Rheumatology outcomes: the patient’s perspective.
A multicentre focus group interview study of Swedish rheumatoid arthritis patients


Objectives. Patients with rheumatoid arthritis (RA) and clinicians have different views about benefits from treatments. More knowledge is needed about how patients assess outcomes in order to update current measurements.

Methods. Focus group interviews were performed at four Swedish rheumatology clinics. A total of 25 patients with RA were included, representing a wide range of ages and disease duration. Predetermined topics relating to important outcomes from and satisfaction/dissatisfaction with RA treatments were discussed.

Results. The participants’ initial outcome assessments included physical and psychosocial items, which comprised overall treatment goals such as impairment in social roles, fatigue, daily activities and self-confidence. The identified themes were ‘Normal life’, ‘Physical capacity’, ‘Independence’ and ‘Well-being’. Satisfaction with treatment was associated with the quality of communication between staff and the patient. The participants assumed this as a prerequisite for a treatment to work. Patients wanted to be accepted as experts on their own bodies, and expected all clinicians to be experts on RA. This made it possible for patients to ‘take charge’ of their life situation. Good resources for and access to rheumatology care were desired.

Conclusions. Suggesting a holistic approach to rheumatology care, the study results indicate that the illness and outcomes have to be evaluated within an individual RA patient’s total life situation, described in the identified themes: ‘Normal life’, ‘Physical capacity’, ‘Independence’ and ‘Well-being’. Development and validation of measurements covering these issues is suggested. More research is needed about communication and how patients experience their roles in the rheumatology clinic.

Key words. Rheumatoid arthritis, Qualitative research, Focus groups, Outcome assessment, Patient perspectives.

The clinical care of rheumatoid arthritis patients requires assessment not only of the condition of organs and laboratory measurements but also of their functional ability. Since its publication in 1949, the assessor-made Steinbrocker Functional Classification [1] has been used clinically for patients with rheumatoid arthritis (RA). However, the paradigm shift in the assessment of disease activity and outcome did not obtain general acceptance for several decades, when it was advocated that professionals involved in rheumatology care should add patient-centred, self-reported measurements of symptoms and disability for use in clinical practice [2]. A large number of measurements have been created and validated [3–7]. Thus, core sets of variables for use in short-term assessments of therapeutic response in RA are suggested. They include joint scores, symptom reports by patients and physicians, measures of inflammation, joint damage and of physical and psychosocial dysfunction influencing quality of life according to the ACR, the EULAR and/or the ILAR definitions. Additionally, measures for the important long-term multidimensional outcome assessments are presented, comprising items suggested not only by health professionals but also by patients, who were interviewed when the measurements were created. A recent reconstruction of the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) [8] is also available for multifatorial assessment of health and health-related states.

There is still no general agreement about which self-report multidimensional functional measurement should be used in routine clinical care. However, the Health Assessment Questionnaire (HAQ) disability index [7, 9, 10] has been used globally as ‘the gold standard’ [11] in spite of its scoring problems [12, 13].

Experts keep evaluating the qualities of the measurements [14–16]. As a result, a growing number of studies have been found to report a discordance in opinion between patients and professionals when it comes to symptoms, the impact of the disease and treatment outcomes [17–20]. Consequently, one vital goal now is to reconsider patients’ perspectives and cooperation in the assessment of important treatment outcomes [21].

Inspired by an on-going British multicentre study exploring RA patients’ preferences on treatment and outcomes [22], we adopted the same qualitative focus group method and topics in this Swedish study. The research questions to be addressed in the interactive discussions by the focus group participants concerned the most important outcomes from their RA treatments, decisions relating to when a treatment is working, and factors associated with satisfaction/dissatisfaction with a treatment.

Methods

The focus group method

A qualitative research approach provides methods for obtaining a better understanding of factors that are not quantifiable but...
undoubtedly influence people’s experiences of health, illness, health-care and rehabilitation. In this study, the focus group interview method was used [23]. This is a well-established research technique in which the participants in each focus group, guided and encouraged by a neutral moderator, discuss different aspects of specific questions designed by the researchers. The participants’ experiences, opinions and concerns relating to the particular topics are thus explored interactively.

