Social participation of patients with hemophilia in the Netherlands.

Iris Plug¹, Marjolein Peters², Eveline P. Mauser-Bunschoten³, Arja de Goede-Bolder⁵, Lily Heijnen³,⁴, Cees Smit⁶, José Willemse⁶, Frits R. Rosendaal¹,⁷,⁸, Johanna G. van der Bom¹,³

¹Department of Clinical Epidemiology, Leiden University Medical Center
²Academic Medical Center, Emma Children's Hospital, Amsterdam;
³University Medical Center Utrecht, Hematology and Van Creveldkliniek, Utrecht;
⁴Rehabilitation Center "De Trappenberg", Huizen;
⁵Erasmus Medical Center, Sophia Children's Hospital, Rotterdam;
⁶Netherlands Hemophilia Society, Badhoevedorp;
⁷Einthoven Laboratory for Experimental Vascular Medicine; Leiden University Medical Center
⁸Department of Thrombosis and Hemostasis, Leiden University Medical Center

Correspondence: Prof. dr F.R. Rosendaal, Department of Clinical Epidemiology, C9-P, Leiden University Medical Center, PO Box 9600, 2300 RC Leiden, Netherlands,
Email: F.R.Rosendaal@lumc.nl

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Abstract

The introduction of replacement therapy in the 1960s has improved medical and social circumstances gradually. The availability of prophylactic treatment has further increased the possibilities of a “normal” life for patients with hemophilia. We examined whether social participation and health related quality of life of today’s hemophilia patients differs from the general male population. 721 participants to the Hemophilia in the Netherlands-5 study (HiN-5 study) were aged between 16 and 64 years. Patients with severe hemophilia participated less in full time work compared to the general population. Occupational disability was reported by 35% of patients with severe hemophilia between 31 and 64 years, compared to 9% in the general population. HRQol of patients with severe hemophilia between 31 and 64 years was lower than of the general population. The differences with the general population in HRQol health related quality of life were least pronounced for patients between 16 and 30 years. Despite major improvements in treatment during the last decades patients with hemophilia are still less involved in full time paid work and suffer more from occupational disability than men from the general population. After the introduction of prophylactic treatment the number of patients who are occupationally disabled is reduced.
Introduction

Hemophilia is an X-linked hereditary bleeding disorder caused by deficiency of coagulation factor VIII (hemophilia A) or factor IX (hemophilia B). Severe forms are characterized by major bleeding occurring spontaneously or after minor trauma. Repeated bleeding into joints may result in orthopedic problems due to hemophilic arthritis and thus limit activities and restrict social participation.

Since its introduction in the late 1960s replacement therapy with clotting factor VIII or IX has improved the medical and social situation of patients with hemophilia. This is illustrated by considerable decreases in the annual number of hemorrhages, hospital stays and absence from work or school. Furthermore, since the 1970s an increasing number of patients have successfully been treated prophylactically. In the 1980s many patients became infected with the Human Immunodeficiency Virus (HIV) and hepatitis C virus (HCV). Since 1985, products have been safe for HIV and since 1992 also for the transmission of HCV.

Our aim was to examine whether social participation and quality of life of today's hemophilia patients differ from that of men without hemophilia and if availability of replacement therapy from childhood on influenced these items. Social participation was defined as the ability to participate in work and education.
Material and methods

Participants

A nationwide postal survey among all known patients with hemophilia, the
Hemophilia in the Netherlands-5 study (HiN-5), was conducted in the Netherlands in
2001, following four previous surveys dating back to 1972. Details on the 2001
survey have been described previously, in short in 2001 1567 questionnaires have
been sent to all know hemophilia patients in the Netherlands, 1066 patients
participated (response was 70%). Patients included were listed with the Netherlands
Hemophilia Society, with the hemophilia treatment centers, or were known from
updated mailing lists from previous surveys.

