

Feasibility and Results of a Mobile Haemophilia Outpatient Care Pilot Project

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Abstract

Introduction Regular visits at haemophilia treatment centres (HTCs) in rural regions are often dependent on the access to a private car due to lack of or limited availability of public means. Therefore, a mobile haemophilia outpatient care (MHOC) concept providing home visits to haemophilia patients has been developed by the Saarland HTC, which is located in a rural German region.

Methods Haemophilia patients and their parents were home visited at least twice (baseline, follow-up) by trained medical staff. Socio-demographic and clinical data were collected and interviews were performed asking the patients and parents about their needs and expectations towards such a MHOC.

Results Seventy-nine patients were enrolled (56 adults, 23 children), 62.0% severely affected, 48.1% on prophylaxis, with a mean age of 37.4 ± 16.4 years (17–78) and 9.8 ± 4.2 years (3–16), respectively. Median travel distance to the HTC was 43.5 km (3–200). Note that 92.4% considered an intense binding to the HTC and a MHOC concept as ‘rather/very important’ (88.6%). They expected from a MHOC to provide consulting and educating activities, support in elderhood issues and treatment. For 35.4%, a MHOC could currently provide additional support, mainly due to patient’s immobility and need of consultancy. They mainly used services in terms of consultancy in social–legal affairs and support in contacting authorities.

Conclusion The results of this study support the hypothesis that a MHOC concept is a needful supplement in haemophilia comprehensive care and will improve the challenging haemophilia treatment, especially for those with limited access to HTCs or with disabilities.

Keywords

- ▶ haemophilia
- ▶ haemophilia treatment centre
- ▶ mobile home care
- ▶ patient needs
- ▶ adherence
- ▶ adults
- ▶ children

Zusammenfassung

Einleitung Regelmäßige Besuche in Hämophilie-Behandlungszentren (HTCs) hängen in ländlichen Regionen oft vom Zugang zu einem privaten Auto ab, da öffentliche Verkehrsmittel nicht oder nur in begrenztem Umfang zur Verfügung stehen. Ein mobiles Hämophilie-Ambulanz-Konzept (MHOC), das Hausbesuche bei Hämophilie-

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Schlüsselwörter

- ▶ Hämophilie
- ▶ Hämophilie-Zentrum
- ▶ mobile häusliche Pflege
- ▶ Patientenbedürfnisse
- ▶ Adhärenz
- ▶ Erwachsene
- ▶ Kinder

Patienten ermöglicht, wurde daher vom Saarland HTC entwickelt, das in einer ländlichen deutschen Region angesiedelt ist.

Methodik Hämophilie-Patienten und ihre Eltern wurden mindestens zweimal (zu Beginn, Follow-up) von geschultem medizinischem Personal besucht. Soziodemografische und klinische Daten wurden gesammelt und Interviews durchgeführt, in denen Patienten und Eltern über ihre Bedürfnisse und Erwartungen an eine solche MHOC befragt wurden.

Ergebnisse Neunundsiebzig Patienten wurden eingeschlossen (56 Erwachsene, 23 Kinder), 62,0% schwer betroffen, 48,1% auf Prophylaxe, mit einem Durchschnittsalter von $37,4 \pm 16,4$ Jahren (17-78) beziehungsweise $9,8 \pm 4,2$ Jahren (3-16). Die mittlere Reiseentfernung zum HTC betrug 43,5 km (3-200). Es ist bemerkenswert, dass 92,4% eine intensive Bindung an das HTC und ein MHOC-Konzept als "ziemlich / sehr wichtig" (88,6%) ansahen. Sie erwarteten von einem MHOC Beratungs- und Aufklärungsaktivitäten, Unterstützung bei Fragen zum Älterwerden und Behandlung. Für 35,4% könnte eine MHOC derzeit zusätzliche Unterstützung bieten, hauptsächlich aufgrund der Unbeweglichkeit des Patienten und des Beratungsbedarfs. Sie nutzten vor allem Dienstleistungen in Bezug auf sozialrechtliche Beratung und Unterstützung bei Behördenanliegen.

