Socio-economic consequences of rheumatoid arthritis in the first years of the disease

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Abstract

Objective. Few data have been presented to document the impact of rheumatoid arthritis
(RA) on socio-economic well-being. In this study, exact figures on socio-economic
consequences were assessed.

Methods. The socio-economic consequences were studied in an inception cohort (186 early
RA patients, mean disease duration 3 yr) by measuring the change in work capability, income,
rest during the daytime, leisure time activity, transport mobility, housing and social support
occurring in the first years of the disease.

Results. For 89% of the patients, RA had an impact on one of the socio-economic items;
for 58%, at least three of these items were affected simultaneously. Work disability appeared
to be 4–15 times higher than in the general population. After 3 yr, 42% of the patients were
registered as work disabled. Nearly a quarter of the patients experienced income reduction.
Over 40% of the patients claimed extra rest during the daytime. Leisure activity changed
towards activities with a lower joint load. There was a decline in transport mobility for 52%
of the patients. Social support increased strongly.

Conclusions. Socio-economic change already presents in the first years of RA and appears
to be influenced by age, gender, marital status and work disability. Furthermore, physical
limitation appeared to be predictive for work-related income reduction, reduced transport
mobility and development of social dependency.

KEY WORDS: Rheumatoid arthritis, Socio-economic, Disease impact, Work disability, Income,
Rest during the daytime, Leisure activity, Transport mobility, Housing, Social support.

For many years, the course of rheumatoid arthritis (RA) in clinical trials was mainly assessed by many different clinical and laboratory variables reflecting disease activity. The validity of many of these variables was questionable and in addition there was a need for a restricted number of variables to be used in all clinical trials. This has lead in the past years to a core set of variables which has been agreed on both by the EULAR and the ACR. In the core set, next to variables assessing disease activity, measurements are included which quantify destructive bone lesions and functional capacity. As it has increasingly been recognized that the effects of RA should be monitored in a more broader sense, many different multidimensional instruments have been developed to measure the impact of RA on physical, psychological and socio-economic well-being [1–5]. Most of these instruments do give a global impression of the effects of RA on health status [6–12]; however, exact figures of the impact of RA on several important socio-economic items are scarce. Nobody will disagree, for instance, that RA will negatively influence the capacity for work or family income, or that RA is a time-consuming disease that will also influence leisure activities [10]; however, data about these items are lacking. Nevertheless, information about these aspects is important for the patient, who wants to know what the future is going to look like. From a societal perspective, it is important to evaluate the socio-economic impact in order to take these into account for future health care services [13–15].

To study the socio-economic impact in the first years of the disease, seven items were selected: employment, income, rest during the daytime, leisure activity, transport mobility, housing, and social support. All items were investigated with descriptive analyses. As data about the magnitude of the socio-economic

consequences of RA are only scarcely available, explanatory analyses were used to evaluate this.

Patients and methods

Study: population and design

Since 1985, all RA patients attending the University Hospital Nijmegen, with a disease duration of <1 yr, not previously treated with slow-acting anti-rheumatic drugs and diagnosed (for the first years retrospectively) according to the 1987 ACR criteria [16], were included in an inception cohort on early RA. At 3-monthly follow-up visits, clinical information (with the exception of physical status, every 6 months) was collected through assessments of rheumatologists and specially trained research nurses. In April 1991, 202 patients had been included. From April 1991 until November 1992, this additional study started to investigate the socio-economic impact of RA in our inception cohort. Structured interviews were used to describe the socio-economic situation both before and after RA diagnosis. This information allowed calculation of the change during the disease period. In the analysis of socio-economic impact, each patient served as his own control. At the beginning of this additional study, 10 patients had died and 31 patients withdrew for reasons of migration ($n = 2$), refusal of additional follow-up ($n = 11$), co-morbidity ($n = 5$) or missed follow-up ($n = 13$), leaving 160 patients to be (partly retrospectively) interviewed. During the period that the interviews were held, 25 patients were newly included in the inception cohort. These patients were only prospectively interviewed.

Assessments

Patients' socio-demographic background was described by age (at inclusion), gender, education and marital status. The education level of the patients was classified according to the Dutch schooling system (primary education, vocational training, secondary education, vocational college, university). For 'marital status' (at the time of the interview), patients were classified as 'single' (if living alone, separated, divorced or widowed) or as 'together' (if married or otherwise living together).