For the present study we included all participants who were between 16 and 64 years
of age at the time of the last questionnaire. Patients of whom data on employment was
missing were excluded. The specific age-category involves the period in which people
are eligible to participate in labor. In the Netherlands the age of 16 was set as from
which full-time education is no longer compulsory. However according to Dutch laws
on education until the age of 18 employment should always be combined with a form
of education. From the age of 65 years patients are legally retired. The Committee of
Medical Ethics of the Leiden University Medical Center approved this study, which
was conducted in accordance with the Declaration of Helsinki.

Assessments

A pre-structured questionnaire was part of a series of questionnaires that were used
between 1972 and 2001 and included many items that were identical. In 2001 we
implemented the Short-Form-36 (SF-36) questionnaire which measures Health-
Related Quality of Life. The SF-36 is a 36-item questionnaire that measures eight
parameters of perceived health status: physical functioning, social functioning, role limitations due to physical problems, role limitations due to emotional problems, mental health, pain, vitality and general health perception. Viral status, treatment modalities, educational levels and annual numbers of hemorrhages were assessed through self-reported data. The self reported type and severity of hemophilia were verified with data from the treatment centers. Self reported measures on joint impairment were obtained for a series of 16 joints which are the neck, the left and right shoulder, the back, the left and right elbow, the left and right wrist, the left and right hand and fingers, the left and right hip, the left and right knee and the left and right ankle. The possible scores were 0 (no impairment), 1 (some impairment without daily problems), 2 (some impairment with daily problems), and a maximum of 3 (severe impairment with complete loss of function). Data on the absence from school or work referred to the year that preceded the survey (2000). Data on employment, occupational disability and employment levels were compared to national figures on the general male population that were provided by the Central Bureau of Statistics Netherlands (CBS)\textsuperscript{8}. All occupations reported by participants were scored according to the Standard Occupational Classification (SBC) published by the CBS \textsuperscript{9}. According to this classification, occupations are distinguished through the level of the needed abilities to perform the occupation. The classification differentiates between the following employment levels: elementary level, low level, moderate level, high level and academic level. The levels of employment are in line with educational level e.g. to perform a job at the elementary level primary education is needed and to perform a job at the high level secondary school at the highest level or college is needed. The jobs at the elementary level and the low level were considered to be blue-collar jobs in contrast to white-collar jobs defined as jobs at the high or academic level.
Temporary jobs like jobs performed during the holiday season were not considered in the assessment of employment.

**Occupational disability according to Dutch law**

The Netherlands has an extensive social security system, which includes several social insurance schemes which offer protection against the risk of loss of income and exceptional expenditure due to old age, death, illness, disablement or unemployment.

In 2001 the Occupational Disability Insurance Act (WAO) provided insurance against the financial consequences of long-term incapacity to work. Under the WAO people were entitled to benefits if they have been disabled for more than 52 weeks.

According to the Dutch system occupational disability is defined as not being able to perform normal labor due to disease or a deficiency. A distinction is made between complete (>80%) and partial (<80%) disablement. In our study occupational disability status was self-reported by the patients.

**Data analyses**

We categorized the patients according to whether they were born before (aged 31-64 years at time of questionnaire) or after (aged 16 to 30 years at time of questionnaire) the introduction of prophylaxis in the Netherlands. As the clinical characteristics of hemophilia A and hemophilia B do not differ we present combined results for hemophilia A and B. The severity of hemophilia was classified according to residual percentage of factor VIII or IX clotting activity: severe (<0.01 IU/ml), moderate (0.01-0.05 IU/ml) or mild (>0.05-0.40 IU/ml).

The outcome values of the SF-36 were compared to age-specific normative data for the Netherlands. In the analyses on health-related quality of life (HRQol) we only included patients without missing values on any of the domains. We calculated mean
values and differences for all health-related quality of life scales; in addition we calculated differences adjusted for age
Results

A total of 1066 patients with hemophilia A or B participated in the Hemophilia in the Netherlands-5 study (response 70%). For the present study analyses were done in 721 patients aged between 16 and 64 years and therefore eligible for the current analyses. Of 6 patients information on employment was missing; they were excluded from the analysis. Table 1 shows the characteristics of patients with severe hemophilia (n=279), patients with moderate (n=114) and patients with mild hemophilia (n=328) according to the two age groups. 537 patients were between 31 and 64 years old and were born before the introduction of prophylaxis and 184 patients were between 16 and 30 years and born after the introduction. Patients with severe hemophilia born after the introduction of prophylaxis more often used prophylactic treatment than patients before the introduction of prophylaxis (81 vs. 53%).

