Patient perceived needs and experiences of person-centered care in patients with inflammatory arthritis
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ABSTRACT
Background: Health care is shifting toward a person-centered care (PCC) approach. For implementation of PCC, there may be a special role for nurse practitioners (NPs).

Purpose: The aim of this study was to explore the patient-perceived levels of and needs for of PCC in inflammatory arthritis patients who visited the NP at the outpatient clinic of an academic hospital in the Netherlands.

Methods: A cross-sectional study was performed. Disease characteristics were inventoried from the patient records. Patients filled out the PCCoc/rheum instrument, an instrument to measure patient perceived PCC, and a questionnaire based on the 14 life areas of the Self-Management Web, extended with areas including pain, fatigue, and night’s rest. Participants were asked which life areas caused problems, and whether these problems were discussed. Mean values were calculated for normally distributed data and medians for nonnormally distributed data.

Results: Most of the patients had well–controlled disease (86.1%). The mean score of the PCCoc/rheum was 55.3 (SD 8.1). Patients experienced most problems in life areas fatigue (37.3%) and pain (35.3%), these were also the life areas that were most often addressed at consultation. The life areas that gave problems and that were least addressed during consultation were intimate relationships & sexuality (66.7%) and household chores (58.8%).

Conclusions: Despite an overall high level of patient perceived PCC delivered by NPs, patient with low disease activity frequently reported problems in life areas not addressed at consultation.

Implications for practice: Implementation of the Self-Management Web and changing the focus of NP consultations may help to improve accommodating individual patient needs.

Keywords: NP consultation; patient needs; person-centered care; self-management support.
consultations contribute to greater patient satisfaction, which can also influence outcomes associated with PCC initiatives (Kippenbrock et al., 2019). Despite these facts, it is unclear how patients experience the person-centeredness of care in the encounter with the NP. Therefore, the aim of this study was to explore current patient-perceived PCC of NP consultations and patients’ needs by assessing in which life areas patients experienced problems and whether they were addressed.

**Methods**

**Context**

The study was performed at the Rheumatology Outpatient Clinic in the Erasmus MC, an academic hospital in the Netherlands. The NP has independent outpatient consultations with patients primarily diagnosed with an inflammatory arthritis. The consultations are most often alternately with those of the treating rheumatologist. During NP consultations, patients’ assessment take place, including history taking and physical examination focusing on disease activity. Based on the results, treatment is continued or adjusted in shared decision with the patient.

**Study design**

To answer the research question, a cross-sectional observational cohort study was performed. The study was judged by the Medical Ethics Committee of the Erasmus MC. They deemed the study to not be subject to Dutch law (WMO; Medical Research Involving Human Participants Act) and provided a waiver (MEC-2019-0089).

All patients with an inflammatory arthritis who consulted the NP between November 2018 and March 2019 were eligible. 170 eligible patients were approached by post and were asked if they were willing to participate. The letter also contained the questionnaires, which patients could fill out at home. After completion of the questionnaires, patients could return them by post or take it with them to the next outpatient clinic visit. In addition, 36 patients were actively approached for participation during NP consultations. The questionnaires were handed out and the patient filled it out directly in the waiting room.

The questionnaire consists of the Person-Centered Care instrument for outpatient care in rheumatology (PCCoc/rheum) and a questionnaire based on the life areas of the Self-Management Web.
The PCCoc/rheum is a validated instrument designed to measure nurse provided patient-perceived PCC. The instrument covers the domains communication, social environment, personalization, shared decision-making, and empowerment. The communication domain is considered to be represented in all other domains. The domains conclude 21 statements, which can be scored on a 4-point Likert scale, from totally disagree (0) to totally agree (3). The total score of the instrument ranges between 0 and 63, and a higher score indicates a higher level of patient perceived PCC. The test–retest reliability of the instrument is 0.82 (Bala et al., 2018).

