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ORIGINAL ARTICLE

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Coordinating physiotherapy care for persons with haemophilia

Merel A. Timmer[1,2] | Johan Blokzijl[1,2] | Roger E. G. Schutgens[1] | Cindy Veenhof[2,3] | Martijn F. Pisters[4]

[1] Van Creveldkliniek, University Medical Centre UtrechtUtrecht University, The Netherlands

[2] Physical Therapy Research, Department of Rehabilitation, Physical Therapy Science and Sport, UMC Utrecht Brain Centre, Utrecht University, The Netherlands

[3] Research Group Innovation of Human Movement Care, University of Applied Sciences Utrecht, The Netherlands

[4] Center for Physical Therapy Research and Innovation in Primary Care, Julius Health Care Centres, The Netherlands

Correspondence
Merel Timmer, Van Creveldkliniek, University Medical Centre Utrecht, The Netherlands.
Email: m.a.timmer@umcutrecht.nl

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Abstract

Introduction: Physiotherapy is highly recommended for persons with haemophilia (PWH), to regain functioning after bleeding and to maintain functioning when dealing with haemophilic arthropathy. However, many PWH live too far from their Haemophilia Comprehensive Care Centre (HCCC) to receive regular treatment at their HCCC. Physiotherapists in primary care may have limited experience with a rare disease like haemophilia.

Aim: To explore experiences of stakeholders with primary care physiotherapy for PWH and develop recommendations to optimize physiotherapy care coordination.

Methods: A RAND approach was used, consisting of a Delphi procedure with e-mailed questionnaires and a consensus meeting. Included stakeholders were PWH, physiotherapists from HCCC's and primary care physiotherapists. HCCC physiotherapists approached patients from their centre and primary care physiotherapists from their network to fill in the questionnaires. Purposive sampling was used to select participants from the survey sample for the consensus meeting.

Results: Ninety-six primary care physiotherapists, 54 PWH and eight HCCC physiotherapists completed the questionnaire. Subsequently, four PWH, three primary care physiotherapists and four HCCC physiotherapists participated in the consensus meeting. The questionnaires yielded 33 recommendations, merged into a final list of 20 recommendations based on the consensus meeting. The final rank-order consists of 13 recommendations prioritized by at least one stakeholder.

Conclusion: Commitment to a formal network is considered not feasible for a rare disease like haemophilia. Development of a practice guideline, easy-accessible information and contact details, two-way and open communication between HCCC and primary care and criteria to refer back to the HCCC are recommended.

KEYWORDS
care coordination, comprehensive care, haemophilia, physiotherapy, primary care, rare disease

1 | INTRODUCTION

With a prevalence of one in 10,000 individuals, haemophilia is a rare disease.[1] Between 6 and 8% of the community suffers from a rare disease.[2] This translates to 30 million people in the European Union alone. To improve health care for persons with a rare disease, several international strategies were developed, including EURORDIS and the European Reference Networks (ERN) in Europe and the Rare Disease Act in the United States.[2,3] An important aim of these strategies is to bundle expertise in expert centres and link expert centre to increase knowledge. The European Association for Haemophilia and Allied Disorders (EAHAD) already has a long and stable history of accrediting European Haemophilia Comprehensive Care Centre (HCCC) in order to bundle expertise for persons with haemophilia (PWH). According to the EAHAD guidelines, access to physiotherapy is one of the requirements to become an HCCC.[4]

Physiotherapy treatment is recommended in addition to clotting factor replacement therapy in case of acute bleeding and as a conservative management strategy for HA related complaints.[1,5,6] Whereas clotting factor replacement therapy is the first priority when a bleed occurs, physiotherapy following acute bleeding is directed at return to activities (daily activities, work, school, sports) and prevention of recurrent bleeding. Despite the introduction of prophylactic clotting factor replacement therapy, two bleeds per year on average still occur in persons with severe haemophilia with access to prophylactic replacement therapy.[7] For persons with haemophilic arthropathy (HA) as a consequence of bleeding in the past, physiotherapy is directed at retaining and optimizing daily functioning. Positive effects were found for several exercise interventions developed for PWH.[8]

Unfortunately, many PWH will not have access to regular physiotherapy treatment by a physiotherapist located at their HCCC, since there are only a few accredited centre in every region.[9] Treatment in primary care could be a solution to increase accessibility of physiotherapy treatment. However, given the rare nature of the disease, physiotherapists in primary care may have limited experience with the treatment of haemophilia. The importance of multidisciplinary care for persons with chronic diseases is widely accepted. However, literature about a primary care approach for chronic rare disease is still lacking. The aim of the current study is to explore the experiences of stakeholders with primary care physiotherapy for PWH and develop recommendations to optimize physiotherapy care coordination.

2 | METHODS

2.1 | Study design

This study uses the RAND method. The RAND method is a hybrid of the Delphi method (using e-mailed questionnaires) and a consensus meeting according to the Nominal Group Technique (NGT).[10] The RAND method therefore allows for the inclusion of a large representative sample during the survey phase and enables stakeholders to perform in-depth discussion and get insight into each other's point of view during the consensus meeting. The research protocol was approved by the Institutional Review Board of the University Medical Center Utrecht, the Netherlands.

