The eumusc.net standards of care for rheumatoid arthritis: importance and current implementation according to patients and healthcare providers in the Netherlands

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Abstract

Objective

The eumusc.net standards of care (SOCs) for rheumatoid arthritis (RA) aimed to improve quality of care across Europe. This study investigated importance and implementation of each standard according to patients and health care professionals (HCPs) in the Netherlands and identified barriers towards implementation.

Methods

Dutch patients, rheumatologists and rheumatology nurses rated importance and implementation (0–10 numeric rating scale (NRS); 10=most important/best implemented) for each of the 20 SOCs. A care gap, adjusted for importance, was calculated: (100=highest gap). Statistical differences between a) patients and HCPs and b) subgroups of patients (demographics, health) were tested. Additionally, patients indicated agreement (0–10) with 6 implementation barriers.

Results

386 patients and 91 HCPs were included. Both ranked adequate disease modifying anti-rheumatic drug treatment (9.3(SD1.2), 9.2(SD0.8)), access to care in emergencies (9.2(SD1.2), 9.2(SD1.0)) and regular re-appraisal when treatment fails (9.2(SD1.3), 9.0(SD1.0)) the most important SOCs, and these were among the best implemented (NRS≥8.5) SOCs. After accounting for applicability, patients and HCP identified care gaps for early diagnosis (25.5(SD32.0), 22.3(SD16.3)), availability of a treatment plan (25.1(SD22.7), 25.7(SD18.5)) and patients also for a regular schedule of assessment of disease (28.6(SD25.5)).Patients with poorer health or higher education scored systematically lower on care received while sharing similar priorities. Patients and HCPs considered limited reimbursement of specific health services a main barrier for implementation and patients additionally identified limited time of physicians.

Conclusion

Dutch patients and HCPs overall agreed on priorities in care and found relevant SOCs well implemented. However, suggestions for improvement were raised especially by patients with poorer health and/or higher education.

Key words

rheumatoid arthritis, patient education, health services needs and demands

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Introduction

To raise quality of care and improve equity in health for all patients with rheumatic diseases across Europe, the European Musculoskeletal Conditions Surveillance and Information Network (eumusc.net) was initiated as a project co-founded by the European League against Rheumatism (EULAR) and the European Union (EU) (1). As part of this initiative, eumusc.net developed the standards of care (SOCs) for the management of rheumatoid arthritis (RA) (2). These were based on existing management recommendations and further selected and refined by an expert panel of health care professionals (HCPs) and patients. In addition to a version for professionals, a lay version has been developed to help patients understand whether they receive adequate care, and strengthen their voice in the management of their disease (2). This is particularly important as, despite the recognised relevance of patients' needs in healthcare, concerns and preferences of patients still receive little attention (3, 4). A recent study revealed that needs and priorities are not the same for all patients, nor for patients and their care providers. Systematic differences were identified *e.g.* for RA patients with different disease severity (5). Other studies found that RA patients share different care priorities compared to HCPs, (6, 7), *e.g.* when choosing treatments patients rather focused on the consequences of disease activity, whereas HCPs primarily focus on disease activity (8). Lack of alignment of care with patients´ needs could be an important barrier for implementation of SOCs. Such insight is relevant for initiatives aiming to improve quality of care.

However, for successful implementation of SOCs in practice, insight into priorities and current level of implementation is not sufficient. It is equally essential to understand the broad range of barriers. In addition to discordance in priorities between patients and professionals, barriers may also include restrictions in the health care environment (*e.g.* health services not covered by the insurance systems or patients without adequate access to specialists) or within the stakeholders' attitudes (*e.g.* clinicians do not see the need for certain health services).

Finally, to facilitate implementation, the SOCs were also meant to educate patients about optimal care and were proposed as a self-care tool to monitor the quality of care. Various previous studies investigated the benefit of different patient education formats and showed that patient education can contribute to improved outcomes in RA (9-13). Other studies suggest that RA patients are able to monitor their disease activity with beneficial effects on outcome, although not all patients were eager to do so (14-19). Hence, when proposing the lay version of the SOCs as a tool for implementation, it is also relevant to identify formats and approaches preferred by patients.

Therefore, the objectives of this study were 1) to investigate the current level of implementation and importance of each SOC reflected in the eumusc.net SOCs from the perspective of the patients and healthcare professionals, 2) to identify potential barriers towards implementation of optimal care, and 3) to understand the attitude of patients and physicians towards using SOCs as a tool to monitor personal care.

