

Patient perceived needs and experiences of person-centered care in patients with inflammatory arthritis

Kim van Slingerland, MSc¹, Margot J.M. Walter, MSc, PhD¹, Heleen A. van der Stege, PhD², AnneLoes van Staa, RN, MD, PhD², Philomine A. van Pelt, MD, PhD¹, & Pascal H.P. de Jong, MD, PhD¹

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.

Journal of the American Association of Nurse Practitioners 34 (2022) 963–967, © 2022 The Authors. Published by Wolters Kluwer Health, Inc. on behalf of the American Association of Nurse Practitioners

DOI# 10.1097/JXX.0000000000000746

Background

Delivering person-centered care (PCC) is a central goal of health care. Different organizations and institutions claim to deliver PCC. Person-centered care is based on a biopsychosocial approach and addresses the patient's values, preferences, needs, and expectations (American

Geriatrics Society Expert Panel on Person-Centered, 2016; Cassell, 2010; Castro et al., 2016; Wolfe, 2001). It is care that is respectful and supportive, in which realistic health and life goals are pursued and where the patient's best interests guide all medical decisions that have to be made (American Geriatrics Society Expert Panel on Person-Centered, 2016; Cassell, 2010; Castro et al., 2016; Wolfe, 2001). The care is based on a relationship of mutual trust, vulnerability, empathy, and shared knowledge between the health care provider, the patient, and their loved ones (American Geriatrics Society Expert Panel on Person-Centered, 2016; Castro et al., 2016). In delivering PCC, there might be a special role for nurse practitioners (NPs). Nurse practitioners are in a unique position to explore patients' needs and may address unmet needs (Cottrell et al., 2013). Studies have shown that NP consultations are of added value in rheumatology care. In the encounter with the NP, patients experience a feeling of security, familiarity, and participation (Larsson et al., 2012). NP

¹Department of Rheumatology, Erasmus MC, Rotterdam, The Netherlands, ²Research Centre Innovations in Care, Rotterdam University of Applied Sciences, Rotterdam, The Netherlands

This is an open access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

Correspondence: Kim van Slingerland, Department of Rheumatology, Erasmus MC, Rotterdam 3015 CN, The Netherlands; E-mail: k.vanslingerland@erasmusmc.nl

Received: 3 December 2021; **revised:** 9 May 2022; **accepted:** 16 May 2022

Can you tell me how it is going in the following areas:

Choose your answer by checking:

