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OP2073

THE SCLERODERMA CLINICAL TRIALS CONSORTIUM DAMAGE INDEX (SCTC-DI) IN A SYSTEMIC SCLEROSIS COHORT WITH 10-YEARS FOLLOW-UP

M. G. Lazzaroni1, M. Breda1, F. Franceschini1, P. Aio1, 1ASST Spedali Civili of Brescia, University of Brescia, Rheumatology and Clinical Immunology Unit, Department of Clinical and Experimental Sciences, Brescia, Italy

Background: Systemic Sclerosis (SSc) is characterized by increased mortality
and organ damage accrual. A composite SSc Damage Index was recently developed by the Scleroderma Clinical Trials Consortium (SCTC-DI) and was demonstrated to be a predictor of mortality both in the Australian derivation cohort and in the Canadian validation cohort.

Objectives: To evaluate in a single centre cohort of SSc patients with 10-years follow-up: (1) the evolution of organ damage over time; (2) factors associated with the development and accrual of organ damage.

Methods: A retrospective analysis was performed on patients prospectively followed in our centre from 1989 to 2019. Organ damage was evaluated with SCTC-DI (0-55 scale; moderate damage >5, severe damage >12) and comorbidities with Charlson Comorbidity Index (CCI, which includes the age of the patient). Patients were included when a follow-up of at least 10 years was available together with SCTC-DI at the diagnosis (baseline, T0), 1 year (T1), 5 years (T5) and 10 years (T10) after the diagnosis. Univariable and multivariable analy-
sis (logistic regression) were performed when appropriated.

Results: 253 SSc patients were included (female 93%; Caucasians; 99%; median age at diagnosis: 52 years (IQR: 43-60); diffuse cutaneous subset: 15%; anti-centromere (ACA)+ 55%; anti-Topoisomerase 1 + 20%; anti-RNA polymer-
ase III+ 4%; ever smokers: 28%). Median interval between the first SSc symp-
tom other than Raynaud’s phenomenon and the diagnosis was 1 year. SCTC-DI progressively increased from diagnosis to T10 (p<0.0001; Kruskal-Wallis test).

Moderate damage (score:6-12) was observed in 22 patients at T0 (8.7%), in 30 at T1 (11.9%), in 45 at T5 (17.7%) and in 73 at T10 (28.9%). None of the patients had severe damage (score:13-55) at T0 and T1, while it was present at 6 at T2 (2.7%), 17 at T5 (4.9%) and 17 at T10 (7.9%).

At T0 no difference in SCTC-DI scores was observed when comparing different subgroups according to gender (female vs. male), disease subsets (diffuse vs. limited) and autoantibodies (ACA- vs. ACA+). At T1, SCTC-DI score was higher in patients with diffuse vs. limited cutaneous subset, and ACA- vs ACA+ (p=0.0001 for both).

Multivariable analysis demonstrated that a moderate or severe organ damage (SCTC-DI score >5) at 5 years was positively associated with diffuse cutaneous involvement (p=0.009, OR 4.55, 1.46-14.1), SCTC-DI at T0 (p=0.015, OR 1.34, 1.06-1.70) and at T1 (p<0.0001, OR 1.65, 1.30-2.07), and negatively associated with ACA+ (p=0.024, OR 0.32, 0.12-0.86), while CCI and male sex showed no association. At 10 years SCTC-DI=5 was associated with diffuse cutaneous involvement (p=0.013, OR 4.30, 1.36-13.7), SCTC-DI at T5 (p<0.001, OR 1.67, 1.38-2.01), while SCTC-DI at T0, CCI, male sex and ACA+ had no association.

Among 253 patients, 90 (36%) died after >10 years of follow-up. In non-survivors, as compared to survivors, SCTC-DI score was significantly higher at the baseline (T0) and during the entire follow-up (p<0.0001 for every timepoint).

Conclusion: At the end of 10-years follow-up (T10), 35% of patients in our cohort had severe organ damage (SCTC-DI score=5). Diffuse cutaneous involvement was associated with higher SCTC-DI scores at different time points (T5 and T10). Organ damage, as defined by SCTC-DI>5, was predictive of mortality in patients who reached more than 10 years of follow-up.

