FEARS AND MISCONCEPTIONS OF WOMEN WITH CHRONIC RHEUMATIC DISEASES ON THEIR JOURNEY TO MOTHERHOOD

A. Tincani1, P. Taylor2, R. Fischer-Betz2, C. Ecroft3, E. Chakravarty5,1

1Università degli Studi di Brescia, Brescia, Italy, 2Institut Cochin, Paris, France, 3University of Oxford, Oxford, United Kingdom, 4Rheumatology & Health Research Unit, University Hospital, Düsseldorf, Germany, 5UCB Pharma, Brussels, Belgium, 6Oklahoma Medical Research Foundation, Oklahoma City, OK, United States

Background: Recent EULAR ‘Points to Consider’ provide guidance on management and treatment of Women of Childbearing Age (WoCBA) with chronic rheumatic diseases (CRD: RA, axSpA, PsA). However, it is still unclear if these patients (pts) feel adequately supported to make informed treatment decisions around pregnancy and breastfeeding.

Objectives: To gain insight into perspectives of women with CRD regarding disease management and pregnancy, and assess whether current clinical practice provides adequate support.

Methods: WoCBA (aged 18–45 years) from Germany, France, UK, Italy, Spain (EUS), the US and Japan participated in a 20-min online survey (Jul-Oct 2017; InSites Consulting). We report data from pts with moderate-severe CRD who were pregnant or had been pregnant in the past 2–5 yrs.

Results: 622/1052 participants had CRD (RA, n=298; axSpA, n=182; PsA, n=142) and resided in the EUS (n=306), US (n=293) and Japan (n=237). 87% pts reported having moderate CRD; 49% WoCBA stated that they had actively planned their most recent pregnancy. Fewer than half (46%) of WoCBA visited a healthcare professional (HCP) before pregnancy, of whom 53% consulted a rheumatologist among other HCPs (figure 1A). Although guidelines recommend addressing family planning/pregnancy in women with CRD before conception, 69% of pts who visited an HCP before pregnancy had to initiate these discussions with their HCPs. 54% WoCBA admitted delaying their decision to become a mother; their main fear was passing on health issues to their child (figure 1B). 32% pts reported having inadequately controlled disease activity during pregnancy; 51% experienced disease improvement, 22% disease worsening. 82% pts visited an obstetrician/gynaecologist (OB/GYN) across trimesters, 68% a rheumatologist among other HCPs (figure 1A); 65% had a treatment plan aligned between different HCPs. Stopping treatment during pregnancy was largely driven by fear of harming the foetus (78%). Among the 113 pts on anti-TNFs, 22% decided to stop treatment themselves at the start of/during pregnancy, and 47% were advised to stop by their HCP. Although 89% pts reported discussing breastfeeding with an HCP (OB/GYNs were most influential), 66% mothers felt they had to decide between treatment and breastfeeding. While information provided by their HCP was generally satisfactory, pts still felt they lacked information on the impact of treatment decisions on pregnancy (38%) and breastfeeding (24%).

Conclusions: Despite current treatment recommendations, WoCBA with CRD continue to have many fears and misconceptions about their journey to motherhood, due to lack of guidance and consistent information regarding family planning, pregnancy and breastfeeding. Survey findings suggest that women’s decisions to delay pregnancy and interrupt their treatment may be linked to a need for greater awareness of disease management options to optimise pregnancy outcomes. Access to this information, consultation with specialists and OB/GYNs earlier in the pregnancy planning process, and an aligned treatment plan could help prevent unnecessary decisions.

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