- 1 = Well
- 2 = Neither good nor bad
- 3 = Bad

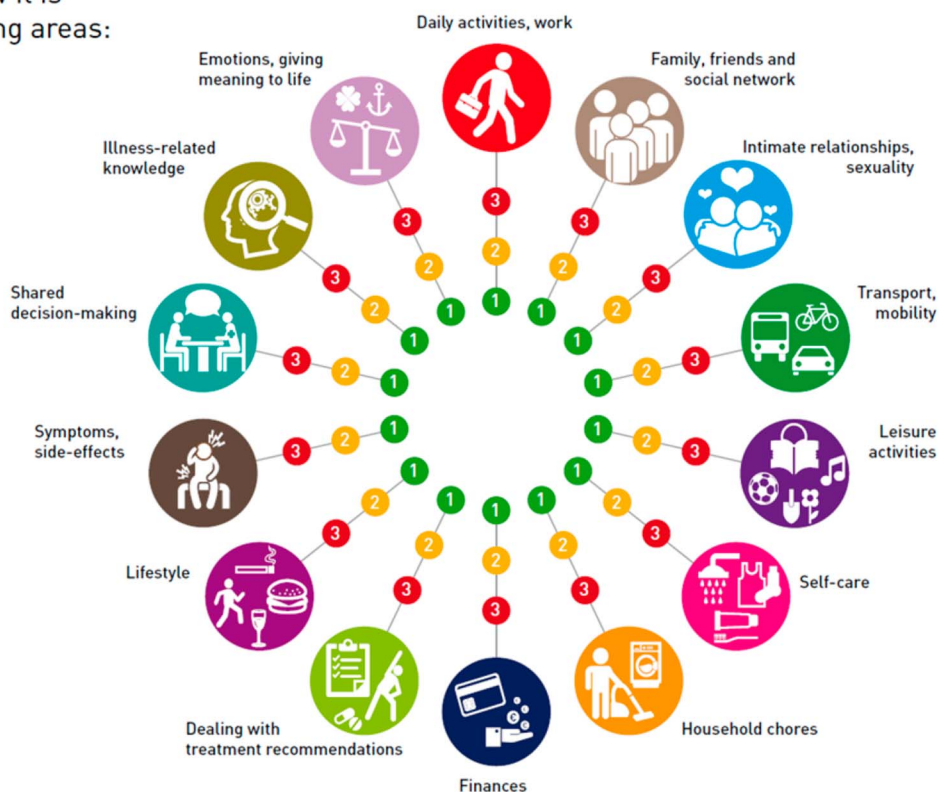


Figure 1. Self-Management Web. The Self-Management Web is a visual tool to assess which problems patients experience on 14 life areas. Patients can evaluate the different life areas and assess if they are doing well, neither good nor bad, or bad. The NP can ask open-ended questions to clarify the problem. If problems are indicated in multiple domains, the patient can rank which problem requires the most attention and the patient wants to work on. The NP guides the patient in setting achievable goals to work on independently (Beck et al., 2019).

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 takes 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.

Table 1. Baseline characteristics

Baseline Characteristics	N = 102
Demographic	
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	

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, life-style, 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

Table 2. Person-centered care instrument for outpatient care in rheumatology (PCCoc/rheum)

	Mean	SD	Median
Items			
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

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."

Table 3. Frequency of problems in daily life areas

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)

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 skills 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.

Authors' Contributions: All authors fulfilled a substantial contribution to the conception of the work and the acquisition, analysis, and interpretation of data for the work. K. van Slingerland wrote the original draft of the manuscript, and all other authors revised it critically for important intellectual content. All authors gave their final approval of the version to be published and agreed to be accountable for all aspects of the work ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Competing interests: The authors report no conflicts of interest.

