Demographic Profile of Survey Respondents

4

The IMAS European survey was conducted across 13 European countries and included a wide range of patients with axSpA from varying sociodemographic backgrounds. Understanding the demographic characteristics of the survey participants allows the comparison of data from the IMAS cohort with data from other real-world studies and provides the context within which the IMAS data should be interpreted. In this chapter, the demographic characteristics of the European IMAS participants is presented.

4.1 IMAS European Patient Survey: Geographic Distribution

The IMAS European survey was completed by 2,846 participants with axSpA from 13 European countries. The majority of participants were from Spain, France, and Norway (Fig. 4.1).

4.2 Age of European IMAS Participants

The average age of participants was consistent with other axSpA studies. Participants' age ranged between 18 and 85 years. The mean age (± standard deviation [SD]) of the survey participants was 44 ± 12 years, which is consistent with other axSpA studies (mean age of approximately 48 years) (Mease et al. 2018; Dougados et al. 2011; Rudwaleit et al. 2009; Reveille 2013). Almost half of participants in IMAS were aged 35–51 years (Fig. 4.2). Only 3% of participants were aged > 68

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Country	Austria	Belgium	France	Germany	Italy	Netherlands	Norway
Number of participants	82	76	638	78	134	107	509
Proportion of survey participants	2.9%	2.7%	22.4%	2.7%	4.7%	3.8%	17.9%

Country	Russia	Slovenia	Spain	Sweden	Switzerland	UK
Number of participants	233	83	680	71	80	75
Proportion of survey participants	8.2%	2.9%	23.9%	2.5%	2.8%	2.6%

Fig. 4.1 Distribution of survey participants by country (N = 2,846)

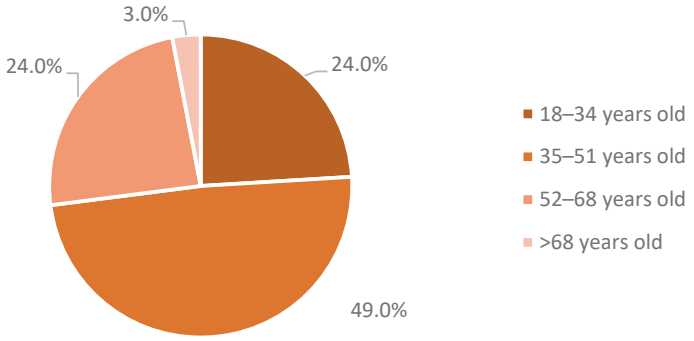


Fig. 4.2 Age of survey respondents by category (N = 2,846)

years, meaning that this age group is under-represented in the survey based on its proportion in the overall European population (Eurostat 2017a).

Reasons why more patients aged under 52 years took part in the IMAS European survey than older patients are unknown but may include greater internet access (and technical confidence) in younger versus older patients, greater concern about their disease (e.g. younger patients were at higher risk of psychological distress than older patients; see Chap. 7), and that younger patients were likely to have been more recently diagnosed with axSpA, and therefore may have been more interested in participating in research.

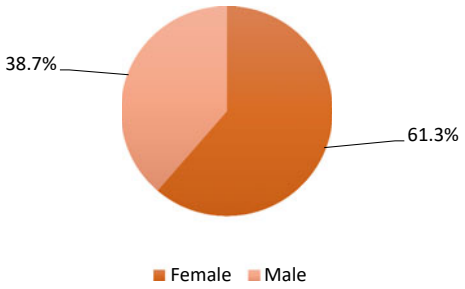


Fig. 4.3 Distribution of participants by gender (N = 2,846)

4.3 Gender Bias in European IMAS Population

While axSpA was historically thought to be more prevalent in men than women, this was predominantly due to under-diagnosis in women (potentially as a result of differences in symptoms, such as the more widespread pain reported by female patients with axSpA resulting in delayed or mis-diagnosis). More recent evidence suggests no difference in prevalence between genders (Slobodin et al. 2011; Polley and Slocumb 1947; West 1949; Rusman et al. 2018).

