Understanding the patient perspective – results of the Rheumatoid Arthritis: Insights, Strategies & Expectations (RAISE) patient needs survey

I.B. McInnes[1], B. Combe[2], G. Burmester[3]

[1]Institute of Infection, Immunology and Inflammation, Glasgow Biomedical Research Centre, University of Glasgow, Glasgow, United Kingdom; [2]Department of Rheumatology, Lapeyronie Hospital, Montpellier I University, Montpellier, France; [3]Department of Rheumatology and Clinical Immunology, Charité University Hospital, Berlin, Germany.

Abstract

Objective

To gain insight into the management and treatment of rheumatoid arthritis (RA) from the perspective of patients with moderate to severe disease.

Methods

We recruited patients with moderate-to-severe, active RA who were either biologic naïve or biologic experienced (i.e. receiving biologic therapy) and then surveyed their perceptions of their disease and its management through a questionnaire. The survey was administered by computer-assisted telephone interview of patients in 9 countries (n=586) and covered diagnosis, treatment, physician interaction, and lifestyle with RA. Mean age at onset of RA symptoms was 41 years, with an average time to diagnosis of 3 years.

Results

Most physician-patient communication centered on symptoms and treatment rather than the impact of RA on quality of life (QoL). Biologic users had significantly more "good" days per month than biologic-naïve patients (71% vs. 61%). Of all patients, 22% reported high levels of pain on the day of the interview. A majority of patients considered their lives to be controlled by RA, despite the fact that they were receiving the current standard of care. Although potentially eligible for biologic therapy, as defined by a broad set of criteria for this investigation, 62% of biologic-naïve patients were not aware of biologic therapies.

Conclusion

The Rheumatoid Arthritis: Insights, Strategies & Expectations (RAISE) survey describes how patients with moderate to severe RA view their disease and which issues are critically important to them. Despite substantial impact on QoL and emotional health, a minority of patients discuss these issues with their physician. Also, despite improvements afforded by biologic therapy, continuing symptoms and pain occur in a proportion of RA patients.

Key words

biologic treatment, healthcare survey, rheumatoid arthritis, disease management

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Iain B. McInnes, MD, PhD, FRCP
Bernard Combe, MD, PhD
Gerd Burmester, MD

Please address correspondence and reprint requests to:
Prof. Iain B. McInnes, MD, PhD, FRCP,
Institute of Infection, Immunology and Inflammation,
Glasgow Biomedical Research Centre,
University of Glasgow,
120 University Place,
Glasgow G21 8QQ, United Kingdom.
E-mail: iain.mcinnes@glasgow.ac.uk

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Introduction

Rheumatoid arthritis (RA) is a progressive disease characterised by chronic inflammation, leading to irreversible structural articular damage, deformity, disability, and reduced quality of life (QoL). RA prevalence is estimated at 0.5% to 1% of the population in North America and northern European countries and 0.3% to 0.7% in southern European countries (1). Treatment with disease-modifying anti-rheumatic drugs and biologic agents has transformed the management of RA and provided benefit to many patients. Nevertheless, patients with RA are still likely to experience substantial physical and psychological consequences from their disease (2, 3). Understanding the views of RA patients – their perceptions of the disease and its treatment – could provide insight valuable to the design of novel therapeutic strategies and to the designation of therapeutic priorities.

Large data sets describing patient attitudes toward RA are scarce, particularly outside clinical trials. The Rheumatoid Arthritis: Insights, Strategies & Expectations (RAISE) survey was designed to gain insight into the management and treatment of moderate to severe RA from the patient perspective. The primary objective was to characterise both biologic-naïve and biologic-experienced patients' views on unmet clinical needs in RA and, secondarily, to assess any meaningful differences between these two groups.

Materials and methods

Survey development

The Steering Committee (I. McInnes, B. Combe, G. Burmester) for the RAISE Patient Needs Survey guided development of the survey with input from 53 expert rheumatologists in 9 participating countries: Canada, France, Germany, Greece, Italy, The Netherlands, Spain, Sweden, and the United Kingdom. The questionnaire was developed through a qualitative phase that included in-person interviews of RA patients and input from expert rheumatologists. This phase aided question formulation, generated items for inclusion, and refined language for optimal patient understanding. Rheumatologists participating in survey development provided additional questions that they believed were pertinent to patients in their country, ensured the accuracy of the questionnaire after translation into local languages, and provided feedback at all stages. Additional input and review were sought from Arthritis Consumer Experts, a patient organisation in Canada. The final survey included questions focused on diagnosis and referral, informational needs regarding RA and its treatment, living with RA, and patients' experience with their current therapy.

The research process complied with standards of the International Chamber of Commerce (ICC), European Society for Opinion and Marketing Research (ESOMAR), and Council of American Survey Research Organizations (CASRO). These standards include codes such as: research shall be legal, honest, truthful and objective; organisations shall manage panels to achieve the highest possible research quality; and data stewardship shall be in accordance with appropriate scientific principles.

Patients

Patients were eligible to participate if they were ≥18 years old, had been diagnosed with RA, and had provided informed consent. Both biologic-naïve and biologic-experienced patients were included in the survey, to obtain data from a broad spectrum of patients with active RA. Biologic-naïve patients were included if they were potential candidates for biologic therapy. The entry criteria for these candidates, developed by the RAISE Patient Needs Survey Steering Committee and expert rheumatologists, included either a Disease Activity Score in 28 joints (DAS28) >3.2 or an acute-phase response, plus erosive disease and moderate-to-severe, active RA. Biologic-experienced patients were included if they were receiving either a subcutaneous or an intravenous tumour necrosis factor inhibitor (TNFi).

Physicians who typically treat patients with RA identified patients meeting the eligibility criteria and issued written invitations to participate in the RAISE survey. Patients indicated willingness by scheduling an interview with the third-party interviewer. Patients again indicated willingness by calling at the scheduled time for the interview and giving verbal informed consent prior to being interviewed. Physicians were unaware of which patients, from those they had invited, elected to participate. Neither the Steering Committee nor the panel of 53 consulting rheumatologists was involved in identifying patients for participation.

Table I. Patient Demographics.

Characteristic	Total (n=586)	Biologic Naïve (n=270)	Biologic Experienced (n=316)
Female	77%	78%	77%
Age (mean, years)	55.6	57.4*	54.1
Living in care/nursing care facility	4%	6%	2%
Living at home alone	19%	21%	18%
Self-reported health status			
Good/very good/excellent	68%	64%	71%
Somewhat poor/very poor	32%	36%	29%
With hand disability	49%	50%	48%
Prescription medications currently taking / ever taken for RA**		*Currently taking*: methotrexate, 51%[#] anti-inflammatories, 45% oral corticosteroids, 36% leflunomide, 11%	*Ever taken*: methotrexate, 37%[#] anti-inflammatories, 36% oral corticosteroids, 36% leflunomide, 21% injected steroids, 19% gold, gold salts, 19% hydroxychloroquine, 17% sulfasalazine, 16%

*$p \leq 0.05$ *vs.* corresponding subgroup.

**Only medications taken by ≥10% of patients are included here. Patients may have taken more than 1.

[#] Importantly, these percentages for methotrexate reflect patient difficulty in remembering medications when asked by a non-medical person (non-rheumatologist) over the telephone. For example, several names for methotrexate in Germany include Lantarel, Metex, and MTX-Hexal. Such variance does not facilitate collection of accurate patient demographics.

Survey execution and data analysis

The final, quantitative phase of the survey was administered by Insight Research Group USA (7 Cedar Street, Suite D, Summit, NJ 07901, USA) from October through December 2008 using a moderator-guided phone-to-Web methodology. These computer-assisted telephone interviews were 30 to 45 minutes long. All patient-reported data were de-identified and held by a third party not involved in data interpretation. Analysis was performed on composite data sets. Parties involved in data interpretation had access only to the composite data, not individual patient data. The Quantum package (SPSS, Inc) was used to set up standard cross-tabulations and statistical analyses of the data. A 2-tailed test on column proportions was used to determine the 95% confidence interval for data comparison between countries and between patient groups, and the standard error was used to calculate significant differences on means.

Results

Data shared here is specific to the needs of the global/general RA patient. It is expected that data specific to the individual participating countries will be disseminated in a separate paper.

