Background

ISM is a rare and chronic condition characterized by chronic inflammation of the synovial membranes of the joints and other connective tissue. Patients often experience symptoms such as fatigue, joint pain, muscle pain, and sensory manifestations. A multidisciplinary approach is recommended for management of ISM. Treatment options include anti-inflammatory medications, immunosuppressants, and biological therapies. Supportive care (e.g., psychological support, physical therapy) is also important. However, despite advances in treatment, ISM remains challenging for patients and caregivers. In-depth qualitative research is needed to better understand the lived experience of patients and caregivers.

Methods

An in-depth qualitative approach to survey-based research has been used to further understand the lived experience of patients with ISM and their support caregivers. This approach involves the use of semi-structured interviews to collect detailed, open-ended information from participants. The data collected are then analyzed using thematic analysis techniques to identify common themes and insights.

Results

1. Patient and caregiver demographics
   - 56 y/o patient
   - 7 y/o patient
   - 47 y/o caregiver

2. Prevalence of patient-reported symptoms (%)
   - 65% joint pain
   - 50% muscle/bone pain
   - 45% dermatological symptoms

3. Psychological and emotional symptoms
   - Fatigue, joint pain, brain fog, and emotional consequences of the condition

4. Impact of symptoms and communication gaps
   - Psychological and emotional symptoms affect patient cognitive function, leading to difficulty in daily activities.

5. Patient empowerment and the need for understanding
   - Patients actively seek information and take charge of their health journey, but caregivers also play a critical role in understanding the patient's condition.
   - They desire greater empathy and understanding, particularly due to the severity of the condition.

6. Conclusions
   - A better understanding of which information surrounding ISM should be prioritized is needed.
   - Supportive care (e.g., psychological support, physical therapy) is also important.

Figure 1: Patient and caregiver demographics
Figure 2: Types of support provided by caregivers
Figure 3: Combination of symptoms reported
Figure 4: Prevalence of patient-reported symptoms (%)
Figure 5: Psychological and emotional symptoms
Figure 6: Impact of symptoms and communication gaps
Figure 7: Patient empowerment and the need for understanding

Presentation details:

The Five Dimensions of the ISM Patient Experience – Uncovering the “Real-world” Experience of Patients with Indolent Systemic Mastocytosis

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