



Johan Blokzijl
j.blokzijl-3@umcutrecht.nl

Primary care physiotherapy for persons with a rare disease such as haemophilia



current situation and opportunities for improvement.

Authors: Merel A. Timmer^{1,2}, Johan Blokzijl^{1,2}, Roger E.G. Schutgens¹, Cindy Veenhof^{2,3}, Martijn F. Pisters⁴

1. Centre for Benign Haematology, Thrombosis and Haemostasis, Van Creveldkliniek, UMC Utrecht | 2. Physica ITherapy Research, Department of Rehabilitation, Physical Therapy Science and Sport, UMC Utrecht Brain Centre, Utrecht University
3. Research Group Innovation of Human Movement Care, University of Applied Sciences Utrecht | 4. Center for Physical Therapy Research and Innovation in Primary Care, Julius Health Care Centres

Introduction

Haemophilia is a rare inherited bleeding condition that affects about 1 in 10.000 persons. The condition leads to a prolonged bleeding time, mostly in joints and muscles.

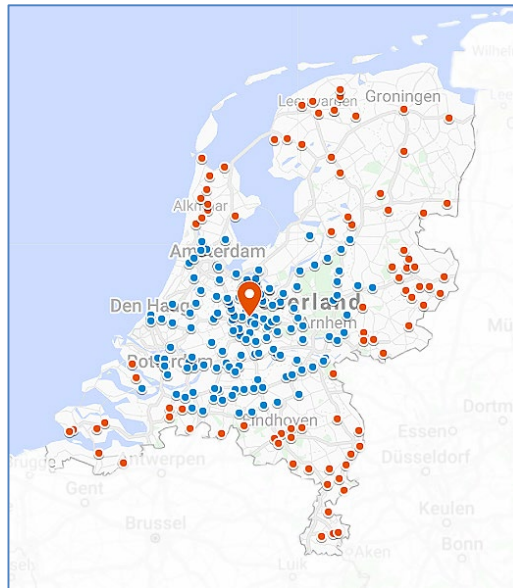
Physiotherapy is indicated for persons with haemophilia in case of:

1. An acute bleed
2. For treatment of long-term consequences of bleeds such as synovitis of haemophilic arthropathy.

Because haemophilia is such a rare condition the distance tot the haemophilia treatment centre is often large (see image) and there is little knowledge and experience in primary care.

Aim

The aim is to explore the experiences of stakeholders with primary care physiotherapy for persons with haemophilia and develop recommendations to optimize physiotherapy care coordination for persons with a rare chronic disease like haemophilia.



Method

Study consisted of two phases:

1. A questionnaire about current situation and experiences.
2. Consensus meetings to collect recommendations for improvement, using the RAND method (consisting of a Delphi procedure and an online meeting).

Data collection

Questionnaire about current situation was completed by 158 relevant stakeholders:

- 96 primary care physiotherapists
- 54 persons with haemophilia
- 8 physiotherapists working in haemophilia treatment centre

Results of questionnaire can be found below the text block below

33 points for improvement emerged from the questionnaire. These were discussed during a consensus meeting. The five most urgent points for improvement are described below.

Potential points of improvement:

1. Formal **guideline** for the treatment in primary care
2. Improve **reimbursement** by insurance companies
3. Ensure **low-threshold communication**
4. Build a **website** with up-to-date information
5. Provide a **decision tool**

Current situation of primary care physiotherapy

The median number of treatment sessions:

- Joint bleed: 8 (IQR 4–12)
- Muscle bleed: 6 (IQR 4–10)
- Synovitis: 9.5 (IQR 5–16.5)
- Haemophilic arthropathy: 15 (IQR 9–24)

In 41% van all treatment plans the primary care physiotherapist indicated that they had insufficient knowledge. 32% of the patients indicated they had the same experience.

73% of patients, 58% primary care physiotherapists and 57% physiotherapists working in the haemophilia treatment centre is satisfied with the collaboration.

Conclusion

For a rare disease such as haemophilia, it is not considered feasible to commit to a formal network. Developing a practice guideline, making information and contact details easily accessible and ensuring good communication between the treatment centre and primary care providers can help make good care available to everyone within primary care.

Want to know more?

