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EMPLOYMENT OF INDIVIDUALS WITH HAEMOPHILIA IN THE NETHERLANDS

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Abstract—A study was performed to determine whether improvements in the treatment of haemophilia over the past 20 years have influenced the prospects of these patients in the labour market Surveys on the medical and social situation of haemophiliacs in The Netherlands were carried out in 1972, 1978 and 1985 Most of the patients participated in these surveys Trends in employment do not show either an increase in the number of employed haemophiliacs or a decrease in the number administratively defined as disabled However, considering the influence of the economic recession on the position of the chronically sick on the labour market and the rise in the number administratively defined as disabled in the Dutch population, haemophiliacs perform well Sick leave has decreased considerably Although the employment rate for the group of haemophiliacs is lower than that for the general male population, the level of employment in relation to educational achievements is high and most of the employed do not feel limited in their daily job activities by the haemophilia Physical mobility is a main factor influencing the employment status but other factors, such as the type of occupation or former occupation and prejudice against people with haemophilia, have to be considered

Key words—employment, haemophilia, disability, The Netherlands

INTRODUCTION

Haemophilia, a hereditary bleeding disorder that predominantly affects males, is caused by a partial or complete lack of coagulation factor VIII or IX Depending upon the residual concentration of the relevant coagulation factor distinction is made between severe (0–1% of the normal concentration), moderately severe (1–5%) and mild (5–40%) haemophilia In severe haemophilia spontaneous haemorrhages occur in joints and muscles In the milder forms bleeding is encountered only after surgery or trauma In the long run haemorrhaging in the joints may lead to irreversible damage, notably in the knees, the ankles and the elbows Since this injury to the joints lessens physical mobility, it is the main cause of disability Older patients are more likely to be affected since they did not have appropriate treatment when they were young In the past, treatment of a haemorrhage consisted mainly of prolonged rest Only in cases of severe bleeding transfusions of whole blood or plasma were administered Since the end of the sixties these patients receive concentrated blood products that are administered intravenously Nowadays most of the patients with severe and moderately severe haemophilia are on home treatment whereby transfusions are administered by the patient himself or his parents Patients who haemorrhage frequently may receive prophylactic therapy consisting of two or three infusions per week

This three-fold improvement administration of concentrated blood products, home treatment and prophylactic therapy, was expected to lead to an improvement in the medical and social prospects for haemophiliacs It was presumed that the decrease in the number of haemorrhages, the prompt treatment and the resulting decrease in damage to the joints would better their position in the labour market

Haemophilia and employment

Employment is a desirable goal for most people The employed generally have a higher income, more prestige and more self-respect than those without a job Often individuals with a chronic disease or a handicap are not blamed for being unemployed Nevertheless, compared to employed haemophiliacs, unemployed haemophiliacs have more psychosomatic complaints, are not as well adjusted to the problems of life and make fewer plans for the future [1]

A chronic disease or handicap can be an obstacle to getting a job, keeping a job and performing daily job activities This article concerns the quantity and quality of employment for haemophiliacs The term 'quantity' refers to the number of haemophiliacs employed in comparison with employment for the general male population The concept 'quality' was described by Blaxter [2] in her book on disability

> There were men ( ) struggling arduously and painfully, but nevertheless successfully, to do jobs which were really beyond their reduced physical capacity, on the other hand there were men bored and resentful because the only jobs they could get were, they thought, below their capabilities

Do employed haemophiliacs reach an occupational level that is comparable to their educational level? In

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addition to this objective measure the quality of employment from the point of view of haemophiliacs themselves was also investigated by asking whether they experienced restrictions in job performance due to haemophilia

As for quantitative aspects of employment, international data are far from uniform Figures on unemployment of haemophiliacs, gathered in 1988 by national haemophilia organisations, were as follows 0% unemployment in the G D R and Kuwait, less then 1% in Yugoslavia, 8% in the F R G and Malta, about 10% in Australia and the U S A , 20% in Poland and Argentina, 30% in Portugal and the U K , 40% in Spain and 60% in Chile [3, 4] However, it is not clear whether these figures apply to some official definition of unemployment or to the number that has no job Scientific publications on the employment of haemophiliacs are scarce [1, 5–11] Although a proper definition of unemployment is also often lacking and samples are sometimes small, some of them hold enough detailed information to offer the opportunity for a cross-national comparison Usually employment of haemophiliacs is lower than employment for the general population In the conclusions and discussion we will put employment of haemophiliacs in international perspective

Unemployment of haemophiliacs as well as differences in unemployment rates between countries may be due to several factors physical, social and economical Most of the time it is a combination of these factors The physical condition is probably an important factor Disability due to damage to the joints may make a regular job impossible Sometimes decreased physical mobility does not make a job impossible but it does reduce job performance, and then it is up to the employer whether the employee keeps his job or not More precisely, it will often depend on the nature of the labour contract between employer and employee Blaxter [2] notes that two groups have discouraging 'post-impairment careers' the self-employed who operate on a fee-for-service basis, and those whose labour agreement with their employer was individual and casual Prejudice may be another cause of the lower employment rate Haemophilia is a rare disease and laymen are not familiar with it Many people relate it to 'bleeding to death' and think that the haemophiliac is unable to function well Inadequate knowledge of haemophilia and modern treatment regimens leads to stereotyped reactions [12] A related phenomenon, which may have consequences for employment, is the 'spread phenomenon' The able-bodied are inclined to form an image of the handicapped as being inferior not only in physical abilities but also in other respects [13] An individual may be slightly handicapped in his mobility but capable of performing many jobs, whereas others—employers in this case—might think that because mobility is decreased other capacities may also be reduced Because of ignorance or the 'spread phenomenon' employers may tend to engage someone else instead of the haemophiliac As has been said, when analysing employment rates of haemophiliacs and differences in rates between countries, it is difficult to differentiate between several factors physical, social as well as economical Some remarks however can be made The inclination of employers not to employ persons with a chronic disease or handicap may cause lower employment rates, but it also may cause employment of lower quality It is known that people with a handicap are sometimes forced to accept a job below their capability They face downward social mobility

In our study we examined

—trends in the employment of men with haemophilia,
—employment of haemophiliacs conpared to that of the general male population,
—occupational level of employed haemophiliacs in relation to their educational level,
—limitations in job performance due to haemophilia,
—correlation between physical mobility and employment situation,
—experiences when applying for a job

METHODS

In 1985 the third Dutch mail survey on the medical and social situation of people with haemop ilia was carried out Earlier surveys were performed in 1972 and 1978 [14, 15] The questionnaire was prestructured and standardised Addresses were obtained by updating the mailing lists of former surveys, the Dutch Haemophilia Society and the large haemophilia centres supplied addresses of additional patients The questionnaire was sent to 1162 persons Assuming a prevalence of 7–9/100,000 [16, 17], we reached at least 90% of the patients in The Netherlands The response was 81% For this article only the questionnaires of men between 15 and 65 years of age were analysed The data were compared to data from the 1972 and 1978 surveys and data on the Dutch 15–65-year-old male population in 1985 When relevant, data are presented separately for severe, moderately severe and mild haemophilia

The definition on unemployment as used in our survey was in search of a job and registered with an employment agency This differs slightly from the definition used in official Dutch statistical analysis out of work and receiving unemployment compensation or actively seeking work The percentage unemployed refers to the total group of men between 15 and 65 years of age, as distinct from many official publications in which percentages refer to the labour force Medical definitions of disability have to be distinguished from administrative definitions in which financial benefits are involved In this study on the employment situation, data on disability are offered which refer to the administrative definition The exact definition used was receiving an income on the basis of one of the two Dutch Disability Compensation Laws (Wet op de Arbeidsongeschiktheidsverzekering, Algemene Arbeidsongeschiktheidswet) This implies a slight underestimation of the number of administratively defined disabled, due to the fact that disabled civil servants receive an income from another fund The number of people employed, unemployed and disabled cannot be added, because individuals may belong to more than one category at one time Respondents were classified according to educational level on the basis of the classification

system of the Central Bureau of Statistics (CBS) They were grouped into occupational levels according to the Occupational Guide [18], which distinguishes six levels 1 = unskilled labour, 2 = skilled labour, 3 = lower employee, 4 = small entrepreneur, 5 = middle employee, 6 = higher vocation

