

## PSO 52

### The Effect of Bleeding Disorder Characteristics on Patient Perceived Challenges and Management Strategies

Oleson, David

#### Submission Group

Peer Support/Outreach/Integration Models

#### Abstract

**Objective:** To investigate how bleeding disorder characteristics influence patient perceived challenges and management strategies. **Methods:** This is a mixed-method, retrospective, cross-sectional continuation of a pilot study identifying themes of self-perceived challenges and management strategies for persons with bleeding disorders. Sixty-one participants with a bleeding disorder (BD), either hemophilia (PWH) or Von Willebrand disease (PWVWD), were asked what their most significant challenge was in managing their BD and how they managed that challenge. Data were collected from March, 2017 through December, 2018, coded for themes and uploaded to NVivo . Similar themes were grouped for analysis. Subject-level data was extracted from the electronic medical record including demographics, disease type, severity and presence of joint disease (JD). Pain interference was determined from participant response to the Brief Pain Inventory (BPI). **Results:** The mean age of the cohort was 31.4 years, with a median of 25 years, and range of 7 to 75 years. 87% were PWH, 13% PWvWD. There were 26% mild, 25% moderate, and 49% severe PWH. 54% had JD. Identified challenges included: participation restriction (24%), acute bleeding (22%), infusion (19%), bleeding sequelae (10%), other's unfamiliarity with bleeding disorder (other's unfamiliarity) (10%), no challenges (10%), and other (6%). Management strategies reported were: acceptance (37%), learning through experience (25%), education/advocacy (11%), seeking help (9%), other (9%), and no challenges (9%). Severe PWH greatest reported challenges were participation restriction (27%) and infusion (27%). Management strategies were acceptance (41%) and experiential learning (31%). Mild-moderate PWH greatest reported challenges were acute bleeding (35%) , infusion and no challenge (17% each). Management strategies were acceptance (30%) and seeks help (26%). Seek help was not identified as a strategy among severe PWH. Reports of no challenges was higher among those <18 years than those  $\geq 18$  years. Mean pain interference was 13.2 out of 70 based on the composite score of BPI measures. As age increased, the likelihood of JD and interference increased. Regardless of challenge, people with JD reported interference averaging 18% (range 0-27%). **Conclusions:** Gaining insight to patient-perceived challenges and management strategies is important to be able to tailor an effective treatment approach that is individualized and meets the changing needs of PWBD across circumstance and life-course.