Wishes and worries of haemophilia patients

A patient survey from Bavaria

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Keywords

haemophilia A/B, patient perspective, unmet medical needs

Summary

Haemophilia care in Germany has achieved a high level and enables the majority of patients to lead a largely normal life. The Bluter Betreuung Bayern e.V. (BBB) aims to improve health care and support for haemophilia patients. A questionnaire has been developed by BBB representatives to evaluate unmet medical needs from the patient perspective. It was sent to 290 haemophilia patients and/or their parents in Bavaria in November 2015. The response rate was 51.4 %: 66 children aged <15 years (66.7 % severe), 30 patients 15–24 years (66.7 % severe), 26 patients 25–44 years (80.8 % severe), 24 patients >44 years (95.8 % severe). Prophylactic therapy in patients with severe haemophilia aged <25 and ≥ 25 years is given „always" in ≥ 80 % and >60 %, respectively. Substitution therapy is mostly uncomplicated. Satisfaction with medical care is high. Chronic pain is a problem with increasing age. Patients aged 25–44 years worry least regarding future health, safety and availability of factor products, patients >44 years most. Overall, 80–100 % of the patients from all age groups are interested in information on the current state of science. Offers of the BBB for psychosocial support in addition to the medical care seem to be helpful and needed in all age groups.

Schlüsselwörter

Hämophilie A/B, Patientenperspektive, unerfüllte medizinische Bedürfnisse

Zusammenfassung

Die Hämophilieversorgung in Deutschland hat ein hohes Niveau erreicht. Den meisten Patienten ist es möglich ein weitgehend normales Leben zu führen. Die Bluter Betreuung Bayern e.V. (BBB) will die Versorgung und Unterstützung der Patienten verbessern. Ein Fragebogen zur Untersuchung von Bedürfnissen aus der Patientenperspektive wurde von BBB Vertretern entwickelt und an 290 Patienten und/oder ihre Eltern in Bayern im November 2015 versendet. Die Rücklaufrate lag bei 51,4 %: 66 Kinder <15 Jahre (66.7 % schwer), 30 Patienten 15–24 Jahre (66.7 % schwer), 26 Patienten 25–44 Jahre (80.8 % schwer), 24 Patienten >44 Jahre (95.8 % schwer). Von den Patienten mit schwerer Hämophilie <25 und ≥ 25 Jahre erhalten ≥ 80% und >60 % „immer" Prophylaxe. Die Substitutionstherapie ist meist unkompliziert, die Zufriedenheit mit der medizinischen Versorgung hoch. Chronische Schmerzen sind mit zunehmendem Alter ein Problem. Patienten im Alter von 25–44 Jahren sorgen sich am wenigsten, Patienten >44 Jahre am meisten bezüglich ihrer zukünftigen Gesundheit, der Sicherheit und Verfügbarkeit von Faktorprodukten. Insgesamt sind 80–100 % der Patienten aller Altersgruppen interessiert an Informationen über den aktuellen Stand der Wissenschaft. Angebote der BBB zur psychosozialen Unterstützung zusätzlich zur medizinischen Versorgung erscheinen in allen Altersgruppen hilfreich und notwendig.

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Haemophilia care in Germany has achieved a high level. According to a survey on haemophilia care in Europe, the average consumption of blood coagulation factor VIII concentrate per capita is 6.95 IU, which is in comparison to 34 European countries only lower than in Sweden with 8.56 IU, Irland with 8.09 IU and UK with 7.49 IU.

In Germany, 76–100 % of children aged <18 years and 51–75% of adults aged ≥ 18 years are currently on prophylaxis according to the survey (1). A current study on 174 German patients with haemophilia A reported that prophylaxis was prescribed for 90.2 % of children <18 years, for 83.3 % of patients ≥ 18 to ≤ 49 years, and for 67.7 % of patients ≥ 50 years (2).

Patients and their treating physicians can choose among 10 plasma-derived blood coagulation factor VIII and 9 plasma-derived factor IX concentrates, as well as 8 recombinant factor VIII and 2 recombinant factor IX concentrates (3). Plasma is screened for the following viral markers:

- HIV (human immunodeficiency virus) 1 and 2 antibodies,
- HBsAG (hepatitis B antigen), and
- HCV (hepatitis C virus) antibodies.

Mini pool NAT (Nucleic Acid Amplification Technology) testing is performed for the following viruses:

- HIV,
- HBV (hepatitis B virus),
- HCV,
- HAV (hepatitis A virus), and
- Parvo B19.

Plasma from Great Britain or France is not utilised (3). Reimbursement is generally guaranteed by statutory health insurances (SHI) in Germany. Therefore, most of the haemophilia patients are able to lead a largely normal life.

