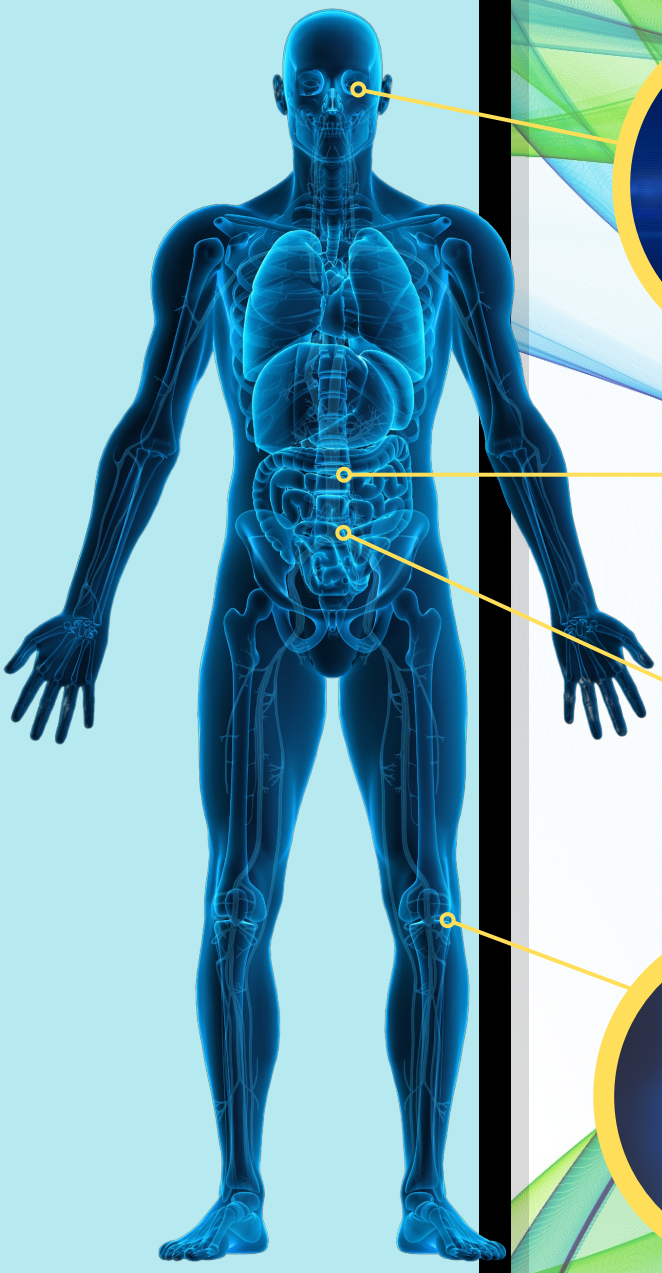
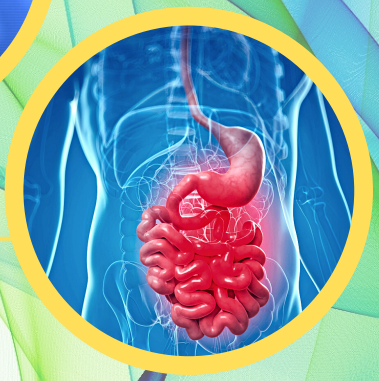
MyNIAR

Axial Spondyloarthritis





Published by :

Malaysia National Inflammatory Arthritis Registry (MyNIAR)

JAN 2020 – FEB 2022

MALAYSIA NATIONAL INFLAMMATORY ARTHRITIS REGISTRY-Axial Spondyloarthritis (MyNIAR-AxSpA) Report

Published by:

Malaysia National Inflammatory Arthritis Registry (MyNIAR)
Ministry of Health Malaysia

Direct line	:	(603) 6126 3333 ext 4167
Fax	:	(603) 6120 2761
Website	:	http://www.crc.gov.my; www.msr.my

Suggested citation : The suggested citation for this report is as follows:
Dato' Dr Azmillah Rosman
Dr Mollyza Mohd Zain
Dr Habibah Mohd Yusoof
Dr Shereen Ch'ng Suyin
Dr Lau Ing Soo

CONTENTS

CONTENTS

ACKNOWLEDGEMENTS

The Malaysia National Inflammatory Arthritis Registry (MyNIAR) would like to express its sincere thanks and appreciation to all who have supported and contributed to this report.

We would like to thank Pusat Informatik Kesihatan (PIK), Ministry of Health Malaysia for hosting and maintenance of the online portal and server of MyNIAR registry. We would also like to thank Ms Fadzliza Hafiza Ramli and Ms Rozalia Mohd Arif, who are the Registry Managers, for their assistance and support. Many thanks too to Dr Yow Hui Yin and her team from TTY Medigraphic Design for their contribution to the data analysis. We also would like to acknowledge Novartis Malaysia for providing financial support for the on-line registry portal development, registry manager and cost for medical writing.

We thank the following for their support:

- The Ministry of Health, Malaysia
- Clinical Research Malaysia (CRC)
- Pharmaceutical Industry

MyNIAR STEERING COMMITTEE MEMBERS

Dato' Dr Azmillah Rosman	Hospital Selayang
Dr Mollyza Mohd Zain	Hospital Selayang
Dr Habibah Mohd Yusoof	Hospital Selayang
Dr Lau Ing Soo	Hospital Selayang
Dr Shereen Ch'ng Suyin	Hospital Selayang
Dr Liza Mohd Isa	Hospital Putrajaya
Dato' Dr Gun Suk Chyn	Hospital Tuanku Ja'afar, Seremban
Dr Asmah Mohd	Hospital Tuanku Ja'afar, Seremban
Datin Dr Asmahan Mohamed Ismail	Hospital Raja Perempuan Zainab II
Dr Chong Hwee Cheng	Hospital Melaka
Dr Lim Ai Lee	Hospital Pulau Pinang

LIST OF CONTRIBUTORS

HOSPITAL PULAU PINANG
Dr Lim Ai Lee
Dr Kan Sow Lai
Dr Nor Hashimah Abu Mansor Matardiah
Dr Ng Choon Seong
Dr Ng Ying Fun
Dr Quake Chuang Tin
Dr Shakira A/P Selvananda

HOSPITAL SELAYANG
Dato' Dr Azmillah Rosman
Dr Lau Ing Soo
Dr Mollyza Mohd Zain
Dr Habibah Mohd Yusoof
Dr Shereen Ch'ng Suyin
Dr Hazlyna Baharuddin
Dr Norliza Binti Zainudin
Dr Malek Faris Reza Jeffrizal
Dr Adrian Mark A/L Masnammany
Dr Avreena Kaur Bhullar A/P Authar Singh
Dr Lim Shiau Li
Dr Chuah Seow Lin
Dr Tay Voon Yaa
Dr Lydia Pok

HOSPITAL PUTRAJAYA
Dr Liza Mohd Isa
Dr Nor Shuhaila Shahril
Dr Wan Rosmaiza Wan Musa
Dr Mariam Hamid Mustapha
Dr Pradeep V Ravindra Dass
Dr Tan Chou Luan
Dr Ng Boon Han

HOSPITAL TENGKU AMPUAN RAHIMAH, KLANG
Dr Eashwary A/P Mageswaran
Dr Suhaida Ahmad Maulana
Dr Diana Ang Lee Min
Dr Ravathy A/P Nasadurai
Dr Manisha Chandran

HOSPITAL MELAKA
Dr Chong Hwee Cheng
Dr Hong Hooi Chuen
Dr Jasmine Yew Sze Yin
Dr Liau Swee Min
Dr Tee Ying Chew

HOSPITAL SULTANAH BAHIYAH, ALOR SETAR
Dr Azwarina Hanim Ramlan
Dr Ng Seow Ching

HOSPITAL TUANKU JA'AFAR, SEREMBAN
Dato' Dr Gun Suk Chyn
Dr Loh Yet Lin
Dr Asmah Mohd
Dr Nadiah Mohd Noor
Dr Chua Siew Houy
Dr Eow Liu Hong
Dr Ng Kooi Heng
Dr Shantene NP Selvadurai
Dr Wong Phing Sue
Dr Yap Wee Fang
Dr Goh Wan Chee

HOSPITAL RAJA PERMAISURI BAINUN, IPOH
Dr Ong Ping Seung
Dr Khor Chiew Gek
Dr Noraini Mat Husin
Dr Lee Chui Yee

HOSPITAL SULTAN ISMAIL, JOHOR
Dr Ng Chun Ruh

HOSPITAL RAJA PEREMPUAN ZAINAB II, KELANTAN
Datin Dr Asmahan Mohamed Ismail
Dr Ng Kiah Loon
Dr Gan Syang Phyng

HOSPITAL TENGKU AMPUAN AFZAN, KUANTAN
Dr Nurulraziquin Mohd Jamid
Dr Dayang Masyrinartie Suahilai
Dr Nurul Aulia binti Zakaria

HOSPITAL UMUM SARAWAK
Dr Teh Cheng Lay
Dr Sharifah Aishah Wan Mohamad Akbar
Dr Anna Farazilah Mohd Salleh
Dr Benjamin Sachdev A/L Manjit Singh
Dr Cheong Yaw Kiet
Dr Lee Kar Hoo
Dr Wendy Lee Wan Hui

HOSPITAL PAKAR SULTANAH FATIMAH, MUAR
Dr H'ng Mooi Khin

UNIVERSITY MALAYA MEDICAL CENTRE
Assoc Prof Dr Fariz Yahya

INTRODUCTION

The MyNIAR AxSpA registry was established in 2020 to capture the demographics, clinical information, management and treatment outcome of axial spondyloarthritis (Axial SpA) patients utilising the public healthcare system in Malaysia. Majority of hospitals with Rheumatology service under the Ministry of Health (MOH) Malaysia and University Malaya Medical Centre participated in this registry.

The data captured in this registry represents useful real-world data that may be utilised to guide future disease management by answering day-to-day clinical practice questions not addressed by clinical trials. Moreover, the registry data provides valuable insights pertaining to the current Axial SpA disease burden in MOH hospitals, which may be useful to all relevant stakeholders for treatment budget planning and projections.

OBJECTIVES

To determine the incidence and prevalence of Axial SpA in Malaysia

To obtain data pertaining to Axial SpA patient demographics, disease patterns and manifestations

To study the clinical management of Axial SpA

To assess the patient outcome, disease activity, and impact of Axial SpA on quality of life (work productivity and activity impairment)

DISTRIBUTION OF CASES ACCORDING TO HOSPITAL

Data were obtained from January 2020 to February 2022. A total of 14 MOH hospitals were involved in the data collection. As a newly established registry, 199 data entries were made in its early stage. The total number of patients is projected to increase over the next few years, which would be useful for epidemiologic studies of the disease in the country.

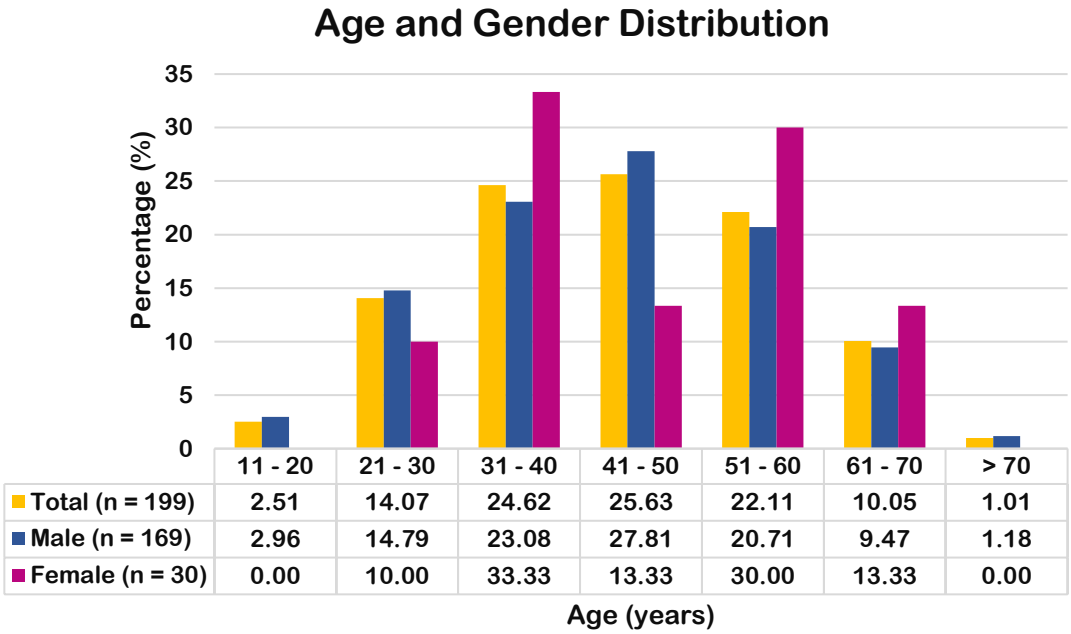
Table 1: Distribution of cases reported in the MyNIAR according to hospitals (n = 199)

No	Hospital	Year			Total (%)
		2020	2021	2022	
1	Hospital Pulau Pinang	44	5	-	49 (24.62)
2	Hospital Umum Sarawak	-	36	-	36 (18.09)
3	Hospital Melaka	18	6	-	24 (12.06)
4	Hospital Tengku Ampuan Rahimah, Klang	6	7	4	17 (8.54)
5	Hospital Selayang	7	9	-	16 (8.04)
6	Hospital Sultanah Bahiyah, Alor Setar	15	1	-	16 (8.04)
7	Hospital Tengku Ampuan Afzan, Kuantan	3	10	-	13 (6.53)
8	Hospital Raja Perempuan Zainab II, Kelantan	3	4	-	7 (3.52)
9	Hospital Tuanku Ja'afar, Seremban	-	6	-	6 (3.02)
10	University Malaya Medical Centre	-	5	-	5 (2.51)
11	Hospital Putrajaya	2	2	-	4 (2.01)
12	Hospital Pakar Sultanah Fatimah, Muar	-	3	-	3 (1.51)
13	Hospital Raja Permaisuri Bainun, Ipoh	1	1	-	2 (1.01)
14	Hospital Sultan Ismail, Johor	-	-	1	1 (0.50)
	Total	**99**	**95**	**5**	**199**

CHAPTER 1: DEMOGRAPHICS

1.1 Age and Gender Distribution

The mean age of the patient cohort was 44.16 ± 12.97 years old - Female: 45.83 ± 13.74 years; Male: 43.86 ± 12.84. Majority of patients (72.36%) were between 31 – 60 years old (Figure 1). Gender distribution was 15.08% and 84.92% for female and male, respectively (Figure 2).



	11 - 20	21 - 30	31 - 40	41 - 50	51 - 60	61 - 70	> 70
Total (n = 199)	2.51	14.07	24.62	25.63	22.11	10.05	1.01
Male (n = 169)	2.96	14.79	23.08	27.81	20.71	9.47	1.18
Female (n = 30)	0.00	10.00	33.33	13.33	30.00	13.33	0.00

Figure 1: Age distribution of patients with axial spondyloarthritis (n = 199)

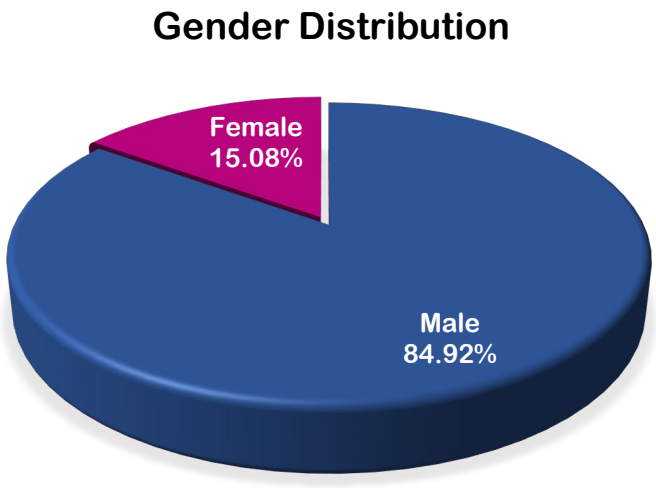


Figure 2: Gender distribution of patients with axial spondyloarthritis (n = 199)

1.2 Ethnic Group Distribution

More than half of the patients in this cohort were Chinese (59.30%), followed by Malay (33.17%) and Indian (5.53%) (Figure 3).

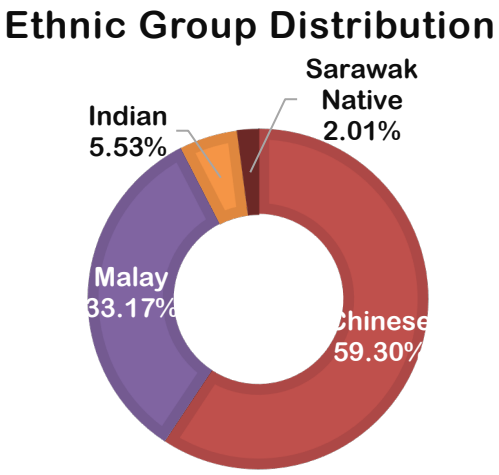


Figure 3: Ethnicity distribution of patients with axial spondyloarthritis (n = 199)

1.3 BMI Distribution

Mean Body Mass Index (BMI) of the patient cohort at first notification (kg/m^2) was 27.08 ± 6.37- Female: 28.24 ± 6.25; Male: 26.89 ± 6.39. More than two-thirds of the patients had BMI above the normal range with 14.43% and 59.27% being overweight and obese, respectively (Figure 4).

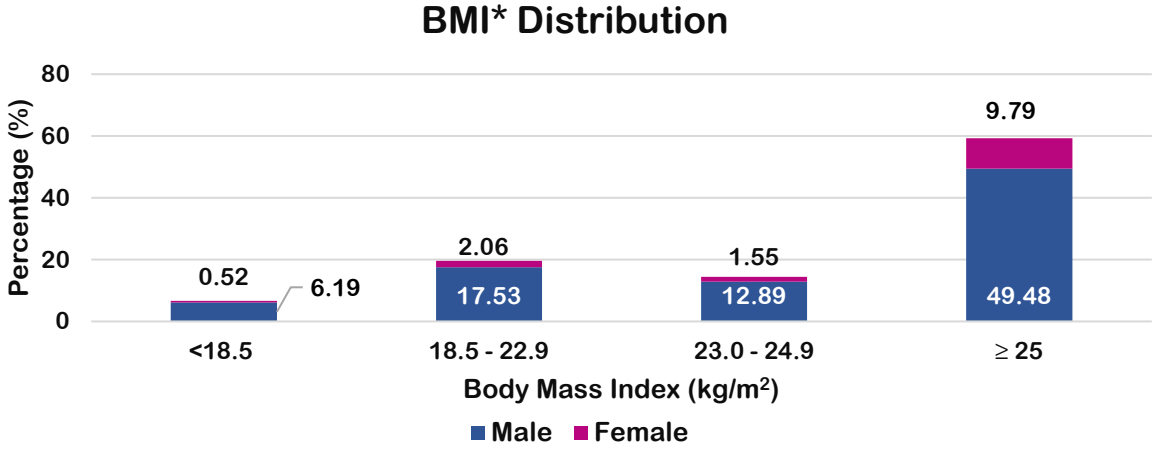


Figure 4: Body Mass Index of patients with axial spondyloarthritis (n = 194)
*Asian criteria-based BMI

1.4 Duration of Disease

Mean duration of disease at first notification for the patient cohort was 7.73 ± 6.32 years. Majority of the patients (65.28%) had a disease duration of less than 9 years (Figure 5).

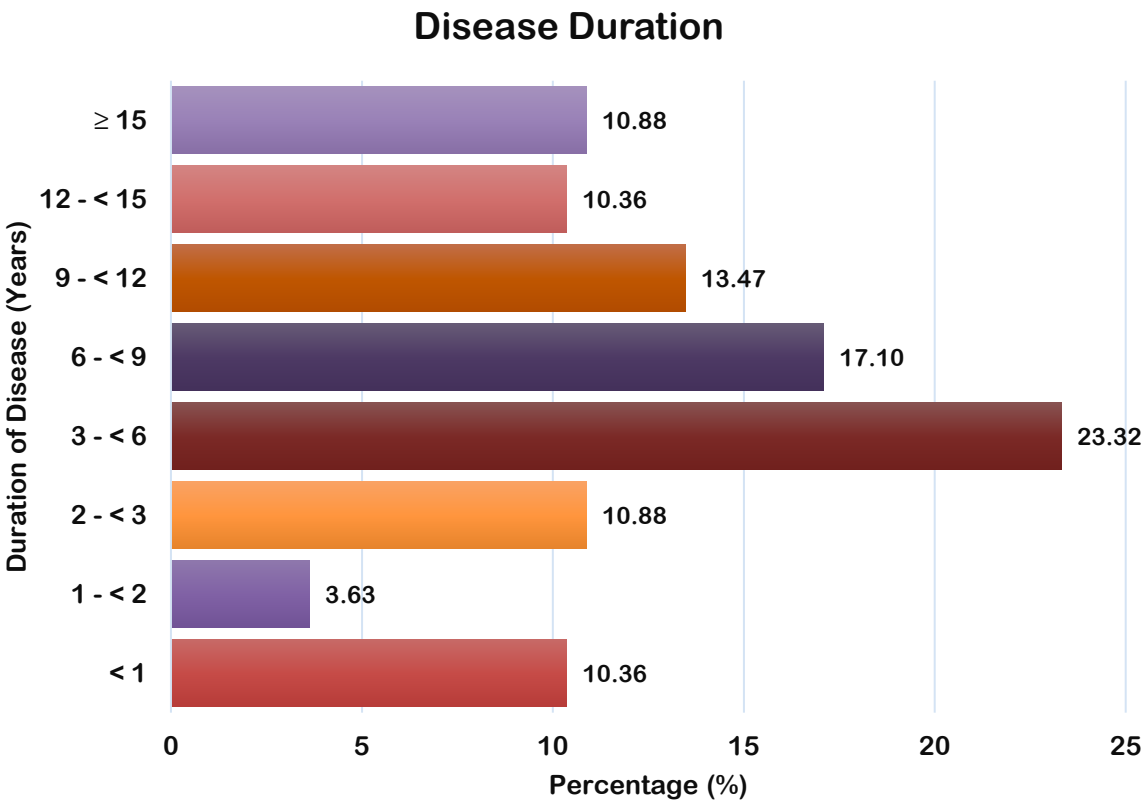


Figure 5: Disease duration of patients with axial spondyloarthritis (n = 193)

CHAPTER 2: SOCIOECONOMIC STATUS AND SMOKING

2.1 Education Level

More than half of the patients (63.31%) had secondary education and below. Approximately one-third of them (36.68%) had tertiary qualifications (Figure 6).

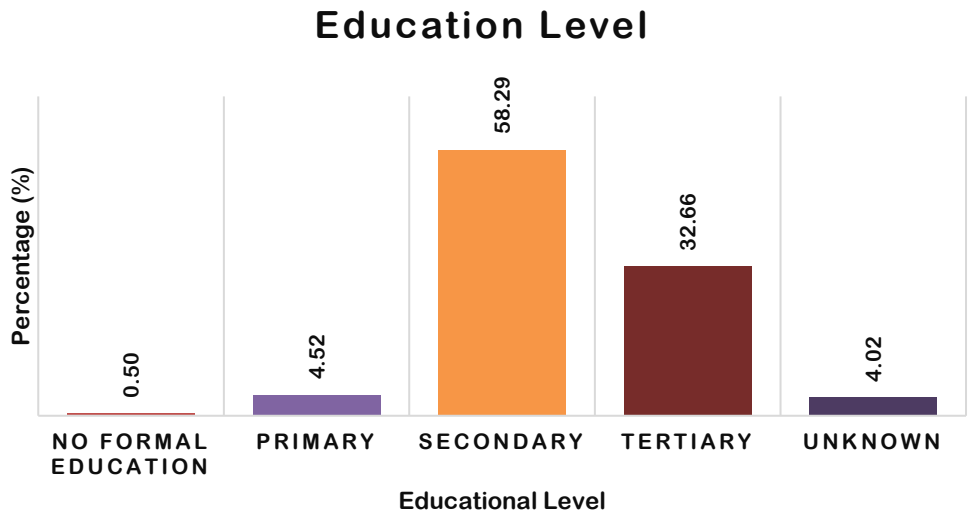


Figure 6: Education level of patients with axial spondyloarthritis (n = 199)

2.2 Employment Status

One-third (33.67%) of the patients were unemployed. Among those who were unemployed, 17.91% attributed the cause of unemployment directly to the disease (Figure 7).

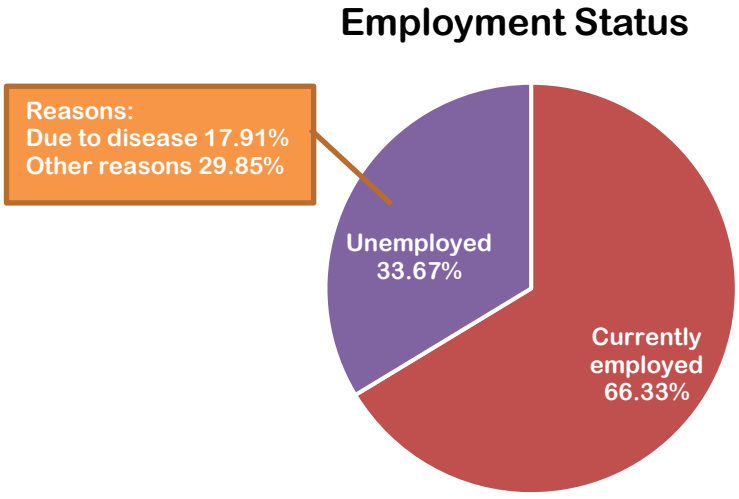


Figure 7: Employment status of patients with axial spondyloarthritis (n = 199)

2.3 Household Income

Approximately 40% of the patients fell under the National Poverty Line Income (PLI) category (i.e., less than RM 2208.00/month) according to the revised PLI in July 2019 (The Star 2020). The most common household income bracket was RM1001 - RM3000 with 28.64% of them falling into this category (Figure 8).

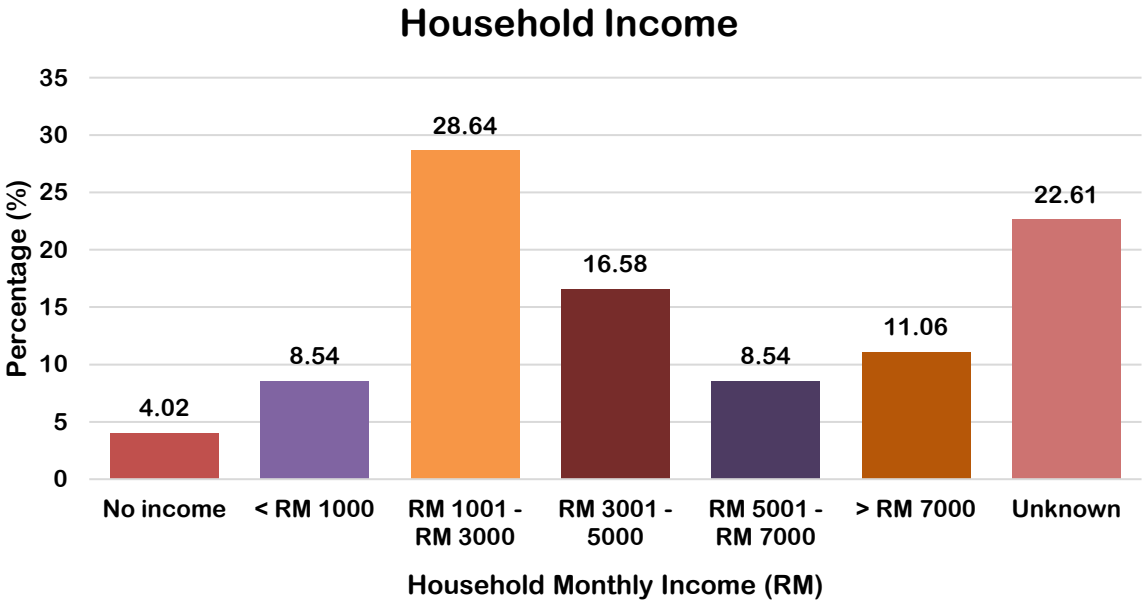


Figure 8: Household income of patients with axial spondyloarthritis (n = 199)

2.4 Medical Insurance

Almost half of the patient cohort did not have medical insurance (49.25%), whilst only 32.66% of patients were medically insured (Figure 9). This might be attributed to the registry being based on data from public hospitals in Malaysia.

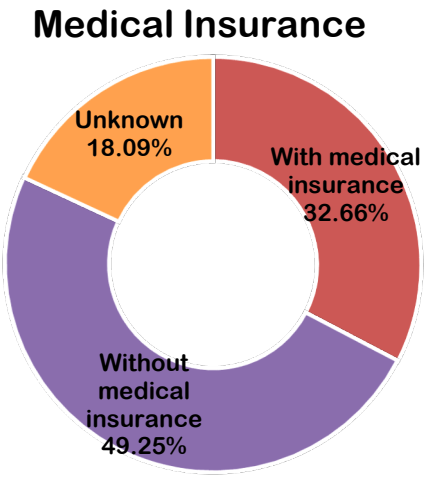


Figure 9: Medical insurance of patients with axial spondyloarthritis (n = 199)

2.5 Smoking Status

More than half of the patients (55.78%) were non-smokers whereas 18.09% and 21.11% were 'current smokers' and 'ex-smokers', respectively (Figure 10).

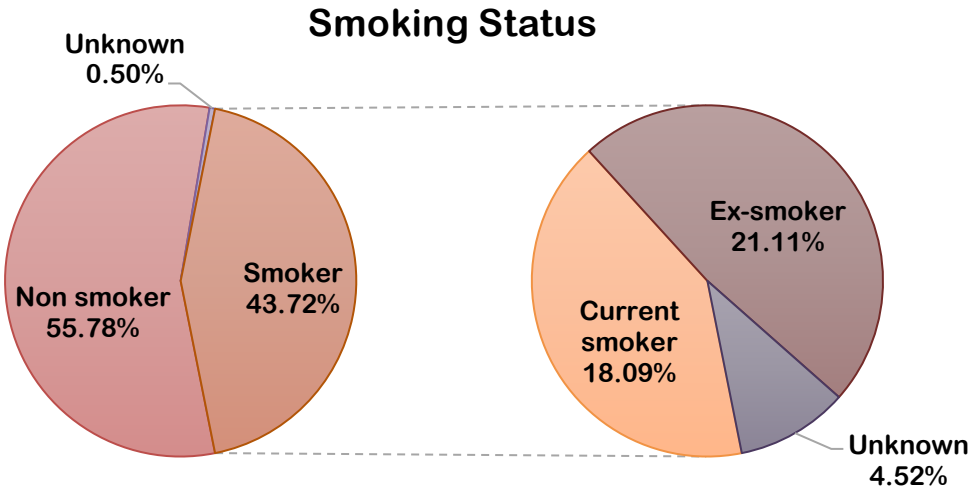


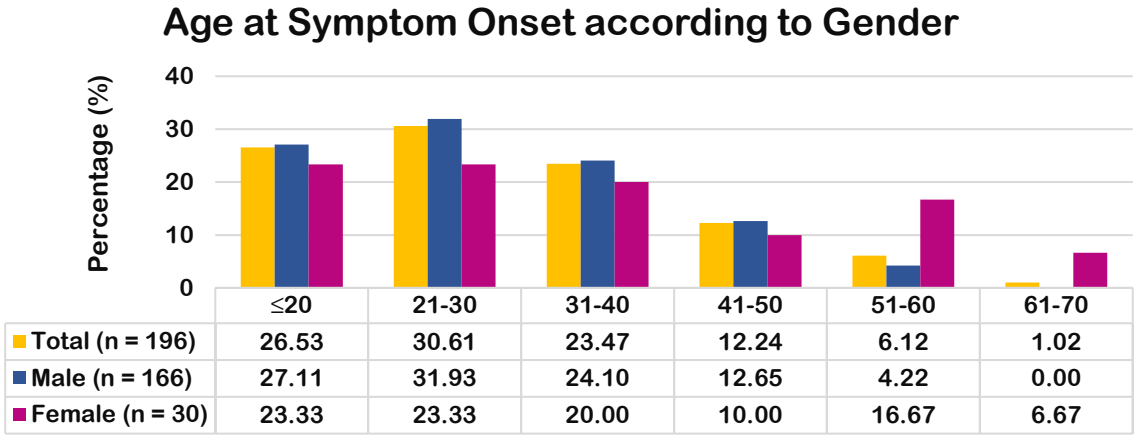
Figure 10: Smoking status of patients with axial spondyloarthritis (n = 199)

CHAPTER 3: DISEASE PATTERN AND MANIFESTATIONS

3.1 Age of Disease Onset and Diagnosis

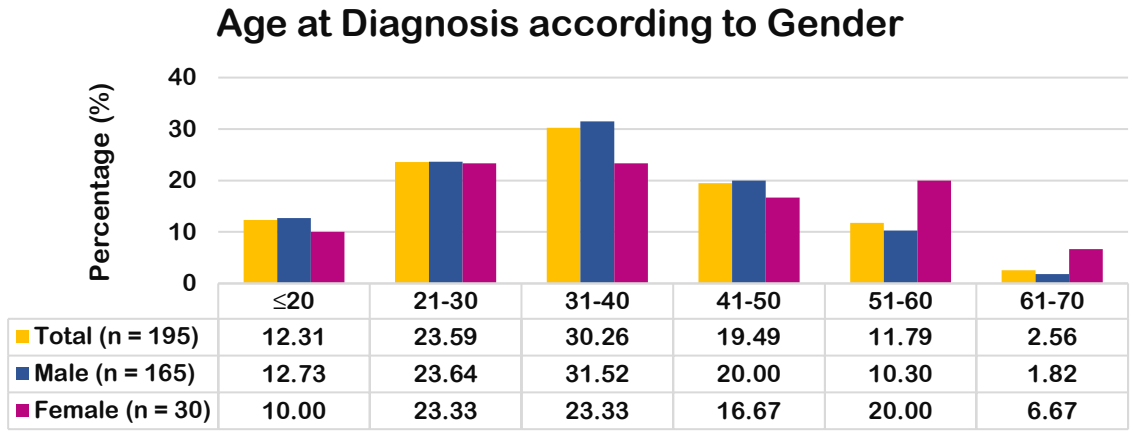
The mean age at symptoms onset for the patient cohort was 29.52 ± 12.41 years old – male: 28.72 ± 11.62 years; female patients: 33.90 ± 15.63 years. More than half of male patients (59.04%) had symptoms onset before or at the age of 30 while 53.33% of females had symptoms onset after 30 years old (Figure 11).

The mean age at diagnosis was 35.51 ± 12.60 years old while male patients were diagnosed slightly earlier than their female counterparts (34.99 ± 12.30 years vs 38.37 ± 14.03 years, respectively). More than half of male (67.89%) and female (56.66%) patients were diagnosed before or at the age of 40 years old (Figure 12).



	≤20	21-30	31-40	41-50	51-60	61-70
Total (n = 196)	26.53	30.61	23.47	12.24	6.12	1.02
Male (n = 166)	27.11	31.93	24.10	12.65	4.22	0.00
Female (n = 30)	23.33	23.33	20.00	10.00	16.67	6.67

Figure 11: Distribution of age at symptom onset according to the gender of patients with axial spondyloarthritis (n = 196)



	≤20	21-30	31-40	41-50	51-60	61-70
Total (n = 195)	12.31	23.59	30.26	19.49	11.79	2.56
Male (n = 165)	12.73	23.64	31.52	20.00	10.30	1.82
Female (n = 30)	10.00	23.33	23.33	16.67	20.00	6.67

Figure 12: Distribution of age at diagnosis according to the gender of patients with axial spondyloarthritis (n = 195)

3.2 Duration of Symptoms Prior to Rheumatology Visit and Diagnosis

The mean duration of disease symptoms prior to the first visit to rheumatology clinic was 8.16 ± 7.93 years – male: 8.53 ± 8.17 years; female patients: 5.79 ± 5.82 years. Approximately one-third (39.06%) of patients had 9 years of symptoms before their first visit to rheumatology clinic (Figure 13). Around two-thirds of female patients (61.53%) and almost half (48.79%) of male patients had symptoms for less than 6 years before their first rheumatology clinic visit (Figure 14).

The mean duration of symptoms prior to the diagnosis of SpA was 5.99 ± 7.07 years for the cohort – male: 6.24 ± 7.29 years; female patients: 4.61 ± 5.59 years. Slightly more than half of the patients (54.69%) were diagnosed after 3 years of symptoms onset and only 24.14% of them were diagnosed within one year (Figure 13). More than half of male patients (56.44%) were diagnosed after 3 years of symptoms onset as compared with 44.83% of females being diagnosed after 3 years of symptoms onset (Figure 15).

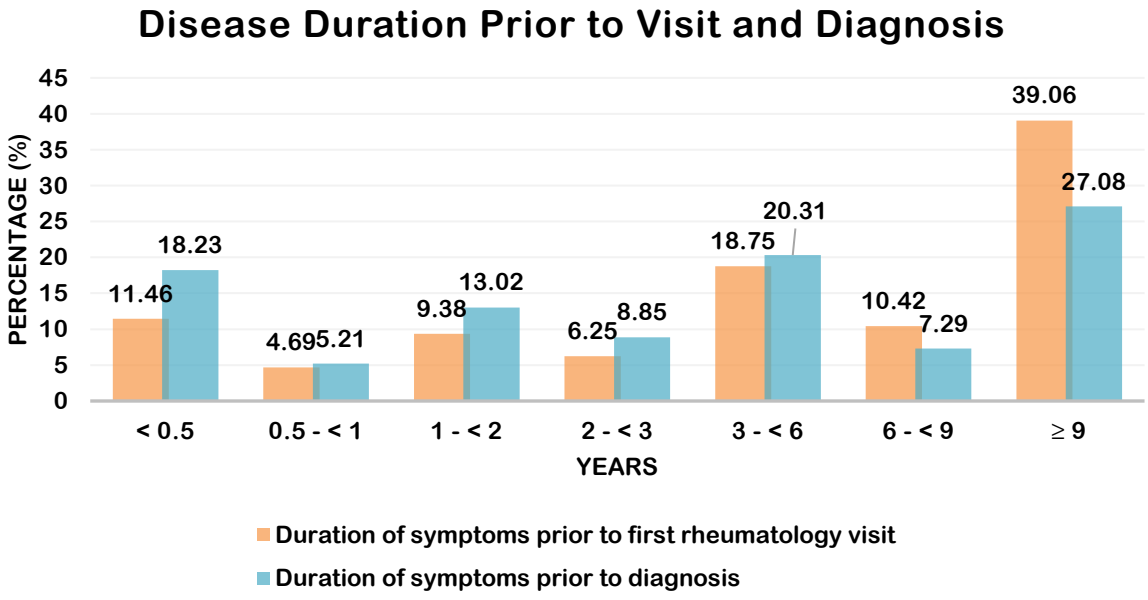
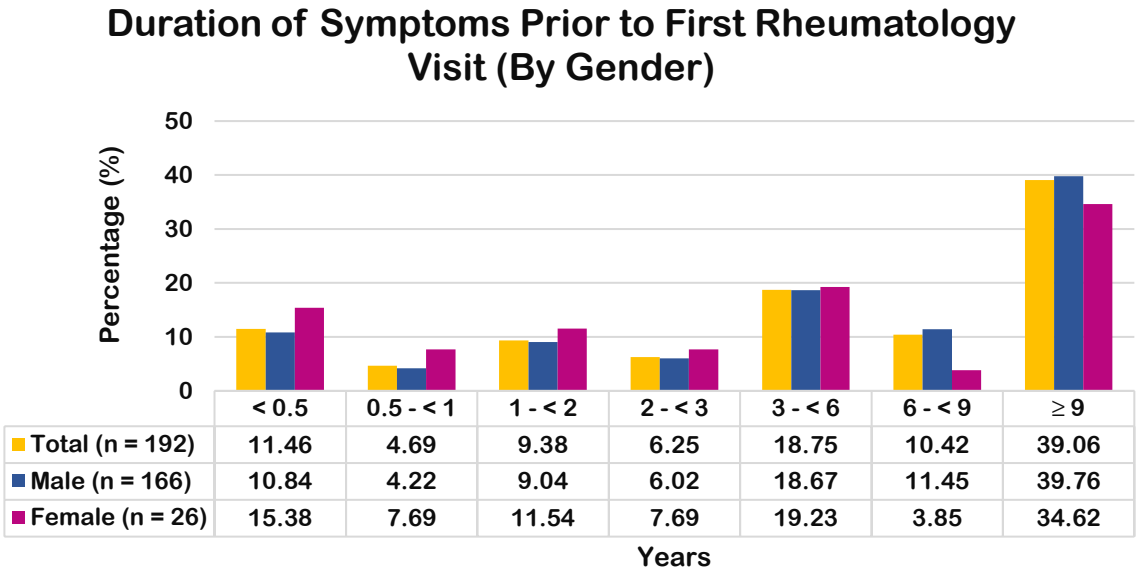
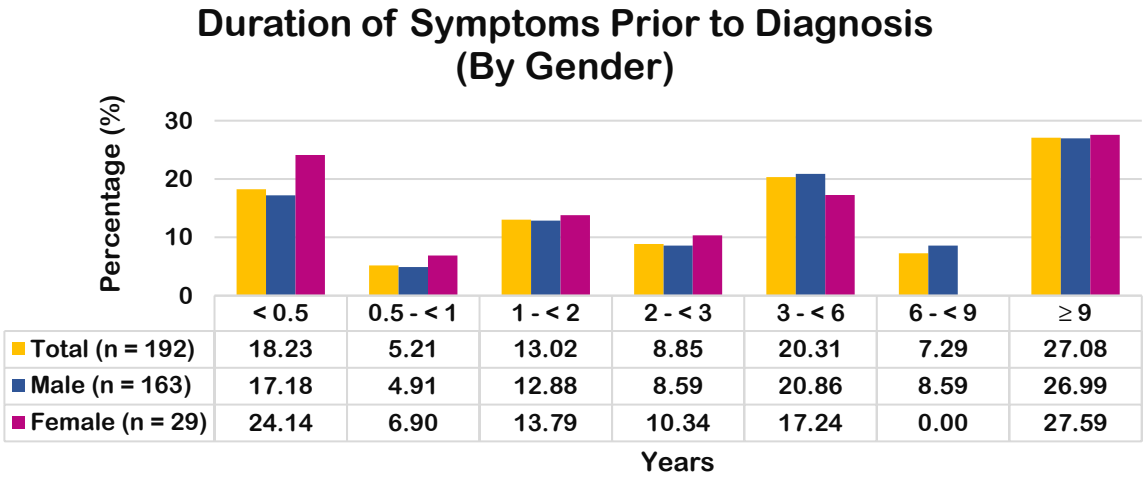


Figure 13: Duration of symptoms prior to rheumatology visit and diagnosis among patients with axial spondyloarthritis (n= 192)



	< 0.5	0.5 - < 1	1 - < 2	2 - < 3	3 - < 6	6 - < 9	≥ 9
Total (n = 192)	11.46	4.69	9.38	6.25	18.75	10.42	39.06
Male (n = 166)	10.84	4.22	9.04	6.02	18.67	11.45	39.76
Female (n = 26)	15.38	7.69	11.54	7.69	19.23	3.85	34.62

Figure 14: Duration of symptoms prior to rheumatology visit among patients with axial spondyloarthritis (n= 192)



	< 0.5	0.5 - < 1	1 - < 2	2 - < 3	3 - < 6	6 - < 9	≥ 9
Total (n = 192)	18.23	5.21	13.02	8.85	20.31	7.29	27.08
Male (n = 163)	17.18	4.91	12.88	8.59	20.86	8.59	26.99
Female (n = 29)	24.14	6.90	13.79	10.34	17.24	0.00	27.59

Figure 15: Duration of symptoms prior to diagnosis among patients with axial spondyloarthritis (n= 192)

3.3 ASAS Criteria at Presentation

A vast majority of the patients (92.15%) presented with sacroiliitis on imaging and at least one other spondyloarthritis (SpA) feature. Among those patients with sacroiliitis, about two-thirds (60.73%) had definitive radiographic sacroiliitis according to the modified New York criteria (indicating ankylosing spondylitis). In this patient cohort, 21.46% matched the ASAS classification criteria as non-radiographic axial spondyloarthritis, with 13.61% found to have active (acute) inflammation on MRI and 7.85% were HLA-B27 positive with at least two other SpA features (Figure 16).

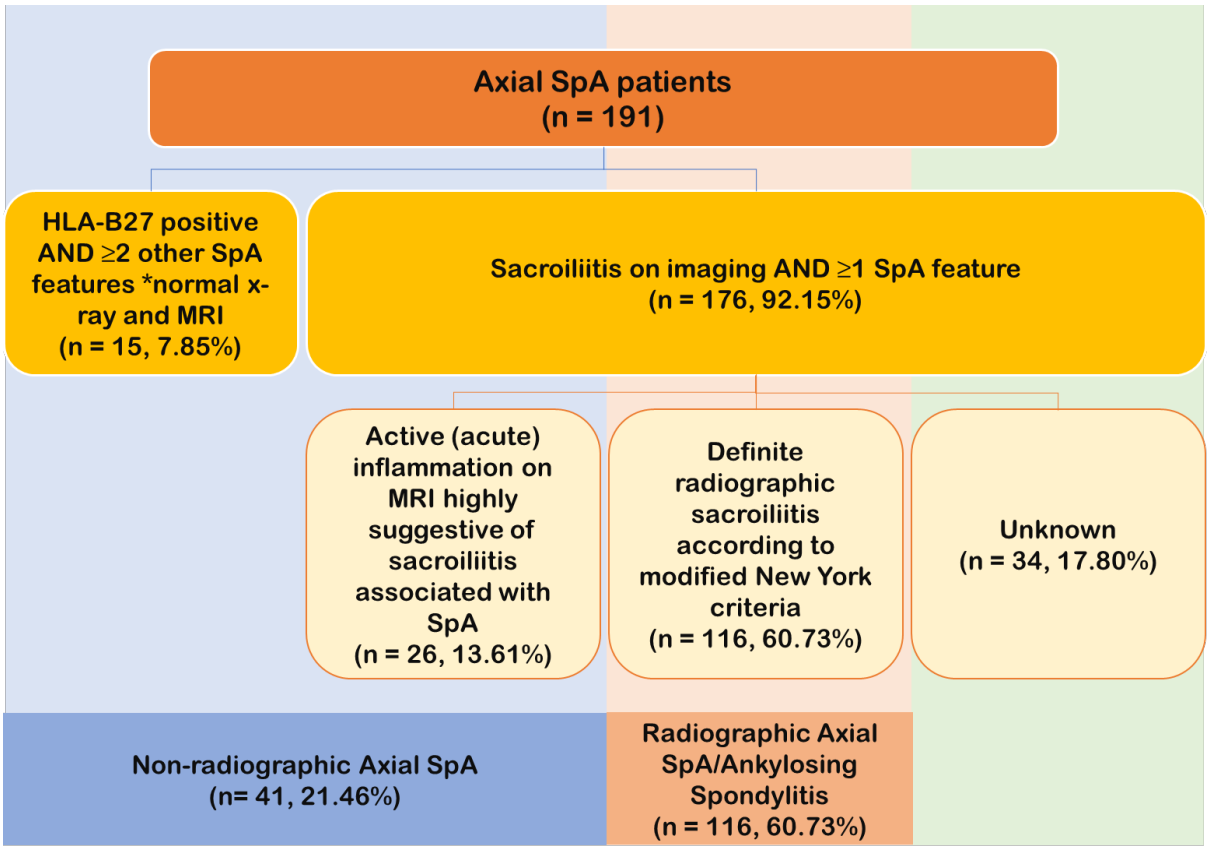


Figure 16: Disease presentation of patients with axial spondyloarthritis according to ASAS criteria and sacroiliitis on imaging (n = 191).

3.4 Spondyloarthritis Features

Inflammatory back pain (87.94%) was the most common spondyloarthritis feature, followed by elevated CRP (43.22%), good response to NSAIDs (38.69%) and arthritis (36.18%) as shown in Figure 17.

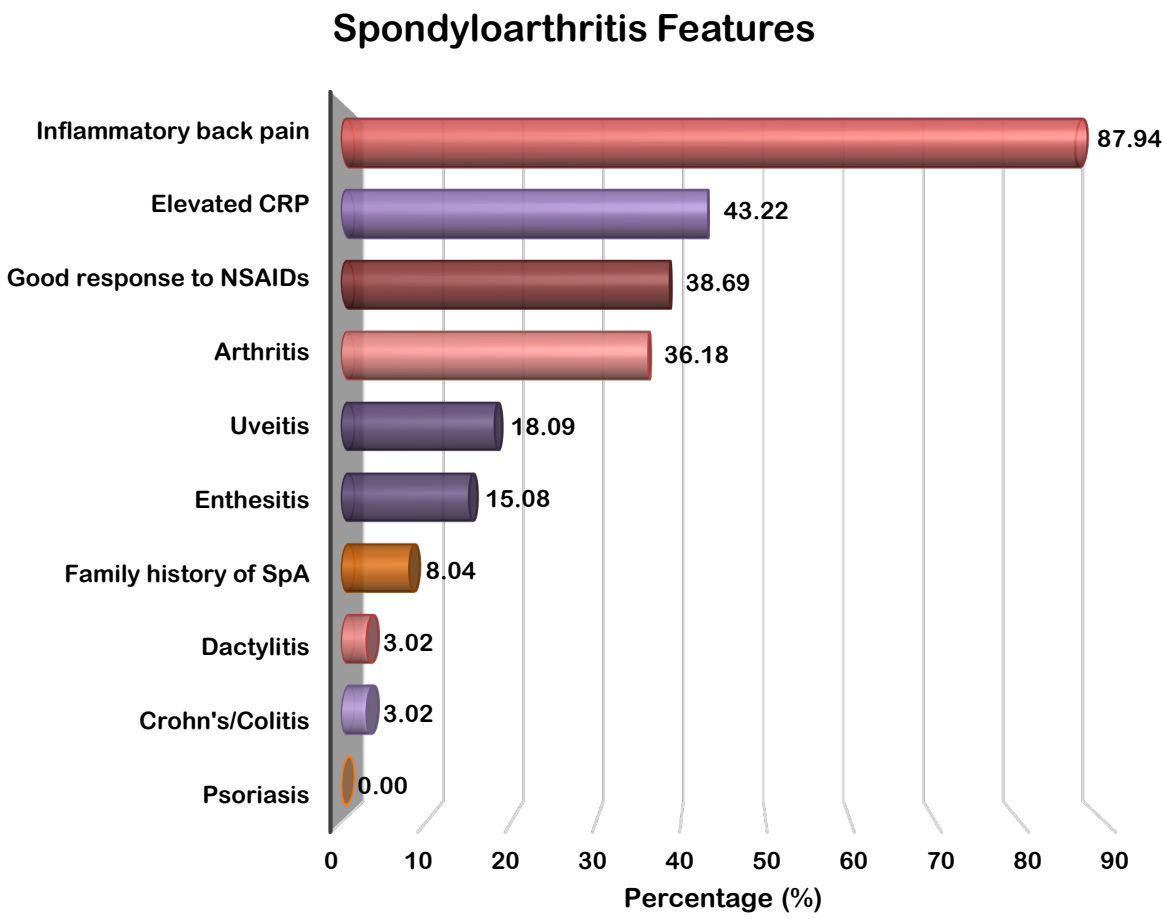


Figure 17: Spondyloarthritis features of patients with axial spondyloarthritis (n = 199)

3.5 Joint Involvement

Approximately two-thirds (62.31%) of the patient cohort had only axial joint affected by the disease while 37.69% had both axial & peripheral joints involvement (Figure 18).

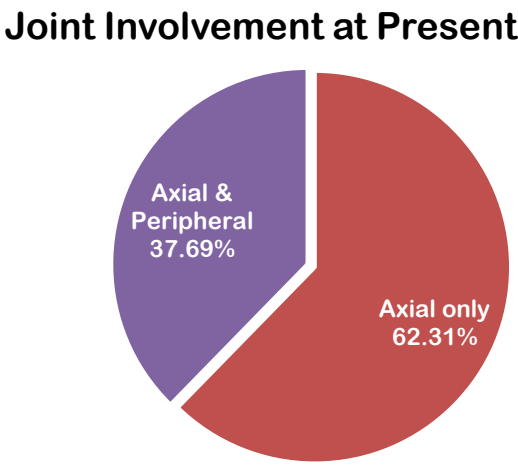


Figure 18: Joint involvement of patients with axial spondyloarthritis (n = 199)

3.6 Extra-articular Manifestations

Majority of the patients (75.38%) did not have extra-articular manifestations. Nevertheless, uveitis was the most common extra-articular manifestation affecting 20.10% of the cohort. (Figure 19).

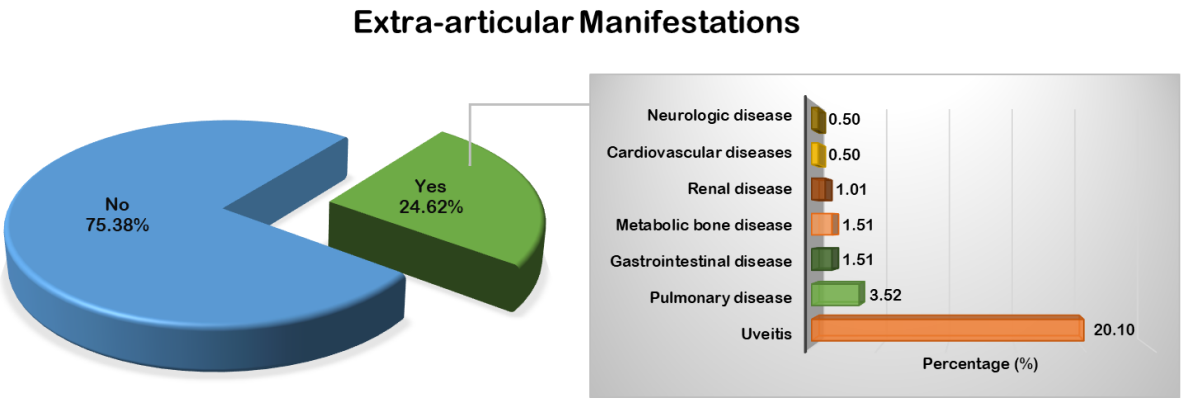


Figure 19: Extra-articular manifestations of patients with axial spondyloarthritis (n = 199)

3.7 HLA-B27 Status

A vast majority (81.97%) of patients with axial spondyloarthritis were found to be HLA-B27 positive (Figure 20).

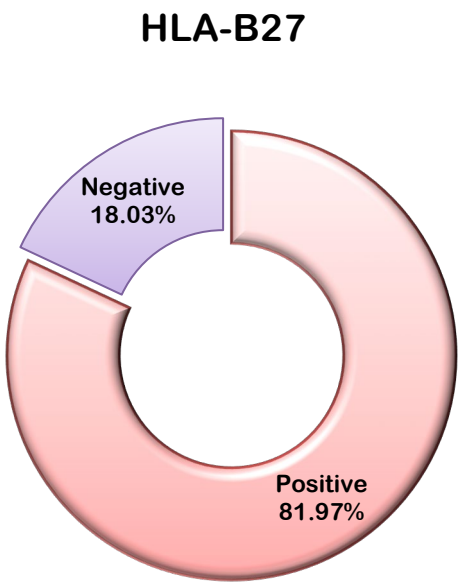


Figure 20: HLA-B27 status of patients with axial spondyloarthritis (n = 61)

CHAPTER 4: COMORBIDITIES

4.1 Medical Comorbidities

On average, the patient cohort had 1.66 ± 1.49 medical comorbidities. The most common comorbid conditions were obesity (57.79%), hypertension (36.18%), dyslipidemia (27.14%) and diabetes mellitus (13.07%)(Figure 21). Cardiometabolic comorbidities appeared common among this cohort of patients (Figure 21).

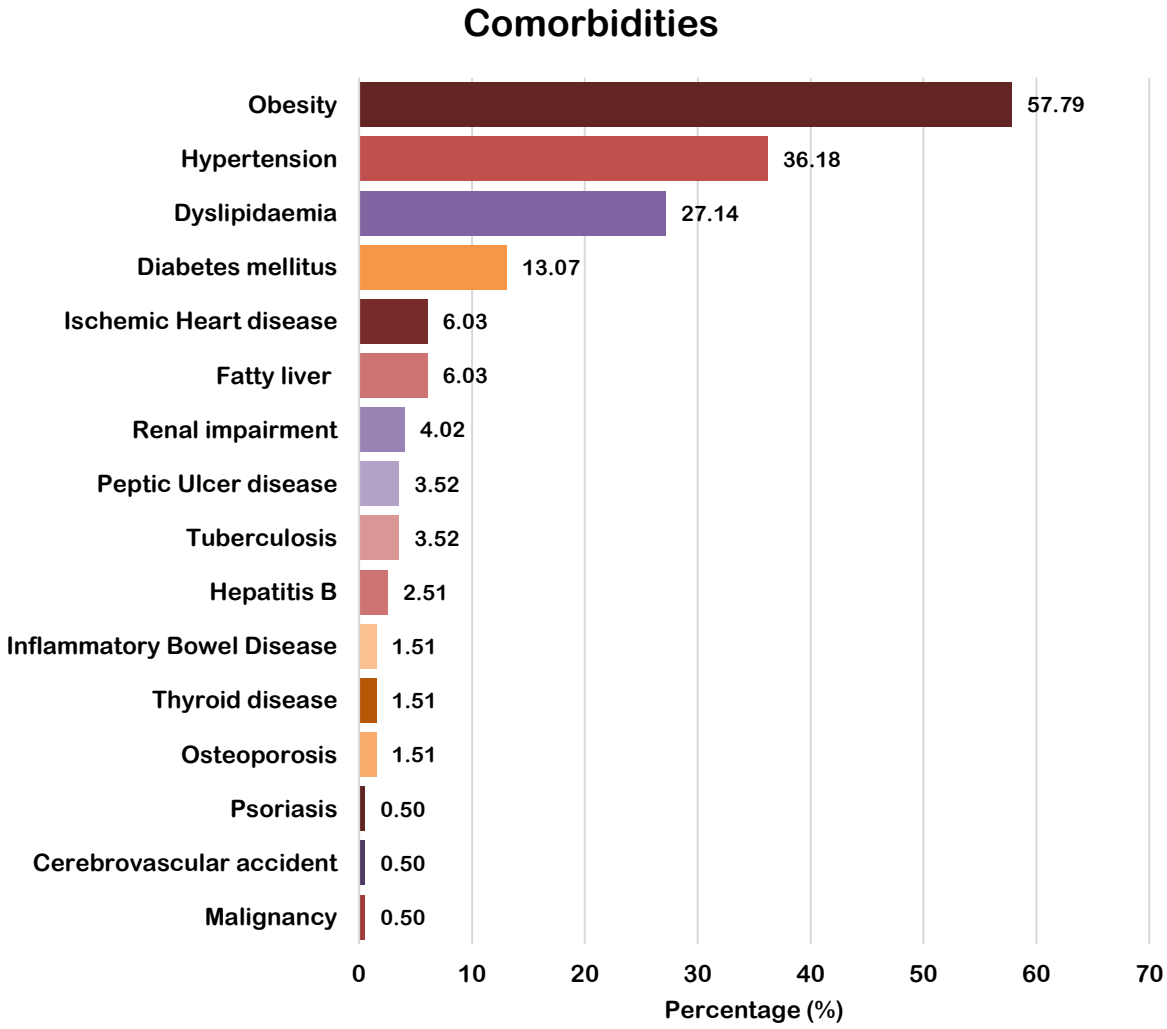


Figure 21: Medical comorbidities of patients with axial spondyloarthritis (n = 199)

Almost three-quarters of the patients (73.87%) had at least one medical comorbidity and over half (46.73%) have two or more comorbid conditions (Figure 22).

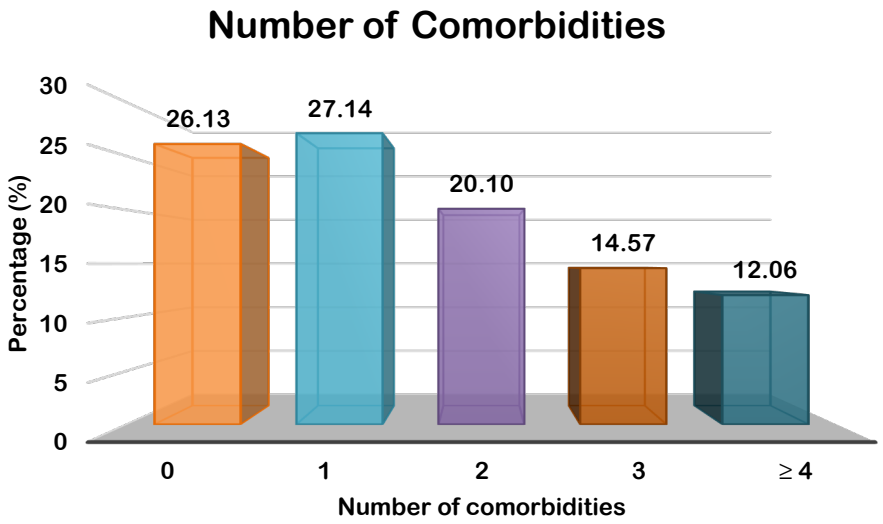


Figure 22: Total number of medical comorbidities of patients with axial spondyloarthritis (n = 199)

5.1 Disease Activity Score

The mean BASDAI, ASDAS CRP and ASDAS ESR scores of the patient cohort were 2.66 ± 1.89, 2.50 ± 0.98 and 2.84 ± 1.14, respectively. A high percentage of the patients (76.84%) had inactive disease based on BASDAI score, whereas only a handful achieved inactive disease state based on ASDAS CRP (9.89%) and ASDAS ESR (9.80%) assessments (Figure 23). With ASDAS being the recommended tool by international guidelines for disease activity assessment in axial SpA, all data pertaining to disease activities would be reported based on ASDAS CRP score henceforth (Smolen et al., 2018; van der Heijde et al., 2016).

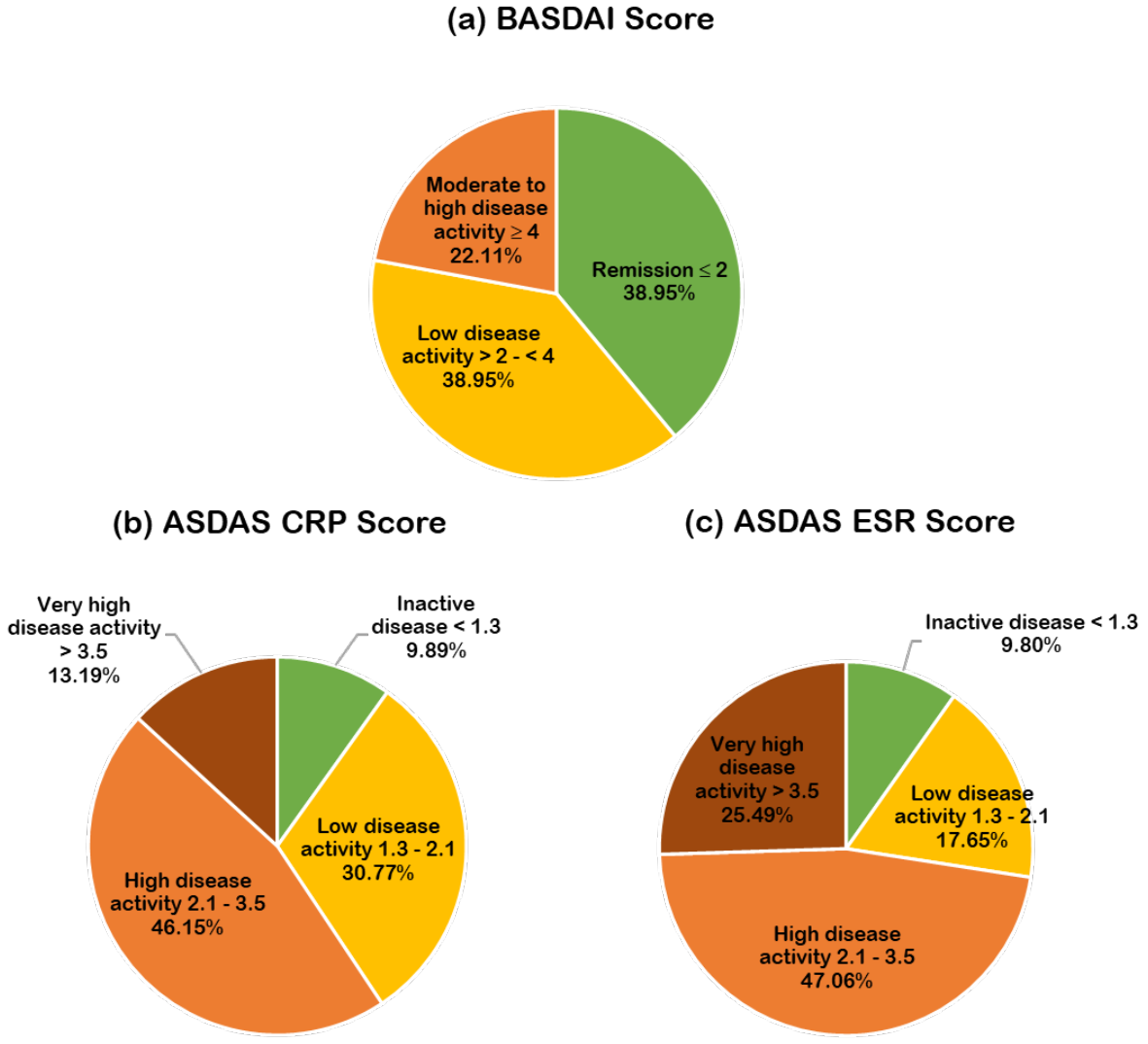


Figure 23: Disease activity score of patients with axial spondyloarthritis. (a) BASDAI (n = 95); (b) ASDAS CRP Score (n = 91); (c) ASDAS ESR Score (n = 51)

Mean MASES Enthesitis score was 0.48 ± 1.44 with 85.71% of the patients having a score of less than 2 (Figure 24).

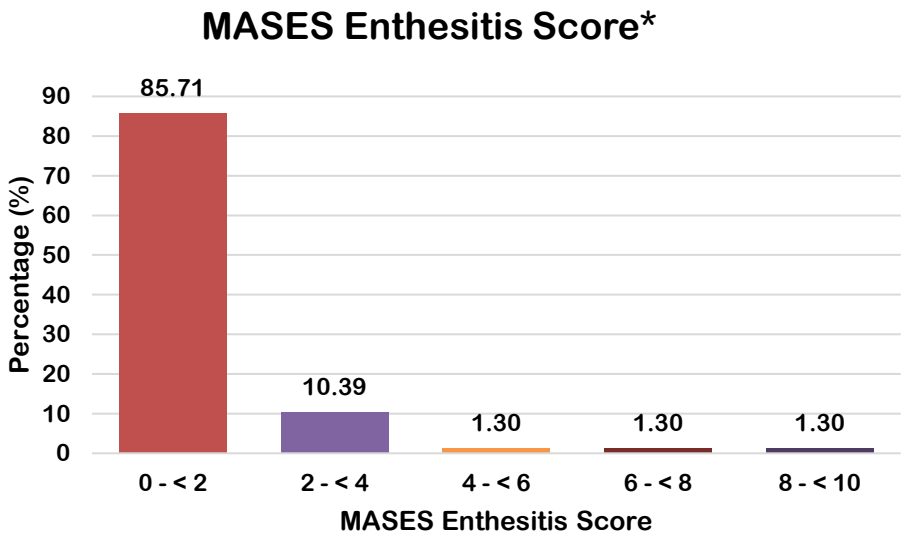


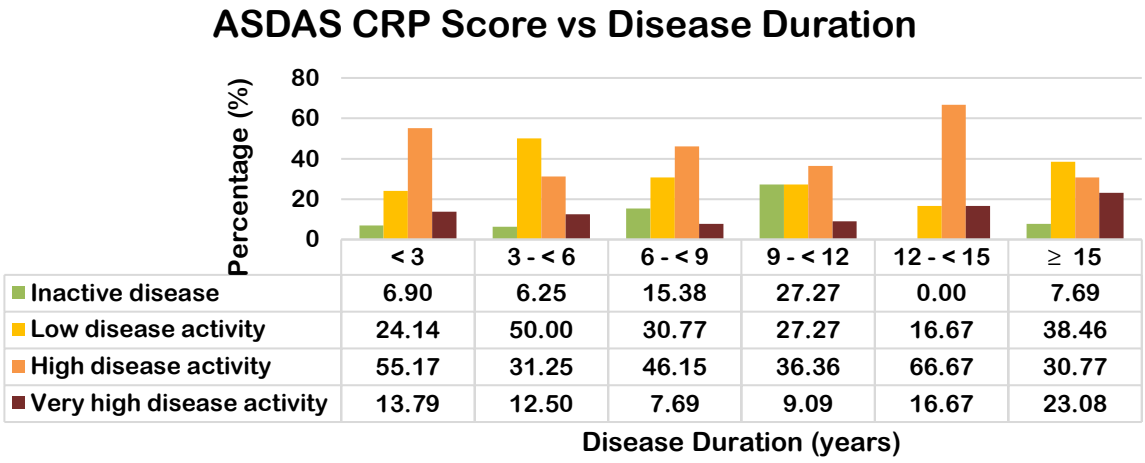
Figure 24: MASES Enthesitis score* of patients with axial spondyloarthritis (n = 77)

*MASES Enthesitis score is an enthesitis index is a grading of tenderness (0/1) at 13 sites (bilateral 1st and 7th costochondral joints, anterior and posterior superior iliac spines, the iliac crests, 5th lumbar spinous process and proximal insertion of Achilles tendon

5.2 Relationship of Disease Activity Score and Disease Duration

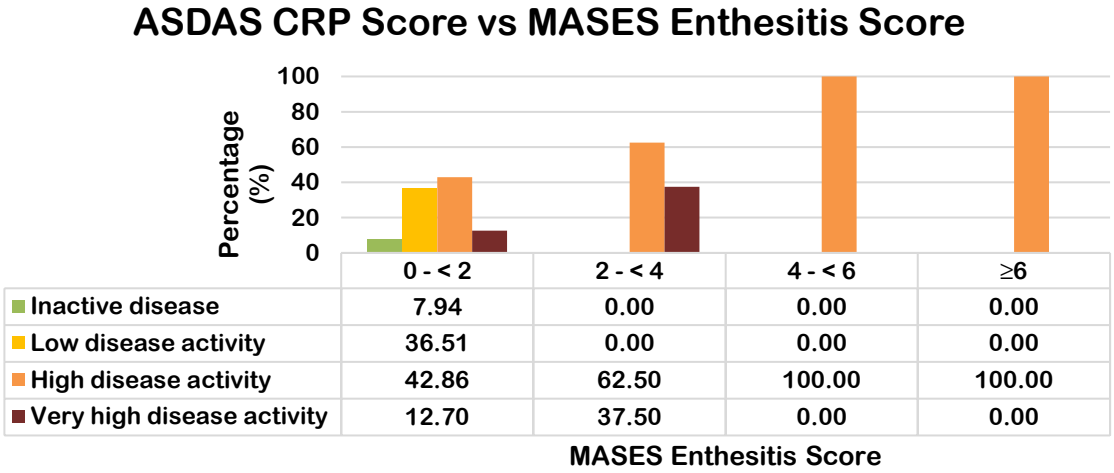
The relationship of disease activity score between ASDAS CRP and disease duration at notification is depicted in Figure 25. There was no clear disease trend observed.

Patients with MASES score of 2 and above were in high and very high disease activity (Figure 26).



	< 3	3 - < 6	6 - < 9	9 - < 12	12 - < 15	≥ 15
Inactive disease	6.90	6.25	15.38	27.27	0.00	7.69
Low disease activity	24.14	50.00	30.77	27.27	16.67	38.46
High disease activity	55.17	31.25	46.15	36.36	66.67	30.77
Very high disease activity	13.79	12.50	7.69	9.09	16.67	23.08

Figure 25: Relationship of ASDAS CRP disease activity score and disease duration (n = 88)



	0 - < 2	2 - < 4	4 - < 6	≥6
Inactive disease	7.94	0.00	0.00	0.00
Low disease activity	36.51	0.00	0.00	0.00
High disease activity	42.86	62.50	100.00	100.00
Very high disease activity	12.70	37.50	0.00	0.00

Figure 26: Relationship of ASDAS CRP disease score and MASES Enthesitis score (n = 73)

5.3 Functional Assessments

The mean BASMI score for this patient cohort was 4.68 ± 2.27. More than half of them (60%) had BASMI score within the range of 4-8 (Figure 27(a)).

Mean BASFI score was 3.81 ± 2.83 with more than half (60%) having BASFI score of less than 4 (Figure 27(b)).

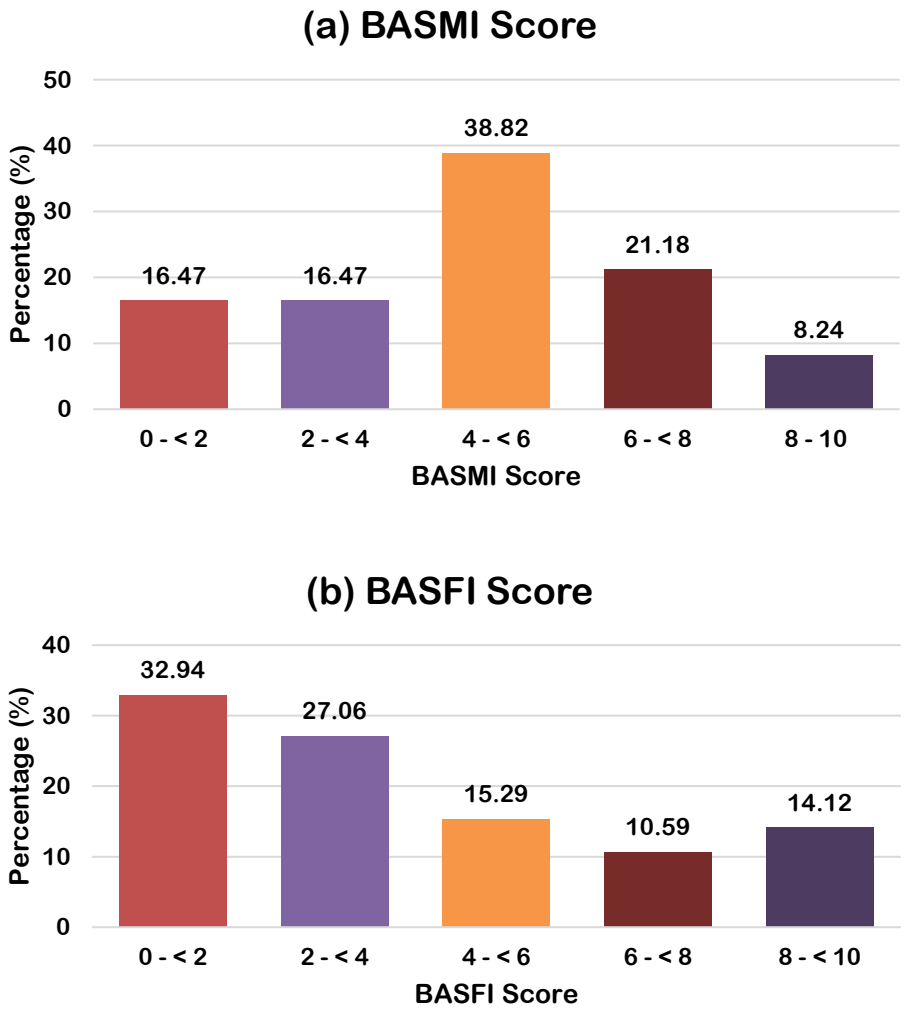
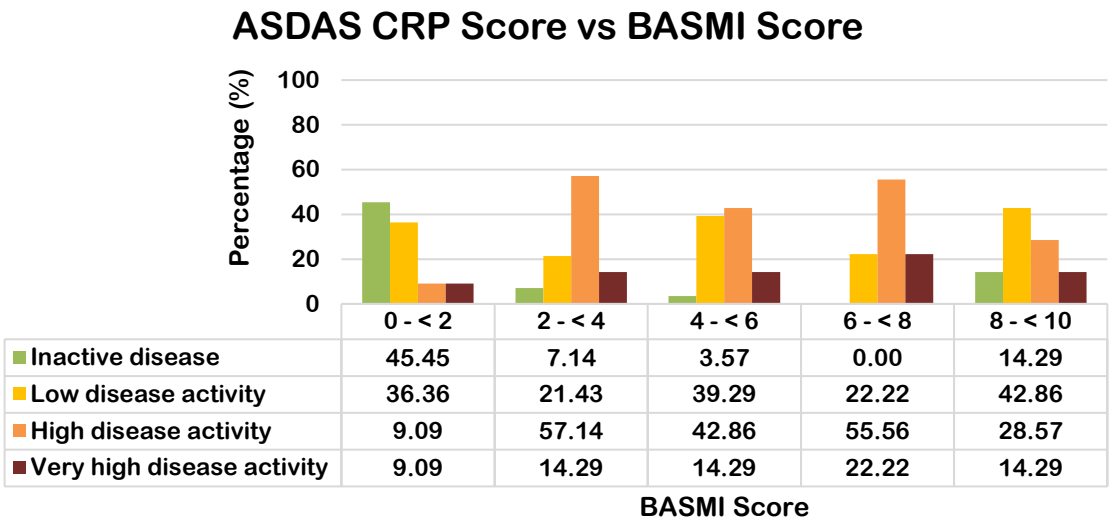
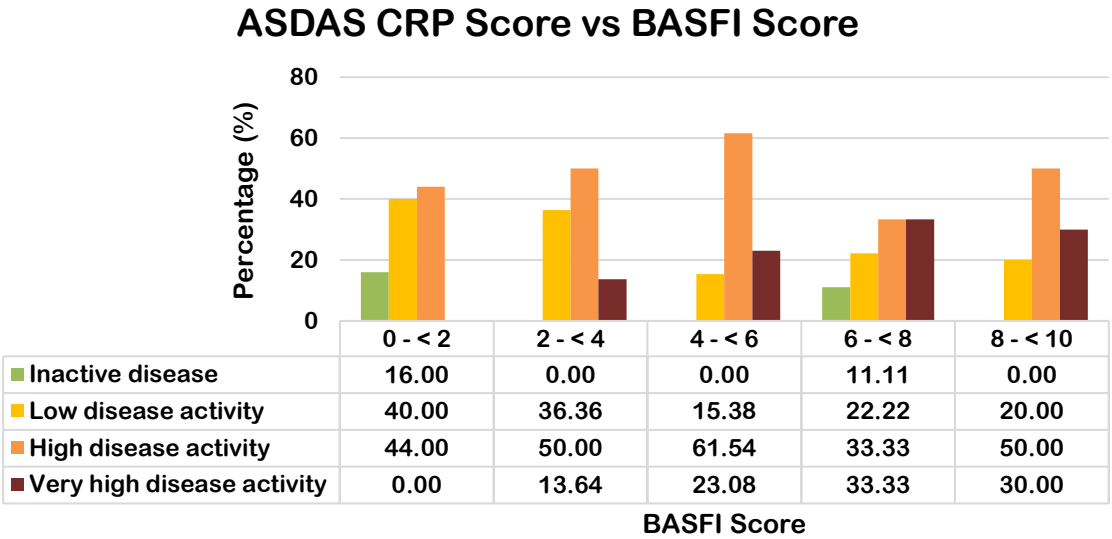


Figure 27: Functional assessments of patients with axial spondyloarthritis. (a) BASMI score (n = 84); (b) BASFI score (n = 85)

The relationship between ASDAS CRP disease activity assessment and functional assessments (BASMI and BASFI scores) is depicted in Figure 28. In general, those who had inactive or low disease activity had lower BASMI and BASFI scores.



	0 - < 2	2 - < 4	4 - < 6	6 - < 8	8 - < 10
Inactive disease	45.45	7.14	3.57	0.00	14.29
Low disease activity	36.36	21.43	39.29	22.22	42.86
High disease activity	9.09	57.14	42.86	55.56	28.57
Very high disease activity	9.09	14.29	14.29	22.22	14.29



	0 - < 2	2 - < 4	4 - < 6	6 - < 8	8 - < 10
Inactive disease	16.00	0.00	0.00	11.11	0.00
Low disease activity	40.00	36.36	15.38	22.22	20.00
High disease activity	44.00	50.00	61.54	33.33	50.00
Very high disease activity	0.00	13.64	23.08	33.33	30.00

Figure 28: Relationship of ASDAS CRP disease score and functional assessments. (a) BASMI (n = 78); (b) BASFI (n = 79)

5.4 Imaging

More than two-thirds of the patients (69.90%) had grade 3 or 4 sacroiliitis (Figure 29 (a)). Within the cohort, 38.75% and 55.42% had syndesmophytes in their cervical and lumbo-sacral regions, respectively (Figure 30 (a),(c)). MRI was done in over half (52.56%) of the patients whilst all patients with grade 0-1 sacroiliitis had been assessed via MRI (Figure 29 (b – c)).

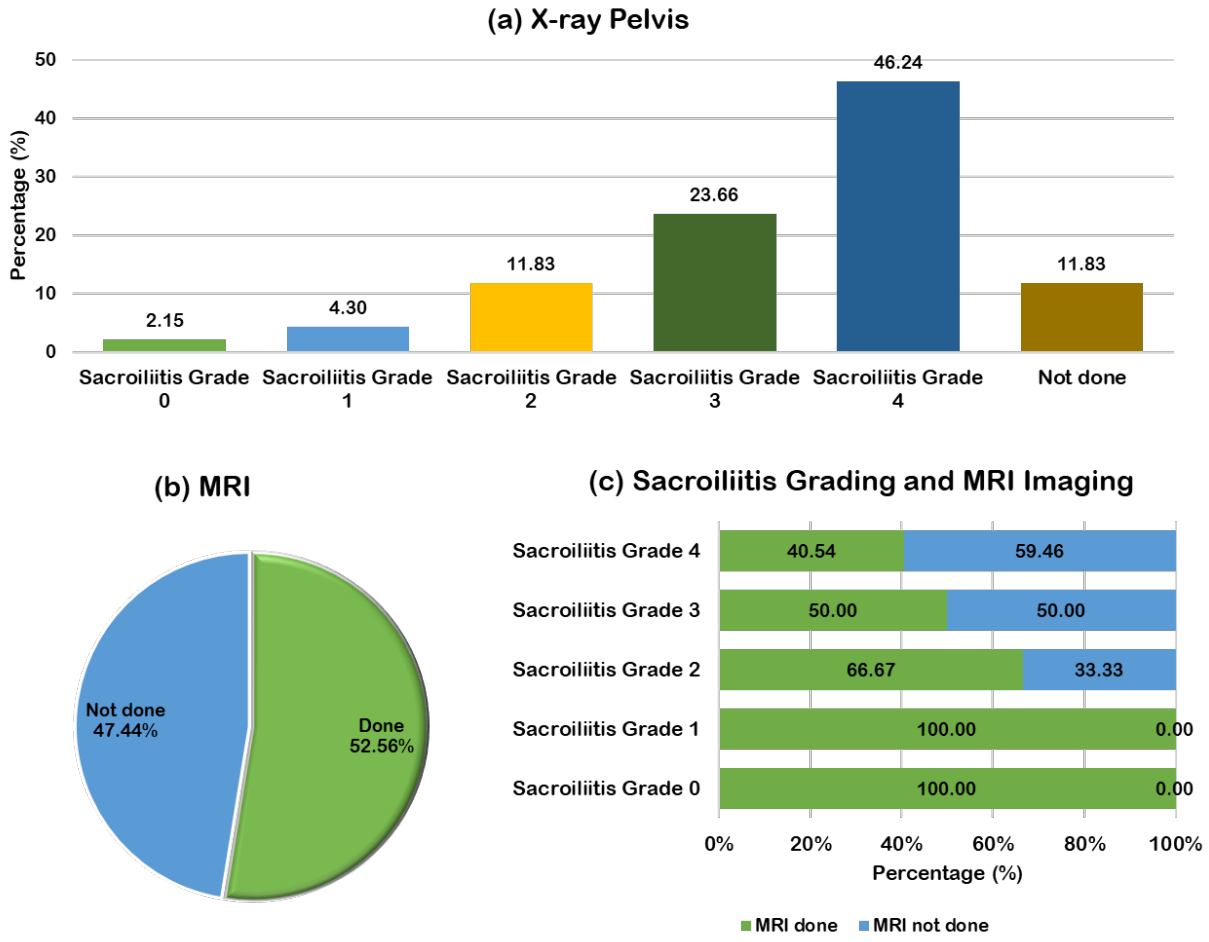


Figure 29: Imaging investigations. (a) Pelvic X-ray (n = 93); (b) MRI (n = 78); (c) Use of MRI in patients with various sacroiliitis grading (n = 71)

Among those with syndesmophytes in their cervical region, 51.72% appeared to have high or very high disease activity with a mean ASDAS CRP score of 2.49 ± 0.99 (Figure 30 (b)). Likewise, for those with syndesmophytes detected in their lumbo-sacral region, 67.44% were in 'high disease activity' to 'very high disease activity' states as shown in Figure 30 (d) (mean ASDAS CRP score: 2.56 ± 0.94). It is also interesting to note that, higher overall disease activity was observed among patients with syndesmophytes found in the lumbo-sacral region when compared to those with syndesmophytes detected in the cervical region. This may call for further investigation as it may serve as a useful predictor of higher disease severity among patients with lumbo-sacral syndesmophytes, potentially necessitating more aggressive intervention.

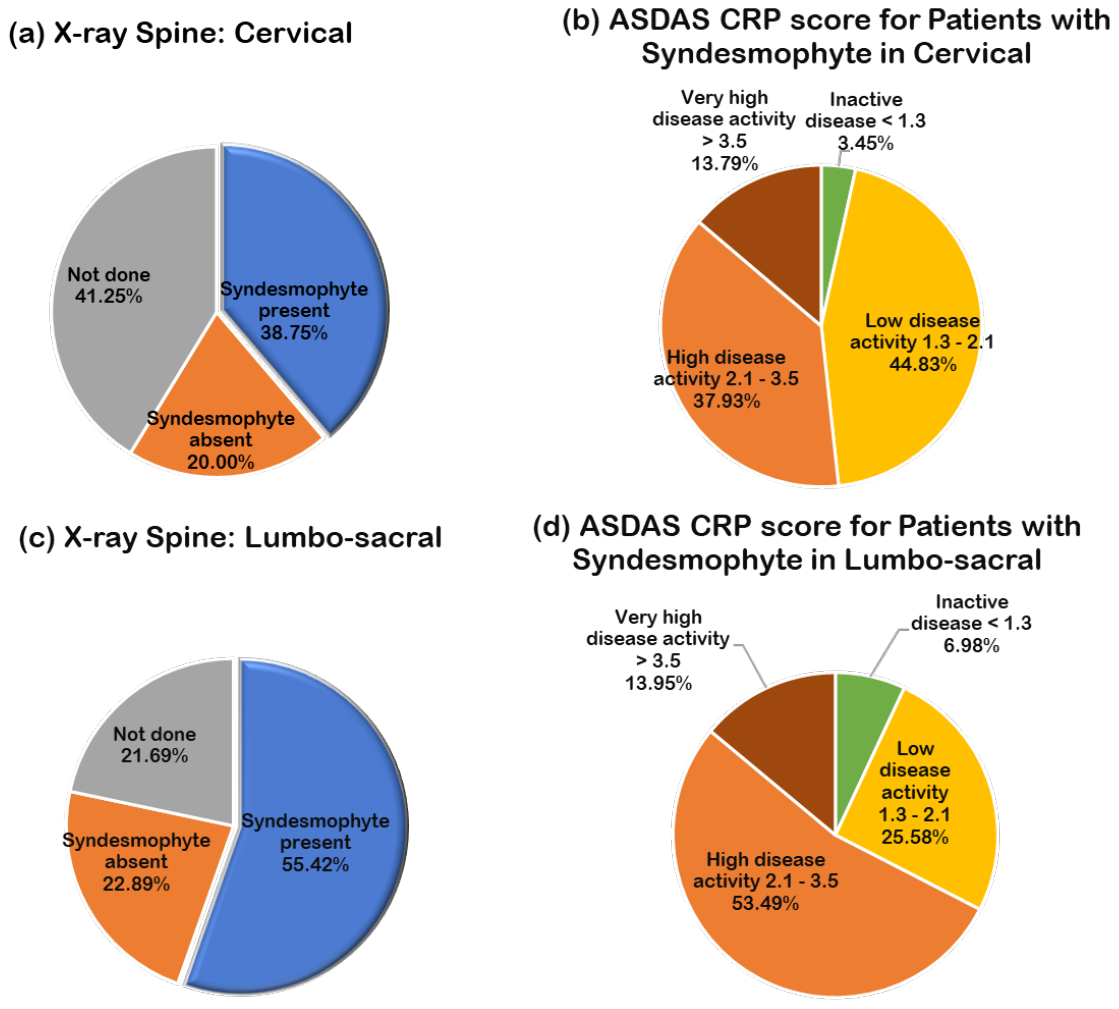


Figure 30: Syndesmophyte on spine X-ray and ASDAS CRP disease activity score. (a) X-ray spine: cervical (n = 80); (b) ASDAS CRP score for patients with syndesmophyte in cervical region (n = 29); (c) X-ray spine: lumbo-sacral (n = 83); (d) ASDAS CRP score for patients with syndesmophyte in lumbo-sacral region (n = 44)

CHAPTER 6: TREATMENT

6.1 Time to Initiate NSAIDs after Diagnosis

The mean time to NSAIDs initiation after disease diagnosis was 11.41 ± 39.38 months. More than half of the patients (57.78%) were started on NSAIDs treatment in less than a month. Meanwhile, NSAIDs treatment was started in 26.11% of patients for other clinical conditions prior to Axial SpA diagnosis (Figure 31). This may include medications started by primary care physicians and orthopedic surgeons prior to referral to rheumatology clinics.

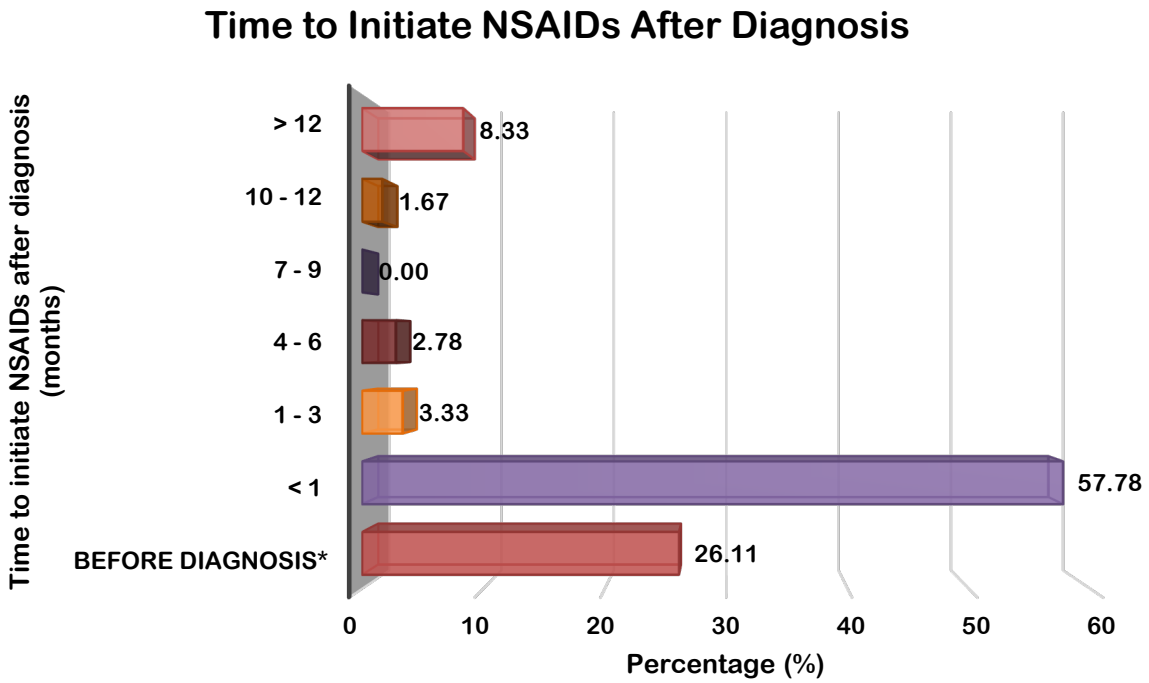


Figure 31: Time to initiate NSAIDs after diagnosis among patients with axial spondyloarthritis (n = 180). *NSAIDs were started before diagnosis for other indications.

6.2 Time to Initiate DMARDs after Diagnosis

The mean time to DMARDs initiation after disease diagnosis was 24.04 ± 68.34 months. Many patients (39.81%) were started on DMARDs treatment in less than a month. Meanwhile, DMARDs treatment was started in 11.11% of patients for other clinical conditions (e.g. peripheral SpA) prior to axial SpA diagnosis (Figure 32).

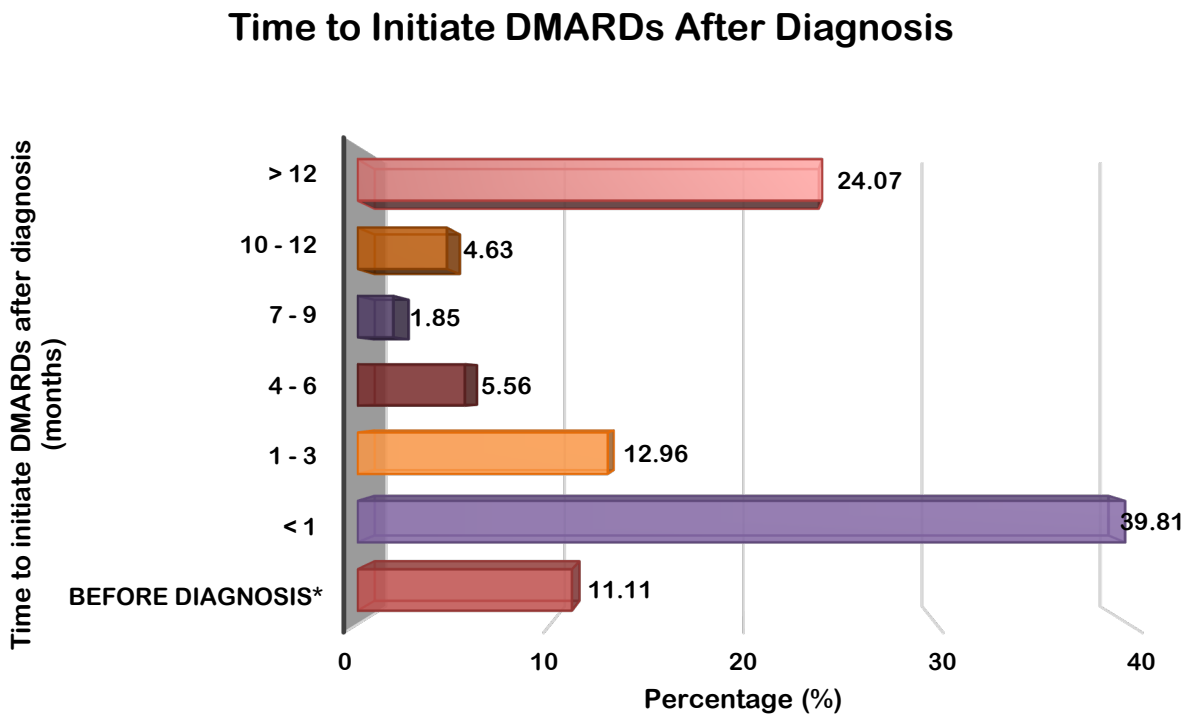


Figure 32: Time to initiate DMARDs after diagnosis among patients with axial spondyloarthritis (n = 108). *DMARDs were started before diagnosis for other indications.

6.3 The Use of NSAIDs and Incidence of Adverse Reactions

The most common NSAIDs prescribed were COX-2 inhibitor (58.79%) and 1st generation NSAIDs (26.13%)(Figure 33). Only 8.65% of patients experienced NSAIDs adverse reactions (Figure 34).

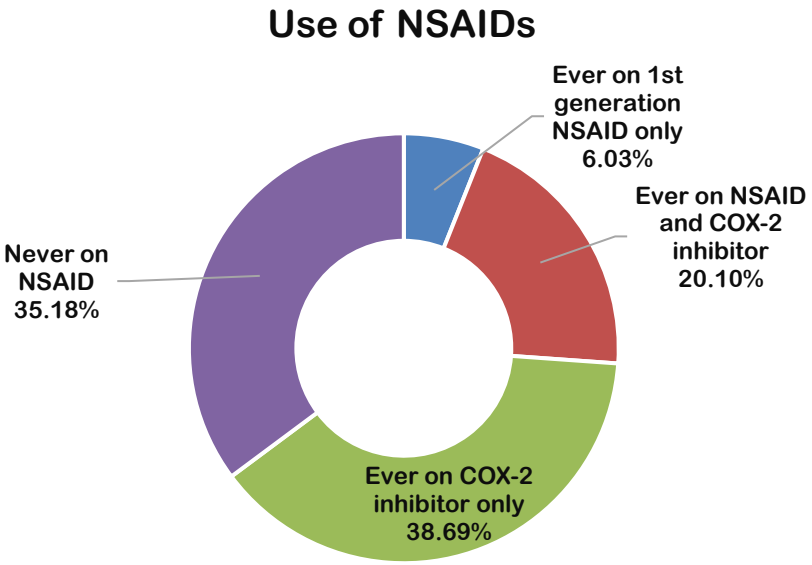


Figure 33: The use of NSAIDs among patients with axial spondyloarthritis (n = 199)

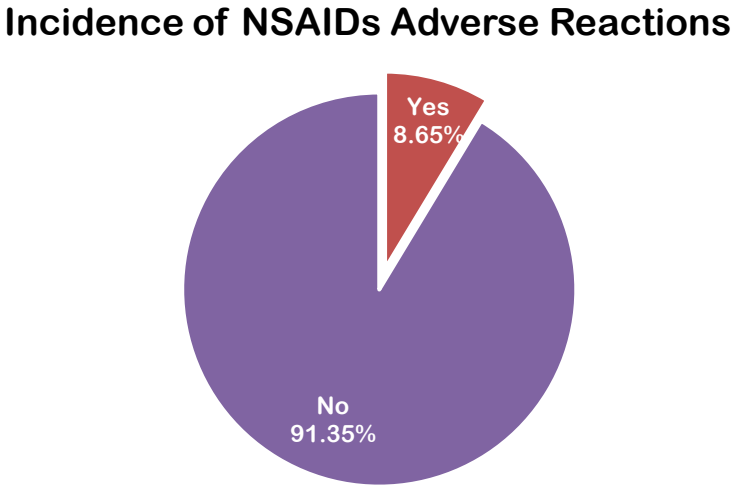


Figure 34: The incidence of NSAIDs adverse reactions among patients with the use of NSAIDs (n = 104)

6.4 Type of Therapies

The most prescribed conventional DMARDs based on past and current treatment were suphasalazine (60%), methotrexate (30.59%), and leflunomide (7.06%). Meanwhile, the most commonly used biologics were adalimumab (32.94%), secukinumab (20%) and golimumab (17.65%). For current biologic treatment, secukinumab (16.47%) was the most commonly prescribed, followed by adalimumab (15.29%) and golimumab (12.94%). Only 8.24% of axial SpA patients were ever on prednisolone and the dose was generally less than 7.5 mg (Figure 35).

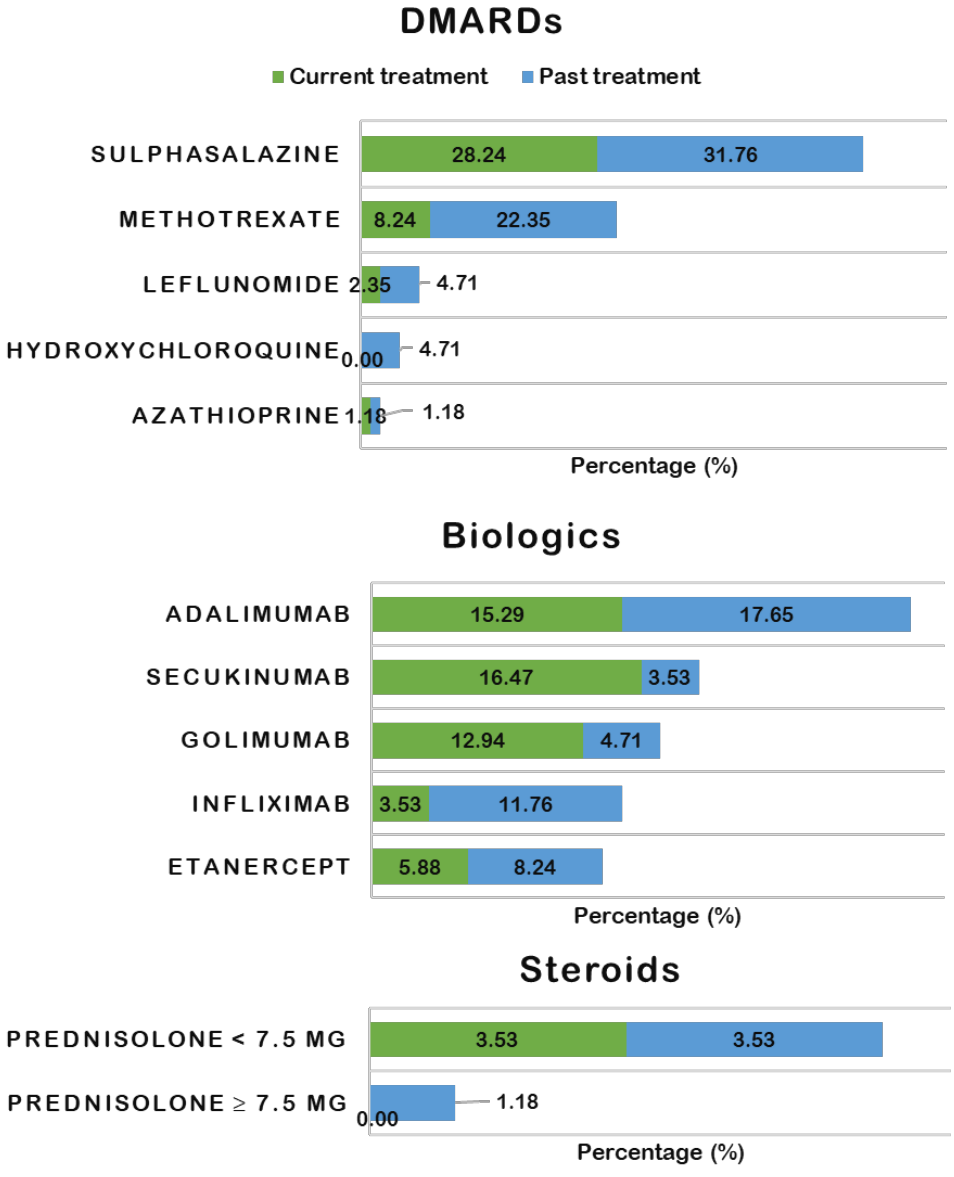


Figure 35: Type of therapies for patients with axial spondyloarthritis (n = 85)

6.5 Types of Current Therapies

Most of the patients were on either single biologic (54.41%) or single conventional DMARDs (26.47%). Biologic accounted for 67.65% of the total prescribed therapies either as monotherapy (54.41%) or in combination with DMARDs (13.24%) (Figure 36).

The overall biologic usage noted here is highly likely to be over-represented. The current treatment section was only completed in 68 out of 199 notifications. In addition, patients who would require or currently on biologics are highly encouraged to be notified and complete the treatment section, as part of the biologics fund planning and future projections.

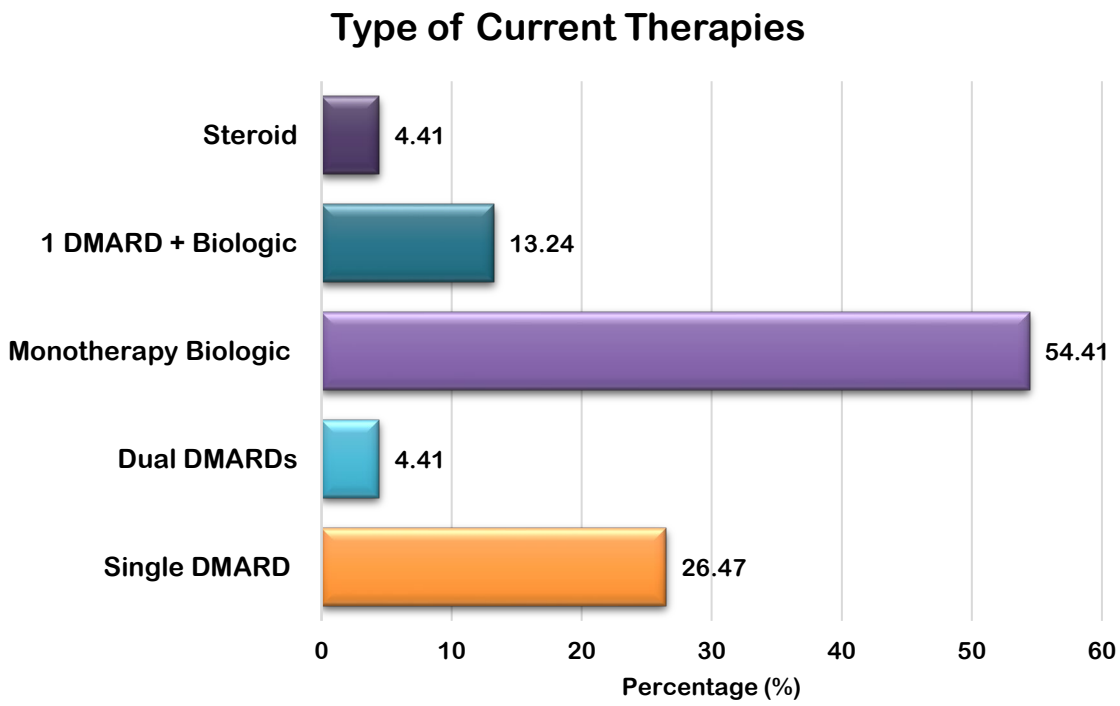


Figure 36: Type of current therapies for patients with axial spondyloarthritis (n = 68)

6.6 Biologic Usage Pattern

The mean duration of biologic usage for this patient cohort was 2.87 ± 2.62 years whereas the mean duration of biologic use for those who had stopped biologic therapy was 2.00 ± 1.39 years. For those who were still on biologic therapy at the time of notification, the average duration of use was 3.61 ± 3.16 years (Figure 37).

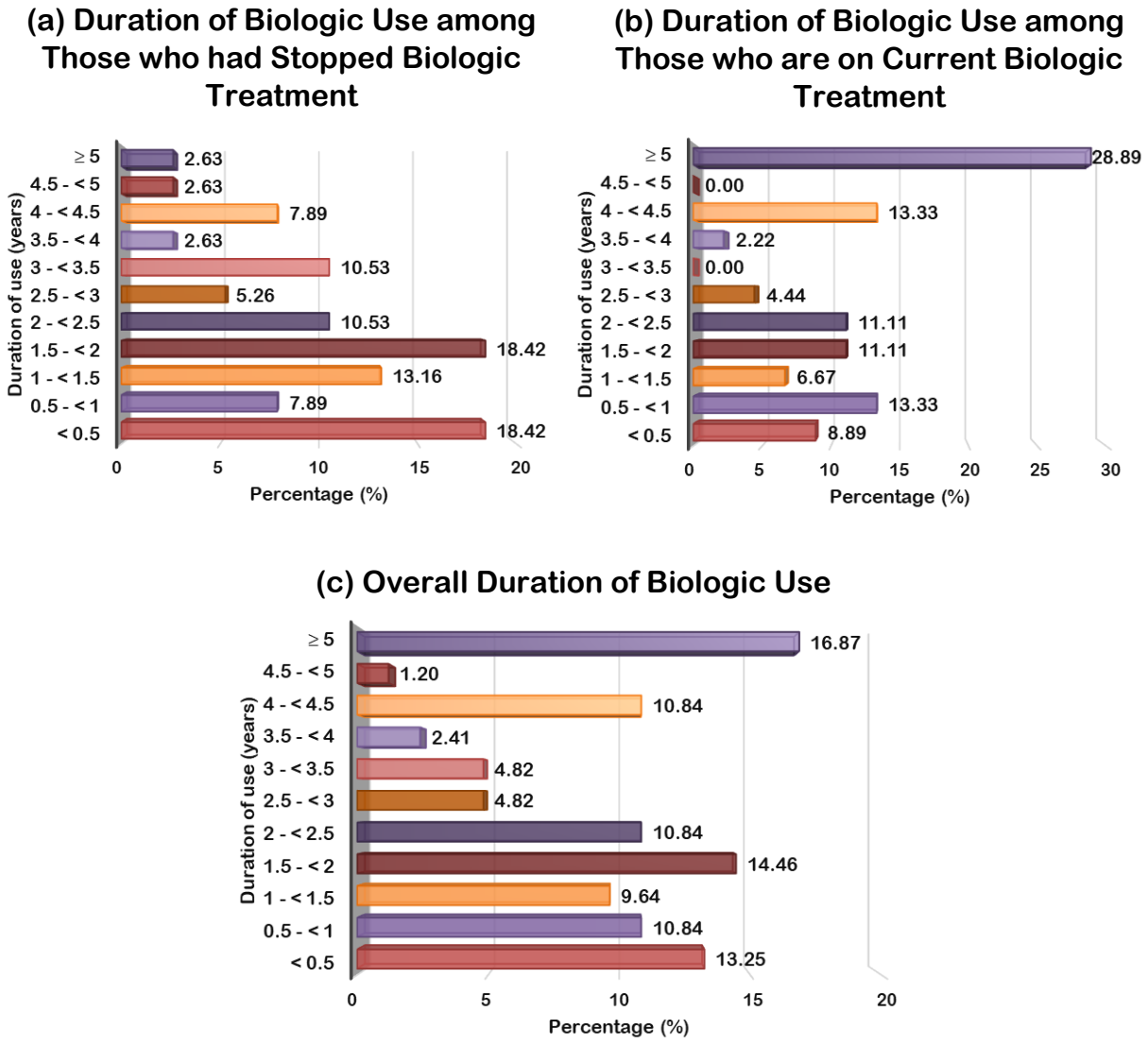


Figure 37: The duration of Biologic use among those who (a) had stopped biologic treatment (n = 38), (b) were currently on biologic treatment (n = 45) and (c) overall use (n = 83)

6.7 Reasons for Treatment Discontinuation

The most common reasons for conventional DMARDs discontinuation were ineffectiveness (32.69%) and side effects (21.15%). Disease remission accounted for 15.38% of DMARDs discontinuation (Figure 38).

