

A man in a dark suit and red tie stands with his arms outstretched on top of a globe. The globe shows green continents and blue oceans. The background is a clear blue sky. The overall image has a halftone or dithered texture.

Frank Andries

**Towards a better understanding of the  
chronically ill, vocational perspectives,  
work adjustments, information technology  
and quality of work**



# **Towards a better understanding of the chronically ill, vocational perspectives, work adjustments, information technology and quality of work**

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Towards a better understanding

Promotor:	Dick van Putten
Copromotoren:	Peter Smulders Anja Kremer Steven Dhondt
Leden manuscriptcommissie:	Caroline Swart Marga van der Zwaan Leonie van Loenen
Overige leden promotiecommissie:	Renée van Amstel Han Anema Ruurt van den Berg Seth van den Bossche Peter Buijs Marije Evers Floor van den Heuvel Irene Houtman Karin Jettingshof Romy Steenbeek Anita Venema Jan Fekke Ybema

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## Do you think that your health or safety are at risk because of your work? A large European study on psychological and physical work demands

FRANK ANDRIES, MICHIEL A. J. KOMPIER†  
and PETER G. W. SMULDERS

TNO Prevention and Health, Division of Work and Health, PO Box 2215, 2301 CE Leiden, The Netherlands

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A secondary analysis was performed on a large scale cross-sectional survey ( $n = 12500$ ) by the European Foundation for the Improvement of Living and Working Conditions. The analysis investigates (1) 'strain', i.e. whether or not employees in 12 European Union (EU) member states considered their health or safety to be at risk because of their work in relation to psychological demands, job control and social support, (2) the unique contribution of (a combination of) these job characteristics in explaining differences in health and safety risk (HSR), (3) the explanatory value of these job characteristics in comparison to physical job demands, and (4) the relative strength of these determinants in each of the 12 EU member states. Results show that (1) psychological demands, job control and social support are all related to a perceived health and safety risk in the work situation; (2) each of these characteristics has an unique contribution; (3) physical demands, when added to the model, are by far the most influential determinant; and (4) in a cross-national comparison, physical demands are found to be the most influential determinant of HSR in all EU member states. The importance of this study is its large scale and European character. An important limitation, however, relates to the operationalization of the dependent variable. It is concluded that high psychological demands *per se* constitute a risk of illness and injury from work. The larger number of European employees who consider their health or safety to be at risk because of their work, underlines the necessity of monitoring risk factors and risk groups and of prevention, and also of adequate legislation with respect to working conditions. An important implication of this study is that one should be careful not to underestimate the impact of traditional blue collar stressors in working life in Europe.

### 1. Introduction

In 1991 a survey was carried out on the work environment in the twelve countries of the European Union (Paoli 1992). This study can be considered to be a first step towards more comprehensive and homogeneous data on working conditions in the EU. The present contribution is based on a secondary analysis of this large scale cross-sectional study. Its aim is to further investigate job characteristics and their unique or combined effects on a perceived health or safety risk ('strain') owing to the work situation. In addition, by means

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† Present address: Department of Work and Organizational Psychology, University of Nijmegen, The Netherlands.

of a cross-national ('country by country') comparison, information can be gathered about the stability of the results found in the overall European population.

The theoretical framework of this contribution is an adaptation of the three-dimensional Demand-Control-Support model (DCS model) of the psychosocial work environment (Karasek and Theorell 1990, Johnson and Hall 1988). Their model—in fact an expanded version of the original Karasek model of 'job demands-job control' (DC model, Karasek 1979)—is characterized by three main health risk dimensions in the work situation: psychological job demands, job control and work-related social support. Job demands include factors such as workload and work pace. Job control includes indicators of individual control over work pace, influence on decisions ('job decision latitude') and opportunities for learning and development of skills ('skill discretion'). Social support (emotional support, feedback, information and help; House 1981) relates to the relations with co-workers, supervisors, and subordinates. The DCS model predicts that negative outcomes (e.g. health complaints, exhaustion, depression, sickness, absenteeism, mortality) as well as positive outcomes (e.g. job satisfaction, work motivation, productivity) may result from a combination of the three dimensions mentioned above. More specifically, the model assumes two main hypotheses: (1 a) the combination of high psychological demands, low job control and low social support increases psychological and physical strain, and (1 b) jobs characterized by a combination of high demands, high control and high support increase well-being, learning and personal growth. According to hypothesis (2), job demands and job control combine interactively rather than additively in predicting health-related outcomes.

During the past decade the DCS model has been the subject of many studies, both multi-occupation (epidemiological) studies and single-occupation studies. A few longitudinal studies (Parkes *et al.* 1994, De Jonge 1996) and many cross-sectional studies have been carried out. Most of the studies carried out are reviewed by Ganster and Fusilier (1989), Karasek (1989), Karasek and Theorell (1990), Ganster and Schaubroeck (1991), Schnall *et al.* (1994), Kristensen (1995) and De Jonge (1996). From these studies several main 'critical, unresolved' issues emerge. Three of these will be studied in this contribution. The first two issues refer to the two main hypotheses of the DCS model. The third issue relates to the interplay between the 'Karasek-dimensions' and 'blue collar' stressors.

First, the overall support for the DC model and the DCS model is mixed. In general far more attention has been paid to investigating the above mentioned 'strain hypothesis' (1 a), when compared to the 'learning hypothesis' (1 b). The early epidemiological studies on the DC model, mainly concentrating on this 'strain hypothesis', provide more evidence for the model than does research at single-occupation level. In particular Johnson and co-workers have tested the DCS model extensively using large-scale, multi-occupation databases (Johnson 1986, Johnson and Hall 1988, 1994, Johnson *et al.* 1989). The evidence from these, and other single occupation studies is still inconclusive.

Second, there is little evidence in support of the postulated interactions between job demands and job control (hypothesis 2). The predicted interaction effect is either not found or the amount of additional variance that is explained by the interaction term is very small (i.e. about 2–3%) (De Rijk *et al.* 1996). Against this background the present study tests the two main hypotheses of the Karasek model on a large scale cross-sectional dataset.

Compared to these two 'classical' questions with respect to the DC and DCS models, the third issue has until now received less attention in the scientific literature. The third point is that these models, essentially, focus on psychosocial job characteristics as determinants of ill health. This should not distract attention from the fact that 'blue collar' stressors, i.e. stressors that stem from the physical workload and physical work environment (e.g. noise



and working in painful positions), are also important in predicting and explaining negative health outcomes (Kompier *et al.* 1990, Scheuch and Schreinicke 1989, Levi 1984, Cox 1993, Evans *et al.* 1994). In fact, putting the emphasis primarily on 'modern' psychosocial factors might lead to an underestimation of the impact of traditional 'blue collar' stressors. Since there still is a 'marked paucity of research on the interplay of physical and psychosocial work environment factors as they affect health' (Evans *et al.* 1994, p. 1, see also Ornstein 1990, and Hedge 1989), the aim is to shed more light on the question of how physical and psychosocial elements of the work environment interrelate to affect health and well-being. As in the DCS model, there may be additive and interactive ('moderator' and 'mediator') relations (Evans *et al.* 1994).

## 2. Questions

Referring to these three central issues, the questions to be answered are:

- (1) Do employees with different jobs in terms of psychological demands, job control and social support also differ in 'strain' (i.e. whether or not they consider their health or safety at risk because of their work)?
- (2) What is the separate—unique—contribution of psychological demands, job control and social support in explaining differences in 'strain', and in what way do these job characteristics possibly interact in their effect on 'strain'?
- (3) What is the contribution of physical job demands in explaining differences in risk of illness and injury from work in comparison to psychosocial job characteristics?

Also the stability of these effects is examined by comparing the results found in the overall population for each separate member state:

- (4) What are the contributions of psychological demands, job control, social support and physical demands in explaining differences in 'strain' in each of the 12 EU member states?

## 3. Methods

### 3.1. Data collection

The survey was carried out in 12 EU countries (Denmark, United Kingdom, Ireland, West and East Germany, Netherlands, Belgium, Luxembourg, France, Italy, Spain, Portugal and Greece) through direct face-to-face interviews in March/April 1991. The questionnaire was developed by a group of experts from various countries and representatives of trade unions and employer organizations at EU level (Paoli 1992). The sample consists of some 12500 employees (approximately 1000 employees per country, except for Luxembourg with 500 employees). West Germany and the former East Germany were treated as two countries, both with 1000 employees in the sample. The sample is representative of the EU work-force distribution according to gender, age, occupation, sectors and company size (Paoli 1992). For reasons of comparability 146 employees older than 65 years were excluded from analyses. Table 1 shows the distribution of gender, age, occupation, sectors and company size in this European sample.

### 3.2. Operationalization of concepts

3.2.1. *Job characteristics*: Scales were developed in order to operationalize psychological demands, job control and social support. Psychological demands include 'working at a very hard speed' and 'working to tight deadlines'. Job control primarily relates to 'decision

Table 1. Characteristics of the sample ( $n = 12655$ ).

Characteristic	Distribution (%)	Characteristic	Distribution (%)
<i>Gender</i>		<i>Sector</i>	
Men	61	Agriculture	6
Women	39	Energy	4
		Metal manufacture	8
<i>Age (years)</i>		Other manufacture	11
15-24	15	Building	6
25-49	66	Distribution	17
≥ 50	19	Transport	6
		Banking and insurances	5
<i>Occupation</i>		Other services	37
Farmer/fisherman	4		
Independent professional	3	<i>Company size</i>	
Owners of shops/small firms	12	Sole owner	16
Employed professionals	4	1-4 employees	13
General management	5	5-9 employees	10
Middle management	13	10-49 employees	23
Other office employees	14	50-499 employees	23
Non-office employees	14	≥ 500	15
Supervisors	14		
Skilled manual workers	2		
Other manual workers	10		

authority' (e.g. 'choose or change order of tasks or methods of work'). Social support has been operationalized mainly through social aspects (superiors, colleagues and information) as well as material aspects (machines, tools, furniture and premises). Questions concerning physical working conditions and physical workload ('traditional blue collar stressors') were taken together into one scale named 'physical demands'. Every employee was given a scale score summing up scores on each of the questions concerned. Reliability coefficients show a satisfying amount of internal consistency for all four scales (table 2).

3.2.2. 'Strain': *perception of a work-related health and safety risk*: The dependent variable ('strain') was operationalized as the positive answer to the single question: 'Do you think your health or safety is at risk because of your work? (for reasons of parsimony: HSR). Unfortunately the present survey cannot provide a more extensively operationalized outcome variable (see also §5).

3.2.3. *Personal data*: Age and gender of the employee were included as control variables. The newly constructed variables psychological demands, social support and physical demands were re-scaled into three levels (low, middle and high). The cut-off points were chosen to take into account the distribution of these variables in the sample (table 2); the three possible scores on job control (two dichotomous items) were labelled in the same way.

The labelling was done according to generally acceptable meaning: a low score referred to the existence of a small amount (of demands, control or support) and a high score referred to a large amount of these job characteristics being present in the work situation. Correlations between job characteristics suggest that they can be interpreted as separate aspects of the work environment. Psychological demands and physical demands are more closely linked.



Table 2. Single questions and operationalizations of concepts with reliability coefficients, minimum/maximum scores and range.

**(1) Independent variables†**

(a) *Psychological demands* ( $\alpha = .70$ ): (1, all the time; 7, never): (range: 2–14)

1. Does your work involve working at a very hard speed?
2. Does your work involve working to tight deadlines?

(b) *Job control* ( $\alpha = .76$ ): (1, yes; 2, no): (range: 2–4)

1. Do you have the possibility to choose or change your order of tasks or your methods of work?
2. Do you have the possibility to choose or change your speed or rate of work?

(c) *Social support* ( $\alpha = .66$ ): (1, yes; 2, no): (range: 5–10)

1. In order to carry out your work, do you have clear and adequate information?
2. In order to carry out your work, do you have sufficient support from superiors or colleagues?
3. In order to carry out your work, do you have sufficient training and experience?
4. In order to carry out your work, do you have appropriate machines and tools?
5. In order to carry out your work, do you have appropriate premises and furniture?

(d) *Physical job demands* ( $\alpha = .80$ ): (1, all the time; 7, never): (range: 7–49)

1. When at work, are you exposed to noise so loud that you would have to raise your voice to talk to people?
2. When at work, are you exposed to breathing vapours, fumes, dust or dangerous substances?
3. When at work, are you exposed to handling and/or touching dangerous substances or materials?
4. When at work, are you exposed to bad weather conditions such as rain, wind, snow?
5. When at work, are you exposed to heat or cold either indoor or outdoor?
6. Does your work involve painful or tiring positions?
7. Does your work involve carrying or moving heavy loads?

**(2) Dependent variable**

Do you think your health or safety is at risk because of your work? (1, yes; 2, no)

**(3) Personal data**

(a) *Gender of the employee*: (1, male; 2, female): (range: 1–2)

(b) *Age of the employee*: How old are you? (1, 15–24 years; 2, 25–49 years; 3,  $\geq 50$  years)

† Psychological demands:	low (scores > 12)	middle (scores 9–12)	high (scores < 9).
Job control:	low (score 4)	middle (score 3)	high (score 2).
Social support:	low (scores > 6)	middle (score 6)	high (score 5).
Physical demands:	low (scores > 45)	middle (scores 40–45)	high (scores < 40).

### 3.3. Data analysis

The four questions are answered by the following types of analysis:

- (1) Differences in the number of people experiencing their health and safety to be at risk in relation to psychological demands and job control and psychological demands and support are shown by a three-dimensional cross-tabulation (*question 1*). Test on significance by chi-square ( $p < .0001$ ).
- (2) The assessment of separate or combined effects of job characteristics in explaining differences in 'strain', is based on logistic regression analysis (*questions 2 to 4*). This multivariate technique is ideally suited to the situation in which the dependent variable can have only two values. The logistic regression model requires fewer assumptions than other forms of multivariate analysis (Hosmer and Lemeshow 1989): it allows for categorical data and curve-linear relations. Logistic regression produces odds ratios, which represent the chance that the predicted phenomenon

Table 3. Job characteristics: frequencies after rescaling and (Pearson's) correlations in overall sample ( $n = \pm 12000$ ).

	Job control	Psychological demands	Social support	Physical demands
<i>Frequencies</i>				
Low (%)	27	30	19	33
Middle (%)	18	37	20	29
High (%)	55	33	61	38
Total (%)	100	100	100	100
<i>Correlations</i>				
Job control		-.15	.06	-.19
Psychological demands			-.12	.39
Social support				-.21
Physical demands				

occurs under the unique influence (i.e. not reducible to other possible determinants) of a specific variable. The method used is stepwise linear regression. The probability for the entrance and the removal of a variable in the model is .05. The 95 % confidence interval shows the precision with which this chance can be ascertained; when the interval reaches a value below 1.0, the odds ratio is considered to be non-significant. All effects are controlled for gender and age.

#### 4. Results

##### 4.1. HSR in jobs typified in terms of psychological demands, job control and social support

Of all the European employees, 30 % indicated that their health or safety was at risk because of their work. Figure 1 shows this score for employees in jobs characterized by psychological demands and job control (the original 'job demands-job control' model, Karasek 1979).

Employees in jobs characterized by more psychological demands and less job control considered their health or safety to be significantly more at risk. Only 16 % of the employees working in jobs with a large amount of job control and few psychological demands indicated this risk, in contrast to 52 % of the employees at the other end of the

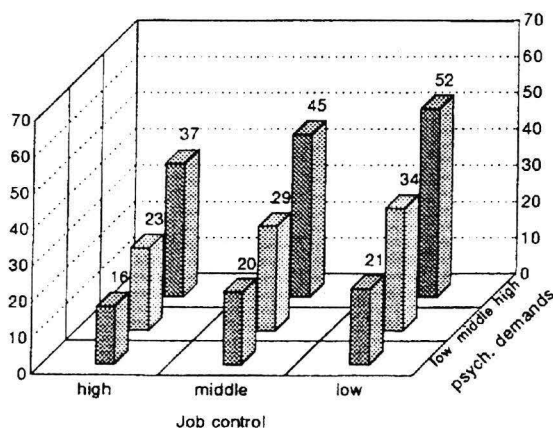


Figure 1. Percentage of employees who considered their health or safety to be at risk in jobs characterized by psychological demands and job control.

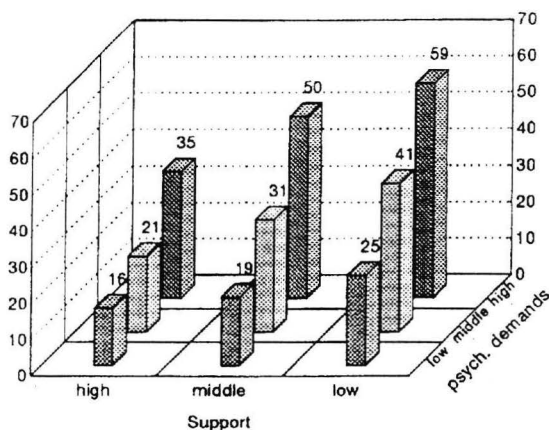


Figure 2. Percentage of employees who considered their health or safety to be at risk characterized by psychological demands and support.

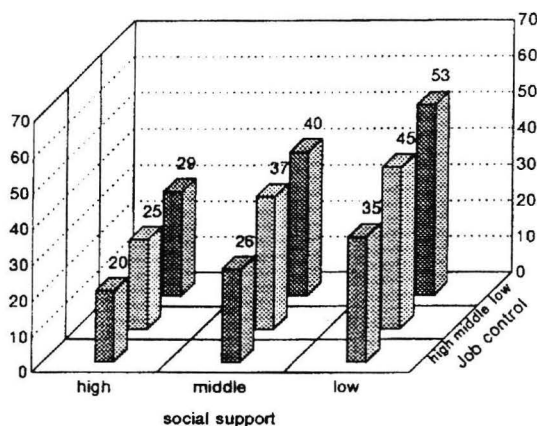


Figure 3. Percentage of employees who considered their health or safety to be at risk in jobs characterized by job control and support.

diagonal (jobs with a large amount of psychological demands and little job control). Figure 2 gives similar percentages using a psychological demands-social support model.

The application of this model yields results which are comparable with those obtained before: the combination of high psychological demands and little social support occurred in a relatively high number of employees who considered their health or safety to be at risk because of their work. The effect of a lack of social support was stronger when psychological demands were higher (§4.2).

Figure 3 shows the third possible relationship between the psychosocial job characteristics: the relationship between job control and social support. There was a significant effect of job control and social support on HSR; the unfavourable effect of low job control was stronger when social support was low.



Table 4. (Combined) effects of psychological demands, job control, social support, gender and age: odds ratios (in bold type) in between 95% confidence intervals in explaining differences in HSR ( $n = 11324$ ).

	Odds ratio in between 95% confidence interval
<i>Psychological demands</i>	
Middle versus low	1.6 - <b>1.8</b> - 2.2
High versus low	3.0 - <b>3.5</b> - 4.5
<i>Job control</i>	
Middle versus high	1.1 - <b>1.3</b> - 1.4
Low versus high	1.6 - 1.7 - 1.9
<i>Social support</i>	
Middle versus high	1.2 - <b>1.4</b> - 1.7
Low versus high	1.6 - 1.7 - 1.9
Gender (men)	1.8 - <b>2.0</b> - 2.2
Age	ns
<i>Interactions:</i>	
Psychological demands $\times$ Job control	ns
Job control $\times$ Social support	ns
Psychological demands $\times$ Job support	significant
<i>The effect of psychological demands (high versus low) when:</i>	
Social support is low or middle	3.1 - <b>3.8</b> - 4.3
Social support is high	2.1 - <b>2.5</b> - 2.9

#### 4.2. Multivariate analysis of the (combined) effects of psychological demands, job control and social support

The second question is concerned with the unique contribution of psychological demands, job control and social support in the 'prediction' of HSR, and the possible effect of all three (second order) interactions between psychological demands, job control and social support.

When compared with the other two independent variables, psychological demands appear to be the most influential determinant. When psychological demands are high, the risk of considering one's health or safety to be threatened by work is more than three times higher than is the case when psychological demands are low. The contribution of job control and social support is at a distinctly lower level. There was a significant interaction between psychological demands and social support: when social support was high, the unfavourable effect of psychological demands on HSR was smaller (figure 2). The low and middle level of social support are taken together, because they have similar effects on the odds ratios of psychological demands.

Gender also played an important role in explaining differences in HSR: being a male employee doubled the chance of HSR. Age made no significant contribution.

#### 4.3. The role of physical demands

The next question is the issue of the effect of physical demands on HSR in comparison with the effects of psychological demands, job control and social support. Table 5 shows the result of the introduction of physical demands into the model. In comparison with the other jobs characteristics, physical demands are by far the most important factor in explaining differences in HSR. The effects of psychological demands, job control and gender are diminished with the introduction of physical demands. Social support and the interaction between social support and psychological demands maintain their position. A second

Table 5. The (combined) effects of physical demands, psychological demands, job control, job support, gender and age: odds ratios (in bold type) in between 95 % confidence intervals in explaining differences in HSR ( $n = 11127$ ).

	Odds ratio in between 95 % confidence intervals
<i>Physical demands</i>	
High versus middle	3.4 - <b>4.2</b> - 4.8
High versus low	7.2 - <b>8.3</b> - 11.3
<i>Psychological demands</i>	
High versus middle	1.2 - <b>1.5</b> - 1.9
High versus low	2.1 - <b>2.6</b> - 3.6
<i>Job control</i>	
Middle versus high	ns
Low versus high	1.1 - <b>1.2</b> - 1.4
<i>Social support</i>	
Middle versus high	1.1 - <b>1.3</b> - 1.6
Low versus high	1.7 - <b>2.1</b> - 2.4
Gender (men)	1.4 - <b>1.5</b> - 1.7
Age	ns
<i>Interactions:</i>	
Psychological demands $\times$ Job control	ns
Job control $\times$ Social support	ns
Physical demands $\times$ Job control	ns
Physical demands $\times$ Social support	ns
Psychological demands $\times$ Social support	significant
Psychological demands $\times$ Physical demands	significant
<b>Models derived from the two significant interactions</b>	
<i>Model 1: Social support is high <math>\rightarrow</math> the interaction between physical and psychological demands is not significant</i>	
Physical demands (low versus high)	6.8 - <b>8.4</b> - 9.7
Psychological demands (high versus low)	1.1 - <b>1.3</b> - 1.6
Job control	ns
<i>Model 2: Social support is low/middle <math>\rightarrow</math> the interaction between physical and psychological demands is significant</i>	
<i>Model 2a: Social support is low/middle and physical demands are high</i>	
Psychological demands (high versus low)	2.5 - <b>2.9</b> - 3.7
Job control (low versus high)	1.3 - <b>1.9</b> - 2.7
<i>Model 2b: Social support is low/middle and physical demands are low/middle</i>	
Psychological demands (high versus low)	1.2 - <b>1.6</b> - 1.8
Job control (low versus high)	1.3 - <b>1.6</b> - 1.8

interaction is significant: the interaction between psychological and physical demands. When physical demands are high, the unfavourable effect of psychological demand is stronger. The middle and low levels of physical demands show no difference in risk perception due to psychological demands and accordingly these levels are combined in the analysis. The interaction between psychological and physical demands is also illustrated in figure 4.

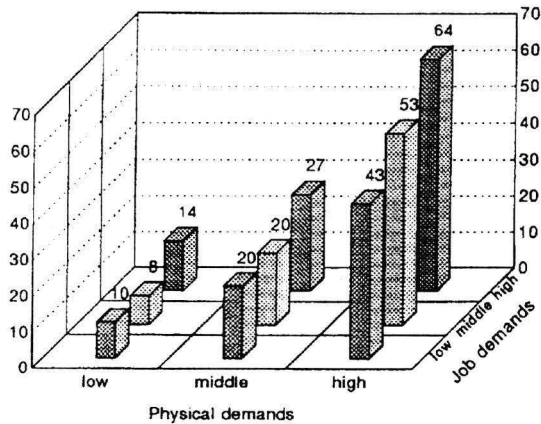


Figure 4. Percentage of employees who considered their health or safety to be at risk in jobs characterized by psychological demands and physical demands.

A further investigation into the interaction between psychological and physical demands, and between psychological demands and social support, was carried out by the use of two models: one in which social support is high (model 1) and one in which social support is at a low or middle level (model 2).

The results show that under the condition of model 1 there is no longer a significant interaction between psychological and physical demands. Model 1 results in a large effect of physical demands and a relatively small effect of psychological demands. There is no significant effect of job control.

In model 2, in which social support is at a low or middle level, the interaction between psychological and physical demands is still significant. This means that again two models must be examined: one in which physical demands are high (model 2a) and one in which physical demands are at a low or middle level (model 2b). When these models are contrasted, the effect of psychological demands on risk perception is considerably larger in the case of high physical demands. In both models job control has a significant effect on risk perception; the effect is stronger in the case of high physical demands.

#### 4.4. Twelve EU member states

The size of the EU sample per country makes it possible to examine the stability of the results found in the previous paragraphs. In a cross-national comparison the (combined) effects of job characteristics on HSR were analysed for each of the 12 EU countries. Table 6 shows the results for 12 EU member states, using a model with psychological demands, job control and social support and the interaction of psychological demands and social support. For reasons of parsimony only the interactions shown to be significant in the overall population are added. For simplicity only the odds ratios comparing high and low levels of determinants are presented.

In all countries except the United Kingdom, psychological demands had a separate, unique effect on risk perception. In all countries except Spain, Portugal and Greece, this was also the case for the effect of social support. In six countries (including the former West and East Germany) job control had a significant effect on risk perception. In three countries the interaction between psychological demands and social support was significant.



Table 6. Effects of (high versus low) psychological demands (PsD), (low versus high) job control (JC), (low versus high) social support (SS) and the interaction between psychological demands and social support on HSR in 12 European countries: odds ratios in between 95 % confidence intervals.

	PsD	JC	SS	Interaction	n
Denmark	1.2-1.6-2.2	1.2-1.9-2.6	1.8-2.6-3.8	ns	1093
United Kingdom	ns	ns	1.1-2.7-2.6	PsD × SS	1089
Ireland	1.9-3.0-4.7	1.1-1.7-2.4	2.1-3.4-5.3	ns	815
W. Germany	3.4-6.1-10.7	1.5-2.2-3.1	2.0-3.4-5.4	ns	1034
E. Germany	1.9-2.8-4.2	1.4-1.9-2.6	1.1-1.6-2.2	ns	1251
Netherlands	1.7-3.0-5.2	1.6-2.7-4.7	2.4-3.9-6.9	ns	816
Belgium	2.3-3.8-5.9	ns	1.3-2.2-3.7	ns	973
Luxembourg	2.3-4.1-7.0	ns	1.9-3.3-5.7	ns	464
France	3.8-5.4-7.8	ns	2.2-3.2-4.5	ns	1053
Italy	2.5-3.8-5.4	ns	1.3-1.9-2.7	ns	877
Spain	1.7-2.4-3.5	ns	ns	ns	888
Portugal	2.0-3.9-8.2	1.4-2.1-3.1	ns	PsD × SS	910
Greece	3.1-8.4-21.8	ns	ns	PsD × SS	856

Table 7. Effects of (high versus low) physical demands (PhD), (high versus low) psychological demands (PsD), (low versus high) job control (JC), (low versus high) social support (SS), the interaction between psychological demands and social support and between physical and psychological demands on HSR in 12 European countries: odds ratios in between 95 % confidence intervals.

	PhD	PsD	JC	SS	Interaction:	n
Denmark	10.3-16.8-26.3	ns	ns	1.5-2.2-3.4	ns	1033
United Kingdom	2.3-3.3-4.8	ns	ns	1.2-1.9-3.0	PsD × SS	946
Ireland	5.0-9.2-16.2	ns	ns	1.8-3.0-5.0	ns	775
W. Germany	17.6-29.4-50.9	1.4-2.6-4.9	ns	1.4-2.2-4.4	ns	924
E. Germany	11.6-19.0-28.5	ns	ns	ns	ns	1103
Netherlands	5.8-9.7-17.3	ns	1.2-2.2-4.0	1.7-3.2-5.2	ns	725
Belgium	3.5-11.3-34.4	1.7-3.6-8.0	ns	2.5-4.0-6.6	PhD × PsD	798
Luxembourg	9.0-18.3-36.8	ns	ns	ns	PsD × SS	431
France	5.9-8.7-13.9	ns	ns	ns	PsD × SS	997
Italy	17.6-12.1-19.5	1.3-2.1-3.4	ns	ns	ns	834
Spain	2.9-4.1-5.7	ns	ns	ns	ns	865
Portugal	8.9-17.1-8.2	ns	1.3-1.9-2.9	ns	PsD × SS	858
Greece	5.8-10.3-17.3	1.6-4.7-12.7	ns	ns	PsD × SS	838

Table 7 shows the results for the 12 EU member states when physical demands are added to the model. This model includes the interactions between psychological demands and social support and between psychological and physical demands, both shown to be significant in the overall population. In all 13 countries (including the former West and East Germany) physical demands were predominant in explaining differences in 'strain'. In six countries social support had a separate effect on risk perception; in four countries this was the case for psychological demands. In five countries psychological demands and social support interacted in their effect on HSR.

This means that in nine countries, psychological demands together with social support—either as two separate or as interacting determinants—played a significant role in estimating risk perception. Job control had a separate effect on HSR in two countries. Only in one country was the interaction between physical and psychological demands significant.

## 5. Discussion

### 5.1. *Limitations of this study*

The importance of the study by the European Foundation for the Improvement of Living and Working Conditions stems from its cross-national character, providing comparable data on various stressors and on a perceived health or safety risk in the working situation. Yet, the study is also characterized by clear limitations. Partly these are the result of any study that aims at high response rates: a limited number of questions. Other limitations are typical for cross-sectional field studies. Statistical correlational designs that relate the work environment characteristics to human health and well-being, face problems with respect to the direction of causality, confounding variables and health- or self-selection (Cook and Campbell 1979, Frese 1985, Frese and Zapf 1988). This study also shares a common weakness of many of these studies, in that it only uses self-report measures in assessing work environment characteristics and health effects. Another limitation is intrinsic to secondary analyses: only those data that are available can be (re)analysed. This especially relates to the operationalization of the dependent variable. This concept could only be operationalized by a single question. Unfortunately the questionnaire did not contain other questions on perceived health or more 'objective' data regarding, for example, sickness, sickness absenteeism or medical treatment. It may be argued that answers to this single question could mix descriptive and evaluative information and may refer to different implicit standards of 'risk', 'health' and 'safety'. It may also be argued that the question 'Do you think your health or safety is at risk because of your work?' favours the association with physical characteristics in the work environment, since employees may primarily relate 'health or safety' to material aspects of work. Nevertheless, although it is without doubt that the operationalization of 'strain' has several shortcomings, it still may be argued that this indicator provides important information with respect to work-related health and safety among European employees. Also, operationalizations of the independent variables may raise some questions. The operationalization of 'job control' primarily relates to decision authority. It is not clear to what extent it also applies to differences in skill discretion. The operationalization of social support does not put emphasis on the socio-emotional components of social support. It is difficult to speculate on the potential effects of these specific operationalizations on differences in HSR.

### 5.2. *Answers to the four questions posed*

What answers can this study provide to the four questions on the relationship between 'health and safety' and the psychosocial and physical work environment?

5.2.1. *Question 1:* The answer to the first question regarding the influence of the psychosocial work environment on risk perception, is a clear 'yes'. As shown in figures 1 to 3, jobs characterized either by high psychological demands and low job control, by high psychological demands and low social support, or by low job control and low social support, offer a significantly higher health and safety risk. This study clearly supports the DC and DCS model hypothesis (1a) that the combination of high psychological demands, low job control and low social support increases psychological and physical strain.

5.2.2. *Question 2:* On the basis of the correlation matrix shown in table 3 it is concluded that the three psychosocial work characteristics can each be interpreted as separate factors. All three psychosocial factors are shown to have a unique effect on risk perception (table 4); this means that such an effect can not be reduced to the effects of any of the other

determinants. From these three determinants of risk perception, psychological demands prove to be the strongest factor. Social support interacts with psychological demands, which means that the favourable effect of social support is stronger when psychological demands are high. In view of the second (interaction) hypothesis in the DC and DCS model, there is moderate support for interactive effects from the independent variables: one of the three interactions was significant (table 4).

5.2.3. *Question 3:* When the physical work environment is included in the analysis, the influence of psychological demands and job control is considerably reduced. Compared to the psychosocial work environment, the physical work environment is clearly the strongest factor in explaining differences in 'strain' (table 5). Social support remains an important factor in this extended model. Social support as well as physical demands interact with psychological demands. Again there is moderate support for the 'Karasek-interaction hypothesis' (two out of six significant interactions) in table 5. However, and in contrast to the 'traditional' expectations, job control does not play a role in these interactions, nor in the interaction in table 4. Further investigation into the nature of these interactions affecting risk perception, suggests that the original Karasek model of 'job demands-decision latitude' is particularly applicable in a blue collar work environment where social support is lacking.