The second questionnaire was based on the life areas of the Self-Management Web (Beck et al., 2019). The Self-Management Web is a visual tool to assess which problems patients experience on 14 life areas. The instrument is developed by using The Intervention Mapping protocol. This intervention incorporates patients’ and nurses’ needs and theories as well as evidence-based methods. An evaluating study of the Self-Management Web showed that the support intervention was found to be feasible and acceptable by professionals and recipients. Because of the small sample, further research is needed into the potential effects on self-management behavior and well-being of recipients (Been-Dahmen et al., 2019). The 14 life areas mentioned in the self-management web are as follows: daily activities & work, family & friends & social network, intimate relationships & sexuality, transport & mobility, leisure activities, self-care, household chores, finances, dealing with treatment recommendations, lifestyle, symptoms & side-effects, shared decision-making, illness-related knowledge, and emotions & giving meaning to life (Figure 1). These areas were extended with the life areas like pain, fatigue, and night’s rest because these domains are also important for IA patients (Gossec et al., 2009, 2011, 2014). Patients could score the occurrence of problems in daily life by using a 4-point Likert scale (1 = never, 2 = sometimes, 3 = often, 4 = always). A score ≥3 was defined as problematic. Patients were also asked whether their experienced problems were discussed during consultation.

Demographic data and disease characteristics were collected from the patient records. The following demographic data and disease characteristics were collected: age, gender, living with partner, educational level (no/lower = none & elementary school; secondary = high school & associate’s degree; higher = bachelor’s degree & master’s degree & university), diagnoses, disease duration, and activity. Disease activity was based on the decision to intensify treatment or not. Active disease means that treatment is intensified, whereas stable disease implies continuation or tapering of treatment.

### Analysis
Statistical analyses were performed using SPSSv24.0. Mean values are presented for normally distributed data and medians for nonnormally distributed data. Missing data were handled by imputing the mean over the entire group.

### Results
A total of 102 patients participated in this study (Table 1). The mean age was 58.9 years, and the most prevalent diagnosis was rheumatoid arthritis (68.6%). The mean disease duration was 12.5 years and 86.1% of the patients had a well-controlled disease.

The mean score of the PCCoc/rheum was 55.3 (SD 8.1) (Table 2). The items with the lowest score are “Strengthened ability to cope” (mean 2.4; SD 0.7) and “Can influence care” (mean 2.3; SD 0.8).

Patients experienced most problems in the life areas like fatigue (37.3%), pain (35.3%), and symptoms & side effects (27.5%). These were also the life areas that were most often discussed at consultation. The experienced problems in life areas that are least addressed during consultation.

### Table 1. Baseline characteristics

| Demographic Characteristics | N = 102 |
|-----------------------------|---------|
| Age (years), mean (SD)      | 58.9 (13.5) |
| Sex, female, n (%)          | 62 (60.8) |
| Living with partner, yes, n(%) | 68 (66.7) |
| Educational level, a n (%)  |         |
| No/lower                    | 13 (12.7) |
| Secondary                   | 58 (56.9) |
| Higher                      | 27 (26.5) |
| Disease characteristics     |         |
| Disease duration (years), mean (range) | 12.5 (2–60) |
| Diagnosis, n (%)            |         |
| Rheumatoid arthritis        | 70 (68.6) |
| Psoriatic arthritis         | 18 (17.6) |
| Juvenile idiopathic arthritis | 1 (1.0) |
| Spondyloarthritis           | 5 (4.9) |
| Disease activity, n (%)     |         |
| Active (medication intensification) | 14 (13.9) |
| Low (no medication intensification) | 87 (86.1) |

a no/lower = none & elementary school; secondary = high school & associate’s degree; higher = bachelor’s degree & master’s degree & university
Table 2. Person-centered care instrument for outpatient care in rheumatology (PCCoc/rheum)

| Items                                      | Mean | SD  | Median |
|--------------------------------------------|------|-----|--------|
| Confirmed as a person                      | 2.5  | 0.6 | 3      |
| Understanding my situation                 | 2.6  | 0.5 | 3      |
| Experiences are respected                  | 2.7  | 0.5 | 3      |
| Problems are taken seriously               | 2.8  | 0.5 | 3      |
| Sufficient time allocated                  | 2.6  | 0.6 | 3      |
| Equality in meeting                        | 2.8  | 0.4 | 3      |
| Self-knowledge is considered               | 2.5  | 0.6 | 3      |
| Confident nurse contacts                    | 2.7  | 0.6 | 3      |
| Opportunity to tell my story               | 2.8  | 0.4 | 3      |
| Personal information documented            | 2.7  | 0.5 | 3      |
| Family participation                       | 2.8  | 0.5 | 3      |
| Good nurse collaboration                   | 2.7  | 0.4 | 3      |
| Needs determine care planning              | 2.5  | 0.6 | 3      |
| Care information shared as needed          | 2.7  | 0.5 | 3      |
| Coordinated care                           | 2.6  | 0.6 | 3      |
| Agree with nurse on what to do             | 2.7  | 0.5 | 3      |
| Care responsibility is clear               | 2.7  | 0.5 | 3      |
| Information facilitating decisions        | 2.6  | 0.6 | 3      |
| Can influence care                         | 2.3  | 0.8 | 2      |
| Gain new knowledge                         | 2.6  | 0.6 | 3      |
| Strengthened ability to cope              | 2.4  | 0.7 | 3      |
| Total score                                | 55.3 | 8.1 | 58     |

