OCCURRENCE AND IMPACT OF PAIN AMONG PATIENTS LIVING WITH HEMOPHILIA

AN ANALYSIS FROM THE PATIENT REPORTED OUTCOMES, BURDENS AND EXPERIENCES (PROBE) STUDY

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Patient-Relevant Outcomes

• PROBE collects outcomes deemed relevant to a patient’s life:
  • Pain – chronic, acute, when it occurs, how it interferes
  • Independence – impact on daily living, activities of daily living
  • Education – attainment, attendance
  • Employment – duration, underemployment, attendance
  • Family life – marriage, children
  • Mobility – assistance required, impairment
  • Current health status (EQ-5D-5L – VAS)

• PROBE also collects:
  • Control data collected from people without a bleeding disorder
  • Demographic and personal characteristics
  • Hemophilia-related info e.g., disease severity, treatment, bleeding, joint impairment

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Acute & Chronic Pain Questions – Yes/No

1. During the past 12 months, have you experienced (Acute / Chronic) pain?
   - “Acute pain” – pain that arises in response to an event (like an injury or bleeding episode).
   - “Chronic pain” – pain from a persistent cause; it can vary in frequency and intensity (like back pain, pain from sore joints, or arthropathy).

2. If yes, when does your (Acute / Chronic) pain occur?
   - 7 pick list options

3. If yes, does your (Acute / Chronic) pain interfere with any of the following?
   - 10 pick list options

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Health-related quality of life (EQ-5D-5L) & Pain Frequency
PWH and Controls (no bleeding disorders)

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Pain Occurrence: When Walking

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Conclusions

• Test-retest reliability of PROBE questionnaire demonstrated
  • Lowest agreement found in item measuring “acute pain”
• Occurrence of pain, its interference with daily activities and its psychological aspects are different between PWH and Controls
• Acute and chronic pain are much more prevalent among PWH as compared to Controls
• Differences of frequency and pattern of pain occurrence in PWH warrant a disease-specific pain control program
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• Federaçao Brasileira de Hemofilia (Brazil)
• Canadian Hemophilia Society
• Association Française des Hémophiles (France)
• Deutsche Hämobiliegesellschaft (Germany)
• Magyar Hemofilia Egyesulet (Hungary)
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• Federazione delle Associazioni Emofilici (Italy)
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