Material and methods

A cross-sectional study was conducted in the Netherlands (NL) in 2015 and 2016 among patients with RA and their HCP, including rheumatology nurses and certified rheumatologists. The study protocol and patient survey were approved by the local Ethics Committee of all participating centres.

Recruitment

Patients diagnosed with RA by a rheumatologist and under care in one of four rheumatology practices (2 non-university and 2 university hospitals) from different regions in NL were invited to participate by letter or email. Further all rheumatologists of the Dutch Society of Rheumatology and all rheumatology nurses from the rheumatology unit of the Dutch Nurses Association were invited by e-mail.

The Questionnaires

Based on the lay version of the eumusc.net SOCs, addressing 16 areas of care through 20 individual items (questions), two questionnaires (for patients and HCPs) were developed. The final patient questionnaire was then translated into Dutch to ensure patients fully understand each question. The available formal Dutch translation of eumusc.net SOCs has been used as basis for the translation of the questionnaire.

In Part 1 of the questionnaire, participants were asked to rate each of the 20 SOC items on a numeric rating scale (NRS) across two dimensions: (1) the level of care received personally (for patients) or the level of care received by average patient (for HCPs) to assess implementation (0 = not received at all; 10 = fully received) and (2) the level of importance to assess priorities in care (0 = not important at all, 10 = very important). In the patients' questionnaire, respondents could alternatively select "not applicable" or "I do not understand" when asked for care received or "no opinion" when asked for importance. All respondents had the opportunity to add personal comments for individual SOCs (patients) or the SOCs overall (patients and HCPs). In addition, patients were asked to rate on a NRS (0-10; 10=fully agree) the level of agreement with 6 statements describing potential barriers for delivery of care according to agreed standards addressing (1) limited applicability of standards to patients´ individual needs (2) restricted access to proposed care (access, availability, cost coverage) and (3) poor physician - patient interplay, resulting from (3a) differences in expectations and attitude and (3b) physician´s time dedicated to patients in clinical practice. To reduce the questionnaire burden, the questionnaire for HCP only contained one open question on potential barriers for implementation. In Part 2, the opinion of patients and physicians on patient self-care and usefulness of a patient tool based on SOCs was assessed. Respondents were asked to rate on a NRS scales (0–10; I fully agree) their level of agreement with 11 statements covering 3 domains: (1) expected role of patients in the management of the disease, (2) possible applications of the self-care tool in clinical practice, and (3) possible sources to access such a tool.

Finally, data on patients' age, gender, disease duration (in years) and educational background (primary, secondary or university education) were collected. Patients' overall health status was assessed using the patient global assessment of disease (PatGA). They were asked to mark on a 0–10 NRS (0=very poor) how they are currently doing, considering all the ways in which illness affects them"). HCPs provided information on age, gender and work-environment (academic hospital, non-academic hospital, private practice or other).

Questionnaires were piloted among 20 patients and 27 HCPs. The patient survey could be completed online or on paper, the HCPs questionnaire was administered online (20).

Statistical analysis

First, for each SOC a third dimension, the "care gap" between optimal care and current implementation was calculated as the difference between the current care received (actual score) and the optimal care (maximal-score: 10) multiplied by the reported importance [(10 – $\text{NRS}_{\text{care received}}$)* $\text{NRS}_{\text{importance}}$]. Resulting scores could range from 0 to 100 (higher scores indicate a higher care gap). When respondents had selected an alternative response options (not applicable, not understandable, no opinion), no care gap could be calculated. Next, scores from patients and HCP on each dimension of the SOC, on potential barriers, and on preferred mode of application (patients only) were presented using descriptive statistics.

Differences between patients and HCPs in assessment for 1) importance or 2) level of care received were tested for each SOC using independent *t*-tests (samples normally distributed) or the Mann-Whitney (samples not normally distributed), as appropriate. Same approach was followed to assess differences between sub-groups of patients based on gender, age (>65 (retired) *vs.* ≤65 (working age)), educational level (primary versus secondary or university education), disease duration (≤2 years *vs.* >2 years) and disease status (PatGA ≥7 *vs.* <7 (median)). Differences were considered statistically significant for $p<0.05$. To visualise the differences for the 20 SOCs between dimensions (for same group) or between (sub)-groups (for same dimension), spider graphs were created. In a scenario analysis, SOCs were also classified into broader domains representing information related SOCs and process/structure related SOCs to explore whether specific response patterns could be found across these traditional domains of quality of care (Supplementary material, appendix A). Written comments of respondents to any of the survey questions were analysed qualitatively by identifying common constructs.

