

Beliefs about exercise in people with severe Haemophilia. A qualitative study

Stephanie Taylor¹, Karen Barker^{2,3}, Fran Toye²

1.Oxford Haemophilia and Thrombosis Centre, Oxford University Hospitals Foundation Trust.

2. Physiotherapy Research Unit, Nuffield Orthopaedic Centre, Oxford University Hospitals Foundation Trust.

3.NDORMS, University of Oxford

Introduction and Objectives

There are many strategies now employed to try and help increase the amount of exercise people undertake. For men with haemophilia, some patients report joint bleeding as a result of activity, whilst some think it protects their joints from bleeds and further destruction. However it is not clear what may influence people with haemophilia to consider exercise as a lifestyle choice. The purpose of this study was to investigate the attitudes and experiences of exercise and activity in persons with haemophilia (PWH).

Methods

We used a purposive sample of PWH registered at the Oxford Haemophilia Centre ages 18-74. All patients with severe haemophilia were invited to take part. We sent 110 invitations, 43 responded and 31 gave consent. Semi-structured interviews were carried out on 6 men with severe haemophilia to explore their attitudes and experiences of activity and exercise. The sample provided a rich insight into attitudes to activity and recruitment ceased at this point. Interview length ranged from 32-60 minutes and were recorded, transcribed and analysed using interpretative phenomenological analysis. Ethical approval for the study was granted by NRES committee (ref no: 15/LO/1095).

"I don't let my limitations hold me back." They are able to adapt as their bodies change over the years.



"The best thing they did was educate me" Having a knowledge of haemophilia, how to treat and recognise bleeds and find activities to suit their bodies.



"Don't think about Haemophilia, I've got to deal with it" A level of acceptance and resilience that they are aware of their condition but they don't want it to rule their lives



FINDINGS

Results

5 key themes were developed and images chosen together with direct quotes to illustrate these. PWH accept their condition, they are positive towards exercise and find it of benefit both physically and psychologically. They are adaptable and can alter activities as required as their bodies change. They value education from both parents and the MDT to give them the knowledge to make informed decisions regarding exercise and activity choice. Finally PWH are no different from the rest of the population regarding some of the barriers to activity; pain from arthritis, lack of motivation and lack of time. These findings provide the clinician with insight into the attitudes and experiences that PWH have towards activity and exercise.

Conclusion

To our knowledge this is the first study to investigate experiences, attitudes and beliefs on activity and exercise in people with severe haemophilia. These findings will help clinicians to provide suitable strategies to motivate and design exercise interventions.

"Time constraints at home" PWH have the same barriers to exercise as the general populations



"The worst thing anyone can do is stop being active" improves not only body but also the mind