We developed an instrument that would allow us to measure physical mobility The respondents were presented with 10 daily activities and asked whether they found these activities easy, somewhat difficult, very difficult or impossible to carry out The answers were analysed by Mokken scale analysis [19], the answers 'somewhat difficult', 'very difficult' and 'impossible', were taken together to obtain dichotomous items The purpose of this analysis was to see whether it is possible to arrange the activities on a scale from easy to difficult, which would mean that if a respondent gives a positive answer about a 'difficult' activity, he should also answer positively about an 'easier' activity Table 1 shows the results of the Mokken scale analysis The 10 activities form a 'strong' scale ($H = 0\ 76$), with a high reliability ($r = 0\ 93$) The minimum score, indicating minimum mobility, is 0, and the maximum score, indicating maximum mobility, is 10

RESULTS

General data

There were 716 persons in the age group 15–64 years, 41% had severe haemophilia, 18% had moderately severe haemophilia and 42% had mild haemophilia Compared to previous surveys more men with mild haemophilia took part in this survey (Table 2)

Table 1 Mokken scale analysis of daily activities, measuring physical mobility

Activity	Difficulty*	Scalability
Long distance walks	0 61	0 87
Walking up the stairs	0 70	0 85
Jobs in around the house	0 77	0 76
Walking 400 m	0 77	0 71
Getting in/out of a car	0 81	0 71
Doing the shopping	0 81	0 74
Getting out of a chair	0 82	0 73
Picking things up from the floor	0 87	0 68
Getting (un)dressed	0 92	0 72
Walking on one floor	0 93	0 83

Scalability of all activities $H = 0\ 76$ Reliability coefficient rho = 0 93

*Difficulty shows the percentage having no problems with the activity

The age distribution for the survey population differs slightly from that found in previous years Whereas the mean age was 30 years in 1972 and 31 years in 1978, it had risen to 33 years in 1985 The comparable figure for the general male population was 36 years in 1985 (Table 2) Figure 1 shows the mean score for physical mobility for different age groups

Trends in employment 1972, 1978 and 1985

Comparison of the survey population in 1985 with the survey populations in 1972 and 1978 shows that the number of employed haemophiliacs has remained fairly stable (Table 3) The data on disability indicate that between 1972 and 1978 the number of administratively defined disabled rose, since 1978 it has remained fairly stable The data for 1985 are not entirely comparable to those for 1972 and 1978, especially as far as disability is concerned The first two surveys included relatively more patients with severe and moderately severe haemophilia and relatively more young patients More people with severe and moderately severe haemophilia 'automatically' cause a higher percentage of disabled, which is counteracted by the fact that more young patients 'automatically' cause a lower percentage Also in 1972 and 1978 another definition of disability was used, which resulted in a slight overestimation of the number of disabled However, with these facts in mind, we may conclude that the number of employed has not risen, but the number of disabled has

Sick leave has decreased substantially from 35 days in 1972 and 29 days in 1978 to 15 days in 1985 For that matter sick leave reported for the general male population has also decreased, from 17 days in 1972 and 1978 to 15 days in 1985 [22–24]

Employment of haemophiliacs compared to employment of the general male population

In 1985 69% of the Dutch male population between 15 and 65 years of age was employed, vs 59% of the survey population (Table 3) However, 10% of the employed haemophiliacs were employed via the Law for Provision of Work for the Disabled (Wet

Table 2 Distribution according to age and severity of haemophilia for the survey populations in 1972 1978 and 1985

	Survey population			General male population 1985 [20] (%)
	1972 ($n = 276$) (%)	1978 ($n = 403$) (%)	1985 ($n = 716$) (%)	
Age				
15 24	41	36	30	25
25 34	29	33	28	24
35–44	17	18	23	21
45 54	9	8	12	16
55–64	4	6	7	13
Mean age	30	31	33	36
Severity				
Severe	36	42	41	
Moderately severe	18	16	18	
Mild	22	27	42	
Unknown	24	14	—	