Between 1978 and 1985, many patients with haemophilia were infected with HIV and died subsequently. The Bluter Betreuung Bayern e.V. (BBB) was founded in Bavaria in 1987/1988 to help these patients and their relatives (4–6). Fortunately, due to high safety standards of blood coagulation factor products in Germany, HIV infection is no longer a major cause of death of haemophilia patients (7).

Other unmet medical needs remain from the patient perspective and the BBB strives for improved patient support. Therefore, a patient survey was designed to evaluate current wishes for extra offers, assistance and information and current worries from the perspective of haemophilia patients in Bavaria. In the following, the results of this survey are presented.

Patients and Methods

A questionnaire containing a total of 45 items has been developed by representatives of the BBB, one physician (WS), one social worker and marriage and family therapist (AS) and one voluntary member (HL). The questionnaire is added as an appendix. It comprises three parts:

1. Questions regarding the status as patient with haemophilia or as parent of a child with haemophilia, age group, haemophilia severity and acute bleeding: The question „acute bleeding“ was asked with regard to bleeding at the time of the survey from the perspective of the patient. „Acute bleeding“ was not specifically defined regarding its detection and confirmation.
2. Questions regarding general health, substitution therapy, worries in relation to haemophilia with the answering options „never“, „seldom“, „sometimes“, „often“ and „always“: These answer categories were also used for the question regarding prophylaxis. Therefore, no differentiation with regard to past treatments and switches between on-demand and prophylaxis is possible. The aim of the questions regarding substitution therapy was to evaluate the occurrence of problems from the perspective of the patient combined with information on the frequency of prophylaxis. Questions regarding satisfaction with medical care had the answering options „that's right“, „that's rather right“, „that's rather not right“ and „that's wrong“.
3. Questions regarding wishes related to extra service and information offers, more information on different topics of haemophilia and suggestions how to improve haemophilia care with the answering options „yes“, „no“, „perhaps“ and open questions regarding suggestions for further improvements.

The questionnaire was sent to 290 haemophilia patients and/or their parents in Bavaria in November 2015. The responses have been anonymised and analysed. Analysis was descriptive comprising number of patients and proportion of patients in percent.

Results

The survey was completed by the beginning of March 2016. A total of 149 questionnaires were filled in and sent back, corresponding to a response rate of 51.4 %. One questionnaire contained double declarations for age, and two questionnaires had a comment, that the disease was not haemophilia but in one case thrombasthenia Glanzmann and in the other parahaemophilia, a congenital deficiency of blood coagulation factor V. These three questionnaires were excluded from the analysis.

For analysis, participants were assigned to four groups according to age. In total, 66 patients (45.2 %) were children aged <15 years, 30 patients (20.6 %) were aged 15–24 years, 26 patients (17.8 %) were aged 25–44 years and 24 patients (16.4 %) were aged >44 years (▶Tab. 1). Prophylactic therapy received „always“ ≥80 % of the <25 year old and >60% of the ≥25 year old patients with severe haemophilia.

More than 80 up to 100 % of the patients in all age groups reported that the injections were „never“ or „seldom“ problematic and „never“ or „seldom“ painful. The question „Do you have negative feelings with the injections?“ was answered by 9 out of 44 patients with severe haemophilia <15 years (20.5 %) with „sometimes“ and „often“, and by 5 out of 23 patients with severe haemophilia >44 years (21.7 %) with „sometimes“, „often“ and „always“. In the age groups 15–24 years and 25–44 years, these were 2 out of 20 patients (10.0 %) and 2 out of 21 patients (9.5 %) with severe haemophilia (results not shown).

Questions regarding general health with haemophilia revealed that „chronic pain due to haemophilia“ increases in patients >24 years old. Overall, 49 out of 66 of the <15 year old patients (74.2 %), 23 out of 30 of the 15–24 year old patients (76.7 %), 5 out of 26 of the 25–44 year old patients (19.2 %) and 2 out of 23 of the >44 year old patients (8.7 %) reported to „never“ have chronic pain due to haemophilia (▶Fig. 1).

With severe haemophilia, 33 out of 44 of the <15 year old patients (75 %), 14 out of 20 of the 15–24 year old patients (70 %), 3 out of 21 of the 25–44 year old patients (14.2 %) and 2 out of 22 of the >44 year old patients (9.1 %) reported to „never“ have chronic pain due to haemophilia (results not shown).

