninger</th>
<th>Årlig status</th>
<th>Lung.</th>
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<tr>
<th>Seneste 10 visits</th>
<th>Klik her for: Alle visits eller 1. visit + seneste 9 visits</th>
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### Biobank Data

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### Output Data

- **Patientnavn** (max 10)
- **Journalnavn** (21022017) [popup]
- **Journalnavn** (20002016) [popup]
- **Journalnavn** (16062016) [popup]
- **Artsnavn** (doc) / (doc)
- **CVR-screening pdf**

### Afdeling Data

- **Afdelsnavn**
- **STANDARD**
- **BIOLEX**
- **RADS report link**
- **Patient**
- **Vidtilfælde**
- **Touch bestilling**

### Log MD VV

- **Log-in**
- **Slik afscannetkode**
- **Kontakt danbio**
- **Adgang andre systemer**

### Projekt Data

- **Tagline**
- **Doakt**
- **Nonlast**

---

**Danbio, Glostrup Hospital, Videnscenter for Reumatologi og Krypoptimisme VDK. Indehaft S. uden, Hør. Rikkei 57, 2600 Glostrup**
Example – joint assessment
Nurses role in patients with IA?

• EULAR recommendations (van Eijk-Hustings et al, 2012)
• Based on 54 studies
  – 1 meta-analysis
  – 8 RCTs
  – 2 controlled trials
  – 9 quasi experimental studies
  – 34 descriptive studies
• Status in Sweden??
The 10 recommendations
Patients should have access to.....

1. A nurse for education to improve knowledge of CIA and its management throughout the course of their disease
2. Nurse consultations in order to experience improved communication, continuity and satisfaction with care
3. Nurse-led telephone services to enhance continuity of care and to provide ongoing support
Recommendations...

Nurses should.....

4. Participate in comprehensive disease management to control disease activity, to reduce symptoms and to improve patient-preferred outcomes

5. Identify, assess and address psychosocial issues to minimise the chance of patients’ anxiety and depression

6. Promote self-management skills in order that patients might achieve a greater sense of control, self-efficacy and empowerment
And finally....
Nurses should....

7. Provide care based on protocols and guidelines
8. Have access to and undertake continuous education
9. Be encouraged to undertake extended roles after specialised training
10. Carry out interventions and monitoring as part of comprehensive disease management in order to achieve cost savings
Implementation?

• Danish association for rheumatology nurses
  – Part of yearly seminar for two years
• Locally – nurses are now involved in newly diagnosed and alternate with rheumatologists throughout the disease course
Nurses role in newly diagnosed?

• Identify patients who need fast intervention (flare-up, joints, feet, symptoms, side-effects, comorbidities, adherence, sexual and sleep problems)
• Psychosocial issues major in this group
  – Discuss feelings; worries, fear, anger, guilt i.e.
  – Coping strategies, attitude to help
  – New identity, hope, beliefs about cause of their disease
• Involve family, how to inform colleagues
• Provide education – individually tailored
• Self-management of symptoms

(unpublished overview of literature)
Nurses role and comorbidities?

1. A nurse for education to improve knowledge of CIA and its management throughout the course of their disease

Includes

• Knowledge about the disease process, treatment strategies, physiotherapy, self-management strategies

• Education about risk factors for comorbidities such as cardiovascular problems
Cardio-vascular risk assessment?

- EULAR recommendations for cardiovascular risk management (Peters et al. 2010, Agca et al. 2016)
- For persons with RA their CV-risk is doubled – comparable to persons with diabetes
- Similar seems to be the case for PsA and AS
- Implementation still difficult, highly relevant task for rheumatology nurses

(Primdahl et al. 2015)
How do we screen our patients for cv-risk?

• 30 minute nurse-consultation
• All patients with RA, PsA, AS and more
• Addition to other follow-up visits
• Full lipid profile and HbA1C in advance
The content of the 30 minute screening consultations?

• Status on the pharmacological treatment?
• Discuss blood-tests
• Habits regarding life-style (smoking, exercise, alcohol, diet) – elements of MI
• Measure BP, height, weight, waist
• Calculate Body Mass Index
• Risk assessment – SCORE (www.escardio.org)
### BMI FOR VOKSNE

BMI (Body Mass Index) er en målemetode, som bruges til at vurdere vægt i forhold til højde. Du finder dit BMI ved at dele vægten i kg med højden i m x højden i m.