2.2 | Participants

Stakeholders approached to participate in the study included patients, primary care physiotherapists and HCCC physiotherapists. PWH or von Willebrand's disease were eligible for inclusion if they had visited a primary care physiotherapist at least once, regardless of the indication. There was no restriction on severity or age. Parents were requested to participate for patients < 16 years. Patients were excluded if they had insufficient skills to read or write in Dutch. Primary care physiotherapists were eligible for inclusion when they had treated at least one PWH or von Willebrand's disease, for any indication. All (paediatric) physiotherapists located at an HCCC in the Netherlands were eligible for inclusion.

2.3 | Procedure and data analysis

2.3.1 | Phase 1: Survey

Three different questionnaires were developed for de different stakeholders (PWH, primary care physiotherapists and HCCC physiotherapists). The researchers drafted a first version of the questionnaires. A patient-representative, a primary care physiotherapist and a HCCC physiotherapist not included in the study reviewed the questionnaires and provided them from feedback. The questionnaires were adjusted until they were approved by all stakeholders. Between January and August of 2020 (parents of) PWH or von Willebrand's disease, HCCC physiotherapists and primary care physiotherapists in the Netherlands were approached to participate in the study. Physiotherapists in the Dutch HCCC's approached patients from their own centre and primary care physiotherapists from their network. All participants were required to fill out a questionnaire, send by email through the electronic data capture system 'Castor'. At the end of the questionnaire participants were able to indicate whether they wanted to be approached for a consensus meeting. Responses to closed-ended questions in the questionnaire were described as proportions, means and standard deviations (SD) or medians and quartiles for not normally distributed data. Open-ended questions were analysed using a thematic approach. Recommendations generated by both open-ended and closed-ended questions were listed by the researchers.

2.3.2 | Phase 2: Consensus meeting

Purposive sampling (for physiotherapists based on specialization and experience and for PWH based on age and indication for physiotherapy treatment) was used to select four PWH, four HCCC physiotherapists and four primary care physiotherapists to participate in the

TABLE 1 Characteristics of primary care physiotherapists ($n = 96$)

Experience as physiotherapist, mean years (sd)	22.6 (12)
Specialization, % (*n*)	
Paediatrics	14.6 (14)
Sports	18.8 (18)
Manual therapy	29.2 (28)
Geriatrics	3.1 (3)
Patients with haemophilia treated, % (*n*)	
1	57.3 (55)
2–10	40.6 (39)
> 10	2.1 (2)
Indication for which they treated a PWH, % (*n*)	
Joint bleed	47.9 (46)
Muscle bleed	38.5 (37)
Synovitis	16.7 (16)
HA	32.3 (31)
Not haemophilia related problem in PWH	52.1 (50)

Abbreviations: HA, Haemophilic Arthropathy; PWH, person with haemophilia.

TABLE 2 Characteristics of persons with haemophilia ($n = 56$)

Age, mean years (sd)	40.1 (20.2) Range 8–75
Disorder, % (*n*)	
Severe haemophilia	60.7 (34)
Moderate haemophilia	16.1 (9)
Mild haemophilia	19.6 (11)
Von Willebrand's disease	3.6 (2)
Indication for received PT treatment, % (*n*)	
Joint bleed	46.4 (26)
Muscle bleed	25.0 (14)
Synovitis	28.6 (16)
HA	51.8 (29)
Not haemophilia related problem in PWH	41.1 (23)

Abbreviations: HA, Haemophilic Arthropathy; PWH, persons with haemophilia; PT, physiotherapy.

TABLE 3 Characteristics of physiotherapists located at a haemophilia comprehensive care centre ($n = 8$)

Experience as physiotherapist, median years (IQR)	20.5 (8.25–38.0)
Specialization, % (*n*)	
Paediatrics	50 (4)
Geriatrics	12.5 (1)
No specialization	37.5 (3)
Experience with haemophilia care, median years (IQR)	10 (2–17)
Hours for haemophilia care per week, median fte (IQR)	.2 (.05–.8)
Physiotherapists that have previously referred a PWH to primary care, % (*n*)	87.5 (7)
Indication for referral to primary care, % (*n*)	
Joint bleed	50 (4)
Muscle bleed	75 (6)
Synovitis	37.5 (3)
HA	37.5 (3)
Not haemophilia related problem in PWH	62.5 (5)

Abbreviations: HA, Haemophilic Arthropathy; PWH, persons with haemophilia.

subsequent consensus meeting. Prior to the consensus meeting, the recommendations listed by the researchers at the end of phase 1 were presented to the participants. A digital consensus meeting was performed according to NGT principles.[11] During the consensus meeting participants were invited to clarify ideas and explain the importance from their point of view. Based on the discussion recommendations were adjusted, merged, split or added. Two researchers (J.B. and M.T.) acted as moderators. After the consensus meeting participants were asked to anonymously prioritize their five most important recommendations to optimize primary care physiotherapy for PWH. The NGT enabled participants to be involved in data-analysis by composing a rank-order. Recommendations were scored based on their position in the priority lists (the most important recommendation received a score of 5, the most important recommendation after that received a score of 4, etc.).

3 | RESULTS

A total of 96 primary care physiotherapists, 54 PWH and eight HCCC physiotherapists completed the questionnaires (response rate of, respectively, 23%, 73% and 57%). Characteristics of the primary care physiotherapists, PWH and HCCC physiotherapists that filled out the questionnaires are presented in Tables 1–3, respectively. Subsequently, 74 PWH and physiotherapists indicated that they wanted to be approached for a consensus meeting. Of the 12 purposively sampled stakeholders, 11 (4 PWH, three primary care physiotherapists and four HCCC physiotherapists) actually participated in the consensus meeting.

3.1 | Phase 1: survey

All three questionnaires included the domains; (1) general information, (2) experiences with primary care physiotherapy for PWH, (3) experiences with cooperation between primary care and HCCC, and (4) desired cooperation. The domain 'general information' ended with the open question 'How do you think we can improve physiotherapy for PWH in primary care and what do you think is needed to achieve that?' The other domains all ended with the question 'Is there anything you want to add about this topic?'. All other questions where closed-ended questions. Questionnaires are attached within Appendix 1.

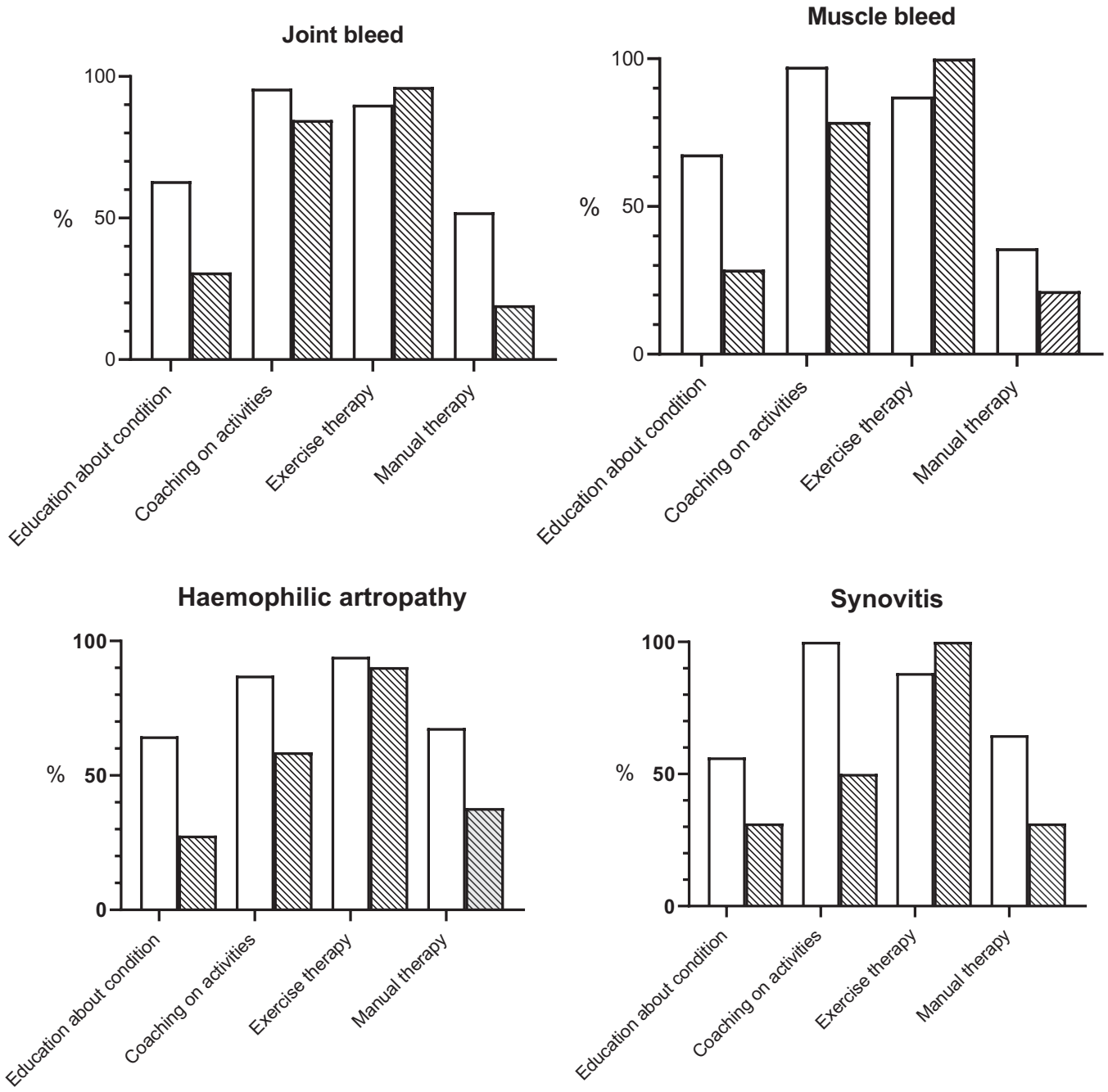

FIGURE 1 (A–D). Treatment modalities used for the treatment of (A) joint bleeds, (B) muscle bleeds, (C) haemophilic arthropathy, D) synovitis as indicated by patients (striped bar) and primary care physiotherapists (empty bar)

