

“It can’t be zero”: A qualitative study of patients’ perspective on Patient Global Assessment in Rheumatoid Arthritis.

Henriques M.¹, Duarte C.^{1,2}, Ndosí M.³, Marques A¹, da Silva J.A.P.^{1,2} Ferreira R.^{1,4}

¹Faculdade de Medicina da Universidade de Coimbra

²Centro Hospitalar e Universitário de Coimbra, Coimbra, Portugal

³University of the West of England, Bristol, United Kingdom

⁴UICISA:E, ESEnFC, Coimbra, Portugal

Background

Patient Global Assessment (PGA) plays an important role in disease activity assessment and treatment decisions in rheumatoid arthritis (RA). However, the meaning of PGA is open to patient interpretation and this may affect the validity and reliability of clinical assessments.

Objectives

We aimed to explore: (i) patients' perspective on PGA and its different formulations (ii) how patients' perspective may be improved by a brief explanation from a health care professional (HCP).

Methods

This was a qualitative study including consecutive patients with RA attending a day hospital and an outpatient department of a university hospital in Portugal. Data collection included 4 focus-groups (FGD) and 3 individual interviews to determine patients' perspectives. To help the discussions, patients completed 3 different PGA formulations consecutively and then a HCP explained what information was expected to inform their PGA. The 3 PGA formulations and their implications were then discussed between the patient and the HCP. Data from the FGDs and the interviews were transcribed verbatim and inductive content analysis was undertaken by two independent researchers. Data were coded and categorised in themes, which were agreed upon with patients, HCP and patient research partners.

Results

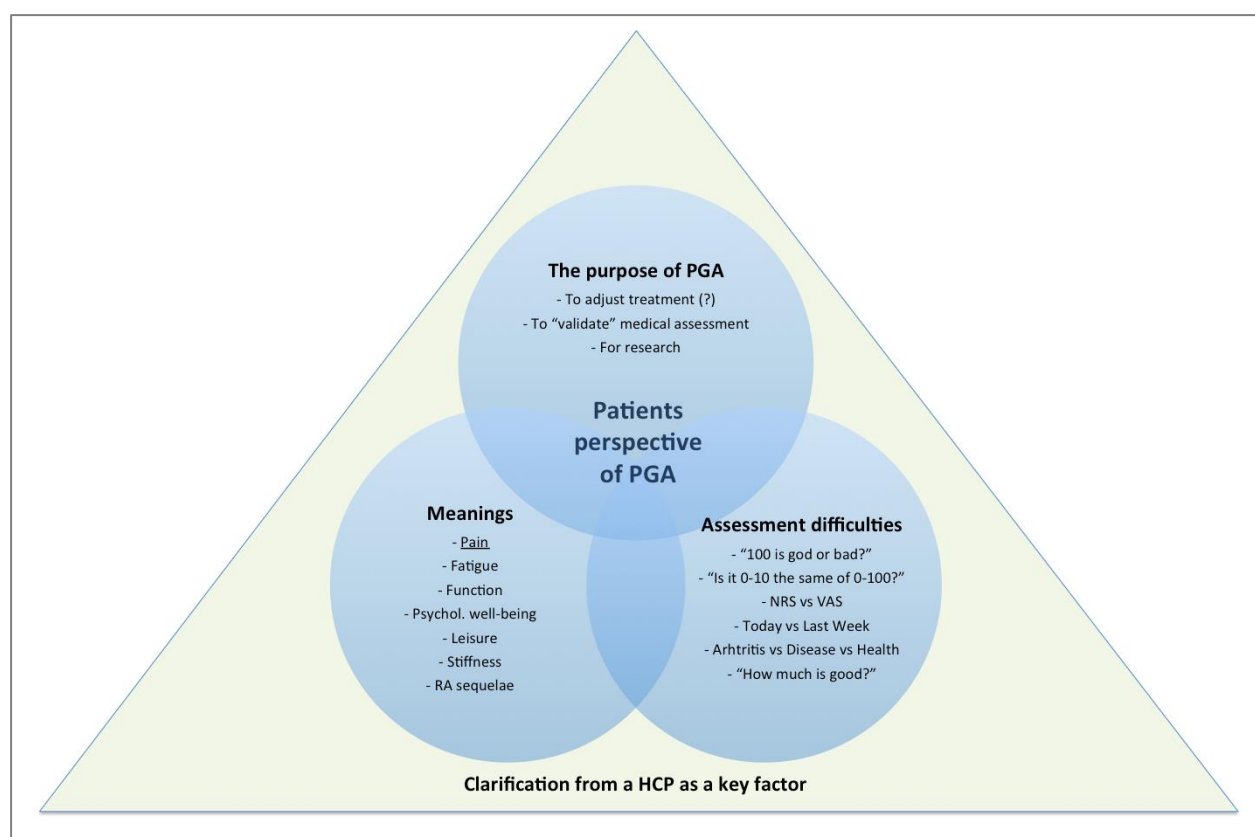
Fourteen patients (12 women) with RA participated. Their age ranged from 49 to 72 years, disease duration 4 to 30 years and 11 were on biologic DMARDs. Four main themes emerged (Figure 1): (1) The purpose of PGA. Some patients did not know whether PGA affects their treatment decisions in the same way as the objective measures do: *“if the answer is not in somehow according to the exams we make (...) obviously they might ignore me”*. Some believed that PGA was only used for research purposes. (2) The meaning of PGA. Pain was by far the main meaning of PGA, but also fatigue, function and other dimensions including RA sequelae; (3) Measurement difficulties. Many of these difficulties arose from the presentation of the three different PGA formulations, anchor points and their presentations: *“I always think that 100 is great: you feel 100%”, “Usually the scale is 0 to 10, here I can see 0 to 100”; “Usually it has the numbers, I answer 2, it's not like a straight line like this*

one”; “Today is different (...) when they ask the last week, we have to go back in time and the pain isn't the same anymore”. Also cultural issues and the subjectivity of the concept were expressed: “We, the patients, can't really assess the intensity of the pain, what could be a 9 for her, for me it might be a 5”; “I can never answer 0, because I always have something that affects me”. (4)
 Clarification from a HCP as a key factor for global understanding: [“Sometimes I just give a random number. (...) now maybe I will think more carefully and try to be as accurate as possible”].

Conclusions

Our results suggest that patients' interpretation of PGA is diverse and may reflect different symptoms such as pain or psychological well-being and comorbidities. Standardization of PGA is warranted and dedicated patient debriefing is likely to improve the reliability of this assessment.

Figure 1. Main themes of Patient Global Assessment's perspective by patients with RA



Citation information

Henriques, M., Duarte, C., Ndosí, M., Marques, A., da Silva, J. and Ferreira, R. ‘It can’t be zero’: A qualitative study of patients’ perspective on Patient Global Assessment in Rheumatoid Arthritis. *Ann Rheum Dis* 2017;76 (Suppl 2):112. Available from: <http://dx.doi.org/10.1136/annrheumdis-2017-eular.6214>