Schlussfolgerung Die Ergebnisse dieser Studie stützen die Hypothese, dass ein MHOC-Konzept eine notwendige Ergänzung in der umfassenden Hämophilie-Versorgung darstellt und die anspruchsvolle Hämophilie-Behandlung verbessern wird, insbesondere für Patienten mit eingeschränktem Zugang zu HTCs oder mit Behinderungen.

Introduction

In the last few decades, state-of-the-art management of haemophilia patients practising a life-long treatment with safe coagulation factor concentrates and offering specialized care through haemophilia treatment centres (HTCs) resulted in a significant reduction of morbidity and mortality.¹⁻⁵ Meanwhile, home treatment of haemophiliacs is the standard of care in developed countries and gets increasingly implemented also in developing countries as it has a positive impact on patients' health-related quality of life (HRQoL).^{4,6} In the United States, approximately 70% of patients with haemophilia receive individualized care by a HTC.⁷ Across Europe, the availability of HTCs and the range of services provided by different centres vary significantly between different countries.⁸ Because of the limited number of HTCs, it is quite common that patients need to travel a longer distance to a comprehensive care HTC providing the highest treatment quality. This fact might generate relevant problems for patients, especially in rural regions with limited access to public transportation systems, causing the necessity of alternative travel organization, e.g. by a private car transport. Parents of young boys with haemophilia seem to prefer home treatment to hospital treatment because it was less time-consuming, less disruptive to family life and provides a greater sense of control.⁹ Families of underage patients or adult patients suffering from haemophilia-related disabilities and age-related co-morbidities might there-

fore face problems in organizing regular visits at a HTC. Thus, families of young haemophiliacs, disabled and/or older patients, or patients with limited travel options could benefit from a mobile haemophilia outpatient care (MHOC) concept where a HTC provides home visits to a patient if necessary.

Here, we report the results of a 3-year pilot project implementing a MHOC concept at the European Haemophilia Comprehensive Care Centre (EHCCC) of the Saarland University Hospital in Homburg, Germany. During this pilot phase, adult haemophilia patients as well as child and adolescent haemophiliacs and their families were home visited at least twice by a social education worker and/or a trained physician of the HTC. The patients were asked about their needs and expectations regarding a MHOC concept, and interviews were performed to measure the HRQoL and treatment satisfaction (TS).

Materials and Methods**Design and Study Population**

The project was implemented in 2010 and designed as a prospective single-centre pilot study testing the feasibility of a MHOC concept at an EHCCC. The project was approved by the local Ethics Committee of the Saarland Medical Council (No 92/11). All of the 88 adults and 28 underage haemophiliacs registered at the HTC were asked to participate in this pilot study, and 79 patients gave informed consent to participate and were enrolled (participation rate 68.1%).

Home Visits

A social worker and/or a trained physician of the HTC performed scheduled patient home visits. As a minimum, the pilot phase comprised two visits, first at the beginning of the study (baseline), and second, at least 1-year follow-up from baseline. If requested and considered as useful by the HTC team, additional home visits were performed to provide an individualized patient support. At the baseline and follow-up visits, patients and/or parents were asked to fill out validated questionnaires to evaluate their HRQoL and TS, these data will be published elsewhere. Furthermore, participants were asked about their requirements and expectations regarding a MHOC concept.

Mobile Haemophilia Outpatient Care Questionnaire

The project-specific questionnaire contained the following nine questions: (1) 'How important is for you a tight connection to the HTC?' (2) 'Do you consider the implementation of the MHOC as important?' (3) 'What kind of wishes and expectations do you have regarding a MHOC concept?' (4) 'Regarding the past: did you wish to have a MHOC service available?' (5) 'Do you remember a situation in the past where a MHOC would have been helpful for you?' (6) 'Would a MHOC concept be helpful at present?' (7) 'Do you think a MHOC could be helpful in the future?' (8) 'Do you assume disadvantages through a MHOC concept?' (9) 'Regarding the MHOC, what kind of services have you utilised so far or would you expect?' (from a list of 13 MHOC services, multiple answers were possible to choose with the following answer categories: 1 = service used; 2 = service desired). The first two questions included 5-point Likert scale answers ranging from not important to very important; the questions 3 to 8 were open questions, first asking dichotomously yes/no, and if yes, the patient or parent should report which aspects.

Statistical Analysis

All analyses were performed by the SPSS statistic tool version 23 (SPSS Chicago, Illinois, United States). Categorical data are presented using counts and percentages, and continuous variables are expressed as patient numbers, means \pm standard deviations, medians and minimums/maximums. For testing on normal data distribution, the Kolmogorov-Smirnov test was performed. Calculations for differences in attitude towards MHOC between different clinical subgroups (age group, treatment, infections) were performed by chi-squared test. A *p*-value of < 0.05 was considered as significant.

Results

Baseline

Socio-Demographic Characteristics

Seventy-nine patients were enrolled, 56 adults and 23 children, with a mean age of 37.4 ± 16.4 years (17–78) and 9.8 ± 4.2 years (3–16), respectively. **Table 1** shows socio-demographic data of all participants (adults and parents of children with haemophilia). The median distance

from patients' home to the HTC was 43.5 km (3–200) with a median travel time of 40 minutes (10–120). Most patients used their private car to reach the HTC (79.5%), even though 16.6% were dependent on private transport by a family member or friends or taxi transfer. Only a small minority used public transport systems.

Clinical Data

Of all study participants, 79.7% suffered from haemophilia A, 19.0% from haemophilia B and one patient from type 3 von Willebrand disease. Forty-nine patients (62.0%) were severely affected. The mean body mass index at enrolment for adults was 26.7 ± 4.5 , and for children it was 17.9 ± 3.6 . More clinical data are provided in **Table 2** as a summary of both adults and children.

Thirty-nine adult patients (69.6%) and 11 children (47.6%) experienced at least one bleeding episode in the last 12 months prior to enrolment, and 23 (41.2%) and 6 (25.9%) experienced two or more bleeding events. The mean bleeding rate in adults was 3.2 ± 5.6 per year with a median of 1 (range, 0–26) and in children it was 1.3 ± 2.1 with a median of 0 (range, 0–8). The majority of episodes were joint bleeds with a mean rate in adults of 2.5 ± 5.4 per year (median 0, range, 0–26) and in children of 0.4 ± 1.7 per year (median 0, range, 0–8).

Mobile Haemophilia Outpatient Care

Overall, 149 home visits were conducted to generate the baseline and follow-up data. Most of the home visits were performed by a social worker, and only four visits were done by a trained physician. Seventy visits were performed in addition to the baseline/follow-up data generation visits to provide a more individualized patient support in terms of (1) information of teachers and physicians outside the HTC to haemophilia-related issues (47.1%), (2) consultancy in social-legal affairs and support in contacting authorities (42.9%) and (3) factor concentrate delivery and support in factor injection (10%).

Regarding questions 1 and 2 of the MHOC questionnaire, all 79 participants responded. Seventy-three participants (92.4%) reported an intense binding to the HTC as 'rather or very important' and 70 (88.6%) considered the implementation of the MHOC service as 'rather or very important' (**Fig. 1**). Out of the 79 participants, 45 formulated their wishes towards a MHOC (57%); some patients mentioned more than one aspect. They expected and requested from a MHOC consulting or educational activities, support in elderhood, care/treatment, factor application/factor delivery, accessibility/transport connection and support in emergency. From all patients, 22 have wished the existence of a MHOC in the past (28.2%), and even 43% stated that they would have needed a MHOC *in the past*, 35.4% reported about conditions in which a MHOC would *currently* provide support—mainly due to information transfer, support in emergency or disease-related immobility and support in factor application or factor delivery—and 74.7% could imagine *future situations* for using a MHOC service (**Table 3**). Only one patient assessed the implementation of a MHOC disadvantageous due to