3.1.1 | Experiences with primary care physiotherapy for PWH

Treatment modalities applied for joints bleeds, muscle bleeds, synovitis and HA as indicated by patients and primary care physiotherapists are shown in Figure 1(A–D), respectively. Physiotherapists stated that they used a median number of 8 (IQR 4–12) treatment sessions for joint bleeds, 6 (IQR 4–10) for muscle bleeds, 9.5 (IQR 5–16.5) for synovitis and 15 (IQR 9–24) for haemophilic arthropathy. PWH recall a number of 6 (IQR 3.8-11.3) treatment sessions for joints bleeds, 5 (IQR 3–15) for muscle bleeds, 8.5 (IQR 2–45) for synovitis and 10 (4.5-41) for haemophilic arthropathy.

Of the primary care physiotherapists that have treated a PWH with a joint bleed, 39.6% (19/48) indicated that they lack knowledge and experience to provide sufficient quality of care. For muscle bleeds, synovitis and HA this was, respectively, 42.2% (16/38), 37.5% (6/16) and 43.8% (14/32). Of the PWH, 32.1% felt that the primary care physiotherapist did not have enough information about haemophilia, and

TABLE 4 Experiences versus preferences in collaboration between primary care physiotherapists and HCCC physiotherapists

	Experience	Preferred
A referral received by the primary care physiotherapist	54.1% [42.0–63.0]	74.0% [64.0–85.4]
A medical handover received by the primary care physiotherapist	56.3% [45.6–66.4]	86.5% [78.0–92.6]
Information about the patient's specific situation received by the primary care physiotherapist	29.2% [20.0–39.3]	63.5% [53.1–73.1]
Information to align treatment with other caregivers received by the primary care physiotherapist	30.2% [21.3–40.4]	71.9% [61.8–80.6]
A specific care plan for the patient received by the primary care physiotherapist	44.8% [34.5–55.3]	75% [65.1–83.3]
An end report received by the HCCC physiotherapist	28.6% [.037–.71]	57.1% [.18–.90]

Results are presented in percentages with confidence intervals.
Abbreviation: HCCC = haemophilia comprehensive care centre.

19.6% felt that the primary care physiotherapist did not have enough information about their specific situation.

3.1.2 | Experienced and desired collaboration

Overall, 73.2% of the patients, 58.2% of the primary care physiotherapists and 57.1% of the HCCC physiotherapists were positive about the collaboration between primary care and HCCC. Table 4 shows differences between experiences and preferences on specific items regarding collaboration between primary care physiotherapists and HCCC physiotherapists. Most primary care physiotherapists (54.2%) prefer to consult the HCCC at least once and in case of questions or problems. This is in accordance with HCCC physiotherapists (42.8%), although some HCCC physiotherapists feel this should be continued monthly for the duration of the treatment (43.0%). A monthly report is not recommended by primary care physiotherapists (2.2%).

From the open-ended questions several themes to improve physiotherapy in primary care evolved, including challenges and recommendations. Both primary care physiotherapist and PWH indicated the little knowledge of primary care physiotherapists about haemophilia as a challenge. Given the small incidence, primary care physiotherapists find it difficult to gain experience and invest time to gain knowledge. PWH think that primary care physiotherapists feel a barrier to cooperate with HCCC physiotherapists. Both PWH, primary care physiotherapists and HCCC physiotherapists put forward three main recommendations: inform primary care physiotherapists about haemophilia, improve collaboration between primary care and HCCC and build a network of primary care physiotherapists with experience in haemophilia care.

3.2 | Phase 2: Consensus meeting

The initial questionnaires yielded 33 recommendations for improvement. Based on the consensus meeting these were merged into a final list of 20 recommendations. A total of 13 recommendations was prioritized by at least one stakeholder. The final list of recommendations is presented in Table 5. One of the recommendations that was not prioritized by any of the stakeholders is the formation of a formal network of physiotherapists, including commitment to following education and treatment according to guidelines. In contrary, items with a high rank on the final list include the development of a practice guideline of the treatment of PWH (1), easy-accessible information and contact details (2) and two-way and open communication between HCCC physiotherapists and primary care physiotherapists (4).

4 | DISCUSSION

Experiences of primary care physiotherapists with the treatment of haemophilia related problems showed that between 37.5 and 43.8% felt they lacked knowledge and experience to provide sufficient quality of care. A smaller part of the PWH felt that the primary care physiotherapist did not have enough information about haemophilia (32.1%) or their specific situation (19.6%). The majority of PWH (73.2%), primary care physiotherapists (58.2%) and HCCC physiotherapist (57.1%) were positive about the collaboration between primary care and HCCC. To optimize quality of physiotherapy care stake-holders propose to develop a practice guideline, provide easy-accessible information and contact details, ensure two-way and open communication between HCCC physiotherapists and primary care physiotherapists and provide criteria to refer back to the HCCC. The formation of a formal network of physiotherapists was not prioritized in the final list of recommendations.

