

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:



100%

For doctors or nurses to know the **full extent of patients' symptoms** and comorbidities

98%

For patients and doctors or nurses to **jointly decide the best course of treatment**

95%

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**



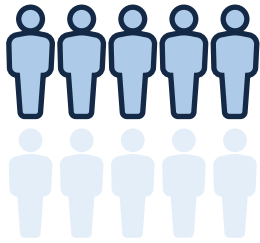
98% OF PATIENTS OVERWHELMINGLY SEE THE NEED FOR:

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

QUESTIONNAIRE FINDINGS

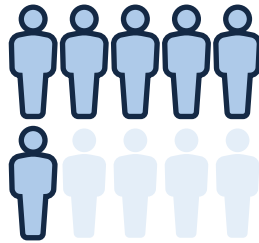
Initial Concerns and Questions about Treatment

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.



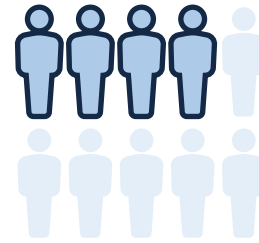
51% OF PATIENTS

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

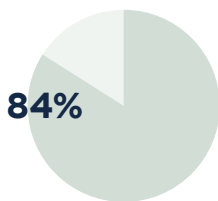


42% OF PATIENTS

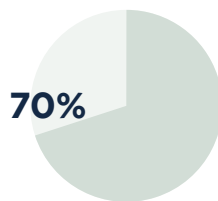
Didn't feel comfortable asking questions about their rheumatoid arthritis diagnosis

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.

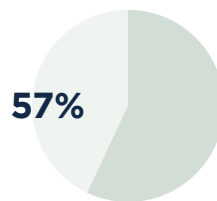
Patients expressed the following initial concerns about talking with their doctor:



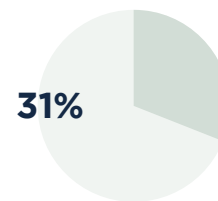
84%
How rheumatoid arthritis would affect life and work



70%
Being prepared to deal with symptoms



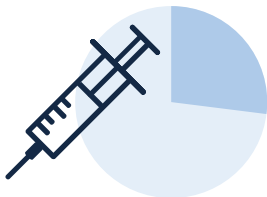
57%
Understanding causes of rheumatoid arthritis



31%
Getting ready to explain rheumatoid arthritis to family and friends

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.



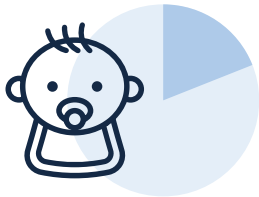
27% OF PATIENTS

Didn't fully understand how treatment would be administered



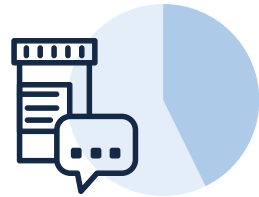
41% OF PATIENTS

Didn't fully understand benefits and risks of each treatment option



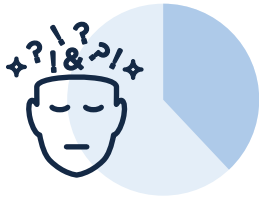
19% OF PATIENTS

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

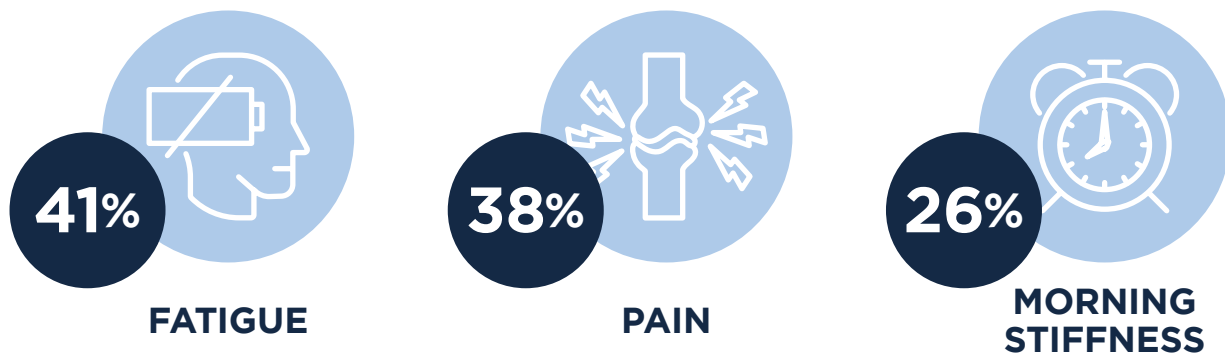
Didn't have confidence to participate in decisions about their treatment

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.