To study the socio-economic impact of RA, the following research questions were addressed to an inception cohort of patients with RA:

- To what extent occurs (partial) work disability?
- Do patients experience loss of income?
- To what extent do patients need extra rest during the daytime?
- Is there a change in leisure activity, transport mobility or housing facility?
- To what extent is social support given (by partner, family, friends or relatives)?

The extra rest during the daytime was measured in quarter of an hour units. To study leisure activity, a six-point scale was developed, describing joint load through physical activity (Table 1). Patients' transport mobility

(either 'being transported' by a partner, children or others, motorized self-transport, public transport or non-motorized self-transport) was classified as normal or as reduced transport. It was investigated whether RA resulted in a house removal. Social support consisted of information on the relationship patient–supporter (partner, family, friends or relatives) and on the amount of support.

Disease characteristics

Rheumatoid factor was measured with the nephelometric method (negative: IgM $\leqslant 10$ IU/ml). The erythrocyte sedimentation rate (ESR) was measured according to the Westergren method (mm in first hour). Information on the physical status was derived from the validated Dutch version [17] of the Stanford Health Assessment Questionnaire (HAQ-functional index). Tender joints were registered according to the Ritchie Articular Index (RAI) [18]. Joint swelling was measured in 44 joints. The Disease Activity Score (DAS) was computed from the RAI, the number of swollen joints and the ESR [19].

Statistics

Analyses were performed using the SAS statistical package (SAS 6.04 PC version). As recall bias cannot be accounted for, an item-non-response analysis was executed. *T*-test and 95% confidence intervals (CI) were used to compare age (by gender), marital status, educational level and employment status of the RA cohort with the general Dutch population [20]. Survival analysis was used to describe time perspective with respect to (partial) work disability. Regression analysis (corrected for disease duration) was used to study income, rest during the daytime, leisure time activity, transport mobility, housing, and social support in relation to socio-demographic and clinical variables. With forward regression analysis, explanatory variables were selected for the final regression model. To avoid type I errors, variables were only accepted at a Bonferroni-corrected *P* level. The variables that were selected for entering the final regression model included age, gender, marital status, work disability and functional index. For dichotomous variables, the odds ratios (ORs), resulting from logistic regression, are presented; for continuous variables, effects (E), resulting from multiple regression, are presented. To present well interpretable effects and ORs, the influence is standardized by comparing quartile differences according to the regression equation. Subtraction of the P25 regression value from the P75 regression value subsequently leads to $OR_{(25-75)}$ or $E_{(25-75)}$. Calculation examples are presented in the Results section on 'income' and 'rest during the daytime'. Confidence intervals are presented to indicate power sufficiency.

Results

In total, 186 patients of our RA inception cohort participated in this study on the socio-economic impact. Item-non-response analysis did not reveal substantial

TABLE 1. Classification of leisure activities, based on joint load

Joint load	Score	Activity	Examples
On upper and lower extremities	6	Intensive motion	Tennis, hockey
	5	Controlled movement	Recreative swimming, calisthenics
On lower extremities	4	Controlled movement	Museum visit, bicycle riding
	3	Weight bearing	Cooking
On upper extremities	2	Intensive mobility	Painting, bridge, needlework
	1	Limited mobility	Reading, television watching

TABLE 2. Explanatory socio-demographic variables and (baseline) disease-specific characteristics ($n = 186$)

Variable/characteristic	n	P25	P50	P75	Mean	S.D.
Age (yr)	186	43	54	64	53	14
Functional index	163	0.1	0.5	1.1	0.6	0.6
Ritchie index	186	5	10	15	11	8
Swollen joints	186	10	16	22	16	8
ESR (mm/h)	179	21	39	58	43	28
DAS3	179	3.4	4.1	5.0	4.1	1.1
		%			Description	
Gender	186	39/61			Male/female	
Educational level	184	77/23			Low/high	
Marital status	184	82/18			Together/single	
Work disabled	186	21/79			Yes/no	
Rheumatoid factor	150	79/21			Positive/negative	

occurrence of recall bias. Disease duration varied between zero and 6 yr (with a mean duration of 2.8 ± 1.8 yr). Baseline demographic and socio-economic characteristics and disease-specific variables are presented in Table 2.