Study sample and procedure

To gather a maximum amount of diversified information, four multicentre focus groups with five to nine RA participants were designed (Table 1). These numbers of groups and participants were thought to be satisfactory as all the participants represented the same diagnosis, and the research questions were clearly defined and delimited to issues about treatments and outcomes, familiar to all study patients from their former rheumatology expert team care contacts.

Written information about the study was sent to the patients. After having obtained their written consent, they were invited to participate in one group session. Permission from each patient’s physician was received before the start of the study. One moderator and one observer with experience of rheumatology team care were responsible for each focus group. The focus group sessions lasted for about 1.5–2 h, including a coffee break. At the start, the participants were informed once again about the topics of their discussion and also about the moderator’s role. The patients were asked to address the following questions: What outcomes from your treatments are important to you? What makes you satisfied or dissatisfied with a treatment? How do you decide that a treatment is working?

The interviews were tape-recorded and the discussion material was transcribed verbatim and analysed using an established method [23]. A first analysis was made by the researchers at each centre who read through their interview material in detail. Codes were developed into the following themes: ‘Normal life’, ‘Physical capacity’, ‘Independence’ and ‘Well-being’.

Results

In all, 25 RA patients (9 males, 16 females) with a median age of 55 yr (range 31–77 yr) and a median disease duration of 14 yr (range 3–44 yr) participated (Table 1). All participants fulfilled the 1987 ACR criteria for RA [25] and belonged to Steinbrocker Functional classes II–III [1]. Eight patients worked full time or part time, while the others were on sick leave (n = 7), had a disability pension (n = 2) or had retired (n = 8). All the study patients had had access to multidisciplinary rheumatology team care.

Analyses of the interview material disclosed that similar items of treatment results were found to be of importance by the participants at all four centres and that similar categories of priority regarding outcome assessments could be created. Identified themes were found to cut across the two questions: ‘What outcomes from your treatments are important to you?’ and ‘How do you decide that a treatment is working?’ The discussions of the first question concerned subjective symptoms that described the patients’ perceptions of ill-health, and specified items on the RA disease such as pain, stiffness and fatigue. Addressing the following question, it became clear that the patients gathered the isolated items of desired symptom relief reported earlier into treatment goals that were of value to them in the context of their overall life situation, both physical and psychosocial. As shown in Table 2 these two questions were therefore combined [23].

The patients’ perceptions, thoughts and feelings about the most important outcomes of RA treatment and when a treatment works were developed into the following themes: ‘Normal life’, ‘Physical capacity’, ‘Independence’ and ‘Well-being’.

Normal life

Regaining full health and living a normal life were overall treatment goals, which were also expected in the later stages of the disease. The patients expressed a desire not to be regarded as differing from ordinary people or to be seen as different because of the disability caused by the RA. Living a normal life also meant feeling no limitations when it came to managing the household and normal social functioning:

‘It is self-evident that you want to be perfectly healthy.’
‘To be able to live the life I had before.’
‘Live as people usually do.’

Physical capacity

The patients’ conceptions of physical disability emerged as an important factor. They had experienced being unhealthy in terms of functional losses. Reduced pain and stiffness, increased mobility, muscle strength, grip force and balance were outcomes that made patients feel more flexible and happy:

‘I feel that mobility has a great deal to do with personal integrity—the more mobile you are, the better you manage and the better you feel.’

A reduction in the oppressive fatigue, invisible and difficult to describe and quantify but acting to screen off reality, was related to the ability to be more active.

‘The treatment is effective when I have been relieved from pain and that terrible fatigue which is like a fog over life.’

‘You become completely unable to act and you want to do nothing.’