Results

In total, 386 patients and 91 HCPs (52 rheumatologists and 39 nurses) were included. Among HCPs, 64 (74%) were female, mean age was 49 (SD 9). Among patients, 247 (66%) were female, mean age was 61 (SD 11) (Table I).

Implementation and importance for each item of Standards of Care

• The patients' perspective

Table II shows for each SOC the mean scores per dimension and Figure 1A visualises patterns in scores in a spider graph. Scores for importance were ≥8.0 for all but two SOCs, confirming their relevance. However, scores for implementation were systematically lower than for importance and this was significant in 19 of 20 SOCs. Highest scores for importance were found for adequate disease-modifying anti-rheumatic drug (DMARD) treatment, regular re-appraisal of treatment targets in case of treatment failure and access to emergency contacts. These SOCs were well implemented. The highest care gaps were identified for information about alternative therapies (SOC 16, 38.1 (SD 29.1)), and information about options of surgery (SOC 10, 29.7 (SD 30.8)) but these were not applicable for 33 and 29% of patients, respectively (supplementary material, appendix B). Moreover, importance was low for SOC 16 (information about alternative therapies). When accounting for applicability, the top three care gaps were found for receiving a schedule of regular assessment of disease (SOC 5, 28.6 (SD 25.5)), early diagnosis within 6

Table I. Patients' and health care professionals' assessment on level of implementation and importance of individual items of Standards of Care.