Content of physiotherapy practice for PWH is investigated in one previous European survey.[9] This survey was filled out by HCCC physiotherapists and gives a general description of applied treatment modalities, without differentiation between conditions. However, similar to the current study, exercise therapy was mostly applied and in about half of the cases manual therapy was used. In contrast to the current study, education about the condition was given more often in the European survey. This could be explained by the fact that primary care physiotherapists in the current study felt they lacked knowledge about haemophilia, whereas HCCC physiotherapists in the previous study probably have more knowledge about the condition. Furthermore, the use of e-health solutions to improve physiotherapy care for PWH is recommended in recent literature and implementation has been

TABLE 5 List of recommendations

Rank	Recommendation	Score[a]	Number of participants that prioritized the recommendation ($N = 11$)
1	Create a formal practice guideline for treatment of PWH in primary care. This guideline will consist of written information on the most recent scientific evidence and expertise from healthcare professionals.	29	9
2	Ensure that Information about haemophilia, treatment options and contact details of HCCC physiotherapists are easily accessible (e.g., on a website).	28	8
3	Improve reimbursement by insurance companies for physiotherapy treatment of PWH in primary care.	25	8
4	Ensure two-way and open communication between primary care physiotherapists and HCCC physiotherapists (e.g., by enabling direct contact between physiotherapists or by letting the HCCC physiotherapist initiate a call to the primary care physiotherapist)	22	6
5	Provide a decision tool to help primary care physiotherapist determine when they should contact the HCCC when they treat PWH with all sorts of physical complaints (joint of muscle bleedings, synovitis or arthropathy)	19	5
6	Ensure sufficient physiotherapy service and if needed expand the number of available hours for HCCC physiotherapists (for treatment within the HCCC and for collaboration with primary care physiotherapists)	13	4
7	Provide education to primary care physiotherapists about haemophilia (either physical or digital)	6	3
8	Refer PWH for treatment to a physiotherapist with previous experience in treatment of PWH when possible	6	3
9	Set up a digital register or map for PWH to find a primary care physiotherapist with previous experience in treatment of PWH in their neighbourhood	6	2
10	HCCC physiotherapists should ask PWH about primary care physiotherapy during periodic visits	5	2
11	Provide available diagnostic imaging (X-ray and/or Ultrasound) to primary care physiotherapists	3	3
12	Ensure communication between the primary care physiotherapist and the physiotherapist from the HCCC is accessible for the PWH	2	1
13	Ensure communication between the primary care physiotherapist and the HCCC physiotherapist whenever treatment in primary care is terminated.	1	1
–	Provide written information about periodic visits at the HCCC to the primary care physiotherapist.	0	0
–	Ask patients to bring, or send, a report from the primary care physiotherapist to the periodic visit at the HCCC.	0	0
–	Always start physiotherapy treatment in the HCCC	0	0
–	Involve a PWH and/or family of this person in creating treatment goals.	0	0
–	Start a formal network for physiotherapists. Participating physiotherapists will commit to following education and treat patients according to guidelines.	0	0
–	Start regional physical therapy training groups led by a physiotherapist.	0	0
–	Provide insight into the number of PWH living in a certain area.	0	0

Abbreviations: HCCC, haemophilia comprehensive care centre, PWH, persons with haemophilia, PC = Primary care.

[a]Score is based on the position of the recommendation on the priority lists of the participants (the most important recommendation received a score of 5, the most important recommendation after that received a score of 4, etc.).

accelerated by the COVID-19 pandemic.[12,13] Although, the use of e-health was not specifically mentioned in the current study, it may be useful to facilitate the implementation of treatment recommendations in the future.

Literature about physiotherapy care coordination for persons with rare diseases in general and PWH in particular is not yet available.[14] Comprehensive care models in haemophilia are primarily directed at multidisciplinary care within the HCCC[15]. However, according to the conceptual framework for integrated care by Valentijn and colleagues comprehensive care includes vertical and horizontal integration.[16] Pathways that connect community-based generalists with hospital-sited specialists are considered vertical integration, whereas horizontal integration involves collaboration between different professions within one organization. Different techniques are required to achieve them. In accordance with this framework, results from the current study emphasize the importance of vertical integration and proposes

steps to improve vertical integration in physiotherapy care for patients with a rare chronic disease like haemophilia.

Previous research shows that the implementation of a formal physiotherapy network for Parkinson's disease (the Dutch ParkinsonNet) resulted in lower health care costs and less complications.[17] Formal physiotherapy networks are also being developed for several other chronic diseases, including Chronic Obstructive Pulmonary Disease, Rheumatoid Arthritis and Intermitted Claudication.[18,19] Although differences in approach exist between networks and between countries, they usually include mandatory education for participating professionals, building of guidelines and commitment of professionals to guidelines. The current study shows that commitment to a formal network is not feasible for a rare chronic disease. Recommendations in the current study aim to improve disease specific knowledge in a way, that is, feasible for a rare chronic disease.

