Building patient led organisations

PARE0005

REFRESHING THE SOCIAL MEDIA STRATEGY OF FIBROMYALGIA ACTION UK: RESULTS OF A NATIONAL PATIENT ORGANISATION SURVEY

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Background: Patient organisations have traditionally provided support for patients. However, the method by which people seek support is increasingly desired across social media, particularly among certain populations within the fibromyalgia community who rely on social media as a key form of communication. In addition, the activity of patient organisations on social media is evolving to encompass greater advocacy and awareness activities with a growing target population of different stakeholders. To address this growing demand, Fibromyalgia Action UK conducted an online survey to inform the organisation's future social media strategy.

Objectives: The aim of the survey was to understand the preferences of people interacting with Fibromyalgia Action UK's social media platforms, in order to inform the organisation's evolving social media and wider communications strategy.

Methods: An online survey was disseminated via Facebook, Twitter and a post on Fibromyalgia Action UK's website over a one-month period, between October and November 2018. Questions focused on general demographics, social media branding, style and content.

Results: A total of 301 people responded to the survey, 89% of whom had been diagnosed with fibromyalgia and 5% of whom were a friend or relative. More than half of respondents (60%) were aged between 45 and 64 years, with only 13% of respondents aged under the age of 35 years. 91% of respondents felt happy with the organisation's current branding, with 78% rating the organisation's social media sites as 'Good' or 'Excellent'. While 92% of respondents were happy with the organisation's current social media content, around half (51%) suggested an increase in the amount of visual posts (such as infographics), and two thirds (66%) suggested an increase in news articles and patient/carer stories.

Conclusion: The survey highlights the need for more visual, engaging content to inform and educate people about fibromyalgia and related activities. Respondent demographics also highlighted a limited interaction on social media with younger people under the age of 35 years. Together, these findings have prompted the organisation to launch of a new campaign, titled #BecomeFibroAware, using visual content to inform, educate and empower the community, as well as an increased focus on engaging younger people with fibromyalgia.

REFERENCE

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Acknowledgement: Fibromyalgia Action UK thanks the Board of Trustees and staff for their involvement, and to all of those who participated in the survey.

Disclosure of Interests: Simon Stones Consultant for: SS has provided consultancy services to Envision Pharma Group, though this is not related to the contents of this abstract., Speakers bureau: SS has undertaken speaking engagements for Actelion, eyeformpharma, Four Health, Janssen and Roche, though these are not related to the contents of this abstract., Reece Henderson: None declared, Des Quinn: None declared
DOI: 10.1136/annrheumdis-2019-eular.1044

PARE0006

LIVING WITH A RHEUMATIC DISEASE: A RESEARCH ABOUT QUALITY OF LIFE AND WORK CONDITIONS

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Background: There are 5 million people who suffer from rheumatic diseases in Italy with an annual expenditure of the health system, estimated for the chronic forms, around 4 billion euros. During the World Arthritis Day 2018 the Association of Persons with Rheumatic and Rare Diseases - Apmar Onlus presented the results of the survey "Living with a rheumatic disease" with the aim of raising public awareness by disseminating

data useful to understand the quality of lives of people living with one of the 150 rheumatic diseases.

Objectives: The research investigated:

- The quality of life of people with a rheumatic disease
- The work problems and conditions experienced by people suffering from a rheumatic disease.

Methods: The survey was both qualitative and quantitative. The qualitative phase was held in Milan and was preparatory to the development of the questionnaire distributed at national level. In this first phase two groups of five people were interviewed for two hours. The people interviewed in the focus groups were women and men, age 25-55 years (50% 25-40; 50% 41-55) with at least one rheumatic disease, currently workers/ laborers at least part-time.

In the quantitative phase, a questionnaire was administered throughout the national territory to a sample of 1,020 people, women and men, age 18-75 years with at least one rheumatic disease, currently workers/ laborers at least part-time or who worked for a period following the diagnosis of rheumatic disease. The used methodology of on-line investigation was the Cawi (Computer Aided Web Interview).

Results:

- 89,1% of separated and/or divorced interviewed reported that the disease caused problems in the sexual relationship with the partner as to cause their divorce/separation;
- 61% of the sample had to reduce working activities significantly, in many cases abandoning the job completely;
- 26,3% of the sample stated that he prefers not to speak about his illness either with his work colleagues or with his boss and/or superiors.