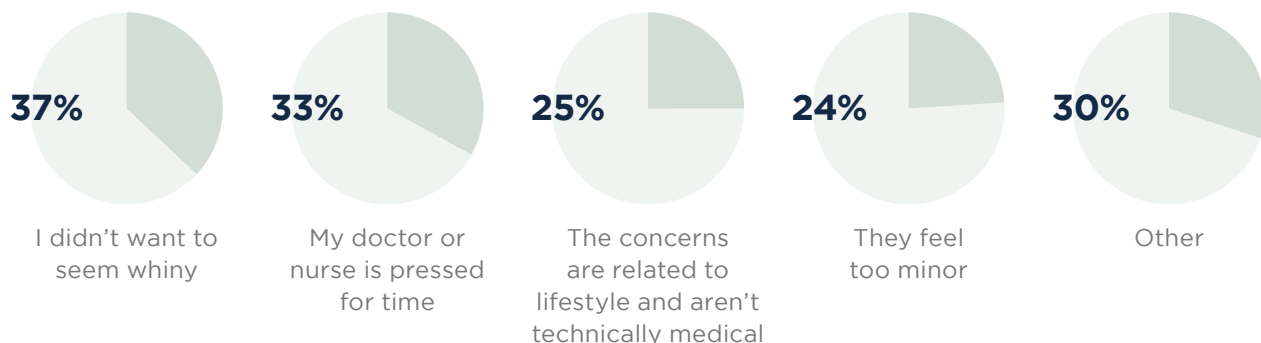
Depending on the symptom, between 26 and 41 percent of rheumatoid arthritis patients admitted they don't always tell their doctor or nurse what they're experiencing. Not being transparent or downplaying the effects of one's condition can influence their health care providers' recommended approach to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

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

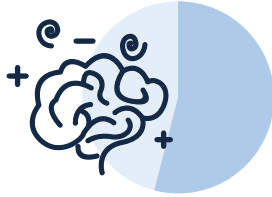


The questionnaire also revealed patients' reasons for not sharing their symptoms. Patients indicated they didn't want to seem whiny (37 percent) or felt the symptoms were too minor to mention (24 percent). Also concerning, one-third of patients didn't fully share because they felt their doctor or nurse 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.

Patients don't share symptoms with their doctor or nurse because:



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.



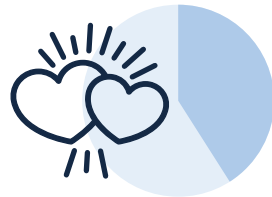
54% OF PATIENTS ACKNOWLEDGED

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

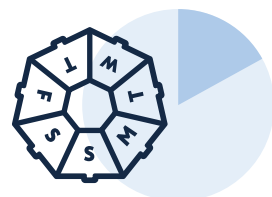
They are not comfortable asking their doctor or nurse questions about how rheumatoid arthritis affects their caregiving responsibilities

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.

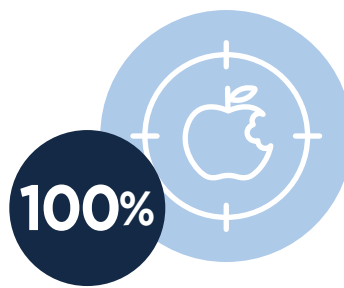
Health care providers are best able to foster the shared decision-making process when patients are forthcoming about concerns. Open dialogue also contributes to improved patient understanding of their rheumatoid arthritis diagnosis, how it affects their health and life, and treatment options. And when 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.



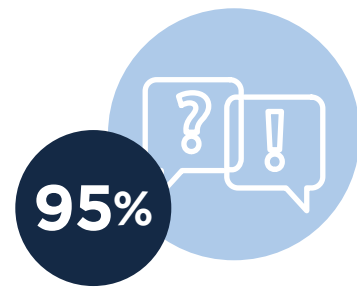
PATIENTS ACKNOWLEDGED

It's important for doctors or nurses to know the full extent of patients' symptoms and comorbidities



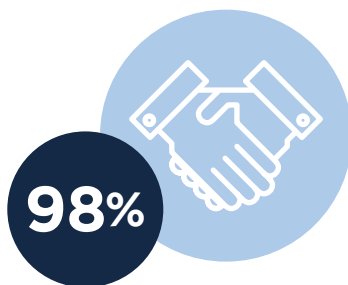
PATIENTS ACKNOWLEDGED

It's important for patients to be forthcoming about lifestyle choices



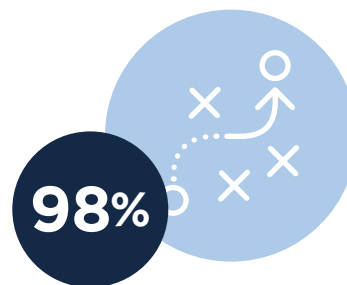
PATIENTS ACKNOWLEDGED

It's important for patients to be comfortable talking with their doctor or nurse about sensitive topics



PATIENTS ACKNOWLEDGED

It's important for patients and doctors or nurses to jointly decide the best course of treatment for rheumatoid arthritis patients



PATIENTS ACKNOWLEDGED

It's important to provide patients with techniques and strategies for talking and making decisions with their doctor or nurse

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

1. Lundkvist J, Kastäng F & Kobelt G. The burden of rheumatoid arthritis and access to treatment: health burden and costs. Eur J Health Econ. 2008. p. S49-60. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/18157732>



About the European Alliance for Patient Access

The European Alliance for Patient Access, a division of the Global Alliance for Patient Access, is a network of physicians and patients advocating for patients' access to approved medical therapies and appropriate clinical care.

To learn more, visit www.GAfPA.org.

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