



Patient Reported Outcomes Burdens and Experiences Study

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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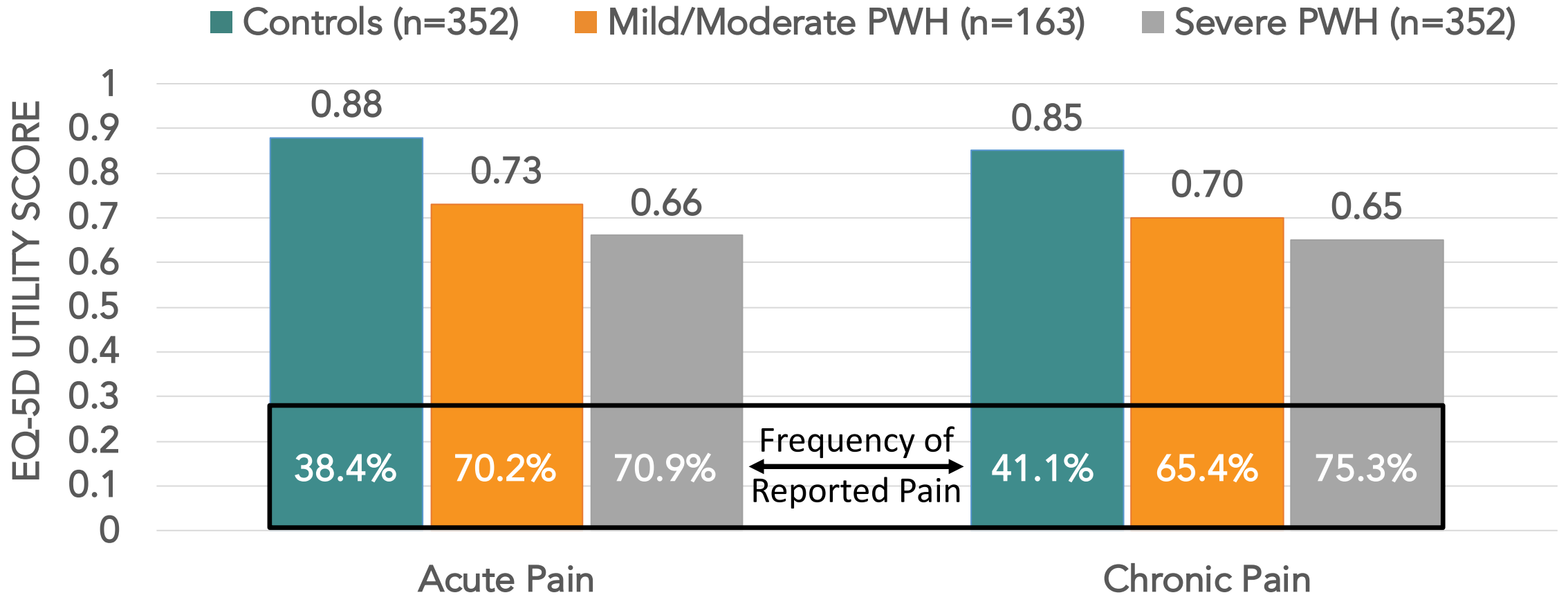
Patient-Relevant Outcomes