A strength of the current study is the use of a RAND procedure, including a survey phase and a consensus meeting. By starting with a survey with a large sample size, we increased generalizability of the results. The advantage of the subsequent consensus meeting is that it enables stakeholders to get insight into each other's point of view, resulting in more in-depth results. A possible limitation of the study is the use of a digital consensus meeting. Literature about the validity of digital variants of focus group techniques is still lacking. However, the moderators ensured that all stakeholders participated in the discussion and within the NGT all participants contribute by making a rank-order of the proposed items. Furthermore, the use of a digital consensus meeting reduces selection bias, because it is less time-consuming considering participants do not have to travel.

Results of the current study can be generalized to countries with a similar health care system as the Netherlands. Differences in roles, responsibilities and clinical practice of physiotherapists between countries and even between different institutes may influence the needs and possibilities for primary care physiotherapy.[9] Although this study was directed at the treatment of PWH, it can be expected that results are applicable for other rare chronic diseases as well given the general nature of the recommendations. Future research is needed to demonstrate whether similar results are found in other rare chronic conditions and in countries with a different health care system.

To conclude, the majority of the stakeholders is positive about the collaboration between HCCC and primary care physiotherapists. However, up to half of the primary care physiotherapists feel that they have insufficient knowledge and experience to provide sufficient quality of care and up to a third of the PWH feel that their physiotherapist lacks information. Commitment to a formal network is considered not feasible for a rare chronic disease. Development of a practice guideline, easy-accessible information and contact details, two-way and open communication between HCCC and primary care and criteria to refer back to the HCCC are recommended.

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CONFLICT OF INTEREST

The authors stated they have no competing interests.

AUTHOR CONTRIBUTIONS

Merel A. Timmer an Martijn F Pisters developed the study. Merel A. Timmer and Johan Blokzijl performed data collection. All authors contributed to data interpretation. All authors contributed to critical reviewing and editing of the manuscript. All authors approved the final manuscript.

DATA AVAILABILITY STATEMENT

Data will be available upon reasonable request.

ORCID

Merel A. Timmer https://orcid.org/0000-0003-1910-999X
Roger E. G. Schutgens https://orcid.org/0000-0002-2762-6033

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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APPENDIX 1: QUESTIONNAIRES

A | Questionnaire primary care physiotherapists

General physiotherapy experience

- How many years of experience do you have as a physiotherapist?
- Do you have a registered physiotherapy specialization? (*no, paediatrics, sports, manual therapy, geriatrics, other…*)

How do you think we can ensure high quality physiotherapy care for persons with haemophilia (PWH) in their own neighbourhood? What do you think we need to achieve this? *(open question)*

Experience with haemophilia

- How many PWH did you treat as a physiotherapist? *(1, 2–10, > 10)*
- With which indication(s) did you treat patients with haemophilia? *(joint bleed, muscle bleed, synovitis, haemophilic arthropathy, not haemophilia related complaint in person with haemophilia)*
  - Joint bleed:
    - How many sessions did you on average use for a person with a joint bleed? (number of sessions)
    - Which treatment strategies did you apply for a joint bleed? (education about the complaint, coaching on activities, advising in sports/work/school, exercise therapy directed at muscle setting, exercise therapy directed at stability, exercise therapy directed at strength, exercise therapy directed at range of motion, exercise therapy directed at a specific activity, manual therapy directed at pain reduction, manual therapy directed at joint mobility, massage, taping, other…)
    - Did you feel you had enough knowledge/information/skills to treat a persons with a joint bleed? (not at all, not completely, neutral, reasonable, completely)
  - Muscle bleed:
    - How many sessions did you on average use for a person with a muscle bleed? *(number of sessions)*
    - Which treatment strategies did you apply for a muscle bleed? *(education about the complaint, coaching on activities, advising in sports/work/school, exercise therapy directed at muscle setting, exercise therapy directed at stability, exercise therapy directed at strength, exercise therapy directed at range of motion, exercise therapy directed at a specific activity, manual therapy directed at pain reduction, manual therapy directed at joint mobility, massage, taping, other…)*
    - Did you feel you had enough knowledge/information/skills to treat a persons with a muscle bleed? *(not at all, not completely, neutral, reasonable, completely)*
  - Synovitis:
    - How many sessions did you on average use for a person with a synovitis? *(number of sessions)*
    - Which treatment strategies did you apply for a synovitis? *(education about the complaint, coaching on activities, advising in sports/work/school, exercise therapy directed at muscle setting, exercise therapy directed at stability, exercise therapy directed at strength, exercise therapy directed at range of motion, exercise therapy directed at a specific activity, manual therapy directed at pain reduction, manual therapy directed at joint mobility, massage, taping, other…)*
    - Did you feel you had enough knowledge/information/skills to treat a persons with a synovitis? *(not at all, not completely, neutral, reasonable, completely)*
  - Haemophilic arthropathy:
    - How many sessions did you on average use for a person with limitations in functioning as a consequence of haemophilic arthropathy? *(number of sessions)*
    - Which treatment strategies did you apply for limitations in functioning as a consequence of haemophilic arthropathy? *(education about the complaint, coaching on activities, advising in sports/work/school, exercise therapy directed at muscle setting, exercise therapy directed at stability, exercise therapy directed at strength, exercise therapy directed at range of motion, exercise therapy directed at a specific activity, manual therapy directed at pain reduction, manual therapy directed at joint mobility, massage, taping, other…)*
    - Did you feel you had enough knowledge/information/skills to treat a persons with limitations in functioning as a consequence of haemophilic arthropathy? *(not at all, not completely, neutral, reasonable, completely)*
- Do you want to add anything about this subject? *(open question)*