5.2.4. *Question 4:* When the total European dataset is split up between the 12 member states of the European Union, generally speaking the conclusions formulated above are confirmed. From table 6 it follows that with respect to the psychosocial work environment, psychological demands are the strongest factor in relation to risk perception. Again, when physical demands are introduced, these appear to be the most powerful (table 7). Among the countries there are different patterns as to the significance of effects due to social support and job control and to interactions between determinants. These differences can not easily be traced to the geographic position of these countries or their degree of industrialization.

### 5.3. *Theoretical and policy implications*

There seem to be several theoretical and practical implications of these answers. An implication that is of both theoretical and practical relevance is that high psychological demands *per se* are an important risk factor for considering one's health or safety at risk because of work: the potentially negative impact of high psychological demands, even when combined with relatively high levels of social support job control, should not be underestimated.

A second, more theoretically interesting point relates to the question as to whether and in which case the effects of psychological demands, job control and social support simply add up to interact. Tables 6 and 7 show that results in this respect vary from country to country. This may be in favour of both a simple and pragmatic conclusion: 'there is no definite answer to this question'. All three factors appear to be related to risk perception, sometimes these factors interact and sometimes they do not.

Finally, three important policy implications are worth mentioning. The first concerns the large amount of European employees (30%) who consider their health or safety to be at risk because of their work. On an European scale this would be equivalent to almost 42 million people (Paoli 1992). This has implications for both monitoring and prevention. This result underlines the necessity of adequate sectorial, national and international monitoring of risk factors and risk groups as well as of preventive policies and practices. Second, European and national legislation might stimulate monitoring and prevention,

provided that there are general rules on desirable working conditions and on the responsibilities of both employers and employees (Cox 1993, Cox and Cox 1993, Kompier *et al.* 1994).

A third policy implication of this study is that we should be careful not to underestimate the impact of traditional 'blue collar' stressors in European working life (Cox 1993, Cox and Cox 1993, Evans *et al.* 1994). Although it is often stated that we are living in an era of modern information technology, physical working conditions still constitute an important problem in Europe.

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Towards a better understanding

Vocational perspectives and neuromuscular disorders.

ANDRIES, F. C.W.J. WEVERS, A.R. WINTZEN, H.F.M. BUSCH, C.J. HÖWELER,  
A.E.J. DE JAGER, G.W. PADBERG, M. DE VISSER, J.H.J. WOKKE.

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## Vocational perspectives and neuromuscular disorders

F. ANDRIES,<sup>1\*</sup> C.W.J. WEVERS,<sup>1</sup> A.R. WINTZEN,<sup>2</sup> H.F.M. BUSCH,<sup>3</sup> C.J. HÖWELER,<sup>4</sup> A.E.J. de JAGER,<sup>5</sup> G.W. PADBERG,<sup>6</sup> M. de VISSER<sup>7</sup> and J.H.J. WOKKE<sup>8</sup>

<sup>1</sup>NIATNO, Amsterdam, The Netherlands

<sup>2</sup>Academic Hospital Leiden, Department of Neurology, Leiden, The Netherlands

<sup>3</sup>Academic Hospital Rotterdam, Department of Neurology, Rotterdam, The Netherlands

<sup>4</sup>Academic Hospital Maastricht, Department of Neurology, Maastricht, The Netherlands

<sup>5</sup>Academic Hospital of Groningen, Department of Neurology, Groningen, The Netherlands

<sup>6</sup>Academic Hospital of Nijmegen, Department of Neurology, Nijmegen, The Netherlands

<sup>7</sup>Academic Medical Center, University of Amsterdam, Department of Neurology, Amsterdam, The Netherlands

<sup>8</sup>Academic Hospital Utrecht, Department of Neurology, Utrecht, The Netherlands

The present study analyses the actual occupational situation, vocational handicaps and past labour career of a group of about 1000 Dutch patients suffering from a neuromuscular disorder (NMD). On the basis of the likelihood of a substantial employment history and sufficient numbers of patients, four types of NMD were selected: dystrophia myotonica (DM), hereditary motor and sensory neuropathy (HMSN), spinal muscular atrophy (SMA) and myasthenia gravis (MG). Results show that a labour career is in reach of most NMD patients, even for those with severe limitations. It is concluded that physical limitations seem not to be decisive in that respect. The loss of the quality of communication, the loss of mental abilities and the effect of the diseases on the facial expression, as with some DM patients, are also important for chances on the labour market. Though the labour participation of NMD patients tends to decrease after the age of 34, the availability of work adaptations makes it possible to prolong the labour career. Analysis of the actual work situation of NMD patients shows that both disorder-related limitations and work characteristics play an important role in the amount of physical work problems encountered. It is argued that physical labour has to be regarded as generally unsuitable for NMD patients. This has implications for the sort and level of education to be attained by NMD patients. Career counselling as a focus point for the choice of an educational programme may improve labour market opportunities as well as quality of employment of NMD patients. Allowing for and accepting the possible effects of the disorder in the work situation are considered to be important in respect to labour participation and work satisfaction of workers with NMD. Reducing time pressure demands and increasing the freedom to organize one's work, are measures to be given especial consideration.

### Berufliche Perspektiven bei neuromuskulären Störungen

Die vorliegende Studie untersucht die konkrete berufliche Situation, berufliche Handicaps und bisherige Arbeitsbiographie einer Gruppe von rund 1000 niederländischen Patienten mit einer neuromuskulären Störung („neuromuscular disorder“ – NMD). Mit Blick auf die Wahrscheinlichkeit einer substantiellen Berufstätigkeit und ausreichende Patientenzahlen wurden vier NMD-Krankheitsbilder ausgewählt: myotonische Dystrophie, hereditäre motorische und sensible Neuropathie,

\*Address for correspondence: NIATNO, P.O. Box 75665, 1070 AR Amsterdam, The Netherlands

spinale Muskelatrophie und Myasthenia gravis. Die Ergebnisse zeigen, daß Berufstätigkeit für die meisten NMD-Patienten erreichbar ist, selbst für diejenigen mit schwerwiegenden Einschränkungen. Demnach scheinen körperliche Krankheitsauswirkungen in dieser Hinsicht nicht entscheidend sind qualitative Einbußen in der Kommunikationsfähigkeit, nachlassende intellektuelle Fähigkeiten und die Auswirkungen der Krankheit auf den Gesichtsausdruck wie bei manchen Patienten mit myotonischer Dystrophie. Obwohl die Erwerbsbeteiligung von NMD-Patienten nach dem 34. Lebensjahr tendenziell sinkt, kann durch angepaßte Arbeitsgestaltung eine längere Berufstätigkeit ermöglicht werden. Die Analyse der konkreten Arbeitssituation von NMD-Patienten zeigt, daß sowohl krankheitsbezogene Einschränkungen als auch Tätigkeitsmerkmale eine große Rolle für das Ausmaß physischer Probleme am Arbeitsplatz spielen. Es wird dargelegt, daß körperliche Arbeit für NMD-Patienten generell als ungeeignet anzusehen ist. Hieraus ergeben sich Folgerungen für Art und Niveau der Ausbildung, die NMD-Patienten anstreben sollten. Durch gezielte Berufs- und Arbeitsberatung als Angelpunkt der Wahl eines geeigneten Ausbildungsangebots können die Arbeitsmarktchancen wie auch die Qualität der Beschäftigung von NMD-Patienten verbessert werden. Als wichtige Faktoren für Erwerbsbeteiligung und Arbeitszufriedenheit von Beschäftigten mit NMD werden Rücksichtnahme auf die Möglichkeit einschränkender Krankheitsauswirkungen und deren Akzeptanz gesehen. Insbesondere sollten mit Zeitdruck verbundene Anforderungen reduziert und größere Spielräume in der Arbeitsorganisation eingeräumt werden.

#### **Perspectives professionnelles et troubles neuromusculaires**

La présente étude, analyse la situation professionnelle actuelle, le désavantage d'occupation et la carrière professionnelle antérieure d'un groupe d'environ 1000 patients néerlandais souffrant de « difficultés neuromusculaires » désignées sous le sigle « NMD ». Partant de la probabilité d'un passé professionnel riche et d'un nombre suffisant de patients on a sélectionné quatre types de patients souffrant de troubles neuromusculaires: dystrophie myotonique, pathologies neurologiques morrices et sensorielles héréditaires, atrophie musculaire d'origine spinale, myasthénie gravis. Les résultats montrent qu'une carrière professionnelle est à portée de la plupart des patients NMD, même de ceux qui ont des limitations sévères. On en déduit que les limitations physiques ne semblent pas représenter un facteur décisif par rapport à cette question. La perte de la qualité de communication, la perte des habiletés cognitives et les conséquences de la maladie sur l'expression faciale comme cela se produit chez certains patients DM, ont également leur importance pour ce qui concerne les chances sur la marché du travail. La participation au travail des patients NMD tend cependant à décroître après 34 ans, mais les possibilités d'adaptation des postes de travail permettent une prolongation de la carrière professionnelle. L'analyse de la situation du travail actuel des patients NMD montre que les troubles à l'origine des incapacités tout comme les caractéristiques du travail jouent un rôle important dans l'ensemble des problèmes rencontrés dans le travail physique. Il est démontré que le travail physique devrait en général être considéré comme peu approprié pour les patients NMD. Ceci a des conséquences sur le genre et le niveau d'éducation à rechercher pour les patients. L'orientation professionnelle considérée comme vitale lors du choix d'un programme de formation doit tenir compte aussi bien des caractéristiques du marché du travail que de la qualité de l'emploi des patients NMD. Tenir compte et accepter les possibles gênes dans le travail suite aux troubles est important en ce qui concerne la participation au travail et la satisfaction professionnelle des patients NMD. Il faut rechercher la réduction du temps des contraintes et la liberté d'organiser soi-même son travail tout particulièrement.

#### **Perspectivas vocacionales y trastornos neuronmusculares**

El presente estudio analiza la situación ocupacional, las minusvalías vocacionales y la trayectoria laboral pasada de un grupo de cerca de 1.000 pacientes holandeses afectados por un trastorno neuromuscular (TNM). En función de la disponibilidad de un número suficiente de pacientes con una historia laboral substancial se seleccionaron cuatro tipos de TNM: Distrofia Miotónica, Neuropatía



Sensoriomotriz Hereditaria, Atrofia Muscular Espinal y Myasthenia Gravis. Los resultados indican que una carrera laboral está al alcance de la mayoría de los pacientes de TNM, incluso de aquellos con graves limitaciones. La conclusión es que las limitaciones físicas no parecen ser decisivas al respecto. La pérdida de la calidad de la comunicación, la pérdida de las capacidades mentales y el efecto de la enfermedad en la expresión facial, que se produce en algunos pacientes de Distrofia Miotónica, también modifican las oportunidades en el mercado de trabajo. Aunque la participación laboral de los pacientes de TNM tiende a decrecer después de los 34 años, la disponibilidad de adaptaciones del puesto de trabajo posibilita una prolongación de la carrera laboral. El análisis de la situación laboral actual de los pacientes de TNM muestra que tanto las limitaciones relacionadas con el trastorno como las características del trabajo desempeñan un papel importante en el aumento de los problemas de trabajo físico que han de afrontar. Se argumenta que, generalmente, el trabajo físico se ha de considerar inadecuado para los pacientes de TNM. Esto tiene implicaciones para el tipo y el nivel de educación que han de alcanzar estos pacientes. La orientación vocacional, punto focal de la elección de un programa educativo, puede mejorar las oportunidades en el mercado de trabajo así como la calidad del empleo de los pacientes de TNM. El tener en cuenta y el aceptar los posibles efectos limitadores que el trastorno produce en la situación laboral se considera importante en relación con la participación laboral y con la satisfacción en el empleo de los trabajadores con TNM. Reducir la tensión apremiante del tiempo e incrementar la libertad de organizar el propio trabajo, son medidas que deben considerarse especialmente.

**Keywords:** neuromuscular disorders, labour participation, work adaptation, physical problems, work satisfaction

## **Introduction**

In the Netherlands, poverty and social insecurity are kept within limits by a well-organized social security system. Social security benefits for people with an illness or disability are higher than those for the unemployed in general. In recent years, however, access to these higher benefits for the disabled has become substantially more limited. Due to this, chronically ill and handicapped people have to rely more often on unemployment benefits only. At the same time unemployment rates remain high despite recent favourable economic developments. Therefore, the vocational perspectives of the chronically ill or handicapped and the enhancement of their remaining vocational abilities are increasingly important. However, the position on the labour market of the chronically ill or handicapped is unfavourable, as shown in a recent review of literature in the Netherlands (Wevers *et al.*, 1993b). From the few studies on the labour market position of people with specific illnesses it has become clear that their participation in the labour force is low compared to that of the general adult population. In fact, many patients report problems, such as limited access to insurance schemes, discrimination when applying for jobs, physical problems in the workplace, difficulties in contacts with colleagues and superiors and little chance for promotion. Amongst others this has been demonstrated for employees with CARA, epilepsy, Crohn's disease, cancer and multiple sclerosis (Wevers *et al.*, 1993b). Also, employees tend to select applicants more strongly on health than in the past (Ministry of Social Affairs and Employment, 1994; National Committee on Chronically Ill, 1995).

Several studies show that employment is an important determinant in well-being (Warr, 1987). This holds for healthy people as well as for the chronically ill (van Elderen, 1995). Work gives meaning to life, places a person in a social context, is accompanied by higher

self-esteem and, not least, a higher income. The latter is especially important because chronic illness increases living costs (van Agt, 1994). For some diseases it has been found that work or returning to work after unemployment can have a favourable effect on the well-being of the patient as well as in coping with the disease. This was demonstrated for multiple sclerosis and cancer (Barofsky, 1989; Ketelaer, 1993). For the unemployed in general, re-employment can reduce physical, depressive and phobic complaints. Social support, the self-concept and coping strategies appear to improve as well (Kessler *et al.*, 1988). In the Netherlands it has been demonstrated that specific diseases and unemployment are associated with poor health and use of health care facilities. Re-employment has an ameliorating effect (Verkleij, 1991).

Findings on working conditions for employees with a chronic disease are inconclusive. In a large Dutch company (Akzo Coatings) chronically ill workers did not report more complaints about working conditions than their healthy colleagues (Nijboer and Wevers, 1991). However in one other study in the general population (including people with a chronic illness) Timmermans found that in comparison to their healthy colleagues, workers with disabilities were less pleased with their job and found their job to be more physically strenuous or monotonous (Timmermans, 1994). They were altogether less satisfied with their job and with their chances for promotion and income.

In a study on job perspectives of patients with facioscapulohumeral muscular dystrophy (Wevers *et al.*, 1993a), physical problems due to the work environment were reported in almost half of the cases. Only a few work places had been adjusted. In general, the work demanded great effort. Still, 85% of these patients were satisfied with their job (a much higher percentage than was the case in a reference population of healthy individuals); 15% reported a higher performance compared to colleagues, 11% reported a lower performance. Similarly to studies on the employment status of patients with chronic disorders, this study demonstrated that characteristics of the disease are not a decisive factor in remaining at work.

In a study on patients with rheumatoid arthritis, Yelin *et al.* (1980) reported that social and work factors, such as the ability to control one's own work place and activities – the so-called 'job decision latitude' (Karasek, 1979) – have a greater impact on employment status than specific disease characteristics. The crucial role of this kind of job modification was also demonstrated for employees with multiple sclerosis (Kornblith *et al.*, 1986; Gulick *et al.*, 1989; Ketelaer, 1993) as well as for the chronically ill in general (ter Huurne *et al.*, 1990; Andries *et al.*, 1993; Nijboer *et al.*, 1993).

### Aim of the study

The present study analyses the actual occupational situation, vocational handicaps and past labour career of a large group of Dutch patients suffering from a neuromuscular disorder (NMD) (Andries and Wevers, 1996). The study details:

1. the health status, physical and mental disabilities of patients with NMD;
2. the main determinants of the labour force participation of patients;
3. the way in which those who are presently employed experience their working situation, particularly with regard to physical and mental disabilities.

The study aims to contribute to the improvement of vocational guidance and employment prospects of patients with a NMD. It strives to promote a more positive image of patients with a NMD among employers.

## **Methods**

Patients suffering from four types of NMD were selected. The four disorders are:

1. Dystrophia myotonica (DM) (only if onset after the age of 10)
2. Hereditary motor and sensory neuropathy (HMSN) type I and II
3. Spinal muscular atrophy (SMA) type II and III
4. Myasthenia gravis (MG)

These disorders have been chosen for two reasons: (1) subjects were more likely to have a substantial employment history, because of the chronic nature of these disorders and (2) it was assumed that sufficient numbers of patients with these four diseases could be reached by the seven university neuromuscular clinics in the Netherlands and by the Dutch patient organization for people with NMD (VSN).

These NMD are rare. Little is known about their prevalence, but it is estimated to be lower than 10 in 100 000. In comparison, multiple sclerosis in Northern Europe has an occurrence of 75 to 110 in 100 000 population (Ketelaer, 1993; Hassinck *et al.*, 1993). Due to the rarity of the disorders and the variability of the symptoms, the diagnosis is difficult. The university neuromuscular clinics act as important centres for referral. Therefore the files of these seven clinics were used for this study.

The first three disorders (DM, HMSN and SMA) are characterized by a progressive muscle weakness and are genetically determined. MG is neither hereditary nor progressive. These four disorders have one characteristic in common: impairment of movement. They differ with respect to the clinical course and the involvement of specific muscle groups, with possible impairment of ocular movements, facial expressions, articulation, power of the arms or locomotion. In addition, psychological problems like lack of incentive may occur in DM. Table 1 summarizes symptoms and disabilities.

Persons with the aforementioned disorders registered at the seven university clinics in the age range of 16 to 65 – 1299 patients in total – were approached. Affected members of the VSN – 1080 persons – were addressed as well. In this first phase of the project the patients received a form from the clinics and the VSN with which they could give their permission to participate in the project. Duplicate reactions were eliminated. For reasons of privacy the files of the clinics and VSN could not be used (and compared) to calculate the response in phase 1. In phase 2 a questionnaire specific for the kind of work experience indicated on the form was sent to each patient: for those presently working (type 1), for those with previous work experience (type 2) and for those with no work experience at all (type 3). The differences between these three types of questionnaires consist of the amount of (possible) questions on labour experience. Table 2 shows numbers and response figures in phase 2 (completing and sending in the questionnaire). Information from patients with no working experience will not be reported in this article.

The questionnaire used was validated in other research projects within the TNO Vocational Handicap Research Programme (Nijboer and Wevers, 1989, and 1991; Wevers *et al.*, 1993a). For the measurement of health status (psychological, physical, social and

overall well-being) a general health questionnaire was used (RAND-36). It measures health perception on eight multi-item dimensions (Stewart *et al.*, 1988).

Vocational handicaps were assessed by comparing job demands and patient/worker (dis)abilities as well as opinions on working conditions and the social atmosphere at work (only in type 1). Topics referring to job latitude and decision and demands are based on the

**Table 1.** Descriptive data on the four neuromuscular disorders

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**Dystrophia Myotonica (DM)**

Multi-system disorder, mainly affecting skeletal muscle

Onset at any age, most commonly in second decade

More severe clinical course with early onset

Muscle weakness and stiffness mainly affecting facial expression, articulation, hands and feet

Often excessive daytime sleepiness

Tendency to delay activities

Dominant inheritance, variable severity, tendency to affect next generation earlier and more severely

**Hereditary Motor and Sensory Neuropathy (HMSN)**

Impairment restricted to the limbs, mainly motor hands and feet

Onset first or second decade, sometimes later

Main symptom deformity of feet, ill-fitting shoes, weakness of feet with ankle sprains, falls and inability to run

More widespread weakness in severe cases

Dominant or recessive inheritance

**Spinal muscular atrophy (SMA)**

Generalized weakness, mainly shoulder and pelvic girdles, legs more than arms

Onset before 1½ years (type II) or later (type III), steady progression

Many patients wheelchair bound before age 10–20

Inheritance usually recessive

**Myasthenia Gravis (MG)**

Weakness and excessive fatiguability of movements of eyes and/or face, articulation, deglutition and/or other skeletal muscles

Typically increasing weakness with prolonged use of corresponding muscles

Acquired auto-immune disease, may occur at any age, but preferential affliction of young women

Disease often progressive in weeks or months with little tendency to spontaneous recovery

Treatment including removal of thymus and medication, often induces recovery within months or years, complete recovery rare, residual minor symptoms common

Sporadic disease, familial occurrence exceptional

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**Table 2.** Response figures for three types of patients relative to their work experience

	<i>phase 1: permission granted</i>	<i>phase 2: completed questionnaire</i>
type 1 (presently working)	442	414 (94%)
type 2 (previously working)	537	499 (93%)
type 3 (no working experience)	93	83 (89%)
Total	1072	996 (93%)

---

Job Control/Job Demands Model (Karasek, 1979) and the Job Characteristics Model (Hackman and Oldham, 1975). Tables 3 and 4 show operationalizations variables. Reliability coefficients (Cronbachs  $\alpha$ ) show a satisfying amount of internal consistency for all scales. Table 5 presents frequencies of the variables used in multivariate analyses for those retired and for those presently working.

Table 6 gives correlations of all independent variables. It thereby gives information on their possible use as separate variables in multivariate analysis.\*

It is concluded that all independent variables presented in Table 6 can be used as separate determinants. The disorder-related characteristics loss of mobility, loss of power and loss of self-care are more closely interrelated.

### *Data analysis*

The following types of analyses are used:

1. Differences in the scores on health status (RAND-36) are analysed by the use of means (test of significance by T-distribution;  $\alpha < 0.005$ ); differences in the scores on disabilities by a two-dimensional cross-tabulation (Chi square;  $P < 0.005$ )
2. The assessment of effects on labour participation and the evaluation of the present labour experiences are based on logistic regression analysis. The logistic regression model requires fewer assumptions than other forms of multivariate analysis (Pedhazur, 1982); it allows for categorical data and curve-linear relations. Logistic regression produces odds ratios, which represent the chance that the predicted phenomenon occurs under the unique influence (i.e. not reducible to other possible predictors) of a specific variable. The method used is Stepwise (LR). The probability for the entrance and the removal of a variable in the model is 0.05. The 95% confidence interval shows the precision with which this chance can be ascertained; when the interval includes 1.0, the odds ratio is considered non-significant.

## **Results**

### *Health status and disabilities among patients with four types of NMDs*

Table 7 presents means of the nine indicators of the RAND-36 and percentages of patients having specific disabilities. Results are given for each type of disorder. Reference data are available for the scores on the RAND-36 (van der Zee and Sanderman, 1993).

Among patients with NMD, the means of all indicators of the RAND-36 – except 'pain' – are significantly below (i.e. more favourable than) those in a reference population of predominantly healthy people. There are more pronounced differences with regard to 'physical functioning', 'role limitations due to physical functioning' and 'general health perception'.

When means of each of the four types of disorders are compared to the means in the total population of patients, it is shown that:

\*Due to high intercorrelations (approximately  $> 0.80$ ) between independent variables estimates of regression weights can become unstable (multicollinearity) (Pedhazur, 1982).



**Table 3.** Operationalization of variables: categories, recodes and Cronbach's  $\alpha$ 

<i>Item</i>	<i>Categories</i>	<i>Recode</i>	$\alpha$
Gender	1, male; 2, female	–	–
Age	–	1, > 35 2, 35–50 3, > 50	–
Education	8 levels (highest completed form)	1, low (1–3) 2, middle (4) 3, high (5–9)	–
NMD	DM MG SMA HMSN	Dummies	–
Loss of mobility	Trouble: climbing ladder, running, walking, sitting, chair/getting up, bending/coming up, keeping balance, accurate movements leg/feet, accurate movements arms/fingers, squatting/kneeling, taking step up	1, no trouble walking/trouble 1 other activity 2, trouble walking/trouble > 1 other activity	0.88
Loss of use hands/arms	Trouble: accurate movements, fingers/hands, gross movement arms; no = 0 yes = 1; sumscore 0–2	1, score 0 2, score 1–2	0.63
Loss of communication	Trouble: speaking audibly, hearing, seeing, expressing oneself in spoken language; no = 0 yes = 1; sumscore 0–4	1, score 0 2, score 1–4	0.65
Loss of mental abilities	Trouble: concentrating, remembering things longer than 5 minutes, planning/organizing; no = 0; sumscore 0–3	1, score 0 2, score 1–3	0.60
Loss of physical power	Loss: hands/fingers, lower part arms, upper parts arms/shoulders, cervical muscles, lower part legs/feet, upper part legs/feet; 0 = none 1 = bit 3 = lot; sumscore 1–12	1, score 1–5 2, score 6–12	0.80
Dependent on help	Dependent on help: personal care (×6), light work in household (score ×5), heavy work in household (×4), cooking (×3), shopping (×2), transport (×1); 0 = not 1 = partly 3 = fully; weighted sumscore 0–42	1, score 1–7 2, score 8–42	0.83
Work adaptation realized	Work adapted in relation to your sickness or disorder: no = 1 yes = 2		
Work adaptation needed	Need for (further) adaptations: 12 aspects regarding working hours, pace, tasks, material aspects, training etc.: sumscore 0–12	1, score 0–2 2, score 3–12	0.98
No acceptance of disorder in work	Negative remarks superior, negative remarks colleagues, not taken seriously by colleagues due to appearance, no consideration by colleagues, no consideration by superiors, less chances promotion, illness become worse due to disorder: no = 0 yes = 1; sumscore 0–7	1, score 0–2 2, score 3–7	0.70

Period: physical demanding work	1, no period, 2, period with physical demanding work	-	-
Period: mentally demanding work	1, no period, 2, period with psychological demanding work	-	-
Period: unemployment	1, no period, 2, period with unemployment	-	-
Period: shift work	1, no period, 2, period with shift work	-	-
Effect disorder finding a job	Due to disorder problems: finding work, finding a new job; disorder plays role in choice of last job; no = 0 yes = 1; sumscore 0-3	1, score 0 2, score 1-3	0.67
Physical strain	Work demands: gross movements with arms, pushing or pulling something, working in bended/twisted position, bending/twisting upper body; no = 0 yes = 1; sumscore 0-4	1, score 0-2 2, score 3-4	0.76
High strain job	Work demands: time pressure, working to deadlines, working under time pressure and autonomy: in pace of work, order of work, manner of work, amount of work, taking a break	1, max. 1 time pressure/> 2 autonomy 2, 2 time pressure/< 3 autonomy	0.60 0.84
Job content	Work demands: learning new skills, thinking out/performing complicated things, taking decisions yourself, being active with different things, dealing with unexpected events, planning/organizing, taking courses; no = 0 yes = 1; sumscore 0-7	1, score 1-5 2, score 6-7	0.82
Social contacts in job	Work demands: cooperating, working together with others, being able to have a chat, regular discussion on progress, helping each other finish a job; no = 0 yes = 1; sumscore 0-4	1, score 0-3 2, score 4-5	0.60
Adverse physical labour conditions	In work: safety insufficient, fumes, stench, dirt, noise, vibrations, insufficient lighting, bad lighting, heat, coldness, change of temperature, humid air, dry air, lack of fresh air, influence of the weather, dust; no = 0 yes = 1; sumscore 0-18	1, score 0-3 2, score 4-18	0.85
Irregular working hours	Working: long hours, irregular hours, extra hours, in weekend, outside office hours, skipping breakfast; no = 0 yes = 1; sumscore 0-6	1, score 1 2, score 2-6	0.76
Physical work problems	Trouble in daily life and work: standing, sitting, climbing ladder, running, walking, sitting in chair/getting up, bending/coming up again, keeping balance, accurate movements legs/feet, accurate movements arms/fingers, squatting/kneeling, talking step up, reaching out arms, gross movements arms, lifting/carrying things more than 5 kg, pushing/pulling no = 0 yes = 1; sumscore 0-16	1, score 0-1 2, score 2-16	0.90
Job dissatisfaction	All in all, your work suits you well (1), reasonably (2), moderately (3) not well (4)	1, score 1 2, score 2-4	-

Table 4. Operationalization of RAND-36 health indicators and Cronbach's  $\alpha$ 

Item	Operationalization	$\alpha$
Physical functioning	How much limitation during a typical day (1, yes, limited a lot; 2, yes limited a little; 3, no, not limited at all): walking (one block, several blocks, more than a mile); climbing a stair (one flight, several flights); lifting/carrying groceries; bending, kneeling/stooping, bathing/dressing yourself, vigorous activities (like running, lifting heavy objects, strenuous sports); moderate activities (like moving a table, pushing a vacuum cleaner). Sumscore range 0–100; higher = more favourable	0.93
Social functioning	To what extent, in past 4 weeks, has your physical health/have emotional problems interfered with normal social activities with family, friends, neighbours or others? (1, not at all; 2, slightly; 3, moderately; 4, quite a bit; 5, extremely). How much of the time has your physical health or have emotional problems interfered with your social activities (like visiting with friends, relatives) (1, all of the time; 2, most of the time; 3, some of the time; 4, none of the time). Sumscore range 0–100; higher = more favourable	0.71
Role limitations physical	Any of the following problems during past 4 weeks, with your work or other regular daily activities as a result of your physical health? (1, no; 2, yes): cut down the amount of time you spent on work or other activities; accomplished less than you would like; were limited in the kind of work or other activities; had difficulty performing the work or other activities. Sumscore range 0–100; higher = more favourable	0.87
Role limitations emotional	Any of the following problems during past 4 weeks with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? (1, no; 2, yes): cut down on the amount of time you spent on work or other activities; accomplished less than you would like; didn't do work or other activities as carefully as usual; higher = more favourable	0.82
Mental health	How much of the time during the last 4 weeks (1, all of the time; 2, most of the time; 3, a good bit of the time; 4, some of the time; 5, a little of the time; 6, none of the time): have you been a very nervous person; have you felt so down in the dumps that nothing could cheer you up; have you felt calm or peaceful; have you felt downhearted and blue; have you been a happy person? Sumscore range 0–100; higher = more favourable	0.89
Vitality	How much of the time during the last 4 weeks (1, all of the time; 2, most of the time; 3, a good bit of the time; 4, some of the time; 5, a little of the time; 6, none of the time): did you feel full of pep; have you felt calm and peaceful; did you have a lot of energy; did you feel worn out; did you feel tired? Sumscore range 0–100; higher = more favourable	0.81
Pain	Bodily pain during past 4 weeks (1, none; 2, very mild; 3, mild; 4, moderate; 5, severe; 6, very severe). Interference pain during past 4 weeks with normal work (1, not at all; 2, a little bit; 3, moderately; 4, quite a bit; 5, extremely). Sumscore range 0–100; higher = more favourable	0.78
General health perception	How true or false is each of the following statements for you? (1, definitely true; 2, mostly true; 3, don't know; 4, mostly false; 5, definitely false): I seem to get sick a little easier than other people; I am as healthy as anybody I know; I expect my health to get worse; my health is excellent. In general would you say your health is (1, excellent; 2, very good; 3, good; 4, fair; 5, poor). Sumscore range 0–100; higher = more favourable	0.79
Health change	Compared to one year ago, how would you rate your health in general now? (1, much better than one year ago; 2, somewhat better now than one year ago; 3, about the same as one year ago; 4, somewhat worse than one year ago; 5, much worse now than one year ago). Score ranging from 0–100; higher = more favourable	

**Table 5.** Frequencies of variables in total population, those retired and those presently working

	<i>Total</i> ( <i>n</i> = 987)	<i>Retired</i> ( <i>n</i> = 498)	<i>Presently working</i> ( <i>n</i> = 410)
<b>I Independent variables</b>			
1. Personal data			
Women	53%	56%	46%
Men	47%	44%	54%
Age > 35	30%	14%	43%
Age 36-50	42%	42%	47%
Age > 50	28%	44%	11%
Education level low	36%	26%	23%
Education level middle	21%	40%	21%
Education level high	43%	34%	56%
2. Disorder-related characteristics			
SMA	8%	5%	9%
HMSN	24%	19%	32%
DM	27%	31%	23%
MG	35%	39%	30%
Loss of mobility	61%	71%	50%
Loss of use hands/arms	60%	68%	51%
Loss of communication	51%	62%	38%
Loss of mental abilities	29%	35%	22%
Loss of physical power	47%	57%	34%
Dependent on help	32%	44%	17%
3. (Former) work/labour market related characteristics			
Work adaptation realized		22%	42%
Work adaptation needed		30%	27%
No acceptance of disorder in work		32%	30%
Periods with:			
- mentally demanding work		49%	49%
- physical demanding work		50%	41%
- shift work		38%	25%
- unemployment		21%	22%
Effect disorder finding a job		36%	41%
4. Present work characteristics			
Physical strain			27%
High strain job			22%
Job content			41%
Social contacts			68%
Adverse physical labour conditions			18%
Irregular working hours			23%
<b>II Dependent variables</b>			
Retired	50%		
Physical work problems			21%
Job dissatisfaction			39%

1. Patients with SMA indicate more limitations in their physical functioning, though their scores on role limitations due to either physical or emotional problems do not differ significantly.
2. Patients with MG indicate fewer limitations in their physical functioning but they experience, on average, more role limitations due to their physical functioning. Their score on change of health (compared to one year ago) is more favourable.
3. Patients with DM indicate less interference in their social functioning and less role limitations due to physical problems, though their general health perception is relatively unfavourable.