- 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

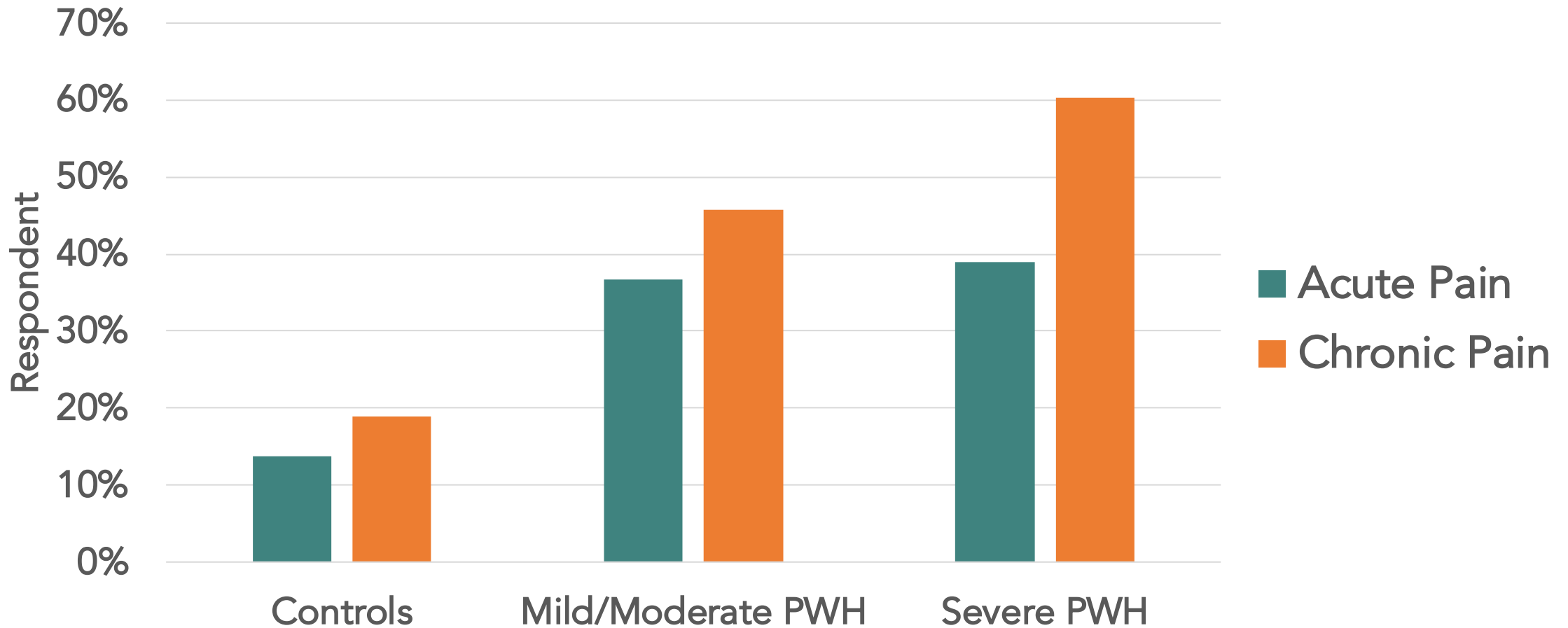
Acute & Chronic Pain Questions – Yes/No

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

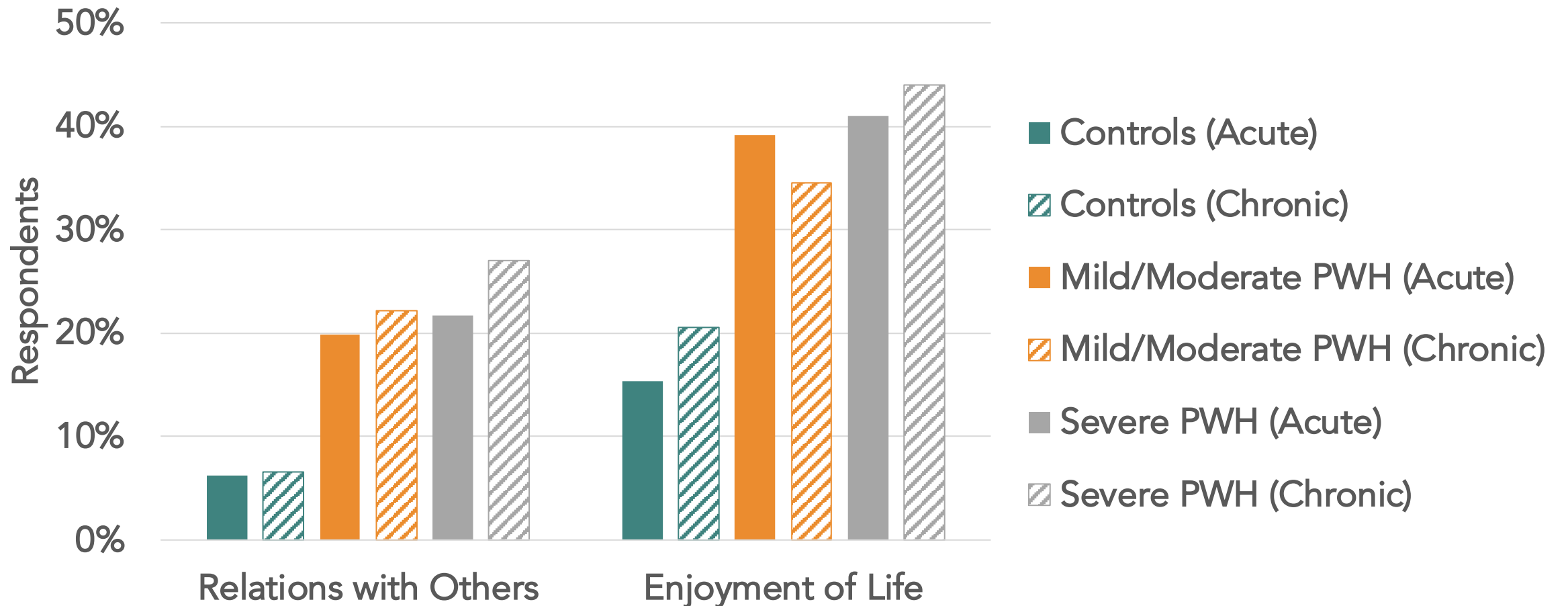
Health-related quality of life (EQ-5D-5L) & Pain Frequency PWH and Controls (no bleeding disorders)



Pain Occurrence: When Walking



Pain Interference: Relations with Others, Enjoyment of Life



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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Collaborating Patient Organizations

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- Hemophilia Foundation Australia
- Federação Brasileira de Hemofilia (Brazil)
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- Federación de Hemofilia de la República Mexicana (Mexico)
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- Haemophilia Foundation of Nigeria
- Polish Hemophilia Society
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