Questions concerning the worries of parents were answered by parents of patients aged <25 years. „I suffer because our child has to get injections.“ was

Tab. 1 Demographics of the 146 patients.

parameter	age group			
	< 15 years	15–24 years	25–44 years	> 44 years
number of patients	66	30	26	24
severity of haemophilia				
severe	44 (66.7 %)	20 (66.7 %)	21 (80.8 %)	23 (95.8 %)
moderate	6 (9.0 %)	1 (3.3 %)	1 (3.8 %)	0 (0 %)
mild	13 (19.7 %)	8 (26.7 %)	3 (11.5 %)	0 (0 %)
acute bleeding				
no	57 (86.4 %)	25 (83.3 %)	21 (80.8 %)	20 (83.3 %)
yes	6 (9.0 %)	2 (6.7 %)	4 (15.4 %)	3 (12.5 %)
prophylaxis in patients with severe haemophilia				
always	43 (97.7 %)	16 (80.0 %)	14 (66.7 %)	14 (60.9 %)
often	0 (0 %)	3 (15.0 %)	6 (28.6 %)	7 (30.4 %)
sometimes	1 (2.3 %)	1 (5.0 %)	1 (4.8 %)	1 (4.35 %)
seldom	0 (0 %)	0 (0 %)	0 (0 %)	0 (0 %)
never	0 (0 %)	0 (0 %)	0 (0 %)	1 (4.35 %)

answered with „often“ and „always“ by 24 out of 86 patients (27.9 %), „I worry about the future of our child.“ by 32 out of 96 patients (33.3%). The majority answered both questions with „never“, „seldom“ or „sometimes“ (results not shown).

Worries and concerns in relation to haemophilia are summarised in ▶Fig. 2. Patients in the age group 25–44 years worried least regarding future health, safety and availability of factor products, patients aged > 44 years most. Questions regarding satisfaction with medical care in haemophilia were

- „I am satisfied with the quality of health care.“,
- „I have confidence in the physicians and the treatment.“,
- „I am satisfied with the availability of a physician in charge.“,
- „Our problems with haemophilia are taken seriously.“.

Overall, 91 up to 100 % of patients from all age groups answered these questions with „that’s right“ or „that’s rather right“ and less then 10 % with „that’s rather not right“ or „that’s wrong”“ (results not shown).

The wishes of haemophilia patients are summarised in ▶Tab. 2. Overall, 80–100 % of the patients from all age groups were interested to be informed on the current state of science, 60–72 % on topics with regard to social legislation, and 49–74 % wished additional information offers from the treating physician regarding the disease and updated information with regard to new developments (▶Tab. 2).

The closing question of the survey was „How could care for haemophilia patients be further improved?“. Suggestions made by patients are listed in ▶Tab. 3.

Discussion

A first survey carried out on the 10th anniversary of the BBB had a reponse rate of only 10 %. At that time, HIV infection was a major topic and important functions of the BBB for patients with haemophilia were „a link to medicine/to the haemophilia center, experts/competence, organizing events, the atmosphere of the events, providing support…“ (8).

> Since then, fortunately the situation has further improved. Patients with haemophilia/parents of a child with haemophilia seem to deal actively and openly with the disease and welcome the offers of the BBB for psychosocial support. This is reflected by a good response rate of the current survey of 51.4 %.

For Germany, detailed data on current treatment patterns in patients with severe haemophilia are scarce. Generally, prophylaxis is reported to be prescribed for largely all children and also for the majority of older adults, which is in accordance with our results (1, 2). Substitution therapy, that is injections, is perceived as uncomplicated by the majority of patients. Generally, satisfaction with medical care, quality of health care, physicians and treatment is high.

General health in children and young adults with haemophilia was often rated by their parents and was „never“ or „seldom“ perceived as impaired by 96.9 % of the < 15 year old patients and by 96.7 % of the 15–24 year old patients. With severe haemophilia, these were 97.7 % and 95 %, respectively (results not shown). In a German study by Wiedebusch et al. (9), 55 parents of children aged 1–20 years suffering from haemophilia were asked about their „perceived limitation by illness“. A total of 3 (5.5 %) answered „not at all limited“, 18 (32.7 %) „hardly limited“, 23 (41.8 %) „moderately limited“, 8 (14.5 %) „highly limited“, and 3 (5.5 %) „very highly limited“. Parents reported relatively low psychosocial strains. Compared to parents of children with juvenile idiopathic arthritis, psychosocial strains in parents of children with haemophilia were lower, but similar to those of parents with children suffering from type 1 diabetes. The questions of these two studies are not exactly comparable.

> Our question „Do you have negative feelings with the injections?“ which was answered by 20.5 % of patients with severe haemophilia < 15 years with „sometimes“ and „often“ seems to better reflect limitation by the disease in contrast to the simple perceived general health status.

