OP0282

OBSTETRIC ANTIPHOSPHOLIPID SYNDROME (OAPS) VS. WITH OBSTETRIC MORBIDITY RELATED WITH ANTIPHOSPHOLIPID ANTIBODIES (OMAPS): A SURVEY OF 1650 CASES FROM EUROAPS REGISTRY

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Background: The obstetric antiphospholipid syndrome is an autoimmune systemic disorder related to antiphospholipid antibodies and pregnancy morbidity. There exist many patients that do not fulfill the Sydney classification criteria. Those cases may be defined as Obstetric Morbidity related with antiphospholipid antibodies (OMAPS).

Objectives: To compare clinical features, laboratory data and foetal-maternal outcomes, between 1000 women with obstetric antiphospholipid syndrome and 640 women with aPL-related obstetric complications not fulfilling Sydney criteria.

Methods: Retrospective and prospective multicenter study from the European Registry on Obstetric Antiphospholipid Syndrome.

Results: 1650 women with 5251 episodes were included of which 3601 were historical and 1650 were latest episodes. 1000 cases (OAPS group) fulfilled the classification criteria and 650 (OMAPS group) did not. Ten OMAPS cases were excluded because they presented a thrombosis during follow-up. In the OMAPS group, 172/640 (26.87%) did not fulfil Sydney clinical criteria (subgroup A), 179/640 (27.96%) had a low titer and/or non-persistent aPL-positivity but fulfilled clinical criteria (subgroup B), and 289/640 (45.15%) had a medium or high aPL titer but did not fulfil Sydney clinical criteria (subgroup C).

Conclusion: Significant clinical and laboratory differences were found between groups. Foetal-maternal outcomes were similar in both groups when they were treated. The results suggest that we could improve our clinical practice with closed defining and monitoring OMAPS patients.

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PARE Abstract session

OP0283-PARE

A DUTCH RESEARCH AGENDA DEVELOPED BY PEOPLE WITH RMDs: WHAT ARE THE MAIN PROBLEMS PEOPLE WITH RMDs FACE AND WHAT ARE THEIR MAIN WISHES FOR RESEARCH AND DEVELOPMENT?

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Background: In the Netherlands much progress has been made with regard to patient participation in research. More and more researchers are finding their way to patient organizations for collaboration. This is also the case for the National Association ReumaZorg Nederland where more and more researchers are asking for the opinion of our patient-experts on their written research proposals. However, this happens mostly because 'asking for the patient's view' is an obligatory (last) part of the submission process of their proposal. ReumaZorg Nederland wants to take patient participation in research to the next level. A level where 'what matters most to patients' is taken into account before a proposal is written. Only then will the patient's voice really be heard in the very heart of a research project.

Objectives: To identify the main problems people with RMDs face in their daily lives and to prioritize their wishes for future research and development. To investigate whether these problems and wishes vary between patients with different types of RMDs. To encourage researchers and product-developers to take these wishes into account at the very start of their research proposal or product-plan.

Methods: Independent and professional research was needed to develop this research agenda. NIVEL, the Dutch Institute for Health Services Research, performed a 7 month research project which consisted of several steps. First, a literature search was performed on scientific publications in PubMed, Embase and PsychInfo on search strings focusing on living with RMDs, problems and wishes of people with RMDs and other known research agenda's for people with RMDs. The second step consisted of 3 focus group sessions: inflammatory RMDs (group 1), osteoarthritis & fibromyalgia (group 2) and soft tissue- & systemic RMDs (group 3). In addition, a combined session of representatives of each focus group (12 participants) was organized to compare and complement the results of the 3 focus groups. In the third step, an online survey (277 respondents) was held to explore how these problems and research wishes were recognized and prioritized within the Dutch community of people with RMDs. After data-analysis in step 4, a stakeholders session was held in step 5 to discuss results amongst patients, researchers, rheumatologists and product-developers.

Results: Among the 89 problems that were recognized, the main problems people with RMDs face are:

1. Uncertainty about their future.
 2. Having to cope with fatigue.
 3. Having to cope with the unpredictability of RMDs.
 4. Preserving boundaries/staying balanced.
 5. Having to cope with the impact of RMDs on social life with family and friends.
- Among the 85 wishes for research and development, the main wishes of people with RMDs are:

1. To develop treatments of RMDs other than surgery.
2. To develop an accessible and affordable network of physical exercise activities under professional supervision.
3. To investigate the cause of inflammatory RMDs.
4. To investigate the cause of fatigue with RMDs and how to cope.
5. To investigate alternative forms of therapy and their effect on specific types of RMDs.

All results were described in the first Dutch research agenda made by people with RMDs.¹

Conclusion: Remarkably, the main problems people face with RMDs are not necessarily the same as the wishes they have for further research or development. The problems people face have to do with issues regarding living and coping with RMDs in everyday life, whereas their research-wishes are more medical. Fatigue is, however, an issue that is highly prioritized as a problem as well as a subject for further research. This goes for people with all types of RMDs.

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