Demographics

A total of 586 patients participated in the survey. Of the 65 patients from each of the 9 participating countries (except Germany, n=66), 30 patients were biologic naïve and 35 patients (Germany, n=36) were currently receiving a TNFi – etanercept, adalimumab, or infliximab. Survey participants were mostly female (77% *vs.* 23% male), with a mean age of 56 years; biologic-naïve patients were older than biologic-experienced patients (57.4 *vs.* 54.1 years, $p \leq 0.05$). Disease duration (mean years since diagnosis) was 10.23 years for biologic-naïve patients and 12.61 years for biologic-experienced patients ($p \leq 0.05$). Overall, 4% of patients lived in a care facility (Table I), with significantly more biologic-naïve than biologic-experienced patients living in such a facility (6% *vs.* 2%, $p \leq 0.05$). Most patients (72%) also used some form of nonprescription therapy, including physical or occupational therapy, exercise, and nonprescription medication.

Diagnosis and referral

The self-reported mean age at presentation of RA symptoms was 41 years; biologic-naïve patients were older at symptom onset than biologic-experienced patients (45 *vs.* 38 years). Patients were diagnosed with RA within 3 years of symptom onset, and at the time of the survey, had been living with the disease for an average of 11.5 years. Primary care physicians (PCPs) were the first point of contact for 73% of patients (n=428), although a majority of patients (77%; n=451) were formally diagnosed with RA by a rheumatologist. Ongoing care was usually provided by a rheumatologist, especially when a biologic had been prescribed (92% biologic experienced vs 86% biologic naive, $p \leq 0.05$). Among patients who originally saw a PCP for their symptoms, the mean time to referral to a specialist was 5 months (20.3 weeks). Following referral, the mean time to receive an appointment with a specialist was 4.3 weeks; no patient reported waiting more than 8 weeks.

Patient informational needs and support

We defined topics that patients most frequently discussed during their last 2 appointments with the physician (Fig. 1). A majority (93%) reported discussion of symptoms. Biologic-experienced patients were more likely to discuss symptom improvement with their physician than were biologic-naïve patients (64% *vs.* 53%, $p \leq 0.05$). Discussions around treatment were also common (78%), with medication dosing most frequently discussed (57%), followed by administration of medication (44%) and availability of other treatments (40%).

Approximately 56% of patients reported discussing the impact of RA on life quality, most commonly the ability to perform daily activities (44%). Less frequently discussed was the impact of RA on patients' social interaction (32%), work (25%), and personal relationships (22%). Only 32% of respondents discussed their overall emotional health with their physician. Overall, most patients (93%) felt that their physician spoke to them about RA in terms that were easily understandable.

Whereas 23% of patients reported relying solely on their physician for information regarding RA, more than 75% of patients also obtained information from other sources. Of those using other sources (n=451), most used the Internet (41%), print media (36%), and patient leaflets (33%) (Fig. 2). Compared with biologic-naïve patients, significantly more biologic-experienced patients received information from print media (40% *vs.* 31%) and the Internet (47% *vs.* 35%; all comparisons $p \leq 0.05$). Only 21% (n=124) of patients reported receiving information from patient support groups or RA patient associations; a significant difference between biologic-experienced and biologic-naïve patients was observed (24% *vs.* 18%, $p \leq 0.05$). Of all those using other sources, 66% reported that they were very satisfied or extremely satisfied with the quality of information available to them; however, one-third of patients felt a need for better sources of information about the management of RA.

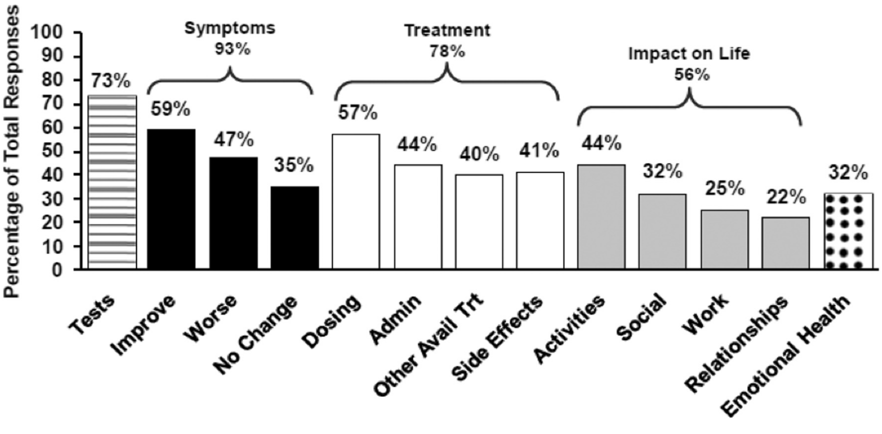

Fig. 1. Discussions between physician and patient during last 2 office visits. All patients (n=586) were asked to specify topics discussed during recent conversations with their physician as they related to symptoms, treatment, or impact of rheumatoid arthritis (RA) on their lives.