Another German study (10) has compared self-reported health-related quality of life (HrQoL) in children with hereditary bleeding disorders and with stroke/transient ischaemic attack (TIA) with the HrQoL of siblings and peers. In children with hereditary bleeding disorders, HrQoL was found to be comparable to that of siblings and peers. In children with stroke/TIA, HrQoL was reported to be comparable to that of

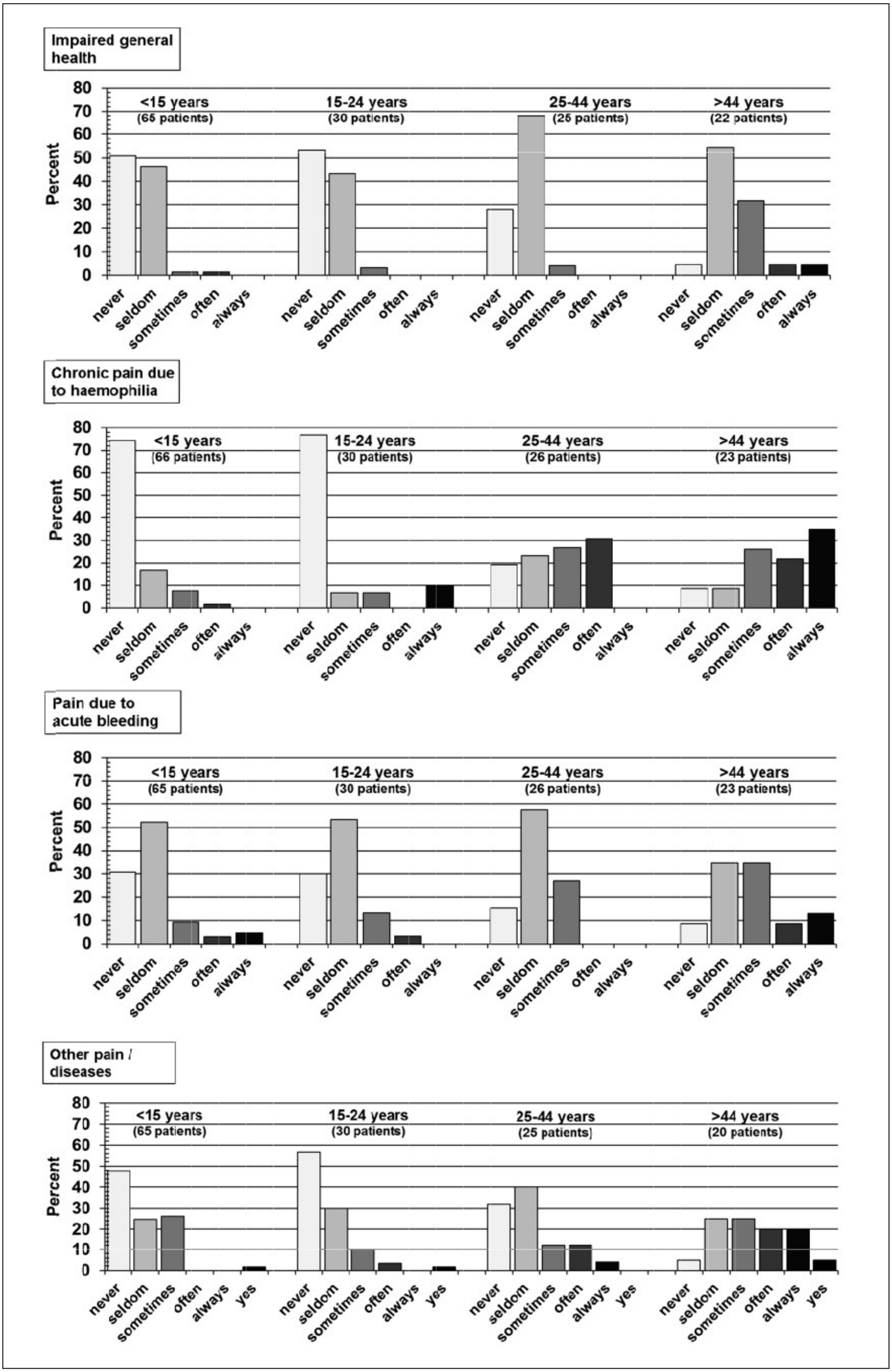

Fig. 1
General health. The following questions were asked: „Are you/your child generally in good health?“ (in the figure expressed negatively as „impaired general health“), „Chronic pain due to haemophilia?“, „Pain due to acute bleeding?“, „Other pain/diseases?“. The options for answering were „never“, „seldom“, „sometimes“, „often“, „always“. For the last question the option „yes“ – „I have another disease“ was included in the analysis, because several patients stated this in the questionnaire.