	Patients (n=386)				Health Care Professionals (HCPs, n=91)			
	Implementation (0-10 NRS$^{1)}$)	*Patients NOT scoring SOC	Importance (0-10 NRS)	Care Gap$^{2)}$ (0-100)	Implementation (0-10 NRS)	*HCPs NOT scoring SOC	Importance (0-10 NRS)	Care Gap$^{2)}$ (0-100)
Standards of Care (SOC) items: Brief description	Mean (SD)	N (%)	Mean (SD)		Mean (SD)	N (%)	Mean (SD)	
1. Diagnosis within 6 months of symptom onset	6.9 (3.6)^{b}	102 (26%)	8.7 (2.0)^{b}	25.5 (32.0)	7.1 (2.3)^{b}	**4 (4%)**	8.5 (1.7)^{b}	**22.3 (16.3)**
2.1. Info and education about disease	8.4 (1.8)^{b}	***14 (4%)***	9.1 (1.3)^{b}	13.7 (16.1)	8.2 (1.4)^{b}	***1 (1%)***	8.9 (1.2)^{b}	15.5 (11.8)
2.2. Info/education on treatment benefits/risks	7.8 (2.3)$^{a, b}$	***21 (5%)***	9.0 (1.2)^{b}	18.9 (20.2)^{a}	8.6 (1.0)$^{a, b}$	***0 (0%)***	**9.1 (0.8)**^{b}	11.7 (8.4)^{a}
2.3. Info/education on patient´s needs	7.8 (2.2)$^{a, b}$	***18 (5%)***	9.0 (1.2)^{b}	19.5 (19.6)^{a}	8.2 (1.1)$^{a, b}$	***1 (1%)***	8.9 (0.9)^{b}	15.4 (9.6)^{a}
2.4. Info about relevant patient organisations and trusted sources of evidence-based information	6.5 (2.8)$^{a, b}$	63 (16%)	***7.5 (2.4)***$^{a, b}$	24.5 (20.7)^{a}	7.3 (1.8)$^{a, b}$	***1 (1%)***	7.9 (1.5)$^{a, b}$	19.8 (12.0)^{a}
3. Availability of a treatment plan	6.7 (2.8)	51 (13%)	***8.3 (1.8)***^{b}	25.1 (22.7)	***6.5 (2.6)***	2 (2%)	8.0 (1.8)	**25.7 (18.5)**
4.1. Clinical status assessment prior treatment	7.7 (2.4)$^{a, b}$	33 (8%)	8.9 (1.5)^{b}	18.1 (19.3)^{a}	**8.8 (1.2)**^{a}	2 (2%)	**9.1 (1.1)**	***10.3 (9.0)***^{a}
4.2. Patients are informed about vaccination	6.8 (3.4)^{b}	125 (32%)	8.5 (1.9)$^{a, b}$	23.1 (26.1)	7.1 (2.2)^{b}	***1 (1%)***	8.0 (1.8)$^{a, b}$	20.5 (14.3)
5. Schedule of regular assessment of disease received?	***6.4 (3.0)***^{b}	53 (14%)	8.6 (1.5)$^{a, b}$	**28.6 (25.5)**^{a}	6.9 (2.5)^{b}	2 (2%)	***7.9 (2.0)***$^{a, b}$	20.3 (13.5)^{a}
6. Patients have access to emergency contact	**8.5 (2.3)**$^{a, b}$	***21 (5%)***	**9.2 (1.2)**^{b}	***12.1 (19.0)***^{a}	**9.1 (1.3)**^{a}	2 (2%)	**9.2 (1.0)**	***7.3 (9.8)***^{a}
7. Adequate DMARD received?	**9.3 (1.2)**^{a}	39 (10%)	**9.3 (1.2)**	***5.7 (9.2)***^{a}	**8.9 (1.1)**^{a}	3 (3%)	**9.2 (0.8)**	***9.4 (9.3)***^{a}
8. Regular re-appraisal of treatment targets in case of treatment failure	**8.7 (2.2)**^{b}	39 (10%)	**9.2 (1.3)**^{b}	***10.0 (17.7)***	8.7 (1.3)	***1 (1%)***	9.0 (1.0)	10.5 (9.6)
9. Patient informed on how to control pain	8.3 (2. 0)$^{a, b}$	25 (6%)	**9.2 (1.3)**$^{a, b}$	14.6 (17.6)^{a}	7.5 (1.2)$^{a, b}$	**4 (4%)**	8.7 (1.1)$^{a, b}$	21.0 (9.5)^{a}
10. Patient informed about options of surgery (benefit/risk)	***6.0 (3.6)***^{b}	**239 (61%)**	8.4 (2.4)$^{a, b}$	**29.7 (30.8)**^{a}	***6.5 (2.2)***	**8 (9%)**	***6.8 (2.1)***^{a}	20.0 (8.9)^{a}
11. Patients have access to treatments (pharm. & non-pharm)	7.7 (2.7)$^{a, b}$	125 (32%)	8.8 (1.7)^{b}	16.7 (20.9)	8.4 (1.5)$^{a, b}$	***1 (1%)***	8.9 (1.1)^{b}	13.2 (12.4)
12. Access to other HCPs (occupational therapist, physiotherapist, etc.)	7.8 (2.8)^{b}	61 (16%)	8.9 (1.7)$^{a, b}$	17.5 (23.7)^{a}	7.6 (2.0)^{b}	3 (3%)	8.3 (1.6)$^{a, b}$	17.5 (12.9)^{a}
13. Info on adequate physical exercise	7.0 (3.0)$^{a, b}$	70 (18%)	8.7 (1.4)^{b}	24.4 (25.3)^{a}	7.8 (1.3)$^{a, b}$	3 (3%)	8.5 (1.3)^{b}	17.7 (10.1)^{a}
14. Training on aids, devices, ergonomic principles	7.0 (2.9)^{b}	**152 (39%)**	8.6 (1.7)$^{a, b}$	22.7 (24.0)	7.5 (1.6)^{b}	2 (2%)	8.3 (1.4)$^{a, b}$	19.0 (10.2)
15. Info on healthy lifestyle	7.0 (2.9)$^{a, b}$	60 (15%)	8.5 (1.7)^{b}	23.2 (24.3)^{a}	7.6 (1.8)$^{a, b}$	3 (3%)	8.4 (1.5)^{b}	18.7 (10.8)^{a}
16. Info about limited evidence of alternative therapies	***3.9 (3.1)***$^{a, b}$	**186 (48%)**	***6.5 (3.3)***^{b}	**38.1 (29.1)**^{a}	***5.7 (2.4)***^{a}	**5 (5%)**	***6.2 (2.4)***	**23.6 (13.4)**^{a}

*respondents who selected an alternative response (not applicable, do not understand, no opinion) did not contribute to the scores (see column patients not scoring SOC); in bold: top 3 highest scores, in bold italic: bottom 3, lowest scores, ^{a}significant differences ($p<0.05$) between patients and health care professionals (HCPs) when either comparing NRS scores for "level of care received" or "level of importance", ^{b}significant differences between "NRS scores level of care received" and "NRS scores level of importance" (patients only or HCPs only).

^{1}NRS: numeric rating scale; ^{2}Care gap: for importance adjusted implementation gap [(10-score for care received) * score for importance], scale 0–100.

DMARD: disease-modifying anti-rheumatic drug; n: number of patients.

Table II. Characteristics of patients and health care professionals.