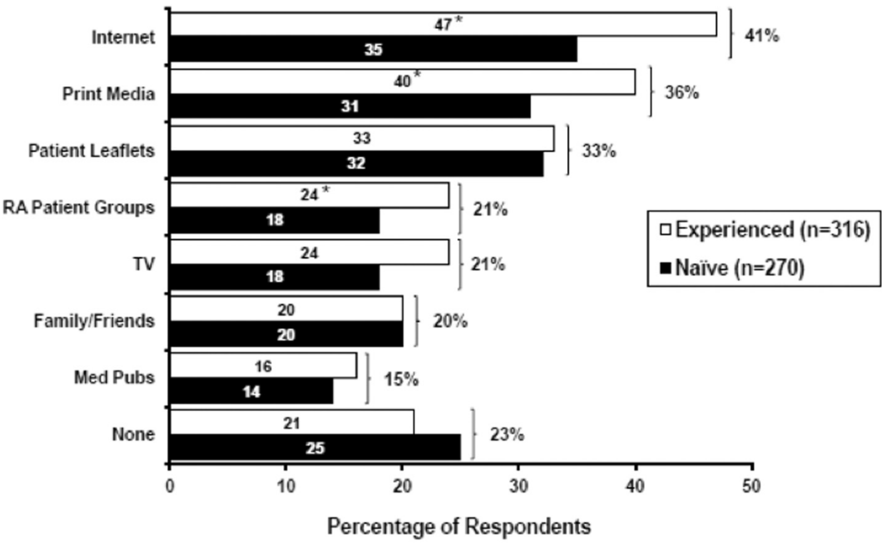

Fig. 2. Sources of information about RA used by patients. All patients (n=586) were asked to name sources, other than their physician, from which they obtain information about their disease and treatment. Note that patients receiving biologics are likely to be more interested in additional information than those not receiving biologics, and our data support this conjecture. *$p \leq 0.05$ *vs.* corresponding subgroup.

Living with rheumatoid arthritis

Patients assessed how many "good" days (waking with no or mild pain/discomfort) and "bad" days (waking with a lot of pain/discomfort) they experienced per month. Prior to their current therapy, patients reported that approximately one-third of days per month would be considered "good" days, but when reporting based on their current treatment, 66% of days per month were considered "good" (Fig. 3). Not surprisingly, the proportion of "good" days per month on current therapy was significantly greater among biologic-experienced patients than biologic-naïve patients (71% *vs.* 61%, $p \leq 0.05$).

Patients rated the level of pain they were experiencing at the time of the interview, and 25% of biologic-naïve and 19% of biologic-experienced patients reported high levels of pain ($p \leq 0.05$). Moreover, 23% of patients reported that they currently felt the best they could feel (27% biologic experienced *vs.* 19% biologic naïve, $p \leq 0.05$), whereas 75% believed they could feel better (71% biologic experienced *vs.* 79% biologic naïve, $p \leq 0.05$).

Over half of the participants (51%) stated that their lives were controlled by RA, and 35% stated that nothing could be done to stop disease progression (Fig. 4). Most respondents believed that their physician was doing everything in his or her power to manage the disease; however, biologic-experienced patients were significantly more likely to concur with this view than biologic-naïve patients (89% *vs.* 77%, $p \leq 0.05$). Patients stated that their current medications were critical to controlling their RA, but a significant difference was observed between biologic-experienced and biologic-naïve patients (89% *vs.* 78%, $p \leq 0.05$).