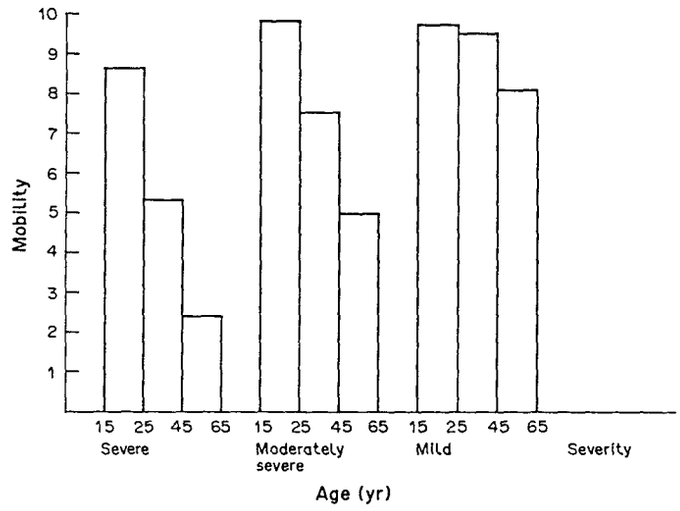

Fig 1 Mean score for physical mobility

Sociale Werkvoorziening), which offers jobs to individuals with a mental or physical handicap For the general population this figure was 1 4% [25] In 1985 9% of the Dutch male population was unemployed, 41 persons of the survey population were registered for employment, which yields an unemployment rate of 6% Therefore unemployment was lower among haemophiliacs than for the general population On the other hand the percentage disabled was higher among haemophiliacs Twenty-two per cent of the survey population was administratively labelled disabled, whereas the national figure was 11% In the general population disability was concentrated in the age group 45–64 years This age group is under-represented in the survey population For this reason comparison between the total survey population and the total general male population will yield an underestimation of the differences Table 4 shows the disability and employment figures for three age groups

The Dutch Disability Compensation Laws discriminate between individuals who are completely disabled and those who are partly disabled, the degree of administratively defined disability being dependent on their physical condition and prospects on the labour market Three-quarters of the disabled haemophiliacs were completely disabled However being partly or even completely disabled does not automatically mean that one is unemployed Thirty per cent of the disabled haemophiliacs had some kind of a job We conclude that in 1985 haemophiliacs were employed less often than non-haemophiliacs, a fact that is attributable mainly to the higher percentage registered as disabled

In 1985 absenteeism from work due to illness was the same for the survey population as for the general male population 15 days per year For individuals with severe and moderately severe haemophilia it was higher, 20 and 23 days respectively, for those with mild haemophilia it was lower, 10 days

Occupational level and educational level

The employed haemophiliacs were asked about their occupation and the highest educational level they had attained We wanted to see whether their occupational career met the expectations of their education for it is possible that haemophiliacs, due to their illness, have to accept jobs below their capabilities General figures are not available For this reason the relation between education and occupation was compared for individuals with severe, moderately severe and mild haemophilia If downward social mobility due to haemophilia does occur, this should become apparent in differences between those with severe, moderately severe and mild haemophilia, because many individuals with mild haemophilia are not bothered by their disease and are therefore presumably comparable to the general population Table 5 shows that the mean occupational level for each educational level is the same for all three categories, individuals with severe and moderately severe haemophilia with lower educational levels even

Table 3 Employment and disability in the survey populations (1972 1978 1985) and the general male population (1985)*

	Survey population			General male population 1985 [20 21] (%)
	1972 (n = 276) (%)	1978 (n = 403) (%)	1985 (n = 716) (%)	
Employed	60	58	59	69
Unemployed	†	†	6	9
Disabled	17	22	22	11

*Percentages employed unemployed and disabled do not add up to 100% because some people were employed and disabled at the same time and others for instance school going persons do not belong to any category
†No figures available

Table 4 Employment unemployment and disability compensation for different age groups*

Age (years)	Survey population: Severe ($n = 292$) (%)	Moderately severe ($n = 126$) (%)	Mild ($n = 298$) (%)	Total ($n = 716$) (%)	General male population [20 21] (%)
Employment					
15–24	27	17	44	32	42
25–44	64	76	91	77	87
45–64	48	52	60	55	64
15–64	50	56	71	59	69
Unemployment					
15–24	9	3	4	6	10
25–44	8	11	5	7	9
45–64	—	—	3	1	7
15–64	7	7	4	6	9
Disability					
15–24	8	—	—	3	1
25–44	40	26	5	23	6
45–64	60	48	33	45	25
15–64	33	22	10	22	11

*Percentages of employed unemployed and disabled do not add up to 100% because some people were employed and disabled at the same time and others for instance school going persons do not belong to any category

had on the average higher occupations than those with mild haemophilia Although general figures on occupation in relation to education are not available we know that 43% of the employed males of the general population have blue collar jobs and 57% white collar jobs [26] For the survey population these percentages were 28 and 72, respectively From these data it can be concluded that downward social mobility is uncommon among the entire group of employed haemophiliacs as well as each subgroup

Restrictions in daily work due to haemophilia

A job may pose problems to handicapped or chronically ill individuals, it may be physically too difficult, treatment of the disease may pose practical problems and other problems may arise We asked the employed haemophiliacs whether haemophilia led to restriction of their daily work performance If they answered affirmatively, respondents were also asked to indicate which problems were encountered at work Most of the respondents, 77%, did not consider haemophilia a restriction A considerable minority, ranging from 12% of the individuals with mild haemophilia to 21% of those with moderately severe and 32% of those with severe haemophilia, stated that it was a restriction The most frequently mentioned problem was being bothered by pain', which was indicated by 42 respondents Other problems had to do with the feeling that they could not meet the requirements of the job 'having to leave at unexpected moments because of a haemorrhage' (30 times), 'the job is physically too difficult' (18 times), 'to have to ask colleagues for help' (18 times) and 'excessive absenteeism' (17 times)

An interesting aspect is whether restriction of job activities is related to occupational level (Table 6) Manual workers more often experience restrictions in daily job activities than non-manual workers and unskilled manual workers more often than skilled manual workers The small entrepreneurs suffered such limitations the most Lower employees and people with higher vocations experienced less restrictions than middle employees The difference between manual and non-manual workers is easily explained by the difference in requirements concerning physical capabilities An additional explanation for this as well as for the difference between unskilled and skilled workers is offered by Blaxter [2] in her survey on disability in the U K

> they (persons who retired from work due to disablement) were likely to be semi- or unskilled manual workers, since it was more likely that impairment would not preclude work for non-manual employees, or that their employers or the employers of valued skilled workers would be willing to offer adjustments in working conditions so that permanent retirement was not necessary '

As we found many problems among the small entrepreneurs, Blaxer often found for them "unfavourable post-impairment careers" and suggested that the lack of a helpful formal employment structure caused

Table 5 Mean occupational level* of employed haemophiliacs according to educational level

Educational level	Severe ($n = 136$)	Moderately severe ($n = 69$)	Mild ($n = 201$)	
Lower education	2 9	2 5	2 0	($n = 38$)
Lower vocational education	2 9	2 5	2 4	($n = 96$)
Middle education	3 5	4 2	3 8	($n = 191$)
Higher education	5 3	5 5	5 0	($n = 81$)
Total	3 8	3 9	3 4	($n = 406$)

*1 = unskilled labour 2 = skilled labour 3 = lower employee 4 = small entrepreneur 5 = middle employee 6 = higher vocation

Table 6 Percentage of employed haemophiliacs listed according to occupational level experiencing restriction of daily job activities

Occupation	Restrictions (%)	
Unskilled manual labour	32	($n = 22$)
Skilled manual labour	25	($n = 95$)
Lower employee	14	($n = 112$)
Small entrepreneur	41	($n = 34$)
Middle employee	21	($n = 88$)
Higher vocation	12	($n = 60$)
Total	21	($n = 411$)

these troubles Katz [5], coming across the same findings, offered the alternative explanation of self-selection

"Because of absenteeism and other problems associated with finding and keeping jobs many haemophiliacs feel that self-employment would be the best situation for them "

