What drives severe haemophilia patients’ decisions to change treatment? A qualitative study

Background
A new extended-half-life (EHL) treatment has been developed for people diagnosed with haemophilia A, an incurable genetic disorder. People with haemophilia A experience frequent internal bleeding, causing pain and stiffness. Compared with typical prophylactic treatment, EHL requires fewer infusions, however patients are reluctant to change to EHL. Research suggests patients face several possible barriers when making decisions about treatment. The present study aimed to further explore the illness and treatment beliefs of haemophilia A patients, and how these may affect treatment decisions.

What is already known on the subject?
- A primary concern is the development of inhibitors, however EHL treatments have not been associated with increased risk of inhibitor development
- Product side effects, product efficacy, safety/purity, product quality and longevity may contribute to a reluctance to switch to EHL. This may, in part, be associated with blood product contaminations in 1980s
- One type of treatment is used for several years and loyalty develops to that brand
- Haemophilia treatments are known to be very expensive therefore it is believed that EHL is too expensive

What does this study add?
- Insight into barriers in treatment switching such as treatment familiarity, wanting to maintain normality, and patient passivity
- Evidence for treatment characteristics which are a barrier to switching
- Understanding of beliefs on the need for treatment and adherence rates

Objectives
Understand factors influencing treatment decisions, and the role of:• Medication beliefs• Treatment characteristics• Doctor-patient relationship

Methods
Sample
Eleven men with severe haemophilia A, aged 27-39
Recruited from Haemophilia Society UK Facebook page

Design interviews were semi-structured, the discussion guide was divided into four major sections (see table 1):

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<th>Topic</th>
<th>Example question</th>
<th>Example prompt</th>
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| Patient Challenges of Living with Haemophilia A | Could you tell me a little bit about what it’s like to live with haemophilia day-to-day? | - What makes a good day for you living with haemophilia?  
- What makes haemophilia difficult to manage? |
| Haemophilia Patient Treatment Perceptions Standardized Prophylaxis and Extended Half Lives | What are your thoughts about your current treatment? | - What are the pros and cons of your current treatments? |
| Haemophilia Treatment Decision Making | Who is involved in making decisions about your treatments for haemophilia? What is your role in making these decisions? | - Who, if anyone, do you discuss your treatment decisions with?  
- Healthcare professional (partner, family, friends, other patients with haemophilia) |
| The Role of Healthcare Professional Communication | What have been your experiences with healthcare professionals (specialists, nurses, healthcare professional etc.) when making decisions about treatments for your haemophilia? | - Are you satisfied with the communications you’ve had with your healthcare team about treatment choices? Why/why not? |

Results: 4 themes

Treatment satisfaction
- All participants said the condition did not impact day to day life
- Taking effective, safe treatment, long-term, creates feelings of loyalty and gratitude
- Reported adherence to treatment was very high

Low interest in new treatments
- When treatment is safe and effective, patients prefer routine
- Something must go wrong to necessitate a treatment change

Risk outweighs reward
- Perceived risks of treatment outweigh EHL benefits
- Doubt in ability to adjust to a new routine
- Effectiveness is more important than convenience

Passivity in doctor-patient relationship
- Patients have long term, trusting relationships with doctors
- They may wait for doctors to suggest and change treatments
- Do not appear engaged in treatment decision making
- Need more collaborative approach

Analysis
Interviews were audio recorded and transcribed, and data analysed using thematic analysis.

Recommended Solutions
- Patient discussion guide/Evaluation tool  
- Patient FAQs and consensus about EHL  
- Encourage Therapeutic alliance and shared decision making

Conclusion
Barriers patients face when considering a change in treatments include familiarity and patient detachment. Further research should investigate potential support solutions to overcome these barriers, and facilitate the doctor-patient relationship.

References