BEYOND THE CONDITION: HOW RHEUMATIC DISEASES AFFECT YOUNG PEOPLE

Professor Suzanne Verstappen discusses how juvenile-onset rheumatic diseases affect education, vocational training, and employment

Juvenile-onset rheumatic and musculoskeletal diseases (jRMDs), such as juvenile idiopathic arthritis (JIA), lupus and vasculitis, are chronic diseases with onset before the age of 16 years. These conditions can cause persistent joint pain, joint swelling and stiffness. Other symptoms include fatigue and functional disability. These symptoms may fluctuate, and children and adolescents with jRMDs may have severe symptoms on some days while feeling better on others. Some children may experience symptoms for only a couple of months or years, while others have symptoms for many years and continue into adulthood. Some types of jRMDs can cause serious complications, such as joint damage, growth problems and inflammation of the eyes. Although disease management has improved in the last decade with more effective drugs and multidisciplinary care, symptoms, adverse events due to medication use, and clinical visits may affect school attendance, career choices and future employment.

Young adolescents with jRMDs have highlighted the importance of research into education, vocation and employment. The transition between education and finding a first job can be challenging for many young adults. Receiving the right careers advice, finding a job, becoming financially independent, and having short-term contracts are all factors that young people entering the workplace face. However, these may be even more challenging for those with juvenile-onset chronic conditions such as jRMDs. These conditions are further influenced by wider health determinants such as gender, ethnicity and deprivation – factors that are also associated with worse educational and work outcomes, resulting in possible unequal opportunities to participate in education and successful employment. Young adolescents with jRMDs must receive the right support throughout their journey, from education through career choices and into the labour market. This includes teachers at school, family, friends, careers advisers, health professionals, patient organisations, government and employers.

Impact of juvenile-onset rheumatic diseases on education, vocation and employment – the JOURNEY study

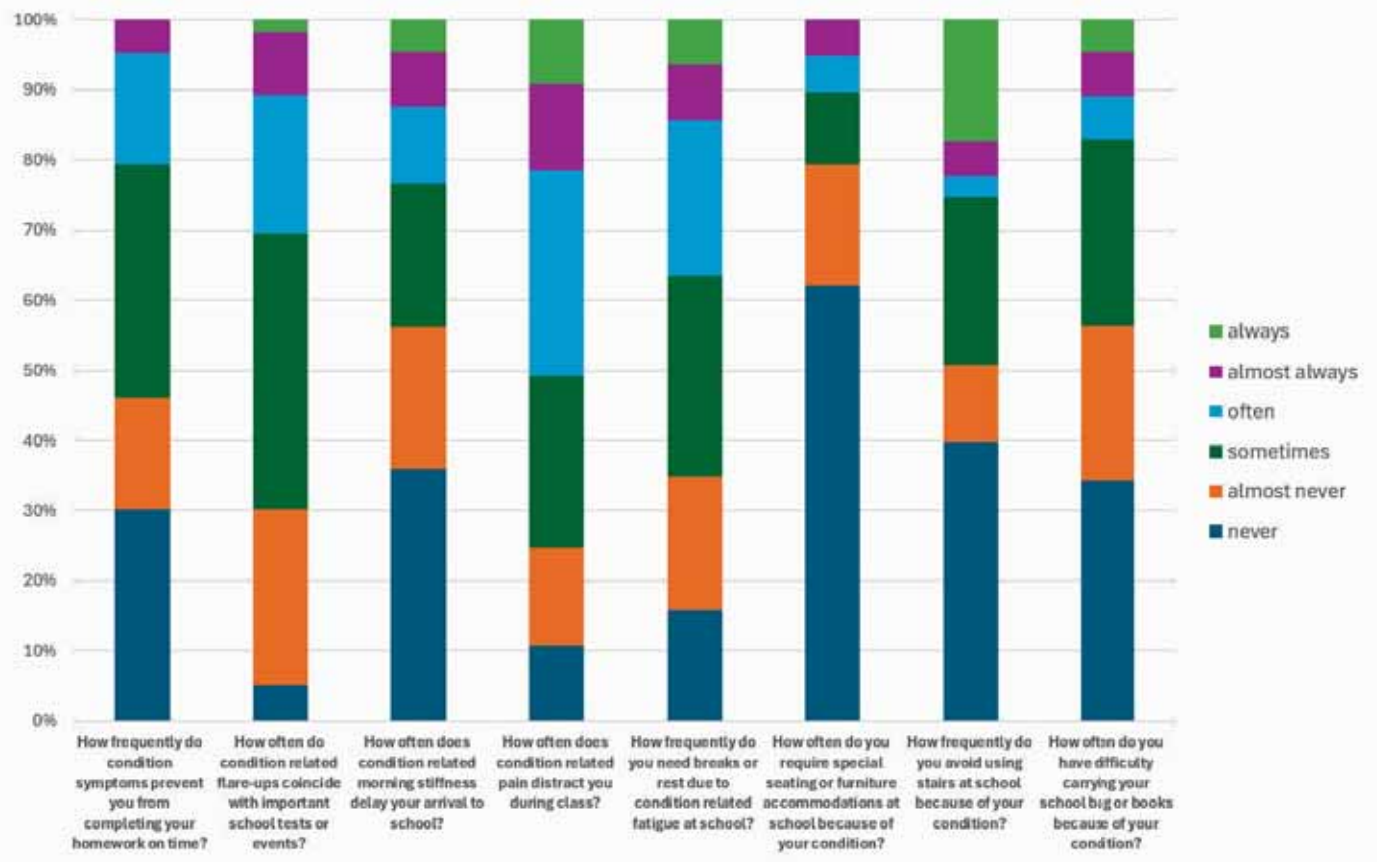
Patients, families of adolescents and young adults with jRMDs, patient organisations, careers advisers, those working in education, healthcare professionals, policymakers and employers need a better understanding of how jRMDs affect education, vocation and employment. The University of Manchester (PI Professor Suzanne Verstappen), in collaboration with Great North Children's Hospital, Liverpool University Hospital NHS Foundation Trust and the University of Dundee, is currently conducting the JOURNEY study (Juvenile-Onset rheumatic diseases: edUcation, vocational ReadiNess and EmploYment), funded by the Nuffield Foundation Oliver Bird Fund and Arthritis UK. The overall aim of the JOURNEY study is to gain an in-depth understanding of how jRMDs affect education, vocation and employment among adolescents and young adults (AYA). In addition, we will investigate the impact the disease has on parents and carers of those caring for or living with someone with jRMDs. The study comprises a survey completed by adolescents and young adults aged 12–30 years with jRMDs. Depending on whether participants are in education, NEET, or employment, they complete an online questionnaire. Rheumatology centres in England and Wales recruit participants.