References

- American Geriatrics Society Expert Panel on Person-Centered, C. (2016). Person-centered care: A definition and essential elements. *Journal of the American Geriatrics Society*, 64(1), 15–18.
- Azzouzi, H., & Ichchou, L. (2020). Seasonal and weather effects on rheumatoid arthritis: Myth or reality? *Population reports. Series M, Special Topics*, 2020, 5763080.
- Bala, S. V., Forslund, K., Fridlund, B., & Hagell, P. (2018). Measuring person-centred care in nurse-led outpatient rheumatology clinics. *Musculoskeletal Care*, 16(2), 296–304.
- Beck, D., Been-Dahmen, J., Peeters, M., Grijpma, J. W., van der Stege, H., Tielen, M., van Buren, M., Weimar, W., Ista, E., Massey, E., & van Staa, A. (2019). A nurse-led self-management support intervention (ZENN) for kidney transplant recipients using intervention mapping: Protocol for a mixed-methods feasibility study. *Journal of Radiological Protection: Official Journal of the Society for Radiological Protection*, 8(3), e11856.
- Been-Dahmen, J. M. J., Beck, D. K., Peeters, M. A. C., van der Stege, H., Tielen, M., van Buren, M. C., Ista, E., van Staa, A., & Massey, E. K. (2019). Evaluating the feasibility of a nurse-led self-management support intervention for kidney transplant recipients: A pilot study. *BMC Nephrology*, 20(1), 143.
- Bryant-Lukosius, D., Dicenso, A., Browne, G., & Pinelli, J. (2004). Advanced practice nursing roles: Development, implementation and evaluation. *J Adv Nurs*, 48(5), 519–529.
- Cassell, E. J. (2010). The person in medicine. *Int J Integr Care*, 10(Suppl), e019.
- Castro, E. M., Van Regenmortel, T., Vanhaecht, K., Sermeus, W., & Van Hecke, A. (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient Education and Counseling*, 99(12), 1923–1939.
- Cottrell, J. E. D., Jonas, M., Bergsten, U., Blaas, E., de la Torre Aboki, J., Howse, C., Korandova, J., Löfman, P., Logtenberg, C., Lupton, T., Mallon, C., Oliver, S., Pickles, D., & Bulinckx, L. (2013). The nurse's role in addressing unmet treatment and management needs of patients with rheumatoid arthritis: Delphi-based recommendations. *Int J Nurs Knowl*, 24(2), 66–76.
- Gossec, L., de Wit, M., Kiltz, U., Braun, J., Kalyoncu, U., Scrivero, R., Mac-carone, M., Carton, L., Otsa, K., Soöaar, I., Heiberg, T., Bertheussen, H., Cañete, J. D., Sánchez Lombarte, A., Balanescu, A., Dinte, A., de Vlam, K., Smolen, J. S., Stamm, T., Niedermayer, D., Békés, G., Veale, D., Helliwell, P., Parkinson, A., Luger, T., Kvien, T. K., & Taskforce, E. P. (2014). A patient-derived and patient-reported outcome measure for assessing psoriatic arthritis: Elaboration and preliminary validation of the psoriatic arthritis impact of disease (PsAID) questionnaire, a 13-country EULAR initiative. *Annals of the Rheumatic Diseases*, 73(6), 1012–1019.
- Gossec, L., Dougados, M., Rincheval, N., Balanescu, A., Boumpas, D. T., Canadelo, S., Carmona, L., Daurès, J. P., de Wit, M., Dijkmans, B. A., Englbrecht, M., Gunendi, Z., Heiberg, T., Kirwan, J. R., Mola, E. M., Matucci-Cerinic, M., Otsa, K., Schett, G., Sokka, T., Wells, G. A., Aanerud, G. J., Celano, A., Dudkin, A., Hernandez, C., Koutsogianni, K., Akca, F. N., Petre, A. M., Richards, P., Scholte-Voshaar, M., Von Krause, G., & Kvien, T. K. (2009). Elaboration of the preliminary rheumatoid arthritis impact of disease (RAID) score: A EULAR initiative. *Annals of the Rheumatic Diseases*, 68(11), 1680–1685.
- Gossec, L., Paternotte, S., Aanerud, G. J., Balanescu, A., Boumpas, D. T., Carmona, L., de Wit, M., Dijkmans, B. A., Dougados, M., Englbrecht, M., Gogus, F., Heiberg, T., Hernandez, C., Kirwan, J. R., Mola, E. M., Cerinic, M. M., Otsa, K., Schett, G., Scholte-Voshaar, M., Sokka, T., von Krause, G., Wells, G. A., & Kvien, T. K. (2011). Finalisation and validation of the rheumatoid arthritis impact of disease score, a patient-derived composite measure of impact of rheumatoid arthritis: A EULAR initiative. *Annals of the Rheumatic Diseases*, 70(6), 935–942.
- Kippenbrock, T., Emory, J., Lee, P., Odell, E., Buron, B., & Morrison, B. (2019). A national survey of nurse practitioners' patient satisfaction outcomes. *Nursing Outlook*, 67(6), 707–712.
- Larsson, I., Bergman, S., Fridlund, B., & Arvidsson, B. (2012). Patients' experiences of a nurse-led rheumatology clinic in Sweden: A qualitative study. *Nursing & Health Sciences*, 14(4), 501–507.
- McInnes, I. B., Combe, B., & Burmester, G. (2013). Understanding the patient perspective - results of the Rheumatoid Arthritis: Insights, Strategies & Expectations (RAISE) patient needs survey. *Clinical and Experimental Rheumatology*, 31(3), 350–357.
- Ter Maten-Speksnijder, A. J., Dwarswaard, J., Meurs, P. L., & van Staa, A. (2016). Rhetoric or reality? What nurse practitioners do to provide self-management support in outpatient clinics: An ethnographic study. *J Clin Nurs*, 25(21-22), 3219–3228.
- van Tuyl, L. H., Sadlonova, M., Hewlett, S., Davis, B., Flurey, C., Goel, N., Gossec, L., Heegaard Brahe, C., Hill, C. L., Hoogland, W., Kirwan, J., Hetland, M. L., van Schaardenburg, D., Smolen, J. S., Stamm, T., Voshaar, M., Wells, G. A., & Boers, M. (2017). The patient perspective on absence of disease activity in rheumatoid arthritis: A survey to identify key domains of patient-perceived remission. *Annals of the Rheumatic Diseases*, 76(5), 855–861.
- Wolfe, A. (2001). Institute of medicine report: Crossing the quality chasm: A new health care system for the 21st century. *Policy, Politics & Nursing Practice*(2), 233–235.