Table 1 Socio-demographic data (n = 79)

Socio-demographic characteristics		Adults (n = 56)		Parents (n = 23)	
		N	%	N	%
Marital status ^a	Single	32	57.1	3	13.0
	Married	20	35.7	16	69.6
	Divorced	2	3.6	2	8.7
Living with a partner ^a	Yes	27	48.2	19	82.6
	No	28	50.0	3	13.0
Number of children living in household ^b	0	46	82.1	–	–
	1	8	14.3	–	–
	2	2	3.6	–	–
Siblings ^b	Yes	43	76.8	–	–
	No	13	23.2	–	–
Educational qualification ^a	No formal qualification	–	–	3	13.0
	Lowest formal qualification	18	32.1	3	13.0
	Middle formal qualification	14	25.0	8	34.8
	Highest school qualification	17	30.4	7	30.4
	University degree	4	7.1	1	4.3
Working status ^a	Full-time	24	42.9	6	26.1
	Part-time (50–75%)	6	10.7	3	13.0
	Part-time (< 50%)	2	3.6	4	17.4
	Not always in work	4	7.1	–	–
Living situation ^a	Big city (> 100,000)	2	3.6	–	–
	Suburbs of a big city	2	3.6	–	–
	Town/small city (20,000–100,000)	9	16.1	7	30.4
	Country village (5,000–20,000)	12	21.4	4	17.4
	Village (< 5,000)	30	53.6	9	39.1
	Single house/farm	1	1.8	2	8.7
Transportation to HTC ^a	Private car	44	78.6	17	73.9
	Dependent on transport by others	8	14.3	3	13.0
	Public transport	3	5.4	–	–
	Taxi	1	1.8	2	8.7

Abbreviation: HTC, haemophilia treatment centre.

^aMissing data.

^bParents have not been asked about children and siblings.

missing direct contact with the HTC. ▶ **Table 4** shows which services participants reported to have used, would be in general desired or were not desired. At baseline, only 31.6% of participants had used at least one of the MHOC services, 1 to 3 services were used by 27.9% and one participant used 7 MHOC services. MHOC services concerning consultancy in social-legal affairs (12.7%), support in contacting authorities regarding haemophilia-related issues (11.4%), factor delivery (11.4%) and permanent availability of HTC specialists (11.4%) were used mainly. Note that 89.9% of participants in general desired to have MHOC services available, in median 3 out of the 13 listed MHOC services, only one participant desired 10 services. Participants mainly desired permanent availability

of HTC specialists (68.4%), visits after bleeding episodes or post-surgery (59.5%) and factory delivery (58.2%). MHOC services that were not mainly desired were regarding support in conflicts in the family (83.5%), support in the documentation of factor use (82.3%), and support in the reduction of anxiety (78.5%).

Significant differences were shown between parents and adults for 'support in social law issues' (30.4 vs. 5.4%; $p < 0.009$) and 'used consultancy concerning leisure activities' (26.1 vs. 1.8%; $p < 0.002$).

Differences in MHOC were also found for clinical subgroups concerning treatment regimen (prophylaxis vs. on-demand) and hepatitis B virus (HBV)/hepatitis C virus (HCV)

Table 2 Clinical data (n = 79)

Clinical characteristics		Total (n = 79)	
		N	%
Type of haemophilia	A	63	79.7
	B	15	19.0
	von Willebrand syndrome type 3	1	1.3
Severity	Severe (< 1%)	49	62.0
	Moderate (1–5%)	6	7.6
	Mild (6–15%)	15	19.0
	Sub-haemophilia (> 15–50%)	9	11.4
Treatment with factor concentrates	Prophylactic	38	48.1
	On-demand	41	51.9
Target joints	Yes	10	12.7
	No	69	87.3
History of inhibitor	Yes	5	6.3
	No	74	93.7
Infections	HBV	17	21.5
	HCV	28	35.4
	HIV	9	11.4
Home treatment	Yes	63	79.7
	No	16	20.3
Factor concentrate administration	Self-administered	40	50.6
	By family member	13	16.5
	By member of HTC	6	7.6
	By family doctor	4	5.1
	No substitution last year	16	20.3

Abbreviations: HBV, hepatitis B virus; HCV, hepatitis C virus; HIV, human immunodeficiency virus; HTC, haemophilia treatment centre.