Conclusion: Rheumatic diseases affect relationships and social life negatively. The research shows how the rheumatic disease can have a particularly critical effect in the relationship with the partner. The problems arising in the relationship of the couple are so meaningful, and cause of misunderstandings and psychological suffering to be considered among the main causes of divorce and separations.

Rheumatic diseases heavily affect the working life. From the research emerges that people with rheumatic diseases that have managed to preserve their work despite the disease, are often reluctant to talk about their health conditions at work. The main reason is the fear of worsening and/or compromising their relations with colleagues and superiors with consequent negative effects on work tasks and the risk of losing their workplace.

People suffering from rheumatic diseases in Italy declare that their condition of difficulty due to the pain, is often underestimated, this leads them to take a closing attitude for the fear of not being understood. The respondents also expressed the fear that in the highly competitive society we live in, there is no place for people to express their pain: they are afraid of being considered weak and in a certain way "to be put aside" and so they must therefore "show themselves strong".

REFERENCE

[1] A. Celano, President - APMAR Onlus; S. Mingolla, Journalist - APMAR Onlus, Matteo Santopietro - Managing Director - WeResearch – ricerche di marketing.

Disclosure of Interests: None declared

DOI: 10.1136/annrheumdis-2019-eular.1217

PARE0007

RHEUMATISM CHALLENGE 2018 – "RHEUMATISM IN MOTION" WE ARE GOING IN THAT TOGETHER!

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Background: Czech League Against Rheumatism plays an important role in promoting rheumatic patients in the Czech Republic. Its activity is aimed at:

- raising awareness about RA for early diagnosis and RA treatment
- improve an attitude of the Czech patients to the modern treatment, including the biological treatment
- co-operate on the change together with the professional community, regulatory authorities and Health Insurance Companies.
- striving to qualify the people with so called "moderate activity" of the disease for the biological treatment

- the struggle for full and equal life for people with rheumatic and musculoskeletal diseases
- the establishment of regional clubs and specific patient groups of Czech League Against Rheumatism

Objectives: Creating a campaign Rheumatism Challenge 2018 - "Rheumatism in motion" We are going in that together! The aim of this campaign is improving the health condition of people with RMDs. To motivate patients to move regularly and raising patient awareness about the importance of physical activity.

Methods: Walking as a means to reach a goal is the main content of this campaign. The aim of each participant in this campaign is to reach as much as possible steps and kilometers every months. Exiting challenges prompts patients to higher goals and giving them courage. Through walking Czech League Against Rheumatism wants to improve physical and mental health of people with RMDs. Wants to maintain a joint mobility and reduce a pain. Know and find the right kind of movement for each patient. Information about this campaign is published on the webpage, Facebook and Instagram of Czech League Against Rheumatism.

Results: This campaign managed to raise awareness about the importance of physical activity in patients with rheumatic and musculoskeletal diseases among the general public. Information about the campaign was in press and television. The campaign continues in 2019.

In response to the campaign has increased the number of members in Czech League Against Rheumatism, an increased number of visitors and fans of the Facebook page Czech League Against Rheumatism.

Conclusion: This campaign seems to be very useful in promoting how important physical activity is for patients with RMDs. This campaign can support patients be more healthy and physically active. Active approach to one another life can inspire other patients and their families and friends. Very important is also the support of this campaign from the professional community, medical doctors and health professionals.

Disclosure of Interests: None declared

DOI: 10.1136/annrheumdis-2019-eular.3819

PARE0008 UNDERSTANDING THE IMPACT OF ANKYLOSING SPONDYLITIS IN DAILY LIFE OF THE PORTUGUESE PATIENTS: RESULTS FROM THE ASSESSMENT OF RESULTS IN ANKYLOSING SPONDYLITIS (AREA) STUDY

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Background: AS is known to have a significant burden upon the individual, family and society. It is essential to assess the impact of AS in patients' lives, to raise awareness and improve early referral, diagnosis and treatment, for a better quality of life.

Objectives: To assess the impact of AS in the life of Portuguese patients (work, daily activities, social life).

Methods: The Assessment of REsults in Ankylosing spondylitis (arEA) study was developed by the NOVA-IMS in cooperation with: Portuguese Society of Rheumatology, Portuguese Association of Family Physicians, National Association of Primary Care Units, National Association of AS Patients and the Portuguese League Against Rheumatic Diseases. The arEA aimed at assessing reasons for delayed referral of suspicious cases of AS to the rheumatologist, as well as disease impact in patients' lives, global health and work. A comprehensive online survey was developed with the collaboration of LPCDR and sent to AS patients. Data on demographics, lifestyle habits, daily life activities, working habits, disease indexes and healthcare utilization, health status/quality of life indicators, EQ-5D and BASDAI scales. A generalized linear model was adjusted in order to identify the factors impacting on quality of life of patients.

