

European Patient Voice in Gout Survey – Subjective Satisfaction in Gout Patients versus Objective Suboptimal Gout Care

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Disclosures

- > I work as a consultant/speaker for Grünenthal, Sanofi and AstraZeneca.
- > The study has been funded by Grünenthal.

Background and Objective

- > Gout is the most common form of inflammatory arthritis
- > Gout is treatable and can be effectively managed in a majority of patients
- > Little information is available about the impact of gout on patient's life
- > The objective of this survey was to evaluate the management of gout in Europe from the patients perspective in order to improve their quality of life

Methods

- > Participants completed a 15-minute online survey (June–Sept 2018)
- > 14 European countries participated in one of 11 languages
- > Patients were included in the analysis if they were adults (18+), diagnosed with gout and finished the survey
- > Patients were recruited via patient associations, and leaflets were provided to doctors and consumer panels
- > The design and content of the survey was developed together with several patient representatives and clinical experts

Participants

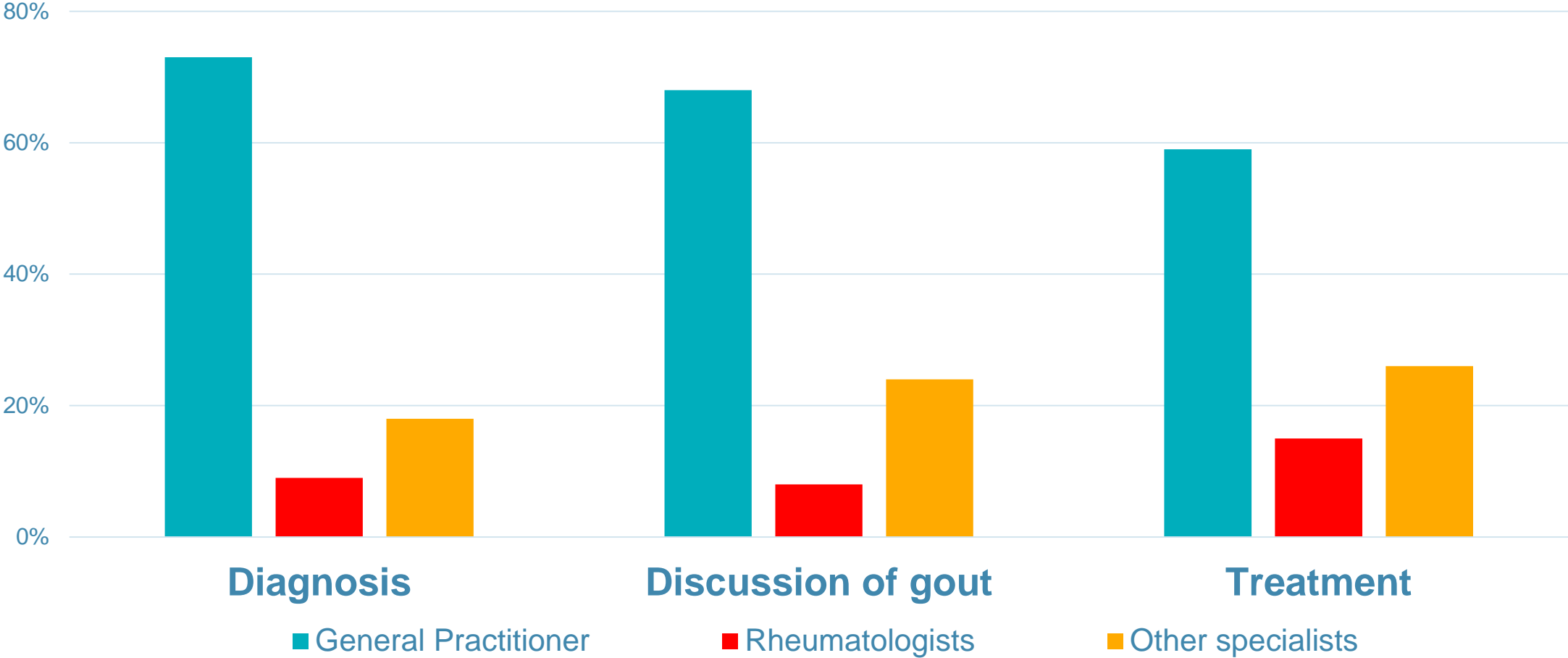
- > 1,100 gout patients
- > 22% Females/ 78% Males
- > Mean age: 55 years
- > Mean age at diagnosis: 45 years
- > Mean number of flares: 2.9 in the past 12 months
- > 77% of patients had co-morbidities
 - > hypertension 52%, dyslipidemia 41%, overweight 40%, type 2 diabetes 23%, long-term illness of kidney/renal insufficiency 17%
- > 56% of patients employed or studying

Country	%	N
Spain	19%	204
Italy	16%	180
Germany	15%	165
France	14%	157
Netherlands	8%	92
Belgium	7%	80
Sweden	4%	47
Denmark	3%	34
Austria	3%	28
Switzerland	2%	27
Ireland	2%	26
Norway	2%	24
Portugal	2%	23
Malta	1%	13

General Practitioners were mainly involved in gout management

% of patients (n=1,100)