When specific disabilities are taken into consideration, the four types of disorder can be broadly divided into two groups: one mainly characterized by loss of mobility (SMA and

**Table 6.** Correlation matrices of disorder-related characteristics ( $n = 986$ ); (former) work and career-related characteristics ( $n = 908$ ) and present job characteristics ( $n = 410$ )

Disorder-related characteristics										
Disabilities	1	2	3	4	5	6	7	8	9	10
1. Loss of mobility	–	0.31	0.43	0.42	–0.02	–0.02	–0.04	–0.30	0.16	0.28
2. Loss of use hands/arms		–	0.35	0.35	0.16	0.14	–0.02	–0.07	0.14	0.03
3. Loss of physical power			–	0.39	0.07	0.08	0.08	–0.17	0.19	–0.02
4. Dependent of help				–	0.16	0.10	0.03	–0.02	0.17	–0.10
5. Loss of communication					–	0.34	0.29	0.12	–0.21	–0.26
6. Loss of mental abilities						–	0.26	–0.06	–0.12	–0.11
7. DM							–	–0.45	–0.18	–0.34
8. MG								–	–0.22	–0.34
9. SMA									–	–0.16
10. HMSN										–
(Former) job and career-related characteristics										
Periods with:	1	2	3	4	5	6	7	8		
1. Physically demanding work		–	0.13	0.35	0.08	0.06	0.02	0.17	0.09	
2. Psychologically demanding work			–	0.13	0.05	0.06	–0.03	0.15	0.09	
3. Shift work				–	0.08	0.03	0.04	0.09	0.02	
4. Unemployment					–	0.30	–0.03	0.17	0.09	
5. Effect of disorder finding job						–	–0.24	0.17	0.22	
6. Work adaptation realized							–	–0.14	–0.26	
7. Work adaptation needed								–	0.28	
8. No acceptance of disorder									–	
Present job characteristics										
	1	2	3	4	5	6	7	8	9	
1. Work adaptation	–	0.18	0.25	–0.13	–0.11	0.00	0.02	–0.16	0.01	
2. Work adaptation needed		–	0.18	0.15	–0.07	–0.01	0.18	0.06	0.30	
3. No acceptance disorder			–	–0.02	–0.07	0.05	0.09	–0.13	0.17	
4. High strain job				–	0.03	–0.04	0.18	0.14	0.10	
5. Job content					–	0.40	–0.02	0.38	–0.04	
6. Physical strain						–	0.01	0.15	0.02	
7. Social contacts							–	0.19	0.18	
8. Irregular working hours								–	0.06	
9. Adverse physical labour conditions									–	



HMSN) and one mainly characterized by loss of quality of communication (DM and MG). For SMA patients loss of power, mobility and the use of hands and fingers is an almost general feature. This is underlined by the fact that 72% of them are partly or complete dependent on the use of a wheelchair.

The data on specific physical and mental disabilities will again figure in the analysis of labour participation and in the analysis of the way in which the actual working situation is perceived. The data on the quality of health (RAND-36) provide a background to the results on labour participation of patients with these NMD but will not be used in further analyses regarding the working situation. After all, on the basis of the available cross-sectional data it cannot be decided whether the perceived health status is the cause or the result of having a job or not having a job.

#### *Estimating determinants of retirement*

As in the overall Dutch population, three personal characteristics are found to be related to labour participation of patients with a NMD: gender, age and level of education. When compared to male labour participation in the overall Dutch population, male NMD patients show a notable drop in their labour participation from the age of approximately 34 years onwards. Between 20 and 30 years, the labour participation of NMD patients increases from 45% to 75% as compared to 66% to 95% in the overall population. While in the

**Table 7.** Quality of health indicators (means: RAND-36) and types of disabilities (as percentages) in neuromuscular disorder

	DM (%) (n = 254)	MG (%) (n = 326)	SMA (%) (n = 77)	HMSN (%) (n = 227)	Total (%) (n = 884)	Reference <sup>a</sup> (n = 1063)
<b>RAND-36 indicators<sup>b</sup></b>						
Physical functioning	53	62*	21*	48	52*	82
Social functioning	80*	71	77	73	74*	87
Role limitation (physical)	71*	55*	67	62	62*	79
Role limitation (emotional)	84	76	83	78	79*	84
Mental health	75	74	77	72	74*	77
Vitality	49	54	60	54	54*	67
Pain	78	83*	77	72*	78	79
General health perception	44*	52	56	57*	52*	73
Health change	35	52*	39	40	43*	52
<b>Disabilities: loss in<sup>c</sup></b>						
Physical power	54	36*	80*	45	47	
Mobility	58	41	90*	84*	61	
Use of hands/arms	54	59	84*	63	60	
Communication	76*	60*	15*	28*	48	
Mental abilities	49*	25	10*	20*	29	
Dependent on help	37	27	66*	26	32	

<sup>a</sup> The reference group consists of a random sample (n = 1063) drawn from the population register of a medium sized town in the Netherlands (Van der Zee and Sanderman 1993).

<sup>b</sup> Asterisk (\*) indicates significance (t-distribution; alpha < 0.005); means per disorder related to overall mean and overall mean related to mean in reference group.

<sup>c</sup> Asterisk (\*) indicates significance (Chi-square distribution; alpha < 0.005); means per disorder related to overall mean and overall mean related to mean reference group.

**Table 8.** Level of education among working and retired patients with a neuromuscular disease compared to the overall Dutch population, working and unemployed

Level of education <sup>a</sup>	Patients		Overall Dutch population	
	Working (%) (n = 409)	Retired (%) (n = 498)	Working (%) (n ± 5.7 million)	Unemployed (%) (n ± 481 000)
Low	23	47	25	38
Middle	51	39	51	44
High	26	14	24	17

<sup>a</sup> For reasons of comparability levels of education are defined differently from those in Table 3; low: elementary level or lower vocational training; middle: general education at a middle or higher level and vocational training at a middle level; high: vocational training at a higher level or university.

overall population this rate remains at approximately 90% until the age of 54, in the group of male patients this percentage drops to a level of about 60%.

In the overall female population labour participation is generally lower than among men except in the age category between 25 and 29. It shows a more rapid decrease of labour participation after the age of 29. With female NMD patients, labour participation follows this overall trend with 53% of the women working until age 34 against 58% in the overall female population. After age 34, labour participation of female NMD patients drops steeply to 34% as compared to 54% in the overall population. Between the age of 40 to 44 this percentage rises again to 47% as compared to 55% in the overall population. After age 44 the percentage drops to 20%, while in the overall population the decrease is more gradual.

A third important factor influencing labour participation – next to age and gender – is educational level. Table 8 shows that the educational levels of the working NMD patients resemble those of the overall Dutch labour force; the educational level of unemployed NMD patients is at a somewhat lower level than among Dutch unemployed in general (Statistics Netherlands, 1994).

On the basis of the data regarding the actual retirement age of male and female NMD patients, the probable length of the labour career of the patients still working in 1994 can be estimated. This estimation results in a probable total labour career of 31 years for men and 26 years for women, whereby the considerably higher educational level of those presently working is not taken into account.

To estimate the effects of disorder and work-related characteristics on retirement from the job, unique effects – not reducible to other effects – were calculated. In this analysis gender, age and level of education were also taken into account. Table 9 shows the results of this calculation.

Next to the considerable effects of age, gender and education as already shown before, all disorder-related characteristics except loss of physical power play a role determining retirement. The effect of loss of physical power is already accounted for through the effects of loss of mobility and loss of the use of hands and arms. Apart from these disorder-related characteristics, patients with SMA and those with HMSN have better chances for a prolonged working career.

None of the characteristics related to the labour career have a separate effect on retirement except the presence (for those working) or absence (for those retired) of work adaptations. Work adaptations consist mainly of possibilities to reduce time pressure

demands: working at a slower pace, for less hours and being able to organize work more freely.

The risk of early retirement is four times greater with an unadapted workplace. Asked whether they could have continued if their work had been adapted, of those who retired from work in the last 10 years, 40% replied in the affirmative.

*Physical work problems and an overall evaluation of the job*

Two aspects in the evaluation of the job of patients presently working are analysed:

1. Disorder-related physical work problems
2. An overall evaluation of the job

**Table 9.** Personal data and disorder-related and (former) work/labour characteristics predicting retirement from the job among persons with neuromuscular disorders in the age up to 55 years ( $n = 712$ ): odds ratio with confidence intervals between brackets

	Odds ratio
1. Personal data	
Gender: women	3.3 (2.2-5.1)
Age: > 35 (reference category)	-
30-50	2.6 (1.6-4.1)
> 50	4.8 (2.1-11.7)
Level of education:	
low	2.5 (1.6-4.1)
middle	NS
high (reference category)	-
2. Disorder-related characteristics	
SMA	0.3 (0.1-8.1)
HMSN	0.3 (0.2-0.6)
DM	NS
MG	NS
Dependent on help	2.2 (1.3-3.8)
Loss of mobility	2.7 (1.7-4.4)
Loss of physical power	NS
Loss of communication	1.7 (1.1-2.7)
Loss of mental abilities	1.8 (1.1-2.9)
Loss of use hands/arms	1.7 (1.1-2.6)
3. (Former) work/labour market related characteristics	
Work adaptations realized	0.2 (0.1-0.4)
Work adaptation needed	
No acceptance disorder	NS
Effect disorder finding job	NS
Periods with:	
mentally demanding work	NS
physically demanding work	NS
shift work	NS
unemployment	NS

Loss of mobility and loss of the use of hands and fingers are determinants of physical work problems (Table 10). Of the job-related characteristics, physical strain and work adaption, wanted as well as realized, are related to physical work problems. The overall evaluation of the job is not related to characteristics of the disorder. Of the job-related characteristics, mental and – especially – physical strain, lack of social contacts, being in want of a work adaption and a poor acceptance of the disorder in the work situation, are determinants of a less favourable evaluation of the job.

### Discussion

The results from this study among NMD patients show that a labour career is in reach of NMD patients, even for those with severe limitations. From data gathered in this study it is estimated that for NMD patients presently working, a labour career of 31 years duration (male patients) and 26 years duration (female patients), is quite probable.

Labour participation of NMD patients decreases more rapidly than in the overall population after the age of about 30 to 35. A temporarily drop in labour participation among women between 30 and 35 can possibly be attributed to a period of childbirth and the extra burden caused by the disorder.

**Table 10.** Personal data and disorder-related and work-related characteristics predicting disorder-related physical work problems and a negative job evaluation among employees with neuromuscular disorders ( $n = 336$ ): odds ratios with confidence intervals between brackets

	<i>Physical work problems Odds ratio</i>	<i>Negative job evaluation Odds ratio</i>
1. Personal data		
Gender	NS	NS
Age	NS	NS
2. Disorder-related characteristics		
SMA	NS	NS
HMSN	NS	NS
DM	NS	NS
MG	NS	NS
Dependent on help	NS	
Loss of mobility	9.5 (4.8–16.9)	NS
Loss of physical power	NS	NS
Loss of communication	S	NS
Loss of mental abilities	NS	NS
Loss of use hands/arms	4.0 (1.8–9.6)	
3. Work-related characteristics		
Work adaptations realized	2.1 (1.2–3.6)	NS
Work adaptation needed	2.6 (1.4–4.6)	2.9 (1.8–5.1)
Physical strain	4.7 (2.3–8.6)	2.1 (1.2–3.9)
High strain job	NS	2.0 (1.2–3.5)
(Lack of) social contacts	NS	2.0 (1.2–3.2)
(Lack of) job content	NS	NS
Irregular working hours	NS	NS
Adverse physical labour conditions	NS	NS
No acceptance disorder	NS	2.4 (1.4–3.9)

Between the four types of NMDs the amount and the type of limitations as well the perceived health status differ considerably. Though most types of limitations due to NMD diminish chances to continue a labour career, it is concluded that physical limitations seem not to be decisive in that respect. This fits in with conclusions drawn by Yelin *et al.* (1980) regarding patients with rheumatoid arthritis. In this study SMA patients, who are almost all confronted with severe physical limitations, have even better than average chances to continue working. Their early experience with limitations caused by the disease could well be an advantage in the process of adaptation to the special demands imposed by the symptoms of the disease. Those who acquire a NMD at an older age probably have more difficulty in adapting, being forced to deviate from already formed patterns of behaviour. It can be argued that the loss of the quality of communication, the loss of mental abilities and the effect of the diseases on the facial expression, as with some DM patients, are also important for chances on the labour market.

Though the labour participation of NMD patients tends to decrease after the age of 34, the availability of work adaptations makes it possible to prolong the labour career. Many of those who stopped working in recent years indicate that they could have continued working if their job had been adapted to their handicaps.

Analysis of the actual work situation of NMD patients shows that both disorder-related limitations as well as work characteristics play an important role in the amount of physical work problems encountered. It can be argued that physical labour has to be regarded as generally unsuitable for NMD patients. This has implications for the sort and level of education to be attained by NMD patients. Career counselling as a focus point for the choice of an educational programme may improve labour market opportunities as well as quality of employment of NMD patients. Work adaptations may prolong the working career of NMD patients, but the implementation of work adaptations seems not to be without problems. Results suggest that adapting the workplace for persons with a NMD requires more effort and should consist of measures that fit personal requirements. Adaptations aimed at the reduction of time pressure are in great demand: working at a slower pace, for less hours and being able to organize the work more freely.

The overall appreciation of the job is not directly linked to disorder-related characteristics. This suggests that work, even for those with serious physical and other disabilities, can be as rewarding as for persons without (serious) disabilities. There is however an indirect effect of disorder-related characteristics: employees who feel a need for (further) adaptations in the workplace and those experiencing negative (social) effects on the workplace due to their disorder, are less satisfied with their job. Allowing for and accepting the possible limiting effects of the disorder in the work situation are considered to be important in respect to labour participation and work satisfaction of workers with NMD. Reducing time pressure demands and increasing the freedom to organize one's work, are measures to be considered especially.

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Towards a better understanding

The use of computers among the workers in the European Union and its impact on the quality of work.

ANDRIES F. & SMULDERS P.G.W.

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# The use of computers among the workers in the European Union and its impact on the quality of work

FRANK ANDRIES, PETER G. W. SMULDERS and STEVEN DHONDT

TNO Work and Employment, PO Box 718 2130, AS Hoofddorp, The Netherlands

**Abstract.** For many people it is impossible to imagine working life today without a computer. What the increase of the use of computers means for the quality of the work, is still under discussion. The object of this study is to show the recent developments (1992-2000) in the use of computers among the working population in the European Union and its impact on the quality of working life. The data used for these analyses were collected on a five-year basis by means of a questionnaire. Results show that the use of computers has increased between 1992 and 2000. The increase in computer use is almost completely the result of developments within white-collar occupations. In general, the use of a computer results in more qualified work and less physical strain. However, those who work with a computer permanently, clearly show more signs of physical and mental strain than those who use the computer only part of the time. This could mean that adding other tasks than computer tasks could improve the working conditions of those using the computer permanently. These results suggest that the increase of the use of computers will further improve the quality of work except when one neglects the dangers connected with a permanent use of computers.

## 1. Introduction

Computers have become part of our daily life, whether at home or at work. Things can be done more easily and more effectively with a computer, but has it made the work easier and more challenging? To answer this question, we will investigate the relation between computer use at work and the quality of working life. The quality of working life is here defined by the number of qualifications required, the lack of unfavourable physical conditions, the degree of time pressure and the possibility of job control. Not only the work itself is considered, but also the setting in which the job is performed. In this way, indirect effects of the degree of information technology on job characteristics in differ-

ent sectors are taken into account. After all, it can well be that the degree of information technology within the sector influences the relation between computer use and the quality of the job.

We will try to answer three questions. The first one is concerned with developments in the use of computers for work purposes in the European Union between 1992 and the year 2000. Are there differences between male and female workers, younger and older workers and employees in different occupations? The second question is whether the time spent working with a computer has a relation with job characteristics. What does working with a computer mean in terms of the qualifications needed for the job and for mental and physical strain? The third question is whether job characteristics of computer workers differ between sectors in which computer use is more or is less common. Computer use is seen as an indication of the degree to which information technology has been introduced in these sectors.

The issue of the possible influence of human-computer interaction on the quality of working life has recently been illuminated by several authors (Burris 1989, Zapf 1995, Medcof 1996, Carayon 1997, Smith 1997, Rantanen 1999, Bijleveld *et al.* 2000, Smulders 2000). The results of the studies are in most cases inconclusive. General upgrading and downgrading effects have been found, as well as a splitting up in upgrading and downgrading effects. High work demands, lack of job control and unfavourable physical characteristics are mentioned in connection to computer jobs. However, there are problems with the interpretation of results because of interrelated effects due to the heterogeneity of computer jobs, the lack of an adequate reference group and the strong effects of the amount of

time spend behind the computer. For this study we made use of a large dataset in which detailed information on the intensity of computer use in a wide variety of jobs and sectors is available.

## 2. Methods

The European Foundation for the Improvement of Living and Working Conditions gathered data on the working conditions of European workers since 1992 (Paoli 1992, 1997, Merli  and Paoli 2001). The surveys that were conducted in 1992, 1996 and 2000 are representative for the workforce in Europe in those years. The number of countries in the European Union has increased from 12 to 15 since 1992. The sample size per country increased since 1996 from approximately 1000 respondents for each country to 1500 in 2000. Therefore, the overall sample size for the three surveys ranges from 11 237 (in 1992), 14 869 (in 1996) to 21 628 in 2000. Due to the fact that after 1992 the questionnaire was drastically revised, only the data from the surveys of 1996 and 2000 can be used for the comparison of occupations and questions with regard to the quality of working life. Since some of the indicators on the quality of working life can have a different meaning for the self-employed, only the data of employees are taken in consideration. Karasek (1979) has introduced a model that states that jobs typified by high time pressure demands and little job control to effectively regulate these demands will cause mental strain. Eventually, this combination can result in health problems. Since the introduction of this model a lot of publications on the basis of this or more

extensive models have shown its value for the effective restructuring of jobs (Sauter *et al.* 1992). Therefore, we created an additional variable, based on the combined effects of both time pressure and job control. Table 1 shows the characteristics of variables and scales used to operationalize job characteristics. The reliability (Cronbach  $\alpha$ ) of the four scales is considered sufficient for their use in the analyses

## 3. Results

### 3.1. Trends in computer use between 1992 and 2000

Table 2 shows the development of the use of computers among workers in the European Union between 1992 and 2000. There is a more substantial increase in the use of computers on the work floor between 1992 and 1996 than in the following five years. Between 1992 and 1996, the biggest shift was in the

Table 2. The use of a computer on the work floor in 1992, 1996 and 2000 (in percentages).

Computer use:	1992	1996	2000
Never	58.9	54.1	49.8
Almost never	10.8	9.0	9.8
Quarter to three quarter of the time	16.6	20.1	21.1
Almost all of the time	6.1	6.6	7.4
All of the time	7.6	10.1	11.9
Total	100	100	100
<i>n</i>	11 237	14 869	21 628
Mean (1–7)	2.3	2.6	2.7

Table 1. Computer use and indicators for quality of working life: construction and reliability.

Variables	Items	#	Range	Recode	Cronbach alpha
Computer use	Amount of time working with computer, pc or mainframe	1	From 1 to 7: never to all of the time	Separate: a quarter, half and three quarter of the time	
Unfavourable physical conditions	Amount of time exposed to: painful posture/heavy work/repeated movements	3	From 1 to 7: never to all of the time	Sum score z-score: 0–100	0.69
Time pressure	Amount of time exposed to: work at high speed/deadlines	2	From 1 to 7: never to all of the time	Sum score z-score: 0–100 high (> 25)	0.65
Little job control	Not free to choose: order of work/method of work/ speed of work	3	1–2 yes/no	Sum score z-score: 0–100 high (> 0)	0.64
Qualifications required	Meet standards/judge quality/ solving problems/work is not monotonous/complicated tasks/learning new things	6	1–2 yes/no	Sum score z-score: 0–100	0.74

direction of two categories: more permanent use and more use of a computer for  $\frac{1}{4}$  to  $\frac{3}{4}$  of the time. And again after 1996, there was a tendency towards more permanent use.

Figures 1 and 2 show differences between men and women and between two age groups: under 35 and 35 years and older. The increase in computer use between 1992 and 1996 is slightly higher among women than among men. After 1996, the balance between men and women has not shifted. Workers over 34 years have almost closed the gap with their younger colleagues. After 1996, the overall increase in computer use is mainly caused by an increase in computer use among workers over 34 years.

Figure 3 shows the development of the use of a computer permanently among younger and older men and women. As we saw earlier, the biggest increase since 1992 is in the category 'all of the time'. Figure 3 shows that the increase is more prominent among women and especially among younger women. Among women under 35 years, 15.9% use the computer all of the time.

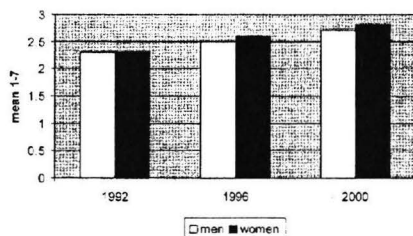


Figure 1. Computer use (mean) and gender in 1992, 1996 and 2000.

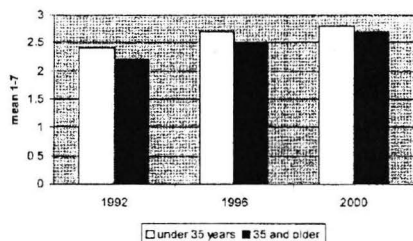


Figure 2. Computer use (mean) for two age groups in 1992, 1996 and 2000.

In what kind of occupations are computers being used and which occupations show an increase in computer use? Figure 4 shows the averages of computer use for nine types of occupations in 1996 and 2000. The increase of the use of computers among employees is entirely the result of an increase in specific occupations such as managers, professionals, technicians and clerks. The use of the computers among workers in elementary occupations in 2000 is just as limited as in 1996. Among service personnel and farmers and fishers the use of computers even diminished after 1996.

### 3.2. Computer use and the quality of working life

Four characteristics of the work situation of employees are considered: unfavourable physical conditions, time pressure in combination with little job control and the degree of qualifications required for the job. A comparison is made for five types of computer use: never using the computer, almost never,  $\frac{1}{4}$  to  $\frac{3}{4}$  of the

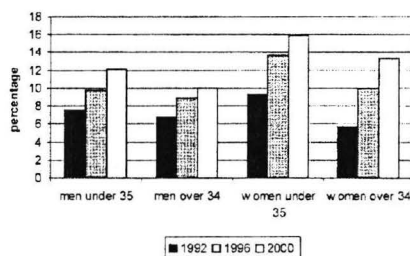


Figure 3. Percentage of workers that uses the computer *all of the time* among younger and older men and women in 1992, 1996 and 2000.

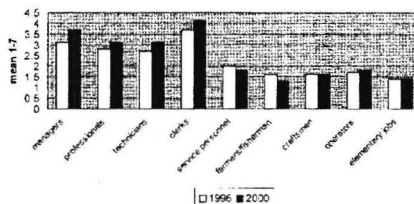


Figure 4. Computer use (mean) and occupations in 1996 and 2000.

time, almost all of the time and all of the time. Figure 5 shows the results for unfavourable physical conditions. More unfavourable physical conditions are found when workers never or almost never use a computer. Compared to other the other categories of computer users, physical conditions are worse for employees using a computer all of the time. Moreover, there is a marked difference between those using the computer *almost* all of the time and those using the computer all of the time. The overall worsening of physical working conditions is mostly due to developments in jobs where there is little or no use of computers. For those who never use a computer or only for a limited amount of time, physical conditions have deteriorated after 1996.

Figure 6 shows results for conditions, which will cause mental strain: time pressure and little job control. The relation between computer use and a situation of time pressure and little job control is U-shaped. This means that those never working with a computer and those working with a computer all of the time are in an almost equally unfavourable situation. Between 1996 and 2000 the balance between the two has shifted somewhat: the number of jobs with time pressure and little job autonomy has increased for workers who never use a

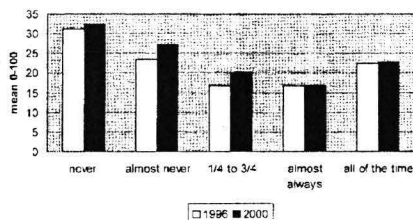


Figure 5. Computer use and unfavourable physical conditions (mean) in 1996 and 2000.

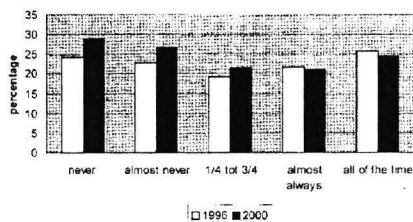


Figure 6. Computer use and percentage of jobs with time pressure/little job control in 1996 and 2000.

computer and has decreased for those using the computer all of the time.

Figure 7 gives information on the qualifications required in relation to computer use. From the results of figure 6, it becomes clear that those working with a computer for any amount of time need more qualifications than those who never work with a computer at all. The amount of qualifications required in the category 'all of the time' is at least as high as in other jobs where a computer is used. Again, the overall change for the worse is mainly found in jobs with little or no use of a computer.

### 3.3. Computer use and quality of working life in different sectors

Is the relation between computer use and the quality of working conditions dependent on the type of sector in which one works? Three clusters of sectors are distinguished: sectors in which the *density* of computer use is high, low or moderate. The allocation to a cluster was done on the basis of the averages in computer use in the different sectors. To increase the possibility for the comparison of sectors, the data of 1996 and 2000 were combined. Table 3 gives information on the degree of computer use in 10 different sectors and shows the clustering of sectors based on the degree of computer use within the branch. Two sectors are clearly ahead in the amount of computer use: finance and real estate business. Three other sectors are clearly falling behind: construction, agriculture and hotels/restaurants. The other sectors are somewhere in between.

The analyses in which working conditions are related to the amount of computer use, are repeated for these three clusters of sectors. Figures 8, 9 and 10 show the results for physical conditions, qualifications required, and time pressure and job control. In the case of physical conditions and the amount of qualifications required, the patterns for the three clusters of sectors are

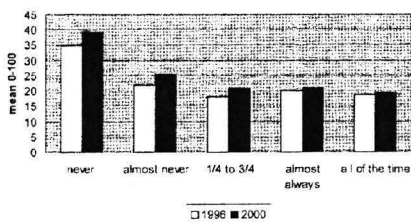


Figure 7. Computer use and little qualification required (mean) in 1996 and 2000.



Table 3. Allocation of sectors to three types of computer density: high, moderate and low based on the mean of computer use (1-7) in sectors.

Sectors:	n	High	Moderate	Low
Finance	1138	5.2		
Real estate business	1721	4.1		
Public utilities	353		3.5	
Public sector	3226		3.3	
Transport	2092		2.9	
Manufacture	5746		2.6	
Sale/retail	4268		2.6	
Social sector	7715		2.5	
Construction	2024			2.0
Agricultural	583			1.9
Hotels/restaurants	1250			1.6

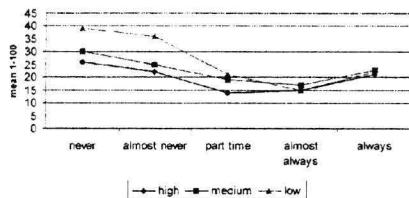


Figure 8. Computer use and unfavourable physical conditions (mean) in sectors with a different computer density.

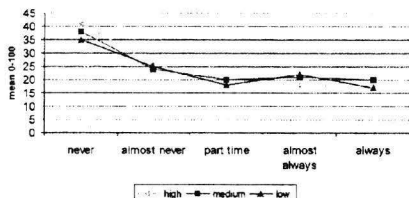


Figure 9. Computer use and little qualification required (mean) in sectors with a different computer density.

quite similar. Figure 8 shows that physical conditions differ between clusters, but only when there is no use or little use of computers. In that case physical conditions are worse in the cluster with low computer density. In all other situations, the pattern in the three clusters is quite similar.

Figure 9 shows that there is no difference between the three clusters in the way computer use and the amount of qualifications required, are related. However, this is not the case for time pressure and little job control.

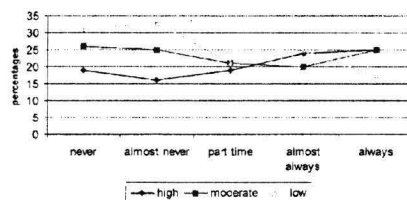


Figure 10. Computer use and percentage of jobs with time pressure/little job control in sectors with a different computer density.

Figure 10 shows that in this case each cluster has its own pattern. In the cluster with low computer density, the situation is unfavourable for those who never or almost never use a computer. On the other hand, the most favourable situation is found for those using a computer all of the time. In the cluster with much use of computers, conditions for mental strain are generally favourable except when employees use their computer all of the time or almost all of the time. In the cluster with moderate computer density, conditions for mental strain are relatively unfavourable when there is no use of computers. It is however also unfavourable when the computer is used all of the time. More computer density in the sector, means more time pressure and less job control for those who use a computer for (nearly) all of their working hours.

#### 4. Discussion

Now that half of the work force in the European Union uses a computer for any amount of time, the question of what the computer brings in terms of the quality of working life is relevant more than ever. Does it make the computer work easier and does it offer a challenge, or does it lead to routine jobs that cause mental and physical strain? This article focuses on three aspects: the actual development in the use of computers in the countries from the European Union, the relation between the amount of computer use and the quality of work and the influence of the degree of information technology in sectors on this relation. The data on which the results are based are unique. They not only cover the opinions of a large and representative sample of the employees of 15 countries of the European Union, but they also offer a time perspective for the last eight years of the 20th century.

Between 1992 and 2000, the amount of people using a computer at work has increased from 41% to 50%. About half of the European workers have access to

computers at work. In recent years (1996–2002), the increase in computer use was smaller than between 1992 and 1996. The increase of computer use is relatively high among women and among employees over 34 years. Thus, the older workers are closing the gap that existed before with workers under 35. In comparison to 1992, the amount of people working with a computer all of their working hours has increased most. These are more often younger workers of under 36 and especially younger women.

The increase of the use of computers since 1996 is almost completely the result of a more intense use of computers among workers in white-collar jobs. This partly explains why working with a computer in most cases means relatively qualified and challenging work. Workers who spend *all of their time* working with a computer are also doing highly qualified work but they are clearly more exposed to conditions that will cause physical and mental strain, as found earlier by for example Smith *et al.* (1981) and Carayon-Sainfort (1992). In our study, however, there is a marked difference in the working conditions of those who work with their computer all of the time and those who work with the computer almost all of the time. This suggests that adding other than computer tasks can improve the working conditions of those now using the computer permanently.

It can be argued that using a computer all of the time, means less qualified work. This would then be the reason for inferior working conditions. However, levels of qualification are almost the same for all types of computer use. The question is raised whether this holds true for sectors where information technology is common or just barely introduced. Could the setting in which one works with a computer be responsible for different levels of qualifications required and, thus, for working conditions that produce physical and mental strain? Child and Loveridge (1990) substantiate that the organizational culture of a country or sector influences the way in which technology determines the quality of work. Three clusters of sectors were distinguished: those where computer density is high, low or moderate. Results show that, in all clusters, the more time one spends working with a computer, the higher the level of qualifications required. The relation between computer use and unfavourable physical conditions is also similar in all clusters. There is one exception and that is when time pressure and little job control are related to computer use. In sectors where many employees work with computers, permanent use or almost permanent use of the computer means relatively often work with time pressure and little control over the work process. There is a clear exception for sectors where computer use is scarce. In these sectors, permanent use of the computer

seems to shield employees from the type of these conditions, which will cause mental strain. So, more computer density in the sector means more time pressure and less job control for those who use a computer for (nearly) all of their working hours. Especially in sectors where information technology has found a foothold, preventive action is required. Mixing computer work with other types of work is probably the best way to prevent mental strain due to intensive computer work.