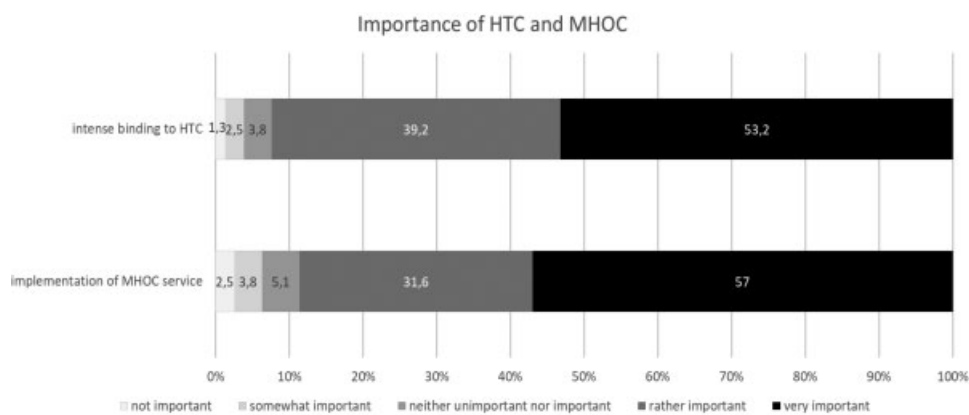


Fig. 1 Importance of tight connection to haemophilia treatment centre (HTC) and implementation of mobile haemophilia outpatient care (MHOC).

infections (yes vs. no). More patients on prophylaxis reported that they would have needed a MHCO in the past ($p < 0.001$) compared with on-demand treated patients (63.9 vs. 26.8%) or ‘used support with contact with authorities’ (21.1 vs. 2.4%; $p < 0.005$). Differences were found for

patients with HCV infection who considered an intense binding to the HTC as more important (4.7 ± 0.8) than patients without HCV infection (4.3 ± 0.7 ; $p < 0.022$). More HCV-infected patients required services for ‘questions concerning correct storage of factor concentrate’ (28.6 vs.

Table 3 Survey about needs and expectations towards a mobile home care program

Responses by the participants		Responding participants	
		N	%
Expectations and requests towards a MHOC (n = 45)	Consulting and educating activities	11	22
	Support in elderhood (disease-related immobilization)	11	22
	Care/treatment	9	18
	Support in factor application or factor delivery	6	12
	Accessibility and transport connection	6	12
	Support in emergency	4	8
	Others	3	6
MHOC service wished <i>in the past</i> ?	Yes	22	28.2
Situation where a MHOC service was needed <i>in the past</i> (n = 21)	Support in immobilization, disease, emergency or following surgery	9	42.9
	Support of families with children	4	19.0
	Injection training	2	9.5
	Support regarding factor application or factor delivery	2	9.5
	Support for social–legal affairs, or contact with authorities	2	9.5
	In general	2	9.5
MHOC service required <i>in the past</i> ?	Yes	34	43.0
Situation where a MHOC service was required <i>in the past</i> (n = 28)	Support in immobilization, disease, emergency or following surgery	9	32.1
	Support of families with children, information of school, kindergarten or physicians	7	25.0
	Injection training, support regarding factor application or factor delivery	3	10.7
	Support for social–legal affairs, or contact with authorities	3	10.7
	Others	6	21.5
MHOC service required <i>at present</i> ?	Yes	28	35.4
Situation where a MHOC service would be required <i>at present</i> (n = 22)	Information of school, kindergarten or physicians	6	27.3
	Support in emergency, elderhood with disease-related immobilization or following surgery	4	18.2
	Injection training, support regarding factor application or factor delivery	4	18.2
	Support for social–legal affairs, or contact with authorities	3	13.6
	Others	5	22.7
MHOC service required <i>in the future</i> ?	Yes	59	74.7
Situation where a MHOC service could be required <i>in the future</i> (n = 48)	Support in emergency, elderhood with disease-related immobilization or following surgery	21	43.8
	Support of families with children; information of school, kindergarten or physicians	8	16.6
	Support for social–legal affairs, or contact with authorities	7	14.6
	Injection training, support regarding factor application or factor delivery	6	12.5
	Others	6	12.5

Abbreviation: MHOC, mobile haemophilia outpatient care.