The adherence region for patients' referral and inclusion covers ~20% of The Netherlands. Urban as well as rural areas are included. Therefore, cohort figures can be compared with those of the Dutch population. If corrected for age and gender, educational level and marital status of the RA cohort were not different from the Dutch population.

For 89% of the patients (Table 3), RA had an impact on either work capability, income, rest during the daytime, leisure time activity, transport, housing, or social support. For 58% of the patients, RA had an effect on at least three of these items. Socio-economic consequences were already observed in the first years of the disease in our cohort (Fig. 1), ranging from 9% (removals) to 59% (social support).

Employment

Patients were asked about their employment status. As work disability is officially registered, onset data could be assessed. Adjusted cohort figures (patients below 65 yr), compared to the Dutch working population (Table 4), showed for male RA patients a relative risk (RR) of registered (partial) work disability of 4.1 (95% CI 2–6); female RA patients face a RR of 14.5 (95% CI 7–22); overall disability was 6.9 (95% CI 5–9). The calculated RR on early retirement proved to be fully comparable for the RA cohort and the working population.
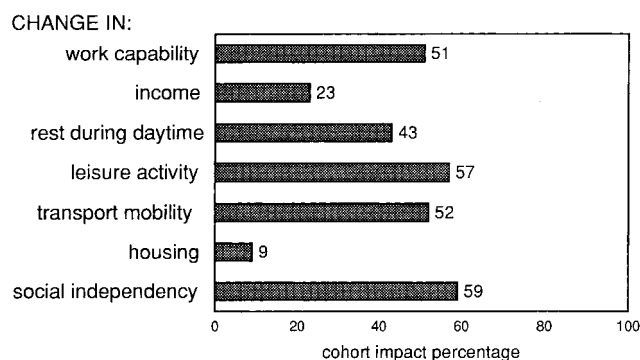

FIG. 1. Socio-economic impact presenting early in the course of RA.

TABLE 3. Impact of RA on socio-economic items[a]

	n	%
No impact	20	11
Impact on at least 1 item	166	89
Impact on at least 2 items	139	75
Impact on at least 3 items	108	58
Impact on at least 4 items	56	30
Impact on at least 5 items	23	12
Impact on at least 6 items	7	4

[a]Employment, income, rest during the daytime, leisure time activity, transport, housing, social support.

If restricting to the at-risk group (i.e. all patients still working shortly before RA diagnosis; $n = 76$) 51% appeared to be officially recognized (partially) as work disabled. For the at-risk patients, descriptive survival

TABLE 4. Age-adjusted figures concerning the work situation of the Dutch working population and RA patients (significant differences are given in bold)

	n		% working		% work disabled		% early retired	
	Dutch	RA	Dutch	RA	Dutch	RA	Dutch	RA
Women	2811	82	30.5	23.3 [14.2;32.4][a]	1.6	**23.4** [14.2;32.5]	0.5	1.0
Men	2124	50	67.6	**51.3** [37.4;65.1][a]	6.1	**25.0** [13.0;37.1][a]	5.6	2.3

[a]95% confidence interval.

analysis (Fig. 2) over the first 5 yr showed a considerable increase in work disability after the second year.

Income

Income reduction was experienced by 23% of the RA patients. Logistic regression results are presented in Table 5. Female RA patients (OR 3.9) more often experienced a reduction of income. Patients registered as (partial) work disabled did not (OR 0) experience a reduction of income. It appeared that patients with minor functional disability [OR, 0.4] more often experienced a reduction of income.

Figures were derived from the logistic regression equation (significant estimates are given in bold): $0.8631 - 0.0381 \times age - 1.3623 \times \textbf{gender} - 0.6643 \times marital\ status + 3.2193 \times \textbf{work disability} + 1.0011 \times \textbf{functional index}$.