	Patients	Health Care Professionals		
		Total (Rheumatologists and Rheumatology Nurses)	Rheumatologists	Rheumatology Nurses
Number of participants	**386**	**91**	52	39
Age in years [mean (SD)]	**61.2 (10.9)**	**48.6 (9.3)**	47.4 (9.4)	50.4 (8.6)
Gender [n (%) female]	**247 (66.2)**	**64 (73.6)**	28 (54.9)	39 (100.0)
Education [n (%) university education]	**118 (31.2)**	NA	NA	NA
Disease duration in years [mean (SD, median, range, interquartile range)]	**15.0 (12.5, 55, 17)**	NA	NA	NA
Patient Global* [mean (SD)]	**6.4 (2.0)**	NA	NA	NA
Work setting [n (%) university setting]	NA	**26 (29.9)**	14 (26.9)	12 (34.3)

*Patient global assessment of disease activity (0-10 numeric rating scale, 0: poor health; 10: good health); NA: not applicable.

months of symptom onset (SOC 1, 25.5 (32.0)) and availability of a treatment plan (SOC 3, 25.1 (SD 22.7)).

Patients with higher education or poorer health scored significantly lower on care received but similar on importance (Fig. 2). Age, gender and disease duration did not reveal important differences with only few items showing significant differences between sub-groups (Supplementary material, appendix C). When grouping SOCs according to information related SOCs and process/structure related SOCs, no specific patterns could be identified (Supplementary material, appendix A)).

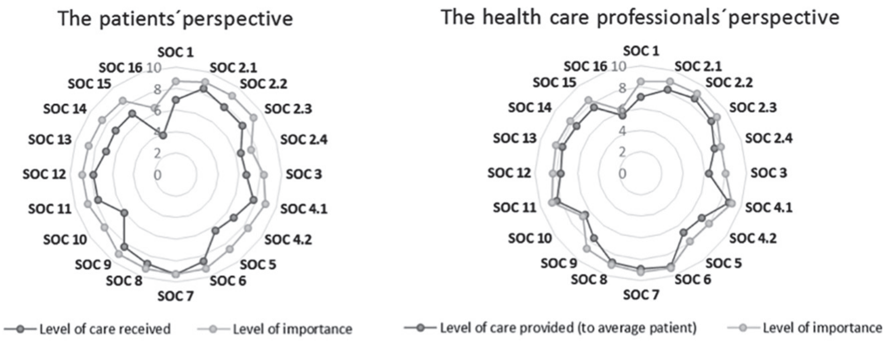
Patients proposed to add information on (a) how to manage impairments beyond disease activity/pain such as fatigue and limitations in physical function or activities of daily life, and (b) how to deal with the consequences of RA on social roles like work and family obligations. In addition, some patients suggested to better explain and/or simplify the language used to describe some SOCs. Of note, 30% of patients responded: "I do not understand" for information about options of surgery (SOC 10). Across SOCs, patients with primary education tended to score "I do not understand" more frequently than patients with secondary or university education (Supplementary material, appendix C).

- *Comparison of patients' and health care professionals' perspective*

Overall, the differences in absolute score for importance and implementation between patients and HCPs were small. However, for implementation patients more frequently scored significantly lower than HCPs. (Table I; Fig. 1B). HCPs shared patients' priorities (importance) in care (SOC 6 to 8) and considered these to be well implemented but also gave priority to educating patients about treatment benefits and risks (SOC 2.2) and clinical status assessment prior treatment (SOC 4.1). For the care gaps, several SOCs (n=12) turned out to be significantly different when comparing patients and HCPs, with patients often rating higher care gaps (n=11). When accounting for the applicability of SOCs, the highest care gaps were similar for patients and HCP (SOC 1, 3 and 16). Additionally, HCPs identified room for improvement when informing patients on comorbidities, and educate them on the importance of family support.

When grouping SOCs as process/structure/information related SOCs no systematic trend for higher or lower scores of either patients or HCPs could be observed (Supplementary material, appendix A).