In the IMAS European survey, more than three out of five participants (61.3%) were female (Fig. 4.3). The reasons for the bias towards female participants is unclear but it could potentially be due to women being more comfortable sharing information/feelings and responding to online questionnaires (Smith 2008).

4.4 Weight of European IMAS Participants

Body mass index (BMI), a measure that reports an individual's weight according to their height, is commonly used to categorize individuals as underweight, within the normal range, overweight, or obese according to World Health Organization (WHO) criteria (2018).

The mean BMI of European IMAS participants was 26.1 kg/m^2, indicating that, overall, the study population was overweight. Half (52.2%) of the participants were categorized as overweight or obese (Fig. 4.4), which is similar to the general European population (51.6%) (Eurostat 2014).

Previous axSpA studies have reported similar BMIs (Mease et al. 2018) and there is evidence that obesity can increase the burden of inflammation and stiffness, decrease the benefits of exercise, and reduce the effectiveness of certain pharmacological treatments (Durcan et al. 2012). All patients with axSpA should therefore be encouraged to maintain a healthy BMI.

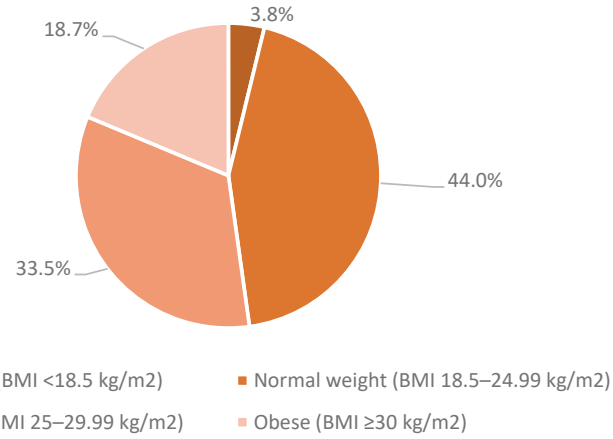


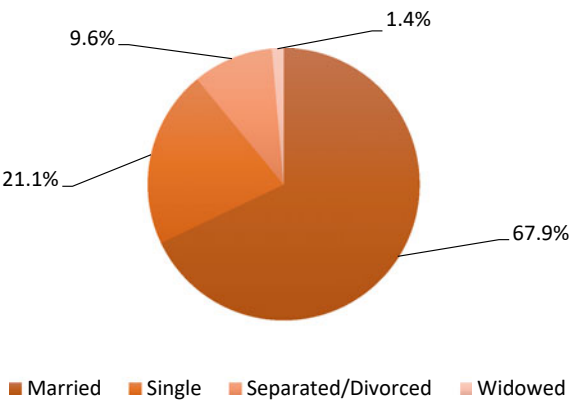
Fig. 4.4 Distribution of participants according to WHO classification of BMI categories (N = 2,846). *BMI* body mass index, *WHO* World Health Organization

4.5 Relationship Status of Participants in the IMAS European Survey

Like any chronic illness, axSpA can have a negative effect on relationships (Ward et al. 2008); in a US study, patients with axSpA were 50% more likely not to get married and 30% more likely to get divorced than healthy individuals. The reasons for these findings were not explored and further data of the impact of chronic rheumatic diseases on the likelihood of marriage or divorce are lacking (Ward et al. 2008).

Marriage or relationships may provide a primary source of social support that has beneficial effects on physical and mental health outcomes in patients with rheumatic disease, including axSpA (Strating et al. 2006; Ward and Leigh 1993; Ward 2002). In IMAS, more than two-thirds of participants were married (Fig. 4.5),

Fig. 4.5 Distribution of participants according to marital status (N = 2,846)



