Figure: A) Participants who felt that their CRD had affected the number of children they have

[a] Light purple/orange shading represents 'I don't know' response. Not all participants responded.

B) Concerns underlying why participants did not want children/more children in the context of CRD

Not all participants responded. Questions with no/very few responses are not shown.
CRD: chronic rheumatic disease; N/A: not applicable.

REFERENCES

- [1] Tincani A. *Ann Rheum Dis* 2018;77:866.

Acknowledgement: We thank the respondents who participated. This study was funded by UCB Pharma, conducted by the Swedish Rheumatism Association, medical writing by Arianna Psichas, Costello Medical, UK.

Disclosure of Interests: Li Alemo Munters: None declared, Nathalie Holmen Employee of: Employee of UCB Pharma, Suzanna Jansson: None declared
DOI: 10.1136/annrheumdis-2019-eular.328

AB1426-PARE THE GLOBAL OSTEOARTHRITIS PATIENT PERCEPTION SURVEY (GOAPPS): A PILOT STUDY

Angie Botto-van Bemden¹, Guy Eakin¹, Rosa Sciortino², Maritza Quintero², Jordi Monfort³, Patrick du Souich⁴, Francisco de Abajo⁵, Ingrid Möller⁶, Elizabeth Oswald⁷, Marco Matucci-Cerinic⁸, Deborah Scotton¹, Marco Bibas⁷, Marianna Vitaloni⁷, Josep Verges⁷. ¹Arthritis Foundation, Atlanta, United States of America; ²Universidad de los Andes, Merida, Venezuela (Bolivarian Republic); ³Hospital del Mar, Barcelona, Spain; ⁴University of Montreal, Montreal, Canada; ⁵Alcala Universidad, Alcala de Henares, Spain; ⁶Institut Poal de Reumatologia, Barcelona, Spain; ⁷Osteoarthritis Foundation International, Barcelona, Spain; ⁸University of Florence, Firenze, Italy

Background: Globally, osteoarthritis (OA) is the third condition associated with disability. Science holds the key to finding better treatments and a cure. Still, it is essential to learn what's important to patients from the patients to implement the most effective global management of OA. The International Osteoarthritis Task Force, an initiative of the Osteoarthritis Foundation International (Barcelona, Spain) and the Arthritis Foundation (Atlanta, United States) with participation from member organizations in additional countries created the Global Osteoarthritis Patient Perception Survey (GOAPPS)-the first global survey to directly compare quality of life (QoL) & patient perceptions of care in the same OA patient survey across languages and cultures.

Objectives: The goal of the survey was to help all stakeholders in OA healthcare develop a better understanding of patients perceptions and how they may differ between cultures by collecting data on adult OA patient perceptions regarding their OA care. The survey will also collect data on patient demographics, OA symptomology, and impact of OA on daily functioning and QoL. Understanding patients needs and perceptions of care is the first step in optimizing global OA management.

Methods: Observational, cross-sectional study by online survey data collection translated into three languages. We collected data on patient demographics, symptomology, OA impact on daily activity and QoL to investigate the relationship between patient perceptions of their OA care, symptoms and impacts, and QoL. The questionnaire comprised of 4

sections: clinical characteristics, relationship with physicians and treatment, perception of attention, treatment and information received and auto-evaluation of QoL. Inclusion criteria included resident age 18 or older with an OA

Results: A total of 1485 surveys were completed from 7 countries. 1264 surveys were answered in English, 218 in Spanish and 3 in Italian; analysis of cultural differences was unable to be carried out in this pilot. Data show that the majority of the respondents were female (90%) and more than 55 years of age (82%). The majority (73%) of patients had knee OA, followed by hand (57%) and spine (54%). Comorbidities included hypertension (50%) and obesity (43%). Nearly all patients reported limitations related to physical activities (97%), followed by work activities (49%), social interaction (43%) and sex life (23%). 37% of patients experience emotional or mental health issue. The 58% says their doctor adequately explained their diagnosis and 55% understand the treatment options. Importantly, 41% of respondents are not satisfied with their OA treatment and 79% would like access to non-drug/non-surgical treatments. While 52% of respondents rate their QoL as good, 95% would rate it better if their OA was eliminated.