A. Differences between importance and care received/provided.



B. Difference in perceptions between patients and health care professional.

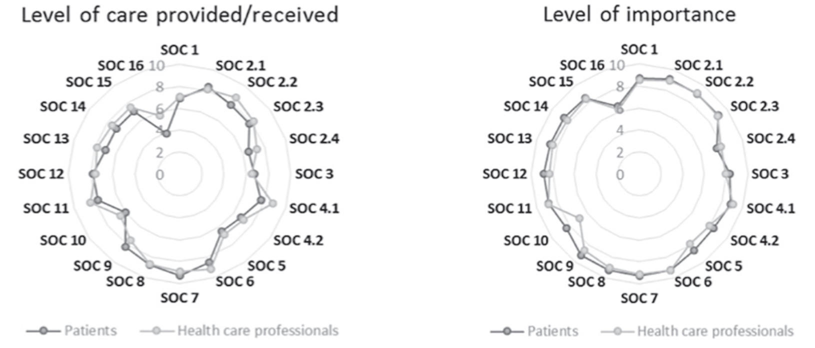
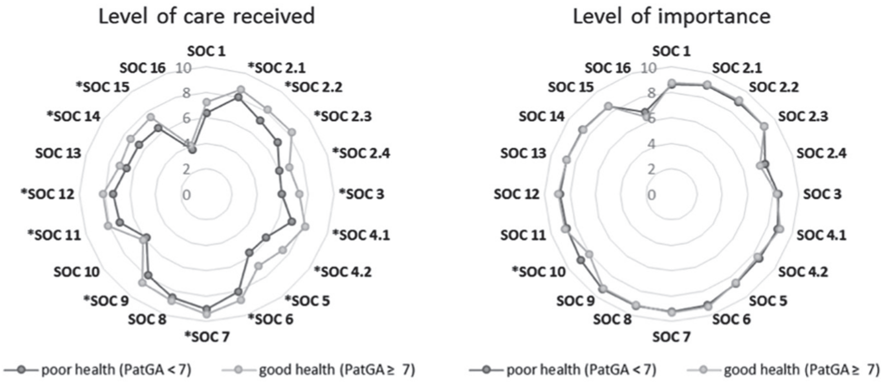


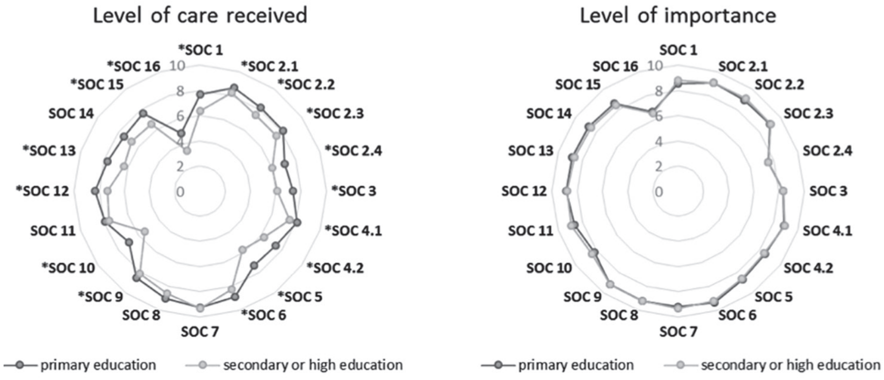
Fig. 1. Differences and synergies in the assessment of RA care in the Netherlands.

A. Patients´ assessment according to global health status (median of global health).



*SOC: Standards of care; SOC items are significantly different between sub-groups ($p<0.05$); PatGA: Patient Global Assessment.

B. Patients' assessment according to education (primary *vs.* secondary or high).



* SOC: Standards of care; SOC items are significantly different between sub-groups ($p<0.05$).

Fig. 2. Ratings of importance and implementation for each of the Standards of Care (SOC) according to patients' characteristics.

Barriers for implementation of standards of care

Overall, patients indicated low agreement with predefined potential barriers for implementations. The highest limitation was reimbursement of services by the health insurance (4.9 (SD 3.6)). Furthermore, patients saw limitations in the applicability of standards due to differences in individual needs (3.6 (SD 3.0)). Although patients recognised that HCPs partly dedicate too little time to consultations (4.2 (SD 3.5)), patients overall acknowledge that clinicians see the need for patient education (2.6 (SD 3.0)) and implementation of SOCs (2.5 (SD 2.8)). On the same line, Dutch patients saw minor limitations in access to specialists (1.8 (SD 2.5)) (Fig. 3). Physicians mainly agreed with patients that reimbursement of services proposed in SOC was the main barrier.

Use of lay version of standards of care as a patient self-care tool in clinical practice

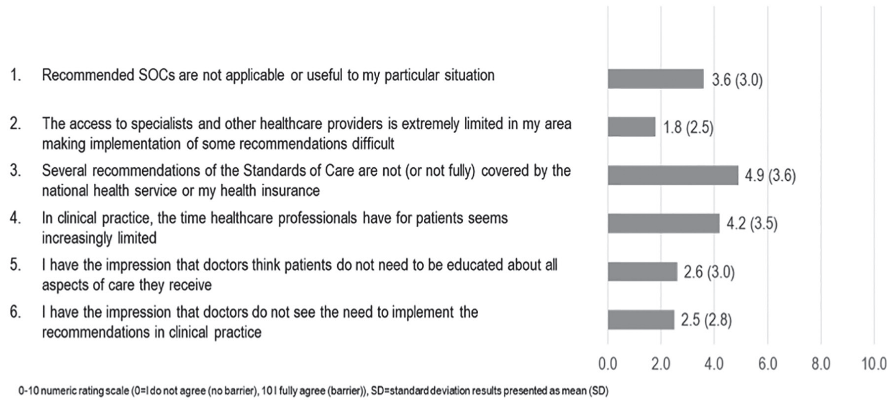
Both physicians and patients agreed on the importance of each other's role in care and both supported active involvement of patients in the management of their disease. However, physicians systematically indicated lower levels of agreement on the use of SOCs as a patient self-care tool. In terms of modes of access, patients indicated that SOCs should be accompanied with explanations (brochure or e-learning) and expected that HCPs ensured access to the SOCs (Table III).