Employment status

Table 2 shows the employment status of hemophilia patients compared to the general population, according to whether patients were born before or after the introduction of prophylactic treatment. The participation in full time paid work for patients with mild and moderate hemophilia was similar to the general population in both age groups (67% and 72% vs. 73% in those aged between 31 and 65 years, and 51 and 44% vs. 52% in those aged between 16 and 30 years). Patients with severe hemophilia, aged between 31 and 64 years participated less in full-time paid work than the general male population, 50% vs. 73% (difference=23%, CI 17-31). In young patients (16-30 yrs) with severe hemophilia the difference with the general population was 18% (34% vs. 52%). One third of the younger patients participated in full time education (n=80, 43%). Although no exact national figures are available of the age category between 16 and 30 years, we can compare figures of the age category between 17 and 22 years
available from the Netherlands ministry of Housing, Spatial planning and the Environment (VROM)\textsuperscript{11}. In this specific age group 69\% of hemophilia patients are involved in full time education compared to 53\% of Dutch males, this was comparable in all levels of severity. Between the ages of 20 and 24 years 34\% of the Dutch general population participates in education, either full time or part time. In Dutch patients with hemophilia this was 57\%.

In both age groups unemployment occurred less often than in the general population: inactive patients were mainly legally disabled.

Table 3 shows the level of employment according to severity of hemophilia and among the general population. Fewer patients were employed in blue-collar work than in the general population (24\%), both for patients with severe hemophilia (13\%) and for patients with mild and moderate hemophilia (20\%). The employment in managerial and academic positions especially in patients with severe hemophilia was higher, 41\% vs. 30\%.

\textit{Limitations in work}

Complete occupational disability was reported by 36\% (69/200) of patients with severe hemophilia between 31 and 64 years, compared to 11\% in the general population. In the younger severe patients this was 5\% vs. 3\% in the general young population. In patients with mild and moderate hemophilia the difference in occupational disability with the general population was less pronounced. The proportion of young patients with moderate and mild hemophilia who were disabled was similar to that in the general population.

Subjective joint score was associated with occupational disability (OR=45.2 CI95 20.3-100). This remained to be an important indicator after adjustment for age,
severity of hemophilia and being HIV positive (Table 4). Both hepatitis C and HIV were associated with a higher risk for being occupational disabled. A substantial number of the employed patients with severe hemophilia reported to experience restrictions in performing their job due to hemophilia (71 out of 181, 39%). In patients with mild or moderate hemophilia this was 19%. These restrictions consisted of pain and frequent absence from work.

**Health-related quality of life**

A total of 623 patients (87%) completed the SF-36 of whom 532 patients were eligible to work. Table 5 shows health-related quality of life of patients involved in a paid job, either full-time or part-time (n=422), and of patients who were unemployed or occupational disabled (n=110). Differences between the employed and unemployed patients were largest in the domain of physical functioning (28 points CI 23-34), role limitations due to physical problems (37 points CI 29-45) and role limitations due to emotional problems (27 points CI 19-34). Employed patients scored higher on all domains of health related quality of life than unemployed patients. Patients with severe hemophilia aged between 31 and 64 years scored lower on all scales of the SF-36 except mental health than the general population (Table 6a). Patients with severe hemophilia between 16 and 30 years scored higher on physical functioning, role limitations due to physical functioning, bodily pain and general health compared to the elder patients with severe hemophilia but still lower than the general population. No differences were found in the different scales in the group of patients with moderate or mild hemophilia compared to the general population.
Discussion

When compared to the general population, elder patients with severe hemophilia participate less in full time work; they suffer more often from occupational disability, and mainly are employed at high job levels. Patients born before the introduction of prophylaxis participate less in full time employment but there is a higher participation in education. Patients with moderate and mild hemophilia differ only slightly or not from their peers. Unemployment in all age categories was lower compared to the general Dutch population.

Our study offers an overview of the occupational status of Dutch hemophilia patients in 2001. The estimated prevalence of hemophilia is 20.3 per 100.000 inhabitants\textsuperscript{12}. With 7.91 million men in the Netherlands the estimated total number of hemophilia patients in the Netherlands is 1606. We reached 1567 patients with hemophilia, and 70\% participated in our study. As the non-responders appeared not to differ from the responding patients in severity and type of hemophilia and were only slightly younger (33 vs. 36 years) we feel confident to state that our findings validly describe the situation of hemophilia patients in the Netherlands. Our data were compared to information from the Central Bureau of Statistics providing information on the social situation of Dutch males. Our data and most of the data by the CBS were assessed using self-reported questionnaires. However misclassification may have influenced our findings on occupational disability; the CBS gathered these data through disability registries while we collected self-reported data.

In 1985, we performed a similar study examining prospects of hemophilia patients in the labor market, and found an overall percentage of employment (either full-time or part-time) of 58\% in patients between 16 and 64 years\textsuperscript{13}. In the present study, overall
employment was 70%. Apparently since 1985 the social situation of hemophilia patients has improved. However, secular trends have also occurred in the general population, and therefore we calculated the inactivity ratio, which was 1.5 in 1985 compared to 1.2 in 2001. A study from Great-Britain reported that 65% of all patients with severe hemophilia were full-time employed.

Despite availability of prophylaxis from an early age, employment figures among young patients were slightly lower than among the general population. One explanation for this difference may reside in the fact that hemophilia patients more often followed full time education over a longer period of time. As a higher level of education is needed for “white collar” jobs this seems likely. Although no exact national figures are available of the age category between 16 and 30 years, we can compare figures of the age category between 17 and 22 years available from VROM. In this specific age group 69% of hemophilia patients are involved in full time education compared to 53% of Dutch males, this was comparable in all levels of severity. Additionally, hepatitis C infections may have affected employment status, especially among patients with severe hemophilia. A previous study showed that quality of life was lower in patients with a HCV infection. As the period between infection and clinical problems is long, not many young patients will have to face physical problems such as liver cirrhosis. However treatment of hepatitis C may temporarily serious side effects, which may also influence participation in employment and "normal" social life.

Our findings confirm those of earlier studies reporting a higher educational level of patients with hemophilia. A survey performed in 1985 showed that 72% of patients with hemophilia were involved in white collar jobs compared to 57% of the general population. This transition towards the "white collar" jobs can be explained by the
fact that blue-collar jobs may not be suitable for patients with hemophilia, in which case it is not so much that hemophilia patients are more often employed in high level jobs, but that they are less often employed in blue collar jobs. There are several aspects that hemophilia patients have to take into account of which in young patients the risk of bleeding due to daily activities in work is probably the most important. In older patients the choice of work may be influenced by the presence of hemophilic arthropathy resulting from repetitive bleeding into joints. Arthropathy causes functional limitations and pain and has a negative effect on labor force participation. Our study shows a strong association between joint impairment and occupational disability, also when age, viral infections and severity of disease were taken into account. Although this complication is often seen at a higher age patients born before the introduction of prophylaxis may have developed joint damage earlier in their lives. It has been shown that prophylaxis started later in life does not halt the progression of arthropathy.

The association between employment and health related quality of life should be interpreted with caution. Many factors may influence health related quality of life, such as viral infections and the presence of arthropathy. Health-related quality of life of patients with severe hemophilia born before the introduction of prophylactic treatment in the Netherlands was lower than that of the general population. In young patients quality of life seems to be similar to the general population.

Due to major improvements in treatment during the last decades patients with hemophilia aged between 16 and 30 years suffer less from occupational disability than the older group of patients compared to the general population.
Acknowledgements

The authors wish to thank the Netherlands Hemophilia Society and treating physicians from all 15 Dutch hemophilia treatment centers that made recruitment of patients possible. Ms Inge Noordermeer is thanked for her secretarial, administrative support and data management. We express our gratitude to all patients who participated to the HiN-5 study.

