



THE PERSPECTIVE OF PATIENTS LIVING WITH RHEUMATIC DISEASES IN BRAZIL

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BACKGROUND

The patient's journey includes all the experiences that a person goes through since the identification of the first symptoms of a disease. This study aimed at understanding the different variables in patient's journey as well as its association. Ultimately, the goal is to generate awareness that can positively impact the life of those who live with Rheumatoid Arthritis, Psoriatic Arthritis, and Axial Spondyloarthritis.

MATERIALS AND METHODS

Data were obtained from a survey containing 58 questions. It was available online for public participation through the GRUPARJ-PETRÓPOLIS website. Based on the questionnaire responses, the association of qualitative variables was calculated through chi-square test. The null hypothesis was that the variables are not associated. To determine the intensity among the variables, Cramer's coefficient was used. Analysis was performed on R software.

RESULTS

Most participants reported no involvement with patient associations (PA) (59.12%, n=350). Furthermore, over half of attendees associated to a PA affirmed to have a significant improvement in their quality of life. Only 13.01% (n=77) of the participants reported to search for information about arthritis and its treatment in the PA. The majority prefer to talk with a health care provider. More than two-thirds of attendees are satisfied with the health care they receive from rheumatologist. While the majority considered themselves knowledgeable about their disease as well as treatment, the topic of family planning is still an issue to be addressed. Half of the women had an unplanned pregnancy (50%, n=71). Moreover, only a minority had discussed with their rheumatologist a treatment plan compatible with pregnancy (16.2%, n=23) or had talked about possibilities for breastfeeding (25.8%, n=31). Analysis of associations indicated that the type of treatment was associated with arthritis' impact on daily activities ($cc=0.478/p=0.001604$), side effects ($cc=0.5/p=0.00222$), and satisfaction with treatment ($cc=0.473/p=0.005009$). Most participants considered that their arthritis had completely impacted their daily activities in the last month, regardless of their treatment. However, in the group of patients treated with immunobiological, there was a lower proportion of low satisfaction with treatment. Furthermore, a higher percentage of patients reported no side effects when compared to analgesics, non-steroidal anti-inflammatory drugs corticoids, and synthetic Disease-Modifying Antirheumatic Drugs.

CONCLUSION

PA seems to impact positively patient's life. Considering the complexity of chronic inflammatory autoimmune diseases it seems to be positive to stimulate their participation in this kind of group. Although most of the participants in this survey indicated a good level of satisfaction with the health care they receive, data also indicate opportunities for improving it.