Discussion

Patients and HCPs agreed that adequate DMARD treatment, access to care in emergencies and regular re-appraisal of treatment targets in case of treatment failure are among the most important aspects of RA care, and that these were well implemented. Still some relevant care gaps were identified including diagnosis within 6 months of symptom onset, availability of a treatment plan and in addition for patients receiving a schedule of regular assessment of disease. Patients and HCPs agreed that limited coverage of some recommended health services was a barrier for implementation; patients additionally pointed to the limited time of physicians during consultations. Patients with overall poor health and/or higher education rated level of care received as lower while still sharing similar priorities. Interestingly, patients and physicians equally shared a positive attitude towards active patient participation in care, but the concept of using SOCs as a patient self-care tool was less supported by physicians. In addition, some linguistic and content related improvements were suggested to optimise usability of the tool for patients.

The substantial agreement on the importance of different aspects of care was partly surprising as earlier international studies found clear discrepancies between patients' and HCPs' views (5, 8, 21, 22). It should be noted that the development of the SOCs was a joint effort of experts and patients that likely contributed to the overall higher level of agreement. Notwithstanding, the present study confirmed that patients (compared to HCPs) rated priority of pain management significantly higher (5, 8, 23). Professionals still underestimate the impact of pain. Also, patient responses revealed that several aspects including management of limitations in physical function, of fatigue, and of the consequences of RA on work participation or family role (8, 24, 25) were poorly reflected in the SOCs. While these points were included in the more detailed elaboration of the original SOCs for HCPs, they were clearly insufficiently emphasised in the lay version.

Room for improvement in care was also identified by all participants. Early diagnosis remained a care gap despite being frequently emphasised as highly relevant for long-term treatment outcomes (26, 27). Interestingly,



0-10 numeric rating scale (0=I do not agree (no barrier), 10 I fully agree (barrier)), SD=standard deviation results presented as mean (SD)

Fig. 3. Patients' agreement with potential barriers when implementing Standards of Care (SOC).

in addition, availability of a treatment plan and receiving a schedule of assessments was identified as an area that requires more attention in clinical care. The findings support an earlier study that emphasise the need of such documents to support patients in the management of the disease (28).

Some structural barriers for implementation of care included increasingly limited financial coverage of recommended health services in NL and the time pressure among physicians in clinical practice that may hinder adequate communication between patient and physician and thus potentially lead to poor outcomes (29). For the rheumatology management team, it will therefore remain challenging to address all the SOCs in a time constraint clinical practice situation. To some extent e-health programs for patients might offer solutions but likely time of HCPs spent in educating patients should also receive better rewards. Also electronic health records, such as METEOR, may help centres and clinicians to optimise quality of care or improve patient education (30). However electronic systems cannot fully replace personal interactions between patients and clinicians and should therefore be used with care (31).

Patients with better overall health status found SOCs better implemented, a finding that is in line with an earlier study that found a positive association between better health status and patient satisfaction (32). However, that study also documented positive relationships between high satisfaction and older age or male gender whereas in the present study age and gender did not play an important role in the patients' assessment of care received. Likely, differences in the construct 'satisfaction' and 'level of care received' are not fully comparable, and contributed to the differences in findings between studies.

In line with earlier studies, patients with lower education rated to receive better care than patients with higher education (33, 34). Possibly, patients with lower education had lower expectations towards information and education on care. Keeping in mind that several studies show that lower educated patients receive less optimal care for the same level of disease activity, results of the current study suggest that these patients might be too easily satisfied and not sufficiently critical. On that line, the impact of helping patients to understand what they can expect from the healthcare system, as part of their health literacy education, should receive more attention (33-35).

Patients and HCPs overall agreed on the active role of patients in care. Earlier studies already advocated for patient

Table III. The use of a patient version of the Standards of Care in RA care.