Table 4 Used MHOC services during the pilot phase

MHOC services	Service		
	Used	In general desired	Not desired
	N (%)	N (%)	N (%)
Consultancy in social-legal affairs	10 (12.7)	41 (51.9)	28 (35.4)
Support in contacting authorities regarding haemophilia-related issues	9 (11.4)	37 (46.8)	33 (41.8)
Factor delivery	9 (11.4)	46 (58.2)	24 (30.4)
Permanent availability of HTC specialists	9 (11.4)	54 (68.4)	16 (20.2)
Information of doctors outside the HTC	7 (8.9)	36 (45.6)	36 (45.6)
Consultancy in leisure-related questions	7 (8.9)	30 (37.9)	42 (53.2)
Support how to correctly store factor concentrates	6 (7.6)	14 (17.7)	59 (74.7)
Support contact school/employer	5 (6.3)	25 (31.7)	49 (62)
Visits after bleeding episodes or post-surgery	4 (5.1)	47 (59.5)	28 (35.4)
Support conflicts in the family	3 (3.8)	10 (12.7)	66 (83.5)
Training on how to inject at home	3 (3.8)	26 (32.9)	50 (63.3)
Support in the documentation of factor use	2 (2.5)	12 (15.2)	65 (82.3)
Reduction of anxiety	2 (2.5)	15 (19)	62 (78.5)

Abbreviations: HTC, haemophilia treatment centre; MHOC, mobile haemophilia outpatient care.

11.8%; $p < 0.044$) or 'consultancy regarding leisure' (53.6 vs. 29.4%, $p < 0.022$), whereas more HBV-infected patients reported that they had expectations towards a MHOC (58.8 vs. 32.3%, $p < 0.046$) and that there are situations in which a MHOC could currently provide additional support for them (58.8 vs. 29.5%, $p < 0.026$).

No differences were observed between patients with varying severities (severe vs. moderate vs. mild/sub-haemophilia) and presence or absence of human immunodeficiency virus (HIV) infection.

Follow-up

At follow-up, 54 out of 56 adult patients and 16 out of 23 paediatric patients participated. None of the patients had more than one follow-up visit. In average, patients were visited 1.94 times during the study period; the mean interval between baseline and follow-up visits for adults was 1.13 ± 0.4 years (median: 1.07, range: 0.44–2.69), and for children it was 1.53 ± 0.5 years (median: 1.75, range: 0.63–2.33). Twenty out of 54 adult patients reported a change in their life compared with baseline assessment. Most of them mentioned positive aspects due to professional changes (such as start of professional life, increase of salary, school or university degree) and to private changes (such as marriage or acquired driving license allowing better mobility/autonomy). Only few patients reported negative changes in their profession or private life (job loss, separation). Five out of 15 parents mentioned a change in their life. Four mothers started to work again, only one had a negative event due to her divorce. Regarding the clinical data of the adult patients, no significant changes between the baseline and follow-up interviews were observed.

Mobile Haemophilia Outpatient Care

At follow-up, 63 participants (90%) reported an intense binding to the HTC as 'rather or very important' and 65 (92.9%) considered the implementation of the MHOC service as 'rather or very important'. Out of the 70 participants, 29 formulated their wishes towards a MHOC (41.4%); some patients mentioned more than one aspect. Their expectations towards a MHOC did not change in general from baseline; additional aspects mentioned were support in contact with authorities, care in rural region, support searching for a HTC at study location and continuation of the MHOC service project. Note that 78.6% could imagine future situations for demanding a MHOC service.