Table 1. Characteristics of the RA participants in the focus groups at the four centres

<table>
<thead>
<tr>
<th>Rheumatology centre</th>
<th>N</th>
<th>Median age (yr)</th>
<th>Age range (yr)</th>
<th>Median RA duration (yr)</th>
<th>RA duration range (yr)</th>
<th>Gender</th>
<th>Functional class</th>
</tr>
</thead>
<tbody>
<tr>
<td>Karolinska University Hospital</td>
<td>9</td>
<td>59</td>
<td>32–77</td>
<td>12</td>
<td>5–35</td>
<td>Male</td>
<td>II</td>
</tr>
<tr>
<td>Linköping University Hospital</td>
<td>5</td>
<td>61</td>
<td>49–72</td>
<td>14</td>
<td>4–37</td>
<td>Female</td>
<td>II</td>
</tr>
<tr>
<td>Sahlgrenska University Hospital</td>
<td>6</td>
<td>38.5</td>
<td>31–49</td>
<td>8.5</td>
<td>3–24</td>
<td>Female</td>
<td>II</td>
</tr>
<tr>
<td>Spenshult Hospital</td>
<td>5</td>
<td>65</td>
<td>37–49</td>
<td>31</td>
<td>12–44</td>
<td>Female</td>
<td>II, III</td>
</tr>
<tr>
<td>Total group</td>
<td>25</td>
<td>55</td>
<td>31–77</td>
<td>14</td>
<td>3–44</td>
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<table>
<thead>
<tr>
<th>Median RA duration (yr)</th>
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<tbody>
<tr>
<td>12</td>
<td>5–35</td>
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<td>31</td>
<td>12–44</td>
<td>Female</td>
<td>II, III</td>
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<td>14</td>
<td>3–44</td>
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</table>
Independence

One much appreciated treatment outcome was being able to manage daily activities such as personal hygiene, dressing, walking and house-keeping:

‘When you begin to feel better, that is when you first realize how unwell you have been…and then you are suddenly capable of dressing yourself again.’

To care for oneself and one’s family and to able to work and enjoy leisure time activities were important. All kinds of treatments given, including assistive devices, became meaningful when the patients could increase their degree of ability and activity:

‘For me, it is important that daily activities function, that I can look after my home, my children and manage to work.’

‘Living as flexibly as possible in spite of your joint deformities—some of which you can do nothing about—you have to compensate for them.’

Well-being

The participants mentioned well-being as an important outcome, but they had difficulty defining the content of this item. They wanted to feel happy, bright and breezy, to be able to enjoy life and regain self-confidence:

‘I didn’t know that the colours were so bright, the music so beautiful, I have lived inside a bubble of glass.’

‘It is a shining moment when you feel that you have been down there for a long period, but now you can climb up to the next level.’

The study participants were aware of and discussed the fact that their RA caused not only physical but also psychological problems. They pointed out that it was very important for them to use positive thinking and a good sense of humour in combination with their physical and medical treatment. Psychological support from the health professionals and fellow network members—including other RA patients—and a positive treatment atmosphere at the rheumatology clinic was found to strengthen the participants’ self-confidence:

‘When you get support, it gives you a boost and you can manage more.’

Regarding the last question, about satisfaction/dissatisfaction with a treatment, the themes identified were ‘Benefit from treatments’, ‘Communication with the rheumatology staff’, ‘Taking charge’ and ‘Resources for and access to rheumatology care facilities’ (Table 2).

Benefit from treatments

Benefit from treatments was a principal factor in terms of satisfaction and it was basically defined as relief from pain, stiffness and fatigue and increased ability and activity. The patients were dissatisfied by the knowledge that several weeks were needed for most disease-modifying anti-rheumatic drugs (DMARDs) to disclose signs of RA improvement, if any. However, partial resolution as a result of medication and other treatments was also regarded as a benefit. The risk of adverse events was well known and caused dissatisfaction. The participants said that drug compliance increased with sufficient information about what to expect, combined with encouragement and support from the physician and the nurse in charge:

‘I began to notice a bit of an improvement after three to four months, but it took about half a year before I felt almost like I did before I got RA.’

‘This is actually the hard part…if you have to start with a new drug that takes three months before you know whether it helps or not.’