Statement	Patients$^{1)}$ n=356	Rheumatologists$^{1)}$ n=31
	Mean (SD)	
The roles and responsibilities of rheumatologists and patients in RA care		
It is the responsibility of my doctor to define and monitor the treatment strategy for me	8.6 (1.8)	9.3 (0.9)
It is also my responsibility as patient to get actively involved in the management of the disease and state preferences	8.1 (2.0)	8.8 (1.2)
Active participation of the patient in the treatment can influence the treatment outcomes/ symptoms	8.9 (1.3)	8.7 (1.3)
A lay (patient) version of the Standards of Care as patient tool		
All rheumatoid arthritis patients should know the Standards of Care (*i.e.* optimal care for their disease)	8.4 (1.7)*	7.7 (2.1)*
The Standards of Care could be used by patients to get an overview of the most relevant aspects of RA care they should receive	8.5 (1.6)*	7.6 (2.5)*
The Standards of Care help patients to evaluate the quality of care they receive	8.6 (1.5)*	7.7 (2.2)*
Knowing the Standards of Care helps patients to request from their doctor additional information, service or care they want/should receive	8.7 (1.4)*	8.0 (2.0)*
Access to a lay (patient) version of Standards of Care		
A brochure/leaflet or e-health program with explanatory information could help to fully understand the content and purpose of the Standards of Care	8.0 (1.4)	8.1 (1.9)
The Standards of Care should be available as a print copy (*e.g.* flyer, leaflet) that patients can receive from their doctor	7.9 (1.6)	7.8 (1.3)
The standards of care should be easy to find on the internet	7.5 (2.2)	7.7 (1.8)
The Standards of Care should be available as an "App" for smartphones and tablets. I want to have fast and simple access to it and receive updates automatically	6.1 (2.7)	7.9 (1.1)

$^{1)}$ 0-10 numeric rating scale (0=I do not agree, 10 I fully agree), * significant difference ($p<0.05$) between patients and rheumatologists.

centeredness and highlighted the positive impact of patients' participation in care (3, 36). However in line with earlier findings, HCPs were somewhat less supportive about a patient tool (based on SOCs) to allow patients to monitor quality of care. Possibly HCPs are partly concerned about the limited additional benefit in patient outcomes (37, 38).

When developing SOCs towards a patient tool, patients further suggested more detailed explanations on individual SOCs to fully understand the purpose of each. Of note, in the present study "I do not understand" was predominantly selected by patients with primary education and rated frequently for SOCs related to information/patient education (SOC 10, 16).

Also, patients frequently considered some of the SOCs as not applicable. In other words, timing of needs in the patients' disease journey should receive attention when developing self-monitoring tools for patients, *e.g.* in contrast to HCPs, patients perceive a high care gap when asked about *SOC 10* - information on options of surgery, however given the success of newer therapies, the need for surgeries significantly decreased in recent years (39) and consequently HCP may not inform patients about therapies not immediately relevant for them.

Some limitations should be considered when interpreting results. First, although the study included 91 HCPs and more than 386 patients with diverse characteristics, response bias cannot be fully excluded. Second, when translating the original SOCs for HCPs into a lay version, simplification was needed but some oversimplification might have occurred, *e.g.* important aspects like how to deal with the consequences of RA on daily living have not been specifically addressed although importance for patients may be high. Third, when comparing patients' and HCPs' scores for implementation, HCPs overall tended to score higher. In this context, it may be relevant to recognise that patients primarily assessed the performance of others, while HCPs primarily assessed their own performances and thus likely tended to be less critical. A gold standard to assess 'care received' is difficult, but discrepancies in opinions can be informative. Last, the study has been conducted in NL, therefore extrapolation of results may partly be limited and we recommend repeating this study in other countries with different health care environment. Still the present study provides valuable and generalisable insights into the needs of patients and could contribute to improvement of care in a number of European countries, especially when health care settings are largely comparable to NL.

Conclusion

With overall high ratings for levels of implementation, patients and HCPs recognised the comparatively high Dutch standards in relation to many other countries. Dutch patients and HCPs overall agreed on priorities in care for patients with RA and considered the most relevant SOCs were also the best implemented ones. Still, some room for improvement in RA care could be found, especially by patients with poorer health or higher education. Improvements should primarily target early diagnosis within 6 months of symptom onset, availability of a treatment plan and in addition address the patients´ need to have a schedule of regular assessment of disease.

Key messages

- Dutch patients and professionals agree on the top three priorities in care and find these well implemented
- Care gaps exist for early diagnosis, availability of treatment plan, and receiving regular follow-up schedules
- Patients with poorer health or higher education rated lower on level of care received.

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