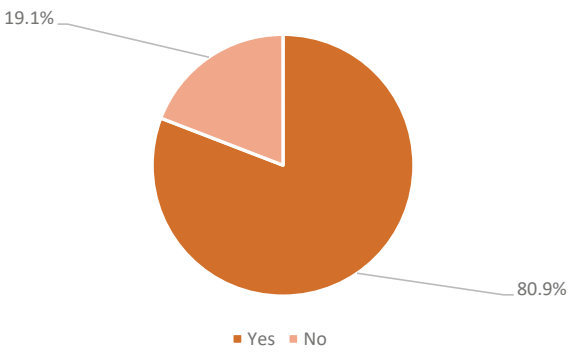


Fig. 4.6 Distribution of participants according to relationship status (N = 2,826)

which is higher than the overall marriage rate in Europe (55.3% (Eurostat 2015)), and four out of five participants were in a relationship (whether they were married or not) (Fig. 4.6), indicating good access to this vital source of social support.

4.6 Impact of axSpA on Participants' Fertility Rate

axSpA did not negatively impact the participants' fertility rate: the mean (±SD) number of children per household reported by participants was 1.4 ± 1.2, which is in accordance with the gross fertility rate (number of children per woman) in Europe (1.6) (Eurostat 2017b). Participants reported a mean (±SD) number of family members per household of 2.9 ± 1.3.

4.7 Education Level of European Participants in IMAS

Although there is some evidence to suggest that patients with axSpA are more likely to have a lower level of education due to their disease (Exarchou et al. 2015), the IMAS European data presented in Fig. 4.7 are in accordance with the levels of education across Europe (Eurostat. Educational attainment statistics 2018).

The mean monthly income of participants per household member was €1,122.58 (N = 2,289), which is lower than the minimum monthly wage reported in many of the countries participating in IMAS (Eurostat. Minimum wages 2015). The common manifestations of axSpA, such as pain fatigue, stiffness, and functional limitation, can greatly diminish work productivity and career prospects (Franke et al. 2009; Boonen et al. 2002, 2003a, b, 2010; Boonen and Linden 2006). Further information on the demographic profiles of IMAS European survey respondents can be found in the Supplement.

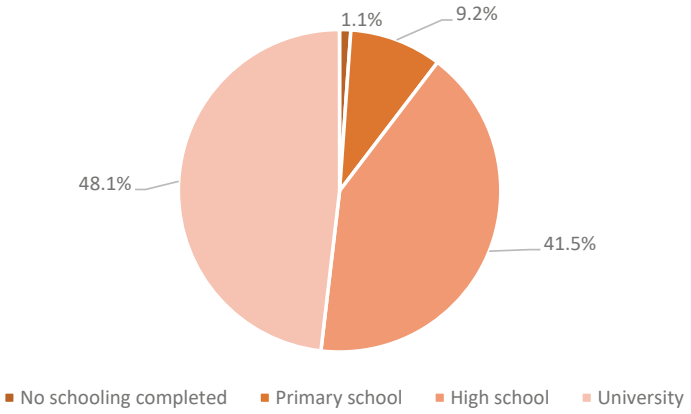


Fig. 4.7 Distribution of participants by educational level (N = 2,846)

4.8 Conclusions

- The IMAS European patient survey was completed by 2,846 participants with self-reported axSpA across 13 European countries (Austria, Belgium, France, Germany, Italy, the Netherlands, Norway, Russia, Slovenia, Spain, Sweden, Switzerland, and the UK).
- In general, the demographic profile of the European IMAS population was broadly similar to axSpA populations reported previously. There was a slight predominance of female and younger participants, which should be considered when interpreting the data.
  - The average (mean) age was 44 years; almost half were aged between 35 and 51 years, and nearly a quarter were young adults aged between 18 and 34 years.
  - More than three out of five participants were female.
  - More than half (52.2%) of participants were categorized as overweight or obese.
- More than two-thirds of participants reported being married, and four out of five participants reported living in a relationship (whether they were married or not), indicating good access to this vital source of social support.
- Participants were well educated, with most having completed high school or university; levels of education in this population were in accordance with those across Europe.
- The mean monthly income of European IMAS participants per household member was lower than the minimum monthly wage reported in many of the countries participating in IMAS.

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