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EVALUATION OF PATIENT SATISFACTION FOR TELEHEALTH (PHONE AND VIDEO) IN RHEUMATOLOGY OUTPATIENTS DURING COVID-19 PANDEMIC

Y. Qin1, 2, A. Hennessey1, 2, L. Young1, 2, D. Yates1, 3, C. Barrett1, 2, 1Redcliffe Hospital, Rheumatology, Redcliffe, Australia; 2The University of Queensland, Medicine, Saint Lucia, Australia.

Background: Telehealth via phone (TPhone) or video conference (TVideo) in rheumatology has been a topic of interest for many years. Its use was rapidly expanded to the internation’s public health emergency in response to the coronavirus dis-
bane-19 (COVID-19) outbreak in 2020. Australian Medicare Benefits Schedule (MBS) swiftly enabled temporary MBS telehealth items on 13 March 2020, cur-
rently extended until 31 March 2021. In the early phase of the COVID-19 pan-
demic, Antony et al. conducted a single-centre public survey to assess patient perception of rheumatology telehealth. Their results showed that 98.4% of patients consider telehealth acceptable during the pandemic2. It is unclear, how-
ever, whether this positive perception persists as patients experience a tele-
health. In addition, a survey data in 2019 suggested more than half of Australian rheumatologists work in private practice3. Therefore, inclusion of private patients will better represent patient perception of telehealth.

Objectives: The aim of this study was to evaluate patient satisfaction with tele-
health during the COVID-19 pandemic. This would determine its feasibility to be integrated into future rheumatology outpatient model.

Methods: A questionnaire containing 30 questions was sent to rheumatology patients who attended telehealth appointments at a level 2 public hospital and a local private clinic between April and May 2020. The questionnaires aimed to obtain information on baseline demographics (sex, age, public or private patient, employment status, visual or auditory impairment), appointment details (TPhone or TVideo, usual arrangement for face-to-face (F2F) appointment, cost effective-
ness) and appointment satisfaction using a 5-point Likert scale. Descriptive sta-
tistical analysis was conducted.

Results: The questionnaire was sent to 1452 patients, of which 494 patients responded (34%). Female predominance (77.1%) and a higher proportion of TPhone (79.1%) was seen in the respondents. A majority of patients were exist-
ing patients known to the services (90.9%). More than 70% of responses indi-
cated overall satisfaction in specialist care via telehealth, and 88.7% perceived this suitable for a pandemic. Of all respondents, 21.7% were prescribed new medication, and the majority of these patients were confident in taking the new medication after the telehealth appointment. Future acceptability for TPhone was significantly lower in private patients compared to public patients (p= 0.01). Sub-
group analysis revealed that higher telehealth satisfaction was associated with needing to take time off work to attend face-to-face appointment (p= 0.02), per-
ception of cost effectiveness (p<0.001) and TVideo (p=0.03).

Conclusion: This is the first study which included both public and private rheumatology patients to evaluate patient satisfaction for telehealth during the COVID-19 pandemic. Overall high level of satisfaction was seen in telehealth most notably assessed with cost effectiveness. A higher percentage of patients in F2F compared to TPhone were receptive to future telehealth via TVideo, supportive of the importance of visual cues. This in turn will have significant administrative and technological burdens to coordinate in comparison to a F2F or TPhone review. This qualitative study provides valuable insight of patient perception of telehealth, which has the potential to compliment the tradi-
tional rheumatology outpatient model of care following the pandemic.

