



Pain in children with bleeding disorders

Daisy Regan

At the WFH 2024 World Congress in Madrid, I attended a session named ‘Pain and PWBD in the new era: Understanding pain beyond joint damage’. This session had speakers from a diverse group of specialties including medical specialists, scientists, physiotherapists, dentists, psychologists and researchers who all contributed to the discussion, and outlined and provided insight into multidisciplinary approaches, educational strategies, and coping techniques to address pain adequately in patients with bleeding disorders.

Pain and PWBD in the new era: Understanding pain beyond joint damage

Chair ~ *Kate Khair, UK*

Concept of pain, IASP concept, adapted to BD - active role of patient in the control and knowledge of pain

~ *Roberto Ucero-Lozano, Spain*

Physiotherapy approach to pain in BD - exercise/movement

~ *Cameron Cramey, Australia*

Pediatric perspective on pain

~ *Adriana Linares, Colombia*

The reality of living with chronic oral and orofacial pain ~ *Rebecca S. Schaffer, USA*

Psychosocial perspective on pain management - techniques to use

~ *Gaby Golan, Israel*

I found the speaker Adriana Linares’ session particularly interesting and thought provoking due to the focus on the paediatric and specifically the ‘paediatric perspective on pain’. Dr Linares is a Scientific Director and bioethicist based in Bogota, Colombia who presented on why health professionals are statistically less likely to ask

paediatric patients if they are experiencing pain at clinic reviews, compared to the adult cohort.

With pain being one of the main clinical characteristics of haemophilia, it was very interesting to see the responses around the room during the session when healthcare workers were asked if they routinely ask their paediatric patients if they have pain specifically, separately to asking if they have experienced any bleeds since the previous review. Few people indicated that they do ask routinely. Comparatively, the patients with haemophilia and other bleeding disorders who were present were invited to raise their hand if their team asks them if they have pain at appointments. There were very few hands raised to indicate that patients are asked routinely.

For myself as a paediatric haemophilia specialist nurse, I could honestly say that I am very proficient in asking patients and their families if there have been ‘any bleeds or concerns’ recently; however, it was brought to my attention that the question that should be included is ‘do you have any pain?’ as it is far more open-ended and the child is invited to disclose more information.

This has been a very helpful reflective process for me, particularly as a nurse new to the specialty of haemophilia (less than 12 months specialising), and has sparked a new consideration in regards to expanding questions I would ask paediatric patients at their clinic appointments.

Australian haemophilia nurses were assisted to attend WFH World Congress through funding from a variety of sources. For more information, see page 12.

Image: Tahla Riaz for Pexels.com

.....
Daisy Regan is the Haemophilia Nurse Consultant at the Michael Rice Centre for Haematology and Oncology, Women’s and Children’s Hospital, North Adelaide, South Australia
.....