At follow-up, 41.4% of participants had used at least one of the MHOC services, and 1 to 3 services were used by 32.9%; three participants had used 5 MHOC services and one had used 7 MHOC services. Only one participant did not desire to have MHOC services available; 98.6% desired services, in median 6 out of the 13 listed MHOC services, 19 participants desired 10 to 13 of the listed MHOC services. From baseline to follow-up, there was a trend to an increased use of MHOC services, but this was not significant. For those patients participating both at baseline and follow-up ($n = 70$), the use of the following MHOC services increased: factor delivery (8.6 vs. 15.7%), consultancy in social-legal affairs (12.9 vs. 20%) and support in contacting authorities regarding haemophilia-related issues (11.4 vs. 14.3%). By contrast, the number of desired MHOC services increased significantly ($p < 0.0001$) from baseline to follow-up ($M = 3.9 \pm 2.7$ vs. 6.6 ± 3.9) (→ Fig. 2). The frequency of all single MHOC services desired increased from baseline to follow-up, but remained stable for wished consultancy in social-legal affairs which was 54.3% (→ Fig. 3).

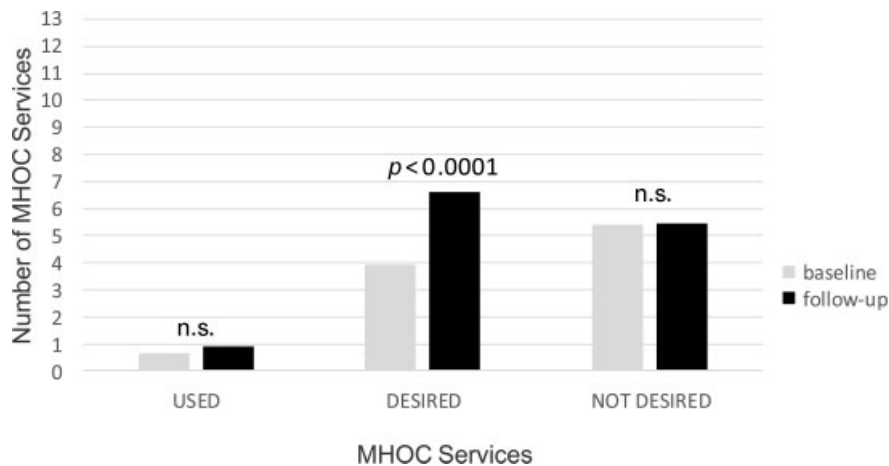


Fig. 2 Differences concerning the mobile haemophilia outpatient care (MHOC) services between baseline and follow-up.

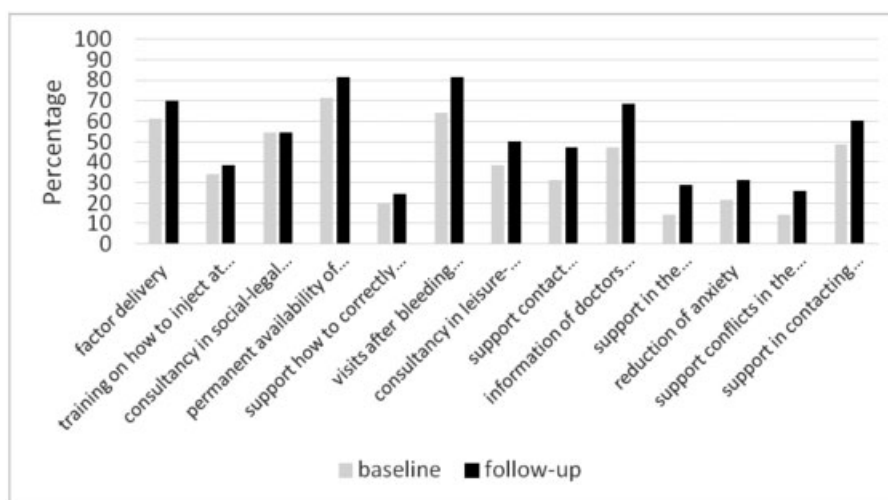


Fig. 3 Mobile haemophilia outpatient care (MHOC) services desired (comparison: baseline vs. follow-up).