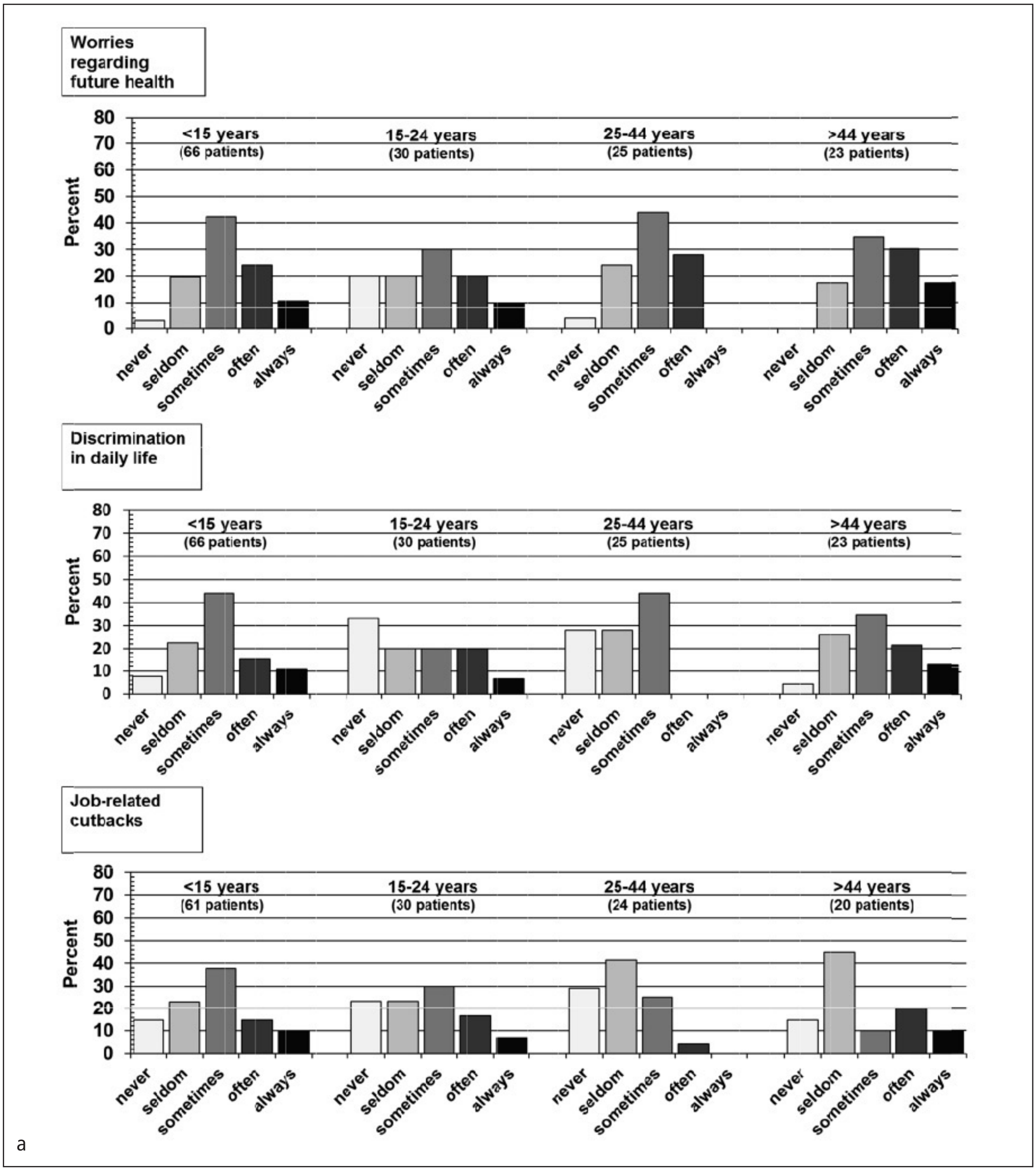

Fig. 2
Which are the questions you think of in relation to haemophilia?
The following questions were asked: „Worries regarding future health?", „Discrimination in daily life?", „Job-related cutbacks?", „Burden in family life?", „Worries related to safety of factor products?", „Worries related to availability of factor products?". The options for answering were „never", „seldom", „sometimes", „often", „always".

siblings, however, peers showed better self-worth and friend-related wellbeing. Both studies illustrate, that it is difficult to capture the sometimes more subtle differences, which a chronic disease can have on health-related quality of life and perceived limitations.