Approximately 30% of patients reported that they had feelings of discouragement (33%), anxiety (34%), anger (31%), and depression (30%), which they believed to be related to RA. Moreover, 58% of

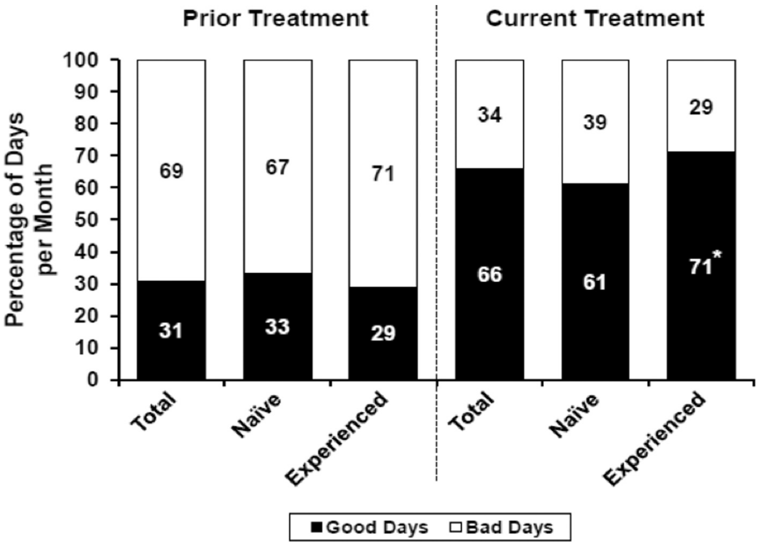

Fig. 3. Biologic treatment increases the proportion of "good" days to "bad" days. Both biologic-naïve (n=270) and biologic-experienced (n=316) patients were asked how many "good" days *versus* "bad" days they experienced in a month on their prior treatment and on their current TNFi treatment for RA. TNFi, tumour necrosis factor inhibitor. $^*p\leq0.05$ *vs*. corresponding subgroup.

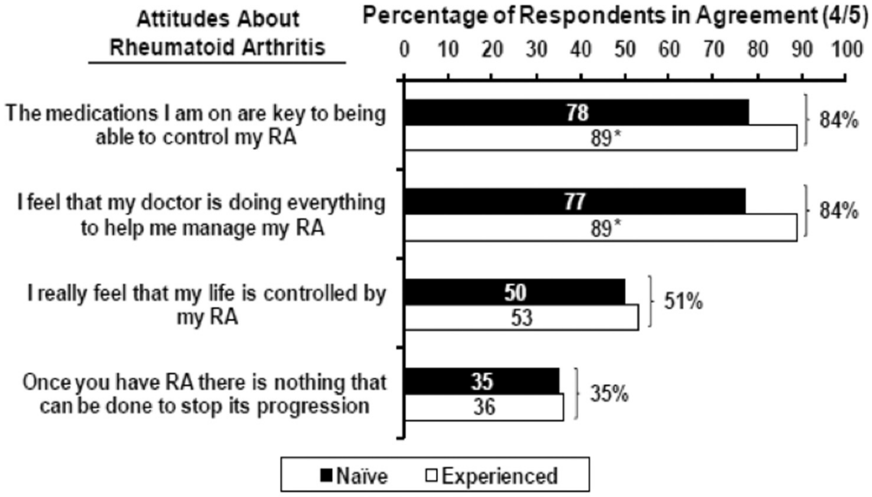

Fig. 4. Patient attitudes about RA. All patients (n=586) were asked their level of agreement on specific statements about RA. $^*p\leq0.05$ *vs*. corresponding subgroup.

patients reported frustration that they could no longer perform their premorbid activities. Half of patients reported that their ability to participate in sports was negatively affected by RA; a negative impact was also reported with regard to pursuing hobbies (44%), performing household chores (43%), getting adequate rest or sleep (36%), and addressing family needs (31%). A negative impact on relationships with friends and family due to RA was reported by 22% of patients; a negative impact on participating in sexual activity was reported by 22% of biologic-experienced and 16% of biologic-naïve patients ($p\leq0.05$).

Use of biologic therapy

1. Biologic-experienced patients' views on biologics

Of the 316 biologic-experienced patients surveyed, most (71%) had a high level of participation in the decision to start biologic treatment; 14% did not participate in the decision at all. All patients received a large quantity of information about biologic therapy at the time of prescription, particularly regarding frequency of dosing and how the product is administered (97%); fewer patients reported receiving information about short-term side effects (73%) and overall safety (65%). The majority of respondents (98%) understood most or all of the information provided.