Between 1996 and 2000 there is, in the European Union, an overall decrease in the level of qualifications required for jobs and an increase in mental and physical strain. This is due to the worsened working conditions of employees who do not or very seldom work with a computer. This means that the improvement of the quality of working life for these employees still needs a lot of attention. This result complies with an earlier results into the working conditions in the European Union (Andries *et al.* 1996) that one should be very careful not to underestimate the impact of the type of working conditions traditionally connected with blue-collar labour. Against this background, it seems justified to say that the advance of the use of computers is beneficial for the working conditions of employees in the European Union, especially when the use of computer is limited to only a part of the total working time. The results show that the more unfavourable working conditions of those working with a computer permanently cannot be attributed to characteristics of inferior jobs. The level of the qualifications required increases with computer use and does not diminish when the maximum time is reached. This is a steady relation whether the job is performed in sectors where computer use is rather unusual or very common. What changes is the effect on possible mental strain. If we expect that more and more sectors will have high computer density, the balance between time pressure and job control needs constant attention.

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Towards a better understanding

Working with a chronic disorder; the development of the Work & Handicap Questionnaire. TNO Arbeid.

ANDRIES F, KREMER AM, HOOGENDOORN L, WEVERS CWJ AND VAN PUTTEN DJ

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## **WORKING WITH A CHRONIC DISORDER**

### **the development of the Work & Handicap Questionnaire**

**Frank Andries<sup>1\*</sup>, Anja M. Kremer<sup>1</sup>, Wilhelmina E. Hoogendoorn<sup>2</sup>,  
Cees W.J. Wevers<sup>1</sup> and Dick J. van Putten<sup>1</sup>**

#### **Abstract**

To improve the vocational perspectives of patients with a chronic disorder the Work & Handicap Questionnaire (WHQ) was developed. The WHQ differs from similar instruments in its explicit linkage between disabilities in everyday life and job demands. This is an important feature which allows for the development of specific strategies to counter work problems of people with a chronic disorder. The WHQ makes an inventory of possibly harmful working conditions and of possible strategies to counter health related work problems by means of the work adjustments. Results of the application of the WHQ are shown for three patient groups (Neuromuscular disorders, Multiple Sclerosis and Asthma) and a group of colleagues with no chronic disorder. It shows similarities and differences between labour conditions and labour experiences between the three patient groups and those working with and without a chronic disorder. Acceptance of the consequences of a chronic disorder for the job performance and a focus on health related work problems, will prolong career opportunities for workers with a chronic disorder. The use of the Work & Handicap questionnaire will hopefully further these aims in determining health related work problems en offering solutions by means of adequate work adjustment.

<sup>1</sup> TNO Work and Employment

<sup>2</sup> Department of Epidemiology Netherlands Cancer Institute, The Netherlands

\* Address for correspondence: TNO Work and Employment, PO Box 718, Hoofddorp, The Netherlands

Tel: +031 23 5549956; fax +031 235549304

**Keywords:** questionnaire, chronic disorders, work handicaps, job demands, work adjustments

## Introduction

There are strong indications that persons with a chronic disease run a high risk of dropping out of the labour force at a relatively early age (for instance: Mitchell, 1990; Yelin, et al, 1987; Siddiqui, 1997; Rumrill et al., 1998;). In the early nineties a national discussion arose in the Netherlands as to the political, financial and social acceptability of a increasing amount of people relying on social security benefits, of which many on the ground of chronic health problems (Wevers, 1995). This created a urgent demand for research data which would be useful in the improvement of vocational perspectives of chronically ill and handicapped people. To gather these data, researchers within TNO developed a the Work & Handicap Questionnaire (WHQ), an instrument meant to survey their labour conditions and labour experiences. This article introduces the WHQ to all those interested in ways of gathering systematic knowledge on the problems and opportunities of disabled and chronically ill employees may confront in their work. Giving these workers a voice, may learn us how to optimise their career perspectives.

At the core of the WHQ is a measurement of work handicaps which are defined as work problems caused by disabilities in every day life. It is assumed that physical and mental strain caused by these work handicaps are a major factor in premature retirement from the labour market (Yelin et al, 1987, Wevers 1997; Gründemann and Nijboer, 1998;). To prevent disabilities turning into work handicaps, job demands should match with remaining abilities. According to the work capacity-workload-model (Van Dijk et al., 1990) work adjustments can overcome specific work problems by affording a better fit between work demands and the (restricted) work capacities of chronically ill worker. Previous research has provided evidence adjustments can enhance the employability of employees with a chronic disorder (Roessler and Rumrill, 1998; Wevers, 1999, Andries, 2000, Baanders et al. 2001).

The WHQ differs from otherwise comparable instruments as for instance the Roland Disability Questionnaire (Roland & Morris, 1983) and the Health assessment Questionnaire (Liang et al , 1978), in its explicit linkage between disabilities in everyday life and job demands. This allows for the assessment of work problems which are related work problem that are and the ones that are not related to disabilities in everyday life and thus the disorder itself. This is all important in strategies to counter these problems. The WHQ also differs from other instruments in that it makes an inventory of possibly harmful working conditions and of possible strategies to counter health related work problems by means of the work adjustments.

Results of the use of this questionnaire are shown for three different patient groups. They serve as examples of similarities and also the differences in the conditions these employees have to confront and the ways in which they react to their physical and social work environment. Comparison with results gathered by a population of employees without a chronic disorder, give insight in the way in which patient groups compare to a relatively 'healthy' population.

## Methods

### Patient groups

The WHQ was first used in a research among patients with a neuromuscular disorder (Andries & Wevers, 1996; Andries et al, 1997) and for a second time in follow-up study (Andries, 2000). The questionnaire was also used amongst patients with multiple sclerosis (Kremer et al, 1998) and asthma (Kremer & Wevers, 1998). In a study among disabled employees, a group of colleagues without a disorder filled out the WHQ (Andries et al, 1998). Table 1 gives some further information on these studies.

Table 1 Information on data-collection of patient groups and group of colleagues

<i>year</i>	<i>Diagnosis</i>	<i>data gathered via</i>	<i># of patients</i>
NMD	Neuromuscular disorders:		
	-Dystrophia myotonica,	specialized clinics/	410
1994	-Myasthenia gravis	NMD-patient organization	
	-Hereditary motor and sensory neuropathy		
	-Spinal muscular atrophy		
MS	Multiple Sclerosis (self-reported)	MS-patient organization	391
1996			
Asthma	Asthma	hospitals	374
1997			
Colleagues	no chronic disorder or disablement	occupational physician	285
1996			

The patient groups differ considerably in age. This is sometimes caused by the criteria for the selection of respondents, as with asthma (aged less than 45). In other cases this is caused by differences in the age of onset of disorders and by the degree to which disorders allow for labour participation. Because of the possible influence of age on work outcomes, we included only employees younger than 46 years. Table 2 shows characteristics of the thus formed three patient groups and the group of colleagues.

Table 2 Background data for three groups of patients and colleagues

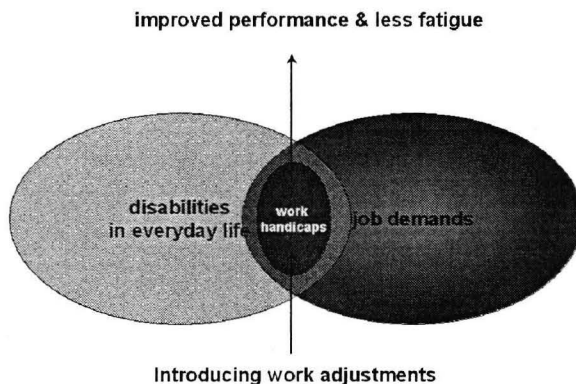
<b>Background</b>	<b>NMD</b>	<b>MS</b>	<b>Asthma</b>	<b>colleagues</b>
<i>gender</i>				
male	50%	38%	42%	56%
female	50%	62%	58%	44%
<i>age</i>				
under 25 years	16%	3%	17%	5%
26-35 years	40%	35%	37%	38%
36-45 years	44%	62%	46%	57%
<i>age of onset</i>				
under 15 years	35%	1%	37%	-
15-25 years	29%	36%	16%	-
26 years and older	26%	63%	43%	-
<b>n=</b>	<b>314</b>	<b>283</b>	<b>374</b>	<b>185</b>



### Concepts and questionnaire

The starting point for the construction of a questionnaire on work and chronic disorders was the notion that there is no direct link between a disorder and job performance. Disabilities in everyday life and job demands are supposed to be mediating variables in regard to job performance. This point of view complies with the generally accepted difference made by the World Health Organization (WHO) as expressed in the International Classification of Impairments, Disabilities and Handicaps (WHO, 1997). The underlying concept of the ICIDH is that diseases may lead to impairments, which, in turn, may induce handicaps either directly or indirectly, via disability. In the case of a working population this means that only if disabilities experienced in everyday life coincide with job demands, job performance will be affected by these disabilities. In other words: the focus should be on health related work problems rather than on work related health problems. These health related work problems are referred to as work handicaps. In order to detect possible work handicaps the measurement of disabilities in everyday life and of job demands are an important part of the questionnaire. This measurement makes it possible to distinguish between work handicaps and 'normal' work problems in which there is no relation with disabilities in everyday life. The activities needed to determine work handicaps need logically to be referred to possible activities common in working situations. The range of disabilities in everyday life must reflect disabilities resulting from all sorts of chronic disorders. The strain which working with a disorder may cause is measured by questions on work related fatigue. In earlier studies (Nijboer & Wevers 1991, Andries et al., 1998) work related fatigue was found to differentiate between employees with and without a chronic disorder. To measure what has been done to prevent or remove work handicaps, questions were asked on work adjustments, as well on those realized as on those still wanted. The main concepts can be linked together as illustrated in figure 1.

figure 1: Model for an improved performance and less work related fatigue among employees with a chronic disorder.



## Towards a better understanding

The model in figure 1 shows that where disabilities in everyday life and job demands coincide, work handicaps may be the result. Work handicaps can be removed or their effect can be mitigated by work adjustments, so to improve the way demands can be fulfilled and at the same time diminish work related fatigue. The questionnaire contains still other questions regarding specific job characteristics. These questions make it possible to typify the work situation. Is the job physically demanding or does it (also) appeal to mental capacities? Are there time pressure demands and how about the autonomy one has in the performance of the job? The measurement of time pressure and autonomy are especially important since earlier research has convincingly shown that time pressure in combination with little autonomy can cause serious health problems (Karasek, 1969). A separate set of questions investigates work experiences that are related to the disorder. Table 3 presents the variables, their operationalisation and the reliability of scales (Cronbach  $\alpha$ ).

Table 3 Concepts, their operationalisation and reliability of scales (Cronbach  $\alpha$ )

concept	items	score	Cronbach $\alpha$
<i>disabilities in every day life</i>			
mobility	<i>trouble with:</i> climbing a ladder, walking, getting up from chair, bending and coming up, keeping balance, squatting and kneeling, accurate movements with feet		
use of hands/arms	<i>trouble with:</i> accurate movements with arms or hands, gross movements with arms, reaching with arms above shoulder hold	0-3	.66
communicative capacities	<i>trouble with:</i> hearing, seeing, expressing oneself in spoken language, speaking audibly	0-4	
mental capacities	<i>trouble with:</i> remembering things for longer than 5 minutes; concentrating, planning and organizing	0-3	.63
physical disabilities	<i>trouble with:</i> standing, walking, sitting, climbing a ladder, walking, getting up from chair, bending and coming up, keeping balance, squatting and kneeling, accurate movements with feet, accurate movements with arms or hands, gross movements with arms, reaching with arms above shoulder hold, movement of head and neck, lifting, pushing	0-16	.90
non-physical disabilities	<i>trouble with:</i> hearing, seeing, expressing oneself in spoken language, speaking audibly, remembering things for longer than 5 minutes; concentrating, planning and organizing, expressing oneself in written language, seeing colours, reading	0-10	.79
<i>work outcomes</i>			
work related fatigue	- my work is too tiring - it is better to slow down in my work none 'yes' (0) one 'yes' (1) both 'yes' (2)		.62
work handicaps	trouble with job demands and with corresponding disabilities in everyday life (categorization as with disabilities)	0-2	
'normal' work problems	trouble with job demands; no corresponding disabilities in everyday life (categorization as with disabilities)		
disorder unknown	- is the disorder common knowledge among colleagues?	0-1	
work worsens disorder	- is your disorder being worsened by your work	0-1	
no social support	- are your colleagues sometimes negative about your disorder - is your superior sometimes negative about your disorder - do you colleagues take your disorder into account?		
	- does your superior take your disorder into account?	0-4	.83
less promotion due to disorder	- is there less chance of promotion because of the disorder?	0-1	

## Towards a better understanding

<i>job characteristics</i>		
physical tasks	<i>regularly</i> : walking, bending and coming up, gross movements with arms, reaching with arms above shoulder hold, working bended forward, squatting and kneeling, lifting, pushing (more than two tasks=physical)	0-8 .79
mental tasks	<i>regularly</i> : sitting, getting up from a chair, reading, writing, speaking, concentrating, remembering things for longer than 5 minutes, planning and organizing, working with a computer (more than 6 tasks=mental)	0-9 .64
time pressure	working to deadlines; working under time pressure (at least one=time pressure)	0-2 .58
job autonomy	being able to decide on: pace, order, manner, amount of work, being able to take a break when needed (more than 3=autonomy)	0-5 .84
irregular hours	not being able to take a break, working extra hours, working in weekends, working outside office hours	0-4 .73
unfavourable working conditions	<i>hindrance</i> by: fumes, stench, dirt, noise, vibrations, insufficient lighting, bad lighting, heat, coldness, change of temperature, humid air, dry air, lack of fresh air, dust, weather conditions, insufficient safety (0 versus 1-3 versus 3-16 items)	0-16 .90
<i>adjustments</i>		
adjustments: working hours	<i>realized/wanted</i> other working hours, less hours, another system of taking breaks	0-3 .79
adjustments: technical	<i>realized/wanted</i> better adapted furniture, other tools or machines, the purchase of helping aids	0-3 .82
adjustments: relief	<i>realized/wanted</i> working at a slower pace, more help from others, more freedom to arrange work	0-3 .75
adjustments: tasks	<i>realized/wanted</i> new tasks, leaving out tasks, extra training	0-3 .77

## Results

Table 4 shows the results of the measurement of four types of disabilities in everyday life and the scores for the combination of physical and non-physical disabilities among three patient groups.

Table 4 Mean number of disabilities in everyday life in percentage of employees with at least one disability for three patient groups; t-test for differences between groups and total\*

<i>Disabilities in everyday life</i>	NMD	MS	Asthma	Total	colleagues**
<i>mean number</i>					
all disabilities	6.06 +++	6.27 +++	2.80 ---	<b>4.86</b>	1.05
physical	4.91 +++	4.65 +++	1.87 ---	<b>3.66</b>	0.64
non-physical	1.14 ns	1.72 +++	0.93 ---	<b>1.20</b>	0.41
mobility	2.87 +++	2.75 +++	0.85 ---	<b>2.06</b>	0.35
use of hands/arms	0.73 +++	0.62 ++	0.24 ---	<b>0.51</b>	0.05
communication	0.58 ns	0.63 ++	0.39 ---	<b>0.51</b>	0.16
mental capacities	0.29 ns	0.45 +++	0.28 ns	<b>0.33</b>	0.07
<i>at least one disability</i>					
all disabilities	88% +++	85% ++	67% ---	<b>79%</b>	36%
physical	81% +++	74% +	63% ---	<b>69%</b>	24%
non-physical	45% -	63% +++	44% -	<b>50%</b>	22%
<i>n</i>	308	277	368	953	185

\* -/+ p=.05-.01 --/++ p=.01-.001 ---/+++ p<.001 (in testing for statistical significance the category itself is excluded from the total)

Patients with NMD and MS are for the greater part physically disabled. However, patients with MS have significantly more non-physical disabilities in everyday life, specifically mental disabilities. As one would expect the number of all types of disabilities in daily life among patients with asthma is considerably

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lower than in the other two patient groups, with the exception of mental disabilities.

Still two third of the employees with asthma has at least one disability. Even among employees without a (known) chronic disorder, more than one third of them has at least one disability.

Table 5 gives information on work outcomes. It shows scores for work related fatigue, the mean number of work handicaps, the percentage of employees with at least one work handicaps and four aspects in which work experiences are directly linked to the disorder

Table 5 Work outcomes for three patient groups and a colleagues group; t-test for differences between patient groups\*

Work outcomes	NMD	MS	Asthma	Total	colleagues**
<i>work related fatigue</i>					
no	63% +	51% --	61% ns	<b>59%</b>	75%
some (one item)	19% ns	22% ns	21% ns	<b>20%</b>	18%
much (both items)	18% ns	28% ++	18% ns	<b>21%</b>	8%
<i>all work handicaps</i>					
mean number	1.88 +++	1.62 +	0.83 ---	<b>1.40</b>	0.39
% at least one	62% +++	59% ++	35% ---	<b>51%</b>	10%
<i>physical work handicaps</i>					
mean number	1.35 +++	0.98 ns	0.56 ---	<b>0.94</b>	0.21
at least one	53% ++	46% +	26% ---	<b>41%</b>	9%
<i>non-physical work handicaps</i>					
mean number	0.54 ns	0.65 ++	0.28 ---	<b>0.47</b>	0.18
% at least one	28% ns	35% +++	19% ---	<b>27%</b>	11%
<i>'normal' work problems</i>					
mean number	0.44 ns	0.49 ns	0.31--	<b>0.41</b>	0.13
% at least one	28% ns	26% ns	19%--	<b>24%</b>	9%
<i>work and disorder</i>					
disorder unknown among colleagues	17% ns	6% ---	19% +	<b>14%</b>	-
less promotion due to disorder	30% ns	56% +++	9% ---	<b>29%</b>	-
work worsens disorder	9% ns	13% ns	11% ns	<b>11%</b>	-
no social support	24% ns	20% ns	22% ns	<b>22%</b>	-
n <sup>a</sup>	303	281	350	<b>934</b>	183

\* -/+ p=.05-.01 --/++ p=.01-.001 ---/+++ p<.001 (in testing for statistical significance the category itself is excluded from the total)

At least some form of work related fatigue is found among 41% of employees with any of the three disorders; one in five thinks his or her work is too tiring and admits that it would be better to slow down. Among employees met MS the percentage of employees that subscribes to both items is especially high. There is surprisingly little difference in work related fatigue between patients with NMD and those with asthma. The number of colleagues that express work related fatigue is clearly smaller especially the amount of employees that subscribe to both items.

The mean number of work handicaps, especially physical work handicaps, is high among employees with NMD and MS. A relatively high number of non-physical handicaps is found among employees with MS. All types of work handicaps are significantly less common among employees with asthma. The number of employees with a chronic disorder that has trouble performing certain

tasks because of disability in everyday life, ranges from one third (asthma) to two third (NMD). Among colleagues this concerns one in ten employees. Table 5 also shows the number of work problems that are not related to disabilities in everyday life. They are apparently the result of the labour circumstances themselves and therefore called 'normal' work problems. Still, the figures show that this kind of work problems are more frequently found among employees with a chronic disorder (24%) than among the colleagues without such a disorder (9%).

In most cases the disorder is known among colleagues, specifically in the case of MS.

More than half of the employees with MS see negative consequences of the disorder for the possibilities for promotion. Employees with asthma are most optimistic in this respect. There is little difference between patient groups to the degree in which employees state that work worsens the disorder. There is no significant difference between patient groups in the lack of social support from colleagues or superior in relation to the disorder.

### Job characteristics and work adjustments

Job demands and disabilities together are responsible for the development of work handicaps. In this sense job demands and other characteristics of the job reflect the manner in which the job is suited to the needs of the worker with a chronic disorder. Table 5 shows job characteristics for the three patient groups and colleagues.

Table 6 Job characteristics for three patient groups t-test for differences between patient groups\*

work characteristics	NMD	MS	Asthma	Total	colleagues
<i>mental/physical work</i>					
physical work	27% ns	17% --	32% ++	26%	20%
mental work	40% ns	48% +++	31% ---	39%	43%
physical and mental work	18% ns	19% ns	27% ++	22%	22%
physical nor mental work	14% ns	16% ns	10% -	13%	16%
<i>time pressure/autonomy</i>					
low : high	24% ns	36% +++	16% ---	24%	23%
low : low	16% ns	12% ns	14% ns	14%	10%
high : high	36% ns	34% ++	46% ++	39%	46%
high : low	24% ns	17% -	23% ns	22%	21%
<i>unfavourable labour conditions</i>					
> 2 items affirmative	28% -	21% ---	46% +++	33%	44%
<i>irregular hours</i>					
> 2 items affirmative	22% ---	20% ---	44% +++	30%	27%
<i>working week</i>					
less than 33 hours	46% -	78% +++	36% ---	51%	29%
n <sup>≠</sup>	302	270	348	920	180

\* ./+ p=.05-.01 --/++ p=.01-.001 ---/+++ p<.001 (in testing for statistical significance the category itself is excluded from the total)

There is a large contrast in job characteristics between employees with MS and those with asthma. The circumstances for employees with MS work are generally more favourable: the content appeals to mental abilities more than physical ones,

## Towards a better understanding

there is little time pressure combined with sufficient job autonomy, labour conditions (f.e. noise, heat, coldness and stench) are relatively good and there are limited and regular working hours. On almost all of these characteristics the circumstances of employees with asthma are significantly more unfavourable. Job characteristics of those working with a NMD are more 'physical' and more often typified through time pressure and little job autonomy than those working with MS. Labour conditions and working hours are more similar with those with MS.

The labour conditions of the colleagues differ mainly on the point of working hours; the amount of people working part-time is considerably lower. In what way are these job demands and working conditions the result of specific measures to suit the work to personal characteristics and abilities?

Table 7 shows the types of work adjustments that have been made en those that are still wanted.

Table 7 For types of realized work adjustments/still wanted adjustments and realized /still wanted professional support for three patient groups and a group of colleagues; t-test for differences between patient groups\*

type of adjustments:	NMD	MS	Asthma	Total	Colleagues
<i>Working hours:</i>					
realized	25% ns	52% +++	6% ---	25%	3%
still wanted	12% ns	14% ns	8% -	11%	11%
<i>Technical:</i>					
realized	13% ns	16% ++	5% ---	11%	2%
still wanted	7% ns	10% ns	9% ns	8%	9%
<i>Relief:</i>					
realized	30% +	41% +++	8% ---	25%	4%
still wanted	13% ns	14% ns	9% ns	12%	8%
<i>Task:</i>					
realized	13% ns	32% +++	4% ---	15%	2%
still wanted	10% ns	12% ns	6% -	9%	9%
n <sup>#</sup>	301	276	360	937	181

\* -/+ p=.05-.01 --/++ p=.01-.001 ---/+++ p<.001 (in testing for statistical significance the category itself is excluded from the total)

Table 7 illustrates the fact that at least part of the differences in working conditions between patient groups, are the result of work adjustments. For all types of adjustments that have been carried through, figures are highest for patients with MS en lowest for those with asthma. Although there are great differences to the degree in which work has already been adjusted, differences in the amount of people (still) wanting a adjustment and the type of adjustments wanted are quite similar.

Even in a population where there is no known chronic disorder, the amount of people wanting (another) work adjustment is almost the same as in the three patient groups. Work adjustment among colleagues are very scarce.

## Discussion

In response to a national discussion on the labour participation among chronically ill people in the Netherlands, TNO started a research program on this issue. In a number of research projects the newly developed Work & Handicap Questionnaire (WHQ), was used. To improve career perspectives of the those working a chronic disorder en to prevent drop out from the workforce, the philosophy underlying this questionnaire is that the focus should be on health related work problems and not so much on work related health problems. The core of the questionnaire consists therefore of a measurement of disabilities and related job demands. If job demands and disabilities in everyday coincide, there is the chance of health related work problems, called work handicaps. The WHQ makes an inventory of possibly harmful working conditions and possible strategies to counter health related work problems and work related fatigue by means of the work adjustments.

The WHQ has been used in a number of research projects of which the data of three of them were selected for this article: employees with a Neuromuscular Disorder (NMD), Multiple Sclerosis (MS), asthma and a group of employees without a chronic disorder (colleagues).

Though the three types of chronic disorders under study show a wide range in the number and type of disabilities, the work experiences are in some respect quite similar. More than a third to almost half of the employees expresses work related fatigue. Even among employees with asthma, with a relatively small amount of disabilities in everyday life, work related fatigue is quite common. This type of fatigue is twice as common among employees with a chronic disorder than in the group of colleagues without such an disorder. We assume that work related fatigue results from the extra burden caused by their limited ability to endure the strain caused by specific or general working conditions. Specific job demands can create work handicaps, when work problems can be traced tot disabilities in everyday life. These work handicaps are quite common among employees with a chronic disorder; it affects between 35% workers with asthma and 62% in the case of NMD. This kind of work problems are found among only one in ten of the colleagues. But apart from work handicaps, employees with a chronic disorder have a relatively large amount of 'normal' work problems: work problems that can not be traced to disabilities in everyday life. This is seen as another indication that the balance between workload and the abilities of workers, is critical in the case of patients with a chronic disorder.

Apart from a clearly limited amount of working hours, the overall working conditions of people with a chronic disorder are in many respects not very favourable. One third of the patients with a NMD or with MS, who are for the most part physically disabled, have jobs which are physically demanding. A quarter of the workers with NMD report time pressure and little autonomy, which is an unhealthy combination for all, but more so for people who have a restricted work capacity. Unfavourable labour conditions as the occurrence of fumes an adverse climatic conditions, are mentioned by almost halve of the employees with asthma who are because of their disorder, especially susceptible to these



conditions. Though the working situation of employees with MS is seemingly the best adapted to their limited abilities, the amount of patients indicating work related fatigue is highest of all three patient groups. This could well be the result of the fact that their work handicaps are more often non-physical. A follow-up study among patients with NMD (Andries, 2000) has shown that non-physical disabilities (especially mental disabilities) in everyday life are less easy to avoid and difficult to adjust than physical disabilities. This follow-up study also showed that in the long term certain adjustments are more effective than others in reducing the number work handicaps and the amount of work related fatigue. Adjustments aimed at 'relieve', giving the employee the permission to slow down and ask help from colleagues, are less effective than adjustments aimed at a change of tasks, often implying a less ambitious job. Though often unpopular with workers themselves, these adjustments have proven to be effective in diminishing the number of work handicaps and thereby work related fatigue. To improve the fit between the remaining abilities of workers with a chronic disorder and their working situation, action is needed on the part of the workers themselves as well as colleagues, supervisors, occupational health physicians and personnel officers. Acceptance of the consequences of a chronic disorder for job performance and a focus on health related work problems, will prolong career opportunities for workers with a chronic disorder. The use of the Work & Handicap questionnaire will hopefully further these aims in determining these health related work problems en offering solutions by means of adequate work adjustment.

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Towards a better understanding

Work adjustments among the chronically ill.  
BAANDERS AN, ANDRIES F., PM RIJKEN, J.DEKKER

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## Work adjustments among the chronically ill

A.N. BAANDERS<sup>1,\*</sup>, F. ANDRIES<sup>2</sup>, P.M. RIJKEN<sup>1</sup> and J. DEKKER<sup>1</sup>

<sup>1</sup>Netherlands Institute for Health Services Research, Utrecht, The Netherlands

<sup>2</sup>NLATNO, Hoofddorp, The Netherlands

Work(place) adjustments can help restore the work capacity of persons with a chronic disease. This study aims to quantify the presence of work adjustments among chronically ill workers in the Netherlands, and to investigate the extent to which the presence of work adjustments are related to the experience of work-interfering problems, disease characteristics or work characteristics. Data for this study are derived from the Dutch Panel of Patients with Chronic Diseases. The results discussed here relate to data collected in 1999 from a representative sample of 556 working people with various chronic somatic diseases. Of the work-interfering problems, the ones related to physical disabilities, concentration or memory deficits and transportation emerged as the most important factors related to the presence of either immaterial (i.e. not material) or material work adjustments. In addition, higher age and lower educational level were associated with a higher probability of immaterial adjustments; pain, attack frequency and physical demands of the job were important predictors of material work adjustments. *International Journal of Rehabilitation Research* 24:7-14 © 2001 Lippincott Williams & Wilkins

**Keywords:** chronically ill; The Netherlands; workplace adjustments

### Introduction

Several studies have conveyed the impression that persons with a chronic disease share a relatively disadvantaged position in the labour market. On the one hand, they have more difficulties in getting a job (Petrides *et al.*, 1995; Mastekaasa, 1996; Van Elderen *et al.*, 1996), and on the other they run a high risk of dropping out from the labour force at a relatively early age (e.g. Yelin *et al.*, 1987; Mitchell, 1990; Siddiqui, 1997; Rumrill *et al.*, 1998). Considering the negative implications of early withdrawal from the labour market, it is increasingly felt that more efforts should be made to enhance the employability of the chronically ill. Above all, efforts to prevent job discontinuation are considered to be crucial, as it has been shown that return to work is particularly troublesome once people take prolonged sick leave (Culenaere *et al.*, 1999; Grossi *et al.*, 1999). In this respect, distinct attention has been focused on the instrument of work adjustments (Mastekaasa, 1996; Gordon *et al.*, 1997; Schall, 1998; Wevers, 1999). According to the work capacity-work load model (Van Dijk *et al.*, 1990; Gründemann and Nijboer, 1998), work

adjustments can help overcome specific work problems by affording a better fit between work demands and the (restricted) work capacities of the chronically ill worker.

Previous research has provided evidence that job adjustments are essential in enhancing the employment prospects of the chronically ill (Andries *et al.*, 1997; Roessler and Rumrill, 1998; Wevers, 1999). There is, however, little insight into the extent to which this instrument is in fact put into practice, and the extent to which the experience of specific problems at work are related to work adjustments. As a first research question we formulate: How many working people with a chronic illness in the Netherlands encounter problems at work as a consequence of their disease (henceforth referred to as work-interfering problems) and how many of them actually have work adjustments?

To the extent that work adjustments are primarily related to work-interfering problems, they can be said to be applied efficiently, that is, they are actually aimed at the ones who need them to overcome specific difficulties in job performance. The question arising subsequently, however, is whether the presence of work adjustments can be explained entirely by work-interfering problems, or whether other factors also contribute to the presence of work adjustments. In line with the work

\*Address for correspondence: Nivel, P.O. Box 1568, 3500 BN Utrecht, The Netherlands

capacity-work load model, several additional explanatory factors emerge. First, on the work-capacity side, several disease characteristics are to be taken into account, viz. disease diagnosis (Lerner *et al.*, 2000), disease duration, disease progression (Robinson, 2000), and functional disabilities resulting from the disease. One might argue that the impact of such disabilities are already accounted for by highlighting the work-interfering problems (Beatty *et al.*, 1995). However, persons with impairments may not be disabled in their ability to work, or conversely, people with low degrees of impairments may nonetheless encounter significant problems with job performance (Greenwood, 1984). Thus, functional disabilities should be included as a separate factor. Next, a person's ability to meet the job demands continuously may also be thwarted by the episodic manifestation of symptoms (Gordon *et al.*, 1997; Rumrill *et al.*, 1998). Similarly, it can be expected that persons who suffer from pain and fatigue may benefit from adjustments in work organization. Age may also be related to work adjustments, considering that labour participation of the chronically ill has been found to decrease with increasing age (Sokka *et al.*, 1999), which can be partly understood as an indication of reduced work capacity. On the work-load side, the effect of two work characteristics will be considered: the physical demands of the job, and the respondent's subjective assessment that his job is harmful to his health. In addition, educational level may have a work load effect. The relatively low participation rate among the lower educated chronically ill (Mitchell *et al.*, 1988) may be related in part to higher work load in the type of jobs they occupy.

To investigate whether work adjustments are effectuated efficiently and whether the above-mentioned factors have an (additional) effect, the second research question in this study runs: Which work-interfering problems emerge as the most important predictors of work adjustments, and what other factors, beside work-interfering problems, are predictive of the presence of work adjustments?

## Material and methods

### Data

The data for this study were derived from the Panel of Patients with Chronic Diseases (PPCD), a longitudinal panel study conducted by Nivcl, which covers the period 1998–2000. Respondents for the panel were recruited in 1997 via a random sample of 56 general practices in the Netherlands. Eligible

for inclusion in the study population were patients, diagnosed by a medical practitioner as having a non-curable or long-lasting somatic illness (not in a terminal stage), who were 15 years or older, and living independently. As it appeared that the sample of 56 general practices slightly differed from the total population of practices with respect to urbanization level and region of their domicile, a weighting factor was computed. To ensure that the findings reported below are representative of the Netherlands population of chronically ill, the analyses in this study are based on weighted data.

The project began with 2487 participants. Twice a year, participants fill out extensive postal questionnaires. For the purpose of this study, data about labour force participation, work adjustments and job characteristics that were collected at the fourth measurement (October 1999) were used. Follow-up response on the fourth measurement was 88.2% (1938 of the 2198 respondents still participating). Only respondents younger than 65 years who were gainfully employed were included in the analyses ( $n = 556$ ). The third PPCD questionnaire (April 1999; follow-up response 84.4%) supplied data concerning sociodemographic or disease-related characteristics, pertaining to the same year of observation.