Involvement of healthcare professional by specialty





Diagnosis

- > 22% of patients were not diagnosed until they had 4 or more flares



Monitoring

- > 71% of patients had flares in the past 12 months (thereof 33% had ≥ 3 flares)
- > 59% of patients did not have regular follow-up appointments for their gout
- > 53% were monitored for serum uric acid less than twice per year



Treatment

- > 58% of patients received uric acid lowering therapies
- > 43% pain killers
- > 25% colchicine
- > 13% non-medical pain relief and
- > 12% corticosteroids

Poor gout control was higher in younger patients (<35 years of age) compared to older patients (65+ years of age)

Gout had a significant impact on the lives of patients

Impact on	% (n=933)
Ability to walk	59%
Sleep patterns	46%
Mental health/mood	43%
Ability to do simple activities of daily living	43%
Sex life	30%
Relationship with the partner(s)	26%
Impact on wider family	27%

10% of patients (or one of their family members) lost a job/retired due to their gout

34% of patients talked about how the pain is intense, severe or unbearable...



“An excruciating sensation in my big toe, which makes me want to cut it off. It completely stops my life” – Spain



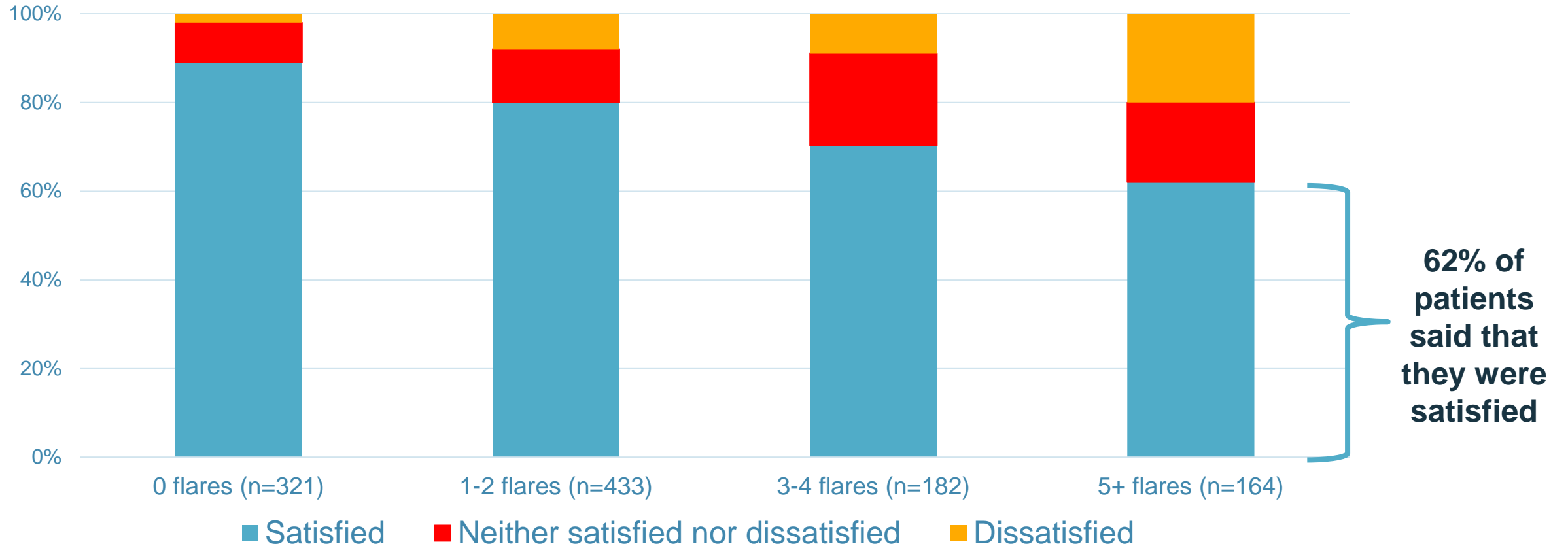
“Very painful experience, it is like [having] a knife in the foot” – Italy



“Feels like something eating your bone from the inside. Prevents normal physical activity and causes anxiety” – Ireland

High level of patient satisfaction, even when they experience flares

% of patients (n=1,100)



Summary

- > Gout is a serious arthritic condition with severe long-term consequences
- > Gout causes debilitating pain and impacts all aspects of patient's life
- > Although gout is treatable, gout patients are diagnosed late, their disease is not well-controlled and not regularly monitored
- > Gout patients do not speak up and hide their disease:
 - > Patients have a low expectation of their treatment and are resigned, so do not seek better quality care
 - > There is a stigma surrounding gout and patients may be embarrassed to discuss their condition and flares with their doctor
- > Doctors are not aware of the impact that gout has on their patients and families

Conclusions

- > The findings of this survey support the high unmet need of gout patients
- > Strategies must be developed to improve diagnosis, monitoring and treatment of gout, which are currently suboptimal*
- > There is a clear need to educate patients and their doctors about adequate management of gout
- > Communication between gout patients and their doctors must be improved

* See also recommendations as described in the EULAR RheumaMap <https://www.eular.org/myUploadData/files/RheumaMap.pdf>

Acknowledgement

> The following patient organisations have supported this survey:

