PERCEIVED BARRIERS AND FACILITATORS FOR PHYSICAL ACTIVITY IN SOUTH AFRICAN PATIENTS WITH AXIAL SPONDYLOARTHRITIS

An explanatory sequential mixed methods approach with the transtheoretical model as a conceptual framework

LAUREN ANGELIL AND ANNA TINA GROB-ÖSTERMAN
ABBREVIATIONS

AxSpA: Axial Spondyloarthritis
ASASA: Axial Spondyloarthritis Association of South Africa
HLA: Human Leukocyte Antigen
IA: Inflammatory Arthritis
IBP: Inflammatory Back Pain
IFAB: Inflammatory Arthritis Facilitators and Barriers
NCD: Non-Communicable Diseases
PA: Physical Activity
RA: Rheumatoid Arthritis
SpA: Spondyloarthritis
SOC: Stage of Change
TTM: Transtheoretical Model
WHO: World Health Organisation
ABSTRACT

**Background:** Physical activity (PA) for individuals with axial spondyloarthritis (axSpA) is highly recommended for the management of the disease. However, maintaining physical activity is challenging for individuals with axSpA.

**Aim:** The aim was to explore perceived facilitators and barriers to PA in relation to stages of change (SOC) in individuals living with axSpA in South Africa.

**Methods:** A mixed method design involving 65 participants with axSpA was used. A web-based survey assessed facilitators and barriers with the Inflammatory Arthritis Facilitators and Barriers questionnaire, SOC, and demographic data. 10 participants were contacted for follow-up interviews and data were analysed with content analysis.

**Results:** Knowledge about the PA benefits to health (69.2%) and mood (60%) were predominant facilitators and levels of symptoms (66.2%) and lack of mindset (64.5%) were barriers indicated in the survey. Lower levels of education were associated with higher barriers. The interview analysis uncovered four barriers: interaction of symptoms, inappropriate care, unsupportive external environment, mindset and three facilitators: mental strength, symptom relief and supportive external environment.

**Conclusion:** There is a complex interplay between physical symptoms, psychological, interpersonal, and environmental barriers and facilitators to physical activity. Since physical activity in axSpA is important for management, future research should involve behavioural medicine approaches.
1 BACKGROUND:

1.1 Axial spondyloarthritis: overview and classification

Axial spondyloarthritis (axSpA) is an inflammatory joint condition where symptoms such as pain and stiffness are mainly localized in the lumbar spine and sacroiliac joints (Sieper and Poddubnyy, 2017). AxSpA is part of the bigger family of spondyloarthritis (SpA) which is visualized in Figure 1. They share common clinical, genetic, and pathophysiological features (Proft & Poddubnyy, 2018). The disease symptoms in axSpA overlap with other diseases in the SpA family as Figure 1 illustrates. The term axSpA has emerged in recent years and defines one disease with two subsets (Proft & Poddubnyy, 2018). The first subset is radiographic axial spondyloarthritis where there are radiographic changes in the sacroiliac joints, previously known as ankylosing spondylitis or Bechterew's disease. The second subset is non-radiographic axSpA which has no radiographic changes detected (Rudwaleit et al., 2009) but similar symptoms as the first subset. As axSpA is a chronic disease it can worsen over time. People diagnosed with non-radiographic axSpA often develop radiographic changes and therefore transfer into the first subset (Deodhar et al., 2016).

AxSpA in this work refers to the “non radiographic axial SpA” and “radiographic axial SpA” in Figure 1. The primary manifestation of symptoms are close to the spine, whereas other diseases in the SpA family show symptoms further away from the centre such as hands/feet or symptoms primarily located in the skin or organs.

Figure 1 From Ankylosing spondylitis and axial spondyloarthritis: recent insights and impact of new classification criteria [illustration], by Proft. & Poddubnyy, (2018).
1.1.1 Clinical presentation and pathophysiology of axial spondyloarthritis

Individuals with axSpA usually first seek medical care after experiencing persistent lumbar pain that is worse at night and in the morning and eases with movement (Sieper and Braun, 2014). These symptoms indicate chronic inflammatory back pain (IBP) which is a predominant symptom in axSpA (Rudwaleit et al., 2004). Chronic IBP is characterized by long-lasting back pain that persists for three months or more and typically begins before the age of 40. However, axSpA can present with various clinical symptoms related to the inflammatory processes associated with the disease. Inflammatory changes can lead to structural alterations in the spine, such as ossifications in the facet joints, resulting in reduced spinal mobility (Sieper and Braun, 2014). Additionally, inflammation can affect different joints and structures in the whole body (Siepert and Braun, 2014). Symptoms manifest as swollen, painful joints and pain associated with inflammation where the tendons connect to the bone, the enthesis (Sieper and Poddubny, 2017). Koenig et al. (2018) discuss that the inflammation of entheses, otherwise known as enthesitis, is a process that differentiates axSpA from other rheumatological conditions. As the pain results from inflammatory processes, it frequently disturbs sleep in this patient group which affects overall well-being (Sieper and Poddubny, 2017). Moreover, individuals with axSpA frequently contend with additional conditions like inflammatory bowel disease, uveitis, and psoriasis (Siebert et al., 2016).

The pathophysiology of spondylarthritis is a complex interactive relationship between genetics, microbial triggers, and inflammation of bone marrow, including bone formation at entheses (Ronneberger & Schett, 2011). Research has discussed the role of the HLA-B27 gene and several immune cells, however, there is little consensus as to which cells drive the inflammatory process observed in axSpA (De Koning et al., 2018). Environmental factors such as infections and disturbances of the microbiome play an important role in triggering the onset of the disease and the cascade of inflammation (Ronneberger & Schett, 2011).

1.1.2 Diagnosis of axial spondyloarthritis

The Assessment of Spondyloarthritis International Society classification criteria for axSpA was developed to aid in effective diagnosis (Akgul & Ozgocmen, 2011). Criteria for diagnosis include, for example, the presence of IBP, findings from radiographic tests, genetic factors, family history and other symptoms discussed previously (Akgul & Ozgocmen, 2011). There is a strong association with the presence of the HLA-B27 gene in the development of the disease (Braun et al., 1998, Díaz-Peña et al., 2013) and it is the most important risk factor for developing axSpA (De Koning et al, 2018). However, having the HLA-B27 does not automatically lead to the development of the disease (Brown et al., 2020). But, the HLA-B27 gene is present in about 70-90% of patients with radiographic axial spondyloarthritis (De Koning, et al., 2018). However, the frequency of this gene in the population of European descent is about 8% and radiographic axial spondyloarthritis occurs in about 0.5% (Stolwijk, et al, 2016). Symptoms usually start displaying in the third decade of life and five years earlier in patients who have the HLA-B27 gene present compared to patients who have not (Rudwaleit et al., 2009).
Deodhar et al., (2016) discuss the role of radiographic imaging in separating the two subsets of axSpA and how this often is not very reliable due to diagnostic error, changes difficult to detect, or the imaging method chosen. However, diagnosis with non-radiographic axSpA when radiographic imaging is doubtful allows earlier treatment and this can prevent structural damage from happening or worsening (Proft and Poddubnyy, 2018). Radiographic axial spondyloarthritis is more often diagnosed in men than in women (ratio 2-3:1) but there is no gender difference in the prevalence of non-radiographic axSpA (Sieper and Poddubnyy, 2017).

1.2 Axial spondyloarthritis: epidemiology and the culturally specific context of South Africa

In a systematic review related to axSpA incidence and prevalence rates, it was estimated from three studies that the prevalence, from screening people with the classification criteria, ranged from 0.13% to 1.4% (Bohn et al., 2018). Incidence rates of ankylosing spondylitis per 100,000 patient-years were reported in four studies and varied from 0.4 (Iceland) to 15.0 (Canada) (Bohn et al., 2018). No studies of axSpA incidence were identified (Bohn et al., 2018). An observational study in England from 2004 to 2020 showed that point-prevalence of axSpA diagnosis increased annually, reaching a maximum in 2020 at 0.113% (Scott et al., 2020).

Dean et al. (2014) reported a prevalence of radiographic axial spondyloarthritis in Africa at 0.074% which was based on a cross sectional study in South Africa. This makes axSpA relatively rare in sub-Saharan Africa. The lower reported prevalence is thought to be due to be near absence of the HLA-B27 gene in many black African populations (Mijiyawa et al., 2000), compared to European and Asian populations (Khan, 2013). There is sparse information on the prevalence and incidence of axSpA in South Africa despite the fact it has a population of around 60 million people within nine provinces. A post hoc analysis was performed from data in a global study estimating the prevalence of non-radiographic-axSpA among patients with IBP (Shirazy et al., 2018). It was found that of the 38 South African patients with IBP, 7 were diagnosed with non-radiographic-axSpA, corresponding with a prevalence rate of 18.4% in South Africa (Shirazy et al., 2018). South Africa has 11 official languages, and it is known for its racial, religious, and cultural diversity. Around 80% of the population are Black South Africans with the remainder comprising of South Africans of European descent, Asian descent, and multiracial ancestry. It is often referred to as the “rainbow nation” as it encapsulates the diversity and unity of post-apartheid South Africa (South African History Online, 2022).
1.3 Physical activity in patients with axial spondyloarthritis

Once diagnosed, treatment includes pharmaceutical medication, physical exercise, and education (Van Der Heijde et al., 2017). Patients with axSpA are recommended to meet a variety of healthcare professionals such as physiotherapists to improve their physical activity level, but also together with shared decision-making and education learn to take an active part in following their exercise plan (Van Der Heijde et al., 2017). However, according to O'Dwyer et al. (2015), individuals with axSpA exhibit significantly lower physical activity levels compared to healthy population controls. According to Fongen et al. (2013), a lower percentage (32%–42%) of axSpA patients meet the recommended physical activity levels. The World Health Organisation (WHO) (2020) PA recommendations to the general adult population also apply to people with axSpA (Rausch Osthoff et al., 2018). These recommendations include at least 150–300 minutes of moderate-intensity physical activity or 75–150 minutes of vigorous-intensity physical activity exercise per week or a combination and two strength training sessions a week. The PA recommended for moderate intensity by the WHO is the one used in this research when talking about meeting recommended PA levels.

The benefits of PA on overall health and well-being and in axSpA disease management are significant and recommended as the cornerstones of disease management (Fongen et al., 2013). It positively impacts pain experience, spinal mobility, physical function, and cardiovascular health for these patients (Dagfinrud et al., 2008; Haglund et al., 2012; O'Dwyer et al., 2014; van den Berg et al., 2017). According to Wendling et al. (2022), patients should be encouraged to be actively involved in both physiotherapy and self-directed rehabilitation as part of being physically active due to the beneficial effects on disease activity. Lifestyle change and self-management in axSpA require a comprehensive approach that includes information from healthcare professionals, patient education programs and associations (Wendling et al., 2022). In addition, high-intensity exercise is tolerated well in the condition and is associated with reduced disease activity despite concerns that it may worsen the condition (Sveaas et al., 2020, Niedermann et al., 2019).

Research related to PA levels in South Africa is limited (Patricios et al., 2022) despite the growing concern about NCD. PA levels in healthy individuals were assessed in 2012 by the South African National Population-Based Survey of more than 26 000 participants (Mlangeni et al., 2018). In this self-report study, participants were asked if they participate in any vigorous and moderate intensity sport, fitness or recreational activities. Their results reported that 57.4% were not physically active, 14.8% were moderately physically active, and 27.8% were vigorously physically active (Mlangeni et al., 2018). In the latest comprehensive nationwide report, the South African National Health and Nutrition Examination Survey report (Shasina et al., 2012). The data included a self-report measure in combination with a 3-minute step test involving a smaller sample. It was found that 27.9% of males and 45.2% of females did not meet the global required PA levels (Shasina et al., 2012). Although this information relates to individuals who are considered healthy, it is worth noting that the cultural context is characterized by a lack of sufficient physical activity among the majority of people.
Despite all the benefits and recommendations for PA in axSpA, adhering to these physical activity guidelines is a challenge (Niedermann et al., 2019). Following to PA recommendation is challenging even in a healthy population, to have a disease affecting your physical and mental health makes it even more difficult. Individuals with axSpA attend physiotherapy for support with their disease symptoms. As PA is an important cornerstone in the management of the disease, it is important that physiotherapists have the knowledge about predominant facilitators and barriers to PA to support individuals to meet recommended PA levels and reduce the burden of the disease.

1.4 Barriers and facilitators to physical activity in axial spondyloarthritis

Physiotherapy interventions have shown to be a cornerstone of disease management, with the aim to increase physical activity levels and to reduce the burden of axSpA including pain, stiffness and reduced function (Perrotta et al., 2019). To do so, the Physiotherapist needs not only the knowledge of suitable interventions but also how to best support the patient in making behaviour changes to reach set goals. Identifying barriers and facilitators to PA in inflammatory joint conditions is important to understanding physical activity choices and behaviours (Davergne, 2021). Barriers and facilitators are related to disease symptoms, psychological states, and environmental and social constructs. They also play a role in enhancing or diminishing motivation for change (Davergne et al., 2020).

However, there is limited research on challenges to PA in axSpA patients, especially qualitative descriptive research. A small number of studies have investigated barriers and facilitators and they are mostly questionnaire-based (O’Dwyer et al., 2016). Research has shown that there are more barriers to PA for axSpA patients compared to controls (Fongen et al., 2015). In a survey of axSpA patients, significant barriers to PA were pain and fatigue (Rouse et al., 2019) as well as not having enough time (Sundström et al., 2002). Niedermann et al. (2019) found that timing and planning PA were barriers as well as motivation and disease symptoms such as pain. Barriers to PA identified in a qualitative descriptive study in Ireland included a lack of resources, negative associations and attitudes towards exercise, lack of awareness and knowledge about PA as well as condition-related symptoms such as pain and stiffness (O’Dwyer et al., 2016).

Facilitators previously identified included an individualised physical activity program and external support from a variety of health and wellbeing specialists, family and friends and online resources (O’Dwyer et al., 2016). Understanding the benefits of participating in regular PA, experiencing a reduction in pain, belonging to an online support group, and experiencing the enjoyment of the PA were other facilitators (Rouse et al., 2019). This research also highlighted the support of friends and family. Niedermann et al. (2019) found that low disease symptoms, good organisational conditions and motivation were facilitators of PA.

There is one noteworthy study in the context of this degree project. It involved the development and validation of a questionnaire related to barriers and facilitators to physical activity for patients with rheumatoid arthritis (RA), axial spondyloarthritis and/or psoriatic
arthritides (Davergne et al., 2020). This questionnaire consists of 10 questions and is called Inflammatory Arthritis Facilitators and Barriers (IFAB) questionnaire and will be further discussed in section 3.1.2 as an instrument of data collection. Davergne et al. (2021) used the IFAB in a cross-sectional study on 150 patients with axSpA, rheumatoid arthritis and psoriatic arthritis to study facilitators and barriers towards PA, stages of change (SOC) and patient’s reported activity levels. SOC is a theoretical framework used to understand and explain the process individuals go through when making behaviour changes, particularly in the context of health-related behaviours and will be discussed further in section 1.5. Davergne et al (2020) found that facilitators and barriers correlated with SOC and PA measurements in patients with axSpA. This indicates that higher SOC (rho 0.35, p < 0.001) correlates with more facilitators and a higher PA-level.

This previous research related to facilitators and barriers in axSpA patients was conducted in high-income, developed countries such as France, Ireland and Norway. However, the findings in these studies are bound to contextual factors in which they were created, and further research is required to represent the unique cultural landscape of South Africa. Previous research about facilitators and barriers towards PA in South Africa is not related to axSpA but may still help to understand possible support and challenges individuals may face. Mlangeni et al., (2018) indicated that levels of PA are associated with socioeconomic position, education, sex, ethnicity, and health status in healthy individuals. Specifically, males and participants with higher levels of education were more likely to be physically active and participants of a lower socioeconomic status were less likely to engage in physical activity. It was also seen that participants with self-reported poor health status were less likely to be physically active (Mlangeni et al., 2018). Provinces in South Africa with a rural-based setting were associated with a larger proportion of physically fit males (Shisana et al., 2012). In contrast, urban provinces that were more economically developed had the highest proportion of unfit male participants. Further, South Africa experiences a high prevalence of interpersonal violence (Norman, 2010). These health and interpersonal factors may relate to facilitators and barriers for PA. Recommendations to improve physical activity levels were to improve infrastructure and incorporate community-based education about PA (Mlangeni et al., 2018). These would act as facilitators of PA. In addition, South Africa is classified as an upper-middle-income, developing country (World Bank, 2022).

As mentioned, there is limited research available, especially descriptive qualitative research on barriers and facilitators in axSpA (O’Dwyer et al., 2016). In this degree project, the transtheoretical model of behaviour change (TTM) provides a conceptual framework for understanding “readiness” for PA, and how barriers and facilitators to PA possibly relate to it.

### 1.5 The transtheoretical model of behaviour change

The TTM is a model used frequently in behaviour change modelling (Johnson & Cook, 2014; Hashemzadeh et al., 2019). It was developed by the researchers Prochaska and DiClemente in the late 1970s in Rhode Island (LaMorte, 2019). The TTM suggests that people have different readiness for change and move through a series of stages in their attempt to change
behaviour. Stages of change is the central construct of the TTM. In this construct, people move through five stages (Figure 2). Precontemplation is the earliest stage, where people are not intending to take action in the next 6 months. This may be because they are demoralised from previous failed attempts at changing behaviour, they are unaware or under-aware of the need to change. The next stage is contemplation, where people are getting ready to make a change and intend on making one in the next six months. In this stage there is ambivalence because, although individuals are more aware of the benefits of changing, they are also acutely aware of the barriers or cons of changing. The next stage is preparation and people in this stage are ready to take action. Action follows, and people in this stage have been engaging in action for less than six months. Finally, maintenance, where people have been engaging in a new behaviour for more than six months (Prochaska & DiClemente, 1982). Behaviour change usually is non-linear as Figure 2 illustrates and it is possible to return to previous levels (Johnson & Cook, 2014).

The model supports an individual to progress through stages of change with the help of three different constructs: decisional balance, processes of change and self-efficacy (Johnson & Cook, 2014, Hashemzadeh et al., 2019). The first construct, decisional balance, refers to weighing up the benefits of change compared to the costs of change. When the benefits exceed the costs, the likelihood of adopting a behaviour increases, which is reflected by transitioning from one stage to another (Johnson & Cook, 2014). In the second construct, which is processes of change, strategies and techniques can be used to change behaviour and reinforce changes that have been made (Johnson & Cook, 2014). The last construct, self-efficacy, refers to an individual's belief that they can meet and sustain the changes, even in challenging situations. This increases when moving along the continuum of stages and can be supported by the processes of change (Johnson & Cook, 2014).

The TTM has been used in different health areas to support behaviour change such as smoking cessation, diet habits or mammography screening (Sutten, 2007 and Prochaska, Redding & Evers, 2015) and also specifically to enhance PA in different populations (Romain

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**Figure 2** The circular process of stages of change. An individual’s relationship with a desired behaviour can move from one stage to another (e.g. preparation to action). Created by the authors.
et al., 2018 and Hutchison et al, 2014). In the PA context, the TTM has been researched related to exercise behaviours in college students or university students (Farmanbar et al., 2013, Mizutani et al., 2012), nurses and midwives (Moattari et al., 2013) and industry workers (Moeini et al., 2010). Most of these studies focus on the effectiveness of TTM on behaviour change facilitation (Hashemzadeh et al., 2019). Research has shown that tailored interventions related to TTM have a bigger chance of success (Prochaska, Redding & Evers, 2015). In the wider category of rheumatology, previous research has linked TTM to RA (Henchoz et al., 2013). A cross-sectional analysis was conducted in a RA cohort to determine the distribution of exercise stage of change (Henchoz et al., 2013). It showed that of the 89 study participants, 34% were in precontemplation, 13% were in contemplation, 6% in preparation, 2% in action and 45% in maintenance.

In the context of this research, the TTM is a conceptual framework. It provides an understanding of how behaviour change occurs over time and that perceived facilitators and barriers may differ during this process.

1.6 Problem formulation

Adequate PA for individuals with axSpA is highly recommended for the management of the disease and physiotherapists play an important role in achieving it. However, this patient group has shown to be less physically active and have more comorbidities compared to a healthy population. Evidence-based knowledge about facilitators and barriers towards PA in individuals with axSpA is important to support behaviour change in clinical practice and make ongoing physiotherapy more successful.

Previous research discusses the different types of facilitators and barriers patients with axSpA possibly experience, such as disease symptoms, psychological states, and environmental and social constructs. However, there is a lack of quantitative and qualitative research on axSpA patients regarding PA and especially in the South African setting. This leads to a lack of perspectives and understanding of PA behaviour, especially in the South African context. Identifying perceived facilitators and barriers to PA in individuals with axSpA in relation to the SOC and with the richness of qualitative data can guide practitioners to support behaviour change.

To the authors’ knowledge, there has been no research on barriers and facilitators for physical activity in South African axSpA patients. In addition, it has been recommended in previous research to explore facilitators and barriers in other socioeconomic and cultural settings as it may provide different insights. The unique socioeconomic and health context of South Africa could impact these themes, and therefore there is a need to better understand this topic in this context.
2 AIM

The aim is to explore perceived facilitators and barriers to PA in relation to the SOC in individuals living with axSpA in South Africa.

2.1 Research questions

1. **Quantitative:** Which facilitators and barriers to PA are perceived as predominant in relation to stages of change in individuals with axSpA living in South Africa?
   1.1. What facilitators and barriers are perceived as predominant in participants with axSpA in South Africa?
   1.2. How do facilitators and barriers correlate to stages of change in the South African axSpA population?
   1.3. How do demographic data, such as age, gender, highest education, marital status, ethnic background, and income, relate to perceived facilitators and barriers?

2. **Qualitative:** In what way do individuals with axSpA living in South Africa perceive their physical activity being impacted by barriers and facilitators?

3. **Mixed:** How does the experience of facilitators and barriers impacting PA among individuals with axSpA living in South Africa align with and deepen the understanding of the quantitative results?
3 METHODS

An explanatory sequential mixed methods design was chosen. This design includes collecting quantitative data first and then qualitative data explaining the quantitative data (Creswell and Creswell, 2018). Figure 3 is an overview of the procedure and product of each stage in this design.

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<tr>
<th>PHASE</th>
<th>PROCEDURE</th>
<th>PRODUCT</th>
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<tbody>
<tr>
<td>Quantitative data collection</td>
<td>Cross-sectional web-based survey (N=65)</td>
<td>• Numeric data</td>
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<tr>
<td>Quantitative data analysis</td>
<td>• Tests for normality</td>
<td>• Descriptive statistics, missing data, normality</td>
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<td></td>
<td>• Frequencies</td>
<td>• Total IFAB scores, Spearman’s rho</td>
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<tr>
<td></td>
<td>• Correlation analysis</td>
<td>• Summary of findings</td>
</tr>
<tr>
<td>Qualitative sample collection; interview protocol development</td>
<td>• Purposefully selecting 2 participants from each group (N=10) based on typical responses and maximal variation principle</td>
<td>• Qualitative sample (N=10)</td>
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<tr>
<td></td>
<td>• Developing interview questions</td>
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<tr>
<td>Qualitative data collection</td>
<td>• Zoom interviews with 10 participants</td>
<td>• Text data (interview transcripts, notes)</td>
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<tr>
<td>Qualitative data analysis</td>
<td>• Coding and content analysis</td>
<td>• Meaning units, condensed meaning units, sub-categories and categories</td>
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<tr>
<td></td>
<td></td>
<td>• Summary of findings</td>
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<tr>
<td>Integration of the quantitative and qualitative results</td>
<td></td>
<td>• Integration of results</td>
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<tr>
<td></td>
<td>• Interpretation and explanation of the quantitative and qualitative results</td>
<td>• Discussion</td>
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<td>• Considerations</td>
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*Figure 3 Phases of the explanatory sequential design*

The following sections provide details about the quantitative and qualitative methods.
3.1 Quantitative phase

3.1.1 Sample

A non-randomized convenience sample was retrieved from the Axial Spondyloarthritis Association of South Africa via their private Facebook group and association membership with over 800 combined members. Inclusion criteria included age above 18 years and a confirmed axSpA diagnosis based on the classification criteria, ASAS classification criteria as described in the background section (Rudwaleit et al., 2009). In addition, eligible participants had to have no physiological participation restrictions from co-morbidities and have the ability to walk, as well as read, write and speak in English. The sample size for the quantitative phase relates to a power calculation and was done a priori to ensure significance before the study started (Field, 2018). The calculation was performed using the free software G*Power for statistical power analysis (Faul et al., 2007). To demonstrate a link between the IFAB and SOC with a relative risk of 0.05, 61 patients were needed (with α 0.05 and β 0.20). We estimate the size of the correlation (rho = 0.35) based on previous research (Cresswell and Cresswell, 2018) by Davergne et al. (2021) where it was found that the global score of the IFAB questionnaire was significantly linked to stage of behaviour change with a correlation of 0.35 with a p < 0.001.

A total of 75 participants with axSpA participated in the survey. 10 people had missing answers (missing or prefer not to answer) in the IFAB section and thus have been excluded. A total of 65 participants have been included in the analysis and results. According to Carter and Lubinski (2016), there are different procedures for handling missing data, and when there is no pattern from the participants leaving missing data like in this case, there is no systematic bias, and they can be excluded from the analysis.

An overview of the demographic properties of the sample can be found in Table 1 below. Fifty-five (84.6%) are female and 10 are male (15.4%), the mean age is 43 years old. Of all participants, 53 (81.5%) are working including both self-employed and paid employees. 54 (83%) participants are white and 63 people (97%) have private health insurance.

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Frequency (Percent)</th>
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<tbody>
<tr>
<td>Gender</td>
<td></td>
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<tr>
<td>Male</td>
<td>10 (15.4%)</td>
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<tr>
<td>Female</td>
<td>55 (84.6%)</td>
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<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>21-25</td>
<td>1 (1.5%)</td>
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<tr>
<td>26-30</td>
<td>6 (9.2%)</td>
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<td>31-35</td>
<td>5 (7.7%)</td>
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<td>36-40</td>
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<td>41-45</td>
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<td>46-50</td>
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<tr>
<td>51-55</td>
<td>4 (6.2%)</td>
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<td>56-60</td>
<td>7 (10.8%)</td>
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<tr>
<td>61-65</td>
<td>6 (9.2%)</td>
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<tr>
<td>Employment</td>
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</tr>
<tr>
<td>Working (paid employee)</td>
<td>31 (47.7%)</td>
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<tr>
<td>Working (self-employed)</td>
<td>22 (33.8%)</td>
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<tr>
<td>Not working (retired)</td>
<td>4 (6.2%)</td>
</tr>
<tr>
<td>Not working (Disabled)</td>
<td>4 (6.2%)</td>
</tr>
<tr>
<td>Not working (other)</td>
<td>3 (4.6%)</td>
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<tr>
<td>Prefer not to answer</td>
<td>1 (1.5%)</td>
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<td>No formal schooling</td>
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<tr>
<td>High school completed</td>
<td>14 (21.5%)</td>
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<tr>
<td>College/University completed</td>
<td>27 (41.5%)</td>
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<tr>
<td>Postgraduate degree</td>
<td>23 (35.4%)</td>
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<table>
<thead>
<tr>
<th>Ethnic/racial background</th>
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<tbody>
<tr>
<td>Black</td>
<td>1 (1.5%)</td>
</tr>
<tr>
<td>Coloured (mixed race)</td>
<td>4 (6.2%)</td>
</tr>
<tr>
<td>White</td>
<td>54 (83.1%)</td>
</tr>
<tr>
<td>Indian</td>
<td>3 (4.6%)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (3.1%)</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>1 (1.5%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Private health insurance</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>63 (96.9%)</td>
</tr>
<tr>
<td>No</td>
<td>2 (3.1%)</td>
</tr>
</tbody>
</table>

### 3.1.2 Data collection

The data collection was a web-based survey including the IFAB questionnaire, SOC questionnaire of PA and demographic data.

The IFAB (Appendix A), as mentioned previously, is a self-administered questionnaire developed to assess facilitators and barriers in rheumatoid arthritis (RA), axial spondyloarthritis (axSpA), and/or psoriatic arthritis (Davergne et al., 2020). It consists of 10 questions, with three questions focusing on facilitators, three questions on barriers, and four questions addressing items that could be either barriers or facilitators. The questionnaire encompasses four themes: psychological status (six questions), social support (two questions), disease (one question), and environmental factors (one question). Participants indicate for each item (e.g. lack of motivation) whether it has encouraged them, prevented them, or had no impact on their physical activity in the previous month. The scoring of the questions depends on their nature. Questions related to facilitators are scored from 0 to +10, questions related to barriers are scored from -10 to 0, and questions related to either barriers or facilitators are scored from -10 (barrier) to +10 (facilitator). The total IFAB score can range from -70 to +70. Davergne et al. (2020) discuss that below -5 justifies an intervention as barriers are dominant. This scoring system includes both the direction (either facilitator or barrier) and intensity of the impact of these factors on PA. The feasibility of using the IFAB questionnaire has been demonstrated (Davergne et al., 2020). It has undergone primary validation, showing good internal consistency with a Cronbach’s alpha coefficient of 0.69. The primary validation study was conducted in France, but the development process involved experts from France,
Norway, and England, ensuring diverse input. To validate the questionnaire, a systematic review of barriers and facilitators to physical activity was initially conducted. Key themes were extracted from this review and subsequently underwent face validity assessment by 11 experts. Additionally, debriefing sessions were held with 14 patients to refine the instrument and ensure its relevance to the target population. The psychometric properties of the IFAB questionnaire were evaluated through convergent validity analysis, to assess the degree to which a new measurement instrument (in this case the IFAB questionnaire) correlates with existing measures that are theoretically related. This analysis involved assessing the correlation of the questionnaire with three established measures: the modified Health Assessment Questionnaire (mHAQ), the Fear-Avoidance Beliefs Questionnaire subscale for physical activity, and the Tampa Scale for Kinesiophobia. Reliability measurements were satisfactory with an interclass correlation coefficient (ICC) of 0.79 (95% confidence interval) examined with a test-retest with one-week interval (Davergne et al., 2020).

The SOC questionnaire (Appendix B) explores an individual’s readiness to be physically active according to the five different stages. The SOC was developed together with the TTM as a core construct within the model (Prochaska, Redding & Evers, 2015). Bulley et al. (2007) published a critical review exploring the validity of the SOC questionnaire and concluded that is it a useful questionnaire when used in a behavioural context as it measures perceived physical activity. Test-retest reliability of the SOC demonstrated satisfactory results with Cohen’s kappa ranging between 0.45 and 0.52 (Donovan et al., 1998, Leslie et al., 2003). Dannecker et al. (2003) investigated the validity of the Stages of Exercise Change Questionnaire and found some evidence of validity. Significant differences were observed among different stages of change for factors such as self-reported strenuous and moderate exercise behaviour, estimated aerobic fitness, and various components of the TTM. However, the expected patterns of stage differences were only found in relation to self-reported strenuous exercise and not for aerobic fitness and BMI (Dannecker et al., 2003). There are therefore risks using it as there is no clear consensus in the literature. In this thesis, the Stages of Exercise Change Questionnaire is used as a self-report measure, of which validity has been found (Dannecker et al., 2003). The questionnaire used in this research was provided by the Health Behaviour Change Research (n.d.). The SOC includes one question with five answer possibilities. The question is if they engage in regular physical activity according to the definition of the WHO for physical activity. Participants can then choose between five alternatives. Depending on the answer chosen, it translates into five different categories (Precontemplation, Contemplation, Preparation, Action, and Maintenance) as visible in Appendix B. To be in Action and Maintenance translates into being physically active according to the WHO recommendations which have been discussed earlier. In the context of this research, this questionnaire is seen fit as it informs about what perceived physical activity behaviour is established and their readiness to change behaviour.

Demographic data (Appendix C) was collected to provide insights into the characteristics of the sample, enabling the generalisability of the results to other populations with axSpA (O’Dwyer, 2016). Further, sheds light on possible relationships between these variables and IFAB-scores.
3.1.3 Procedure

Information about the survey was posted on the Axial Spondyloarthritis Association of South Africa (ASASA), a private Facebook group with an infographic summary (Appendix D). When participants followed the link provided, they reviewed a short information text (Appendix E) and got the chance to read a longer study information sheet (Appendix F). Finally, they were asked to consent. Once participants had consented, they could fill out the survey.

To ensure a response rate, the authors decided to adapt the four-step recruitment phase as recommended by Creswell and Creswell (2018) for email sent communication:

1. A short-written post and video about the upcoming survey was posted on the axSpA Facebook Group
2. The survey link was posted on the axSpA Facebook Group and sent in an email to all ASASA association members when it was launched.
3. Follow up after four days: repeat step 2.
4. An additional post containing the same information was posted after three days with an update of how many participants had filled out the survey and how many were needed. A link to the survey was in the description of the post.

3.1.4 Data analysis

To answer the quantitative research questions about predominant facilitators and barriers, three different statistical analyses have been chosen. Firstly, to answer research question 1.1., descriptive statistics with SPSS were used to display frequencies on how often a question in the IFAB was perceived as a facilitator, barrier or neither. Secondly, to test the relationships between facilitators, barriers and SOC (research question 1.2.), normality of the data (Appendix G) was checked to choose an appropriate test (Field, 2018). The total IFAB scores followed a normal distribution and were measured on a ratio scale. However, since the relationships with SOC involved ordinal data, Spearman’s rho test, a non-parametric test, was selected. Additionally, since not all the different questions in the IFAB displayed a normal distribution, the correlations between SOC and these specific facilitators and barriers were also assessed using Spearman’s rho correlation test. This test assigns ranks to values to evaluate relationships. Possible minus values in the IFAB are handled the same way as plus values and do not pose any issues for this test (Field, 2018). Third, to display relationships between IFAB scores and demographics, visualizations with Boxplots were chosen. As the IFAB scores were a continuous variable and demographic data in either categorical or ordinal scale, visualization techniques were seen fit to indicate possible relationships (Field, 2018). Appendix H provides information on how the quantitative data was analysed.

3.1.5 Quantitative results inform the qualitative methods

In an explanatory sequential design, the results of the quantitative phases are considered so that the follow-up qualitative phase explains and expands on the results from the initial qualitative phase (Creswell and Plano, 2017). The quantitative results were examined closely to explore interesting or surprising findings. The question arising was if facilitators and
barriers towards PA in this population are highly individual or if the IFAB may not be representing essential options. The approach taken was to gain a deeper understanding of facilitators and barriers in participants.

3.2 Qualitative phase

The characteristics of the method are presented in chronological order to provide a comprehensive overview of the qualitative methodology used in this degree project. The headings "sample," "data collection," "procedure," and "data analysis" are used to organize and provide insight into each stage of the process.

3.2.1 Sample

The aim for the sample size for the qualitative data was between 10 to 12 interviews to gain in-depth understanding of facilitators and barriers towards PA and create richness of data (Creswell & Creswell, 2018).

A total of 54 (83.1%) participants said that they are willing to be contacted for a follow-up interview. As the focus was to gain a deeper understanding of facilitators and barriers, the authors purposefully identified participants who represented the sample. This was achieved by retrieving participants that had IFAB scores typical of the average scores for each SOC group as similarly performed by Ivankova and Stick (2007) and discussed in Creswell and Plano (2017). The upper quartile and lower quartile total IFAB scores were identified for each SOC group, and we purposefully selected 15 “typical” participants based on typical responses and maximal variation principle (Creswell and Plano, 2017). Of the 15 people, 10 people responded that they were still available for an interview.

The age of participants ranged from 26 to 61 years old. The interviews incorporated three males and seven females. A summary of information relating to those interviewed is shown below in Table 2.

Table 2 Additional data of those interviewed.

<table>
<thead>
<tr>
<th>Stage of change</th>
<th>Gender</th>
<th>Diagnosis year</th>
<th>Delay to diagnosis (years)</th>
<th>Age</th>
<th>Total IFAB score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintenance</td>
<td>Male</td>
<td>1980</td>
<td>5</td>
<td>61</td>
<td>29</td>
</tr>
<tr>
<td>Maintenance</td>
<td>Male</td>
<td>2014</td>
<td>0</td>
<td>36</td>
<td>19</td>
</tr>
<tr>
<td>Action</td>
<td>Female</td>
<td>2022</td>
<td>1</td>
<td>46</td>
<td>17</td>
</tr>
<tr>
<td>Action</td>
<td>Female</td>
<td>2011</td>
<td>6</td>
<td>51</td>
<td>-10</td>
</tr>
<tr>
<td>Stage</td>
<td>Gender</td>
<td>Year</td>
<td>Age 1</td>
<td>Age 2</td>
<td>Difference</td>
</tr>
<tr>
<td>---------------</td>
<td>--------</td>
<td>------</td>
<td>-------</td>
<td>-------</td>
<td>------------</td>
</tr>
<tr>
<td>Preparation</td>
<td>Female</td>
<td>2021</td>
<td>0</td>
<td>26</td>
<td>-2</td>
</tr>
<tr>
<td>Preparation</td>
<td>Female</td>
<td>2015</td>
<td>25</td>
<td>61</td>
<td>19</td>
</tr>
<tr>
<td>Preparation</td>
<td>Female</td>
<td>2022</td>
<td>20</td>
<td>36</td>
<td>-12</td>
</tr>
<tr>
<td>Contemplation</td>
<td>Female</td>
<td>2008</td>
<td>5</td>
<td>41</td>
<td>6</td>
</tr>
<tr>
<td>Contemplation</td>
<td>Female</td>
<td>2020</td>
<td>3</td>
<td>41</td>
<td>-26</td>
</tr>
<tr>
<td>Pre-contemplation</td>
<td>Male</td>
<td>2022</td>
<td>12</td>
<td>61</td>
<td>-34</td>
</tr>
</tbody>
</table>

### 3.2.2 Interview data collection

To gain a deeper understanding of the facilitators and barriers to physical activity (PA), interviews were conducted. These interviews, conducted via Zoom, lasted between 30 to 45 minutes and were carried out by one of the researchers. Recordings of the interviews were made using an external recorder and transcribed verbatim. The interview protocol can be found in Appendix J, providing more details about the interview process.

The interviews were designed to be semi-structured, allowing for a comprehensive exploration of participants’ thoughts, feelings, motivations, and experiences related to physical activity or inactivity (Huang et al., 2022). By employing a semi-structured format, participants had the freedom to delve into their unique experiences and emotions associated with physical activity (Adams, 2015). Consequently, the qualitative data collected through these interviews offered a deeper insight into the specific facilitators and barriers to PA, taking into account cultural and environmental factors.

### 3.2.3 Interview procedure

The participants selected were directly contacted by one of the authors. The content of the email can be found in Appendix K. A short follow-up email was sent four days later if participants had not yet replied. Before the interview, the authors discussed with one another interview questions, presence and approach. The first interview was analysed separately and coded and discussed together to create a common coding standard. Interviews started on the 4th of April 2023 and were completed on the 5th of May 2023. There were approximately 3 months between the end date of the survey and the start date of the interviews.

### 3.2.4 Data analysis of interviews

A conventional content analysis approach was utilized to analyse the interviews. This method, as defined by Graneheim and Lundman (2003), is a qualitative research method that involves systematically examining textual data. The analysis focused on the manifest content, which refers to the obvious and clear components extracted from the data, as outlined by Graneheim and Lundman (2003). A total of 10 interviews were analysed.
inductively, meaning that the analysis process involved exploring the interview data and allowing themes and patterns to emerge from the data itself rather than being guided by preconceived theories or frameworks. Graneheim and Lundman's (2003) approach was employed to systematically analyse the data, aiming to identify patterns and categories rigorously. The analysis had a low level of abstraction, suggesting that it stayed close to the explicit content of the interviews without seeking deeper interpretations. Furthermore, the analysis did not involve interpreting the underlying meaning of the data. The interview text was categorized into two main content areas: barriers to physical activity and facilitators to physical activity. These categories were derived from the participants' responses to the question, "What supports you and what hinders you from doing physical activity?" This question aimed to evoke participants' experiences and perspectives related to physical activity.

The interviews were listened to repeatedly to obtain a sense of the broad picture. The meaning units about the participants’ experiences of barriers or facilitators were then extracted and synthesised into one document. This was divided into meaning units that were then condensed and labelled with a code. The whole context was considered during this process. The various codes were first grouped into sub-categories. Out of these, seven categories were extracted that shared common content and meaning. A process of reflection and discussion followed to agree about how to categorise the codes (Graneheim & Lundman, 2003). An example of this coding process for one category, “inappropriate care” is provided in Table 3 which was in the content area of barriers towards PA.

Table 3 Sample of the qualitative analysis for the category, “inappropriate care” from participants’ experiences of challenges to PA presented as sub-categories, codes, condensed meaning units and meaning units

<table>
<thead>
<tr>
<th>Meaning units</th>
<th>Condensed meaning units</th>
<th>Codes</th>
<th>Sub-categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>And that was accurate, but because it took it took many years to get to the diagnosis. I wish I had been diagnosed earlier</td>
<td>Took many years to get diagnosed</td>
<td>Slow diagnosis</td>
<td>Delay to diagnosis</td>
</tr>
<tr>
<td></td>
<td>Wishing for an earlier diagnosis</td>
<td>Disappointment in slow diagnosis</td>
<td></td>
</tr>
<tr>
<td>She [rheumatologist] never really sort of pushed the idea that exercise would be a good idea or what exercise would be a good idea. And I worked closely with my physiotherapist and the rheumatologist. And I for the life of</td>
<td>She never pushed that exercise would be good or what exercise would be good.</td>
<td>Rheumatologist not encouraging exercise</td>
<td>Poor information</td>
</tr>
<tr>
<td></td>
<td>Healthcare professionals did not emphasise exercise</td>
<td>Exercise not emphasized</td>
<td></td>
</tr>
</tbody>
</table>
me cannot remember that emphasis was placed on exercises.

I was, you know, I was actually told more to behave myself. And, you know, in the sense that they said I was being too busy and too active, and that because of being so busy and active I was causing a lot of mechanical pain the whole time.

[I was] told to you know, don’t be so active. You’ve got to calm down, rest, you know, that type of thing.

<table>
<thead>
<tr>
<th>Instructed to be less active</th>
<th>Instructed to rest</th>
<th>Avoidant behaviour encouraged</th>
</tr>
</thead>
<tbody>
<tr>
<td>Told not to be so active, rather rest</td>
<td>Rest encouraged</td>
<td></td>
</tr>
</tbody>
</table>

3.3 Ethical considerations

Several ethical considerations as suggested by Creswell and Creswell (2018) have been considered. Ethical considerations apply to all parts of this research and include thoughts in planning the study, conducting the study, the data storage, analysing the data and presenting the study. It also applies to both the quantitative and qualitative parts of the study, but different considerations can be more relevant for one or the other (Creswell and Creswell, 2018).

3.3.1 Participant consent and data storage

All participants of the survey and the interviews had access to a written text which explains the purpose of the study, including what is required when taking part and possible risks and benefits of the study. The participants were informed that taking part in the study is voluntary and they can withdraw consent at any time.

Data was stored anonymously. The researchers kept participants’ data confidential, and password protected. It was only possible to link research data with participants personally via a secure identification list kept on an external USB kept by Anna-Tina.

3.3.2 Mitigating ethical risks

An ethical consideration when conducting the interviews was that there was a risk that participants might want to please Lauren, one of the authors and vice-chairperson of the Axial Spondyloarthritis Association of South Africa (2018). However, as this is an explorative study and not an intervention study there is little conflict of interest with regards to the outcome of the study. The relationship she has with the group is organisational,
administrative, and educational and she does not have personal or professional relationships with any members. To strengthen internal validity, the researchers reflected on and clarified possibility for bias to ensure transparency and self-reflection (Cresswell & Cresswell, 2018). As Lauren is also the co-administrator in their Facebook support group, it is likely that the participants will know her role and thus could infer bias. To reduce this bias, survey participants were anonymous to Lauren. Anna-Tina was the only one who had access to the identifying spreadsheet. It could be seen as a strength that Lauren has spent a prolonged time in the field (Cresswell and Cresswell, 2018), and therefore already has an in-depth understanding of facilitators and barriers. The more experience a researcher has with the participants, the more valid and reliable the results are likely to be (Cresswell and Cresswell, 2018).

Considering that Anna-Tina, the second author, is not culturally connected to the members, there was a risk that she may miss nuances related to the culture during the interviews. This could have led to misunderstandings during the conversation or the participant feeling misunderstood. However, the interview questions were not targeting sensitive information and all interviews were listened to by both Lauren and Anna Tina to ensure that the answers were understood correctly. In each interview, participants were requested to be honest, and the authors stated their intention of creating a space of non-judgement to ensure the participant’s well-being and trust towards the authors. Participants had the option to keep in touch with one of the authors to ask further questions. This supported the welfare of participants.

When analysing and presenting the data, further ethical considerations were considered to ensure that participants’ views were reflected honestly and transparently, without supporting any of the authors’ own opinions. The results of the participants remained anonymous, with no possibility of tracing which participant could have said what for the reader. Throughout the process, the authors met with their supervisor to discuss any possible ethical issues that could arise. Also, the researchers reviewed the ethical regulations guidelines in Sweden (The Ethics Review and Appeals Board, n.d) and followed its content.
4 RESULTS

4.1.1 Results from the survey

The survey results identified the most prominent perceived facilitators as, “knowledge of the benefits for health”, followed by “knowledge of the benefits for mood”. This indicates that knowledge was an important part of helping participants to be physically active. The most predominant perceived barrier was “level of symptom”, followed by “lack of motivation”. It shows the perceived barrier to PA in relation to disease symptoms such as pain or fatigue and motivation in general. The two most prominent barriers that had no impact on PA were “A belief that PA will make symptoms worse” and “lack of knowledge of which exercise to do”. In addition, the facilitators that had no impact on PA were, “weather conditions,” support from others” and “support/advice from healthcare professionals”. Table 4 shows the frequency and percentage of answers for the IFAB questionnaire.

Table 4 Frequencies of quantitative results per question

<table>
<thead>
<tr>
<th>Question</th>
<th>Encouraged me</th>
<th>Prevented me</th>
<th>Had no impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1-Q4 either barriers or facilitators</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q1) Levels of symptoms</td>
<td>15 (23.1%)</td>
<td>43 (66.2%)</td>
<td>7 (10.8%)</td>
</tr>
<tr>
<td>Q2) Weather conditions</td>
<td>1 (1.5%)</td>
<td>22 (33.8%)</td>
<td>42 (64.6%)</td>
</tr>
<tr>
<td>Q3) Support from others</td>
<td>23 (35.4%)</td>
<td>6 (9.2%)</td>
<td>36 (55.4%)</td>
</tr>
<tr>
<td>Q4) Support and/or advice from healthcare professionals</td>
<td>28 (43.1%)</td>
<td>2 (4.6%)</td>
<td>34 (52.3%)</td>
</tr>
<tr>
<td>Q5-Q7 Barriers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q5) Belief that PA will make symptoms worse</td>
<td>n/a</td>
<td>13 (20%)</td>
<td>52 (80%)</td>
</tr>
<tr>
<td>Q6) Lack of motivation</td>
<td>n/a</td>
<td>42 (64.5%)</td>
<td>23 (35%)</td>
</tr>
<tr>
<td>Q7) Lack of knowledge of which exercise to do</td>
<td>n/a</td>
<td>10 (15.4%)</td>
<td>55 (84%)</td>
</tr>
<tr>
<td>Q8-Q10 Facilitators</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q8) Knowledge of the benefits for health</td>
<td>45 (69.2%)</td>
<td>n/a</td>
<td>20 (30.8%)</td>
</tr>
<tr>
<td>Q9) Knowledge of the benefits for mood</td>
<td>39 (60%)</td>
<td>n/a</td>
<td>26 (40%)</td>
</tr>
<tr>
<td>Q10) Confidence on how to do it safely</td>
<td>33 (50.8%)</td>
<td>n/a</td>
<td>32 (49%)</td>
</tr>
</tbody>
</table>

*n/a=not applicable
To explore the relationship between facilitators and barriers and different SOC, a two-tailed bivariate correlation analysis showed a significant correlation between total IFAB scores and the five different SOC ($r=-.63$, $p<.001$). This means that participants who perceived more facilitators than barriers to PA were more likely to be in a later SOC and vice versa.

There were six significant facilitators and barriers which correlated with SOC tested with a two-tailed bivariate correlation analysis. The values can be found in Table 5. Disease symptoms, lack of knowledge and knowledge about the benefits for mood showed the strongest correlation to the different SOC ($p<.001$). This indicates that perceiving these items as facilitators or weak barriers corresponded to higher SOC of behaviour change.

**Table 5** Correlation between the scores of the IFAB and SOC

<table>
<thead>
<tr>
<th></th>
<th>Facilitators or Barriers</th>
<th>Barriers</th>
<th>Facilitators</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Q.1</td>
<td>Q.2</td>
<td>Q.3</td>
</tr>
<tr>
<td>Symptoms</td>
<td>- .56</td>
<td>- .09</td>
<td>- .24</td>
</tr>
<tr>
<td>Weather</td>
<td>.40</td>
<td>.50</td>
<td>.06</td>
</tr>
</tbody>
</table>

The average IFAB score in the sample was 4.54, with a standard deviation of 18.75. The scores ranged from -34 to +48. A summary of the distribution of SOC in the sample can be found in Figure 4. The distribution of exercise stages of change was as follows: precontemplation (3.4%), contemplation (26.2%), preparation (18.9%), action (13%), and maintenance (n = 38.5%). The summation of the participants in the maintenance and action stages show that 51.46% of the sample were physically active according to the WHO recommendations. On the contrary, 48.5% of participants were in the inaction stages of change, namely precontemplation, contemplation and preparation.

![Figure 4](image-url)
To explore relationships between different demographics and facilitators and barriers, visual information is provided in Figure 5.

Figure 5 Visualization of the total IFAB scores in relation to demographics.
The boxplot showing IFAB scores and “education”, imply that participants in our survey with a lower level of education perceived more barriers towards PA than participants with higher levels of education. There was also a trend between total IFAB scores and age, implying that the middle-aged group perceived more barriers towards PA compared to younger and older participants in the survey.

The data relating to IFAB items that had “no impact” was surprising. The modal answer to five out of 10 IFAB questions was “had no impact”. This included “weather conditions”, “support from others”, “support/advice from healthcare professionals”, “belief that PA will make symptoms worse” and “lack of knowledge of what exercise to do”.

4.1.2 Results of the qualitative content analysis

The content analysis explored how South African individuals with axSpA perceive the impact of barriers and facilitators on their physical activity. The four categories related to the content area of barriers towards PA were 1) inappropriate care, 2) an unsupportive external environment, 3) mindset and 4) the interaction of symptoms. The three categories related to the content area of facilitators were 1) mental strength, 2) symptom relief and 3) supportive external environment. These content areas will be described below, and quotations will be presented to provide further explanation.

Content area of perceived barriers towards PA

The first category, “inappropriate care”, revealed statements related to delay in diagnosis and misbeliefs about exercise with axSpA. Participants expressed that healthcare professionals were inaccessible and indirective, stating that the role of physical activity in the management of axSpA was not emphasised: “And I worked closely with my physiotherapist and the rheumatologist. And I for the life of me cannot remember that emphasis was placed on exercises”. Some participants felt that they received poor information and fear-inducing advice about physical activity which led to the experience of PA avoidance. They were advised to be less active and, in some cases, rest, to reduce the risk of a flare. Statements from healthcare professionals were received with feelings of fear and guilt:

*I was, you know, I was actually told more to behave myself. And, you know, in the sense that they said I was being too busy and too active, and that because of being so busy and active I was causing a lot of mechanical pain the whole time. [I was] nearly told to you know, don’t be so active. You’ve got to calm down, rest.*

The second category, “unsupportive external environment”, contains statements about the role of different environmental barriers to PA. Participants expressed inaccessibility to both medical specialists and exercise areas, lack of social support from friends and family, bad weather interfering with intentions to exercise and finally, challenging working environments. Quotes such as “in South Africa, we have so few rheumatologists that there’s just not enough” or “doctors are very far away” were mentioned in connection to the accessibility of healthcare. Other participants mentioned that they felt unsafe walking alone and there was the high cost of exercise classes which hindered physical activity. Participants
also raised concerns about having either a significant number of working hours, or high stress which led to a prioritisation of professional goals over PA.

The third category was "mindset", which encompasses mental barriers and negative self-talk. This includes expressions from participants of low self-efficacy, self-criticism, and a tendency to focus on self-defeating comparisons to others, which demotivates the participants and acts as a perceived barrier to PA. This statement expresses comparison to others who have different PA capabilities: “But watching people who can do, you know, a gym session and a Pilates session and a 5k is almost self-defeating for me, because I look at that and go, oh, I'll never do that.” Several participants mentioned difficulties with prioritising exercise and motivating themselves to start. Others expressed overwhelm with the burden of axSpA symptoms which had a negative impact on their PA behaviour:

[There] is a feeling of being overwhelmed. It’s just, “how am I going to get through this day?” There’s this complete feeling of being overwhelmed. And I mean, you know, “how do I put the tekkies [sneakers] on?” And then the mental battle starts...

The fourth category, “interactions of symptoms”, uncovered the difficulty of balancing different axSpA symptoms which was expressed as a perceived barrier to PA. In some cases, there was a delicate balance between medication or treatment side effects and PA, or in others, the idea that exercise may help one aspect but hinder another. “Medication helps pain, but [another medication] increases fatigue and therefore makes it difficult to exercise”, was expressed. Other participants shared that for some manifestations of axSpA, such as joint pain and stiffness, exercise was encouraged, but for other aspects, rest was encouraged. A participant mentioned, “It’s a very delicate balance between what is good and not good for me.” In some other instances, there was a balance between activities of daily life, PA and avoiding a flare. Several mentioned the negative impact disease symptoms such as fatigue and pain had on their overall PA behaviour. Further, experiencing an increase in symptoms after exercising led to frustration and a negative experience of PA.

**Content area of perceived facilitators towards PA**

Here the first category is “mental strength” which encompasses the perceived motivation to do PA through meaning and purpose, a positive mindset and doing PA one enjoys. For example, having relationships with family members created meaning in doing PA. This was expressed by a person with axSpA who is contemplating her possible future role as a grandmother:

*I sort of start thinking of, gee whiz, I hope I have grandchildren. I’m going to be able to pick them up and play with them [...]. So it’s actually a motivation for me. I want to strengthen myself and keep mobile [...], because I still want to live a full life. So that is a big motivation for me.*

In addition, goals and achievements created purpose for PA. Setting goals to attain by a certain period created feelings of challenge and commitment and supported accomplishment and feelings of satisfaction. This included both long and short-term goals related to activities of daily life, such as “I’ll walk a kilometre around the block, or I’ll go shopping with my kids.
That is an achievement”. These goals were supported by positive mindsets held by participants. Participants expressed the belief that to achieve success and maintain motivation, it was necessary to overcome challenges and adopt a positive outlook. This category contains statements about the importance of not allowing setbacks or negative thoughts to hinder progress, instead choosing to view exercise as compulsory and essential to their routine. Additionally, participants acknowledged the need for flexibility in scheduling and adapting to their circumstances, finding opportunities for physical activity in everyday tasks. Furthermore, individuals expressed a determination to defy limitations and prove doubters wrong, reflecting a resilient mindset.

The second category, “symptom relief”, expressed the overall benefits to exercise, both for physical and mental health. Participants shared that PA relieves axSpA joint stiffness, improves mental health and that there was a direct connection between experiencing more pain when PA was disregarded:

*It’s just unbelievable. How much better you feel after that. [...] nobody can stressing that how important that is not just for your physical body but also for your brain. [...] the happy endorphins [...] Because if you don’t keep moving, the stiffness overwhelms you within a week.*

Participant mentioned the profound impact it had on supporting mental health. This category also includes support from healthcare professionals, such as specialists and physiotherapists who have provided tools to manage axSpA. One participant mentioned that PA was a non-negotiable part of her axSpA management, as described by her rheumatologist: “The way she said it was, ‘Look like: we have 1) exercise and then 2) that medication we will try you on. You have to do both.’” For some, biologic medication has had a profound impact in creating a pain-free experience of axSpA.

The third category, “supportive external environment”, includes support from family, friends, exercise partners, group exercise classes, online communities, and access to natural spaces such as parks. An emphasis was placed on exercise partners or group classes which provided accountability. One participant mentioned “I managed to find a walking partner... it’s when you made a commitment [that] it’s more difficult to lie in bed... And if you’ve got that commitment, you don’t want to let anyone down.” Online communities were mentioned as having helpful roles in supporting and motivating PA and creating an environment where the participant with axSpA feels seen and heard.

4.1.3 Integration of results

The combined results from the survey and the follow-up interviews indicate that certain facilitators and barriers towards PA are more dominant than others in the South African sample living with axSpA. The interviews reflected these themes as well but further highlighted the role of a positive mindset towards PA and the need for a supportive external environment. It is evident that knowledge about the benefits of PA emerged as a key facilitator in both sets of data. This suggests that well-informed individuals were more likely to engage in PA. Additionally, the survey identified lack of motivation as a significant barrier,
which aligns with the qualitative content analysis's finding about mindset barriers, such as low self-efficacy and negative self-talk.

In the survey, the major barriers towards PA were related to the strength of disease symptoms and lack of motivation towards exercise. Interviewees brought up these themes as well but had further categories emerging such as an unsupportive external environment, inappropriate care from healthcare professionals and barriers related to mental resources and mindset. The most predominant facilitators of PA identified in the survey were participants’ knowledge about its benefits on physical health and mood. The modal answer to five out of 10 IFAB questions was “had no impact”. The interviews reflected these themes as well and further highlighted the role of a positive mindset towards PA and the need for a supportive external environment. Overall, participants were more likely to be in higher SOC related to PA when they perceived more facilitators than barriers towards PA. The burden of disease symptoms, lack of motivation and the benefits for mood were individually highly important as facilitators and barriers in relation to SOC.

Although various relationships were observed among individual facilitators and barriers to physical activity (PA), certain factors such as the severity of symptoms, motivation-related issues, and the positive impact on mood consistently emerged across both the survey and interview analyses.
5 DISCUSSION

5.1.1 Summary of the results

Knowledge about the PA benefits to health and mood were predominant facilitators, indicating the importance of information in promoting PA. Levels of symptoms, and lack of positive mindset were barriers indicated in the survey, showing the impact of disease symptoms and general motivation on PA. Surprisingly, many participants indicated that certain factors, such as beliefs that PA would worsen symptoms and lack of knowledge of appropriate exercises, weather conditions, support from others, support/advice from healthcare professionals, had no impact on their PA behaviour. The participants’ stage of change (SOC) analysis revealed that the majority were in the maintenance stage. The relationship between facilitators or barriers and SOC showed that perceiving more facilitators and fewer barriers was associated with higher SOC, suggesting a positive correlation between these factors and behaviour change. Significant correlations were found between certain facilitators or barriers and SOC, with disease symptoms, lack of knowledge, and knowledge about mood benefits showing the strongest correlations. Lower levels of education were associated with higher barriers to PA, and middle-aged participants perceived more barriers compared to younger and older participants.

The qualitative content analysis examined how individuals in South Africa with axSpA perceive the impact of barriers and facilitators on their PA. Four categories were identified in relation to barriers: 1) inappropriate care, including delay in diagnosis and misbeliefs about exercise with axSpA, stemming from poor information and fear-inducing advice about PA; 2) an unsupportive external environment, encompassing barriers like inaccessibility to healthcare specialists and exercise areas, lack of social support, bad weather, and work-related constraints; 3) mindset, which involved mental barriers such as low self-efficacy, negative self-talk, and a tendency to compare oneself negatively to others; and 4) the interaction of symptoms, highlighting the challenge of balancing different axSpA symptoms, medication side effects, and the impact of exercise on different aspects of the condition.

On the other hand, three categories were related to facilitators: 1) mental strength, which included motivation derived from meaningful goals, positive mindsets, and enjoyment of PA; 2) symptom relief, indicating the benefits of exercise for physical and mental health, relieving joint stiffness and improving overall well-being; and 3) a supportive external environment, comprising family, friends, exercise partners, group classes, online communities, and access to natural spaces, all contributing to accountability and motivation for PA.

The combined results from the survey and interviews indicate that knowledge about the benefits of physical activity (PA) on health and mood is a significant facilitator among individuals with axSpA in South Africa. Lack of motivation and the impact of disease symptoms emerged as major barriers. The interviews further highlighted the role of a positive mindset and the need for a supportive environment.
5.1.2 Results discussion

The findings derived from this degree project contribute to a broader understanding of axSpA, considering the limited research available globally, in this South African context and particularly in the realm of descriptive qualitative research on barriers and facilitators in axSpA (O'Dwyer et al., 2016). According to the survey results, the most prominent barrier was related to physical health and the experience of axSpA symptoms. This was emphasised in the qualitative research, where both the experience of pain, fatigue and managing the disease impacted not only PA but also daily life. This is in line with prior research, where significant barriers for PA were pain (Niedermann et al., 2019, Rouse et al., 2019, O'Dwyer et al., 2016), fatigue (Rouse et al., 2019) and stiffness (O'Dwyer et al., 2016). This indicates that axSpA symptoms have a significant impact on people’s lives. There is an emerging theme of axSpA-related distress revolving around pain and its biopsychosocial implications.

An additional category that was not reflected in the IFAB survey results but featured in the interviews, was the perception of limited access or inadequate healthcare. This was similarly described in a qualitative descriptive study in Ireland which uncovered the challenge of a lack of resources (O'Dwyer et al., 2016). This reflects the state of rheumatology care in Africa, where the continent had only 120 rheumatologists in 2016 (Tikley & McGill, 2016), with the majority, 85 rheumatologists, practising in South Africa and serving 56 million people (Mody, 2017). Interestingly, although the axSpA symptoms are a barrier of PA, the experience of PA relieving symptoms also emerged as a facilitator to PA in the interviews. This is affirmed in prior research which showed that experiencing a reduction in pain (Rouse et al., 2019) and low disease symptoms (Niedermann et al, 2019) were facilitators of PA. However, in the IFAB survey, “level of symptom” could either be a barrier or a facilitator and not both.

A prominent barrier in the survey results was a lack of motivation for PA. The explanatory qualitative findings uncovered the presence of mental barriers, negative self-talk and low self-efficacy. To give context to this finding, it has previously been reported that anxiety and depressive symptoms are more prevalent in people with arthritis (He et al., 2008) and are predictors of poor function (Sharma et al., 2003). This affirms the results of Niedermann et al. (2019) who also found that lack of motivation was a barrier to PA. Similarly, results in a qualitative descriptive study in Ireland, found that negative associations and attitudes towards PA were barriers to PA (O'Dwyer et al., 2016).

It is therefore important, clinically, that healthcare professionals are aware of the distress often experienced by axSpA patients and be equipped to address it and refer for psychological assessment and intervention where necessary. The most prominent facilitator to PA in the IFAB results was knowledge of the benefits for physical health followed by knowledge of the benefits for mood. This indicates that knowledge plays an important part in helping participants to be physically active. Participants expressed that PA itself provided benefits for both physical and mental health, not just the knowledge thereof. This corresponds to previous research done by Rouse et al. (2019) where understanding the benefits of participating in regular PA was a facilitator to PA. Therefore, a recommendation is further validation of the IFAB questionnaire, considering the use and complexity of language. In relation to the role of knowledge as a facilitator, it is interesting to explore its connection with
the survey finding, which suggest that lower education was linked to more barriers towards PA. As Solar and Irwin (2010) discuss, education is an important predictor to good health in general and may influence lifestyle choices such as PA.

The impact of interpersonal experience and social context on PA were clearly indicated in these results. For example, the presence of a supportive external environment improved motivation and accountability for PA. This is shown in previous research where facilitators included external support from a variety of health and wellbeing specialists, family and friends and online resources (O’Dwyer et al., 2016). Rouse et al. (2019) also highlighted the support of friends and family. As a barrier, participants expressed inaccessibility to both medical specialists and exercise areas, and lack of social support from friends and family. This shows that interpersonal and social elements are essential to supporting PA (Rhodes and Quinlan, 2015).

Another facilitator represented in the qualitative results was the importance of mental strength, which included meaning and purpose, a positive mindset and enjoyment. Rousse et al., (2019), found that experiencing the enjoyment of PA was a facilitator to PA. However, these are not reflected in the IFAB survey as possible facilitators. The IFAB questionnaire asks about social support from family and friends, yet it does not encompass the potential support that can be derived from the wider community. Rouse et al. (2019) and Niedermann et al. (2019) have explored the potential advantages of online support groups as facilitators, a theme that emerged in the interviews as well.

The quantitative results showed high frequency of the “had no impact” answers as already discussed. More than 50% of participants said the following factors had no impact on their PA levels: “weather conditions”, “support from others”, “support/advice from healthcare professionals”, “belief that PA will make symptoms worse” and “lack of knowledge of what exercise to do”. However, these themes were all expressed in the qualitative results. The qualitative categories, therefore, offer distinct perspectives and nuanced insights that complement the survey results (Creswell & Plano Clark, 2018), uncovering additional barriers and facilitators that were not addressed in the existing IFAB literature. If the IFAB survey is used in a clinical setting, we recommended that clinicians also enquire with open-ended questions as to their patients’ perceived barriers and facilitators to PA.

The TTM was used to explore how PA behaviour was connected to facilitators and barriers. TTM constructs that emerged in the findings of this research were decisional balance, self-efficacy and processes of change. In terms of decisional balance, our results identified that lower IFAB scores are associated with lower SOC. In this case, as barriers or cons outweighed facilitators or pros to PA, this resulted in a negative decisional balance towards change (Johnson and Cook, 2004). This occurred in 48.5% of our participants who were in the inaction stages of change, namely precontemplation, contemplation and preparation. For example, the belief and concern that PA might worsen the disease progression overrides the possible enjoyment of participating in a social and safe exercise class. The results of this study also show that total IFAB scores have a significant correlation with SOC (r=-.63, p<=.001). Higher SOC indicates, according to Johnson and Cook (2004), the readiness to change behaviour and being more likely to adopt and maintain a PA behaviour. The interview
questions related to decisional balance in the TTM, by evoking both the pros and cons of behaviour change. The cons can include barriers or obstacles that participants perceive as hindering their ability to change, while the pros may include, but are not limited to, the supports or facilitators that can help them overcome those barriers. For example, barriers such as lack of social support and inaccessibility to PA facilities would fall under the cons category in decisional balance. In contrast, a facilitator such as symptom relief would be considered a pro in decisional balance. The results also revealed the concept of self-efficacy in TTM where low self-efficacy was a feature of a mindset barrier. In addition, different processes of change were discussed by participants during the interviews, such as “helping relationships” by creating accountability through the support of training partners.

5.1.3 Methods discussion

The mixed-methods design provided detailed and complementary data and was a true strength that enabled a full understanding of barriers and supports to PA. However, there were methodological considerations and clear limitations to acknowledge when interpreting the results. The following paragraphs explore how accurately the methods were used to answer the research questions, other possible relevant methods and, finally, the validity and trustworthiness of the results.

An explanatory sequential design was used. Aligning quantitative and qualitative findings in this design was challenging, as pointed out by Creswell and Creswell (2018). Therefore, the intention was to explain quantitative findings, however, the qualitative findings went beyond mere explanation and created more exploration of facilitators and barriers to PA. Nevertheless, the authors see this as a strength because the qualitative findings not only explain the facilitators and barriers measured in the IFAB but also provide a deeper exploration and understanding of these factors.

The use of the TTM in a cultural and patient-specific context similar to this study has not been previously examined. Consequently, there is a concern about the appropriateness of this measurement, despite its widespread application in the broader healthcare domain. Additionally, an important point for discussion is that the assessment of SOC, related to the WHO physical activity recommendations in this study, was based on self-report measures. There are limitations and potential problems to this method, including memory limitations and social desirability bias. This bias occurs when participants provide responses that they believe are more socially acceptable or align with societal expectations, rather than reflecting their true thoughts or behaviours. This bias can be diminished in the future by measuring activity using a smartphone as utilised by Davergne et al., (2020). However, as discussed by Johnson & Cook (2014) self-report still indicates the participants’ readiness to change.

Choosing a sample to represent the axSpA population in South Africa was challenging. South Africa has a population of around 60 million people within nine provinces and it is known for its ethnic, religious, and cultural diversity. There are some limitations with respect to the generalisability of our results because most of them were well-educated, working and female. In addition, the sample consisted of a non-random convenience sample drawn from the ASASA membership and a private Facebook community group thus potentially implicating
quantitative findings. It is important to acknowledge the potential presence of selection bias resulting from the sampling method employed within an online support group. Consequently, caution must be exercised in drawing conclusions that may not accurately represent the entire population. The chosen sampling method carries a risk of selection bias, resulting in a less diverse pool of interview participants than initially expected. To address this limitation, the authors ensured transparency by collecting and reporting the characteristics of this sample, following the recommendations of Graneheim and Lundman (2003).

A further bias relates to self-selection bias. Individuals who actively participate in Facebook community groups may have different characteristics or opinions compared to those who do not participate. This self-selection bias can lead to a skewed sample that does not represent the larger population adequately. This situation could as well affect how well the sample is reflecting the overall axSpA population in South Africa. A strength of our sample was that they had experiences of the topic under investigation and can express themselves about it which increased credibility (Graneheim et al., 2017). Of the sample of 65 participants, 83.1% were willing to be contacted for a follow-up interview. The number of total interviews was 10 and therefore the aim to ensure rich data was met (Graneheim et al., 2017). The qualitative sample was not as heterogenous as we had aimed for as already discussed. Therefore, the ability to shed light on many different aspects of the research question was diminished, thus risking the credibility of the data (Graneheim and Lundman, 2003). For example, the intention was to have at least two participants per SOC group. However, two participants retracted their availability for an interview and two participants did not reply to our interview request. This limited our sample heterogeneity. For example, only one participant in the qualitative interviews was in the “pre-contemplation” SOC.

Considering the measurements used in the survey, there may also be language and cultural barriers and influences that have impacted the results (Bowen et al., 2017). This could therefore influence the responses, analysis, and evaluation. No live participant support during the survey data collection was available. However, if participants of the survey had questions, they could always contact the authors directly for support. The IFAB survey has not been validated in South Africa and therefore some of the questions may not be relevant or appropriate for the South African axSpA population. As discussed by Davergne et al., (2020) the cultural setting plays a role in assessing barriers and facilitators. For example, the IFAB questions related to social settings and psychological states can be influenced by culture (Jia et al., 2018). In addition, questions related to significant barriers or facilitators may be missing from the survey as seen in the qualitative findings. Still, due to the interviews conducted, this issue could be addressed, and a wider understanding of facilitators and barriers gathered.

Since the SOC questionnaire was self-report, it could be that people overestimated their PA-levels (Helmerhorst et al., 2012). The sample in this research was predominantly in the maintenance SOC, which does not align with O’Dwyer, et al.’s (2015) findings that less than half of axSpA patients meet the recommended PA levels. The fact that most participants were in maintenance SOC might be related to both self-report and self-selection bias. The quantitative data-analysis was guided by Field (2018) and a non-parametric test such as
Spearmen’s rho was seen fit for correlation analysis. The choice to examine correlations rather than regression was based on the research questions and the primary goal was to deepen the understanding of facilitators and barriers towards PA and not to make predictions about different possible relationships. As there is no non-parametric test which allows correlation analysis with continuous variables such as the IFAB and categorical outcomes such as most demographics, it was concluded that visualization is a good way to display possible relationships. To ensure statistical power and validity in the findings (Field, 2018), a prior power calculation was performed and indicated 61 participants. Our sample size (n=65) met the requirements.

Regarding validity and trustworthiness of the qualitative findings, the focus of the interviews, the sample chosen, and analysis preformed were aligned with each other according to Creswell and Creswell’s (2018) recommendations. The most interesting findings from the survey were used to create the interview direction. Further, the focus could be led back to the core questions of this degree project. However, there is always the possibility of bias included in what is perceived as dominant or important as Creswell and Creswell (2018) discuss.

Each interview duration was scheduled for 30 minutes. Longer interviews or follow-up interviews could have provided richer and more credible findings. However, reflecting on the data collected, we could see clear patterns and categories arising. The credibility of content analysis also relates to how well categories and sub-categories represent the data and that no relevant data has been excluded or irrelevant data included (Graneheim and Lundman, 2003). To mitigate this risk, an iterative and reflective process was conducted including re-reading transcripts, re-organising meaning units and discussing categories to ensure agreement by the co-authors (Woods and Catanzaro, 1988). However, the time pressure related to handing in the degree project was a challenge and such prevented further possible iterations. In the context of this degree project, there was no possibility to include experts in the discussion which may have influenced the categories in the analysis in a positive way (Graneheim & Lundman, 2003). As described by Graneheim and Lundman (2003), a text includes multiple meanings and there is always some level of interpretation when analysing a text. We have therefore included appropriate quotations to enhance transferability (Graneheim and Lundman, 2003).

### 5.1.4 Implications of research findings

Healthcare professionals, including rheumatologists, physiotherapists, and other specialists involved in the care of individuals with axSpA, can use these findings. For example, it is crucial that patients are educated about the benefits of PA to health and mood and the importance engaging in regular PA. Talking to patients about the positive impact of PA on symptoms and overall wellbeing, may motivate them to be more physically active. In addition, by understanding the identified barriers to PA, such as symptom levels and negative mindset, healthcare professionals can tailor their counselling and interventions to address these specific challenges. For instance, they can work with patients to develop strategies to manage symptoms during exercise or offer psychological support to overcome mindset-related barriers. Finally, with knowledge of the barriers faced by patients with different
educational backgrounds, healthcare professionals can develop more personalized treatment plans. For patients with lower levels of education, additional support and guidance may be necessary to help them overcome barriers and engage in PA more effectively.

With regards to further research, knowledge about the field of PA in axSpA patients can lead to the development of more effective interventions and policies, that could enhance the overall well-being and quality of life for this population. Longitudinal studies to track PA engagement and its associated facilitators and barriers over an extended period would provide insights into both the dynamic nature of PA behaviour in individuals with axSpA and the tendency of movement between SOC. Long-term observations could reveal how PA levels change over time in response to different life events, disease progression, and interventions. Additionally, implementing intervention studies that target the identified barriers to PA among axSpA patients could provide valuable evidence regarding the effectiveness of different approaches in promoting PA behaviour. The TTM processes of change could be utilised at appropriate stages of change to support PA behaviour. Comparing the outcomes of various interventions, such as physiotherapy programs, psychosocial support, and environmental modifications, can help identify the most efficient strategies.

5.1.5 Ethical discussion

The principles of beneficence and non-maleficence were used to guide the students to prioritise the well-being and safety of participants while achieving positive outcomes and avoiding unnecessary harm (Beauchamp and Childress, 2013). These principles help ensure that actions and decisions are made in the best interests of participants and the community, promoting ethical conduct and responsible practice in research of healthcare settings.

Although sensitive information was not directly asked, participants shared prior experiences that were sensitive such as mental health challenges and, in one case, suicidal thoughts that occurred many years ago. The interviewer created a space of non-judgement and acknowledged the participants' vulnerability. In the interview, it was not deemed a current red flag and referral to a mental health specialist was not indicated. After the interview, the interview was listened to again by both authors and discussed and decided it was not a cause for action or concern. The participants knew that they were able to contact the authors for a follow-up call if they felt it necessary or important. In this way, the interviewer-interviewee relationships were respectful, clear communication was maintained and they had the opportunity to provide feedback at all stages of the data collection.

The authors were aware of any power dynamic or inequality related to the interviewees and the participants (Berndtsson et al., 2007). For example, Lauren interviewed half of the participants and she is also the vice-chairperson of the association. There is a conflict of interest and a possible reason to express oneself as a participant in a certain way to validate the association. Transparency about our research intentions, potential biases and any conflicts of interest was important and considered. The authors engaged in reflexivity about their own beliefs, assumptions and values that might influence the research process and findings. Finally, ethical considerations anticipated for the survey could be followed and no extra adaptations were made during the study.
This study aimed to explore perceived facilitators and barriers to PA in relation to SOC among individuals living with axSpA in South Africa. A mixed methods design was used, combining quantitative survey data with qualitative interview analysis to gain a comprehensive understanding of the factors influencing PA engagement in this population. The results revealed several important findings. From the survey, it was evident that knowledge about the benefits of PA to health and mood was a predominant facilitator, while levels of symptoms and lack of positive mindset acted as significant barriers to PA participation. Furthermore, the survey data indicated that lower levels of education were associated with higher barriers to PA. The qualitative interview analysis provided deeper insights, identifying four barriers—interaction of symptoms, inappropriate care, unsupportive external environment, and mindset—and three facilitators—mental strength, symptom relief, and supportive external environment. These qualitative findings enriched the understanding of the complex interplay between physical symptoms, psychological, interpersonal, and environmental barriers, and facilitators to physical activity. Since physical activity in axSpA is important for management, future research should involve behavioural medicine approaches.

The integration of quantitative and qualitative data through the mixed methods design allowed for a comprehensive examination of the research topic. By integrating the findings from both approaches, we gained a more nuanced understanding of the factors influencing PA behaviour in individuals living with axSpA, identifying the interrelated psychological, social, and environmental determinants of PA participation.

The findings have practical implications for healthcare professionals and policymakers. Greater awareness of the benefits of PA and targeted interventions addressing the identified barriers can help promote PA engagement among axSpA patients, thereby potentially improving their overall well-being and health outcomes. In conclusion, this mixed methods study highlights the importance of considering both quantitative and qualitative data when exploring complex health-related behaviours. The integration of these methods has provided valuable insights that would not have been fully captured by using either approach in isolation. Further research in this area can build upon these findings and contribute to the development of more effective interventions aimed at promoting PA and enhancing the quality of life for individuals living with axSpA.
REFERENCE LIST


APPENDIX

APPENDIX A

IFAB QUESTIONNAIRE

Please take a few moments to think about all the physical activity you did in the previous month: walking, jogging, gardening, other kind of sport… Now, think about all the things that have encouraged you, and all the things that prevented you from doing physical activity in the previous month. This questionnaire has 10 items. It aims to collect all the things that have encouraged you or prevented you from doing physical activity in the previous month.

Please indicate for each item if it has rather encouraged you, prevented you, or had no impact on your physical activity in the previous month (only one answer). If needed, rate the importance.

A: Items that may have encouraged me or prevented me from doing physical activity in the last month.

<table>
<thead>
<tr>
<th>Item</th>
<th>Impact Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Level of symptoms (pain, fatigue, lack of mobility)</td>
<td>Had no impact on my physical activity: 0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>□ rather prevented me from doing physical activity in the previous month</td>
<td>Had a maximal impact on my physical activity</td>
</tr>
<tr>
<td>□ rather encouraged to do physical activity in the previous month</td>
<td></td>
</tr>
<tr>
<td>□ had no impact on my physical activity in the previous month</td>
<td></td>
</tr>
<tr>
<td>2. Weather conditions</td>
<td>Had no impact on my physical activity: 0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>□ rather prevented me from doing physical activity in the previous month</td>
<td>Had a maximal impact on my physical activity</td>
</tr>
<tr>
<td>□ rather encouraged to do physical activity in the previous month</td>
<td></td>
</tr>
<tr>
<td>□ had no impact on my physical activity in the previous month</td>
<td></td>
</tr>
<tr>
<td>3. Presence or absence of support from others (friends, family)</td>
<td>Had no impact on my physical activity: 0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>□ rather prevented me from doing physical activity in the previous month</td>
<td>Had a maximal impact on my physical activity</td>
</tr>
<tr>
<td>□ rather encouraged to do physical activity in the previous month</td>
<td></td>
</tr>
<tr>
<td>□ had no impact on my physical activity in the previous month</td>
<td></td>
</tr>
<tr>
<td>4. Presence or absence of support and/or advice from healthcare</td>
<td>Had no impact on my physical activity: 0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>professionals</td>
<td>Had a maximal impact on my physical activity</td>
</tr>
<tr>
<td>□ rather prevented me from doing physical activity in the previous month</td>
<td></td>
</tr>
<tr>
<td>□ rather encouraged to do physical activity in the previous month</td>
<td></td>
</tr>
<tr>
<td>□ had no impact on my physical activity in the previous month</td>
<td></td>
</tr>
</tbody>
</table>

B: Items that may have prevented me from doing physical activity in the last month.

<table>
<thead>
<tr>
<th>Item</th>
<th>Impact Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. A belief that physical activity will make symptoms worse</td>
<td>Had no impact on my physical activity: 0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>□ rather prevented me from doing physical activity in the previous month</td>
<td>Had a maximal impact on my physical activity</td>
</tr>
<tr>
<td>□ had no impact on my physical activity in the previous month</td>
<td></td>
</tr>
</tbody>
</table>
6. Lack of motivation
   - □ rather prevented me from doing physical activity in the previous month
   - □ had no impact on my physical activity in the previous month
   - Had no impact on my physical activity
   - 0 1 2 3 4 5 6 7 8 9 10
   - Had a maximal impact on my physical activity

7. Lack of knowledge on which exercises to do and how much
   - □ rather prevented me from doing physical activity in the previous month
   - □ had no impact on my physical activity in the previous month
   - Had no impact on my physical activity
   - 0 1 2 3 4 5 6 7 8 9 10
   - Had a maximal impact on my physical activity

C: Items that may have encouraged me from doing physical activity in the last month.

8. Knowledge of benefits of physical activity for health
   - □ rather encouraged to do physical activity in the previous month
   - □ had no impact on my physical activity in the previous month
   - Had no impact on my physical activity
   - 0 1 2 3 4 5 6 7 8 9 10
   - Had a maximal impact on my physical activity

9. Knowledge of benefits of physical activity for mood
   - □ rather encouraged to do physical activity in the previous month
   - □ had no impact on my physical activity in the previous month
   - Had no impact on my physical activity
   - 0 1 2 3 4 5 6 7 8 9 10
   - Had a maximal impact on my physical activity

10. Confidence on how to exercise safely
    - □ rather encouraged to do physical activity in the previous month
    - □ had no impact on my physical activity in the previous month
    - Had no impact on my physical activity
    - 0 1 2 3 4 5 6 7 8 9 10
    - Had a maximal impact on my physical activity

Items which can be considered as either barriers or facilitators are rated from -10 to 10, items which are barriers only are rated from -10 to 0, and items which are facilitators only are rated from 0 to 10. When an item is not affecting physical activity, score it at 0. If one question is missing impute the item as 0. If two questions are missing, we recommend not calculating the total score. The global score ranges -70 to 70. Results below -5 might justify a targeted intervention.

This questionnaire is free to use, please cite the paper. (thomas.davergne@gmail.com)

APPENDIX B

STAGES OF CHANGE QUESTIONNAIRE FOR REGULAR PHYSICAL ACTIVITY

For physical activity to be regular it must be done for 30 minutes at a time (or more) per day and be done at least 5 days per week. For example, you could take three 10-minute brisk walks or ride a bicycle for 30 minutes. Physical activity includes such activities as walking briskly, hiking, swimming, line dancing, and aerobics classes or any other activities where the exertion is similar to these activities. Your heart rate and/or breathing should increase, but there is no need to exhaust yourself.

Do you engage in regular physical activity according to the definition above? Mark the one statement that applies to you.

SCORING

☐ Yes, I have been doing physical activity regularly for more than 6 months.
   o Scoring: Maintenance

☐ Yes, I have been doing physical activity regularly, but for less than 6 months.
   o Scoring: Action

☐ No, but I intend to do regular physical activity in the next 30 days.
   o Scoring: Preparation

☐ No, but I intend to do regular physical activity in the next 6 months.
   o Scoring: Contemplation

☐ No, and I do not intend to do regular physical activity in the next 6 months.
   o Scoring: Precontemplation

References for the questionnaire:


APPENDIX C

DEMOGRAPHIC DATA

How old are you? (Drop down)

Which statement best describes your current employment status?

- Working (paid employee)
- Working (self-employed)
- Not working (temporary layoff from a job)
- Not working (looking for work)
- Not working (retired)
- Not working (disabled)
- Not working (other)
- Prefer not to answer

What is the highest level of education you have completed?

- No formal schooling
- Some primary school
- Primary school completed
- High school completed
- College/University completed
- Post graduate degree
- Prefer not to answer

What is your ethnic/racial background?

- BlackColoured
- White
- Asian
- Indian
- Other______________________________
- Prefer not to answer

What is your gender?

- Male
- Female
- Other______________________________
- Prefer not to answer

Do you have private medical insurance?

- Yes
No

End of Block: Demographics
Start of Block: axSpa disease delay to diagnosis

New block: axSpa disease delay to diagnosis

Which year were you diagnosed with axSpa?
[Drop down with year]

Which year did you first experience axSpA symptoms?
[Drop down with year]

End block: axSpa disease delay to diagnosis
APPENDIX D

INFORMATION TEXT ON THE FACEBOOK-SITE

YOU ARE INVITED TO TAKE PART IN A MASTER’S THESIS

We want to answer the following questions:

• What challenges do you face in being physically active?
• What support is most helpful in being physically active?

We want to learn from your experience by requesting you to fill out a survey. Your participation will help us understand important obstacles and solutions to support patients’ disease management.

DO YOU QUALIFY TO TAKE PART?

Eligible people:

• Over 18 years old
• Diagnosed with axial spondyloarthritis
  • Able to walk
  • Able to use a computer
  • Read and speak English
  • Willing to fill out a survey

ARE YOU INTERESTED?

CONTACT:

Lauren Angelil WhatsApp: +27 76 155 2626 | Email: laurenkangelil@gmail.com

Anna Tina Grob-Österman: +46 70 796 5886 | Email: agn21012@student.mdu.se
APPENDIX E

INFORMATION PRIOR TO THE SURVEY

You are enrolled into the exciting study "Understanding the perceived barriers and facilitators to physical activity for South African patients with axial spondyloarthritis".

This Baseline Questionnaire will take about 25 minutes.

Please answer the following questions as honestly as you can. Your honest answers are important to us. Remember that your responses are confidential and there are no right or wrong answers. Your name and personal identifying information will not be analysed or published.

You can contact us if you have any questions about the study

- Lauren WhatsApp: +27 76 155 2626  
  Student Msc, Sweden
- Anna Tiina WhatsApp: +46 70 796 5886  
  Student Msc, Sweden
Appendix F

Research Information for Participants

Perceived Barriers and facilitators for physical activity in South African patients with axial spondyloarthritis

We are pleased that you are interested in our research. In it, we look at challenges and support to movement with people who have axial spondyloarthritis. We would like to invite you to join us and help to generate more valuable research around axial spondyloarthritis in South Africa.

Your participation in this interview is entirely up to you.

What is required of me?

You have been asked to take part in a 30 minute interview about the challenges you might face and support you might have around physical activity. We request that you are honest and self-compassionate in talking about your experiences.

What will happen with my information?

Your data, including data on health, sex, age, ethnicity will be recorded and analysed in coded form so there is no way to identify you. It will only be possible to link research data with you personally via an identification list kept secure at Mälardalens University. Only the study researchers will have access to this data. The data collected during the interview will be recorded. After the research ends, all data will be stored and secured for a period of 10 years. Afterwards the data will deleted.

With your permission, the answers of this interview will be stored and analysed as part of our Master Thesis

Can I withdraw my consent?

You can take away your consent at any time, in writing, without giving reasons and without any disadvantage to you. If you decide you want to quit, no further data will be collected.

If you decide to quit, you may be asked for your consent that the data already collected may be used. If you do not agree all your data will be deleted immediately.

Do you have any questions?

In case you have any questions or if you would like to get more information on the study, you can contact the research team:

Lauren Angelil, Student Msc: laurenkangelil@gmail.com
Anna Tina Grob-Österman, Student Msc.: agn21012@student.mdu.se
Anna Karin Andersson. Senior Lecturer at Mälardalens University: anna.karin.andersson@mdu.se
### APPENDIX G

#### DISTRIBUTION OF THE DATA

<table>
<thead>
<tr>
<th>Item</th>
<th>Skewness</th>
<th>Kurtosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>All five SOC</td>
<td>.231</td>
<td>-1.467</td>
</tr>
<tr>
<td>Total IFAB scores</td>
<td>-.097</td>
<td>-.450</td>
</tr>
<tr>
<td>Q2</td>
<td>-1.031</td>
<td>-.125</td>
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<tr>
<td>Q3</td>
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<td>.230</td>
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<td>Q5</td>
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<td>2.740</td>
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<tr>
<td>Q6</td>
<td>-.168</td>
<td>-1.356</td>
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<tr>
<td>Q7</td>
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<td>-1.547</td>
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<tr>
<td>Q19</td>
<td>-.431</td>
<td>-1.338</td>
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</table>
## APPENDIX H

**CONNECTION BETWEEN DIFFERENT RESEARCH QUESTIONS AND ANALYSIS**

<table>
<thead>
<tr>
<th>Question</th>
<th>Measurement and Variables</th>
<th>Hypothesis</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1.1. What facilitators and barriers are perceived as predominant in participants with axSpA in South Africa?</strong></td>
<td>IFAB-questionnaire with 10 questions. Scores from -70 to +70</td>
<td>-</td>
<td>Descriptive.</td>
</tr>
<tr>
<td><strong>1.2. How do facilitators and barriers correlate to stages of change in the South African axSpA population?</strong></td>
<td>IFAB-questionnaire with 10 questions. Scores from -70 to +70 Stages of change questionnaire with 5 questions in different groups</td>
<td><strong>H0</strong>: There is no correlation between total scores in the IFAB and SOC <strong>H1</strong>: There is a correlation: Total scores in the IFAB correlate with SOC. Indicating that higher scores related to higher SOC and lower IFAB-scores to lower SOC.</td>
<td>Two-tailed bivariate analysis with Spearman’s rho for correlation</td>
</tr>
<tr>
<td><strong>1.3. How do demographic data, such as age, gender, highest education, marital status, ethnical background, and income, relate to perceived facilitators and barriers?</strong></td>
<td>Demographic data IFAB-questionnaire with 10 questions. Scores from -70 to +70</td>
<td><strong>H0</strong>: There is no correlation between the scores of the individual questions of the IFAB and SOC <strong>H1</strong>: Q1- Q10 correlate with the stages of change</td>
<td>Two-tailed bivariate analysis with Spearman’s rho for correlation</td>
</tr>
</tbody>
</table>
APPENDIX J

INTERVIEW PROTOCOL

Prior to interview ensure recording is on

Introduction:

- Thank you for being here
- Set expectations for the interview
  - 30 mins
  - Talking about your axSpA experience and what has been a support, and what has been a challenge in doing PA
  - Feel free to ask questions
  - Know that this space is a space of non-judgement. I'll ask quite a few questions and you get to answer as much or as little as you like. We ask that you share your honest experience
  - How does it all sound?

Semi-structured interview questions:

1. [Easy, build rapport] What were you thinking about when you were filling out the survey?
2. Tell me about your relationship to PA (Frequency, what works?)
3. What stands in your way of doing PA?
   a. What are your biggest challenges? What else?
4. What gets you out of the door to do PA?
   a. What supports you in doing PA? What else?

Close:

- We have a few minutes left, I wonder if there is anything you’d like to add before we close the call?
- Thank you for your time.
- I’m available on email if any other thoughts come up in the next few days that you’d like me to know.
APPENDIX K

CONTENT OF EMAILS TO INTERVIEW-PARTICIPANTS

Heading in email: You are invited to take part in a follow-up interview.

Hi axSpa warrior

You’re receiving this email because recently you filled out a survey about exercise and axial spondyloarthritis. We are very grateful for your insights so far, and thank you for being willing to jump onto a follow up interview.

We’re now in the second phase of the study.

Attached is an information sheet to give you an idea of why we’re doing it and what your involvement would be.

In the interview, we want to hear from you – what supports you in getting out the door to exercise? And what are the difficulties you encounter?

If all is okay, the next step is to schedule a 30min Zoom call for the interview.

Do either of the following days / times work for you?

- [Times]

If none of these times work, I’m sure we could find another time that suits you.

Let me know if you have any questions or thoughts.

Looking forward to connecting.

Keep well

Lauren (or Anna Tina)

Team:

Lauren Angelil, Student Msc: laurenkangelil@gmail.com

Anna Tina Grob-Österman, Student Msc.: agn21012@student.mdu.se
This self-report should be added as an appendix to the project plan (PM) and to the final Master’s thesis. The self-report should be discussed with the supervisor and agreed upon by the students and the supervisor.

The report is based on the Vancouver rules for shared authorship

<table>
<thead>
<tr>
<th>I have contributed with:</th>
<th>My contribution in percentage of 100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning of the degree project, including background literature, theoretical/conceptual framework, problem formulation, aim and possible study questions and methods.</td>
<td>Lauren 50   Anna Tina 50</td>
</tr>
<tr>
<td>Implementation of sampling, data collection, data analysis, and interpretation of data.</td>
<td>50          50</td>
</tr>
<tr>
<td>Ethical considerations and ethical discussion.</td>
<td>50          50</td>
</tr>
<tr>
<td>Reporting in the form of a thesis, including a critical discussion between the authors about the scientific content in the thesis</td>
<td>50          50</td>
</tr>
<tr>
<td>Agreement to be accountable for all parts of the degree project (yes/no question)</td>
<td>yes         yes</td>
</tr>
</tbody>
</table>