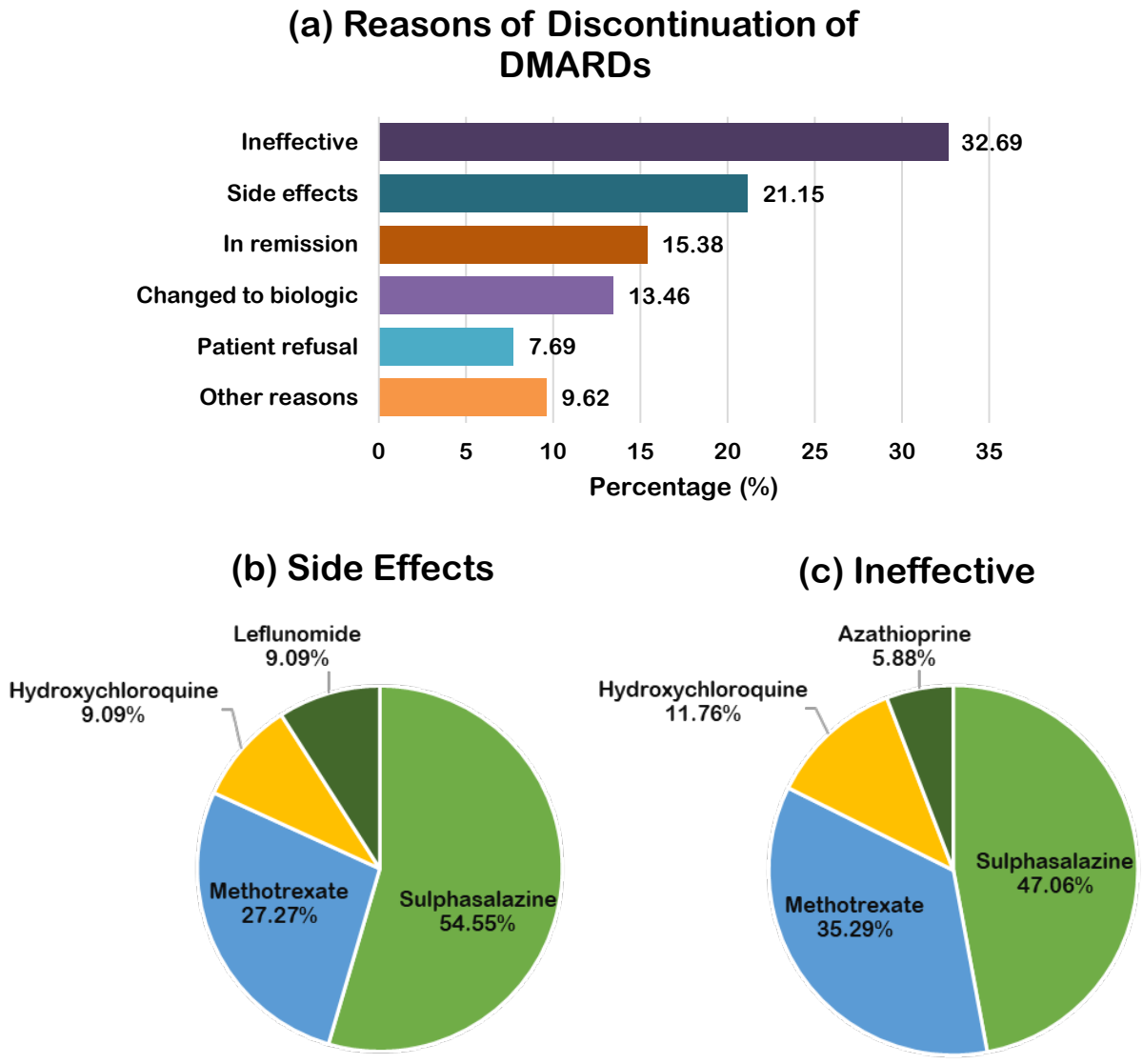


Figure 38: Reasons for discontinuation of DMARDs among patients with axial spondyloarthritis. (a) Reasons of discontinuation of DMARDs (n = 52): (b) Side effects (n = 11); (c) Ineffective (n = 17)

**Other reasons might include patients completed industry-sponsored RCTs, industry assisted patient access program or self-pay patients that decided to stop treatment.*

The key reason for biologics discontinuation was ineffectiveness (31.43%). Minority of patients (14.29%) stopped their treatments upon achieving remission (Figure 39). Discontinuation due to side effects only accounted for 8.57% (n = 3), and these are patients on infliximab.

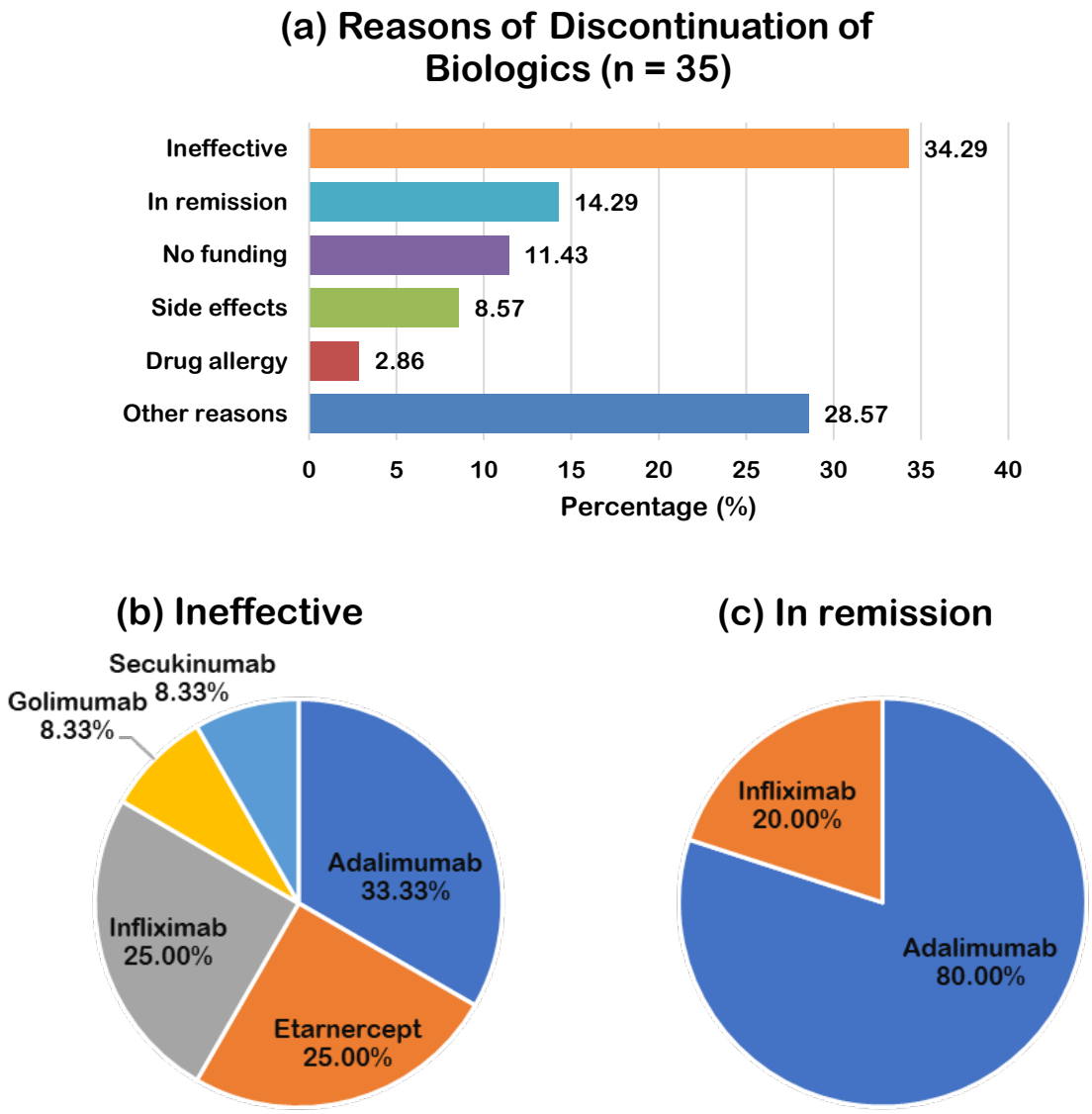


Figure 39: Reasons for discontinuation of biologics among patients with axial spondyloarthritis. (a) Reasons of discontinuation of biologics (n = 35): (b) Ineffective (n = 12); (c) In remission (n = 5)

**Other reasons might include patients completed industry-sponsored RCTs, industry assisted patient access program or self-pay patients that decided to stop treatment.*

6.8 Indication for Biologic Therapy

Among patients in whom biologic therapies were indicated (46.46%), most of them were started on biologics (Figure 40).

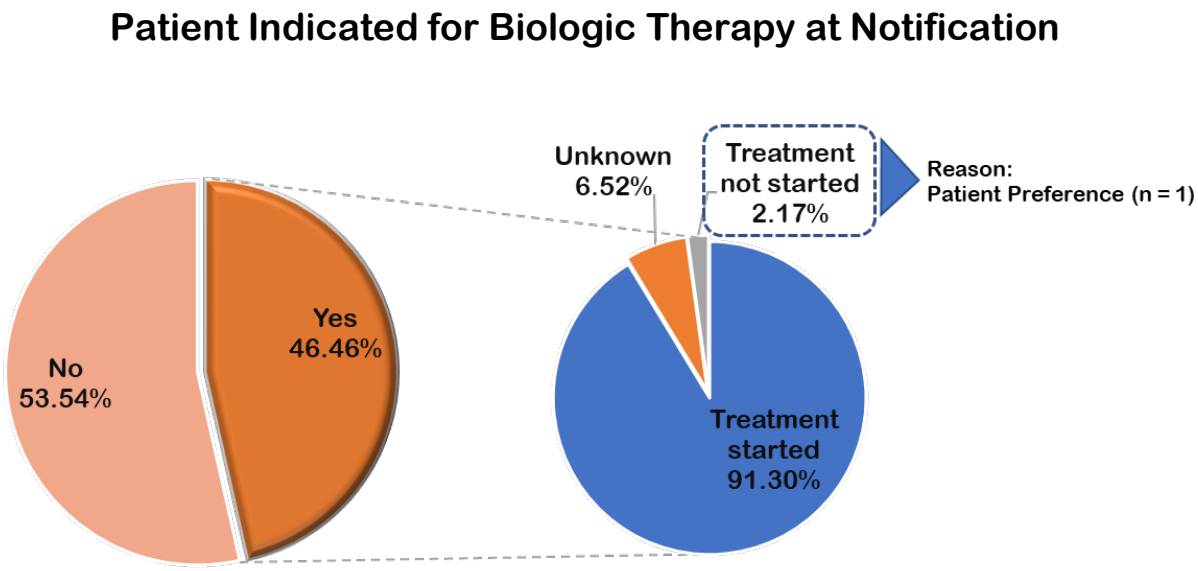


Figure 40: Indication for biologic therapy among patients with axial spondyloarthritis (n = 99)

6.9 Traditional and Complementary Medicines

A vast majority (84.17%) of the patients were not using any traditional and complementary medicines. Of those who were taking alternative treatment concurrently, most were using Chinese Traditional Medicine (52.63%) followed by Acupuncture (31.58%), Malay Traditional Medicine (15.79%) and Unprescribed supplements (5.26%) (Figure 41).

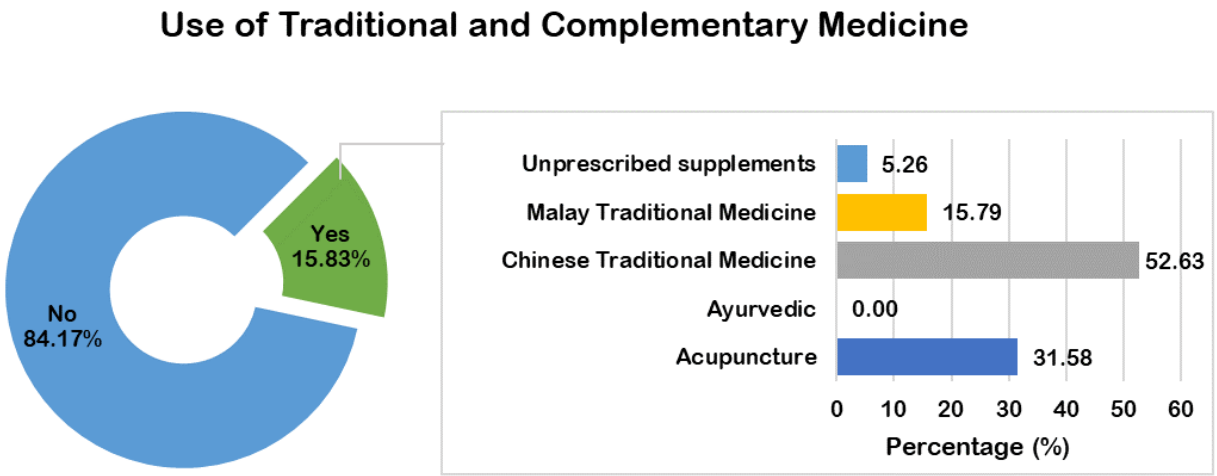


Figure 41: The use of traditional and complementary medicine among patients with axial spondyloarthritis (n = 120)

6.10 Surgeries

A small number of patients required surgeries, namely arthroplasty (4.52%) and spinal surgery (2.01%) as shown in Figure 42.

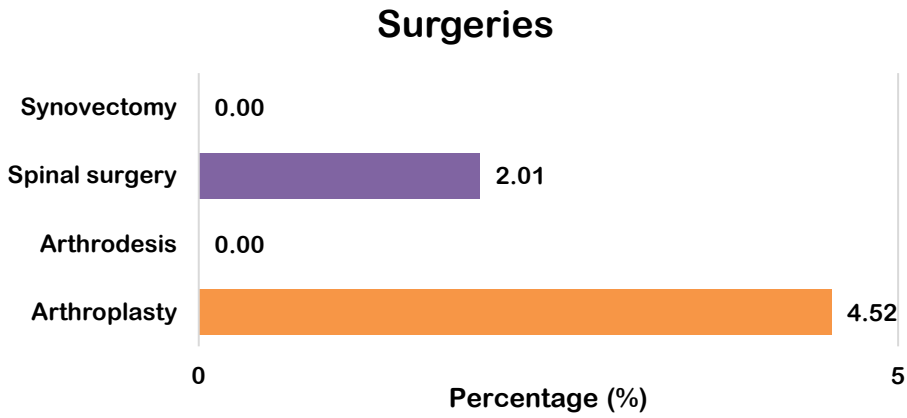


Figure 42: Surgeries performed on patients with axial spondyloarthritis (n = 199)

7.1 Work Productivity and Activity Impairment Questionnaire (WPAI)

Among patients with reported employment status (n = 92), more than half (60.87%) of them were working. The mean percentage of work time missed, impairment and overall work impairment were 20.03 ± 36.16 %, 32.67 ± 27.917 % and 30.45 ± 28.13 % respectively. The mean percentage of activity impairment was 28.61 ± 24.51 % (Figure 43).

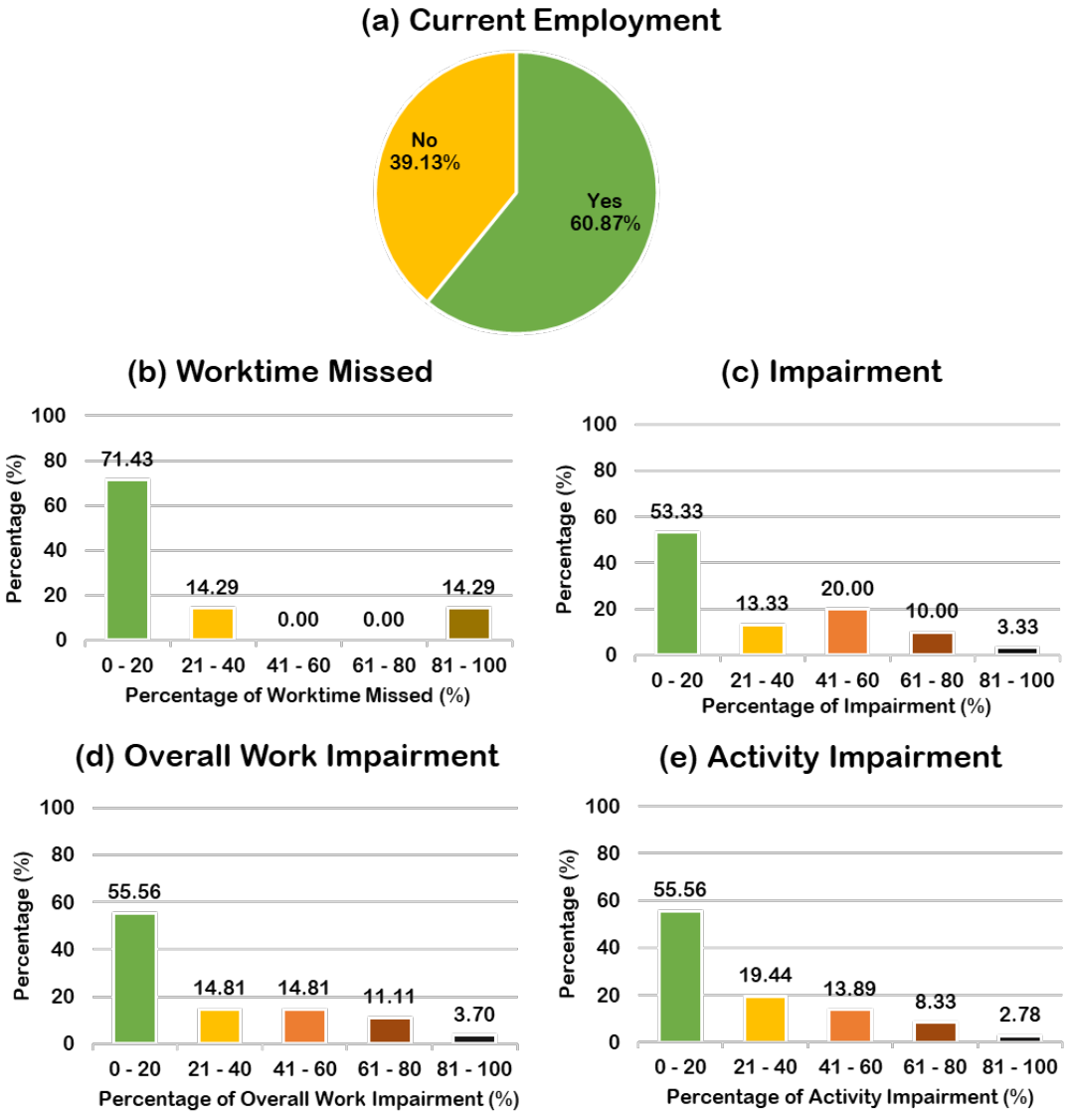


Figure 43: Work productivity and activity Impairment (WPAI)* among patients with axial spondyloarthritis. (a) Current employment (n = 92); (b) Worktime missed (n = 7); (c) Impairment (n = 30); (d) Overall work impairment (n = 27); (e) Activity impairment (n = 36)

**Work Productivity and Activity Impairment (WPAI) questionnaire measures impairments in pain work and unpaid work; absenteeism, presenteeism as well as impairments in unpaid activity because of health problems during the past 7 days.*

7.2 Assessment of SpondyloArthritis international Society (ASAS) Health Index

The mean ASAS-HI score for this cohort was found to be 5.75 ± 4.59. Overall, 51.11% of the patients had ASAS-HI score of ≤ 5 with almost half (48.89%) of the patients having either moderate or poor scores (Figure 44).

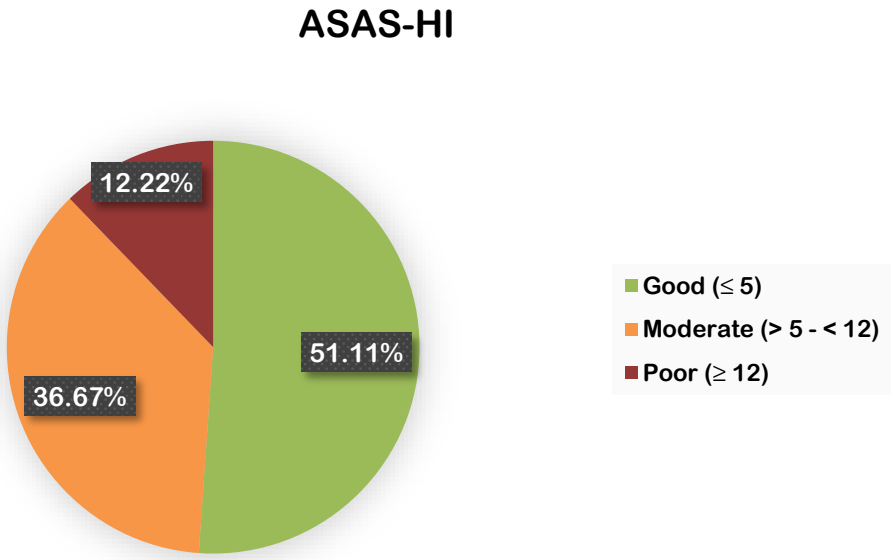


Figure 44: Assessment of Spondyloarthritis (ASAS-HI)* among patients with axial spondyloarthritis (n = 90)

**ASAS-HI is a self-reported questionnaire to measure functioning and health across 17 aspects of health and 9 environmental factors in patients with spondyloarthritis.*

7.3 Health Assessment Questionnaire Disability Index (HAQ-DI)

The patient cohort had a mean HAQ-DI score, HAQ-DI pain score and HAQ-DI health score of 1.37 ± 0.59, 34.62 ± 24.51 and 34.54 ± 24.70, respectively (Figure 45). Among patients with axial and peripheral joint involvement, the mean HAQ-DI score, HAQ-DI pain score and HAQ-DI health score were 1.36 ± 0.54, 40.15 ± 26.79 and 38.18 ± 26.10, respectively (Figure 46).

