

Psychosocial, work, education, peer/social life, relationships

Jasmin Kümmerle-Deschner

Prof. Kümmerle-Deschner gave a few examples of what parents have to endure until they are taken seriously and helped. She mentioned one family where the patient was hospitalised 14 times without a diagnosis. The mother had to give up her job, the parents were having problems in their marriage, it was affecting the other siblings and they had to seek psychological help. Once the patient was correctly diagnosed (with CAPS) and given anti-IL1, he improved dramatically.

At the center where she works, in Tübingen, they have identified that having a diagnosis and treatment is only part of the problem. Therefore, they have a weekly meeting that includes a psychologist and a resident teacher. It was noted that, the years of not knowing what the child had, not having been taken seriously, not only had caused some trust issues with physicians, but it had also affected the family. Additionally, there is the burden of continuous monitoring, worries about the future, school performance, ability to find a job, starting a family, etc. Tübingen realised that there were other issues they had to address, not just the illness.

As such, Tübingen offers psychosocial care for patients, with follow-up visits if needed. They make school visits, meet with local social workers, and also have their autoinflammatory patients' day.

In 2018, they did a study on "unmet needs" with a total of 83 participants with CAPS, FMF and unspecified AID (G. Erbis et al., *Pediatric Rheumatology* 2018; 16:81). <https://ped-rheum.biomedcentral.com/articles/10.1186/s12969-018-0300-7>

After looking at the psychosocial burden of AID patients and their families, some key themes were identified in the focus groups, such as long-term consequences, socio-economic burden, lack of understanding and emotional factors.

As for quality of life, the following areas were affected: family, partners, sexuality, school, job, leisure time. 75% of children reported a lack of understanding by teachers and 87% experienced mobbing in school.

They also did a "HEROES study" to understand the humanistic and economic burden of FMF, MKD/HIDS and TRAPS during and between flares for the patient, caregivers and their families; identify unmet needs; describe the potential benefit of an effective treatment and flare burden. This study enrolled 67 patients across 10 sites in France, Germany, Israel, the UK and the US. 73% reported having at least one more affected family member with a Periodic Fever Syndrome (PFS) condition in the household.

The study also included the impact of PFS on young patients' (<18 years) educational attainment. It had an impact on 40% of students.

The impact of PFS on adult patients' (>18 years) work achievement was also measured. In 78% of cases, it impacted their employment.

71% caregivers reported that their child's PFS had impacted their employment. 100% caregivers were not working full-time because of their child's PFS.