Communication with the rheumatology staff

A good relationship with the health professionals played a prominent role in the degree of satisfaction. It was associated with mutual respect, increased patient trust in the treatment and a reduction in uneasiness. The participants established the fact that:

‘If the communication doesn’t work, then the treatment won’t work. It doesn’t depend on the physician, it doesn’t depend on the patient. It is all about the mutual relationship and this teamwork requires good communication.’

Another demand was that all the rheumatology staff members should be experts in rheumatology. Only kindness and sociability were not regarded as a consultation. A desired condition for good communication was continuity with care givers:

‘Perhaps some of the health professionals at the rheumatology clinic are not experts in rheumatology. I really don’t know how this works.’
Taking charge

The participants reflected on their roles as patients making a distinction between the expert roles. The rheumatology staff members were regarded as experts in their area, while the patients regarded themselves as experts on their own bodies and on living with arthritis. They expected to be regarded as appreciated, valuable communicating partners:

‘...the clinicians are specialists in rheumatology, but as a patient you are an enormous specialist on your own body, and so every patient with RA studies books and articles about the disease.’

With this expert knowledge and relationship as the starting point, patients were willing to take charge of/take responsibility for their disease situation and to mobilize the best possible mood and strength:

‘You must fight and not just now but for your whole life—and you must fight hard.’

Resources for and access to rheumatology care facilities

The availability of rheumatology care facilities including local rheumatology departments, rehabilitation facilities and complementary treatment options elsewhere, was important. This related to the patients’ wish to ‘take charge’ of their treatment and situation:

‘I was referred to a rheumatologist during an early phase of my disease and received help. So I could make full use of all the specialist resources and assistive devices and all the things that you are informed about.’

For some participants, satisfaction with treatment involved access to rehabilitation facilities close to their place of work and at late hours. For others, it included access to rehabilitation centres in the country or abroad in a subtropical climate.

Discussion

This multicentre focus group study reports Swedish RA patients’ perspectives on outcome assessments from treatment. Basically, improvement of physical and psychological disease symptoms were of importance according to the participants. However, these specified items of ill-health were found to be related to the patients’ individual treatment goals and valued in their overall life situations. The patients wanted to regain normal life, physical capacity, independence and well-being.

Satisfaction/dissatisfaction with treatments comprised benefits from medical and physical procedures and good mutual communication with the rheumatology staff. Expert rheumatology knowledge on the part of all the health professionals was assumed, together with the fact that the RA patients were accepted as experts on the symptoms of their own bodies and were authorized to ‘take charge’ of their disease. Moreover, multiple resources for and access to rheumatology care facilities were important.

As was noted in the British focus group report on RA patients’ perspectives on treatment outcomes [22], our RA study not only confirms earlier findings but also reports new findings of special interest. Fatigue, described as devastating and consuming with a negative impact on all functional activities and psychosocial factors, was one important outcome. This symptom complex has been discussed in several studies [26–29], is repeatedly reported by patients, but is seldom included in routine clinical assessments [2] or in core sets of items of RA activity [5].

Increased well-being was of vital importance for the patients. One psychological aspect of this outcome probably includes overcoming the crisis that occurs when the risk of becoming severely disabled by the RA makes patients lose their self-confidence. As reported by Dildy [30], this impact of suffering from the disease includes a disintegration of self and the disappearance of normal roles. New strategies and resources have to be identified by the patients in order to rebuild their self, while still fighting the chronic impacts and unforeseeable flares of their RA.

Getting better may have a different meaning for each patient and, as mentioned in the report by Beaton et al. [31], our study participants reviewed not only the resolution—also partial—of disease symptoms but also the readjustment of life and redefinition of self and health as important recovery outcomes from treatments. In later stages of the disease patients were willing to adapt to a certain amount of pain and to cope with other RA symptoms, mastering their dysfunctional qualities.

In all the study focus groups, ‘taking charge’ [32] was important for satisfaction with treatment. The patients wanted the rheumatology staff to adopt a holistic approach to care [32–34] and see the whole person behind the disease and not only the arthritic individual. In addition, a positive, realistic approach was required by the staff to inspire the patients to search for adequate information about the disease. Other studies eliciting the experience of living with RA report similar aspects [17, 30–38].