Odds ratios (Table 5) were calculated as follows:

Functional index: S.E. 1.3778
(P75–P25) interquartile range: 0.94
Calculation: $OR = e^{-1.0011\ (0.94)} = 0.39$
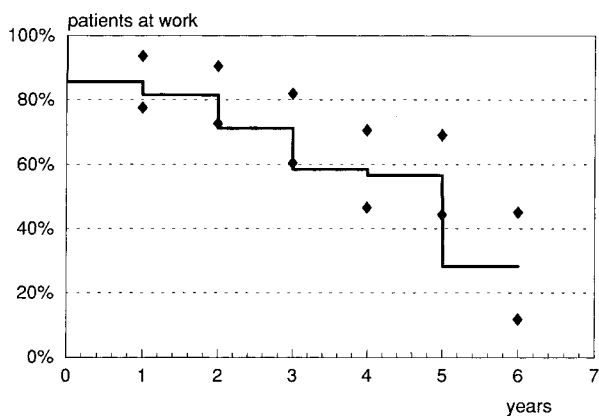$$OR_{(95\%\ CI)} = [e^{-1.0011(\pm 1.96) \times 1.3778}]^{0.94}$$

FIG. 2. Officially recognized work disability (◆, 95% CI) in an early RA cohort, for working patients, at baseline younger than 65 yr.

Rest during the daytime

Extra rest during the daytime, attributed to RA, is considered expressive for increased fatigue and was applied by 43% of the patients. The median rest during the daytime amounted to 1 h per day (range 15–240 min). The regression results are presented in Table 5 (model explained variance 58%). It appeared that a shared household (effect = −0.5) and increasing age (effect = 0.5) were associated with extra rest. Figures were derived from the multiple regression equation (significant estimates are given in bold): $0.0248 \times \textbf{age} + 0.1792 \times gender - 0.4683 \times \textbf{marital status} + 0.0043 \times work\ disability + 0.2609 \times functional\ index$.

TABLE 5. Influence of socio-demographic variables and (baseline) disease characteristics on socio-economic factors (measured at a mean disease duration of 2.8 yr). Influence (with 95% confidence interval) is expressed as the OR[a] or as the effect (E[a]) from multiple regression analysis (significant estimates are given in bold)

	Income (*n* = 186) OR	Rest (*n* = 186) E	Leisure activity (*n* = 103) E	Transport (*n* = 184) OR	Housing (*n* = 184) OR
Age	2.2 [0.9;5.4]	**0.5** [0.5;0.5]	**1.1** [1.1;1.1]	**12.1** [4;36.2]	0.5 [0.1;1.5]
Gender (m *vs* f)	**3.9** [1.3;11.5]	0.2 [−0.2;0.5]	**1.1** [0.4;1.7]	**2.8** [1;7.6]	2.6 [0.7;9.1]
Marital status	1.9 [0.4;8.5]	**−0.5** [−0.9;−0.1]	0.2 [−0.5;1]	0.6 [0.2;1.8]	0.6 [0.1;2.5]
Work disability	**0** [0;0.1]	0 [−0.4;0.4]	**1.1** [0.4;1.8]	**4.4** [1.3;14.8]	0.4 [0.1;1.7]
Functional index[a]	**0.4** [0.2;0.9]	0.2 [−0.1;0.6]	−0.2 [−0.8;0.3]	**2.4** [1.2;5]	**0.4** [0.2;0.9]

[a]OR$_{(P25–P75)}$ or E$_{(P25–P75)}$ (i.e. RC$_{P25}$–RC$_{P75}$).

Effects (Table 5) were calculated as follows:

Age: s.e. 0.0048
(P75–P25) interquartile range: 21.03
Calculation: $E = 0.0248 \times 21.03 = 0.52$
$$E_{(95\%\ \mathrm{CI})} = [E \pm 1.96 \times 0.0048] = [0.51;0.53]$$

Leisure time activity

Fifty-seven per cent of the patients mentioned that, due to RA, their leisure activities had changed (Table 6). On the six-point scale, these patients appeared to drop by one point (mean score before diagnosis: 2.9; mean score after diagnosis: 2.0; paired *t*-test *P* value = 0.0001). Regression analysis (model explained variance: 89%; Table 5) showed a tendency towards increased risk for patients with (partial) work disability. Results also tend to indicate a gender effect (i.e. smaller risk on leisure activities with a lower joint load if male) as well as an age effect (i.e. if older, more often leisure activities with a lower joint load).

Transport mobility

Fifty-two per cent of the patients ascribed reduced transport mobility to their RA. Logistic regression results are presented in Table 5. Reduced transport mobility is associated with higher age [OR 12.1], higher (HAQ) values of the functional index [OR 2.4] and work disability (OR 4.4). Women more often develop a reduction in transport mobility (OR 2.8).