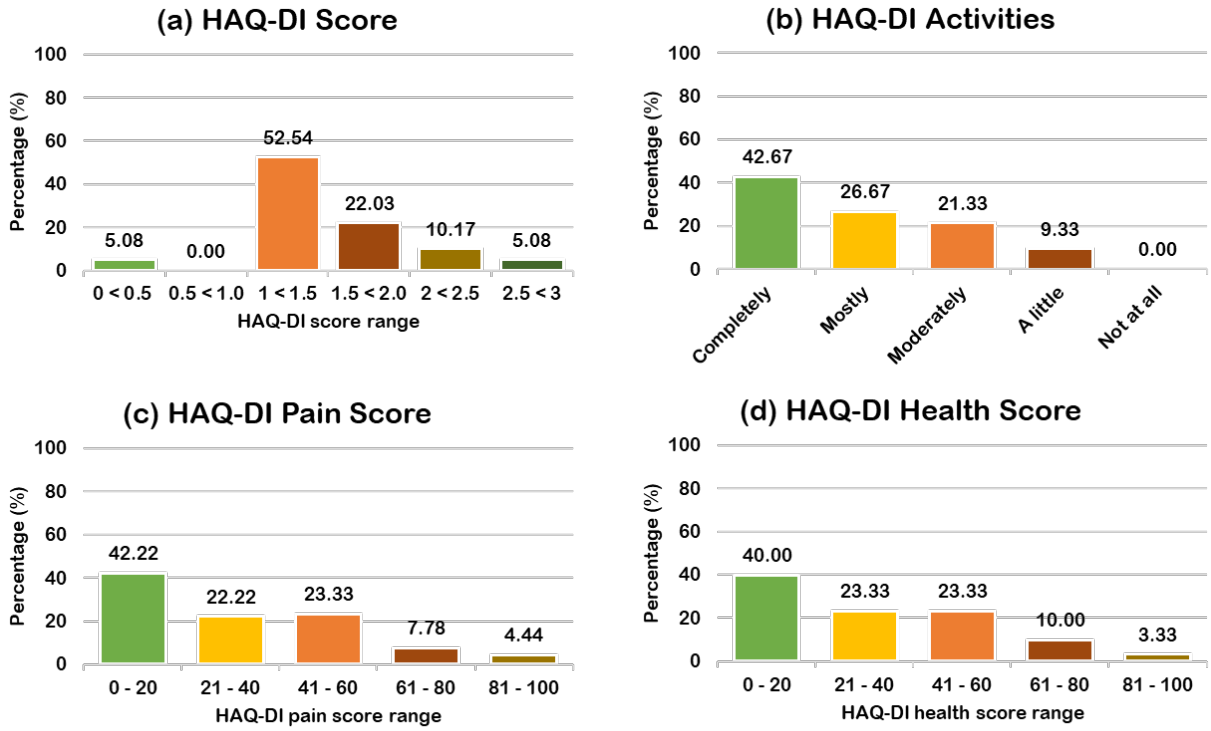


Figure 45: Health Assessment Questionnaire Disability Index (HAQ-DI)* among patients with axial spondyloarthritis. (a) HAQ-DI score (n = 56); (b) HAQ-DI activities (n = 75); (c) HAQ-DI pain score (n = 90); (d) HAQ-DI health score (n = 90)

**HAQ is a patient-filled questionnaire to assess functional status in adults with arthritis, specifically 20 specific functions to evaluate patient difficulty with activities of daily living over the past week; it covers eight categories including dressing and grooming, arising, eating, walking, hygiene, reaching, gripping and, errands and chores, as well as the use of specific aids or devices and the need for assistance from another person.*

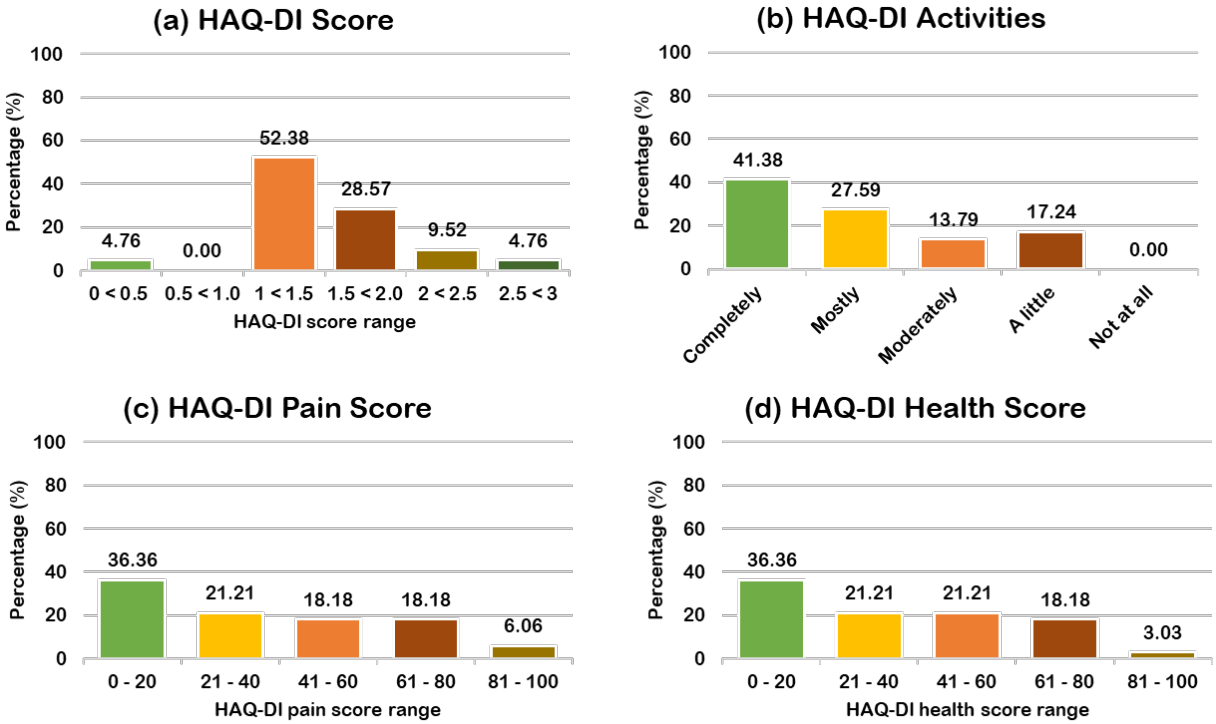


Figure 46: Health Assessment Questionnaire Disability Index (HAQ-DI)* among axial spondyloarthritis patients with axial and peripheral joint involvement. (a) HAQ-DI score (n = 21); (b) HAQ-DI activities (n = 29); (c) HAQ-DI pain score (n = 33); (d) HAQ-DI health score (n = 33)

**HAQ is a patient-filled questionnaire to assess functional status in adults with arthritis, specifically 20 specific functions to evaluate patient difficulty with activities of daily living over the past week; it covers eight categories including dressing and grooming, arising, eating, walking, hygiene, reaching, gripping and, errands and chores, as well as the use of specific aids or devices and the need for assistance from another person.*

DISCUSSION

The MyNIAR Axial Spondyloarthritis (AxSpA) registry is a relatively new registry under the MOH, established back in 2020. At present, a total of 13 MOH hospitals and University Malaya Medical Centre are involved in the data collection. To date, a total of 199 axial SpA patients have been notified to this registry since its inception in 2020. This is likely to be under-reported due to factors such as non-mandatory notification and limited resources at the hospital level. Furthermore, this is compounded by the fact that the registry was launched during the COVID-19 pandemic. Nevertheless, this is encouraging given the fact that it is a complex rheumatic condition which is relatively under-recognised and under-diagnosed. The patient number is poised to increase in the coming years owing to continuous efforts by the Malaysian Society of Rheumatology in improving early disease recognition among primary care healthcare professionals (HCPs) and swift referral of patients to rheumatology centres (Lau et al., 2021). Globally, we have also witnessed significant progress in the diagnosis and management of axial SpA, especially with the advent of the Assessment of Spondyloarthritis International Society (ASAS) classification criteria.

It is interesting to note that, Chinese patients made up more than half (59.30%) of the cohort. This appeared to point to ethnic preponderance, potentially due to genetic predisposition within this ethnic group (Ho & Cheng, 2013). This corroborated the similar observation made among the Chinese axial SpA patient population in Singapore and Indonesia (Lim et al. 2021; Nasutan et al., 1993). There were 5 times more male patients (84.92%) reported in the cohort than their female counterparts (15.08%).

Axial SpA is associated with chronic symptoms of back pain, morning stiffness, fatigue, frequent physical disability and impaired quality of life (Boonen et al., 2001). The disease commonly affects young adults (Boonen et al., 2001). This was similarly observed in our patient cohort where the mean age for both symptom onset (29.5) and disease diagnosis (35.5) were reported to be in the 30's, which coincided with the general work-productive age. Axial SpA can lead to significant functional limitations and reduced work productivity. The average overall work impairment was reported at 30.5%. This is slightly higher than US and Singapore cohorts with reported work impairments of 28.1% (Mease et al., 2018) and 27.6% (Goh et al. 2019), respectively. This highlighted the potential socioeconomic burden posts by the disease due to its progressively debilitating nature that can affect work productivity in the long run. This is further compounded by the fact that 4 out of 10 patients were already falling under the National Poverty Line Income (PLI) (i.e., less than RM 2208.00/month) according to the revised PLI in July 2019 (The Star, 2020). If left unaddressed, the long-term societal impact is devastating. This points to the needs of better social welfare assistance for axial SpA patients. Employers should also be more understanding to allow time off for patients to seek treatment including regular physical therapy and rehabilitation which can further improve patient outcomes (Perrotta et al. 2019). Goh et al. (2019) reported that active disease, reduced physical function and poorer quality of life are associated with reduced work productivity in patients with axial SpA and addressing these factors can potentially improve work productivity in patients with axial SpA. There is also consistent evidence that treatment with biological therapy significantly improves work productivity and activity impairment in people with axial SpA (Shim et al. 2018).

Our patient cohort was assessed using several disease activity assessment tools i.e. BASDAI, ASDAS. Depending on the tools used, this yielded different outcomes pertaining to the proportion of patients in different disease states, attributable to the difference in the clinical components assessed. Over half of the patients in this cohort were reported to be in 'high disease activity' or 'very high disease activity' states via ASDAS CRP (59.34%) or ASDAS ESR (72.55%) assessments. This was in stark contrast with BASDAI assessment which reported only 22.11% of the patients in moderate to high disease states (BASDAI score ≥ 4). In other words, ASDAS assessment pointed to a higher proportion of patients in active disease state as compared to BASDAI. The ASDAS assessment includes ESR/CRP levels which are objective assessments of clinical inflammation in addition to the self-reported outcomes seen in BASDAI. These inflammatory markers are known to correlate better with subsequent syndesmophyte formation which explains the preference of ASDAS tool for a more accurate disease activity assessment in axial SpA (van der Heijde et al., 2016; EULAR Press Release, 2022). The recent 2022 EULAR/ASAS recommendations on Axial Spondyloarthritis also endorsed ASDAS over BASDAI for disease activity assessment (EULAR Press Release, 2022). Based on the data from the current cohort and international guidelines, the use of ASDAS over BASDAI in local settings should be adopted for a more accurate assessment of disease activity in axial SpA patients.

With many patients reported being still in 'high disease activity' or 'very high disease activity' states based on ASDAS CRP/ESR assessments, correspondingly, almost half (48.9%) of the patient cohort reported moderate/poor health status based on ASAS-HI assessment. Moreover, the spinal mobility (mean BASMI: 4.7) and functional limitations (mean BASFI: 3.8) scores were also higher than those reported in the Singaporean patient cohort (mean scores of 3.4 and 2.3, respectively for BASMI and BASFI) with similar disease duration and age (Lim et al., 2021). Over 55.4% of the patients presented with lumbo-sacral syndesmophytes and 38.8% with cervical syndesmophytes. It is known that baseline radiographic damage is a predictor for future radiographic spinal progression in axial SpA (Poddubnyy et al., 2012). The goals of axial SpA treatment are to control the clinical symptoms and inflammation, preserve an individual's physical function and quality of life as well as preventing radiographic progression. As such, the clinical management of this cohort of patients should be further optimised. This may entail escalation to the more efficacious biologic therapies in combination with non-pharmacological treatment modalities (i.e. physiotherapy, rehabilitation and exercises) among those with persistently high disease activities despite current conventional treatments (van der Heijde et al., 2016). Research conducted at Royal National Hospital for Rheumatic Diseases in Bath (RNHRD) has demonstrated that well-designed axial SpA rehabilitation course could lead to long and short-term improvements in spinal mobility (BASMI), function (BASFI) and disease activity (Barnett et al., 2021).

In addition, delayed diagnosis of axial SpA is associated with worse mobility and functional impairment, as well as radiographic damage (Yi et al., 2020; Seo et al., 2015). The delay in referral was evident among this patient cohort with a mean interval of approximately 8 years between symptom onset and rheumatology clinic visit. Therefore, there is an urgent need for earlier referral, diagnosis and treatment to prevent irreversible structural damage. Furthermore, delayed diagnosis is also associated with higher healthcare costs, and worse quality of life, highlighting the importance of early recognition of axial SpA to reduce extensive burden on patients and society (Yi et al., 2020). This calls for continuous medical education to raise disease awareness, especially among primary care physicians and orthopedic surgeons with the aim to improve disease recognition hence expediting referral. The clinical challenge faced by HCPs, particularly among the non-rheumatologists would be to recognise the early symptoms of axial SpA i.e. differentiating inflammatory pain from mechanical pain among patients with chronic back pain whilst identifying those with serious underlying pathologies (Lau et al., 2021). The introduction of the referral algorithm by the Malaysian Society of Rheumatology is timely, although an efficient referral network should also be established between primary care clinics with the rheumatology centres (Lau et al., 2021). Other factors such as patient delay in seeking care, long appointment times for rheumatology clinic may further inhibit timely referral of patients (Magrey et al., 2020). Adequate access to MRI is also important, especially in the diagnosis of the non-radiographic stage of the disease. There is also an on-going effort with the aim of expediting axial SpA patient journey with Malaysia Spondylarthritis Accelerated Management (SAM) Model. The SAM initiative has shown promising initial results in improving referrals, promoting earlier diagnosis and establishing the importance of having timely access to optimal care (Yahya et al., 2022).

Cardiometabolic comorbidities were common, with cohort prevalence of 59.3% for obesity, 36.2% for hypertension, 27.1% for dyslipidaemia and 13.1% for diabetes mellitus, being comparable to the national prevalence of 50.1%, 30%, 38.1% and 18.3%, respectively for Malaysian adults population (NHMS, 2019). In addition, over 60% of these patients appeared obese while 6.03% also suffered from either ischaemic heart disease or fatty liver disease. Of note, the comorbidities burden of our cohort appeared to be higher compared with the reported pooled prevalence of hypertension (22.3%), hyperlipidaemia (17.1%), obesity (13.5%) and any ischaemic heart disease (5.5%), liver disease (2.9%) in a large meta-analysis (Zhao et al., 2020). Given the correlation between disease activity and cardiovascular risks, close monitoring of patients' cardiovascular health is advised (Ferraz-Amaro et al., 2021). With about one-fifth (19.05%) of the patient cohort reported having uveitis (the most common form of extra-articular manifestation), a collaboration between ophthalmologists and rheumatologists should be mooted.

The treatment should be tailored to each person's current signs and symptoms. NSAIDs are frequently recommended as the first line treatment with the aim of reducing back pain and stiffness (van der Heijde et al., 2017). Over half of the patients in this cohort (57.8%) were started on NSAIDs treatment within less than a month after diagnosis although the mean duration to NSAIDs initiation was 11 months. Approximately a third (38.7%) had a good response to NSAIDs.

Conventional DMARDs were also prescribed for those having peripheral joint involvement, with sulphasalazine, methotrexate and leflunomide being the most commonly used. Ineffectiveness (32.69%) and side effects (21.15%) accounted for the most common reasons for DMARDs discontinuation. The most commonly prescribed classes of biologics in this cohort were the TNFi (adalimumab & golimumab) and IL17i (secukinumab), both of which are recommended by current ASAS/EULAR guidelines in the management of axial SpA (van der Heijde et al., 2016; Ramiro, 2022).

Since registry notification was highly encouraged especially among patients who were put on biologics, the overall biologic usage noted in this current report is highly likely to be over-represented. Approximately a third had to stop their biologic therapies due to ineffectiveness while treatment was stopped in some patients (14.29%) who were deemed to be in clinical remission. Another common reason for biologics discontinuation was due to depletion of funds which occurred in 11.43% of the patients. With almost half of this patient cohort not having medical insurance, continuous access to effective, but expensive biologic therapies outside of the MOH setting remains a big challenge. As such, it is important for new sources of funding to be identified, to ensure continuous treatment for patients who require biologic therapies.

CONCLUSION

The MyNIAR AxSpA registry provides valuable insights pertaining to the burden of illness of axial SpA disease and its current management in MOH hospitals. The number of axial SpA patients reported has been encouraging despite being a relatively young registry. Although the actual prevalence and incidence of the disease could not be estimated, the data from this registry allows a greater understanding of the disease patterns among axial SpA patients. The registry highlights several key findings, including the socioeconomic burden posed by the disease as well as the need for greater adoption of ASDAS as disease measurement tool with the goal of achieving reliable low disease activity or remission status in all patients. Importantly, there is an urgent need for greater partnership between rheumatologists and other HCPs especially those in the primary care settings. The aim is to expedite referral and diagnosis for the early management of such a debilitating disease. The introduction of the referral algorithm by the Malaysian Society of Rheumatology is a step in the right direction. Pertinent to this is the sources of funding required to allow all eligible patients to be treated with advanced therapies in a sustainable manner to ensure a good long term prognosis. The high prevalence of cardiometabolic diseases compared to the general population also warrants attention.

The registry could benefit from the participation of all rheumatology centres not only under MOH but all hospitals including those in the private and universities. In order to achieve this goal, a greater collaboration among all relevant stakeholders is vital.

REFERENCES

1. Barnett, R., McGrogan, A., Young, M., Cavill, C., Freeth, M. & Sengupta, R. (2021). P181 Long-term improvement in axial spondyloarthritis clinical outcomes following 2-weeks of intensive education and rehabilitation: results from the Bath residential rehabilitation programme. Rheumatology, 60, Suppl. 1: keab247.176.
2. Boonen, A., Chorus, A., Miedema, H., D van der Heijde, D., van der Tempel, H., van der Linden, S. (2001). Employment, work disability, and work days lost in patients with ankylosing spondylitis: A cross sectional study of Dutch patients. Ann. Rheum. Dis., 60:353–358
3. EULAR Press Release 2022. EULAR 2022: New Insights Into Treatment Effectiveness in People with Axial Spondyloarthritis. July 22. Accessed on June 12, 2022. https://www.eular.org/sysModules/obxContent/files/www.eular.2015/1_42291DEB-50E5-49AE-5726D0FAAA83A7D4/new_insights_into_treatment_effectiveness_in_ people_with _axial_spondyloarthritis.pdf
4. Ferraz-Amaro,I., Rueda-Gotor, J., Genre, F., Corrales, A., Blanco, R., Portilla, V., et al. (2021). Potential relation of cardiovascular risk factors to disease activity in patients with axial spondyloarthritisTher Adv Musculoskel Dis , Vol. 13: 1–10
5. Goh, YH., Kwan, YH., Leung, YY., Fong, W., Cheung, P. (2019). A cross-sectional study on factors associated with poor work outcomes in patients with axial spondyloarthritis in Singapore. Int J Rheum Dis., 22:2001–2008
6. Ho, HH., Chen JY. (2013) Ankylosing spondylitis: Chinese perspective, clinical phenotypes, and associated extra-articular systemic features. Curr Rheumatol Rep., 15(8):344.
7. Lau, IS., Gun, SC., Yeap, SS., Zain, MM., Yusoof, HM., Sargunam, S., Yahya, F. (2021). Algorithm for the referral of patients with inflammatory back pain from primary care in Malaysia. Malays Fam Physician, 16(2):2–6.
8. Lim, WZ., Fong, W., Kwan, YH., Leung, YY. (2021). Exploring the prevalence and factors associated with fatigue in axial spondyloarthritis in an Asian cohort in Singapore. Front. Med., 3:doi.org/10.3389/fmed.2021.603941
9. Magrey, M., Yi, E., Wolin, D., Price, M., Chirila, C., Davenport, E., & Park, Y. (2020). Understanding Barriers in the Pathway to Diagnosis of Ankylosing Spondylitis: Results From a US Survey of 1690 Physicians From 10 Specialties. ACR open rheumatology, 2(10), 616–626.
10. Mease, P. J., Heijde, D. V., Karki, C., Palmer, J. B., Liu, M., Pandurengan, R., Park, Y., & Greenberg, J. D. (2018). Characterization of Patients With Ankylosing Spondylitis and Nonradiographic Axial Spondyloarthritis in the US-Based Corrona Registry. Arthritis care & research, 70(11), 1661–1670.
11. Nasution, AR., Mardjuadi, A., Suryadhana, NG., Daud, R., Muslichan, S. (1993). Higher relative risk of spondyloarthropathies among B27 positive Indonesian Chinese than native Indonesians. J Rheumatol., 20(6):988-90.
12. NHMS. (2019). Vol I: Non-communicable diseases, risk factors and other health problems. Suvery, KL: National Institute of Health, Ministry of Health Malaysia.

13. Poddubnyy, D., Haibel, H., Listing, J., Märker-Hermann, E., Zeidler, H., Braun, J., et al. (2012). Baseline radiographic damage, elevated acute-phase reactant levels, and cigarette smoking status predict spinal radiographic progression in early axial spondylarthritis. Arthritis Rheum., 64(5):1388-98

14. Perrotta, FM., Musto, A., Lubrano, E. (2019). New Insights in Physical Therapy and Rehabilitation in Axial Spondyloarthritis: A Review. Rheumatology and Therapy, 6:479–486.

15. Ramiro, S. (2022, June 01). Update of the ASAS/EULAR Recommendations on the management of axial spondyloarthritis [Oral presentation]. EULAR 2022 Congress, Copenhagen. https://bit.ly/3wOi7hG; https://www.youtube.com/watch?v=L0ehBOrVhEw.

16. Seo, M. R., Baek, H. L., Yoon, H. H., Ryu, H. J., Choi, H. J., Baek, H. J., & Ko, K. P. (2015). Delayed diagnosis is linked to worse outcomes and unfavourable treatment responses in patients with axial spondyloarthritis. Clinical rheumatology, 34(8), 1397–1405.

17. Shim, J., Jones, G.T., Pathan, E.M.I., Macfarlane, G.J. (2018). Impact of biological therapy on work outcomes in patients with axial spondyloarthritis: results from the British Society for Rheumatology Biologics Register (BSRBR-AS) and meta-analysis. Ann Rheum Dis, 77:1578-1584.

18. Smolen JS, Schols M, Braun J, et al. (2018). Treating axial spondyloarthritis and peripheral spondyloarthritis, especially psoriatic arthritis, to target: 2017 update of recommendations by an international task force. Ann Rheum Dis, 77: 3–17.

19. The Star (2020). Govt revises poverty line income from RM980 to RM2,208. July 20. Accessed on April 19, 2022. https://www.thestar.com.my/news/nation/2020/07/10/govt-revises-poverty-line-income-from-rm980-to-rm2208

20. van der Heijde, D., Ramiro, S., Landewé, R., Baraliakos, X., Van den Bosch, F., Seprianoet, A., et al. (2017). 2016 update of the ASAS-EULAR management recommendations for axial spondyloarthritis. Ann Rheum Dis, 76:978–991.

21. Yahya, F., Mohd Yusoof, H., Mohd, A., et al. AB0781 Malaysia Spondylarthritis Accelerated Management (SAM) Model: Expediting AxSpA patient journey from early referral, diagnosis and access to optimal care. Annals of the Rheumatic Diseases 2022;81:1517.

22. Yi, E., Ahuja, A., Rajput, T., George, A. T., & Park, Y. (2020). Clinical, Economic, and Humanistic Burden Associated With Delayed Diagnosis of Axial Spondyloarthritis: A Systematic Review. Rheumatology and therapy, 7(1), 65–87.

23. Zhao, S. S., Robertson, S., Reich, T., Harrison, N. L., Moots, R. J., & Goodson, N. J. (2020). Prevalence and impact of comorbidities in axial spondyloarthritis: systematic review and meta-analysis. Rheumatology (Oxford, England), 59(Suppl4), iv47–iv57.