### Concepts and operationalization

Working respondents were asked whether their work(place) had been adjusted to overcome health-related problems at work, and if so, what kind of adjustments had been effectuated. A distinction was made between immaterial adjustments, including schedule modifications, reduced working hours, reduced working pace, more breaks, adjusted job assignments, help from colleagues (Yelin *et al.*, 1980; Gordon *et al.*, 1997), and material adjustments, i.e. assistive devices, adjusted tools or machinery, adjusted furniture, transportation facilities, education and (re)training opportunities, improved accessibility of the building, and rest room (Roessler *et al.*, 1998; Pell *et al.*, 1999). Respondents could mark one or more of these options.

To get an impression of the prevalence of work-interfering problems, respondents were asked to indicate whether they experienced problems at work related to transportation, mobility at work, vision/hearing, physical disabilities, physical endurance/weariness, concentration or memory deficits, or mental problems.

Disease diagnosis and disease duration were registered by the general practitioner. Diagnosis has been classified according to the official ICD codes (Lamberts and Wood, 1987). In the case of comorbidity, the disease first diagnosed was used as the index disease (Schellevis and Van Lisdonk, 1993). In the analyses below, several ICD categories have been merged, resulting in a classification of eight diagnostic categories. Several rare diseases have been combined in the category of 'other diseases'.

Functional disability was assessed by a shortened version of the Sickness Impact Profile (SIP68, De Bruin *et al.*, 1994). In this study, two scales of the SIP68 were included: mobility control (12 items;  $\alpha = 0.83$ ), and cognitive autonomy and communication (11 items;  $\alpha = 0.73$ ). The scale for mobility control contains items concerning difficulty in walking and standing, bending or stooping, and hand control. 'Cognitive autonomy and communication' relates to problems with planning, reasoning, concentration, adequate reaction, remembering, speaking, confusion, writing, and typing. In accordance with the instructions, a total-score variable was computed for each dimension by adding all the affirmative responses. A large proportion of respondents reported no disabilities at all on these subscales, so the variables were then dichotomized (no disabilities versus one or more disabilities). In addition, the questionnaire inquired to what extent the respondent's health condition was characterized by pain, fatigue and progression of the disease. Response categories ranged from 'not at all' through 'to some extent' to 'to a large extent'.

Physical demands of the job were measured by asking respondents whether their job was characterized by physically very heavy, moderately heavy, physically light or sedentary work. To determine work load in relation to work capacity, respondents were also asked whether they felt that their work has a harmful effect on their health, yes or no.

#### *Analysis*

First, the percentage of chronically ill workers having immaterial and material work adjustments are presented. To investigate the impact of work-interfering problems, the proportion of working chronically ill having any of the seven complications posing problems at work will be assessed, as well as the proportion of those with work-interfering problems who have (im)material work adjustments.

To determine subsequently whether any additional variables contribute to the probability of work

adjustments, multivariate logistic regression was performed, in which the work-interfering problems were entered together with the disease characteristics, work characteristics and sociodemographic characteristics. As disabilities, as measured by the SIP, and work-interfering problems may be partly overlapping, correlations between these sets of items as well as between the seven work-interfering problems were assessed in advance to check for multicollinearity. Correlation coefficients ranged between 0.01 and 0.51, so all variables could be entered in the analyses. Separate analyses were performed for immaterial and material work adjustments as the outcome measures. A stepwise procedure with forward inclusion was used, to identify the most important predictors ( $P < 0.05$ ).

## **Results**

### *Demographics and descriptives*

Of the PPCD respondents aged 15–64 years, 52.4% were employed ( $n = 556$ ). Almost 22% of them work less than 20 hours per week, 28.8% work between 20 and 31 hours per week, and 49.4% work 32 hours or more per week. Of the working population 46.9% is male, and 53.1% is female. On average, the working chronically ill are 44.3 years old ( $SD = 9.9$ ), which is significantly younger than the unemployed chronically ill (students excluded; mean = 53.0;  $SD = 9.98$ ). Almost half of the employed respondents has primary, lower or intermediate vocational education, 25.2% has lower or intermediate secondary education, 18.2% has an education at higher vocational level, and 8.4% has an academic degree.

It appeared that 15.7% of the chronically ill involved in paid labour had undergone some kind of work adjustment. Twelve per cent of the respondents indicated that they had immaterial work adjustments; 8.1% had material adjustments. The work adjustments mentioned most frequently were reduced working hours (5.8%), adjusted working schedule (4.9%), reduced working pace (4.5%), adjusted job assignments (4.3%), adjusted furniture (4.8%), assistive devices (4.2%) and additional breaks (4.3%). Less common work adjustments were help from colleagues (2.3%), adjusted tools or machinery (1.5%), transportation facilities (0.7%), education and (re)training opportunities (0.5%), improved accessibility of the building (0.3%) and resting rooms (0.4%). Most respondents with work adjustments reported one or two work adjustments



**Table 1.** Working chronically ill encountering problems at work (column 1), and proportion of those with work-affecting problems having (im)material work adjustments

Problems at work relating to	Having work-related difficulties		% with work adjustments (of those having difficulties)	
	n	%	Immaterial	Material
Physical endurance, weariness	315	58.5	19.6	11.6
Physical disabilities	204	38.9	27.9	16.4
Concentration, memory	110	21.3	29.1	13.6
Mental problems	72	14.4	18.1	8.2
Sight/hearing	65	12.8	25.4	18.8
Transportation to work	55	10.7	41.1	25.5
Mobility at workplace	44	7.9	32.6	29.5

(64.7%), either material or immaterial, whereas one-third reported more than two adjustments.

#### *Work-interfering problems and presence of work adjustments*

Table 1 shows that physical endurance and physical disabilities are the most frequently reported health complications that pose problems at work for chronically ill workers (58.5% and 38.9% respectively). In addition, 21% of the chronically ill workers encounter problems at work owing to concentration and memory deficits. Less prevalent problems were mental problems, visual/hearing problems, problems with transportation to and from work, and problems with mobility at work.

The last two columns of Table 1 show that, depending on the type of work-interfering problem, the proportion having immaterial adjustments

ranges from 18% to 41%, whereas the proportion with material work adjustments varies between 8% and 29%. Clearly, not all kinds of work-interfering problems concur with the presence of work adjustments to the same extent. Remarkably, immaterial work adjustments are reported with the highest frequency by those having problems with transportation, mobility, and physical activities. This indicates that work adjustments such as altered work schedules or more break opportunities are important in meeting this kind of problem also.

#### *Multivariate analysis*

Now that the relation between work-interfering problems and the presence of work adjustments has been identified, we will proceed by investigating whether disease characteristics, work characteristics and sociodemographic characteristics add to

**Table 2.** Disease characteristics and work characteristics of the working chronically ill ( $n = 556$ ). SIP = Sickness Impact Profile

Variables	%	Variables	%
Index disease		Pain	
asthma/COPD	21.5	none	60.4
locomotor diseases	12.6	somewhat	30.3
diabetes mellitus	8.7	a lot	9.3
neurological diseases	8.7	Fatigue	
heart/vascular diseases	5.1	none	33.8
cancer	4.3	somewhat	49.8
digestive disorders	4.2	a lot	16.4
other diseases	34.9	Progressive deterioration	
Mean disease duration (years)	10.7 (SD = 8.8)	none	67.8
Mobility problems ( $\geq 1$ ) (SIP)	20.8	somewhat	29.7
Cognitive problems ( $\geq 1$ ) (SIP)	12.9	a lot	2.5
Attacks of symptoms		Physical demands of job	
daily	7.0	very heavy work	9.1
once or more a week	13.5	heavy work	28.8
once or more a month	16.8	light work	22.8
once or more a year	26.9	sedentary work	39.3
never	35.8	Work causes deterioration of health (yes)	12.2

the prediction of work adjustments. First, Table 2 gives a descriptive overview of the disease and work characteristics of the working chronically ill. Table 3, part A, then presents the results of the logistic regression with immaterial adjustments as the outcome measure. It appears that problems at work resulting from physical disabilities, concentration and memory deficits, and transportation difficulties constitute the strongest predictors for immaterial work adjustments. When taking into account the effect of these work-interfering problems, it appears that higher age, primary, lower vocational or intermediate vocational education and daily occurrence of disease symptoms independently increase the probability of immaterial work adjustments.

With regard to the presence of material work adjustments (Table 3, Part B), having pain appears

to be the main predictor, followed by having problems at work owing to physical disabilities. Frequency of attacks is also significantly related to material adjustments, but the relationship is not very straightforward: the probability of having material adjustments is significantly higher for those who suffer from their symptoms once or more a month, and lowest among those whose symptoms occur once or more a week or once or more a year. Next, a significant effect of physical demands of the job is observed. The probability of material adjustments increases with the level of physical demands, with the remarkable exception of the category of sedentary work, for which the probability of material adjustments is relatively higher than for physically light or moderately light work. Furthermore, the work-interfering problems related to transportation and to concentration deficits sig-

**Table 3.** Work-interfering problems, disease characteristics, work characteristics and background characteristics predicting the presence of immaterial work adjustments (part A) and the presence of material work adjustments (part B)

<i>Explanatory variables</i>	<i><math>\beta</math>-coeff.</i>	<i>(SE)</i>
<b>Part A: Outcome measure = immaterial adjustments</b>		
Problems at work due to physical disabilities	3.30	(0.74)
Problems at work due to concentration/memory deficits	3.17	(0.61)
Problems at work due to transportation to work	2.55	(0.67)
Age	0.08	(0.03)
Educational level		
primary, lower or intermediate vocational	1.19	(1.16)
lower or secondary preparatory	-1.45	(1.40)
higher vocational	0.54	(1.34)
university education (reference category)	0.00	
Attacks of symptoms		
daily	1.48	(0.77)
once or more a week	-0.98	(0.79)
once or more a month	0.15	(0.80)
once or more a year	-0.93	(0.76)
never (reference category)	0.00	
<b>Part B: Outcome measure = material adjustments</b>		
Pain		
no (reference category)	0.00	
somewhat	0.14	(0.58)
a lot	1.97	(0.88)
Problems at work due to physical disabilities	1.70	(0.60)
Attacks of symptoms		
daily	-0.43	(0.91)
once or more a week	-1.62	(0.94)
once or more a month	0.78	(0.61)
once or more a year	-1.43	(0.82)
never (reference category)	0.00	
Physical demands of job		
very heavy work	0.01	(0.75)
heavy work	-1.00	(0.64)
light work	-2.71	(1.10)
sedentary (reference category)	0.00	
Problems at work with transportation	1.37	(0.63)
Problems at work due to concentration/memory deficits	1.14	(0.54)

nificantly raises the probability of material adjustments.

### Discussion

To support integration of the chronically ill into the labour force and prevent early withdrawal, high policy priority is given to the instrument of work(place) adjustments, not only in the Netherlands (Van Gelder and Gorter, 1997; Wevers, 1999), but also in other countries such as the United States (Roessler and Rumrill, 1998), Canada (Zimmermann, 1992) and Norway (Mastekaasa, 1996). This study revealed, however, that in the Netherlands they are in fact used by a limited number of working persons with a chronic illness, a situation which was also observed for the United States (Schall, 1998). Almost 85% of the Dutch working chronically ill report as having no work adjustments, which is striking considering the fact that the rate of early job exits among persons with a chronic illness is disproportionately high (e.g. Robinson *et al.*, 1989; Doeglas *et al.*, 1995). It thus seems that much can be gained by optimizing the further implementation of work adjustments and increasing the number of working people making use of the potentials of this instrument. This may prevent or postpone job discontinuation for many chronically ill.

When work adjustments are present, it appears that immaterial work adjustments, such as adjusted working hours or revised job assignments, are more common than material adjustments such as assistive devices or adjusted furniture. This suggests that immaterial work adjustments can probably be fitted in more easily than material work adjustments, that the former can be arranged with less effort or on a more informal basis than the latter, or that immaterial adjustments are a more obvious solution and come to mind more easily.

The present findings give reason to suspect that many chronically ill may not be fully aware of the possibilities and/or procedures of applying for work adjustments (see Scherich, 1996). This emphasizes the need to provide more adequate information on the subject, for instance by job counsellors. From the results of this study, we now know that this information should be directed specifically at older workers with lower or vocational education, with physically demanding jobs and frequent hindrance from their symptoms, who encounter problems at work owing to physical disabilities, concentration deficits and transportation problems. However, the

limited presence of work adjustments may also be attributable to negligence on the part of employers. It may very well be that they too are not sufficiently informed about their responsibilities towards employees who need work adjustments or the possibilities of acquiring subsidies for necessary adjustments. The present study cannot elucidate on this matter, however. Another aspect to consider regarding the limited use of work adjustments is that, as a consequence of the prevailing negative image of the chronically ill, persons with a chronic illness may feel reluctant to request work adjustments as they prefer not to reveal any existing health problems (e.g. McReynolds, 1998). Continued efforts should therefore be given to present a more positive image of the abilities of persons with a chronic disease to employers, and dispel any reticence among chronically ill people to raise the issue with their employers.

The results of the logistic regression reveal that having problems at work (notably problems owing to physical disabilities, concentration deficits and transportation) are among the most important predictors of work adjustments. This finding endorses that work adjustments are effectuated quite efficiently, in the sense that they are deployed to overcome specific work-interfering problems. The other work-interfering problems that were discerned here are not decisive in this respect. With respect to the problem of physical weariness it can be argued that this problem is now generally very common (Houtman *et al.*, 2000), making it in the eyes of chronically ill people a less legitimate reason to apply for work adjustments. It also became clear, however, that the presence of work adjustments cannot be traced back entirely to work-interfering problems. With respect to immaterial adjustments, age, educational level and attack frequency appeared to have independent effects also, whereas the presence of material adjustments is also associated with pain, symptom frequency and job demands. Disease diagnosis is not a decisive factor in predicting work adjustments. Although previous research showed varying risks of job discontinuation for different diseases, this is not reflected in higher (pre-exit) prevalence of work adjustments. Apparently, rather than the type of disease diagnosis, it is the kind of health-related problems one encounters that determines whether work adjustments are present. This justifies the Netherlands policy objective of developing disease-generic measures, aimed at the total group of chronically ill, i.e. with any kind of chronic disease.

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Towards a better understanding

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BIJLEVELD CCJH, ANDRIES F, RIJCKEVORSEL JLA.

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## Positive and negative aspects of the work of information technology personnel: an exploratory analysis

CATRIEN C.J.H. BIJLEVELD†, FRANK ANDRIES‡ and  
JAN L.A. VAN RIJCKEVORSEL§

†Department of Research, WODC Research and Documentation Centre, Ministry of Justice, The Hague, The Netherlands; e-mail: cbijleve@best-dep.minjus.nl

‡TNO-Arbeid- TNO Netherlands Labour Institute, Hoofddorp, The Netherlands; e-mail: f.andries@arbeid.tno.nl

§Department of Statistics, TNO-Preventie en Gezondheid- TNO Netherlands Prevention and Health, Leiden, the Netherlands; e-mail: jla.vanrijckevorsel@pg.tno.nl

**Abstract.** This paper re-analyses data gathered in a 1989 research among Dutch information technology personnel. Working from Karasek's job stress model, we use exploratory multiple correspondence analyses on the aggregated data matrix of occupations and work items. We employed two models: one that emphasised the negative evaluations of job aspects, and one that emphasised positive evaluations. The structuring of positive evaluations of job aspects proved most meaningful. Occupations could be distinguished into three groups. The first and largest group is characterised by a fairly balanced degree of autonomy and workload. A second group comprised of middle management occupations is characterised by unfavourable judgement on workload, matched by insufficient autonomy; as such, employees in these occupations appear at risk of overburdening. A third group of computer specialists report a workload that is too slight given their degree of autonomy; this group appears to be at risk of underburdening.

### 1. Introduction

In information technology, the confrontation of commercial demands with techniques and methods often fresh from the laboratory, creates labour conditions that may be well worth while to investigate, especially from the perspective of strain and stress. For this reason a questionnaire was administered in 1989 to approximately 3000 persons employed in the information technology sector in the Netherlands (Andries 1990, Andries *et al.* 1991). The objective of this study had been

to obtain information on the working conditions of employees with widely ranging responsibilities in the creation of information technology products.

The job-demands job-control-model (Karasek 1979, Karasek and Theorell 1990) predicts that negative outcomes (e.g. health complaints, exhaustion, depression, sickness absenteeism, mortality) as well as positive outcomes (e.g. job satisfaction, work motivation, productivity and motivation to learn new behaviour) result from specific combinations of demands and control. More specifically, the model postulates: (1) that the combination of high psychological demands and low job control increases psychological and physical strain; and (2) that jobs characterized by a combination of high demands and high control increase well-being, learning and personal growth. As such, it is the particular combination or clustering of negative and positive aspects that relates to well-being and strain, rather than absolute values on separate indicators.

The homogeneous setting of the 1989 research into information technology personnel creates a particularly suitable opportunity for relating the research findings to Karasek's job-demands job-control model. In contrast to other research into the quality of work in occupations affected by new technologies, which mostly focused on Visual Display Terminal (VDT) work in general (see e.g. Dainoff 1982, Kahn and Cooper 1986, Sauter and Hurrell 1988, Carey 1992), this survey was conducted in



a homogeneous setting with well-defined heterogeneity of responsibilities, ranging from production to sales to supervisory tasks. In fact, several authors (Fletcher and Jones 1993, Kristensen 1995) have recommended to investigate the applicability of the job-demands job-control model for well-described jobs within a homogeneous setting - rather than among representative population samples. Though representativeness is of vital importance in descriptive studies, it is of minor importance in analytical studies (Kristensen 1995). For that matter, even though the 1989 data have their limitations for generalizing to present-day working conditions of information technology personnel, they lend themselves still well to a re-analysis in which the focus is on the application of relatively unused methodologies that enable to investigate aspects of Karasek's model. The chosen perspective of contentment versus discontent fits in with an analysis of jobs in which next to strain and stress, positive aspects such as challenge and learning opportunities, are relevant.

For the 1989 study, given that little was known about the specific working conditions of information technology personnel, preliminary interviews with key-persons had been held to explore specific problems encountered in the information technology sector (Andries 1990). It was found that, towards the end of the eighties, chronic shortages of qualified personnel, high staff-turnover, and difficulties in the planning of computerization projects had created a potentially stressful environment for this sector. The interviews indicated that the generally perceived indispensability of key information technology personnel adds the risk of neglecting symptoms of physical and mental strain. In the literature, similar topics have been addressed (see for instance Kraemer and Danziger 1990). The specific demands of computer technologies increase perceived workload and work pressure and decreased job control (Carayon-Sainfort 1992); in studying the impact of the balance between such positive and negative aspects in the work of office and computer workers, Carayon (1994) showed how combinations of small numbers of stressors related significantly to job-title information and strain. In the still rapidly changing environment of computer technology, the likelihood of there being senior staff schooled 'the old way' remains high, which qualitatively overloads supervisory staff and in turn threatens subordinates with overload (Backlund 1986, Aronsson 1989). Ultimately, this may even adversely affect the quality of relationships in the workplace (Sutherland and Cooper 1988). Work overload—but also underload—can also result from irregular flow of work which is outside worker control (Johansson and Aronsson 1984). Work pace has been reported to vary from complete shutdown to very hectic as workers try to

keep to contract deadlines (Sutherland and Cooper 1988). Additional problems particular to the information technology industry are the daily frustrations and sudden interruptions because of software bugs or systems crashes (Fisher 1988). As Sauter and Hurrell (1988) stated, changes in job content and worker control in the continuously changing and growing information processing industry is a subject of interest in preventing job stress and strain.

In the following sections the data gathered in the 1989 research among information technology personnel is re-analysed. Attempts are made to identify occupations at risk of stress and strain. In doing so, the clustering of negative as well positive aspects in job evaluation is examined. Working from an exploratory framework, no distinction is made between dependent or independent variables nor are specific hypotheses tested regarding the relation between stressors and stress outcomes. Rather, how various aspects of job complaints and contentment relate is investigated, thus enabling the authors' technique to identify not only expected, but also unexpected relations.

## 2. Methodology

### 2.1. Sample

In the 1989 study, a questionnaire was mailed to a sample of information technology personnel. From the subscribers of the widely read Dutch computer-trade journal *Computable* (read by approximately 80% of the target population), a 10% sample had been drawn that was stratified over occupations. Because of uncertain demarcations of occupations, because of job mobility in the period between the moment the list of subscribers had been compiled and the moment the sample was actually drawn, and because of differences in response levels per occupation, the number of respondents per occupation varied. Due to the stratified sampling over occupations, the response group—though a considerable proportion of the target population—can not be considered representative of Dutch information technology personnel in general. However, as subgroups within the sample will be compared, this does not constitute a serious limitation.

From the total of 5461 persons in the sample, 60% returned a completed questionnaire (3233 respondents). The mean age of the sample was 36 years; on average 5% were women.

A total of 32 different occupations could be distinguished. The occupations ranged from those in the top management (directors), middle management (heads of departments) and lower management (system managers,

Table 1. Occupations and labels.

Occupation	Label	n
<i>Directors</i>		
financial director	(dir financial)	41
managing director	(dir managing)	115
<i>Middle management</i>		
head of computing department	(head computing)	142
head of information-processing department	(head info proces)	58
head of programming department	(head programming)	45
head of system-analysis department	(head system)	41
<i>Lower management</i>		
system manager	(system manager)	182
applications manager	(applic manag)	70
network manager	(network manag)	48
project coordinator	(coordinator)	218
<i>Computer specialists</i>		
system-analyst	(system analyst)	70
system-analyst/programmer	(programmer)	166
system-designer	(designer)	126
application-programmer/analyst	(application)	174
network analyst/programmer	(network)	26
data-/telecommunications-specialist	(telecom)	96
information-analyst	(info analyst)	95
micro-computer programmer	(micro)	33
<i>Marketing/sales personnel</i>		
marketing personnel hard- & software	(marketing)	101
sales-personnel hardware	(sales hardware)	119
sales-personnel hardware	(sales hardware)	56
<i>Administrators</i>		
accountant-administrative advisor	(adm advisor)	53
internal accountant	(internal)	79
external accountant	(external)	21
head of administration/ controller	(controller)	124
<i>Teachers</i>		
business-applications course leader	(course)	34
informatics teacher	(informatics)	105
<i>Consultants</i>		
consultant/advisor	(advisor)	179
management-consultant	(manag consul)	93
<i>Support personnel</i>		
work-planner	(planner)	61
operator	(operator)	62
service-engineer/customer-support	(service)	106

applications managers etc.) to occupations such as computer specialists (in design, analysis and/or applications), marketing/sales personnel, administrators, teachers, consultants and support personnel (work planners, operators etc.). The different occupations that were investigated are shown in table 1, clustered into nine subgroups that reflect the different responsibilities in the realization of information technology products. For a more detailed description of the investigated sample, see Andries *et al.* (1991).

## 2.2. Questionnaire

The basis for the questionnaire used in the 1989 study was the 'VAG' questionnaire (a TNO standard questionnaire on work and health) (Dijkstra *et al.* 1986). This questionnaire has been used in a multitude of studies into working conditions, job stress and job satisfaction in the Netherlands. As such, it has the advantage that scores on the questionnaire can be compared to those of a Dutch reference population. Most of the studies in which the questionnaire had been used took place well before the Karasek model became so widely acknowledged, so the 'VAG' questionnaire is not based on the Karasek model.

In order to address the particular nature of the sector under investigation, preliminary interviews with key-persons in information technology had been held. A number of findings were translated into specific questions that were added to the standard questionnaire for obtaining information particular to the working conditions of information technology personnel. Additional job aspects thus included are lack of education, lack of control and career-prospects, workers' roles in the organisation and possibilities for delegation of responsibilities. Possibilities for delegation have been identified as a major risk for strain and stress (Cooper 1986). The operationalization of control in fact complies with recommendations made recently by others (Wall *et al.* 1996), identifying timing control and method control as key concepts.

The final questionnaire contained 40 items, referring to a wide range of job-aspects, such as salary and prospects, challenge, workload, qualifications, quality and amount of consultation by management as well as contacts with colleagues. Items on work-related physical and mental strain were present as well. The wording of the items was such that answers could be interpreted as representing contentment ('Is your daily work generally interesting?') or as representing discontent ('Are you often bothered by poor performance of others?'). Table 2 lists all questionnaire items, clustering them according to their perceived intrinsic similarity. In table 2, for ease

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Table 2. Questionnaire items<sup>1</sup>, percentages of affirmative answers, labels and differences with reference group.

Item	% Affirmative answers	Label	Difference reference group
<i>Workload</i>			
(n) Working more than 45 hours a week	36	(> 45 hrs)	n.a.
(n) Not being able to use up all one's days off	30	(no days off)	n.a.
(p) Not being able to use up days off in desired period	22	(days off period)	n.a.
Work is physically strenuous	8	(physical)	-18%
<i>Hectic working conditions</i>			
(n) Workload unequally divided over time	59	(unequal)	n.a.
(n) Working under time-pressure	69	(time pressure)	+10%
Progress of work delayed in case of one's absence	41	(delay absence)	-
Often hampered by unexpected events	66	(unexpected)	-
Often bothered by poor work of others	47	(others poor work)	-
Often hampered by the absence of others	26	(others absence)	-
<i>Qualifications</i>			
(p) Not the right education for the job	48	(not qualified)	n.a.
(p) Not enough experience for the job	38	(no experience)	n.a.
(n) Doubts about keeping up with innovations	27	(innovations)	n.a.
<i>Challenge</i>			
(p) Work is not engaging	5	(engaging)	-26%
(p) Work offers no pleasure	3	(pleasure)	-10%
(p) Work is not mentally demanding	12	(mental)	-27%
<i>Stress</i>			
Work is often too tiring	21	(tiring)	-
Regular problems with pace of work	13	(pace)	-
Feeling it is better to slow down	28	(better slow)	-
Often feeling tense	23	(tense)	-10%
Often feeling nervous	9	(nervous)	-12%
Often feeling agitated	28	(agitated)	-
<i>Health</i>			
Recent health complaints	10	(health)	-17%
Not sleeping well	4	(sleep)	-
Regular headaches	10	(headache)	-
<i>Leadership</i>			
(p) Work is badly organised	38	(organised)	-
(p) Insufficient consultation	24	(consultation)	-
(p) Bad day-to-day management	48	(day-to-day)	+14%
(p) Management has no clear image in one's work	35	(image)	-
(p) Management does not take one's opinion into account	27	(account)	-
<i>Autonomy</i>			
(p) Not able to decide on the organisation of work	8	(organisation)	n.a.
(p) Not able to decide on the method of working	12	(method)	n.a.
(p) Not able to decide on the pace of the work	21	(pace)	n.a.
<i>Social aspects</i>			
(p) Relations among colleagues not pleasant	11	(relations)	-11%
Irritated by colleagues	18	(irritation)	-23%
Work influences private life in a negative way	31	(private)	-
<i>Salary and prospects</i>			
(p) Salary dependent upon performance	10	(salary depend)	n.a.
(p) Salary doesn't concur with performance	34	(salary concur)	+18%
(p) More than 5 hours a week spent on study	27	(study)	n.a.
(p) Prospects for career are dim	13	(prospects)	-22%

<sup>1</sup>Items indicated with (p) had been formulated positively in the questionnaire; those with (n) neutrally; all others as complaints/stressors.

of interpretation, all aspects are worded negatively; those items that had been worded positively in the original questionnaire form have been indicated with '(p)' before the item, items that had been worded neutrally have been indicated with '(n)'. The column indicated as 'difference reference group' in table 2 gives the difference in percentage scores on the negatively worded items of the group under study with a Dutch reference group: for instance, +10% means that in the group of information technology personnel under study, the percentage of respondents scoring on this item was 10% higher than in the Dutch reference group.

### 2.3. Method

As labour conditions in the information technology sector are a relatively new area for research, and because relationships between the variables may be non-linear (Kristensen 1995), the assumption that a model should be used that is as free from assumptions as possible was the starting point. Techniques like factor analysis are therefore a less attractive option. Because the intention is to reduce the data content to manageable quantity, an exploratory kind of factor or principal components analysis must be sought. Non-linear principal components analysis would be an option. In order to be able to explore the relations between the variables, nominal measurement levels for the variables would have to be assumed. In that case, the non-linear principal components analysis technique reduces to homogeneity analysis or multiple correspondence analysis (MCA) (see Greenacre 1984).

Subjects' scores on the 40 aspects for each occupation were averaged; the number of subjects per occupation, and the variability of scores within occupations was such that analysis on this level was considered justified. For almost all occupations, variation was considerably smaller within than between occupations. A  $32 \times 40$  data matrix of the average scores of the occupations on the work aspects was thus obtained. Next all items were pooled such, that a high score implied a negative evaluation. Following the choice of exploratory analysis technique, it was decided to explore the relationship between occupations and aspects at category level. The average scores of the occupations were recoded. If an occupation had an average score on a work aspect that was higher (more unfavourable) than the mean plus 0.2 times the standard deviation of that item, it received a score on that aspect of 3; if it had an average that was lower (more favourable) than the mean minus 0.2 times the standard deviation, it received a score of 1; otherwise, it was given a score of 2. Thus, after recoding, the higher the score of an occupation on an item, the

more unfavourable that occupation scored on that item. This categorization is in a sense arbitrary, as no external criterion was used. It is also fairly coarse, and implies loss of information. Of course, the scores could have been split into five categories, or seven. This refinement would, however, have come at a considerable price in terms of complexity and interpretability of the solution. In addition, the demarcations we used (that is, the choice for 3 categories and a demarcation at 0.2 SD) ensured reasonably evenly filled categories over all aspects, which is considered conducive for technically sound solutions in MCA.

MCA explores at category level the relationship between several categorical variables. MCA finds a best-fitting solution for both subjects as well as variables. In the solution, each subject (in this case: occupation) is assigned a set of co-ordinates, and each variable is assigned a set of co-ordinates. The configuration is optimal in the sense that subjects are located close to the variables on which they have scored frequently. Therefore, a cloud of variables is centred around each subject: variables that 'belong' to that subject. Similarly, around each variable a cloud of subjects is placed who all score frequently on that particular variable. The positions of the occupations are comparable to factor scores in factor analysis; the positions of the variables are comparable to factor loadings. Explained variances per dimension reflect the fit of the respective dimensions (comparable to the eigenvalues in factor analysis).

Clusters of subjects and variables indicate homogeneous subgroups of subjects, which exhibit a similar scoring pattern. The more specific or homogeneous groups are, the more peripherally they are placed in the configuration or structure. Conversely, centrally placed subjects and variables play a more diffuse and heterogeneous role. In the analysis conducted here, the occupations assume the role of subjects, with the work aspects as variables. By inspecting the resulting configuration—looking for clusters of occupations as subjects and work aspects as variables—one gets an impression of the structure of occupations and the aspects.

The scores '1', '2', and '3' into which the average values for each occupation have been recoded are interpreted as pattern frequencies by the technique. As such, the placement of occupations and aspects is done in such a way that occupations that score high on a certain aspect (interpreted as the occupation exhibiting this scoring pattern often) are situated close to that aspect. This implies that for the data matrix described above, in which a high score implies that a work aspect has been evaluated negatively, multiple correspondence analysis produces a configuration that stresses the negative evaluations on the aspects for the different occupations.

Next, for analysing the positive evaluations, the data matrix was modified, recoding every score of 3 into 1 and every score of 1 into 3. A high score on a work aspect for an occupation now thus signifies that the work aspect has been evaluated positively, implying that subjects in this occupation had few problems with or complaints on this aspect. Multiple correspondence analysis on this data matrix will again place occupations that score high on a certain aspect in the vicinity of that aspect. As such, multiple correspondence analysis will now produce a configuration that stresses the positive instead of the negative evaluations on the aspects for the various occupations. Thus, while multiple correspondence analysis on the first matrix produces a structure of occupations and work aspects which is based on their similarity in *negative* evaluations, the same analysis on the second matrix produces a solution based on the occupations' similarities in *positive* evaluations.

The second type of solution will not be an exactly mirrored image version of the first solution because the frequency distributions over high and low scores are not symmetric. Therefore, if an occupation has been placed on a certain spot in the configuration based on a high number of complaints on certain items, it does not imply that this occupation will receive opposite co-ordinates when structuring according to contentment. The exploratory framework is thus reflected as well in the sense that analyses will be performed from the perspective of negative as well as positive evaluations of the job.

For performing MCA, the procedure CORRESP was used in SAS version 5 (SAS 1988). For either analysis, a two-dimensional solution was chosen. The reason for choosing a two-dimensional solution is mainly ease of interpretation: experience has shown that higher-dimensional solutions are so much harder to interpret that in practice not much additional insight is derived from the

added dimensions. In practice, two-dimensional solutions are thus more or less chosen as a standard and more dimensions are added only when two-dimensional solutions produce insufficient insight.

