

How men with haemophilia manage their home treatment – an interactive workshop

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OBJECTIVES

The objectives of the workshop were:

- For healthcare professionals to further their understanding of the experience of self-management of severe haemophilia from the patients' perspective.
- To collaborate with experienced patients to understand decision making processes relating to home therapy
- To provide a forum for sharing of experience and expertise.
- To improve partnership working with patients in the management of home treatment
- To identify any areas for improvement in education

METHODS

Men with severe haemophilia A or B aged over 18 and on home treatment were invited to a workshop to meet with others and share their knowledge and experience – 16 participated. The workshop was held on a Saturday between 11.00 and 15.00 and a buffet lunch was provided. Members of the multidisciplinary team facilitated the discussion (haematologist; nurses; physiotherapist; family therapist). A number of questions were considered in turn:

- How do you know when you have a bleed?
- What do you do next?
- How do you decide if and when to treat?
- How do you decide what dose to give – and how often?
- What prompts you to contact the Centre?

The responses were written up on flip-charts. The participants were then each asked to choose the 3 most important/interesting themes that emerged – the highest scoring themes were selected to discuss in more depth. One of the participants volunteered to draft a report to be circulated to all present.

RESULTS

Some key themes emerged for the patients:

1. **Bodily awareness** – importance of monitoring sensation so you can detect the start of a bleed by some subtle change of state. Experience helps – felt that this would be more difficult for younger patients to learn as they would not have the “bleed experience”.
2. **Risk assessment** – criteria for treating included where they were and what they were doing, balancing interference with life and perceived consequence of particular bleed. Usually adopt a wait and see policy for soft tissue bleeding.
3. **Decision to treat is influenced by multiple factors:**
 - Pain that gets rapidly worse judged as likely to be a bleed rather than arthritis
 - Past relationship with treatment e.g. availability; HIV; HCV;
 - Older men may be more cautious both in lifestyle and use of treatment
 - Venous access – can inhibit initiating treatment if anticipated to be difficult.
 - Others e.g. partners, feedback that they may notice a change in mood when the person with haemophilia has a bleed e.g. irritability
4. Decisions about **what dose to use** can depend on the site of bleed and how much time has elapsed between the onset and initiation of treatment
5. Beyond the initial dose **unclear about how treatment works and how long it lasts** – judgment about follow-up treatments based on experience of previous bleeds and own clinical assessment.
6. **Deciding whether to contact the haemophilia centre** – in general would do this if a bleed had not improved within 48 hours; also for bleeding episodes affecting sites that were unfamiliar; expected reassurance or an action plan; anticipated that staff would advise them to come to the Centre so often wait and only call when they have decided they need to come in anyway.

CONCLUSIONS

The patient participants appreciated the opportunity for peer support and were keen to share their expertise with each other. They wanted to support younger patients and raised the possibility of offering mentorship. The staff participants felt they learnt about the patients' experience of the reality of home treatment and how they made decisions.

The meeting report will be used to produce educational materials and plan further interventions. Discussions revealed particular need for education about the rationale for factor dosing and the pharmacokinetics of factor concentrate. They also indicated a need for individualised treatment plans for the overall management of different types of bleeding episode. This type of workshop with a focused theme was a useful and enjoyable format for mutual learning.

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