In this study there were four focus groups and the total number of participants in the study was 25. This number of participants can be regarded as small, but the focus groups represented both male and female patients of varying ages and with a wide range of disease durations. The participants appeared to have stimulated each other in the interactive discussions and the sessions resulted in new and important knowledge about how the patients viewed RA treatments and outcomes. However, a limitation of this study is the fact that we did not use saturation as a criterion to decide how many groups we needed to interview. It is thus possible that new groups might have contributed with further aspects to the results.

Three focus group moderators were occupational therapists and the fourth was a nurse. All the researchers were familiar with rheumatology expert team care and the multitude of patient information commonly received and discussed at team conferences. This ‘researchers’ pre-understanding’ was of help when guiding and encouraging the participants at the focus group sessions.

The transcribed interviews from the four groups were similar in character, as were the categories, which were first formulated separately by the researchers at each local centre. We assume that these facts increase the validity of the results representing all the groups. Two of the three questions that initiated the discussions in the focus groups resulted in similar categories, indicating that the questions about ‘outcomes’ and ‘what works’ overlapped. Thus, all the answers to these two questions were formed into the four themes of normal life, physical activity, independence and well-being. This also indicates that the three research questions were not exclusive enough, which is another limitation of the study.

Information about the degree of reduction in RA symptoms was scarce. The only ‘quantity’ issue that was mentioned was that improvement in pain was most important during the early phase of RA and in RA flares. This has also been reported in the British study [22] and in other studies [12, 17]. Interestingly, a small improvement in symptoms could also be regarded as a valuable improvement according to the participants.

In conclusion, the results of this study indicate that the illness and treatment outcomes have to be evaluated in the individual RA patient’s total life situation, described in the themes of normal life, physical capacity, independence and well-being, suggesting a holistic approach to rheumatology care. Multifactorial symptoms like pain, fatigue and diminished well-being, emphasized by the patients, indicate that further development and validation of measurements covering these issues are needed. More research is also needed about how patients experience their roles at a rheumatology clinic, as improvement of communication skills, the wish
to ‘take charge’ of their disease, and the scarcity of adequate resources of and access to care were highlighted by the participants in this study. These results also indicate that previous suggestions of including rheumatic patients as co-workers in rheumatology clinical research [21, 39, 40] is still of importance.

<table>
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<tr>
<th>Key messages</th>
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<td>- Prioritized outcomes should include the overall situation of the individual RA patient, e.g. Normal life, Physical capacity, Independence and Well-being.</td>
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<td>- More research is needed about communication and about patients ‘taking charge’.</td>
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### Acknowledgements

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The authors declare no conflicts of interest.

### References

Clinical Vignette

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doi:10.1093/rheumatology/keh255

Sciatic nerve entrapment secondary to heterotopic ossification: imaging findings and potential effect of selective cox-2 inhibitors

A young woman was admitted with a 3-week history of pain and restricted mobility. Six weeks previously she had developed sudden respiratory distress and was successfully extubated 3 weeks after this episode, and later she returned home. On examination she had weakness in the muscles of the right lower extremity, almost exclusively in the territory of the tibial nerve. The diagnosis of neurogenic heterotopic ossification (NHO) was established by X-ray. Axial CT scanning of the pelvis demonstrated NHO that had developed along the fibres of the obturator internus muscle (straight black arrows) and between the obturator internus muscle and the gluteus maximus muscle (straight white arrows), including the sciatic nerve (white star). High signal on T1-weighted pelvic MRI images with gadolinium-DTPA injection was also demonstrated inside the NHO and around the right sciatic nerve (black stars).

Following treatment with 3 weeks of selective cox-2 inhibitors, the range of motion improved. Surgical release of the sciatic nerve was not appropriate because of her improvement and the presence of significant inflammatory phenomena on MRI.

Our case illustrates the importance of radiology in therapeutic decisions. The MRI clearly highlighted inflammatory phenomena [1] around the sciatic nerve. Our observation suggests that a study to assess the effectiveness of selective cox-2 inhibitors in inhibiting NHO would be of interest.

The authors have declared no conflicts of interest.

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