SHARED DECISION-MAKING: Insights from Rheumatoid Arthritis Patients in Europe

Pain, decreased mobility, frailty and disability. These are all potential effects of rheumatoid arthritis, a degenerative autoimmune disease that affects more than 2.3 million Europeans.¹

According to a European Alliance for Patient Access questionnaire of 128 patients from the United Kingdom, Germany and Portugal, patients with rheumatoid arthritis overwhelmingly agree that trust and shared decision-making with their health care provider are critical. Yet some patients struggle to share their experience or have straightforward discussions with their health care provider about sensitive issues.

To maximise the patient-health care provider relationship, responses revealed, patients need resources to guide them on how to engage more fully in treatment discussion and decisions.
FINDINGS SUMMARY

Shared decision-making matters to patients...but it can be difficult. Rheumatoid arthritis patients acknowledged that it’s important:

- For doctors or nurses to know the full extent of patients’ symptoms and comorbidities
- For patients and doctors or nurses to jointly decide the best course of treatment
- For patients to be comfortable talking with their doctor or nurse about sensitive topics

But, thinking back on their initial diagnosis, patients reported that they:

- 42% Didn’t feel comfortable asking questions about their rheumatoid arthritis diagnosis
- 41% Didn’t fully understand benefits and risks of each treatment option
- 30% Didn’t have confidence to participate in decisions about their treatment

And patients still report that they:

- 54% Find it difficult to talk to their doctor or nurse about how rheumatoid arthritis affects their psychological well-being
- 46% Don’t always tell their doctor or nurse about how their rheumatoid arthritis affects their home or work life
- 41% Feel embarrassed to talk with their doctor or nurse about how rheumatoid arthritis affects their ability to be intimate with their partner

98% OF PATIENTS OVERWHELMINGLY SEE THE NEED FOR:

Techniques and strategies for talking and making decisions with their doctor or nurse
QUESTIONNAIRE FINDINGS

Initial Concerns and Questions about Treatment

Before addressing any other concerns, patients must grasp the meaning of their rheumatoid arthritis diagnosis. The questionnaire found, however, that more than half of patients admitted to not fully understanding the meaning of their diagnosis, even after their doctor or nurse explained it.

51% OF PATIENTS
Didn’t fully understand the disease even after a doctor or nurse explained it

57% OF PATIENTS
Didn’t fully realise how the disease would impact life

42% OF PATIENTS
Didn’t feel comfortable asking questions about their rheumatoid arthritis diagnosis

Despite having questions about their new rheumatoid arthritis diagnosis, patients expressed concerns about talking with their doctor. The vast majority of patients (84 percent) indicated their initial anxiety related to learning how rheumatoid arthritis would affect their life and work. And seven in 10 patients were apprehensive about conversations about how to cope with new symptoms like swollen or stiff joints and fatigue.

Patients expressed the following initial concerns about talking with their doctor:

- How rheumatoid arthritis would affect life and work: 84%
- Being prepared to deal with symptoms: 70%
- Understanding causes of rheumatoid arthritis: 57%
- Getting ready to explain rheumatoid arthritis to family and friends: 31%
Patients’ need for information also extended to treatment. Nearly half (47 percent) indicated they didn’t fully comprehend how treatment for their rheumatoid arthritis might affect other health conditions and their treatments, and 41 percent didn’t fully understand the benefits and risks of each treatment option.

Given these knowledge gaps, it’s understandable that more than a third of patients (38 percent) felt they didn’t have enough information to participate in treatment decisions while three in 10 patients lacked the confidence to participate in treatment decisions. This can make it difficult for both new patients and those whose condition is not being optimally managed to bring up treatment preferences or concerns with their health care provider.