### 3. Results

#### 3.1. General

In table 3 we give, as an overview of the (unrecoded) results of the study, the sumscores on a number of clustered aspects over ten clusters of occupations that have intrinsic similarity. For a more detailed description of the results, see Andries *et al.* (1991). From table 3 we can see that directors report a very heavy workload, much challenge, as well as quite favourable scores on autonomy, co-ordination, and qualifications. Middle management report heavy strain and workload, very hectic working conditions, and favourable scores on challenge and autonomy. Lower management personnel have a fairly average profile with only hectic working conditions and little co-ordination and insufficient qualifications deviating from average scores. Computer specialists report little strain, a very light workload and no hectic working conditions, paired with little challenge and very little autonomy. Marketing and sales personnel resemble middle management personnel, although they score more favourably on autonomy. Administrators report strain, hectic working conditions and a very heavy workload. They score favourably on autonomy, but very unfavourably on qualifications. Teachers report a pattern of non-hectic but straining and heavy work, with very little autonomy, little co-ordination and quite insufficient qualifications. Consultants are again more average: they report below average strain, and

Table 3. Occupations and job evaluations

Occupation	Strain	Hectic	Workload	Challenge	Autonomy	Coordination	Qualifications
Directors		-	>>	>	>>	>>	>>
Middle management	>>	>>	>>	>	>	-	-
Lower management	-	>	-	-	-	<	<
Computer specialists	<	<<	<<	<	<<	-	-
Marketing/sales personnel	>>	>>	>>	>	>>	-	-
Administrators	>	>	>>	-	>	-	<<
Teachers	>>	<<	>>	-	<<	<	<<
Consultants	<	-	>	>	>	-	-
Support personnel	<	<	<<	<<	<<	<	-

>> = 20% above sample average

> = 10% above sample average

- = approx. at sample average

< = 10% below sample average

<< = 20% below sample average

above average favourable scores on autonomy and challenge. Support personnel are distinguished by the lowest average level of challenge, very low autonomy and workload, insufficient co-ordination, low strain and below average scores on hectic working conditions.

3.2. Multiple correspondence analysis of the negative evaluations on work aspects

We performed multiple correspondence analysis on the 32 × 40 data matrix. For reasons outlined above, we chose a two-dimensional solution. The first and second dimension explained respectively 30.5% and

10.2% of the variance of the rescaled variables. Given the fact that we are analysing a high-dimensional problem, this result may be labelled as good.

A representation of the scores of the occupations is in figure 1a, a similar representation of the scores of the work aspects is in figure 1b; for the labels see tables 1 and 2. Both figures in fact have been extracted from the solution that contains scores of work aspects and occupations; for reasons of clarity they are presented separately. In figure 1b, we have for reasons of overview omitted a number of work aspects that were placed centrally. From figure 1a it appears that four clusters of occupations have particular patterns with regard to the

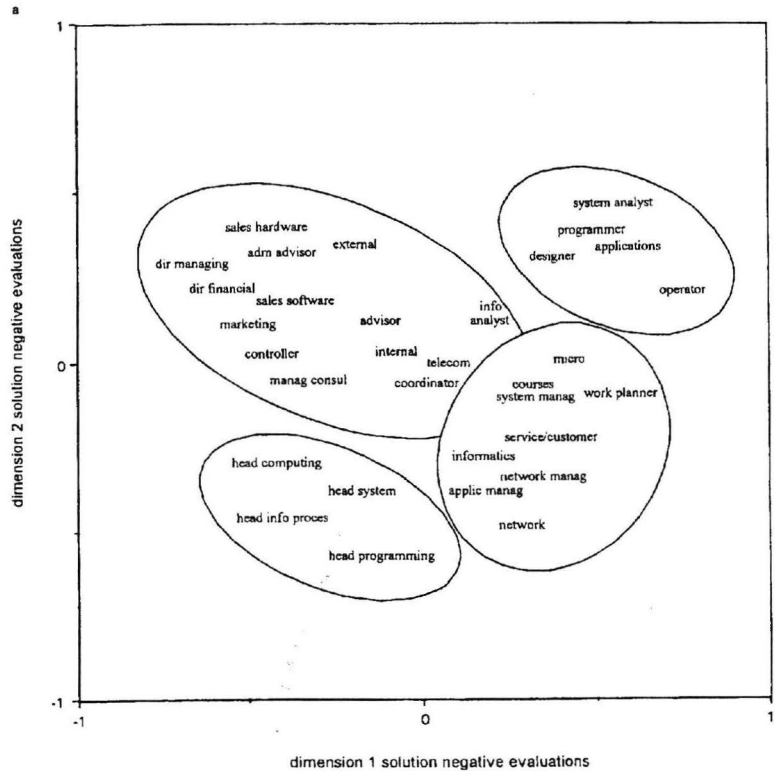


Figure 1a. Occupations in solution based on negative evaluations.

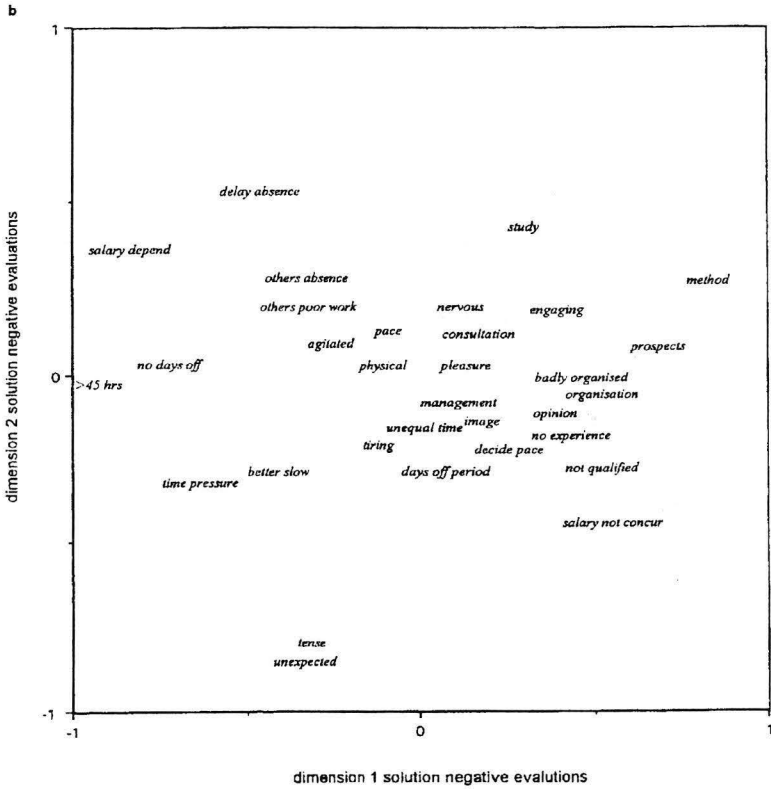


Figure 1b. Aspects in solution based on negative evaluations.

presence of job-related complaints. The clusters have been tentatively indicated in the figure; the demarcations between the clusters in between the more centrally placed occupations should be taken as fuzzy, however, as cluster membership cannot be defined that strictly with such centrally placed occupations. The first cluster is situated in the upper left-hand side of the configuration: it is composed of directors, consultants, administrative and marketing/sales personnel. The external accountant is placed, somewhat oddly, well within the first cluster, while his/her counterparts, the internal accountant and controller assume more intermediate

positions, close to the advisor and management consultant. A second fairly distinct cluster of occupations is situated in the lower left-hand side of the configuration. This cluster contains all four middle management occupations: the head of computing department, the head of information-processing department, the head of programming department and the head of system-analysis department. A third cluster is situated in the upper right-hand side of the picture. This cluster contains four computer specialists (the system-analyst, the system-analyst/programmer, the system-designer, and the applications-programmer/analyst). A little bit

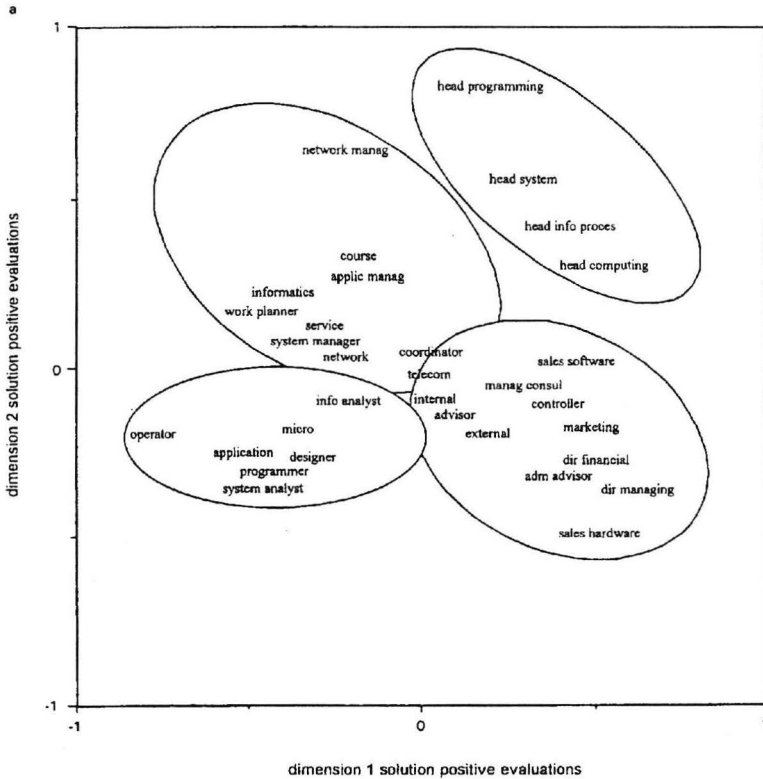


Figure 2a. Occupations in solution based on positive evaluations.

to the side but definitely still belonging to the cluster is the operator, whose occupation had been categorised 'support personnel'. A fourth cluster is formed by the mixture of all remaining occupations, namely lower management personnel, teachers and remaining support personnel (without the operator). Because it has been placed in a central position, this cluster is less marked and probably more heterogeneous than the previous ones. The network analyst is placed closest to the group of heads of departments. The network manager on the other hand, who holds a far more responsible position, is placed somewhat at odds with his qualifications and

responsible position, within the group of support personnel.

The profiles of each of the four clusters can be described using figure 1b. The occupations in the first cluster of directors, consultants, administrative- and marketing/sales-personnel are all characterized by the demanding and responsible character of their work. Typical aspects of these occupations are delay in progress in the case of absence, problems with the poor work of others and problems with the absence of others. Personnel in these professions characteristically complain that their salaries are dependent upon perfor-



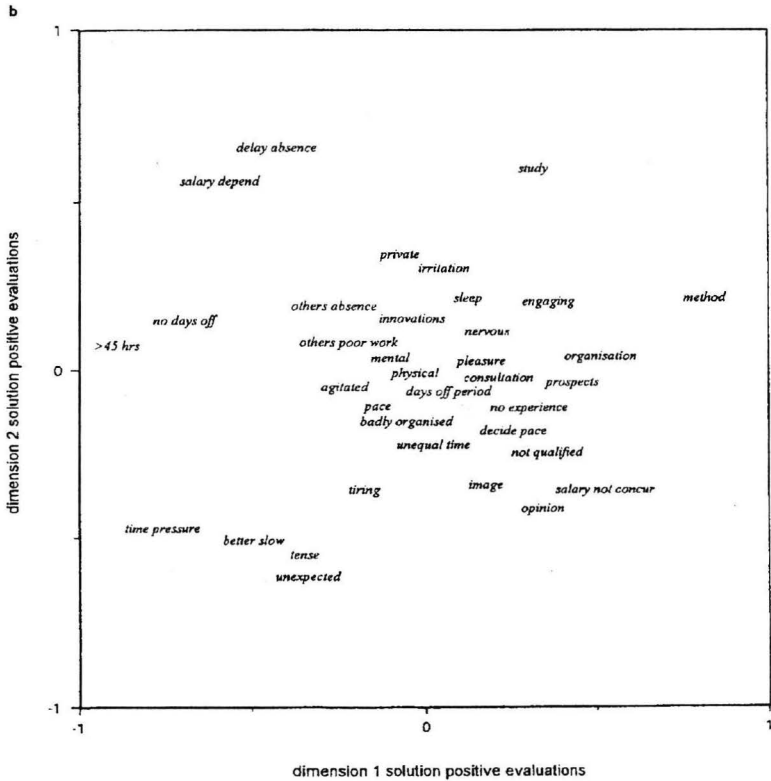


Figure 2b. Aspects in solution based on positive evaluations.

mance. Although they share this characteristic with the heads of departments in the second cluster, they report working more than 45 hours a week, and are not able to spend all their days off. They are further characterized by feelings of agitation and problems with the pace of the work.

The four heads of departments in the second cluster negatively evaluate the time pressure exerted by the job, they report a sense that they had better slow down, tension as well as bother from unexpected events. Though less characteristically so, employees in these professions also complain that the job is tiring, and that

they cannot use their off-days in the periods they would like. With the first cluster, they share long working weeks, and not being able to use days-off.

The third distinct cluster of computer specialists together with the operator are characterized by large numbers of hours spent on study, autonomy problems in deciding on the method of working, unengaging work and dim prospects. This group is characterized by nervousness, a general feeling that the management does not consult them, that the work is badly organized, as well as a desire for more autonomy in the organization of their work. The last cluster of remaining occupations,

primarily consisting of lower management, teaching and support personnel, share unfavourable judgements on salary, lack of education and experience, on daily management and the degree of autonomy in the management and pace of work.

### 3.3. Multiple correspondence analysis of positive evaluations

The same analysis was performed on the data matrix that emphasized the positive evaluations. Again, a two-dimensional solution had been chosen; the first and second dimension now explained respectively 30.0% and 11.3% of the variance of the rescaled variables, which is again a more than satisfactory result. Representations of the scores of the occupations and the work aspects are in figures 2a and 2b; for the labels again see tables 1 and 2. As in figures 1a and 1b, for reasons of clarity the most centrally placed occupations and work aspects have not been indicated. Again, clusters of work aspects have been tentatively indicated; also here the demarcations between the clusters in between the more centrally placed occupations should be taken as fuzzy rather than definite.

The structure of aspects matches that obtained in the previous analysis of negative evaluations, but for small changes on a number of items. For example, the four items 'time pressure', 'better slow', 'tense' and 'unexpected' have moved closer together. The item 'work is tiring' has moved somewhat to the periphery, meaning that the positive evaluation on this item apparently discriminates occupations better than a negative evaluation. The same applies to the items 'work influences private life in a negative way', 'irritated by colleagues' and 'sleeping problems'. Conversely, the items 'often bothered by poor work of others' and 'often hampered by the absence of others' have moved to a more central position, showing that negative evaluations on these items were fairly typical for the professions in whose vicinity they had been placed. The same applies to the 'prospects' item. All in all, the aspects configuration has become more constricted: the various items are less spread out, and especially the central part of the figure now contains a dense cloud of aspects.

Compared to the previous analysis, the structuring in the occupations picture has been mirrored on both dimensions—as indeed should be the case. Several occupations have changed position, however. The network manager has moved to a much more peripheral position, close to the heads of departments. This is consistent with the high level of complaints on salary, leadership and qualifications in this occupation. In fact, the network manager and network analyst have more or

less swapped their positions. The network analyst moved from an odd-one-out position in the group of teachers, lower management and support personnel, to a position closer to the other computer specialist occupations. This more central position matches the fairly average scores and generally low level of complaints in this group. The external accountant has moved to a position closer to his/her counterparts, the internal accountant and controller. Software sales personnel has also moved to a more central position, away from the directors, hardware sales personnel and the administrative advisor.

Apart from these changed positions of several occupations, the clustering itself of occupations has improved: it has generally become more condensed. In fact, where the first analysis showed four clusters of occupations, the present configuration can be viewed as a cloud of occupations, with two smaller deviating clusters. The main cloud contains occupations ranging from the informatics teachers, work planners and applications managers at the one extreme, towards the directors and hardware sales personnel at the other extreme. Given that items reflecting heavy workload and hectic working conditions are positioned in the right hand side of the figure, and that items reflecting favourable scores on decision making, co-ordination and education are positioned in the lower right-hand side of the figure, the area in which the main cloud of occupations has been placed can in fact be considered as an area in which job control and job demands are in a state of equilibrium.

In the upper left hand side of the cloud we find occupations that have low job demands matched with little job decision latitude and skill discretion. Moving down along the continuum to the right hand side, workload as well as autonomy and co-ordination increase. At the right end of the continuum we find occupations with high job demands matched with high skill discretion and high levels of job decision latitude. At the left end of the continuum have been placed, amongst others, informatics teachers, network managers and work planners with little autonomy, complaints on co-ordination and a small workload. Moving along to the right-hand side we encounter amongst others the system manager, network analyst, telecommunications specialist, and further onwards amongst others the internal and external accountant, management consultant, and controller. At the upper extreme are the directors and hardware sales personnel with heavy job demands matched with a relatively high degree of skill discretion and job decision latitude.

Two clusters have been placed away from the continuum, implying that these occupy a specific position of imbalance in job demands and job control.

These are the cluster of middle management occupations with the network manager—in the upper part of the configuration, and the cluster of computer specialists, together with the operator—in the lower left-hand side of the configuration. In both clusters, employees do not show extreme scores on job decision latitude items: the middle management occupations have a somewhat above average degree of autonomy, the computer specialists have a below average degree of autonomy. The two clusters differ markedly, however, in the workload they experience. From the first analysis, the employees in the cluster of computer specialists had been unfavourably characterized by little challenge, few opportunities for study and unfavourable prospects. The middle management occupations on the other hand are characterized by their heavy workload and hectic working conditions, giving rise to tension, with employees expressing that they feel they should slow down.

#### 4. Discussion

An important question to be addressed is what our results signify in terms of the job-demands job-control model (Karasek 1979). At first glance the two dimensions of the MCA-charts seem to coincide with Karasek's dimensions of job demands and job control, in which one of the diagonals expresses a tendency to more strain (low strain-high strain jobs) and another to more learning motivation to develop new behaviour (passive-active jobs). The cluster containing the directors would comprise the active jobs, the cluster with programmers the passive jobs, and the cluster with middle management the high strain jobs. The fourth cluster does not seem to fit in with the Karasek typology completely, however. To call these jobs 'low strain' does not fit with the respective items in this section, though lack of future possibilities and lack of learning motivation do suggest resemblance in content.

Our unconstrained exploratory analyses produced a structure of work aspects in which the main components of Karasek's model emerged. At the same time, we thus found some instances, where things may be more complicated. Given the resemblances in overall structure between the positive and negative configurations, the likelihood that the solutions were based on chance placements of occupations and/or aspects is small. In addition, by referring back to the original data and summary tabulations, we were able to corroborate those relations that had emerged as most characteristic. In principle, one disadvantage of our technique, is that we compare occupations only in terms of their relative number of complaints. Thus, it is theoretically possible that one occupation is interpreted as having very high

levels of complaints while in fact the level is high compared to the other occupations, but not high in an absolute sense. The comparison of the scores with respect to the reference group indicated that in general such tendencies were not present in the data.

All in all, the authors believe that the techniques employed for the analysis of their data are, although definitely not new, a useful addition to available procedures. It should be stated that the authors' techniques are not the only option. In fact, it would have been possible to apply the same kinds of recoding we applied, and fit linear and quadratic relations between the variables, and more or less the same insights might have been gained. The authors' techniques are less restrictive and more efficient. MCA, and related non-linear exploratory techniques, are strong in that they give a multivariate exploration of the pertinent relations in the data. This overview comes at the price of specificity: no tests of particular relations are made and findings should in general be taken as indicative and guiding for further, quantitative confirmatory research. (Those favouring 'standard' techniques often forget to mention that there is also a price to pay for specificity: testing ever so many bivariate cross-tabulations has distinct disadvantages as well). Another implicit gain is that the unexpected is not excluded *per se*: the structure is arrived at without constraints. An added nicety is the possibility illustrated to focus on the 'bright side of life': to employ a reverse perspective by focusing on the positive evaluations. Again, no pre-specified hypotheses were tested. Rather, comparison of the two structures revealed some unexpected patterns, which may be useful topics for further study.

The authors identified a cluster of occupations stretched out as a continuum along which equilibrium exists between psychological job demands (as indicated by workload and hectic working conditions) and job control (as indicated by autonomy, co-ordination and education). Two clusters of occupations assumed distinctly off-line positions: the middle management on the one hand and the computer specialists on the other hand. The fact that these classifications emerged more clearly in the second analysis of positive evaluations may be explained by the general result that all occupations had in absolute terms fairly low levels of complaints, which might have made it difficult to classify them on the basis of their complaints. This finding may be taken as additional use for our approach.

For the occupations in the sample with high autonomy coupled with heavy workload, pressure and hectic circumstances, the Karasek model postulates that their high job-control makes it possible to cope with high job-demands. This group should thus be less at risk of stress. For the marketeers in this group, such a

conclusion is contradicted by their unfavourable scores on the combined indicators of strain. This may be seen as an illustration of the limitations of our technique referred to above, as the multiple correspondence analysis produced a necessarily coarse summary of the relations between occupations and work aspects. It could also be taken as an indication that more complicated relations than those prescribed by the Karasek model are present. It may also be caused by a deficiency of our questionnaire that, as indicated above, was not designed with the Karasek model in mind. More research is needed to arrive at an answer here.

At the other extreme, the low-level balanced occupations (lower management, teachers and support personnel exclusive of the operators) share a relatively pessimistic outlook on their career-prospects. This is not only substantiated by their own unfavourable judgement on their degree of qualification and future prospects, but also by other data regarding their former career and actual level and type of education (Andries 1990). This applies especially to lower management regarding their degree of education and to teachers regarding the type of education needed for the job. These occupations might tentatively be labelled as 'blind-alley' occupations.

The off-balance cluster of middle management personnel is of further special interest. Heads of departments carry responsibility not only for their own work, but also for that of others. While above average, autonomy scores for this group are apparently not high enough for satisfactory management of the busy and unexpected nature of the work and for coping with their heavy workload and hectic working conditions. For this group, the risk of overburdening seems real. Added to this, middle management personnel usually have to operate between 'hammer' and 'anvil' (Mintzberg 1973), in this case the managing board and subordinate computer specialists respectively. The difficulties in planning computerization projects add further to the stressfulness of their position, especially when taking into account that for a long time turnover of personnel within project-teams was considerable (Andries 1990). In the Netherlands at the beginning of the 1990s, most middle management personnel originated from the ranks of computer specialists (such as system-analysts or programmers). Earlier research (Couger and Zawacki 1980) into work preferences of computer specialists had demonstrated a marked preference for career prospects and relatively little interest in social aspects of the job, reinforced by a process of self-selection during education. One could tentatively argue that, once arrived at the managerial level, lack of social skills may consequently cause problems in one's own functioning and the functioning of others. Perhaps the relatively

unfavourable judgement on day-to-day-management in the overall population should also be viewed in this context. A last explanation for this group's position may be lack of education in the rapidly changing world of information technology (Backlund 1986, Aronsson 1989).

The second group suffering from imbalance are the programmers, system-analysts and system-designers. They emerge as an underchallenged group: workload, hectic elements in the working situations and elements of work-related strain play a small role. The group is typified instead by negative judgements on the challenge and degree of autonomy, especially concerning the method of working. The fact that these computer specialists reportedly spend a lot of time on study, can be explained as an effort to escape from their unstimulating job through further education. They can be characterized as 'starters': the average age is just over 30, and for most this is their first job (Andries 1990). This generalization applies to the operators as well, especially regarding the lack of autonomy in their method of working. Combined with their position in this analysis close to low workload and the absence of hectic aspects, it appears that for this group the risk of 'under-burdening' may be present (Cox 1985).

Even though the authors have thus found an interpretable and manageable structure of occupations and work aspects, further research is needed to assess whether occupations that are theoretically at risk, will indeed experience stress, lowered motivation, decreased performance and increased absenteeism. Our results showed that for a number of occupations, indicators of strain did not match model-driven expectations. Some elements may therefore need to be added to the model to explain the patterns found. One such element may be the interaction with customers, and the manner in which personnel succeed in translating customers' needs into marketable products. The uncontrollability of this process and its impact on mental strain could be further intensified by the (social) distance between those responsible for customers contacts and those who have final responsibility for automation products. Furthermore, the deviations found may also be due to occupation- or sector-specific invalidity of operationalizations of job decision latitude. Autonomy is a concept of little practical use if employees are free to choose their method and pace of working, but still need to finish their unplannable work on time in a heavily competitive environment.

The information technology sector has witnessed ongoing rapid growth in volume, with corresponding growth in the number of new or newly titled occupational and educational domains. For that matter we would like to stress that, given that the

occupational spectrum within information technology is rapidly changing, it has to be doubted whether all of our findings (based on data collected in 1989) can be generalized to present-day working conditions. For some occupations, this is doubtful for sure: for instance network administrators' job contents have changed substantially over the past decade. At the same time, the authors believe that the findings for managerial personnel are still valid to a large extent, as their job content has altered far less. These developments are only part of the many justifications for scientific interest in the rapidly changing world of information technology, not in the least for the sector's impact on future working- and living-conditions. For these reasons, ongoing research into working conditions and their effect on indicators of physical and mental well-being among information technology personnel is warranted.

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Towards a better understanding

Arbeidsuitval door burn-out.

OTTEN F, SMULDERS PGW EN ANDRIES F.

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## arbeidsmarkt

# Arbeidsuitval door burn-out

*De overmaat aan psychisch gerelateerde arbeidsuitval bij vrouwen hangt niet samen met werkbelasting. Kinderloosheid speelt wel een rol.*

F. Otten, P. Smulders en F. Andries\*

Het aantal arbeidsongeschikte Nederlanders nadert het miljoen. Eerdere maatregelen om de trendmatige stijging structureel om te buigen, haalden weinig uit. Van de deze zomer door de commissie-Donner voorgestelde aanpassing van de WAO wordt, indien deze wordt aangenomen door het parlement, wel degelijk verwacht dat ze de WAO-problematiek terug zal dringen. Kern van het wijzigingsvoorstel is dat iedere nieuwkomer die niet voor de volle honderd procent langdurig arbeidsongeschikt wordt verklaard, geen WAO-uitkering krijgt. Dat de lat zo hoog wordt gelegd, is mede ingegeven door de huiver voor het steeds groter wordende contingent dat op grond van psychische klachten de WAO instroomt. Al bijna de helft van de instroom van jonge mensen komt voor rekening van psychische klachten<sup>1</sup>. Daarbij gaat het in hoofdzaak om depressies, angststoornissen en burn-out. Er stromen meer vrouwen dan mannen in met psychische klachten.

Tot op heden is het grotendeels onduidelijk welke factoren precies verantwoordelijk zijn voor de overmaat aan psychisch gerelateerde arbeidsuitval bij vrouwen. Weliswaar hebben vrouwen vaker dan mannen minder autonomie en minder mogelijkheden om zich in

het werk te ontplooiën<sup>2</sup>, maar dat houdt slechts beperkt verband met hogere arbeidsuitval<sup>3</sup>. Bovendien is de veelgehoorde suggestie dat meervoudige belasting van vrouwen door werk, zorg voor kinderen of anderen, en zorg voor het huishouden een belangrijke reden is voor de overmaat aan arbeidsuitval, nimmer empirisch hard gemaakt. Wel zijn er aanwijzingen dat vrouwen bij langdurig ziekteverzuim vanwege psychische klachten minder snel hun werk hervatten dan mannen<sup>4</sup>.

Er moeten nog andere factoren bestaan die de verschillen tussen mannen en vrouwen in psychisch gerelateerde arbeidsuitval kunnen verklaren. Het gegeven dat juist meer vrouwen zonder kinderen burn-out klachten berichten dan vrouwen met kinderen is wellicht een indicatie<sup>5</sup>. Aangezien gescheiden en verweduwd personen bovengemiddeld kwetsbaar zijn voor psycho-sociale belasting speelt burgerlijke staat mogelijk eveneens een rol<sup>6</sup>.

### Empirie

Met gegevens van ruim 4000 werkenden uit de TNO Arbeids-situatie Survey 2000 (TAS), is onderzocht of huishoudensamenstelling, burgerlijke staat en psychische werkbelasting bij vrouwen sterker aan burn-out zijn gerelateerd dan bij mannen<sup>7</sup>. Vervolgens is onderzocht of deze kenmerken bij vrouwen in vergelijkbare mate aan zowel burn-out als ziekteverzuim zijn gerelateerd. Dit laatste wijst op grote overlap tussen de door het betreffende kenmerk gegenereerde aandelen ziekteverzuim en burn-out-klachten. Indien beide onderzoeksvragen worden bevestigd, speelt het betreffende kenmerk waarschijnlijk een relevante rol in de huidige, verhoogde WAO-instroom van vrouwen.

*Werkende vrouw heeft niet meer burn-out klachten...*

Burn-out is in de TAS gemeten aan de hand van vijf vragen uit de zogeheten *Utrechtse burnout schaal*<sup>8</sup>. Deze vragen verwijzen naar emotionele uitputting op het werk, wat te beschouwen is als de kern dimensie van burn-out. Zij die gemiddeld minimaal een keer per week met deze vormen van emotionele uitputting kampen, zijn ingedeeld als personen met burn-out-klachten. Aldus wordt vijftien procent van de werkzame beroepsbevolking geconfronteerd met burn-out. Er is geen verschil tussen mannen en vrouwen.

*...maar verzuimt meer*

Van de werkzame beroepsbevolking heeft 29 procent twee keer of vaker het werk verzuimd. Naar verhouding verzuimen meer vrouwen dan mannen het werk (35 tegen 25 procent).

### Werkstress

Volgens een veel gebruikt model voor werkstress worden psychische gezondheidsklachten vooral veroorzaakt door de combinatie van hoge werkdruk met wei-

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6. J.S. House, C. Robbins en H.L. Metzger, The association of social relationships and activities with mortality: prospective evidence from the Tecumseh Community Health Study, *American Journal of Epidemiology*, 1982, blz. 123-140.

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\* De auteurs zijn werkzaam bij TNO Arbeid te Hoofddorp. Ferry Otten werkt tevens bij het CBS te Heerlen.

	mannen	vrouwen	totaal
psychische werkbelasting			%
beperkte werkdruk + hoge controle	40	37	39
beperkte werkdruk + lage controle	29	32	31
hoge werkdruk + hoge controle	21	16	19
hoge werkdruk + lage controle	9	15	12
totaal	100	100	100

Tabel 1.  
Psychische  
werkbelasting  
naar geslacht,  
in procenten

nig controlemogelijkheden in het werk<sup>9</sup>. Controlemogelijkheden verwijzen naar de mate van taak-autonomie en ontplooiingsmogelijkheden in het werk. In de TAS is naar alle aspecten van werkdruk en controlemogelijkheden gevraagd. Per concept zijn samenvattende tweedelingen gemaakt die vervolgens zijn gecombineerd. Tabel 1 laat zien dat de voor de psychische gezondheid meest fnuikende combinatie van hoge werkdruk en lage controlemogelijkheden bij vrouwen vaker voorkomt dan bij mannen: vijftien tegen negen procent. De meest gunstige combinatie, te weten beperkte werkdruk en hoge mate van controle, komt het vaakst bij mannen voor: veertig procent.

#### Institutioneel leefpatroon

Om overlap te vermijden zijn de kenmerken burgerlijke staat en huishoudensamenstelling samengevoegd tot één kenmerk, in het verdere verloop steeds aangeduid als institutioneel leefpatroon. Het institutionele leefpatroon verschilt tussen mannen en vrouwen. Werkende vrouwen maken relatief vaker dan mannen deel uit van een samenlevingsvorm zonder kinderen (32 tegen 24 procent) en relatief minder vrouwen van een samenlevingsvorm met kinderen (34 tegen 54 procent). Verhoudingsgewijs meer vrouwen dan mannen maken deel uit van een eenoudergezin (negen tegen twee procent). Deze vrouwen zijn grotendeels gescheiden of verzuimd. Ook zijn werkende vrouwen vaker alleenstaand dan mannen van wege een scheiding of overlijden van de partner (vijf tegen twee procent). Bij zowel mannen als vrouwen heeft ongeveer twintig procent nooit een samenlevingspartner gehad.

#### Psychische belasting en uitval

Met regressieanalyse zijn apart voor mannen en vrouwen de kenmerken burn-out en ziekteverzuim gerelateerd aan psychische werkbelasting en het institutioneel leefpatroon. Daarbij is tevens rekening gehouden met de invloed van leeftijd, opleiding en meerdere objectieve werkkenmerken, waaronder lichamelijke werkbelasting en werkdruk.