<table>
<thead>
<tr>
<th>Højde i meter</th>
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**Regneeksempl:** $\frac{65 \text{ kg}}{1.70 \times 1.70 \text{ m}} = 22.5$  
Er dit BMI under 18.5 - er du undervægtig  
18.5-24,9 - er du normalvægtig  
25-29,9 - er du overvægtig  
30 og derover - er du fed
SCORE 10-year risk for CV death?

(Conroy et al., 2003 and www.escardio.org)
Screening for cardio-vascular risk

**Female**
- non-smokers
- smokers
- Age
- non-smokers
- smokers

**Male**
- non-smokers
- smokers
- Age
- non-smokers
- smokers

The numbers in the table reflect the calculated % risk for cardiovascular death in 10 years based on gender, age, blood pressure and cholesterol level.

5% risk for cardiovascular death in 10 years concurs to 20% risk for development of cardiovascular disease in 16 years.

### Risc factors used to calculate risk SCORE

<table>
<thead>
<tr>
<th>Smoking (yes/no)</th>
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<tr>
<td>Total cholesterol (&lt; 5,0 mmol/l)</td>
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<tr>
<td>HDL-cholesterol (female &gt;1,2, male &gt;1,0 mmol/l)</td>
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<tr>
<td>LDL-cholesterol (&lt; 3,0 mmol/l)</td>
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<td>Triglycerid (&lt; 1,7 mmol/l)</td>
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<tr>
<td>Total cholesterol / HDL-cholesterol ratio</td>
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<td>Blood pressure (&lt; 140/90)</td>
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**Risc SCORE (%)**

When yes to at least 2 out of 3 following factors occur the risk SCORE is multiplied with 1.5

- Have been diagnosed for > 10 years: (yes/no)
- Rheumafactor positive and/or anti-CCP positive: (yes/no)
- Extra articular manifestations: (yes/no)

### Final 10-year risk SCORE:

**Other risks**

| Fasting glucose (< 6,0 mmol/l) |
| HbA1C (< 6,5 % el. 48 mmol/l) |
| BMI (weight in kg/height*height) (18,5-25 kg/m²) |
| Waist circumference (female<80 cm, male < 94 cm) |
| Exercise (min. 30 min. 5 times weekly)(yes/no) |
| Alcohol (female < 7 units/week, male < 14/week) |

**Known diabetes (yes/no):**

**Known cardio-vascular disease (yes/no):**

**Pharmacological treatment for hypertension (yes/no):**
Offer pamphlets to take home
Prevalence of risk factors?

In patients with Rheumatoid Arthritis without CVD and DM:
• 64% Overweighty (47 % in general population)
• 25% Obese (13% in general population)
• 13% had fasting glucose >6 mmol/l and 2% >7mmol/l

 Patients with CVD: 27% and 10%!!

• 55% had increased LDL-cholesterol (>3.0 mmol/L)
• Lipids not treated to target in patients with CVD and DM

• 84% SCORE <5% (93% female, 57% male) invited every 2. y
• 16% SCORE ≥ 5%(7% female, 43% male) – invited every y

(Primdahl et al, Ann Rheum Dis 2013)
Implementation - how?

- Hospital management approval
- Established a multi-disciplinary group
- Coordinator with specified time
- Defined the aim, the content, letter for the patients
- Clinical guideline, flow-chart, documentation materials
- Room, booking, blood-samples, communication with GPs
- Staff resources
- 30 minute consultations
Education of the nurses?

• 4 hours specific education:
  – CV diseases and the atherosclerotic process
  – CV risk assessment and management
  – Cardio-protective and low-cholesterol diet
  – Opportunities for support in the municipalities

  – Motivational interviewing

  – Followed another nurse before undertaking consultations
Health promotion and prevention

- Health promotion as well as prevention
- Focus on tailoring the content to the individual patient
- Focus on beliefs, values and resources (social and individual)
- Improve the patients action competence
- Links primary and secondary care sectors
Patients experiences of screening

• The participants find it important
• Some anxious when invited
• Screening brought a sense of relief
• They could do something
• Screening consultations need to be individualized and based on patients needs
• Some patients decline – is it the ones with high risk?

(Frølund et al, 2015)
Thank you for your attention!

jprimdahl@gigtforeningen.dk
References


References