Preliminary results

Education

Eighty-seven participants with jRMDs (average age 17 years) completed the survey. 69% were female, which is representative of the jRMD population. Of those who completed the survey, 80.5% were in education (including higher education), 5.7% were NEET, and 13.8% were in employment. For those in education, their condition affected various school activities (Figure).

Across schools, support varies widely. Some students do not always know whom to ask for support. In the JOURNEY study, approximately 50% received support such as lunch passes, lifts, extra breaks, toilet passes, extra time on homework, extra time in exams and pastoral support. 33% would like further support. Most support is not very costly but can make a huge difference in taking part in education. 15.9% had an Education, Health and Care Plan (EHCP). However, 21.7% were not aware of this plan.



For adolescents, discussing future careers is important, and work placements may offer opportunities to work in an environment that interests them. Young people with chronic conditions such as jRMDs may consider their condition when thinking about their future career. 59% mentioned that they took their condition into account when discussing work-related experiences. They need the right support from careers advisers, parents/carers and health professionals to make future decisions.

NEET and employment

Of those who were NEET, 40% were unemployed, and 60% were work-disabled. This is a young population struggling to stay in employment for health reasons. There is a real need to provide the right services to help them enter and remain in healthy, sustainable jobs. However, employers and line managers in organisations with a young workforce may not always consider interventions specifically for those with musculoskeletal conditions, since these conditions are seen as part of an older workforce (https://pubmed.ncbi.nlm.nih.gov/41995630/). Of those in employment, 66.7% had made changes to their working environment (e.g., adapted tools/furniture, flexible hours, more breaks, fewer hours). 8.3% had applied for the Access to Work programme, while 25% were not aware of the programme. 41.7% of those in employment had received Personal Independence Payment (PIP).

Next steps

In addition to the survey, we are conducting interviews and focus groups to better understand the impact jRMDs may have on education, vocation and employment. With the recently published report on NEET (Young people and work: interim report – GOV.UK) highlighting the impact of chronic conditions on young people who are NEET, this study provides a detailed analysis of how adolescents and young adults experience their JOURNEY from education into employment. Information toolkits will be developed and freely accessible for AYA with jRMDs, for those working in education and providing career advice, health professionals and parents/carers.

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