In tabel 2 zijn de samenhangen weergegeven door 'odds'-ratio's<sup>10</sup>. Deze kunnen bij benadering als kansverhoudingen worden geïnterpreteerd. Bijvoorbeeld: mannen die moeten werken onder hoge werkdruk met tegelijkertijd lage controle over hun werk, hebben 8,31 keer meer kans op burn-out-klachten dan mannen die onder beperkte werkdruk met tegelijkertijd hoge controle werken. Nadeel van een odds-ratio is dat deze maat niets zegt over de omvang van het betreffende gezondheidsprobleem. Een groep mensen kan wel een sterk verhoogde kans op een bepaalde gezondheidsklacht hebben, maar als deze groep in aantal beperkt is, dan is ook het onderliggende gezondheidsprobleem relatief beperkt.

Om dit probleem te ondervangen is steeds voor het gehele kenmerk het zogeheten populatie attributieve risicopercentage berekend<sup>11</sup>. Het populatie attributieve risicopercentage van psychische werkbelasting ten aanzien van burn-out bedraagt bij mannen 45 procent. Dit betekent dat indien er geen belasting zou zijn, dus indien alle mannen alleen onder beperkte werkdruk met tegelijkertijd hoge controle over hun werk zouden werken, het aandeel mannen met burn-out klachten met 45 procent zou verminderen. Voor burn-out is op vrouwen een vergelijkbare samenhang van toepassing. De odds-ratio's zijn vrijwel eender aan die bij mannen. Ook het populatie attributieve risicopercentage ligt met 48 procent niet significant hoger dan dat van mannen. Indien ziekteverzuim het te analyseren eindpunt vormt, geldt dat bij

mannen de odds-ratio's voor het merendeel aanmerkelijk kleiner zijn, evenals het populatie attributieve risicopercentage (28 procent). Bij vrouwen is de reductie in odds-ratio's en attributief risicopercentage (vijftien procent) nog fors. Psychische werkbelasting is bij vrouwen dus minder sterk aan ziekteverzuim gerelateerd als bij mannen.

Voor wat betreft psychische werkbelasting verschillen mannen niet van vrouwen in daarmee gepaard gaande burn-out-klachten. Zowel bij mannen als vrouwen zijn de samenhangen bij ziekteverzuim echter aanmerkelijk kleiner dan die bij burn-out. Dit betekent waarschijnlijk dat psychische werkbelasting niet bijdraagt aan verklaring van het verschil in WAO-instroom tussen vrouwen en mannen.

#### Leefpatroon en uitval

De samenhangen tussen institutioneel leefpatroon enerzijds en burn-out klachten en ziekteverzuim anderzijds zijn veelzeggender. Ten aanzien van burn-out klachten draagt het populatie attributieve risicopercentage bij vrouwen 43 en bij mannen twintig

9. R.A. Karasek en T. Theorell, *Healthy work, stress, productivity and the reconstruction of working life*. Basic Books, New York, 1990.

10. Een odds-ratio staat voor een verhouding van conditionele kansverhoudingen en kan bij benadering beschouwd worden als een verhouding van kansen op het optreden van een bepaalde gebeurtenis tussen twee groepen. Bij de twee groepen gaat het om de verhouding tussen een expositiegroep, de groep personen die is blootgesteld aan een bepaalde omstandigheid, en een standaard referentiegroep. Indien er geen samenhang is heeft de ratio de waarde 1. Is er een negatieve samenhang, dan ligt de waarde ervan tussen 0 en één; bij een positieve samenhang ligt de waarde van de odds-ratio tussen 1 en oneindig.

11. Een populatie attributief risicopercentage is een soort gewogen som van, voor het merendeel, positieve odds-ratio's. De weegcoëfficiënten worden gevormd door de proportionele verdeling van de desbetreffende expositiegroepen. Het aldus verkregen percentage varieert tussen 1 en oneindig en heeft betrekking op het percentage gebeurtenissen dat niet zou zijn opgetreden als de desbetreffende 'expositie' in de populatie niet van toepassing zou zijn.



procent. Bij vrouwen gaat het institutioneel leefpatroon dus gepaard met ruim dubbel zoveel burn-out-klachten als bij mannen. Bovendien laten de odds-ratio's zien dat bij vrouwen het verband voor een belangrijk deel voortkomt uit verschillen tussen de twee getalsmatig grootste groepen: vrouwen met partner maar zonder kinderen en vrouwen met zowel partner als kinderen. De eerstgenoemde groep loopt ruim tweemaal meer risico op burn-out-klachten als laatstgenoemde. Bij de mannen is dit verband compleet afwezig. Wel is er overeenstemming van een tendens tot overeenstemming tussen mannen en vrouwen bij de overige onderscheiden groepen van institutioneel leefpatroon.

Worden de samenhangen tussen institutioneel leefpatroon en ziekteverzuim gezien dan valt op dat voor zowel vrouwen als mannen de omvang van het verzuimprobleem vrijwel even groot is als de omvang van de burn-out-klachten. Wederom is bij vrouwen sprake van een ruim dubbel zo groot probleem als bij mannen. Bovendien laten de afzonderlijke odds-ratio's zien dat de aard van de samenhang sterk overeenkomt met die van burn-out klachten. Uitzondering hierop is de getalsmatig zeer kleine groep vrouwen die bewust gekozen heeft voor een eenoudergezin.

#### Kinderloosheid

Grosso modo mag geconcludeerd worden dat bij vrouwen de verbanden tussen institutioneel leefpatroon met burn-out en met ziekteverzuim in hoge mate sporen. De in vergelijking met mannen bij vrouwen geconstateerde overmaat aan burn-out klachten en ziekteverzuim komt vrijwel geheel voor rekening van de verhoogde risico's bij vrouwen die met een partner samenleven maar geen kinderen hebben. Daarmee hebben we hier een belangrijke factor te pakken die bijdraagt aan de verklaring van het verschil in arbeidsuitval op grond van psychische klachten en daarmee aan

Tabel 2. Odds-ratio's (OR's) en populatie attributieve risicopercentages (PAR's) van psychische werkbelasting en institutioneel leefpatroon t.a.v. burn-out klachten en ziekteverzuim bij werkende vrouwen en mannen, gecorrigeerd voor leeftijd, opleiding en meerdere objectieve werkkenmerken, waaronder lichamelijke werkbelasting en werkdruk

	mannen		Burn-out		verschil	ziekteverzuim		verschil
	OR	PAR	OR	PAR	ΔOR	ΔPAR	OR	PAR
psychische werkbelasting		45%*		46%*		3%		28%*
beperkte werkdruk + hoge controle	1,00		1,00				1,00	1,00
beperkte werkdruk + lage controle	1,68*		1,99*		0,31		2,04*	0,97
hoge werkdruk + hoge controle	4,46*		5,83*		1,37		1,84*	0,83
hoge werkdruk + lage controle	8,31*		9,40*		1,09		3,05*	2,45*
institutioneel leefpatroon		20%*		43%*		23%*		18%*
samenleefpartners zonder kinderen	0,99		2,62*		1,63*		1,18	2,02*
samenleefpartners met kinderen	1,00		1,00				1,00	1,00
eenoudergezin: gescheiden of verweduwd	0,69		0,95		-0,40		4,60*	1,29
eenoudergezin: bewust voor gekozen	nvt		0,24		nvt		nvt	2,68*
alleenstaand: gescheiden of verweduwd	2,05		2,53*		0,48		1,32	3,41*
alleenstaand: nooit samenleefpartner gehad	2,25*		1,90*		-0,35		1,64*	2,28*

\* = significant op vijfprocentniveau tweezijdige toetsing.

WAO-instroom tussen mannen en vrouwen.

De uitkomsten rondom de andere gehanteerde kenmerken in de analyses leverden geen verdere aanwijzingen op voor verklaring van het verschil in WAO-instroom tussen mannen en vrouwen vanwege psychische klachten.

#### Conclusie

In 2000 kampte ongeveer vijftien procent van zowel het vrouwelijke als het mannelijke deel van werkend Nederland met burn-out-klachten. Meer vrouwen dan mannen verzuimden het werk wegens ziekte. Bovendien waren meer vrouwen dan mannen blootgesteld aan psychische werkbelasting in de vorm van een hoge werkdruk en weinig controle-mogelijkheden. Onze analyses laten echter zien dat de psychische werkbelasting bij vrouwen niet sterker aan burn-out-klachten is gerelateerd dan bij mannen. Ten aanzien van het ziekteverzuim geldt zelfs dat bij vrouwen de samenhang aanmerkelijk minder sterk is dan bij mannen. Dit betekent dat de met psychische werkbelasting gepaard gaande arbeidsuitval bij vrouwen waarschijnlijk kleiner is dan bij mannen. De overmaat aan vrouwelijke WAO-instromers houdt dus geen

verband met deze psychische werkbelasting.

De enige factor die wel duidelijk samenhangt met de overmaat aan psychisch gerelateerde arbeidsuitval bij vrouwen is het institutioneel leefpatroon. Vrouwen met een samenleefpartner maar zonder kinderen dragen hoofdzakelijk bij aan de overmaat in arbeidsuitval. Hoewel deze bevinding een belangrijke schakel vormt in de zoektocht naar risicofactoren voor psychisch gerelateerde arbeidsongeschiktheid bij vrouwen, kunnen we hiervoor geen empirisch onderbouwde verklaring aanvoeren.

Vanwege de geconstateerde samenhang verwachten we dat concretisering van de plannen van de commissie-Donner relatief veel samenlevende vrouwen zonder kinderen financieel zal treffen. Het is waarschijnlijk dat deze vrouwen bij optredende, gedeeltelijke arbeidsongeschiktheid voor het merendeel terugvallen op het inkomen van hun partner. Daarmee zou na Donner het gemiddelde besteedbare huishoudensinkomen van relatief jonge partners zonder kinderen kunnen dalen.

Ferdie Otten, Peter Smulders en Frank Andriess

Towards a better understanding

Which chronic conditions are associated with better or poorer quality of life?

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DE BOER JB, FOETS M, HOEYMANS N, JACOBS AE, KEMPEN GIJM,  
MIEDEMA HS, TIJHUIS MAR, DE HAES HCJM.

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## Which chronic conditions are associated with better or poorer quality of life?

Mirjam A.G. Sprangers<sup>a,\*</sup>, Ellen B. de Regt<sup>a</sup>, Frank Andries<sup>b</sup>, Heleen M.E. van Agt<sup>c</sup>,  
Rob V. Bijl<sup>d</sup>, Josien B. de Boer<sup>e</sup>, Marleen Foets<sup>f</sup>, Nancy Hoeymans<sup>g</sup>, Annelies E. Jacobs<sup>h</sup>,  
Gertrudis I.J.M. Kempen<sup>i</sup>, Harold S. Miedema<sup>j</sup>, Marja A.R. Tijhuis<sup>k</sup>, Hanneke C.J.M. de Haes<sup>l</sup>

<sup>a</sup>Department of Medical Psychology, Academic Medical Center, University of Amsterdam, Meibergdreef 15, 1105 AZ Amsterdam, The Netherlands

<sup>b</sup>NIA TNO, Leiden, The Netherlands

<sup>c</sup>Instituut Maatschappelijke Gezondheidszorg, Erasmus University, Rotterdam, The Netherlands

<sup>d</sup>Netherlands Institute of Mental Health and Addiction, Utrecht, The Netherlands

<sup>e</sup>Department of Medical Psychology and Psychotherapy, Erasmus University, Rotterdam, The Netherlands

<sup>f</sup>Netherlands Institute of Primary Health Care (NIVEL), Utrecht, The Netherlands

<sup>g</sup>National Institute of Public Health and the Environment, Bilthoven, The Netherlands

<sup>h</sup>Centre for Quality of Care Research (WOK), University of Nijmegen, Nijmegen, The Netherlands

<sup>i</sup>Northern Center for Healthcare Research, Groningen and Department of Medical Sociology, Maastricht University, Maastricht, The Netherlands

<sup>j</sup>TNO Prevention and Health, Leiden, The Netherlands

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### Abstract

The objective of the present study is to compare the QL of a wide range of chronic disease patients. Secondary analysis of eight existing data sets, including over 15,000 patients, was performed. The studies were conducted between 1993 and 1996 and included population-based samples, referred samples, consecutive samples, and/or consecutive samples. The SF-36 or SF-24 were employed as generic QL instruments. Patients who were older, female, had a low level of education, were not living with a partner, and had at least one comorbid condition, in general, reported the poorest level of QL. On the basis of rank ordering across the QL dimensions, three broad categories could be distinguished. Urogenital conditions, hearing impairments, psychiatric disorders, and dermatologic conditions were found to result in relatively favorable functioning. A group of disease clusters assuming an intermediate position encompassed cardiovascular conditions, cancer, endocrinologic conditions, visual impairments, and chronic respiratory diseases. Gastrointestinal conditions, cerebrovascular/neurologic conditions, renal diseases, and musculoskeletal conditions led to the most adverse sequelae. This categorization reflects the combined result of the diseases and comorbid conditions. If these results are replicated and validated in future studies, they can be considered in addition to information on the prevalence of the diseases, potential benefits of care, and current disease-specific expenditures. This combined information will help to better plan and allocate resources for research, training, and health care. © 2000 Elsevier Science Inc. All rights reserved.

**Keywords:** Quality of life; Health status; Functioning; Chronic disease; Comparison

### 1. Introduction

The past decades have witnessed an increasing prevalence of chronic disorders, as a result of better prevention, management of infectious diseases, improved living conditions, medical technological improvements, and the overall aging of the population. The health-related quality of life (QL) of patients with chronic disorders is frequently impaired. An important objective of health care in the U.S. and other Western countries is to increase the span of life years while maintaining an optimal QL [1,2]. QL is not only a primary concern of patients, their families, and clinicians, but is also of policy interest. Estimates of the relative impact of

chronic diseases on QL are needed to better plan and allocate resources for research, training, and health care.

While numerous studies have addressed the impact of chronic diseases and their treatment on QL, the relative impact of different chronic conditions on patients' level of subjective functioning is mostly unknown [3,4]. On the basis of a systematic literature review,<sup>1</sup> we identified only 20 studies [3–22] that compared the QL across chronic disease

<sup>1</sup>A series of literature searches was conducted on MEDLINE and CLINPSYCH databases for the years 1992–1998, to identify studies that compared the QL across chronic disease populations. The medical subject headings "quality of life" and its equivalents (i.e., "well-being," "health status," "physical, psychological or social functioning") were combined with "chronic disease." Additionally, searches were performed on the basis of the combinations "psychological adaptation," "psychological distress,"

\* Corresponding author. Tel: 31-20-566-4661; fax: 31-20-566-9104.  
E-mail address: m.a.sprangers@amc.uva.nl (M.A.G. Sprangers).

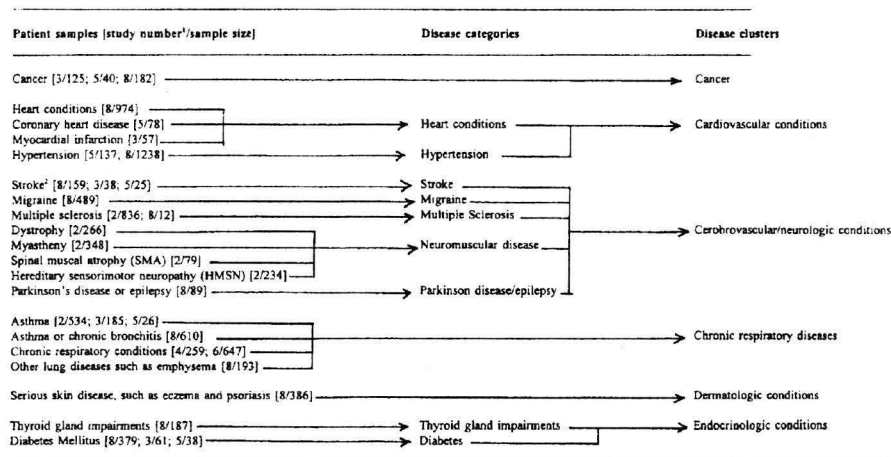


Fig. 1. Composition of patient samples, disease categories, and disease clusters.

populations. The question arises what these studies reveal about the relative position of the conditions regarding QL. To enable a comparison across conditions, they were aggregated into disease clusters. For example, hypertension and myocardial infarction have been grouped into a cluster labeled "cardiovascular conditions" (Fig. 1). These disease clusters were then compared within each study. These comparisons resulted in a positive, an equivalent, or a negative position of each disease cluster relative to other disease clusters with respect to physical/functional and/or psychosocial well-being. The relative position of each disease cluster was then established across studies (Table 1).

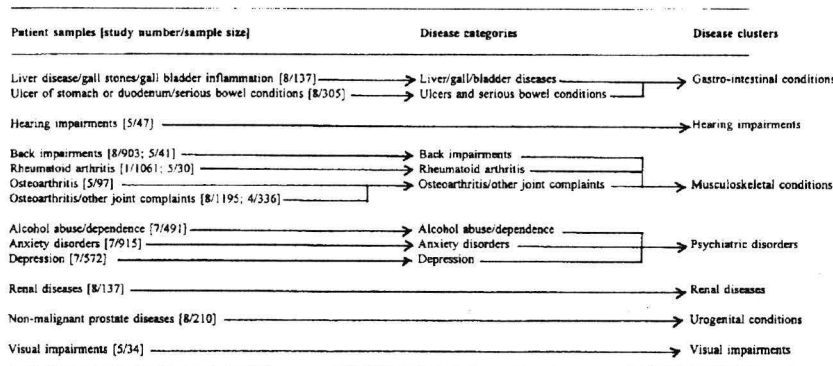
Both musculoskeletal and renal disease were found to result in greater physical and functional impairments, while the psychosocial sequelae were modest. The remaining chronic conditions appear to have a comparable impact on both physi-

cal/functional and psychological/social aspects of well-being. Hearing or visual impairments, gastrointestinal diseases, and endocrinologic conditions appear to hold a predominantly positive position relative to other diseases. A broad group encompassing chronic respiratory diseases, cancer, urogenital conditions, cardiovascular conditions, musculoskeletal conditions, and renal diseases was found to have both a positive and negative position relative to other conditions. Finally, the disease clusters that were found to hold mainly a negative position include AIDS, cerebrovascular/neurologic conditions, and psychiatric disorders. Clearly, given the underrepresentation of a number of disease clusters (e.g., hearing impairments and renal disease), the heterogeneity of the studies with respect to sample composition, sample size, instruments and procedures, and the methodological limitations inherent in such comparisons, these results need to be viewed with caution.

Empirical data are needed to corroborate these findings. We therefore investigated the level and profiles of QL in a wide range of chronic disease populations in response to a request of the Netherlands Committee of Chronic Diseases. This committee wished to gain insight into the relative impact of chronic diseases on QL, which could help to better allocate research funds. A secondary analysis on eight existing data sets was conducted. The research questions were threefold and pertained to the extent to which: a) sociodemographic characteristics and comorbidity affect QL across chronic disease patients, b) disease categories within their respective disease clusters differ in the level and pattern of QL, and c) the disease clusters themselves differ in the level and pattern of QL. The terms QL, well-being, health status, and functioning will be used interchangeably.

"social support," "social adjustment," "activities of daily living" on the one hand and "chronic disease" on the other. Additional searches were conducted via the references lists of the selected articles. Studies published in English and Dutch were included in the review. Studies were selected for review in which: a) at least two different chronic diseases were compared; b) at least one of the four QL dimensions was examined (i.e., physical, functional, psychological, or social well-being); and c) the levels (means) of these dimensions were compared and/or tested across the chronic disease populations. Studies were excluded from this review that were concerned with pediatric subjects (i.e., children, adolescents), because the problems involved in pediatric health care are substantially different from those encountered with adult patients. The search identified 20 studies that met these criteria. Because the research in this area is multidisciplinary, it is difficult to know if one has collated an exhaustive list of references. Nevertheless, given the identified approach, we are confident that the studies included provide a representative picture of the current research in this area. The literature study is documented in: Haes de JCJM, Sprangers MAG, Regt de HB et al. *Adaptieve Opgaven Bij Chronische Ziekte*. Nederlandse Organisatie voor Wetenschappelijk Onderzoek. Den Haag, 1997.

Figure 1. Continued



<sup>1</sup> For a description of data sets, see Appendix.

<sup>2</sup> There is some dispute whether stroke should be subsumed under cardiologic or neurologic conditions. Since the consequences of stroke have striking similarity with those of neurologic conditions and stroke patients are frequently treated at neurologic departments, stroke is here subsumed under neurologic conditions.

Fig. 1. Continued.

## 2. Methods

### 2.1. Selection of data sets

To identify relevant data, all research groups known to examine chronic diseases in the Netherlands were mailed a questionnaire asking detailed information about available data sets that could be used for secondary analysis. Thirty-two potentially relevant data sets were thus identified. The following guidelines were used to select studies: 1) full coverage of QL domains (i.e., physical, functional, psychological, and social well-being) [23,24]; 2) use of standardized QL instruments; 3) inclusion of a range of chronic diseases; 4) large overall sample size (preferably more than 200); 5) medically confirmed diagnoses (In contrast to self-report); 6) recency of data (since 1992); and 7) breadth of accrual in terms of geographical regions. While these criteria were not always fulfilled (e.g., diagnoses were frequently based on self-report), the use of a similar, standardized QL instrument was employed as the most important criterion, given the study objective. Eight data sets were thus selected. The remaining 24 data sets employed a different questionnaire, included only one or two disease categories, and/or were based on small samples accrued in restricted geographical regions. A detailed description of the selected data sets is provided in the Appendix.

### 2.2. Levels of aggregation

These eight data sets provided information of 47 patient samples and over 15,000 patients (see Appendix). Two levels

of aggregation were distinguished. First, patient samples were combined when they belonged to the same disease category (e.g., hypertension in datasets 5 and 8). Second, the disease categories were combined to form disease clusters (e.g., hypertension and heart condition were grouped into a cluster labeled cardiovascular conditions). In some cases, all the individual patient samples could be combined into one cluster (e.g., chronic respiratory diseases), or the cluster consisted of only one patient sample (e.g., hearing impairments) (Fig. 1).

### 2.3. Provided data

#### 2.3.1. Dependent measures

The MOS 36-Item Short-Form Health Survey (SF-36) has been used in seven studies. The SF-36 is a generic health status instrument designed for use across a wide range of chronic disease populations. The SF-36 has been shown to have excellent reliability and validity when employed with diverse patient populations in the U.S. [25,26] and the Netherlands [27,28].

The SF-36 is composed of 36 items, organized into 8 multi-item scales covering a similar number of dimensions, including physical functioning (PF), physical role functioning (PRF), bodily pain (BP), general health (GH), vitality (V), social functioning (SF), emotional role functioning (ERF), and mental health (MH). These dimensions are ordered from first to last according to the extent to which they measure physical or mental functioning [29]. One additional item pertains to health transition (HT). On the basis of these separate subscales, component summary scores were calculated to pro-

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Table 1  
Relative position of disease clusters according to physical/functional and psychological/social well-being: results from the literature\*

Disease clusters	Physical/functional well-being			Psychological/social well-being <sup>b</sup>		
	Positive <sup>c</sup> N [references]	Equivalent N [references]	Negative N [references]	Positive N [references]	Equivalent N [references]	Negative N [references]
Hearing impairments	1 [19]	—	—	1 [9]	—	—
Gastrointestinal diseases	4 [5,10,18,21]	—	1 [3]	3 [12,18,21]	—	1 [3]
Visual impairments	2 [10,19]	—	1 [4]	1 [9]	—	—
Endocrinologic conditions	8 [6,10,11,13,15,16,21,22]	2 [3,20]	1 [19]	6 [7,11,12,13,21,22]	3 [3,17,20]	1 [9]
Chronic respiratory diseases	6 [10,13,15,16,19,21]	2 [3,4]	1 [5]	2 [13,21]	—	3 [3,4,9]
Cancer	4 [4,6,15,16]	—	3 [5,10,19]	3 [4,7,9]	1 [17]	1 [12]
Urogenital conditions	1 [10]	—	1 [4]	1 [9]	1 [13]	—
Cardiovascular conditions	5 [5,10,11,13,16]	1 [20]	5 [3,6,15,19,21]	4 [1,12,13,21]	2 [17,20]	2 [3,9]
Musculoskeletal conditions	3 [3,10,21]	1 [14]	5 [13,15,16,18,19]	5 [3,7,8,13,21]	1 [17]	2 [9,18]
Renal diseases	—	—	1 [5]	2 [7,8]	—	—
AIDS	—	1 [4]	—	—	—	1 [4]
Cerebrovascular/neurologic conditions	2 [13,20]	2 [4,14]	7 [5,6,10,15,16,18,22]	1 [13]	2 [4,20]	4 [8,9,18,22]
Psychiatric disorders	1 [13]	—	4 [10,11,20,21]	—	—	5 [7,11,13,20,21]

\*Two papers [32,33] were identified that reported results which, in part, were included in the secondary analysis. These two papers were therefore not included in this overview.

<sup>b</sup>Results pertaining to satisfaction or judgements on intrusiveness are reported under the heading of psychological/social well-being, also if these ratings concern physical functioning. If the physical and psychosocial results are combined, these results are subsumed under the heading of psychosocial well-being.

<sup>c</sup>Positive is better well-being (significantly higher well-being score) in comparison to other chronic disease clusters; equivalent is equivalent well-being (insignificantly different well-being score) relative to other clusters; negative is poorer well-being (significantly lower well-being score) in comparison to other clusters. The level of statistical significance was set at  $p < 0.05$  [7-10,12,14,16,18]. Two studies [4,19], however, did not statistically test the differences among mean scores. In these cases, the conclusions of the authors were followed. In other studies [3,5,6,11,13,15,17,20-22], disease categories had to be combined, in which case the mean scores were averaged. In these cases the comparisons could not be based on statistical significance.

—: not applicable.

<sup>d</sup>The integers pertain to the papers cited in the references list. These studies include the following outcome variables: [3] Stewart *et al.* 1989: physical and mental functioning based on the MOS SF-36; [4] Schlenk *et al.* 1998: physical and mental functioning based on the MOS SF-36; [5] Bos van den, 1995: activity level based, in part, on a standardized questionnaire derived from ICDH and QL studies; [6] Boulton *et al.* 1994: functional limitations based, in part, on (Instrumental) Activities of Daily Living; [7] Cassileth *et al.* 1984: global and specific emotional well-being based on the Mental Health Index; [8] Devins *et al.* 1993: negative impact on social and personal functioning based on the Illness Intrusiveness Rating Scale; [9] Dorfman 1995: satisfaction with health, activities and social functioning based on the Retirement Descriptive Index; [10] Haber 1971: functional limitations and handicap based on the disability classification and functional limitations classification; [11] Hays *et al.* 1995: physical and mental functioning based on the MOS SF-36; [12] Hornquist *et al.* 1992: emotional well-being, satisfaction with life domains based on nonstandardized instruments; [13] Lyons *et al.* 1994: physical and mental functioning based on the MOS SF-36; [14] Martinez *et al.* 1995: pain, functional limitation, helplessness, sleep and work based on a range of standardized instruments including the Health Assessment Questionnaire, the Fibromyalgia Impact Questionnaire, the Arthritis Helplessness questionnaire and the Modified Post-Sleep Inventory; [15] Nusselder *et al.* 1996: functional limitation based on the Dutch National Survey of General Practice in '87/88; [16] Picavet *et al.* 1994: mobility impairment based on health interviews of the Conspicuous Netherlands Health Interviews Surveys; [17] Rijken *et al.* 1995: global and emotional well-being based, in part, on the global items of the Rotterdam Symptom Checklist; [18] Rudick *et al.* 1992: functional, emotional and social functioning based on the Farmer Quality of Life Index; [19] Verbrugge *et al.* 1995: functional limitation based, in part, on the '83-85 National Health Survey, the '85 National Ambulatory Medical Care Survey, and the '84 National Hospital Discharge Survey; [20] Vickrey *et al.* 1994: physical and mental functioning, global QL, based on the MOS SF-36 and the global item of the Dartmouth Coop Charts; [21] Wells *et al.* 1989: physical and social functioning, health perception, based on items of the Medical Outcomes Study and the RAND Health Insurance Study; [22] Hermann *et al.* 1996: physical and mental functioning based on the MOS SF-36.

vide a global measure of physical (PCS) and mental functioning (MCS), respectively. These summary scores were calculated according to guidelines provided by the director of the International Quality of Life Assessment project (Barbara Gandek, New England Medical Center, personal communication, 1998). The means and standard deviations of the general population of Amsterdam were used to transform the raw subscale scores to Z-scores. These Z-scores were multiplied with the weights of the American general population because the weights of the Dutch general population were not available at the time.<sup>2</sup> These scores were subsequently multiplied

by 10 and summed with 50 to obtain transformed summary scores that are normally distributed with a mean of 50 and a standard deviation of 10. The scales, single item, and summary scores range from 0 to 100, with higher scores indicating a better health status. Means and standard deviations were provided by the original researchers for each subscale, the single item, and the two summary scores.

In one large data set (the GLAS study), the MOS Short-Form General Health Survey (SF-20) [30] has been used, supplemented by the four items of the vitality scale as used in the SF-36, resulting in the SF-24. Because both instru-

<sup>2</sup>Ware *et al.* [36] have compared PCS and MCS scores using standard U.S. scoring algorithms with factor weights derived from the U.S. general population, with those using country-specific factor weights. The correlations between the two SF-36 summary measures using standard U.S. and

country-specific scoring algorithms were 0.991 and 0.990, respectively, for a Dutch sample. The strength of these findings led the authors to recommend the use of U.S.-derived scoring algorithms.

ments originate from the Rand Health Insurance Study Questionnaire, the two questionnaires are comparable in content, albeit not entirely identical with respect to the wording of some of the items and response options. With the exception of the subscale "emotional role functioning" and single item "health transition," the SF-24 encompasses the same dimensions as the SF-36. The Dutch version of the questionnaire has established levels of reliability and validity [31]. Summary scores for the SF-24 cannot be calculated.

#### 2.3.2. Sociodemographic characteristics and comorbidity

The variables included: age (<45 years; 45-64 years; >64 years); gender, education level (low, intermediate, high); living situation (married or living together vs. other); and comorbidity (at least one comorbid condition vs. none). Per background characteristic, means and standard deviations were provided for each patient sample for the subscales of the SF-36/SF-24, and the single item and the two summary scores of the SF-36.

### 2.4. Analysis

#### 2.4.1. Influence of sociodemographic characteristics and comorbidity

First, the potential influence of the sociodemographic characteristics and comorbidity was examined for each patient sample separately. Clear, unequivocal guidelines for interpreting differences between mean scores as clinically and socially relevant are not available yet [29,32]. However, Ware [29] considers a difference of 2 points on a scale from 0 to 100 as "very small" (p. 7:9). We therefore decided that mean scores that differed less than 2 points were equivalent. This criterion was employed for the mean subscale scores and the mean summary scores. Subsample sizes less than 10 patients were ignored.

Second, the extent to which a difference between subgroups pointed systematically in one direction (e.g., a systematically higher score for women than for men) was established for each patient sample. The following decision rules were employed. A difference between two means (e.g., males vs. females) for the dimensions was considered to be systematic if: a) at least six of nine dimensions pointed into one direction, while the remaining three dimensions were equivalent; or b) at least seven of nine dimensions pointed into one direction, while only one remaining dimension showed a difference in the opposite direction. All other cases were considered indicative of the absence of a systematic effect of a particular background characteristic. In case of seven dimensions (for the SF-24) and/or three categories (i.e., for age and education) comparable decision rules were employed. Third, the number of times a background characteristic was found to exert a systematic effect was calculated across patient samples.

#### 2.4.2. Comparison of disease categories within their respective disease clusters

For those disease categories that encompassed more than one patient sample (Fig. 1), overall means were calculated

by averaging the means of the constituent samples, weighted by sample size. With respect to specific QL dimensions, a difference of less than 1 point between mean scores was considered equivalent. This difference is smaller than the 2-point difference employed for individual samples (see former paragraph), because the variance of aggregated means is smaller than the variance of their component means. For each dimension, the mean scores were ranked across the disease categories within the disease cluster. Ties (cases where differences in mean scores were less than 1 point) were given a mean ranking. The rankings were subsequently summed for each disease category across the dimensions. To enable comparison across studies, only the seven scales used by both the SF-36 and SF-24 were used. The summed ranking score is minimally seven (the number of subscales) and maximally seven times the number of disease categories compared. A lower ranking sum is indicative of better functioning. Because the two summary scores were missing in a number of data sets, these were not taken into account.

#### 2.4.3. Comparison across disease clusters

Mean scores were calculated per disease cluster for each separate dimension and for the physical and mental component summary scores. If the cluster consisted of the original patient samples, a weighted mean score was calculated. If the disease cluster consisted of disease categories (Fig. 1), the mean score was based on the means of these disease categories.<sup>3</sup> The means were subsequently ranked per QL dimension across the disease clusters. A rank score of 1 indicated the most favorable health status and a ranking of 13 indicated the poorest level of functioning, given the number of disease clusters. Mean rank scores were given to ties (a difference of less than 1 point). The rank scores for the seven dimensions were subsequently summed per disease cluster to obtain an overall rank order of the disease clusters.