Conclusion: The results emphasize the significant impact of OA disease on patients daily activities and their desire to play an active role in managing their disease. Notably the majority asks for access to additional options for non-drug/non-surgical treatments stressing the need for an OA management improvement. This is a pilot survey and the results do not permit analysis of cultural differences. Continued survey distribution & analysis will determine differences in patient perception of QoL between OA patients living in different countries to further optimize global OA management.

Disclosure of Interests: Angie Botto-van Bemden: None declared, Guy Eakin: None declared, Rosa Sciortino: None declared, Maritza Quintero: None declared, Jordi Monfort Speakers bureau: Bioibrica Procure Health, Patrick du Souich: None declared, Francisco de Abajo: None declared, Ingrid Möller: None declared, Elizabeth Oswald: None declared, Marco Matucci-Cerinic Grant/research support from: Actelion, MSD, Pfizer, BMS, Chemomab, Sanipedia, Speakers bureau: Actelion, BMS; MSD, Janssen, Deborah Scotton: None declared, Marco Bibas: None declared, Marianna Vitaloni: None declared, Josep Verges: None declared

DOI: 10.1136/annrheumdis-2019-eular.4100

AB1427-PARE PATIENTS AS RESEARCHERS OF TIETZES SYNDROME AND COSTOCHONDRITIS USING PARTICIPATORY NARRATIVE METHODS OF INQUIRY

Elke van Delft^{1,2}, Harold van Garderen³, Rob Braamburg¹, Raymond Pieters⁴.

¹Association of Tietze and costochondritis patients, Heukelum, Netherlands;

²Maasstad Hospital, Rotterdam, Netherlands; ³StoryConnect, Wageningen,

Netherlands; ⁴University of Applied Sciences Utrecht, Utrecht, Netherlands

Background: Tietzes syndrome and costochondritis are rare, inflammatory rheumatic disorders characterised by chest pain. Pain is most commonly localised unilaterally at the costochondral junctions, with more than one junction generally affected (1). Whereas the conditions are considered self-limiting and in two third of the cases resolve within one year (2,3), they can last up to several years or be recurring (4), limiting the patients ability to function in occupational demands and activities of daily living. The exact cause is not known and therefore it remains a challenge to take on an effective treatment approach.

Objectives: This study aims to gain more insight into patients and medical professionals experiences with and handling of Tietzes syndrome and costochondritis.

Methods: It was noticed that hardly any research is done on Tietzes syndrome and costochondritis and hardly any medical professionals are specialised in these conditions. This sparked the idea to involve patients themselves as researchers of the conditions. To that end an online platform called a StoryPoint was designed, based on the Participatory Narrative Inquiry (PNI) approach (5). This StoryPoint allowed patients and medical professionals to anonymously share and do research on their personal experiences with the conditions.

This online assessment was followed by a live meeting with patients suffering from Tietzes syndrome or costochondritis. During this meeting the online gathered narratives were evaluated using group narrative evaluation methods (5).

Results: In total 53 experiences were retrieved. Approximately 60% of patients experienced complaints on a daily basis (figure 1). The reported limitations in daily living were inability to perform physical exercise, a lack of energy and incomprehension from the environment.

Treatments advised by specialists that relieved complaints were physical therapy, breathing techniques and NSAIDs. Relaxation, low impact movement and warmth were solutions that patients initiated themselves and were perceived helpful. Of all treatments advised by a medical professional 70% improved complaints, 22% had no effect at all, and 8% worsened the complaints (figure 2). Of the treatments that patients initiated themselves, 78% improved complaints and 22% had no effect (figure 2). We are currently involving a wide variety of medical professionals and researchers for further evaluation of the narratives.

Conclusion: Tietzes syndrome and costochondritis can be very limiting conditions, especially when complaints become chronic. Treatments advised by medical professionals are hardly any more effective than treatments initiated by patients themselves. Since both conditions are rare and relatively unknown, medical specialists have difficulties recognising, diagnosing and treating these conditions. It is important that medical professionals become more familiar with Tietzes syndrome and costochondritis and become involved in this type of patient-driven research approaches.

