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Introduction

Longer acting recombinant factor treatments for haemophilia A and B have been developed by drug companies and have just entered the NHS Market. These drugs have been cited as making a potential positive contribution to prophylactic therapy for children, by helping them to overcome some of the challenges faced with the current regimen of frequent intravenous infusions which can lead to interruption in daily life and reduced adherence (4, 6). The aim of this study was to determine the confidence of parents when dosing their children with long acting factor products before sporting activities and evaluate if parental levels of behaviour, attitudes and interventions change with long acting factor products.

Primary Objectives

To determine the confidence of parents when dosing their children with long acting factor products before sporting activities.
To assess the feasibility of conducting a larger scale study.

Secondary Objectives

To evaluate if parental levels of behaviour, attitudes and intentions change with long acting factor products.
To assess any differences in parental experiences when treating with long acting factor products compared to standard factor products.
To be aware and understand what helps to decide the timings of prophylactic treatment in relation to sporting activities and potential recommendations that can be made in the future.

Method

Parents of boys with Severe Haemophilia A or B from two Haemophilia Centres in the UK currently participating in trials of Long Acting Factor Products for 6 months or more were identified (n=10). Data was collected by interviewing participants using a semi structured interview technique with partial pre-planning of the questions with an ability to expand on specific issues. Interviews were taped and then transcribed verbatim. A constant comparative method was used to analyse data (2).

References

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"...I'd really like to continue on the long acting factor because to date it has been extremely effective you know and that leads into us being more confident, in that there won't be a joint bleed..."

"Well for short acting factor you are doing every other day..., long acting factor it's a bit more complicated really because what you want to do is give the dosage when it's needed most and then hopefully it sustains through the sport level..."

"Obviously it's much more convenient not having to do it every other day. And knowing that in his body there is much more factor VIII than before, all of the time is much more peace of mind".

"...you still wish there was a little dial on him that said whether he was full or empty, but because it's longer lasting you think, well, there's got to be enough in there to cover him".

"No, I think it is great, it has helped me be less worried about my child's factor levels..."

"Although it's got an if you like shorter half-life, on match day it doesn't make any difference and the spike straight after injecting was as good with the other drug as with this when we started".

Results

Results indicated a high level of confidence in relation to sporting activity in all 10 parents and an individualised treatment regimen was favoured. The study also went on to assess any differences in parental experiences when treating with long acting factor products compared to standard factor products in regards to sporting activities.

- Level of sporting activity** - Most parents reported standard restrictions and no difference found when compared with standard factor.
- Decisions in timings of prophylaxis treatment** - Strongly relied on haemophilia healthcare professionals for advice with long acting factor products.
- Experiences of comparisons between long and standard factor** - The major theme with this question was the feeling of being protected and the convenience of not having to inject frequently.
- Timing of prophylactic treatment in relation to sporting activities** - An interest in wanting to know their son's levels on particular days of the week to help them decide whether they were covered for sporting activities with longer acting factor products.
- What works well and what doesn't work well in the current service to support boys with haemophilia benefiting from regular exercise** - The major theme to emerge from this category was that encouraging boys with haemophilia to participate in sporting activities should be the prime responsibility of the parents.

Discussion

The majority of parents interviewed felt extremely confident dosing their children with long acting factor products and said that they did not feel the need to 'top up' with factor between injections before sporting activity, as previously recommended (1, 5). However this view changed when their son's was more involved with competitive sport and parents indicated a higher level of concern whether their son's would be adequately covered by factor. Additionally some concern was also expressed on allowing them to re-participate in previous sporting activity such as football, due to the experience of bleeding episodes while on standard factor products. Significantly all parents when asked, requested a desire to know their son's factor levels on certain days of the week and suggested this could be achieved through a visual paper chart or app.

Conclusion

It is determined that the confidence of parents when dosing their children with long acting factor products before sporting activities is high. However, the results may indicate the need for the haemophilia nurses and health professionals to be more pro-active in reassuring parents about factor levels before sporting activity, particularly when their son participates in competitive sport. It is suggested that this could be achieved through individualised PK studies to reduce the possibility of parents giving extra doses 'just in case'. This format of interview identified the responses required to answer the question posed and could be put forward for a larger scale study.