Authorship


Acquisition of data: M. Peters, E.P. Mauser-Bunschoten, A. de Goede-Bolder, J. Willemse and I. Plug

Analysis and interpretation of data: J.G. van der Bom, F.R. Rosendaal, I. Plug

Drafting of the manuscript: J.G. van der Bom, M. Peters, E.P. Mauser-Bunschoten, A. de Goede-Bolder, L. Heijnen, C. Smit, J. Willemse, F.R. Rosendaal and I. Plug

Critical revision of the manuscript for important intellectual content: J.G. van der Bom, F.R. Rosendaal and I. Plug

Conflict-of-interest disclosure: The authors declare no competing financial interests.
Reference List


Table 1  
Personal characteristics of participants according to age and severity of hemophilia

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<th>Moderate</th>
<th>Mild</th>
</tr>
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<tr>
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<td></td>
</tr>
<tr>
<td>Type of hemophilia</td>
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<td></td>
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<td>Hemophilia A</td>
<td>170 (85)</td>
<td>71 (92)</td>
<td>226 (87)</td>
</tr>
<tr>
<td>Hemophilia B</td>
<td>30 (15)</td>
<td>6 (8)</td>
<td>34 (13)</td>
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<tr>
<td>Treatment modalities</td>
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<td>7 (9)</td>
<td>1 (0.4)</td>
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<tr>
<td>On demand</td>
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<td>218 (91)</td>
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<tr>
<td>Viral infections</td>
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<tr>
<td>Hepatitis C</td>
<td>149 (75)</td>
<td>42 (64)</td>
<td>66 (43)</td>
</tr>
<tr>
<td>HIV</td>
<td>17 (9)</td>
<td>3 (5)</td>
<td>3 (2)</td>
</tr>
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<td>N=37</td>
<td>N=68</td>
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<td>Type of hemophilia</td>
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</tr>
<tr>
<td>Hemophilia A</td>
<td>65 (82)</td>
<td>32 (86)</td>
<td>59 (87)</td>
</tr>
<tr>
<td>Hemophilia B</td>
<td>14 (16)</td>
<td>5 (14)</td>
<td>9 (13)</td>
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<tr>
<td>Treatment modalities</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Prophylactic</td>
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<td>7 (19)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>On demand</td>
<td>8 (10)</td>
<td>22 (59)</td>
<td>52 (76)</td>
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<td>Viral infections</td>
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<td>7 (10)</td>
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<td>HIV positive</td>
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### Table 2
Professional characteristics of hemophilia patients born before or after the introduction of prophylaxis

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<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
<td>%</td>
</tr>
<tr>
<td><strong>Born before introduction prophylaxis (31-64 yrs)</strong></td>
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<tr>
<td>Full time education</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>N/A</td>
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<tr>
<td>Part time education</td>
<td>11 (6)</td>
<td>3 (4)</td>
<td>12 (5)</td>
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<tr>
<td>Full-time work</td>
<td>99 (50)</td>
<td>53 (67)</td>
<td>187 (72)</td>
<td>73</td>
</tr>
<tr>
<td>Part-time work</td>
<td>35 (18)</td>
<td>3 (4)</td>
<td>23 (9)</td>
<td>10</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2 (1)</td>
<td>3 (4)</td>
<td>3 (1)</td>
<td>2</td>
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<tr>
<td>Occupational disability (&gt;80%)</td>
<td>69 (36)</td>
<td>17 (22)</td>
<td>3 (1)</td>
<td>11</td>
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<td>Retired</td>
<td>7 (4)</td>
<td>2 (3)</td>
<td>10 (4)</td>
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<tr>
<td><strong>Born after introduction prophylaxis (16-30 yrs)</strong></td>
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<tr>
<td>Full time education</td>
<td>33 (42)</td>
<td>15 (41)</td>
<td>32 (47)</td>
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<tr>
<td>Part time education</td>
<td>6 (8)</td>
<td>5 (14)</td>
<td>9 (13)</td>
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<tr>
<td>Full-time work</td>
<td>27 (34)</td>
<td>19 (51)</td>
<td>30 (44)</td>
<td>52</td>
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<tr>
<td>Part-time work</td>
<td>21 (27)</td>
<td>4 (11)</td>
<td>13 (19)</td>
<td>24</td>
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<tr>
<td>Unemployed</td>
<td>1 (1)</td>
<td>0</td>
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<tr>
<td>Occupational disability (&gt;80%)</td>
<td>4 (5)</td>
<td>1(3)</td>
<td>1(2)</td>
<td>3</td>
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</table>