LIST OF ABBREVIATIONS

Axial SpA	:	Axial spondyloarthritis
ASAS	:	Assessment of SpondyloArthritis International Society
ASAS-HI	:	Assessment of Spondyloarthritis Health Index
ASDAS	:	Ankylosing Spondylitis Disease Activity Score
BASDAI	:	Bath Ankylosing Spondylitis Disease Activity Index
BASFI	:	Bath Ankylosing Spondylitis Functional Index
BASMI	:	Bath Ankylosing Spondylitis Metrology Index
BMI	:	Body Mass Index
COVID-19	:	Coronavirus disease
COX-2	:	Cyclooxygenase 2
CRP	:	C-reactive protein
DMARD	:	Disease-modifying antirheumatic drug
ESR	:	Erythrocyte sedimentation rate
EULAR	:	European League Against Rheumatism
HAQ-DI	:	Health Assessment Questionnaire Disability Index
HCPs	:	Healthcare professionals
HLA-B27	:	Human leukocyte antigen B27
IL17i	:	Interleukin 17 inhibitor
MASES	:	Maastricht Ankylosing Spondylitis Entheses Score
MOH	:	Ministry of Health
MRI	:	Magnetic resonance imaging
NSAID	:	Non-steroidal anti-inflammatory drug
PLI	:	Poverty Line Income
RNHRD	:	Royal National Hospital for Rheumatic Diseases in Bath
SAM	:	Spondylarthritis Accelerated Management
SpA	:	Spondyloarthritis
TNFi	:	Tumor necrosis factor inhibitor
WPAI	:	Work Productivity and Activity Impairment

Appendix A: MyNIAR Forms

NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (MyNIAR) NOTIFICATION FORM (AS)

Date of Notification		Date 1st Visit to Rheumatologist	

SECTION 1 PATIENT DEMOGRAPHIC			
Name			
MyKad/MyKid		Old IC	
Other ID Document			
Specify Document Type (if Others)	◯ Passport ◯ Birth Certificate ◯ Police ID	◯ Armed Force ◯ Army ID ◯ Others, specify :	◯ Foreigner ID ◯ Unregistered
Address			
Contact Number	Home :	HP :	
Gender	◯ Male	◯ Female	
Date of Birth		☐ Estimated/presumed year	Age
Ethnic Group			

SECTION 2 EDUCATION, OCCUPATION			
Education Level	◯ No formal education ◯ Tertiary	◯ Primary ◯ Unknown	◯ Secondary
Work Status	◯ Not employed	◯ Unemployed/Retired : ◯ Home-maker ◯ Student	◯ Due to disease ◯ Other reasons
	◯ Currently Employed (Self Employed)	◯ Full-time	◯ Part-time
Household Income (RM)	◯ Less than RM1000 ◯ RM5001 - RM7000 ◯ No Income, on social welfare :	◯ RM1001 - RM3000 ◯ Above RM7000 ◯ Yes ◯ No	◯ RM3001 - RM5000 ◯ Unknown ◯ Unknown
Has Medical Insurance	◯ Yes	◯ No	◯ Unknown

SECTION 3 DIAGNOSIS		
Diagnosis	◯ Rheumatoid Arthritis ◯ Psoriatic Arthritis ◯ Connective Tissue Disease	◯ Ankylosing Spondylitis/Spondyloarthropathy ◯ Juvenile Idiopathic Arthritis ◯ Gout
Connective Tissue Disease		

SECTION 4 DIAGNOSIS CRITERIA (AS)			
ASAS Criteria for Axial SPA	◯ Sacroilitis on imaging* AND ≥ SpA feature	◯ Active (acute) inflammation on MRI highly suggestive of sacroiliitis associated with SpA *if no sacroilitis on x-ray ◯ Definite radiographic sacroiliitis according to modified New York criteria	
	HLA-B27 positive AND ≥ 2 other SpA feature *x-ray and MRI is normal		
	SpA Feature		
	☐ Inflammatory Back Pain ☐ Arthritis ☐ Enthesitis (heel) ☐ Uveitis ☐ Dactylitis ☐ Psoriasis ☐ Crohn's/colitis ☐ Good response to NSAIDs ☐ Family history of SpA ☐ HLA-B27 ☐ Elevated CRP		
Date of Diagnosis		Date of onset of Symptom	
Date DMARD		Date of First NSAID Initiation	
Joint involvement	☐ Peripheral	☐ Axial	

SECTION 5 COMORBID CONDITIONS					
Comorbid Conditions					
◯ No ◯ Yes	☐ Hypertension ☐ Hyperlipidaemia ☐ Diabetes Mellitus ☐ Ischemic Heart Disease (HD) ☐ CVA ☐ Peptic Ulcer Disease ☐ Entrapment neuropathy ☐ Malignancy Type: ☐ Haematology ◯ Leukemia ◯ Lymphoma ☐ Others ☐ Lung ☐ Breast ☐ Colorectal ☐ Endocrine ☐ Others, specify: _____	☐ Stomach ☐ CNS ☐ Liver ☐ ENT	☐Uterus/Ovary ☐ Bladder ☐ Skin ☐ Unknown	☐ Hepatitis B ☐ Hepatitis C ☐ Fatty Liver ☐ Renal Impairment ☐ Osteoporosis ☐ TB ☐ Demyelination ☐ Thyroid Disease ☐ Others, specify: _____	
Smoking Status	◯ Never	◯ Yes ◯ Ex ◯ Current			
Weight (kg)		Height (cm)		BMI	

SECTION 6 EXTRA-ARTICULAR MANIFESTATIONS (AS)		
Extra-articular Features		
◯ No ◯ Yes	☐ Uveitis ◯ Anterior Uveitis ◯ Posterior Uveitis ☐ Cardiovascular Disease ◯ Aortitis ◯ Others ☐ Pulmonary Disease ◯ Restrictive Lung Disease ◯ Pulmonary Fibrosis ◯ Others ☐ Renal Disease ◯ Amylodosis ◯ Others	☐ Neurologic Disease ◯ Atlantoaxial Subluxation ◯ Cervical Myelopathy ◯ Cauda Equina Syndrome ☐ GI Disease ◯ Crohns Disease ◯ Ulcerative Colitis ☐ Psoriasis ☐ Metabolic Bone Disease ◯ Osteoporosis ◯ Fractures

◯ Not Applicable for this section

NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (MyNIAR) JOINT ASESSMENT

Patient Name			
NRIC Number		Date of Assessment	

SECTION 1 JOINT ASSESSMENT

Joint Evaluation-Upper Extremities

RIGHT SIDE				LEFT SIDE		
Not Evaluable ☐	Yes ◯ No ◯	Yes ◯ No ◯	*JOINT	Not Evaluable ☐	Yes ◯ No ◯	Yes ◯ No ◯
Not Evaluable Yes	Tenderness	Swelling		Not Evaluable Yes	Tenderness	Swelling
☐	Yes ◯ No ◯	Yes ◯ No ◯	Temporomandibular	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	Sternoclavicular	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	Acromioclavicular	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	Shoulder	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	Elbow	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	Wrist	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MCP1	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MCP2	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MCP3	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MCP4	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MCP5	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	IP1	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP2	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP3	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP4	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP5	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	DIP2	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	DIP3	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	DIP4	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	DIP5	☐	Yes ◯ No ◯	Yes ◯ No ◯

Joint Evaluation-Lower Extremities						
RIGHT SIDE				LEFT SIDE		
Not Evaluable ☐ Yes	Yes ◯ No ◯ Tenderness	Yes ◯ No ◯ Swelling	*JOINT	Not Evaluable ☐ Yes	Yes ◯ No ◯ Tenderness	Yes ◯ No ◯ Swelling
☐	Yes ◯ No ◯		Hip	☐	Yes ◯ No ◯	
☐	Yes ◯ No ◯	Yes ◯ No ◯	Knee	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	Ankle	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	Tarsus/Mid Tarsal	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MTP1	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MTP2	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MTP3	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MTP4	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	MTP5	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	IP1	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP2	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP3	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP4	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP5	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP4	☐	Yes ◯ No ◯	Yes ◯ No ◯
☐	Yes ◯ No ◯	Yes ◯ No ◯	PIP5	☐	Yes ◯ No ◯	Yes ◯ No ◯

28 Joint Count (Tenderness)		28 Joint Count (Swelling)	
Total Joint Count (Tenderness)		Total Joint Count (Swelling)	

ACR functional status	◯ Normal (I) ◯ Limited in social activities (II) ◯ Limited in avocational / vocational activities (III) ◯ Wheel-chair or bedridden (IV)
Radiographic erosion at assessment	◯ Yes ◯ No ◯ Not available/Not Done
MASES Enthesitis score	
Dactylitis	◯ Yes, Number of digits involved ◯ No

NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (MyNIAR) JOINT ASESSMENT

Patient Name			
NRIC Number		Date of Assessment	

◯ Not Applicable for this section

SECTION 1: JOINT ASSESSMENT	
BASDAI	
a. How would you describe the overall level of fatigue/tiredness you have experienced?	
b. How would you describe the overall level of AS neck, back or hip pain you have had?	
c. How would you describe the overall level of pain/swelling in joints other than the neck, back or hips you have had?	
d. How would you describe the overall level of discomfort you have had from any areas tender to touch or pressure?	
e. How would you describe the overall level of morning stiffness you have had from the time you wake up?	
f. How long does your morning stiffness last from the time you wake up?	
g. Total Score	

◯ Not Applicable for this section

ASDAS	
a. How would you describe the overall level of AS neck, back or hip pain you have had during the last week?	
b. How long did your morning stiffness last from the time you wake up during the last week?	
c. How active was your rheumatic disease on average during the last week?	
d. How would you describe the overall level of pain/swelling in joints other than neck, back or hips you have had during the last week?	
e. ◯ C-reactive protein (mg/l) ◯ C-reactive protein (mg/dl)	
Erythrocyte sedimentation rate (mm/h)	
MASES Enthesitis score	
Dactylitis	◯ Yes, Number of digits involved ◯ No

◯ Not Applicable for this section

BASMI	
a. Tragus to wall (score)	
b. Lumbar side flexion (score)	
c. Lumbar flexion (modified Schober's) (score)	
d. Cervical rotation (score)	
e. Intermalleolar distance (score)	
f. BASMI Score	

◯ Not Applicable for this section

BASFI	
a. Putting on your socks or tights without help or aids (eg sock aid).	
b. Bending from the waist to pick up a pen from the floor without aid.	
c. Reaching up to a high shelf without help or aids (eg helping hand).	
d. Getting up from an armless chair without your hands or any other help.	
e. Getting up off the floor without help from lying on your back.	
f. Standing unsupervised for 10 minutes without discomfort.	
g. Climbing 12-15 steps without using a handrail or walking aid.	
h. Looking over your shoulder without turning your body.	
i. Doing physically demanding activities (eg physiotherapy exercises, gardening or sports).	
j. Doing a full day activities whether it be at home or at work.	
k. BASFI Score	

SECTION 2 INVESTIGATIONS			
Blood test	Result		
ESR	☐ (mm/hr)	☐ Not Available	
CRP	◯ ☐ mg/L	◯ ☐ mg/dL	◯ Not Available ◯ Unknown
HLA B27	◯ Positve	◯ Negative	◯ Not Available
X-ray Pelvis	◯ Sacroilitis Grade 0 ◯ Sacroilitis Grade 3	◯ Sacroilitis Grade 1 ◯ Sacroilitis Grade 4	◯ Sacroilitis Grade 2 ◯ Not done
X-ray Spine	☐ Cervical Xray	◯ Syndesmophyte Present	◯ Syndesmophyte Absent

		◯ Not done
	☐ Lumbo-sacral Xray	◯ Syndesmophyte Present ◯ Syndesmophyte Absent ◯ Not done
	☐ MRI	◯ Done ◯ Not done

SECTION 3 DISEASE ASSESSMENT		
How active was your arthritis during the past week?		
Activity	Measurement	
Patient global health assessment (PaGA)	(mm)	Value : 0 - 100
Physician's global health assessment (PrGA)	(mm)	Value : 0 - 100

SECTION 4 DISEASE ACTIVITY SCORE		
Clinical Variable	Value	
DAS 28 ESR SCORE		◯ Remission < 2.6 ◯ Low disease activity >2.6 - 3.2 ◯ Moderate disease activity 3.21 - 5.1 ◯ High disease activity >5.1
DAS 28 CRP SCORE		◯ Remission < 2.6 ◯ Low disease activity >2.6 - 3.2 ◯ Moderate disease activity 3.21 - 5.1 ◯ High disease activity >5.1
DAP SA SCORE		◯ Remission 0 - 4 ◯ Low disease activity 5 - 14 ◯ Moderate disease activity 15 - 28 ◯ High disease activity > 28
BA SDAI SCORE		◯ Inactive disease < 1.3 ◯ Low disease activity 1.3 - 2.1 ◯ High disease activity 2.1 - 3.5 ◯ Very high disease activity > 3.5
ASDAS ESR SCORE		◯ Inactive disease < 1.3 ◯ Low disease activity 1.3 - 2.1 ◯ High disease activity 2.1 - 3.5 ◯ Very high disease activity > 3.5

SECTION 5 INDICATION FOR BIOLOGIC THERAPY			
Indication for biologic	◯ No		
	◯ Yes	◯ Treatment Started	
		◯ Treatment Not Started	Reason : ☐ No fund available ☐ Patient preference ☐ Awaiting fund approval ☐ Other Reason

NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (MyNIAR) TREATMENT

TREATMENT			
Drug		Ongoing ☐ Reason for stopping	
Date started		Date stopped	
Drug		Ongoing ☐ Reason for stopping	
Date started		Date stopped	
Drug		Ongoing ☐ Reason for stopping	
Date started		Date stopped	
Drug		Ongoing ☐ Reason for stopping	
Date started		Date stopped	
Drug		Ongoing ☐ Reason for stopping	
Date started		Date stopped	

OTHER THERAPY		
Ever on ☐ NSAIDs ☐COX2 inhibitors?	◯ No	
	◯ Yes	Adverse reaction ever ◯ No ◯ Yes ☐ Allergy ☐ Peptic ulcer disease (confirmed on OGDS) ☐ Dyspepsia ☐ Renal impairment
Traditional Complementary, medicine	◯ No	◯ Yes ☐ Acupuncture ☐ Ayurvedic ☐ Chinese traditional medicine ☐ Malay traditional medicine ☐ Unprescribed supplements

SURGERY			
Arthroplasty	◯ No	◯ Yes	
Arthrodesis	◯ No	◯ Yes	
Spinal surgery	◯ No	◯ Yes	
Synovectomy	◯ No	◯ Yes	
Other surgery, specify	◯ No	◯ Yes	

NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (MyNIAR) OUTCOME

Patient Name		Date of Outcome	

SECTION 1 PATIENT STATUS			
Patient Status	◯ Alive		
	◯ Death	Date of Death	
		Primary cause of Death	◯ RA related, specify the cause: ____ ◯ Infection secondary to RA drugs ◯ Lung fibrosis ◯ IHD etc ◯ Unknown
	◯ Transfer to a new centre	Date of Transfer	
		Centre	a) Centre code
			b) Name of New Centre
		Reason	
	◯ Lost to Follow Up		

◯ Not Applicable for this section

SECTION 2 WORK PRODUCTIVITY AND ACTIVITY IMPAIRMENT QUESTIONNAIRE (WPAI)	
Work Productivity And Activity Impairment Questionnaire (Wpai)	
a. Are you currently employed (working for pay)?	◯ Yes ◯ NO
b. During the past seven days, how many hours did you miss from work because of problems associated with your Ankylosing Spondylitis? Include hours you missed on sick days, times you went in late, left early, etc., because of your Ankylosing Spondylitis. Do not include time you missed to participate in this study.	____ HOURS
c. During the past seven days, how many hours did you miss from work because of any Other Reason, such as annual leave, holidays, time off to participate in this study?	____ HOURS
d. During the past seven days, how many hours did you actually work?	____ HOURS
e. During the past seven days, how much did your Ankylosing Spondylitis affect your productivity while you were working?	◯0 ◯1 ◯2 ◯3 ◯4 ◯5 ◯6 ◯7 ◯8 ◯9 ◯10
f. During the past seven days, how much did your Ankylosing Spondylitis affect your ability to perform your normal daily activities, excluding your job?	◯0 ◯1 ◯2 ◯3 ◯4 ◯5 ◯6 ◯7 ◯8 ◯9 ◯10
Percentage work time missed due to problem:	
Percentage impairment while working due to problem:	
Percentage overall work impairment due to problem:	
Percentage activity impairment due to problem:	

◯ Not Applicable for this section

EVENT OF SPECIAL INTEREST (after baseline notification)	
☐ Infection requiring hospitalization Total Number of Hospitalization: ☐	☐ Pneumonia ☐ Skin and Soft Tissue (Exclude Herpes Zoster) ☐ Septic Arthritis ☐ Septic Arthritis ☐ Urinary Tract Infection ☐ Septicaemic Shock ☐ Others - specify ☐
☐ Herpes Zoster	
☐ Tuberculosis	☐ Pulmonary ☐ Extra-pulmonary
☐ Cardiovascular Event	☐ Ischemic Heart Disease ☐ Cerebrovascular Disease ☐ Pulmonary Embolism ☐ DVT
☐ Pregnancy	◯ Live Birth ☐ ◯ Normal ◯ Congenital Malformation ☐ ◯ Miscarriage ☐
☐ Malignancy	
☐ Interstitial Lung Disease	Type: ☐ Haematology ◯ Leukemia ◯ Lymphoma ☐ Other ◯ Lung Stomach Uterus/Ovary ◯ Breast CNS Bladder ◯ Colorectal Liver Skin ◯ Endocrine ENT Others, specify: ☐ ☐ Unknown
☐ Hepatitis B	
☐ Hepatitis C	
☐ Osteoporosis	
☐ Diabetes Mellitus	
☐ Hypertension	
☐ Dyslipidaemia	

◯ Not Applicable for this section

ASSESSMENT OF SPONDYLOARTHRITIS (ASAS-HI)			
Please answer all statements by placing one check mark per statement to indicate which response best applies to you at this moment in time taking into account your rheumatic disease (the term "rheumatic disease" contains all forms of spondyloarthritis including Ankylosing Spondylitis).			
Questions	Agree/not Agree		
Pain sometimes disrupts my normal activities.	◯ Agree	◯ Not Agree	
I find it hard to stand for long.	◯ Agree	◯ Not Agree	
I have problems running.	◯ Agree	◯ Not Agree	
I have problems using toilet facilities.	◯ Agree	◯ Not Agree	
I am often exhausted.	◯ Agree	◯ Not Agree	
I am less motivated to do anything that requires physical effort.	◯ Agree	◯ Not Agree	
I have lost interest in sex.	◯ Agree	◯ Not Agree	◯ Not Applicable
I have difficulty operating the pedals in my car.	◯ Agree	◯ Not Agree	◯ Not Applicable
I am finding it hard to make contact with people.	◯ Agree	◯ Not Agree	
I am not able to walk outdoors on flat ground.	◯ Agree	◯ Not Agree	
I find it hard to concentrate.	◯ Agree	◯ Not Agree	
I am restricted in traveling because of my mobility.	◯ Agree	◯ Not Agree	
I often get frustrated.	◯ Agree	◯ Not Agree	
I find it difficult to wash my hair.	◯ Agree	◯ Not Agree	
I have experienced financial changes because of my rheumatic disease.	◯ Agree	◯ Not Agree	
I sleep badly at night.	◯ Agree	◯ Not Agree	
I cannot overcome my difficulties.	◯ Agree	◯ Not Agree	
ASAS-HI SCORE			

HEALTH ASSESSMENT QUESTIONNAIRE (HAQ-DI)				
Please select in the button which best describes your abilities OVER THE PAST WEEK:				
Questions	Without Any Difficulty	Without Some Difficulty	Without Much Difficulty	Unable to Do
Dressing & Grooming				
Are you able to dress yourself, including shoelaces and buttons?	○	○	○	○
Are you able to shampoo your hair?	○	○	○	○
Arising				
Are you able to stand up from a straight chair?	○	○	○	○
Are you able to get in and out of bed?	○	○	○	○
Eating				
Are you able to cut your own meat?	○	○	○	○
Are you able to lift a full cup or glass to your mouth?	○	○	○	○
Are you able to open a new milk carton?	○	○	○	○
Walking				
Are you able to walk outdoors on flat ground?	○	○	○	○
Are you able to climb up five steps?	○	○	○	○
Please check any AIDS OR DEVICES that you usually use for any of the above activities:				
☐ Devices used for Dressing (button hook, zipper pull, etc. ☐ Special or built up chair. ☐ Cane ☐ Walker			☐ Built up or special utensils. ☐ Crutches. ☐ Wheelchair	

Please check any categories for which you usually need HELP FROM ANOTHER PERSON:			
☐ Dressing and Grooming.	☐ Arising	☐ Eating	☐ Walking

Please select in the button which best describes your abilities OVER THE PAST WEEK:				
Questions	Without Any Difficulty	Without Some Difficulty	Without Much Difficulty	Unable to Do
Hygiene				
Are you able to wash and dry your body?	○	○	○	○
Are you able to take a tub bath?	○	○	○	○
Are you able to get on and off the toilet?	○	○	○	○
Reach				
Are you able to reach and get down a 5	○	○	○	○

pound object (such as a bag of sugar) from above your head? Are you able to bend down to pick up clothing from the floor?	○	○	○	○
Grip				
Are you able to open car doors?	○	○	○	○
Are you able to open previously opened jars?	○	○	○	○
Are you able to turn faucets on and off?	○	○	○	○
Activities				
Are you able to run errands and shop?	○	○	○	○
Are you able to get in and out of a car?	○	○	○	○
Are you able to do chores such as vacuuming or yard work?	○	○	○	○

Please check any AIDS OR DEVICES that you usually use for any of the above activities:

☐ Long-handled appliances in bathroom.
☐ Bathtub Bar.
☐ Jar opener (for jars previously opened).
☐ Raised toilet seat.
☐ Long-handled appliances for reach.
☐ Bathtub Seat.

Please check any categories for which you usually need HELP FROM ANOTHER PERSON:

☐ Hygiene. ☐ Reach. ☐ Gripping and Opening Things. ☐Errands and Chores.

HAQ-DI Score	

Your ACTIVITIES:

To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?

○ Completely. ○ Mostly. ○ Moderately. ○ A Little. ○ Not At All.

Your PAIN:

How much pain have you had IN THE PAST WEEK? On a scale of 0 to 100 (where zero represents “no pain” and 100 represents “severe pain”), please record the number below.

Your HEALTH:

Please rate how well you are doing on a scale of 0 to 100 (0 represents “very well” and 100 represents “very poor” health), please record the number below.