Chronic pain is an increasing problem with age. A total of 9.1% and 16.9% of children aged <15 years reported to „sometimes", „often" or „always" suffer from chronic pain due to haemophilia or pain due to acute bleeding, respectively. In the age group >44 years, 82.6% and 56.5% of the patients reported to suffer „sometimes", „often" or „always" from chronic or acute pain, respectively. In a German survey (11), the percentages were considerably higher with 66% of children <18 years experiencing episodes of pain („even if occasionally") and 96% of adults >40 years of age. The higher percentages may result from the inclusion of occasional episodes of pain and therefore not represent chronic pain per definition.

A European survey (12) reported chronic pain in 4.5% and 9.6% of children <18 years with haemophilia and severe haemophilia, respectively. In adults ≥18 years, chronic pain was present in 16.5% and 38% of patients with haemophilia and severe haemophilia, respectively. The age groups are only overlapping and may explain the differences in the results for the adult patients. In addition, the over-

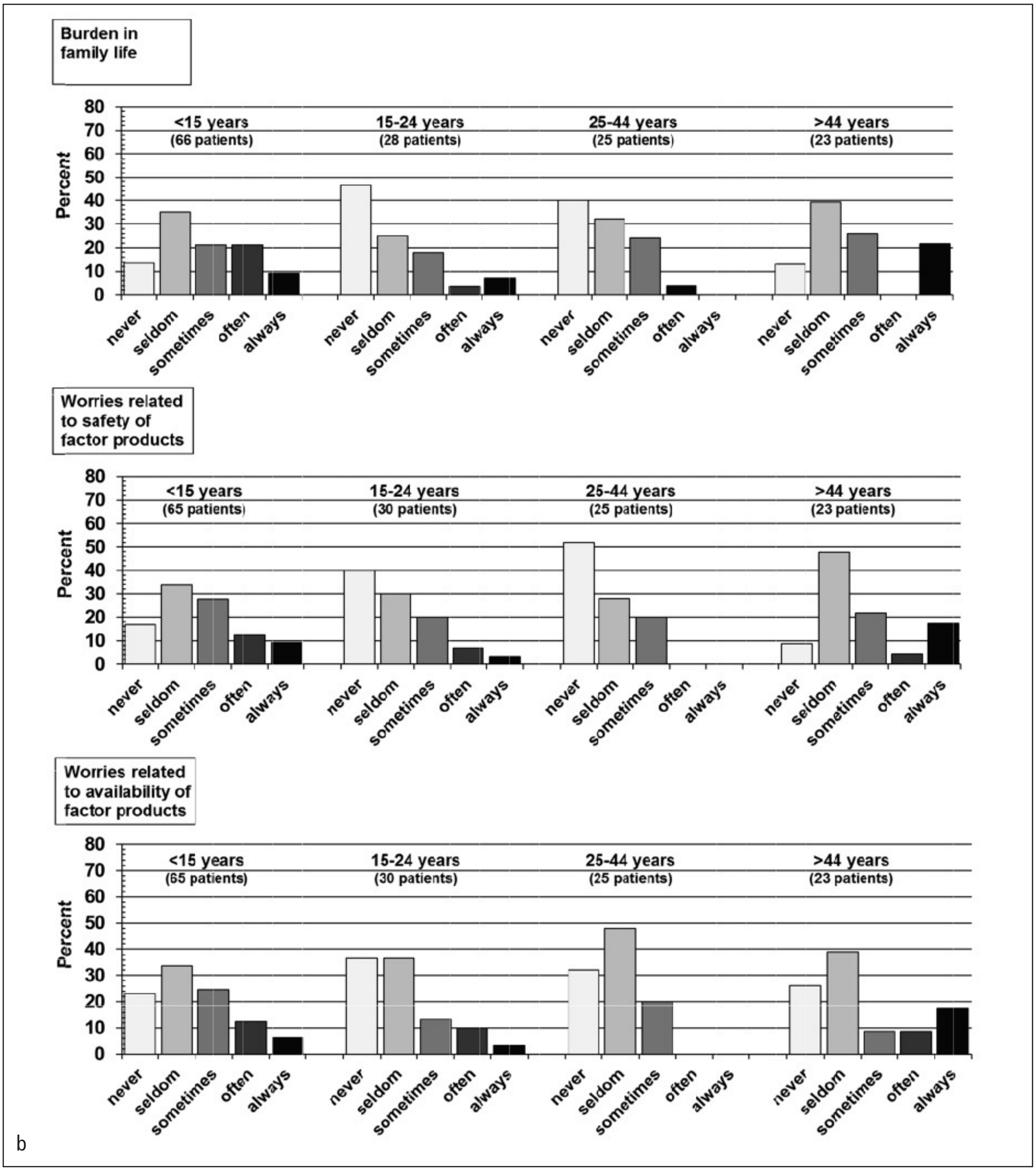

Fig. 2
continued

all higher reporting of pain in our groups may originate from the differentiation in „sometimes“, „often“ or „always“.