Data presented are numbers or number (percentage), N/A=not available

*8 patients were involved in either full-time or part-time work, †15 patients were both disabled and involved in either full-time or part-time work, ‡13 patients were also involved in full-time or part-time work and 1 patients was disabled, §12 patients with severe hemophilia were also involved in part-time work and 13 patients with moderate or mild hemophilia, ‡5 patients with severe hemophilia and 12 with moderate/mild hemophilia hemophilia were involved in either full-time or part-time work
<table>
<thead>
<tr>
<th>Employment level*</th>
<th>Severe hemophilia N=181</th>
<th>Moderate/mild hemophilia N=331</th>
<th>General population</th>
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<td>Lower level</td>
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<tr>
<td>Moderate level</td>
<td>36 39 38</td>
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<tr>
<td>High level</td>
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<td>Academic level</td>
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<td>Unknown</td>
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</table>

Data presented are percentages
Only patients included who have a full-time or part-time paid job
*All reported professions were scored according to a standard classification in which the employment levels resemble educational levels.
### Table 4
Factors associated with complete or partial occupational disability

<table>
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<tr>
<th></th>
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<th>Multivariate OR</th>
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<tr>
<td><strong>Severity of hemophilia</strong></td>
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<tr>
<td>Mild</td>
<td>49 (29)</td>
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<tr>
<td>Moderate</td>
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<td>Severe</td>
<td>98 (57)</td>
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<td>Age (10 year category)</td>
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<td>2.2 (1.8-2.6)</td>
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<tr>
<td>Hepatitis C</td>
<td>42 (30)</td>
<td>2.3 (1.5-3.5)</td>
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<tr>
<td>HIV</td>
<td>12 (7)</td>
<td>2.4 (1.1-5.1)</td>
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<td>Inhibitory antibodies at time questionnaire</td>
<td>8 (5)</td>
<td>3.3 (1.2-9.0)</td>
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<td><strong>Joint problems</strong></td>
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<td>None</td>
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<tr>
<td>Mild</td>
<td>43 (25)</td>
<td>2.1 (1.0-4.1)</td>
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<tr>
<td>Moderate</td>
<td>58 (33.9)</td>
<td>12.8 (6.3-25.9)</td>
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<td>Severe</td>
<td>59 (34.5)</td>
<td>45.2 (20.3-100)</td>
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Table 5 Health-related Quality of life in relation to employment.

<table>
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<tr>
<th>Employment</th>
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<th>Difference (95CI)</th>
<th>Adjusted for age (95CI)</th>
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<td>n=110</td>
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<tr>
<td>Physical functioning</td>
<td>81.6 (24.0)</td>
<td>47.8 (31.9)</td>
<td>33.8 (28.3-39.2)</td>
<td>28.3 (22.9-33.6)</td>
</tr>
<tr>
<td>Social functioning</td>
<td>87.1 (20.2)</td>
<td>63.0 (26.9)</td>
<td>24.1 (19.5-28.7)</td>
<td>21.6 (16.9-26.3)</td>
</tr>
<tr>
<td>Role-Physical</td>
<td>79.6 (35.5)</td>
<td>39.8 (43.0)</td>
<td>39.8 (32.0-47.7)</td>
<td>37.3 (29.3-45.4)</td>
</tr>
<tr>
<td>Role-Emotional</td>
<td>88.2 (29.3)</td>
<td>59.4 (45.2)</td>
<td>28.8 (21.9-35.8)</td>
<td>26.5 (19.3-33.7)</td>
</tr>
<tr>
<td>Mental health</td>
<td>78.9 (15.9)</td>
<td>67.1 (20.9)</td>
<td>11.8 (8.2-15.4)</td>
<td>10.6 (6.9-14.3)</td>
</tr>
<tr>
<td>Vitality</td>
<td>69.1 (18.7)</td>
<td>54.7 (20.1)</td>
<td>14.4 (10.4-18.4)</td>
<td>13.2 (9.0-17.3)</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>81.5 (21.3)</td>
<td>61.0 (29.0)</td>
<td>20.4 (15.6-25.3)</td>
<td>19.4 (14.4-24.4)</td>
</tr>
<tr>
<td>General health</td>
<td>70.3 (20.8)</td>
<td>50.7 (26.1)</td>
<td>19.6 (15.0-24.3)</td>
<td>18.0 (13.3-22.8)</td>
</tr>
</tbody>
</table>