About 75% of patients receiving subcutaneous biologics responded that they performed the injection themselves; however, approximately 25% did not self-inject, but instead relied on caregivers, physicians, nurses, or other healthcare providers. Of those who self-inject (n=228), approximately 12% described the process as somewhat or very difficult. Overall, few respondents reported having a problem either preparing or administering their injection, but 17% of patients stated that they need some help preparing the injection and approximately 22% reported needing at least some help administering it.

The majority of biologic-experienced respondents reported that their current medication was satisfactory for most aspects of managing their disease. Reduced pain and swelling was the most cited benefit (77%), followed by easy and convenient dosing (69%), good tolerability (66%), ability for self-administration (63%), fewer flares (53%), and decreased fatigue (43%). Dosing frequency was an important factor in respondents' willingness to consider a different biologic: 8% found it to be one of 3 top drawbacks of their current medication. Of respondents receiving subcutaneous biologics (n=271), 24% reported experiencing pain on injection and 20% experienced irritation at the injection site. Of the 45 patients receiving their biologic intravenously, 9% reported experiencing irritation at the infusion site.

2. Biologic-naïve patients' views on biologics

Of the 268 biologic-naïve patients participating in the study, only 38% were aware of biologic treatment options for RA, mostly through medical staff and the media. The majority of biologic-naïve patients would be willing to try an injectable biologic medication if it stopped progression of RA (89%), was considered an important advance in treatment of RA (87%), allowed them to experience fewer symptoms over a longer period of time (86%), provided more immediate pain relief (85%), required less frequent dosing (81%), and

Table II. Suggestions for implementation of RAISE survey findings.

- Consider that consistent efficacy and reduced frequency of administration are drivers in the patient decision about using a biologic for the first time or switching biologics.
- Encourage your patients to discuss with you the impact RA has on their lives and their overall emotional health.
- Try to allow your patients a few moments to focus on issues beyond symptoms and treatment. Schedule appointments more frequently if a patient seems to require additional attention.
- Be alert to whether disease activity warrants accelerated therapy. These patients could potentially experience improved QoL with a biologic.
- Even with biologic therapy, some patients still have pain. Consider adjuvant pain medication.
- Patients want lots of information about their disease and available treatments. Physicians could prepare handouts with current information about reputable web sites, global organisations, and journal/magazine articles.

Sample Web Sites:
American College of Rheumatology: www.rheumatology.org/
European League Against Rheumatism: www.eular.org
National Institute of Arthritis and Musculoskeletal and Skin Diseases:
www.niams.nih.gov/Health_Info/Rheumatic_Disease/default.asp
National Rheumatoid Arthritis Society: www.nras.org.uk
Major universities with rheumatology centers in your area

was easy to use (73%). For 76% of all patients (both biologic experienced and naïve), the most frequently reported feature that influenced or would influence willingness to switch biologics or try a biologic for the first time was consistent effectiveness.

Treatment and unmet needs

Biologic-experienced patients were asked about the impact of RA on their lives both before they began receiving biologic therapy and currently. The majority agreed that since receiving a TNFi, their symptoms have improved over what they experienced on non-biologic therapy (91%), as did their overall QoL (89%), including the ability to perform and enjoy daily activities. All patients were questioned about treatment options, and significantly more biologic-naïve patients compared with biologic-experienced patients expressed a definite need for improvement (42% *vs.* 27%, $p \leq 0.05$).

Discussion

The RAISE Patient Needs Survey assessed patient perceptions about living with moderate to severe RA and characterised the unmet needs of both biologic-experienced and biologic-naïve patients. The importance of considering measures of health-related QoL and other patient-reported outcomes is increasingly being recognised. (4, 5, 6) Although the results of the RAISE survey are not readily comparable to clinical assessments of health-related QoL, they do provide valuable insight regarding the patient perspective. For example, RAISE results show that consistent efficacy and reduced frequency of administration are drivers in considering whether to switch biologics or use a biologic for the first time.