Results: 354 patients responded the survey, 42.1% female, most frequently from the 35-44 year-old age group. Mean age at disease onset was 27 years old, while the diagnosis was confirmed 7 years later. In the previous 12 months, the average of working days lost due to AS issues was 37 (including sick leaves). During that period, AS has affected work productivity in average around 73 days. Cumulatively,

patients' relatives or friends had also lost about 13 days of work, to provide them assistance. Regarding limitations in daily life activities, house cleaning (55.5%), physical exercise (46.5%), getting in/out of bed (45.6%), using stairs (37.9%), shopping (37.4%) and tying shoes (35.2%) were reported as being highly limited by AS. As for the social life, family and friends' relationships were reported as not being affected by over 60% of AS patients. However, 19.8% of the respondents have reported a worse relationship with their partners after diagnosis, and 29.7% reported having decreased the frequency of sexual intercourse. Leisure activities, were only reported as not being affected by 34.6% and 40.5% of patients, while the practice of sports has much decreased in 40.7% of the respondents. Almost 80% had mobility issues during the last year, and over 65% had their usual activities/routines affected by AS. The average BASDAI score is 5.5 and the EQ visual analogue scale 55. Analyzing the impact of treatment, biologics and biosimilars were reported as having significantly improved patients' quality of life, except for physical or sexual activity.

Conclusion: AS has a major impact in the daily life of patients, work productivity, social relationships and leisure activities. Early diagnosis and treatment, along with physical rehabilitation/exercise plans, can reduce this impact and improve their quality of life.

Disclosure of Interests: None declared

DOI: 10.1136/annrheumdis-2019-eular.6277

Best practice campaigning

PARE0009 THE PHYSICAL AND EMOTIONAL BURDEN OF RHEUMATOID ARTHRITIS: DATA FROM RA MATTERS, A WEB-BASED SURVEY OF PATIENTS AND PHYSICIANS IN EUROPE AND CANADA

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Background: Rheumatoid Arthritis (RA) is a chronic inflammatory disorder that negatively affects the patients' health-related quality of life (QOL).¹ Despite much progress in addressing the burden of RA, a gap exists in terms of understanding 'what really matters' to patients with RA, and balancing patients' QOL aspirations with clinical targets in key treatment decisions.

Objectives: This international survey investigated how RA affects the lives of patients according to the perceptions of both patients and healthcare providers (HCPs), in order to help health professionals attune their care on the domains that really matter to patients.

Methods: Data were collected from patients with RA, and rheumatologists or HCPs who treat RA in Canada, France, Germany, Italy, Netherlands, Spain, Sweden, and UK using a structured, closed-ended questionnaire in their local language. Respondents for the survey were recruited from survey panels of verified unique responses, as well as through social media. Data were summarized in terms of both frequency and percentages of patients to understand the experience of patients living with RA on daily activities, relationships, work, and aspirations.

Results: Overall, 5400 adult patients (81% female; mean age 52 years), and 808 rheumatologists or HCPs participated in the survey between November 2016 and February 2017. Of these, the highest proportion of patient and HCP respondents were from the UK (n=1250) and France (n=230), respectively. Overall, 52% of patients and 62% of HCPs believed that the emotional impact of RA is not well understood by people without the disease; whereas 46% of patients and 52% of HCPs had a similar belief with regards to the physical impact of the disease. Patients who felt that the impact of RA is less well understood by others expressed more negative feelings about every aspect of their life with RA. Important relationships with spouse or partner, children, family, friends, and colleagues were generally affected negatively. Almost half of the patients (48%) who participated in the survey reported that they were forced to take long-term leave/retirement or experienced slow career progress since being diagnosed with RA; more than 3 in 5 patients found exercising to be difficult; and almost 1 in 4 patients found difficulties in taking care of personal grooming. Aching/stiff joints, pain, and fatigue were the key physical barriers to activities for patients, and 65% of patients felt frustrated when they were unable to undertake or complete daily activities due to their disease. Two-thirds of patients wished to be able to accept their life with RA and do what they can to cope with it in the future. Over half of