



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

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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 treatment¹. The present study aimed to further explore the illness and treatment beliefs of haemophilia 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 development²
- 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 1980's
- One type of treatment is used for several years and loyalty develops to that brand^{1,3,4}
- Haemophilia treatments are known to be very expensive therefore it is believed that EHL is too expensive^{5,6}

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

- UK-based and offered £50 as remuneration
- Treatments included prophylaxis (n=9), EHL (n=1) and 'other' (n=1)

Exclusion: Already participated in EHL trials and had inhibitors present



Analysis

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

Design

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

Topic	Example question	Example prompt
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?	<ul style="list-style-type: none"> • 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?	<ul style="list-style-type: none"> • 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?	<ul style="list-style-type: none"> • 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?	<ul style="list-style-type: none"> • Are you satisfied with the discussions/communication you've had with your healthcare team about treatment choices? Why/why not?

Table 1: Discussion guide topics, with example questions and prompts

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 a more **collaborative approach**

"I'd say it is allowing me to do day-to-day what I wish to do" - P1

"It is basically essential. Without it, trust me, it is a horrible life" - P2

"If I had more problems with the treatment I was on at the moment, I would be keener to look into other options" - P3

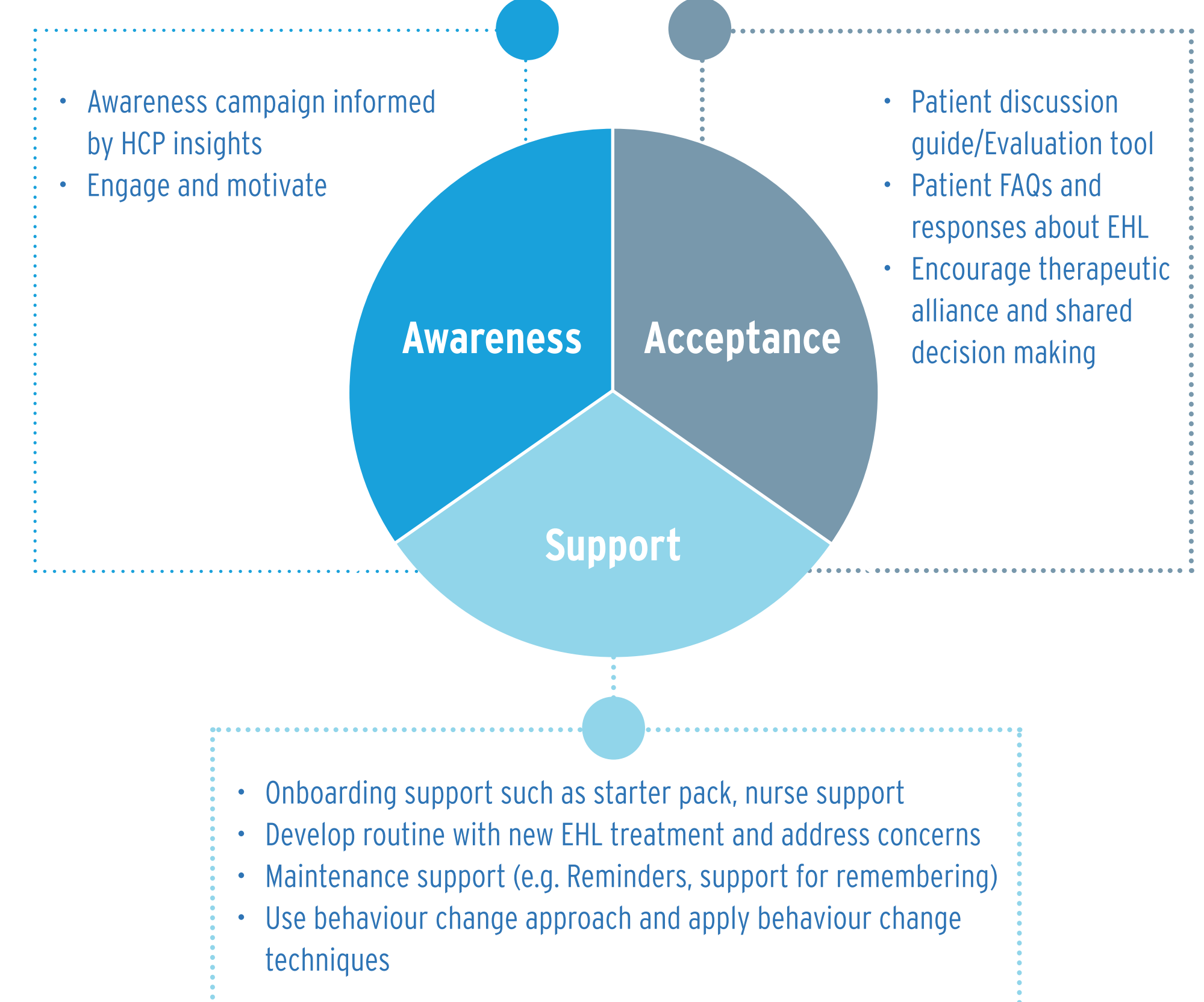
"It would be really good not to have to have it every other day, but initially, psychologically I'd find it a bit different" - P3

"I've always had it drilled into me that switching products increases your risk of inhibitors...so I've always been quite hesitant to switch" - P4

"I trust the doctors a lot. I feel they're the main ones to convince me" - P2

"If there were other options, and then given me the pros and cons of each, if there were other options to choose from at the time" - P5

Recommended Solutions



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.

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