### 3. Results

#### 3.1. Influence of sociodemographic characteristics and comorbidity

##### 3.1.1. Age

Older patients reported a poor QL than younger ones on the QL dimensions and physical functioning. None of the comparisons revealed results that were in the opposite direction. There was no effect of age on mental functioning (Table 2).

##### 3.1.2. Gender

Male patients reported a more positive or comparable level of QL than female patients on the separate QL dimensions and mental functioning. No such gender effect was found for physical functioning.

<sup>3</sup> Because these means were not further corrected for sample size, we examined whether the ranking differed when it was based on weighted means. While these different approaches resulted in a slightly different rank order, the general distinction among disease clusters was not affected.

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Table 2  
Influence of sociodemographic characteristics and comorbidity: number of patient samples<sup>a</sup>

Characteristics	QL dimensions <sup>b</sup>	Physical functioning <sup>c</sup>	Mental functioning <sup>c</sup>
Age <sup>d</sup>			
Older > younger	-	-	3
Older < younger	26	11	1
Older = younger	11	3	10
Gender			
Male > female	29	2	9
Male < female	-	1	-
Male = female	7	11	5
Education <sup>e</sup>			
Low level > high level	-	-	1
Low level < high level	26	12	7
Low level = high level	12	3	7
Living situation			
With partner > other	29	2	11
With partner < other	-	4	-
With partner = other	15	13	7
Comorbidity			
With > without	-	-	-
With < without	35	13	11
With = without	1	-	2

<sup>a</sup>The number of patient samples (maximum is 47, see Fig. 1) may vary per background characteristic due to missing data and small subsample sizes (i.e., less than 10 patients).

<sup>b</sup>The QL dimensions refer to the nine subscales of the SF-36 or the seven subscales of the SF-24 (see dependent measures).

<sup>c</sup>Based on the physical and mental component summary scores, respectively.

<sup>d</sup>Because the data sets adopted different inclusion criteria with respect to age, different thresholds need to be employed. Older is 45-64 years, younger is <45 years for datasets 1, 2 (asthma), 3, and 7; older is >64 years, younger is <64 years for datasets 2 (MS and neuromuscular disease), 4, and 6; older is >64 years and younger is 45-64 years for data set 8. For data set 5, no distinction according to age could be made (see Appendix and Fig. 1).

<sup>e</sup>> is better functioning; < is poorer functioning; = is comparable functioning.

<sup>f</sup>Low level is primary school and lower vocational education; high level is higher vocational education and university.

### 3.1.3. Education

In general, a low level of education coincided with poor QL as indicated by the results of the separate dimensions and physical functioning. This effect was less clear for mental functioning. No differences were found for the QL dimensions, physical and mental functioning between an intermediate or high level of education (data not shown).

### 3.1.4. Living situation

Patients who live with a partner reported a better QL than patients who have a different living situation on the specific dimensions and mental functioning. This effect was not reflected in physical functioning.

### 3.1.5. Comorbidity

Patients with at least one comorbid condition reported a poorer QL on the separate dimensions, the physical and mental functioning. The results never pointed in the opposite direction.

## 3.2. Comparison of disease categories within their respective disease clusters

### 3.2.1. Cardiovascular conditions

Patients with hypertension reported better functioning than patients with a heart condition on all dimensions, with the exception of mental health (Table 3).

### 3.2.2. Cerebrovascular/neurologic conditions

The following rank order was obtained (from best to poorest QL): 1) neuromuscular disease; 2) migraine; 3) stroke; 4) multiple sclerosis; and 5) Parkinson/epilepsy. Patients with neuromuscular disease and migraine clearly reported the most favorable levels of functioning. However, patients with migraine had a different score pattern than the remaining patient groups. While they reported better physical and role functioning, general health, and vitality, they reported the highest level of pain. While multiple sclerosis patients and patients with neuromuscular disease reported the lowest level of pain, the health status of patients with multiple sclerosis, Parkinson's disease, or epilepsy was most severely impaired.

### 3.2.3. Endocrinologic conditions

While the summed rank scores were comparable, they were more favorable for patients with thyroid gland impairments than for those with diabetes. The largest differences between these disease categories were found for role functioning, general health, and social functioning.

### 3.2.4. Gastrointestinal conditions

Patients with an ulcer in the stomach or duodenum or with bowel disease had systematically higher levels of physical, role, and social functioning than patients with liver disease, gall stones, or gall bladder inflammation. However, the mean scores of the remaining dimensions were comparable across the two disease categories.

### 3.2.5. Musculoskeletal conditions

The ranking resulted in the following order: 1) rheumatoid arthritis; 2) back impairments; and 3) osteoarthritis/other joint complaints. While patients with rheumatoid arthritis reported less pain, better social and mental functioning, they reported poorer role functioning, general health, and vitality.

### 3.2.6. Psychiatric disorders

Patients with alcohol abuse/dependence reported better functioning on all dimensions than patients with either anxiety disorders or depression. Patients with depression reported consistently the poorest level of functioning.

## 3.3. Comparisons across disease clusters

### 3.3.1. Specific QL dimensions

Table 4 presents the rank order across the QL dimensions, with urogenital conditions having the best and musculoskeletal conditions the poorest QL. Three striking results merit attention. First, the health status profiles vary



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Table 3

Means and range of means of the QL dimensions and summed rank scores per disease category (dataset/sample size)

	PF M range <sup>b</sup>	PRF M range	BP M range	GH M range	V M range	SF M range	MH M range	Summed rank scores <sup>c</sup>
<b>Cardiovascular conditions</b>								
Hypertension (5/137; 8/1238)	62.4 46.0-80.1	68.5 50.7-86.7	66.4 18.1-89.7	62.4 56.8-77.5	66.1 61.8-78.8	78.7 68.2-89.4	73.6 67.9-82.8	7.5
Heart conditions (3/57; 5/78; 8/974)	56.1 41.7-86.0	56.9 40.0-82.5	62.9 21.4-83.9	53.3 43.6-68.5	62.6 50.1-72.0	73.5 63.5-86.7	73.3 61.0-80.4	13.5
<b>Cerebrovascular/neurologic conditions</b>								
Neuromuscular disease (2/266; 2/348; 2/79; 2/234)	52.3 NA	62.7 NA	78.4 NA	51.5 NA	53.6 NA	74.5 NA	74.1 NA	13.5
Migraine (8/489)	61.8 47.9-82.0	66.5 41.0-91.3	50.6 35.5-55.6	56.4 48.2-70.5	60.2 53.7-69.4	72.3 57.5-85.3	66.8 60.5-73.8	15.5
Stroke (3/38; 5/25; 8/159)	48.2 32.0-95.0	48.7 16.7-100.0	62.5 23.7-80.7	51.3 40.0-69.7	57.8 35.0-68.9	62.4 49.8-87.5	71.2 59.6-80.0	23.5
Multiple sclerosis (2/836; 8/12)	44.2 3.3-68.0	50.2 0.0-66.7	75.0 25.0-86.9	46.1 26.7-55.5	47.6 36.7-62.5	65.1 20.0-80.0	71.1 63.0-78.4	26.0
Parkinson/epilepsy (8/89)	49.2 30.8-70.1	45.7 31.3-67.3	62.0 19.3-50.0	50.2 42.5-62.5	58.6 51.0-70.7	66.9 58.3-86.4	67.7 57.1-78.7	26.5
<b>Endocrinologic conditions</b>								
Thyroid gland impairments (8/187)	59.4 44.4-81.8	64.4 48.3-90.0	62.5 13.6-45.3	59.3 55.0-78.2	63.4 59.7-77.5	75.1 64.8-90.3	70.5 65.0-81.0	9.5
Diabetes mellitus (3/61; 5/38; 8/379)	58.0 45.0-80.0	56.9 6.3-90.6	64.1 67.3-87.8	54.3 36.4-69.6	62.8 50.4-72.9	71.8 46.9-89.1	73.2 62.9-83.9	11.5
<b>Gastrointestinal conditions</b>								
Ulcer in stomach or duodenum/ bowel disease (8/305)	57.1 44.8-78.8	56.7 38.0-82.6	52.7 26.7-55.0	52.4 46.8-71.6	62.5 56.6-74.6	71.7 62.9-91.6	70.3 66.1-76.6	9.0
Liver disease/gallstones/gall bladder inflammation (8/137)	51.6 35.4-83.3	51.9 40.4-100.0	53.4 18.2-50.3	53.7 50.5-80.0	61.5 57.7-80.6	66.7 62.1-90.9	71.1 66.4-84.7	12.0
<b>Musculoskeletal conditions</b>								
Rheumatoid arthritis (1/1061; 5/30)	50.2 42.5-87.5	46.0 32.7-87.5	56.9 42.9-81.6	49.5 41.7-75.0	54.3 41.3-85.0	73.2 57.1-87.5	72.8 43.0-78.0	11.0
Buck impairments (5/41; 8/903)	49.4 36.6-61.8	52.2 41.7-90.0	49.4 40.4-78.4	55.5 50.8-78.0	61.5 56.9-83.0	71.6 61.3-95.0	70.8 64.0-93.6	14.5
Osteoarthritis/other joint complaints (5/97; 4/336; 8/1195)	49.3 33.4-66.9	51.4 22.4-78.9	50.0 38.0-86.5	55.3 36.7-72.3	59.7 45.0-79.2	70.0 50.8-92.3	69.9 61.5-84.9	16.5
<b>Psychiatric disorders</b>								
Alcohol problems (7/491)	92.5 85.9-95.9	86.7 79.0-94.6	84.4 78.3-90.5	72.2 65.7-79.9	68.1 60.9-74.6	86.5 78.8-91.5	78.0 69.7-83.7	7.0
Anxiety disorders (7/915)	87.6 80.0-93.0	79.3 70.8-100.0	78.3 72.1-87.5	63.8 59.4-67.9	56.2 51.1-62.5	73.3 66.8-78.0	65.6 58.9-73.8	14.0
Depression (7/572)	85.2 77.2-95.6	69.8 63.7-88.8	72.6 64.4-88.7	61.3 52.8-75.1	51.3 40.6-60.8	71.2 63.8-84.0	59.1 48.4-67.7	21.0

PF = physical functioning; PRF = physical role functioning; BP = bodily pain; GH = general health; V = vitality; SF = social functioning; MH = mental health. NA = not available.

<sup>a</sup>For a description of data sets, see appendix A.

<sup>b</sup>The range of the smallest and largest means.

<sup>c</sup>A lower summed rank score indicates better functioning.

widely across disease clusters. For example, while patients with gastrointestinal conditions, cerebrovascular/neurologic conditions, renal disease, or musculoskeletal conditions reported the lowest levels of physical functioning and physical role functioning they differ in other respects. Patients with cerebrovascular/neurologic conditions reported relatively favorable levels of pain, but were found to have the poorest levels of social functioning and mental health. Patients with musculoskeletal conditions reported the poorest levels of physical functioning, role functioning and pain, while patients with renal disease reported the poorest level of general health. Second, the pattern of mean scores of psychiatric patients is en-

tirely different from that of physically ill patients. Psychiatric patients reported relatively poor levels of vitality and mental functioning, while the levels of physical and role functioning were highest in comparison to all other patient clusters. Third, the discrepancies in mean scores of the mental functioning subscales varies within narrower margins across the disease clusters than those of the physical functioning scales.

## 3.3.2. Physical and mental health

The available mean scores of the physical and mental component summary scores are depicted in Fig. 2. Because the means of these summary scores are set at 50 (see section

Table 4

Means and range of means of the QL dimensions and summed rank scores per disease cluster

	PF	RPF	BP	GH	V	SF	MH	Summed rank score <sup>b</sup>
	M	M	M	M	M	M	M	
	range <sup>a</sup>	range	range	range	range	range	range	
Urogenital conditions	67.6	72.4	69.0	62.9	68.9	79.3	77.6	15.5
	57.5-84.5	60.8-95.0	18.3-34.3	59.1-77.4	66.3-79.4	73.0-86.3	74.0-82.0	
Hearing impairments	61.6	63.8	73.8	59.6	61.8	76.6	73.1	29.5
	53.6-88.1	43.2-90.6	71.2-89.0	47.0-76.3	39.0-77.5	56.8-82.6	58.8-86.0	
Psychiatric disorders	88.4	78.6	78.4	65.8	58.5	77.0	67.6	30.5
	77.2-95.9	63.7-100.0	64.4-90.5	52.8-79.9	40.6-74.6	63.8-91.5	48.4-83.7	
Dermatologic conditions	62.6	69.3	64.1	62.1	66.5	77.0	72.1	32
	46.5-85.3	57.3-88.9	14.8-42.4	57.8-78.8	62.4-74.8	65.4-91.6	66.5-78.8	
Cardiovascular conditions	59.3	62.7	64.7	57.9	64.4	76.1	73.5	37
	41.7-86.0	40.0-86.7	18.1-89.7	43.6-77.5	50.1-78.8	63.5-89.4	61.0-82.8	
Cancer	67.4	60.3	68.6	56.9	62.6	74.8	72.2	43
	40.0-86.0	30.4-90.0	20.1-95.3	46.4-69.4	53.2-73.1	54.0-97.9	59.1-86.0	
Endocrinologic conditions	58.7	60.7	63.3	56.8	63.1	72.7	72.5	49.5
	44.4-81.8	6.3-90.9	13.6-87.8	36.4-78.2	50.4-77.5	46.9-90.3	62.9-83.9	
Visual impairments	56.5	59.6	70.7	58.1	52.9	72.1	72.6	51
	51.5-82.5	50.0-100.0	63.4-84.4	57.2-72.5	43.3-59.0	62.5-87.5	62.0-76.0	
Chronic respiratory diseases	65.4	62.5	72.7	52.0	58.4	72.7	70.8	52.5
	38.4-89.6	25.0-100.0	15.8-100.0	34.2-67.9	32.5-75.0	50.0-90.6	51.7-82.0	
Gastrointestinal conditions	55.4	55.2	52.9	52.8	62.2	70.2	70.5	69
	35.4-83.3	38.0-100.0	18.2-55.0	46.8-80.0	56.6-80.6	62.1-91.6	66.1-84.7	
Cerebrovascular/Neurologic conditions	51.1	54.8	69.7	51.1	55.6	68.2	70.2	74
	3.3-95.0	0.0-100.0	19.3-86.9	26.7-70.5	35.0-70.7	20.0-87.5	57.1-80.0	
Renal diseases	51.7	51.6	55.9	48.5	60.5	69.1	72.4	75
	34.2-79.2	37.8-95.8	18.8-52.7	44.5-70.8	54.0-74.1	61.7-85.0	65.4-85.7	
Musculoskeletal conditions	49.6	49.9	52.1	53.4	58.5	71.6	71.2	78.5
	33.4-87.5	22.4-90.0	38.0-86.5	36.7-78.0	41.3-85.0	50.8-95.0	43.0-93.6	

PF = physical functioning; RPF = physical role functioning; BP = bodily pain; GH = general health; V = vitality; SF = social functioning; MH = mental health.

<sup>a</sup>The range of the smallest and largest means.<sup>b</sup>A lower (summed) rank score indicates better functioning.

on Dependent Measures), the figure can be divided into four quadrants. First, the most positive quadrant (physical and mental component summary scores >50) is empty, indicating that patients in all disease clusters were impaired with respect to at least one dimension. Second, while psychiatric patients reported the highest level of physical functioning (>50), their mental functioning was poorest. Third, patients with cardiovascular conditions, hearing impairments, and musculoskeletal disease reported relatively positive levels of mental functioning (>50), while their level of physical functioning was among the most negative. Fourth, the majority of disease clusters were found to have levels of physical as well as mental functioning below 50, including visual impairments, cerebrovascular and/or neurologic conditions, endocrinologic conditions, cancer, and chronic respiratory conditions.

#### 4. Conclusions

##### 4.1. Influence of sociodemographic characteristics and comorbidity

The extent to which the sociodemographic characteristics and comorbidity exert a systematic effect on perceived QL was examined for each patient sample separately. Some clear trends emerged, despite the heterogeneity of the data

sets. Patients who were older, female, had a low level of education, were not living with a partner, and had at least one comorbid condition, in general, reported the poorest level of QL.

##### 4.2. Comparisons of disease categories within their respective disease clusters

Within disease clusters comparisons were made of component disease categories to examine the extent to which these disease categories differ in magnitude and type of impaired QL. Frequently, clear and interpretable patterns of functioning emerged as was the case with hypertension versus heart condition; thyroid gland impairments versus diabetes; ulcer in the stomach/duodenum versus liver disease/gallstones; and alcohol abuse/dependence versus anxiety disorders and depression. The profiles of neuromuscular disease and migraine compared to stroke and to multiple sclerosis and Parkinson's disease/epilepsy were not entirely clear and straightforward. Additionally, the levels and profiles of functioning of rheumatoid arthritis versus back impairments versus osteoarthritis/other joint complaints were at odds with clinical expectations and may need to be viewed with some reserve.

##### 4.3. Comparisons across disease clusters

Disease clusters were compared to examine the extent to which they differ in the level and pattern of reported QL.

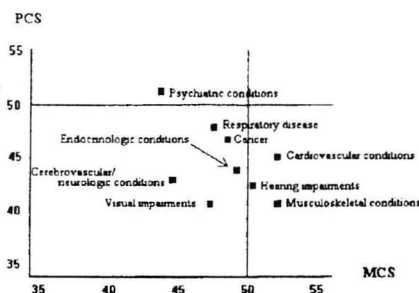


Fig. 2. The position of the disease clusters with respect to physical (PCS) and mental (MCS) functioning.

Behind the resulting rank order very different profiles of functioning were hidden as revealed by the score pattern of the different dimensions and of the physical and mental component summary scores. Some disease clusters, such as musculoskeletal conditions, were characterized by profound impairments. Others were typified by adverse psychosocial or mental functioning, as was the case with psychiatric conditions. Clearly, the majority of disease clusters were plagued by physical as well as mental dysfunctions.

The results of the extant literature are generally in line with those of the secondary analysis. Hearing impairments were found to result in relatively favorable functioning. A group of disease clusters assuming an intermediate position encompassed cardiovascular conditions, cancer, endocrinologic conditions, and chronic respiratory diseases. Patients who reported the poorest levels of functioning were those with cerebrovascular/neurologic conditions, renal disease, and musculoskeletal conditions. Discrepancies between the extant literature and the current study were found with respect to visual impairments and gastrointestinal disease, which assumed a less favorable position in the secondary data analysis than in the literature. Conversely, urogenital conditions and psychiatric disorders, in particular, had a more favorable position in the current data analysis in comparison to the extant literature.

Overall, the level of functioning of all disease clusters was lower than that of a healthy population, despite the strong variations across disease clusters. Three studies [28,33,34] have provided the responses to the SF-36 or SF-24 of Dutch healthy individuals. A comparison with these QL results indicates that the discrepancies are substantial. Relatedly, the mean summary scores were occasionally more than half a standard deviation (5 points) below the mean of 50, thus revealing a difference of a moderate to large magnitude.

## 5. Discussion

A number of conceptual and methodological constraints of the study merit attention. Conceptually, the choice of a

generic health status instrument was needed, by definition, to enable comparison across different patient populations. However, this has inherent limitations regarding the domains of comparison. Moreover, such a generic instrument may not address those issues of relevance to particular patient groups, such as disease symptoms or treatment side effects. To the extent that such disease-specific aspects do not affect the generic domains, the resulting score is only a limited reflection of patients' health status.

Additionally, a number of issues may have compromised the representativeness of the data. First, a number of diseases within a disease cluster or disease clusters themselves may not be represented. For example, psychiatric patients with psychoses or schizophrenia and AIDS patients are not included. Second, a number of chronic conditions may have been underrepresented with respect to levels of severity (see Appendix). For example, some data sets excluded patients under the care of a specialist or with serious comorbidities. Additionally, an underrepresentation in the spectrum of severe levels of disease due to nonresponse may have occurred [35]. This nonresponse might have exerted a differential bias across conditions. For example, one could imagine that persons with mild levels of hearing and visual impairments are more inclined to complete written questionnaires than those who are more seriously afflicted. Conversely, persons with severe levels of dermatologic disorders or respiratory diseases are expected to be more motivated to complete a lengthy questionnaire than those with mild levels of disease. Third, in a number of data sets the selection of patients was limited with respect to sociodemographic characteristics (e.g., where inclusion criteria have been restricted to specific age ranges or to gender). Fourth, the representativeness may also have been affected adversely by limited sample size, as was the case with hearing impairments, renal disease, and visual impairments. Finally, the number of subsamples per condition varies considerably. Clearly, the larger the number of subsamples the more likely the combination of samples will provide a representative picture of the particular disease. Despite these limitations, the data are expected to provide a realistic representation of these chronic conditions in the Netherlands, given the diversity and magnitude of the eight data sets, the face validity of the results, and the concordance with results from the literature.

The influence of comorbidity on perceived QL is worthy of note. Patients with comorbid conditions in particular reported the poorest levels of physical and mental function. Given the age ranges of the subjects included in the analyses, a substantial percentage of subjects will have one or more comorbid conditions. For example, hypertension, heart condition, and diabetes mellitus have a likely high rate to concur. Additionally, renal failure may result from long-standing hypertension or diabetes mellitus. Moreover, in three data sets (3, 5, and 8, see Appendix) individuals could have been classified in several disease categories. Because we were unable to separate systematically and uniformly the influence of the disease categories from concomitant conditions, the reported QL levels result

from the combined effect of disease and comorbidity. Whereas this constraint limits the conclusions regarding the influence of disease categories, it pays credit to the disease burden experienced by patients diagnosed with these diseases.

The interpretation of the ranked differences also merits attention. There are no clear-cut ways of interpreting the clinical relevance of the observed differences [32]. While the adopted criterion of a difference of at least 2 points (or 1 point for aggregated means) is plausible, it is not empirically substantiated. Moreover, given the heterogeneity inherent to higher order clustering, the variability in the range of means is substantial. Relatedly, the combination of all data into one dataset would have allowed for statistical analysis, controlling for interactions among different factors, and would provide information regarding the statistical significance of the differences. However, because combining the data into one database was impossible, we have adopted a conservative, descriptive approach aimed at ranking the different disease categories and clusters, thus setting limits to the interpretation of the results.

While secondary data analysis makes use of a wealth of information that would otherwise be ignored, its limitations are profound as a result of which primary data collection is preferable. Studies in this area should ideally be characterized by the use of large overall samples that are representative of the full range of chronic diseases qua disease severity and relevant background characteristics. The diagnoses should be medically confirmed. Additionally, standardized QL instruments should be administered according to similar procedures. Statistical analysis should provide information regarding interactions among disease and sociodemographic characteristics and comorbidity. Finally, standardized differences between health status profiles need to be established.

In order to guarantee a fair and rational health care system, societal costs associated with research, training, and use of health services, need to be allocated according to the criteria a society adopts. Those areas need to be identified that are in greatest need according to those criteria and/or offer the greatest benefits in relation to their costs. In this context, the comparisons across the 13 disease clusters are worthy of note. If these results are replicated and validated in future studies, they can be considered in addition to information on the prevalence of the diseases, potential benefits of care, and current disease-specific expenditures. This combined information can serve a number of purposes. For example, health care service provision can be better planned. Distributive injustice where resource allocation is not empirically warranted can thus be diminished. Finally, as was the purpose of our study, research funds can be allocated to patient groups with those chronic diseases and/or sociodemographic characteristics who are in greatest need.

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## Appendix: Description of the data sets

### 1. TNO-Prevention and Health Study

**Context.** Data were collected in the context of the study "Skills of individuals with rheumatoid arthritis" conducted in 1996.

**Sample.** Age: 16–60 years, identified by 17 rheumatology practices, the sample was stratified by age and gender, 1693 patients were approached by their treating rheumatologist, 1061 (63%) responded positively.

**Assessment of diagnosis.** Rheumatoid arthritis was diagnosed by the treating physician. Comorbidity was assessed by means of a self-report list including 22 conditions.

### 2. NIA TNO Project

**Context.** Three data sets were provided, including those on a) neuromuscular conditions, collected in the context of the study "Working with a neuromuscular condition" in 1994; b) asthma, collected in the study "Asthma and work" in 1996; and c) multiple sclerosis in the study "MS and work" in 1996.

**Sample.** Neuromuscular conditions: Age: 16–65 years, identified either by their treating specialist (N = 1299) or by the patient society of neuromuscular diseases (N = 1080); 996 completed questionnaires were returned (42% in case there is no overlap between the two patient samples, which cannot be established due to privacy regulations). Data are included of patients with dystrophy (N = 266), myastheny (N = 348), spinal muscular atrophy (SMA) (N = 79), or hereditary sensorimotor neuropathy (HMSN) (N = 234). Asthma: Age: 18–45 years, identified by pulmonologists in five provinces of the Netherlands (i.e., Drenthe, Groningen, Limburg, Noord-Holland, Zuid-Holland). Of the 1335 patients approached, 534 (40%) returned completed questionnaires. Multiple sclerosis: Age: 18–65 years identified via the patient society of multiple sclerosis. A sample of 1045 patients was approached, 836 (80%) returned completed questionnaires.

**Assessment of diagnosis.** Neuromuscular conditions were diagnosed by the specialist or by means of self-report, dependent on the procedure of accrual. Comorbidity was assessed by means of the question "Do you have any other chronic condition?" The diagnosis asthma was established by the treating physician. Comorbidity was not assessed. The diagnosis multiple sclerosis was assessed by self-report. Comorbidity was assessed by means of the question "Do you have any other chronic conditions?"

### 3. MORGEN Project

**Context.** Data were collected in the context of the study "Monitoring Risk factors and Health in the Netherlands (MORGEN)." This study purported to examine the health and prevalence of risk factors in a sample of the Dutch population during 1993 to 1997. The data used in this article were collected in 1995.

**Sample.** Age: 20–60 years, living in the cities of Amsterdam, Maastricht, or Doetinchem. The response rate was on average 43%, 4946 individuals were included. Only the data

of individuals with a myocardial infarction ( $n = 57$ ), stroke ( $n = 38$ ), diabetes ( $n = 61$ ), asthma ( $n = 185$ ), or cancer ( $n = 125$ ) were included in the current article.

**Assessment of diagnosis.** The presence of these chronic conditions was assessed by means of self-report (e.g., "Have you ever had a heart attack?"). Comorbidity was defined as the presence of two or more of these five conditions. This implies that respondents may have been included in more than one disease category.

#### 4. NIVEL Study

**Context.** The data forwarded by the NIVEL research institute originate from a study into the continuity of care of chronically ill patients. The objective was to develop an instrument to measure continuity of care from the patients' perspective. The data used in this article were collected at the end of 1995 and the beginning of 1996.

**Sample.** Age: 18 years and older, identified either by GPs or specialists in the regions surrounding the cities of Amsterdam and Tilburg. Consenting patients received the questionnaire from the NIVEL research institute. Data of patients with rheumatoid arthritis, ankylosing spondylitis, or arthrosis deformans ( $n = 336$ ; response rate 52.5%) or with asthma, chronic bronchitis or lung emphysema ( $n = 259$ ; response rate 43.1%) were included.

**Assessment of diagnosis.** The diagnoses were established by specialists or GPs. Comorbidity was assessed by means of self-report.

#### 5. Zutphen Elderly Study

**Context.** The Zutphen Elderly study is a longitudinal population-based health study among men born between 1900 and 1920 and living in the town of Zutphen at the start of the study in 1985. Data collected in 1995 were included in the current study. A nonresponse analysis revealed that nonrespondents were older, of a lower socioeconomic class, less frequently living independently, and with a poorer health status in comparison to those who participated.

**Sample.** Of the 462 surviving patients, 343 (74%) participated. Data are included of patients with: diabetes mellitus ( $n = 38$ ); asthma ( $n = 26$ ); rheumatoid arthritis, osteoarthritis, back impairments ( $n = 168$ ); hearing impairments ( $n = 47$ ); visual impairments ( $n = 34$ ); heart disease ( $n = 78$ ); stroke ( $n = 25$ ); cancer ( $n = 40$ ); and hypertension ( $N = 137$ ).

**Assessment of diagnosis.** The diagnoses of diabetes mellitus, asthma, rheumatoid arthritis, osteoarthritis, back impairments, hearing and visual impairments were established via self-report. Stroke and heart disease were determined on the basis of information from the hospital and the GP. The diagnosis cancer was verified with information of the national cancer registries. Hypertension was established with the WHO definition (i.e., systolic  $\geq 160$  mmHg; diastolic  $\geq 90$  mmHg and/or use of antihypertension medication). Comorbidity was defined as the presence of two or more

endorsed chronic conditions. This implies that respondents may have been included in more than one disease category [34,35].

#### 6. WOK Project

**Context.** Data were collected in the context of the study "Monitoring and feedback regarding asthma and chronic obstructive pulmonary disease (COPD) in the general practice" performed by the Center for Quality of Care Research (WOK) of the research school CaRe, and financed by the Dutch Asthma Foundation. The objective was to evaluate systematic monitoring of patients with asthma or COPD in general practices. The data presented in this article were baseline data collected in 1996.

**Sample.** Age: 18 years and older, random sample of patients with asthma or COPD from 24 GP practices in the Eastern part of the Netherlands. Exclusion criteria included: a) being under active treatment of a specialist; and b) having serious comorbidities. Patients were approached by their GPs, 647 (70%) consented. The majority of these patients (70%) had light or moderate forms of asthma or COPD.

**Assessment of diagnosis.** The diagnosis was established on the basis of lung function and the prevalence of symptoms. Comorbidity was assessed by means of a self-report list including 18 conditions.

#### 7. NEMESIS Project

**Context.** Data were collected in the context of the Netherlands Mental Health Survey and Incidence Study (NEMESIS) a prospective, ongoing study into the prevalence, incidence, course, and outcome of psychiatric conditions in the Netherlands. Baseline data collected in 1996 were used in the current article [37]. Nonresponse was found to be associated with better mental health, gender (more females), and age (more individuals in the lower age ranges). Psychiatric morbidity did not differ significantly between respondents and nonrespondents.

**Sample.** Age: 18-64 years, representative sample of the general population of the Netherlands; 7147 persons (69.7% response) were included. Only data of respondents with anxiety disorders ( $n = 915$ ), depression ( $n = 572$ ), and alcohol abuse/dependence ( $n = 491$ ) were used.

**Assessment of diagnosis.** Diagnoses were established by trained interviewers, using the Composite International Diagnostic Interview (CIDI), according to the criteria of the DSM-III-R. Comorbidity was noted if at least one additional psychiatric disorder was present and/or a chronic condition was endorsed in the self-report list as used by the Central Office for Statistics in the Netherlands.

#### 8. GLAS Study

**Context.** The Groningen Longitudinal Aging Study is a population-based prospective study of the determinants of

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the QL of late-middle-aged or older people who live in the Northern part of the Netherlands. Baseline data collected in 1993 were included in the current study. Nonresponse was found to be associated with gender (fewer females), age (fewer individuals in the higher age range), and the presence of malignancies.

**Sample.** Age: 57 years or older, 8723 individuals were approached by their GPs, 62.5% consented. Data are included of patients with: asthma/chronic bronchitis ( $n = 610$ ); other lung diseases, such as emphysema ( $n = 193$ ); heart condition ( $n = 974$ ); hypertension ( $n = 1238$ ); stroke ( $n = 159$ ); ulcer in the stomach/duodenum or serious bowel conditions ( $n = 305$ ); liver disease/gallstones or gall bladder

inflammation ( $n = 137$ ); renal disease ( $n = 137$ ); non-malignant prostate disease ( $n = 210$ ); diabetes mellitus ( $n = 379$ ); thyroid gland impairments ( $n = 187$ ); back problems ( $n = 903$ ); rheumatoid arthritis/osteoarthritis/other joint complaints ( $n = 1195$ ); migraine/chronic headache ( $n = 489$ ); eczema/psoriasis ( $n = 386$ ); cancer ( $n = 182$ ); multiple sclerosis ( $n = 12$ ); and Parkinson's disease/epilepsy ( $n = 89$ ).

**Assessment of diagnosis.** A self-report checklist of 19 chronic medical conditions as employed by the Central Office for Statistics in the Netherlands, was employed. Comorbidity was defined as the presence of two or more endorsed chronic conditions. This implies that respondents may have been included in more than one disease category [32].

## Towards a better understanding

Frank Andries was born on July 12, 1946 in Amsterdam. After finishing secondary school (Gymnasium) in Rotterdam, he studied Western Sociology at the University of Leiden.

From oktober 1974 until november 2003 he worked as a researcher at TNO Work and Employment. He is an expert in the field of survey techniques and has published widely on subjects like the working experiences of people with a chronic disorder, working conditions in general and computer use in the European Union.