Housing

Nine per cent of the patients claimed that house removal was induced by their RA. Regression analysis showed removal to be related to less functional limitation [Table 5; functional index: OR 0.4].

Social support

Support was received by 59% of the patients. Whether or not social support is given seems to be highly preconditioned (Table 7). Patients with a single household (OR 6.2) and as well as men (OR 0.3) received more support. The initial functional index [OR 0.5] was also predictive for support receipt. It appeared that patients taken care of by their partner (71%) received mainly daily support. Support increased with age [OR 2.6]. In 30% of the cases, (mainly) weekly support was given by children of the patients. Family support (12% of the cases) was arranged monthly and increased with patient's age [OR

2.7]. Support from neighbours and/or friends (11% of the cases) was also characterized by monthly support.

Discussion

Although it has been widely recognized that RA has huge socio-economic consequences, information as to the extent of this impact remains sparse [21]; besides, most studies mainly focus on work disability [22–24]. The present study not only evaluates the effects of RA on a wide range of socio-economic consequences in the first years of RA, but also presents effect figures to demonstrate the magnitude of these consequences.

To compare the work disability figures of our cohort with those of the Dutch working population, we had to investigate the socio-demographic background. Both the level of education and marital status (if age and gender adjusted) appeared to be similar in the RA cohort and in the Dutch population. This is in contradiction with conclusions drawn in other studies. In the mid-1980s, based on National Health Survey data, Pincus *et al.* [25] found that a lower level of education was associated with an increased risk for all types of chronic diseases. Formal educational level was suggested to be a marker in the pathobiology of disease. In a later report on data from the same survey [26], it was concluded that the strength of the association between schooling and arthritis was overestimated. The association weakened when occupation, income and body mass were accounted for. A further explanation can be derived from the study designs. The mean age of RA patients in a National Health Survey (where all disease durations are included) is expected to be higher than the mean age of patients in an inception cohort. As higher age is associated with a lower level of education, overestimation can be expected in population-based samples. Our findings on education levels are in concordance with those found by Bankhead *et al.* [27], stating that there is no such trend as increasing RA incidence with declining social class. Thus, there is no indication of education level being related to disease susceptibility. Also, education level did not contribute in our explanatory analyses of socio-economic change. However, as education is considered to reflect general behaviour [28], a relationship with future health status can be assumed. In terms of support efficacy, this implies that policy makers and health care providers should aim at interventions early in the course of the disease.

To our knowledge, effect figures illustrating the magnitude of (RA-attributed) work disability are still lacking. Therefore, cohort figures on work disability were compared to those of the (Dutch) working population. It was shown that RA had an enormous impact on work disability: 27% of all patients below the age of 65 yr were officially recognized as (partly) work disabled, i.e. exceeding the figures of the Dutch working population by 4–15 times (mean: seven times). If restricted to the population at risk (i.e. still working shortly before RA diagnosis), 51% were (RA-attributed) work disabled. Other (population-based) studies [6, 7, 23, 29–32]

TABLE 6. Presentation of the leisure activities as practised before and after RA diagnosis

Joint load	Score	Before RA (%)	After RA (%)
On upper and	6	23	4
lower extremities	5	30	31
On lower extremities	4	9	6
	3		1
On upper extremities	2	36	31
	1	3	27

TABLE 7. Influence of socio-demographic variables and (baseline) disease characteristics on social support (as measured at a mean disease duration of 2.8 yr). Influence (with 95% confidence interval) is expressed as the OR[a] from multiple regression analysis (significant estimates are given in bold)

		Patients, receiving support (n = 109)			
Frequency	Support (n = 186)	By partner Daily	By children Weekly	By family Monthly	By relatives Monthly
Age	0.7	**2.6**	0.9	**2.7**	1.5
	[0.4;1]	[1.1;6.3]	[0.5;1.7]	[1;7.3]	[0.3;7.4]
Gender	**0.3**	0.6	0.5	0.5	1.4
	[0.1;0.6]	[0.2;1.8]	[0.2;1.4]	[0.1;8.6]	[0.2;10.1]
Marital status	**6.2**	n.a.	1.7	1	**0**
	[2.4;16.4]		[0.4;6.7]	[0.1;8.6]	[0;0.2]
Work disability	0.6	1.1	0.8	1.5	0.3
	[0.2;1.4]	[0.3;3.9]	[0.3;2.3]	[0.3;7.9]	[0;3.5]
Functional index	**0.5**	0.7	1.8	1.2	0.3
	[0.3;0.9]	[0.3;1.5]	[0.8;4.3]	[0.3;4.8]	[0.1;1.5]