Employment and physical mobility

To investigate the influence of physical mobility on employment status we determined how many respondents in each group of scores on the mobility scale were employed and how many were administratively defined as disabled Individuals still going to school were excluded from this analysis To create groups containing comparable numbers of respondents, data for two or three lower scores were combined (Fig 2) It appears that the mobility score is only a partial predictor of employment status Although lower mobility scores are accompanied by a lower percentage employed males, even the group with the lowest mobility scores included employed people 45% of the patients with a mobility score of zero or one or two were employed, whereas 62% were administratively labelled disabled We may conclude that factors other than physical mobility also play a role in the employment situation

Experiences when applying for a job, prejudice of employers

One of the factors affecting the employment situation may be prejudice We asked the respondents whether they mentioned having haemophilia when they applied for a job And if so, whether this produced any problems And if not, why they did not mention it Three hundred and sixty-two men were too young or too old to apply for a job or they had not done so in recent years Of the remaining 354 85% told about having haemophilia at the time of

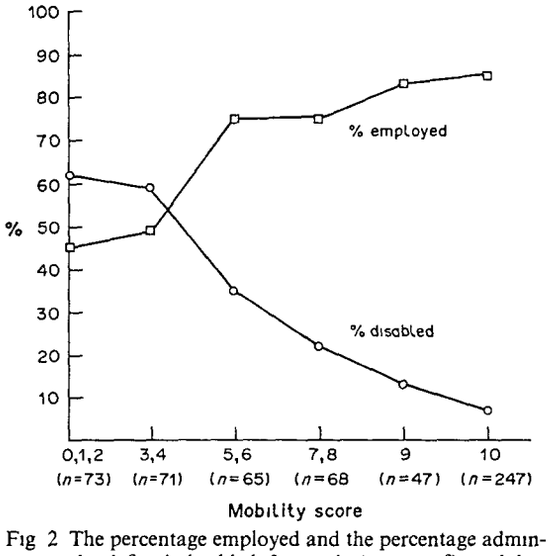

Fig 2 The percentage employed and the percentage administratively defined disabled for each (group of) mobility score(s) School-going persons are excluded

application (Table 7) They told the boss, the personnel manager or the medical officer Fifteen per cent did not mention having haemophilia Usually a medical officer was involved in the application procedure, when there was none a higher percentage did not report their haemophilia Most respondents thought having haemophilia caused no problems A large minority of the men with severe and moderately severe haemophilia believed nevertheless that they were not accepted for the job because of haemophilia It is incorrect to assume that employers are prejudiced in every case The opinion of the respondent on the reason for rejection is a subject a measure of prejudice In addition some may have been rejected because they really were too handicapped to perform well However, 32% of the group with negative experiences had a maximum score on the mobility scale, indicating that nothing was wrong with their physical mobility

A small group did not mention having haemophilia at all The main reason given was unfavourable experiences in the past or the supposition that haemophilia might be a reason for not being accepted for the job Others did not mention haemophilia because they thought it was not sufficiently important

Table 7 Experiences when applying for a job do haemophiliacs mention their haemophilia or not if so what happened if not why not

	Severe ($n = 131$) (%)	Moderately severe ($n = 62$) (%)	Mild ($n = 161$) (%)	Total ($n = 354$) (%)
Mentioned haemophilia	89	90	79	85
Experience				
No problem	41	53	58	51
Was not accepted presumably because of haemophilia	34	16	9	20
Does not mention haemophilia	11	10	21	15
Reasons				
Not important	2	5	7	5
Bad experiences in the past	2	2	3	2
Supposed he would not be accepted	5	3	7	6

CONCLUSIONS AND DISCUSSION

Comparing the employment situation of Dutch haemophiliacs in 1985 with that in 1972 and 1978, we see that the percentage employed has remained roughly the same. The number of administratively defined disabled increased between 1972 and 1978 and then remained stable Sick leave has dropped substantially over the years and compares well in 1985 to sick leave data for the general population In 1985 only a small percentage of employed haemophiliacs experienced restriction of job performance due to haemophilia.