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The unacceptable delay to diagnosis in axial spondyloarthritis: Developing a call to action for a global healthcare challenge

W. Gerhart, M. T. Duruöz, J. Lowe, D. Webb, L. Wermskog, J. Davies, R. Howard, M. Mallinson, C. L. Koehn, Canadian Spondylitis Association, Director, Toronto, Canada; 2Marmara University School of Medicine, PMR Department, Istanbul, Turkey; 3Axial spondyloarthritis International Federation, Projects, London, United Kingdom; 4National Axialspondyloarthritis Society, Director, London, United Kingdom; 5Spafo Norge Spondyloarthritisforbundet, Director, Oslo, Norway; 6Axial spondyloarthritis International Federation, Executive, London, United Kingdom; 7Spondylitis Association of America, Executive, Los Angeles, United States of America; 8Axial spondyloarthritis International Federation, Volunteering, London, United Kingdom; 9Arthritis Consumer Experts, Director, Vancouver, Canada

Background: The current delay to diagnosis from symptom onset represents one of the greatest challenges in axial spondyloarthritis (axSpA). Research shows an average global delay of almost 7 years — as long as 15 years in some cases — during which time the condition can progress and lead to irreversible damage. Data indicates that women wait longer than men for a diagnosis, and there has been very limited progress in reducing the time to diagnosis.

Methods: A full literature review was carried out to identify relevant available global evidence exploring the axSpA diagnosis delay. In autumn 2020 ASIF held two virtual global forum events, involving patients and patient group representatives, researchers, rheumatologists and other healthcare professionals, to methodically explore key diagnosis challenges across different healthcare systems and the opportunities for addressing these. Break-out discussions were held and participants were asked to identify the personal and societal effects of the diagnostic delay; the reasons it occurs; and initiatives to tackle the challenge. Alongside key stakeholder testimonies, best practices from around the world were also identified. 92 stakeholders participated in the events; they represented patients and healthcare professionals from 23 countries across five continents.

Results: The findings from these activities were incorporated within a new ‘Delay to Diagnosis report’, written for the first time definitively sets out the lived realities from a global perspective of the axSpA diagnosis delay. The report identified important commonalities across different countries and healthcare systems contributing to the current average global 7-year diagnosis delay, including:

- Poor awareness of axSpA, particularly in primary care services
- Complexities in diagnosing the disease
- Poorly defined referral pathways
- Insufficient patient access to rheumatologists and appropriate diagnostics

The report also highlights the significant impact this delay has on individuals and wider society, providing a foundation for future advocacy work. A series of recommendations have also been identified, the implementation of which will help to instigate tangible progress in reducing the current delay.

Conclusion: Despite longstanding challenges, there are now clear opportunities for transforming how axSpA is diagnosed around the world. This message needs to be heard and acted upon urgently by all those involved in the management and delivery of axSpA care. The future programme of work for ASIF’s Delay to Diagnosis project will respond to these findings and be centred around supporting axSpA patient associations globally to take this call to action forward throughout 2021 and beyond.

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CREATING POLITICAL LEVERS TO IMPROVE AXIAL SPONDYLOARTHRITIS CARE


Background: Research carried out in 2016 by NASS showed that the range and quality of axial spondyloarthritis (axSpA) services generally offered around the UK were variable. The publication by the regulator, the National Institute for Health and Care Excellence (NICE), of a Guideline for Spondyloarthritis (NG65) in 2017 and the corresponding Quality Standard (QS170) in 2018, for the first time provided national guidance and standards of services that should be available for people with axSpA. NASS oversight of the implementation of these however was missing.

Methods: The group is a unique forum in the UK, bringing together patients, clinicians, researchers, policy makers, national bodies and parliamentarians. The group has met five times covering a range of topics including the delay to diagnosis, the uptake of NG65 and hydrotherapy.

In 2019 the group carried out a national inquiry into the standards of axSpA services in the UK, developing a ten-question quality framework, based largely on the NICE Guideline recommendations and Quality Standard. In July 2020 a meeting was convened to discuss the impact of COVID-19 on axSpA services. The meeting presented research carried out by NASS and M&F Health with patients and clinicians respectively.

Results: The national inquiry for England were published in January 2021. The discrepancy between the national large discrepancies remain in the provision of axSpA services. Only 21% of local commissioning bodies have an inflammatory back pain pathway, and less than half of NHS providers have a specialist axSpA clinic. The results of COVID survey shows significant impacts on the health of axSpA patients and on the availability and modality of rheumatology services. The survey was published in October with a set of recommendations, creating minimum service specifications for axSpA services during crisis periods such as the recent pandemic, as well as service recovery. Comment on this research was also published in The Lancet Rheumatology.

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