Only patients included who were eligible to work (not involved in full-time education or retired).
Table 6a Quality of life of hemophilia patients born before the introduction of prophylaxis

<table>
<thead>
<tr>
<th>Born before introduction of prophylaxis (30-65 years)</th>
<th>Severe N=144</th>
<th>Moderate/mild N=244</th>
<th>General population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>45.9 (28.5)</td>
<td>83.1 (23.8)</td>
<td>84.0 (19.6)</td>
</tr>
<tr>
<td>Social functioning</td>
<td>72.5 (25.7)</td>
<td>83.5 (23.8)</td>
<td>83.5 (22.1)</td>
</tr>
<tr>
<td>Role-Physical</td>
<td>49.5 (43.8)</td>
<td>78.4 (37.5)</td>
<td>74.5 (36.8)</td>
</tr>
<tr>
<td>Role-Emotional</td>
<td>67.4 (42.9)</td>
<td>85.2 (33.0)</td>
<td>81.6 (33.2)</td>
</tr>
<tr>
<td>Mental health</td>
<td>73.4 (19.1)</td>
<td>76.6 (18.5)</td>
<td>75.6 (18.5)</td>
</tr>
<tr>
<td>Vitality</td>
<td>61.4 (20.7)</td>
<td>66.6 (21.1)</td>
<td>68.6 (20.2)</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>64.5 (24.3)</td>
<td>82.5 (23.5)</td>
<td>71.8 (24.1)</td>
</tr>
<tr>
<td>General health perception</td>
<td>56.8 (23.5)</td>
<td>68.3 (23.3)</td>
<td>69.7 (20.6)</td>
</tr>
</tbody>
</table>
Table 6b Quality of life of hemophilia patients born after the introduction of prophylaxis

<table>
<thead>
<tr>
<th></th>
<th>Severe N=102</th>
<th>Moderate/mild N=133</th>
<th>General population</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Born after introduction of</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>prophylaxis (15-30 years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical functioning</td>
<td>82.2 (21.4)</td>
<td>94.0 (12.9)</td>
<td>93.1 (11.8)</td>
</tr>
<tr>
<td>Social functioning</td>
<td>87.6 (20.2)</td>
<td>91.4 (17.5)</td>
<td>87.8 (19.1)</td>
</tr>
<tr>
<td>Role-Physical</td>
<td>73.0 (38.0)</td>
<td>90.4 (24.6)</td>
<td>86.4 (27.6)</td>
</tr>
<tr>
<td>Role-Emotional</td>
<td>86.6 (29.0)</td>
<td>94.9 (20.3)</td>
<td>85.4 (30.0)</td>
</tr>
<tr>
<td>Mental health</td>
<td>79.9 (14.0)</td>
<td>80.1 (14.5)</td>
<td>78.7 (15.2)</td>
</tr>
<tr>
<td>Vitality</td>
<td>71.9 (15.1)</td>
<td>72.2 (15.6)</td>
<td>70.7 (16.4)</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>76.9 (22.9)</td>
<td>88.7 (18.9)</td>
<td>80.9 (19.4)</td>
</tr>
<tr>
<td>General health</td>
<td>69.9 (22.2)</td>
<td>76.2 (18.3)</td>
<td>78.4 (17.3)</td>
</tr>
</tbody>
</table>
Social participation of patients with hemophilia in the Netherlands

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