Experience with collaboration

These questions are about the collaboration you experienced **in the past**:

- Did you receive a referral from the HCCC? *(yes/no/sometimes)*
- Did you receive a care plan from the HCCC? *(yes/no/sometimes)*
  - Which caregiver created the care plan? *(physiotherapist, nurse, physician, other…)*
  - What was the content of the care plan? *(general information about haemophilia, specific information about the patient, aligning treatment with other caregivers, proposed treatment plan, other…)*
- Did you send a report back to the HCCC? *(yes/no/sometimes)*
  - To which caregiver did you send the report? *(physiotherapist, nurse, physician, other…)*
  - Which information did you report back to the HCCC? *(contact in case of problems, results of the treatment, interim progress, content of the treatment, other…)*
- How did you contact the HCCC? *(letter, phone, email, other…)*
- How often did you have contact with the HCCC? *(once, twice, weekly for the duration of the complaints, monthly for the duration of the complaints, only in case of questions or problems)*
- How satisfied are you with the collaboration with the HCCC? *(not at all satisfied, not satisfied, neutral, satisfied, very satisfied)*
- Do you want to add anything about this subject? *(open question)*

These questions are about how you **prefer** the collaboration:

- Do you prefer to receive a referral from the HCCC? *(yes/no/sometimes)*
- Do you prefer to receive a care plan from the HCCC? *(yes/no/sometimes)*
  - Which information do you prefer to receive? *(general information about haemophilia, specific information about the patient, aligning treatment with other caregivers, proposed treatment plan, other…)*
- Which caregiver do you prefer to receive the information from? *(physiotherapist, nurse, physician, other…)*
- How often do you prefer to be in contact with the HCCC? *(once, twice, weekly for the duration of the complaints, monthly for the duration of the complaints, only in case of questions or problems)*
- How do you prefer to be in contact with the HCCC? *(letter, phone, email, other…)*
- Do you think primary care physiotherapists should report back to the HCCC? *(yes/no/sometimes)*
- Which information should be reported back in your opinion? *(contact in case of problems, results of the treatment, interim progress, content of the treatment, other…)*
- To which caregiver should this information be reported back? *(physiotherapist, nurse, physician, other…)*
- Do you want to add anything about this subject? *(open question)*

B | Questionnaire PWH

General information

- What is your age/ your child's age?
- Which condition do you/ your child have? (mild haemophilia, moderate haemophilia, severe haemophilia, von Willebrand's disease)

How do you think we can ensure high quality physiotherapy care for PWH in their own neighbourhood? What do you think we need to achieve this? *(open question)*

Experience with primary care physiotherapy

- For which condition did you/your child go to the primary care physiotherapist? (joint bleed, muscle bleed, synovitis, haemophilic arthropathy, synovitis, not haemophilia related problem)
  - Joint bleed
    - How often did you/ your child go to the physiotherapist for a single joint bleed (on average)?
    - What kind of treatment did you/ your child receive for a joint bleed? *(education, exercise at the practice, home exercise, manual techniques, taping, other…)*
    - Did you/ your child also have an appointment at the HCCC for a joint bleed? (apart from regular check-ups) *(no, yes with the physician, yes with the physiotherapist, yes with both)*
    - How many appointments did you have at the HCCC for a single joint bleed? *(once, twice, weekly for the duration of the complaints, monthly for the duration of the complaints)*
  - Muscle bleed
    - How often did you/ your child go to the physiotherapist for a single muscle bleed (on average)?
    - What kind of treatment did you/ your child receive for a muscle bleed? *(education, exercise at the practice, home exercise, manual techniques, taping, other…)*
    - Did you/ your child also have an appointment at the HCCC for a muscle bleed? (apart from regular check-ups) *(no, yes with the physician, yes with the physiotherapist, yes with both)*
    - How many appointments did you have at the HCCC for a single muscle bleed? *(once, twice, weekly for the duration of the complaints, monthly for the duration of the complaints)*
  - Synovitis
    - How often did you/ your child go to the physiotherapist for a single synovitis (on average)?
    - What kind of treatment did you/ your child receive for a synovitis? *(education, exercise at the practice, home exercise, manual techniques, taping, other…)*
    - Did you/ your child also have an appointment at the HCCC for a synovitis? (apart from regular check-ups) *(no, yes with the physician, yes with the physiotherapist, yes with both)*
    - How many appointments did you have at the HCCC for a single synovitis? *(once, twice, weekly for the duration of the complaints, monthly for the duration of the complaints)*
  - Haemophilic arthropathy
    - How often did you/ your child go to the physiotherapist for complaints related to haemophilic arthropathy? (on average)?
    - What kind of treatment did you/ your child receive for complaints related to haemophilic arthropathy?? *(education,*

exercise at the practice, home exercise, manual techniques, taping, other…)