In agreement with other patient-perception studies (2, 3), the RAISE survey demonstrates the substantial negative impact of RA on QoL and emotional health. Globally, only 32% of patients discussed their overall emotional health with their physician and approximately half discussed the impact RA had on their lives, supporting results of other studies showing that many physicians do not address these issues (7, 8). Our survey did not explore the reasons that these QoL topics were discussed less frequently than symptoms or treatment; however, country differences suggest that variations in frequency of physician visits and length of time scheduled per appointment may impact the ability to focus on issues beyond symptoms and treatment. Furthermore, we recognise that individual patients vary in their desire to address private concerns and distinct elements of their lifestyle during consultations with their physician. In future studies of this type, it will be important to ascertain whether it is the patient or the physician who initiates discussions around QoL when they do occur.

Although few differences existed between groups in the survey, biologic-experienced patients reported having more "good" days in a given month than did patients who were not receiving biologics. Although this is not unexpected given the difference in therapy, it is concerning that biologic-naïve patients were, as detailed in the study design, experiencing a level of disease activity that may have warranted accelerated therapy. These patients could have potentially experienced improved QoL.

While significantly more biologic-naïve than biologic-experienced patients reported high levels of pain at the time of the interview, approximately 20% of biologic-experienced patients also reported high levels of pain. Clinical evaluations of disease activity were not performed or collected prior to the survey, and it is unknown whether this reported pain was specifically due to RA or to other coexisting conditions. This may be an area worth exploring in future studies. These findings agree with the results of other patient-perspective studies showing that despite biologic therapy, patients were still in pain and continued to experience multiple symptoms (9-11). In most cases, the impact of RA on various aspects of patients' lives was not different between the 2 patient subgroups; surprisingly, however, significantly more biologic-experienced than biologic-naïve patients reported that RA had a substantial negative impact on their ability to participate in sports and sexual activity. Symptomatic benefits associated with biologics over non-biologic therapies suggest that biologic-experienced patients would experience less negative impact in these areas. It is possible that biologic-experienced patients have achieved a certain level of symptomatic response and are therefore willing to report on different concerns than biologic-naïve patients, who may still be focused on reporting the pain, discomfort, and immobility they are experiencing, rather than issues related to other aspects of QoL.

Specific to patients receiving subcutaneous biologics, 20% of patients reported pain on injection; and pain, stinging, and discomfort at the injection site were cited as the main drawbacks of their therapy. In a study focusing on injection-site burning and stinging with biologics, patients' medical charts revealed a 17% incidence of burning and stinging, but when specifically asked by their physician, 58% of patients reported that they had experienced some of these types of reactions (12). Note that during the time this study was completed, only 2 subcutaneous TNFi products were available for the treatment of RA; evaluation of newer agents may extend these findings (12). However, both studies demonstrate the value of physicians having specific discussions with patients regarding elements of their disease and treatment.

Our survey results show that a majority of patients seek additional information beyond what their physician provides; these data also support the trend toward increasing use of the Internet in this endeavor (13-15). Since one-third of patients reported dissatisfaction with the quality of Internet and other information, physicians should suggest specific Web sites and print media so that patients are accessing accurate and unbiased information (Table II). Addtionally, since 62% of candidates for biologic therapy were not aware of biologic therapy for RA, physicians can address this unmet educational need.

Our survey has a few limitations. While we classified patients according to whether or not they received biologic agents, further study of patient variables such as age, severity of disease, socioeconomic status, and marital status, and alignment of these variables with communication preferences and unmet needs, may be beneficial. Additionally, we excluded patients with mild disease under the assumption that management and treatment are not prominent issues for patients with inactive RA, and therefore they are unlikely to have in-depth, experienced perspectives regarding their disease. We also did not assess patients for fibromyalgia, and the presence of this disorder could have affected the results. Lastly, use of the Health Assessment Questionnaire (HAQ) would have facilitated comparison of survey results and clinical data. Our survey did include several questions about the ability to perform daily activities (*e.g.* hobbies, household chores, ability to dress): 60% of biologic-naïve patients and 55% of biologic-experienced patients reported experiencing limits on daily activities most days. The inclusion of HAQ in future studies can expand upon the data collected here.

The results of this large-scale patient survey provide key insights into how patients with moderate to severe RA view their disease and which issues are of critical importance to them. These results demonstrate that opportunities for improvement exist in patient-physician consultation on disease impact on patients' lives and emotional health. Understanding these results may allow rheumatologists to widen their own perspectives, looking beyond signs and symptoms to become more aware of their patients' concerns and unmet needs.

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