Table 3. Frequency of problems in daily life areas

| Life Areas                          | Occurrence, n (%) | Not Discussed at Consultation, n (%) |
|-------------------------------------|-------------------|--------------------------------------|
| Fatigue                             | 38 (37.3)         | 5 (13.2)                             |
| Pain                                | 36 (35.3)         | 2 (5.6)                              |
| Symptoms & side effects             | 28 (27.5)         | 3 (10.7)                             |
| Night’s rest                        | 27 (26.5)         | 7 (25.9)                             |
| Daytime activities & work           | 22 (21.6)         | 5 (22.7)                             |
| Shared decision-making              | 21 (20.6)         | 0                                    |
| Illness-related knowledge           | 19 (18.6)         | 3 (15.8)                             |
| Household chores                    | 17 (16.7)         | 10 (58.8)                            |
| Leisure activities                  | 15 (14.7)         | 5 (33.3)                             |
| Emotions & giving meaning to life   | 12 (11.8)         | 7 (58.3)                             |
| Self-care                           | 12 (11.8)         | 4 (33.3)                             |
| Transport & mobility                | 11 (10.8)         | 6 (54.6)                             |
| Family, friends, & social network   | 10 (9.8)          | 5 (50.0)                             |
| Lifestyle                           | 9 (8.8)           | 4 (44.4)                             |
| Intimate relationships & sexuality   | 9 (8.8)           | 6 (66.7)                             |
| Dealing with treatment recommendations | 9 (8.8)       | 1 (11.1)                             |
| Finances                            | 7 (6.9)           | 3 (42.9)                             |

Consultation are intimate relationships & sexuality (66.7%), household chores (58.8%), and emotions & giving meaning to life (58.3%) (Table 3).

Discussion

Previous studies also showed that despite well-controlled disease, pain and fatigue are still most important domains that cause problems in daily life (van Tuyl et al., 2017). Nevertheless, patients also experience problems at nonmedical domains. It seems that problems at nonmedical domains are frequently not discussed at consultation, although patients do have a desire to discuss these problems (McInnes et al., 2013). This is supported by the low score for the PCCoc/rheum item “Can influence care.”

The current role of a NP is mostly characterized by an emphasis on physician replacement or support rather than a person-centered, health-focused, holistic nursing orientation to practice. As a result, the content of the NP consultation is mainly focused on the medical domain rather than the social, psychological, and behavioral dimensions of illness (Ter Maten-Speksnijder et al., 2016). For a holistic nursing orientation, the NP should focus on the health needs of patients, which can make the nursing role more visible and valuable (Bryant-Lukosius et al., 2004). Using a visual conversation tool, such as the Self-Management Web, during NP consultations helps to assess patient needs and improves communication. By using the Self-Management Web, patients are invited to talk about possible problems they experience in different life areas. Consequently, the NP can help patients assess the challenges in their lives and encourage patients to develop...
specific goals, action plans, and pursuit to solve these challenges (Beck et al., 2019).

Limitations of this study were that only patients who visited the NP were included. Previous studies have already shown that NP consultations add value to rheumatologic care (Kippenbrock et al., 2019; Larsson et al., 2012). Second, by coincidence, the study population consisted of established IA patients with a stable disease. The outcomes of the study, therefore, might be different in newly diagnosed patients or patients with an active disease. Finally, our study was done in the winter period in which patients often experience more problems, which could have resulted in an overreportage of problems at medical domains (Azzouzi & Ichchou, 2020).

In conclusion, despite the patient perceived PCC of the NP consultation is high, patients still frequently report problems on life areas that are not addressed during NP consultations. Experienced problems differ per patient. Through implementation of the Self-Management Web, during NP consultations, the individual patients’ needs can be assessed and addressed. As a result, the NP role will be strengthened because of a more holistic nursing orientation. Furthermore, it creates an opportunity for optimal support of shared decision making and empowerment.

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