- Did you/ your child also have an appointment at the HCCC complaints related to haemophilic arthropathy?? (apart from regular check-ups) *(no, yes with the physician, yes with the physiotherapist, yes with both)*
- How many appointments did you have at the HCCC for complaints related to haemophilic arthropathy?? *(once, twice, weekly for the duration of the complaints, monthly for the duration of the complaints)*

- How satisfied are you with the treatment in primary care physiotherapy? *(not at all satisfied, not satisfied, neutral, satisfied, very satisfied)*
- Do you want to add anything about this subject? *(open question)*

Collaboration between primary care and HCCC

These questions are about the collaboration you experienced **in the past**:

- Did the HCCC contact the primary care physiotherapist (as far as you know)? *(no, about haemophilia in general, about my specific situation, other…)*
- Did you inform the primary care physiotherapist? *(yes, no)*
- Did the primary care physiotherapist have enough information about haemophilia, to your opinion? *(yes, no)*
- Did the primary care physiotherapist have enough information about your specific situation, to your opinion? *(yes, no)*
- Did the primary care physiotherapist report back to the HCCC, as far as you know? *(yes, no)*
- How satisfied are you with the collaboration between primary care and HCCC? *(not at all satisfied, not satisfied, neutral, satisfied, very satisfied)*
- Do you want to add anything about this subject? *(open question)*

These questions are about how you **prefer** the collaboration:

- Do you think the HCCC should provide information to the primary care physiotherapist? *(no, about haemophilia in general, about my specific situation, other…)*
- Do you think the patient should inform the primary care physiotherapist about haemophilia himself? *(no, about haemophilia in general, about my specific situation, other…)*
- Which information do you think the primary care physiotherapist should have? *(about haemophilia in general, about my specific situation, other…)*
- Do you think the HCCC should receive a report back from the primary care physiotherapist? *(yes, no)*
- Which information do you think that should be reported back to the HCCC? *(contact in case of problems, contact in case the treatment does not yield the expected results, results of the treatment, interim progress report, content of the treatment, other…)*
- Who should inform the primary care physiotherapist? *((parents of)patients, physician, nurse, HCCC physiotherapist, other…)*
- In which way should this information be provided? *(letter, flyer, phone call, other…)*
- Do you want to add anything about this subject? *(open question)*

C | Questionnaire HCCC physiotherapists

General information

- How many years of experience do you have as a physiotherapist?
- Do you have a registered specialization as physiotherapist? *(no, paediatrics, sports, manual therapy, other…)*
- Since how many years to you treat PWH?
- How many hours per week do you have for haemophilia care?
- How do you think we can ensure high quality physiotherapy care for PWH in their own neighbourhood? What do you think we need to achieve this? *(open question)*

Collaboration with primary care physiotherapists

These questions are about the collaboration you experienced **in the past**:

- Did you ever refer a PWH to a primary care physiotherapist? *(ja/nee)*
  - Did you refer this patient(s) to a physiotherapist who had treated a PWH before? *(no, yes, sometimes)*
- With which indication did you refer a PWH to a primary care physiotherapist? (*joint bleed, muscle bleed, synovitis, haemophilic arthropathy, not haemophilia related complaint)*
- Did you provide a care plan when you referred a PWH to primary care physiotherapy? (*yes, no, sometimes)*
  - Which information did you provide to your colleague in primary care? *(general information about haemophilia, specific information about the patient, proposed treatment plan, other…)*
- Did you receive a report back from the primary care physiotherapist? *(yes, no, sometimes)*
- Which information did you receive from the primary care physiotherapist? *(contact in case of problems, contact in case the treatment does not yield the expected results, results of the treatment, interim progress report, content of the treatment, other…)*
- How often did you contact the primary care physiotherapist? *(once, twice, weekly for the duration of the complaints, monthly for the duration of the complaints, only in case of questions or problems)*
- How did you contact the primary care physiotherapist? *(letter, email, phone call, other…)*
- How satisfied are you with the collaboration with primary care physiotherapists? *(not at all satisfied, not satisfied, neutral, satisfied, very satisfied)*
- Do you want to add anything about this subject? *(open question)*

These questions are about how you **prefer** the collaboration:

- Do you prefer to have contact with the primary care physiotherapist? (yes, no, sometimes)
- Which information do you prefer to receive from the primary care physiotherapist? (contact in case of problems, contact in case the

treatment does not yield the expected results, results of the treatment, interim progress report, content of the treatment, other…)

- How often do you prefer to have contact with the primary care physiotherapist? (once, twice, weekly for the duration of the complaints, monthly for the duration of the complaints, only in case of questions or problems)
- How do you prefer to have contact with the primary care physiotherapist? (letter, phone call, email, other…)
- Which information does a primary care physiotherapist need, to your opinion? (general information about haemophilia, specific information about the patient, proposed treatment plan, other…)
- Do you want to add anything about this subject? (open question)