Generally, most parents worry about the future of their children. In a German survey of the general population (13), parents of children aged <18 years were asked about their worries. Overall, 48 % worried that their child could get an incurable disease, 36.2 % were worried about their children suffering from unemployment, 28.4 % were worried about psychological problems due to pressure to perform. Only 11.1% stated not to be worried. By comparison, it seems to be appropriate that a total of 33.3 % of parents are worried about the future of their child with haemophilia. In the HERO Study (Haemophilia Experiences, Results and Opportunities), 53 % and 48 % of adult patients with haemophilia gave as a reason for a perceived adverse impact of haemophilia on close relationships with partners „I am worried about the impact of haemophilia in future years.“ and „I am worried about being able to support a family in future years.“, respectively (14).

In our survey, patients aged >44 years worried most. In this age-group, the items „worries related to safety of factor products“ and „availability of factor products“ were answered with „often“ or „always“ by 21.7 % and 26.1 %, respectively. In view of the HIV crisis and batch recalls of French plasma-derived products due to variant Creutzfeld-Jakob disease risk (15), these

Tab. 2 Wishes of patients with haemophilia. The options for answering were „yes", „no", „perhaps" for the questions number 1.1–1.6, 2.1–2.6 and 3.1–3.5. Only the percentages of answers with „yes" are shown. Questions 1.7, 2.7 and 3.6 were designed as open questions. The percentage of patients answering these questions with „yes" is given.

	questions answered with „yes“, in percent ("yes" / total number with an answer)			
	< 15 years	**15–24 years**	**25–44 years**	**> 44 years**
1. Which additional service offers do you wish for?				
1.1 guidance to optimised self treatment	39.3 (24/61)	20.0 (6/30)	17.4 (4/23)	15.0 (3/20)
1.2 individual counselling for topics, e.g. kindergarten, school, professional education, incapacity to work, retirement pension	57.4 (35/61)	31.0 (9/29)	43.5 (10/23)	28.6 (6/21)
1.3 individual offers for e.g. sport, gymnastics, travel etc.	52.5 (32/61)	27.6 (8/29)	45.8 (11/24)	34.8 (8/23)
1.4. exercise programme especially balanced for haemophilia	45.2 (28/62)	20.7 (6/29)	33.3 (8/24)	58.3 (14/24)
1.5 support in questions with regard to social legislation, e.g. severely disabled ID card, disadvantageous balancing, rights etc.	58.7 (37/63)	55.2 (16/29)	69.6 (16/23)	43.5 (10/23)
1.6 psychological family counselling for coping	31.3 (20/64)	6.9 (2/29)	4.2 (1/24)	13.0 (3/23)
1.7 other service offers, namely …	12.3 (8/65)	10.0 (3/30)	4.0 (1/25)	4.2 (1/24)
2. Which additional information offers do you wish for?				
2.1 permanent contact person in the haemophilia centre	43.3 (26 / 60)	37.0 (10/27)	50.0 (12/24)	82.6 (19/23)
2.2 more information from the treating physician regarding the disease and updated information with regard to new developments	49.2 (31/63)	55.6 (15/27)	73.9 (17/23)	60.9 (14/23)
2.3 more exchange with other families affected with haemophilia	30.2 (19/63)	3.4 (1/29)	12.5 (3/24)	9.1 (2/22)
2.4 more advice on additional information resources, e.g. advice centres, brochures, patients association, websites	37.5 (24/64)	20.7 (6/29)	16.7 (4/24)	26.1 (6/23)
2.5 online information especially for Bavarian patients, e.g. moderated chatroom, blog, e-journal	36.9 (24/65)	23.3 (7/30)	21.7 (5/23)	36.4 (8/22)
2.6 information for female carriers	48.3 (29/60)	33.3 (9/27)	37.5 (9/24)	5.0 (1/20)
2.7 other information offers, namely …	1.5 (1/65)	3.3 (1/30)	4.0 (1/25)	8.3 (2/24)
3. What would you like to be informed on?				
3.1 general treatment methods / possibilities	67.7 (44/65)	43.3 (13/30)	45.8 (11/24)	91.7 (22/24)
3.2 current state of science	92.3 (60/65)	80.0 (24/30)	84.0(21/25)	100 (24/24)
3.3 topics with regard to social legislation, e.g. disadvantageous balancing	70.5 (43/61)	66.7 (20/30)	72.0 (18/25)	60.9 (14/23)
3.4 practical everyday helps for the life with haemophilia	82.8 (53/64)	40.0 (12/30)	48.0 (12/25)	65.2 (15/23)
3.5 activities for patients with haemophilia	63.5 (40/63)	26.7 (8/30)	32.0 (8/25)	63.6 (14/22)
3.6 other information, namely …	0 (0/65)	0 (0/30)	0 (0/25)	8.3 (2/24)