[a]$OR_{(P25-P75)}$.

showed a comparable reduction in labour force in RA cohorts. Data viewed in a time perspective (Fig. 2) showed that 14% had become work disabled 1 yr after inclusion, with 42% after 3 yr, increasing to 72% after 5 yr (95% CI 55, 88). Such progression in work disability during the first 5 yr supports the statement [33] that the risk of becoming work disabled is predicted by disease severity rather than by work structure. Although these figures are already impressive, it should be remembered that registered work disability only applies to those who are officially employed. For example, housekeeping disability is not registered, implying that female figures are underestimated. This is further illustrated as 49% of the employed (thus at risk) RA patients are female, 49% of the work-disabled patients are female, and 62% of RA patients aged <65 yr are female. Thus, in the near future, as a result of increased female labour participation, RA work disability figures are expected to incline.

Besides work disability, socio-economic impact was allocated to income, rest during the daytime, leisure time activity, transport, housing, and social support (Table 3). A quarter of our patients experienced income reduction. The regression model showed experienced income change to be explained by gender, physical function and work disability. These results are in accordance with the figures presented by Eberhardt *et al.* [8] and with the associations described by Callahan *et al.* [24]. The observations that (1) patients with only minor functional disability experience more income reduction and that (2) work-disabled patients did not experience income reduction may refer to the quality of our social insurance system. In our cohort, 43% of the patients claimed extra bedrest during the daytime. In a recent study by Wolfe *et al.* [34], fatigue, measured by the visual analogue scale (VAS: 0–10 cm), was defined as clinically important if VAS ⩾ 2.0 cm. Although this applied to >41% of his patients, multivariate analysis showed no association of the inflammatory process with fatigue. Wolfe concluded fatigue to be a predictor of work dysfunction and overall health status. In our cohort, extra rest during the daytime was related to

increasing age and sharing of the household, but there was no relationship with work disability or physical limitation. Of course, 'experienced fatigue' (VAS) is not similar to 'rest during the daytime': where the VAS records the phenomenon, 'needed rest' gives a further quantification of the extent of fatigue. As over 40% of the patients claim 'experienced fatigue' or 'extra rest during the daytime', fatigue seems to be an important aspect of RA. Therefore, further research on fatigue measurement in early RA patients is strongly recommended.

Evaluation (8 yr of follow-up) of leisure time activity in an early RA inception cohort [11] showed a change in activities for three-quarters of the patients, with half of them being not satisfied with their recreation. In our study, leisure time activities turned out to change to activities with a lower demand on functional capability, especially for the group of work-disabled patients. Preference for patterns with low joint load was more often applicable if the patient was female and older.

Although the reduction in transport mobility proved to be mainly age related, the reduction due to work disability (OR 4.4) and physical decline (OR 2.4) was still considerable. Restriction of transport mobility more often concerned women. Only 9% of our patients had to move house due to the RA. Removal was mainly explained by limited loss of function. It has to be investigated further whether social care (adaptations, aids, devices, health care facilities) adds to an explanation for this low figure.

Taal *et al.* [35] concluded that, for RA patients, disability, pain and feeling dependent constitute the most important health-related problems. Revenson *et al.* [36] considered social network interactions as a potential source of both stress and support for individuals coping with a chronic illness. Both studies indicated that the need for support exposed a major impact on social independency. In our cohort, social support was received by more than half of the patients. Male patients and patients with a single household more often received support. Patients with less physical limitation also

received more support. This might imply that, at a certain point, care becomes institutionalized. Support by children consisted mainly of weekly support.

In conclusion, early after diagnosis, RA already has a huge impact on patients' socio-economic well-being. Most striking is the magnitude of work disability occurring: RA patients exceed by seven times Dutch working population figures. Nearly half of the patient group experienced increased fatigue and needed extra bedrest during the daytime. Leisure time activities changed toward activities with a lower joint load. Physical limitation, considered to be an important disease outcome measure, appeared to be predictive for work-related income reduction, reduced transport mobility and development of social dependency.

Acknowledgements

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