- **27% of patients** didn’t fully understand how treatment would be administered.
- **41% of patients** didn’t fully understand benefits and risks of each treatment option.
- **19% of patients** wanted to know how treatment would affect family planning, but hesitated to bring it up.
- **47% of patients** didn’t fully understand how treatment might affect other conditions and their treatments.
- **38% of patients** didn’t feel like they had enough information to participate in decisions about treatment.
- **30% of patients** didn’t have confidence to participate in decisions about their treatment.
Open Dialogue between Patients & Health Care Providers

While nearly all patients (93 percent) indicated they regularly see a doctor, not all patients are making the most of their appointment.

Depending on the symptom, between 26 and 41 percent of rheumatoid arthritis patients admitted they don’t always tell their doctor or nurse what they’re experiencing. Not being transparent or downplaying the effects of one’s condition can influence their health care providers’ recommended approach to treatment or disease management techniques.

Patients admitted they don’t always tell their doctor or nurse about:

- **41%** Fatigue
- **38%** Pain
- **26%** Morning Stiffness

The questionnaire also revealed patients’ reasons for not sharing their symptoms. Patients indicated they didn’t want to seem whiny (37 percent) or felt the symptoms were too minor to mention (24 percent). Also concerning, one-third of patients didn’t fully share because they felt their doctor or nurse was too pressed for time. Worth noting, some patients do report being forthcoming with their health care providers. Of participants who selected “other,” many indicated that they try and share all symptoms with their doctor or nurse.
Not all patients find it easy to bring up touchy subjects. More than half (54 percent) indicated they found it difficult to talk about how rheumatoid arthritis affects them emotionally. And four in 10 shared they feel embarrassed discussing how their disease affects their ability to be intimate with their spouse or partner.

54% OF PATIENTS ACKNOWLEDGED
They find it difficult to talk to their doctor or nurse about how rheumatoid arthritis affects their psychological well-being

46% OF PATIENTS ACKNOWLEDGED
They don’t always tell their doctor or nurse about how their rheumatoid arthritis affects their home or work life

41% OF PATIENTS ACKNOWLEDGED
They feel embarrassed to talk with their doctor or nurse about how rheumatoid arthritis affects their ability to be intimate with their partner

24% OF PATIENTS ACKNOWLEDGED
They are not comfortable asking their doctor or nurse questions about how rheumatoid arthritis affects their caregiving responsibilities

Patients also admitted they weren’t always forthright when it came to sharing how they managed their rheumatoid arthritis with medication (17 percent) or lifestyle choices such as those related to diet or exercise (32 percent).

32% OF PATIENTS ACKNOWLEDGED
They are not always honest with their doctor or nurse about how they manage their rheumatoid arthritis on a daily basis (lifestyle such as diet or exercise)

17% OF PATIENTS ACKNOWLEDGED
They are not always completely honest with their doctor or nurse about how they manage their medication
Shared Decision-Making and the Clinician-Patient Relationship

Personalized medical care is rooted in honest dialogue between patients and their health care providers. Despite some respondents admitting they don’t always adhere to this principle, they universally agreed that it’s important to fully inform their health care provider about their symptoms, comorbidities and lifestyle choices.

Health care providers are best able to foster the shared decision-making process when patients are forthcoming about concerns. Open dialogue also contributes to improved patient understanding of their rheumatoid arthritis diagnosis, how it affects their health and life, and treatment options. And when patients’ questions are answered, they should feel more confident in expressing their treatment preferences or requesting to change treatment when their current therapy isn’t working for them.

Finally, patients realize the benefits of open dialogue and shared-decision making, and nearly all (98 percent) see the value of techniques and strategies for improving their conversation and decision-making skills.
CONCLUSION

Shared decision-making is important, as the European Alliance for Patient Access questionnaire revealed, but not all patients are engaging as fully in their rheumatoid arthritis treatment as they could. Patient-focused educational resources can empower those who are open to learning techniques and strategies for improving interaction with health care providers. Maximising this relationship can have immediate and long-term benefits to patients’ overall health and well-being.

REFERENCE