Discussion

The German federal state 'Saarland' where the EHCCC is located is a more rural region with limited availability of public means regarding transport issues. For patients who do not own a private car this implies a high dependency on other family members or friends when planning a visit to the EHCCC. The major goal of the MHOC pilot study was to provide an extended social and medical care in the private environment of haemophilia patients and their families. By visiting the patients at home, we expected to get a more complete picture about the individual disease-specific problems and resulting needs of the patients and their families. Of the participants, 74.7% were open to use the services of a MHOC concept in the future, especially for support in emergency, elderhood and their immobility. They were generally very satisfied with the MHOC concept and felt quite supported by the care of the HTC.

The implementation of the MHOC concept provided patients with an extra support in social- and work-related issues allowing them to deal better with the circumstances

and social consequences of their disease. There was a significant increase of desired number of MHOC services from baseline to follow-up, which can be interpreted as an indicator that participants appreciated the provided services and want to use them in the future, if necessary, implying the feasibility of the MHOC services. This assumption is underlined by the direct expectation concerning the continuation of the MHOC service project.

In terms of marital status and living with a partner, our German adult haemophilia cohort was different compared with an Austrian haemophilia cohort in which more patients were married (35.7 vs. 57%) or were living with a partner (48.2 vs. 68%).¹⁰ The prevalence of HIV and HCV infections in our cohort was comparable to a huge multi-national study in 21 European countries.¹¹

A limitation of this pilot project was the relatively small number of enrolled patients. Nevertheless, 68.1% of the patient population registered at the HTC participated in the study. Another limitation could be the short follow-up period. A real impact of the implementation of a MHOC concept is probably only detectable after a couple of

years when patients are using such a service on a routine basis.

Irrespective of the current structures for the treatment of haemophilia patients, all health care players have to prepare for an increasing number of patients over 65 years of age due to the increasing life expectancy of this population.¹² Although the treatment quality of haemophilia has significantly improved over the last decades, older haemophiliacs often suffer from an increasing burden of their disease, e.g. due to infections and arthropathy in combination with age-related comorbidities, psychological and economical aspects.¹³ Therefore, the provided care by HTC should be adapted or expanded to age-related problems such as impairments and problems in daily living.¹⁴ Another problem which occurs in haemophilia patients is the development of inhibitors requiring frequent infusions.⁸ Besides the patients with limited access to public means, families of younger patients and disabled and elderly patients would benefit from the implementation of a MHOC concept, e.g. to ease the procedure of factor application. Moreover, current data show that acceptance of the disease and self-management skills are important aspects for patient's adherence to treatment, and patients may require tailored professional support.¹⁴ Services for home treatment by qualified staff could be such a support tool; this is also reflected by the engagement of pharmaceutical companies supporting HTCs for the integration of MHOC concepts.¹²

In conclusion, the results of this prospective pilot study do support our hypothesis that a MHOC concept is a helpful supplement to improve the treatment portfolio of a comprehensive care HTC for patients of all age groups. It supports patients and families with limited access to HTCs living in rural regions to receive regular health care on request.

Authors' Contributions

H.E. was involved in the planning of the project, analysing the data and writing of the manuscript. C.S. was involved in the management of the study, patient recruitment, data generation by performing patient interviews, data analysis and gave relevant input during the review of the manuscript. S.H. was involved in patient recruitment and reviewed the results and the manuscript. N.G. was involved in the management of the study and gave relevant input during the review of the manuscript. S.v.M. was involved in planning of the project, analysing the data and contributed to the writing of the manuscript.

Disclosure Statement

H.E. and C.S. received travel expenses from Baxter Deutschland GmbH regarding the project. S.v.M. received travel expenses in the frame of the project grant. S.H. and N.G. have nothing to disclose.

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