percentages do not appear to be unreasonably high. In a German survey (16) with 53 % of polled haemophilia patients aged > 50 years, patients were mainly afraid of insufficient medical care with older age, care-dependency, and the occurrence of age-related comorbidities.

The majority of the patients in our survey were interested in information on

- the current state of science,
- subjects with regard to social legislation, and
- more information from their treating physician.

Generally, interests were age-dependent. Wishes regarding improvements in various areas were expressed by several patients and parents of children with haemophilia. In the study of Wiedebusch et al. (9), 35.2 % of 55 parents with children with haemophilia pronounced a „strong“ or „very strong“ need to have „more information about haemophilia“, 38.9 % to have „more information about management of haemophilia“, 55.6 % to have „more information about communication with offices (e.g. insurances)“, 22.6 % to have „more information about handling the child with haemophilia“, 16.7 % to have „psychosocial care in my haemophilia centre“. With regard to our survey, 58.7 % of the parents of children aged < 15 years wished to have more support in questions with regard to social legislation", which corresponds to the aforementioned German study „communication with offices". The other percentages were higher in our survey. One explanation might be, that the questions regarding additional information could only be answered with „yes", „no" or „perhaps" without a differentiation in the urgency of the information need. The overwhelming interest in the current state of science in our study might originate from the emergence of new treatment possibilities in the last years, which were not yet available at the time of the older study by Wiedebusch et al. (9).

Limitations

There are some limitations to the study. Firstly, the survey was restricted to the region of Bavaria. An extrapolation to Germany as a whole is therefore not possible. Secondly, as to expect for a rare disease the number of patients in the different age groups was low except for the group of children aged < 15 years. Thirdly, the questions regarding service and information offers and topics to be informed on included the option of answering with „perhaps" in addition to „yes" or „no". This might have lowered the significance of the results.

Conclusions

The survey confirmed that in Germany health care for patients with haemophilia is provided on a high level. Patients of all age groups are generally satisfied to a great extent with the medical care and support they receive. Worries and wishes are understandably age-dependent. Patients of all age groups agree, however, in their wish for additional information on the current state of science and on topics with regard to social legislation. Most patients wished more information by their treating physicians. Worries of elderly patients with haemophilia and chronic pain should be addressed. Offers of the BBB for psychosocial support in addition to the medical care seem to be helpful and needed in all age groups.

Tab. 3 Suggestions from patients.
In an open question at the end of the survey, patients had the opportunity to make suggestions how to improve health care for haemophilia. If not otherwise indicated, these were single statements.

category	suggestion
improvement of health care	decentralised health care for haemophilia patients in rural areas
	improvement in the cooperation between big city hospitals and physicians in rural areas
	more physicians experienced in haemophilia care close to the place of residence
	organisation of health care of adult patients with haemophilia as good and as personal as the health care of children with haemophilia
	continuity of treating physicians
	increased cooperation with other specialist divisions also in haemophilia centres
	improved information for e.g. hospitals, especially emergency and surgical wards, general practitioners, physiotherapists, schools
	progress in science e.g. long-acting blood coagulation factor concentrates or factor VIII in tablet form (suggestion made 3 times)
	improved delivery of factor concentrates homeward
	provision of a wheel chair instead of crutches after bleeding in the leg
improvements for children with haemophilia and their parents	creation of an organisation to give assistance with the substitution therapy at home and help in educational issues (suggestion made 3 times)
	provision of several haemophilia identification cards to each patient, especially children for e.g. parents, child, school bag, sport bag
	support for children in need of care when parents have to work
general improvements	financial support by the statutory health insurance regarding sport and fitness courses
	recognition of haemophilia as a disease to use parking areas for the severely disabled
	counselling for disability and accident insurance
	supplemental insurance for female carriers in case of private surgical procedures, e.g. dental procedures to cover the costs for factor VIII
	more empathy for patients with haemophilia and more psycological support
improvements of online offers for patients with haemophilia	database with names and adresses of haemophilia patients who are willing to register
	online substitution diary
	database with information ranked by subject regarding haemophilia for different age groups

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Conflicts of interest

The authors declare that they have no conflicts of interest.

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