Comparing the employment situation of haemophiliacs in 1985 with that of the general male population, we see that fewer haemophiliacs are employed and more haemophiliacs are disabled than in the general population

A major cause of the low employment rates is the haemophiliac's physical condition Individuals with reduced physical mobility are less likely to be employed However, not everyone with decreased physical mobility is out of work The questions on problems with daily job activities show that the kind of job, e g the distinction between manual or non-manual labour, plays a major role in the occurrence of problems The same will probably apply to the matter of employment vs disability manual labourers will be more readily defined as disabled than non-manual labourers.

One out of every four haemophiliacs applying for a job believes he was not accepted for a job because of his haemophilia And although not all of these men were in optimal physical condition, thus giving the employer a reason for choosing another applicant, 32% were in optimal physical condition as far as joint problems were concerned. This argues for the occurrence of prejudice against men with haemophilia Katz' study among haemophiliacs in the U S A in the sixties revealed that discrimination by employers, caused by ignorance of haemophilia, was felt to be one of the major problems encountered on the labour market [5] We have to bear in mind however that the results of this kind of survey are based on subjective feelings and not on an objective measure of prejudice In a study on epilepsy it was found that a distinction should be made between 'felt' stigma and 'enacted' stigma The majority of respondents in this survey referred to the fear of being discriminated against but only a third could cite incidents of enacted stigma [28] The relatively high occupational level of employed haemophiliacs and the low number of officially unemployed in our survey suggest that for haemophiliacs without joint problems prejudice, resulting in lack of employment, does not play a major role Perhaps when prejudice does occur the haemophiliac tries once again and is then successful

It was expected that modern substitution therapy would influence the employment of Dutch haemophiliacs, just as this was expected in other countries This influence is most clearly seen in the substantial reduction in sick leave The expected decline in the number of disabled failed to appear The main reason for this is that such improvements will not become manifest in a few years Joint impairment is for the greater part irreversible and the survey population of 1985 contained only a few younger individuals who had had appropriate treatment from the beginning Another cause is that the general unemployment has had a negative influence on the position in the labour market of individuals with a handicap or chronic disease Whereas haemophiliacs without joint problems may find the labour market reasonably accessible, those with slight impairments will discover that the 'spread phenomenon' and higher demands from employers may pose problems National disability figures are covariant with the unemployment figures [29] In The Netherlands the number of disabled receiving income through the Disability Compensation Laws has risen from 218,000 in 1972 and 451,000 in 1978 to 545,000 in 1985 which means an increase of 150% since 1972 [25] We may suppose that part of the disability of the survey population is attributable to hidden unemployment For 1978 it was calculated that hidden unemployment represented one-third of the disability in The Netherlands [30] Compared to other groups with chronic conditions Dutch haemophiliacs have maintained their position in the labour market quite well

The position of the Dutch haemophiliacs differs sometimes from that of haemophiliacs in other countries Table 8 gives an overview of the international studies in this respect As has been pointed out physical, social and economical factors affect the employment/unemployment ratio of people with haemophilia The relative importance of those factors varies in time, causing different levels of unemployment between countries This makes an international comparison of unemployment rates hazardous. This holds the more so because of methodological weaknesses in some of these studies Some samples are small or biased Exact definitions of unemployment are usually not given, so it is not clear whether they refer to official registration for employment, or simply to lack of employment. Also it is not clear whether the percentages refer to the entire survey population, the survey population except school-going persons, or the labour force General unemployment figures usually refer to the labour force For these reasons it is more appropriate to compare the employment figures of haemophiliacs Three studies give sufficiently detailed data to permit longitudinal and cross-national comparison [5, 8, 10]. A comparison between the situation in 1963–64 and 1983 in the U S A shows an increase in employment and a decrease in unemployment This is partly explained by the exclusion of the 16 and 17 year olds in 1983 Nimorwicz thinks that a part of the unemployed in 1963–64 have moved to the category of the disabled since in 1963–64 only a limited social security programme for disabled workers was available and not until 1973 were benefits available for the young disabled that were never employed [10] Recently the employment situation in The Netherlands resembles the situation in the U S A and the U K 59–73% is employed and a rather large group is unemployed or disabled A remarkable difference between the U K and The Netherlands is that in the U K employed haemophiliacs often have manual occupations (haemophiliacs 55% manual work, general population 39%), whereas in The Netherlands they are concentrated in the non-manual occupations