Figure 1: How often patients experience complaints from their Tietzes syndrome or costochondritis

Figure 2: Comparison of the effect of treatment methods advised by a medical specialist or initiated by patients themselves

REFERENCES

- Proulx AM, Zryd TW. Costochondritis: diagnosis and treatment. *Am Fam Physician*. 2009;80(6):617-620.
- Disla E, Rhim HR, Reddy A, Karten I, Taranta A. Costochondritis. A prospective analysis in an emergency department setting. *Arch Intern Med*. 1994;154(21):2466-2469.
- Brown RT, Jamil K. Costochondritis in adolescents. A follow-up study. *Clin Pediatr (Phila)*. 1993;32(8):499-500.
- Freeston J, Karim Z, Lindsay K, Gough A. Can early diagnosis and management of costochondritis reduce acute chest pain admissions? *J Rheumatol*. 2004;31(11):2269-2271.
- Kurtz C. *Working with Stories in Your Community or Organization: Participatory Narrative Inquiry* (Third Edition). New York: Kurtz-Fernhout Publishing. 2014.

Disclosure of Interests: None declared

DOI: 10.1136/annrheumdis-2019-eular.4764

AB1428-PARE FAMILY PLANNING IN CHRONIC RHEUMATIS DISEASES

Li Alema Munters, Suzanna Jansson. *Stockholm, Stockholm, Sweden*

Background: Family planning (FP) in the context of chronic rheumatic disease (CRD) can be challenging for both women and men, with additional requirements for information and support.¹ However, it is unclear whether the needs of this population are being met by current clinical practice in Sweden.

Objectives: To gain insight into the perspectives of men and women with different CRDs on FP, and to assess whether they feel adequately supported to make informed decisions.

Methods: A 10-minute survey focusing on participants experiences and current needs around FP was designed. The survey was distributed (24 Aug5 Sep 2018) via a web-based system to members of the Swedish Rheumatism Association; men and women aged 1847 years were included. Data are reported for participants with arthritic or systemic

CRDs (rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, juvenile idiopathic arthritis, systemic sclerosis, systemic lupus erythematosus, polymyositis, dermatomyositis). Participants with fibromyalgia, Ehlers-Danlos Syndrome, other or no CRD were excluded.

Results: Of 944 participants, 542 (57%) women and 60 (6%) men with arthritic or systemic CRDs responded. Over a quarter of women (28%) who had children/were expecting felt their CRD had affected their ability to have children and more than half either believed that their CRD had influenced the number of children they had or were undecided (**Figure A**). Men were less affected by their CRD with respect to FP, with >60% reporting no impact on their ability to have children and/or how many. Of participants who did not want children/more children in the future, around a third attributed this to their CRD (women: 37% [n=86/232]; men: 30% [n=9/30]). Their biggest concerns were not being able to physically handle and/or cope with taking care of a child, and passing on their disease (**Figure B**). Womens concerns regarding disease activity after pregnancy were not unfounded, with 66% reporting disease worsening postpartum. The most common treatments reported by women with CRD while trying to conceive were DMARDs (20%), NSAIDs (18%), corticosteroids (14%) and anti-TNFs (13%). Of women on anti-TNF therapy (n=71), 68% discontinued treatment during pregnancy. Only around a third of women felt they had received adequate support and information about FP from their healthcare provider (HCP; 33%) and that this information was consistent between HCPs (28%). Men with CRD were even less satisfied with both the level of support (13%) and the consistency of information received around FP (13%).

Conclusion: The results of this survey suggest that in Sweden, CRD has a marked impact on FP for women, and to a lesser extent for men. Furthermore, the level of support and information on FP provided by HCPs to people with CRD, as well as the consistency of information received from different HCPs, were deemed inadequate. Providing better information on FP by HCPs, to both women and men with CRD, would help to support them on their journey to parenthood and overcome perceived obstacles to having children and continuing therapy.

Figure: A) Participants felt that their CRD had affected the number of children they have

[a] Light purple/orange shading represents 'I don't know' response. Not all participants responded.

B) Concerns underlying why participants did not want children/more children in the context of CRD

Not all participants responded. Questions with no/very few responses are not shown. CRD: chronic rheumatic disease; N/A: not applicable.

REFERENCES

- Tincani A. et al. *ARD* 2018; 77:866.

Acknowledgements: We thank the patients who participated. This study was funded by UCB Pharma and conducted by the Swedish Rheumatism Association. Editorial services were provided by Costello Medical.

LAM: None declared; **NH:** Employee of UCB Pharma; **SJ:** None declared.

Disclosure of Interests: None declared

DOI: 10.1136/annrheumdis-2019-eular.5255