Table 8 Employment of individuals with haemophilia An international overview*

Authors	Country	Year of survey	*N*	Characteristics of the survey population	% employed	% unemployed	% school going	% disabled	Further characteristics
Katz (1970) [5]	U S A	1963 64	1055	age ⩾16 years	52	20	26	†	general unemployment 5% (1960)
Steinhausen (1977) [6]	Hamburg F R G	1971 73	54	age 16–60 years, $\bar{x} = 27$, severity of haemophilia almost all severe or moderately severe	48	4	43	2	
Markova *et al* (1977 1980) [1 7]	Scotland	1974	66	age of working age' severity of haemophilia ±35% severe, ±25% moderately severe and ±40% mild	†	29	†	†	general unemployment 5%
Stuart *et al* (1980) [8]	U K and Scotland	1978	502	age 16–65 years, $\bar{x} = 34$, severity of haemophilia 48% severe, 24% moderately severe and 28% mild	73	18	11	48	general umemployment 7%
Lineberger (1981) [9]	U S A southeastern rural states	1977 79	106	age ⩾18 years, severity of haemophilia almost all severe	47	44	†	31	
Nimorwicz *et al* (1986) [10]	Pennsylvania U S A	1983	421	age ⩾18 years, $\bar{x} = 34$, severity of haemophilia 53% severe, 18% moderately severe and 29% mild	61	15	7	12	general unemployment 6%
Goldsmith (1986) [11]	Massachusetts, U S A	1985	†	age †	†	3	†	†	general unemployment is higher
	U S A 82 haemophilia comprehensive care centres	1985	7247	age 0–100 years, unemployment refers to adults	†	9	†	†	
Varekamp *et al* (1988)	The Netherlands	1985	716	age 15 65 years, $\bar{x} = 33$, severity of haemophilia 41% severe, 18% moderately severe and 42% mild	59	6	19	22	general unemployment 15%

*Percentages cannot be added to 100% because persons may belong to more than one category
†No figures available

Markova [1,7] also noted that the more severe the haemophilia, the more often employment was in manual work, which in her opinion was accounted for by the low educational level.

The rise in employment that failed to appear, despite better treatment facilities, stresses the importance to distinguish between impairment and disability on the one hand and handicap on the other hand as these concepts were defined by the World Health Organisation in 1980 [31] Whereas impairment of the joints and restrictions in physical mobility decreased, the handicap did not economic independence in terms of earning a living is still not attained by many One could ask whether this is completely attributable to the inaccessible labour market and furthermore how far this 'stability' in employment rates is regrettable As to the first question we refer to a discussion on the objectives of rehabilitation [32–34] In this discussion a distinction was made between resource enhancement (development of a person's potentials to render them good coping resources) and resource compensation (replacement of resources, e g financial assistance) It was supposed that beyond a certain limit resource compensation is a restraint on successful integration [33] The Netherlands have Disability Compensation Laws that guarantee 70% of former income, and since 1976 there is a Disability Compensation Law for young handicapped that were never employed The rise in the number of administratively defined disabled and the slight fall in the number employed between 1972 and 1978 may be attributed to the introduction of this law As to the second question concerning the 'stability' in employment rates we would reflect as follows economic independence in the sense of earning a living did not increase in The Netherlands But in case of employment the occupational level is mostly high It seems that haemophiliacs are not compelled to accept jobs below their educational level or jobs that are unfit for them This is different from the English situation, where haemophiliacs more often have manual jobs [8] and the handicapped frequently experience downward social mobility [2] One explanation for the favourable Dutch situation is perhaps the fact that the educational achievements of Dutch haemophiliacs are good [27], which gives them a good start on the labour market Another explanation may be that social security regulations for the disabled are (at least were until 1985) good in The Netherlands in comparison with other countries [35] This may have prevented downward mobility in the occupational career From this perspective low employment of good quality is preferable to high employment of bad quality

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