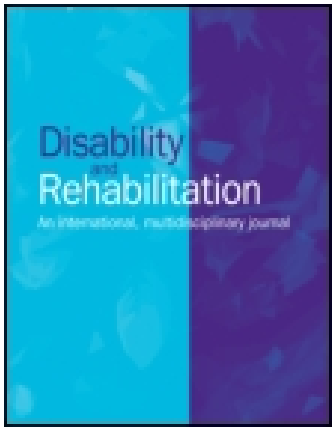

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The level and time course of disability: Trajectories of disability in adults and young elderly

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RESEARCH PAPER

The level and time course of disability: Trajectories of disability in adults and young elderly

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Abstract

Objectives. The objectives of this study were: (i) to identify trajectories in the level and time course of disability, (ii) to determine the relative frequency of each trajectory, and (iii) to assess the relationship of these trajectories with age, sex and the presence of four chronic diseases (asthma/chronic obstructive pulmonary disease (COPD), heart disease, severe low back complaints and diabetes mellitus).

Methods. We used six measurements of disability and information on mortality from a longitudinal study in Dutch persons aged 15 – 74. We used cluster analyses to group persons with similar levels and time courses of disability into disability trajectories. Deaths were classified into a separate trajectory. Multinomial regression was used to assess the relationship of the trajectories with age, sex and the four chronic diseases. Information on disability in the last year(s) prior to death was used to examine disability prior to death.

Results. Nine trajectories of disability were identified, while all deaths were classified into a separate trajectory; 74% was entirely non-disabled. The size of the other trajectories varied from 10% (permanently mildly disabled) to 0.5% (severely disabled with large increase in disability). Significant associations were found with age and, correcting for age and sex, with asthma/COPD, heart disease and low back complaints, but not with diabetes. The ORs were generally highest for trajectories characterized by severe disability, although disease-specific associations were also found. Among the deaths, 41% of the trajectories were associated with disability prior to death. Disability prior to death was more prevalent among persons with heart disease, back complaints, and asthma/COPD.

Conclusions. These findings suggest that disability is a dynamic process, and that important differences exist within the 'disabled' population. This is important for assessing the need for care and shows the limitations of modeling disability change based on two measurements only.

Keywords: *Time course of disability, chronic diseases, longitudinal study*

Introduction

Ageing of baby boom generations and declining mortality has caused a substantial rise in the number of people with a chronic disease. Chronic disease may be accompanied by difficulties in physical functioning, summarized as 'disability'. Disability greatly affects the quality of life, the need for (health) care and supportive services, and institutionalization [1].

Traditionally, disability was considered irreversible. The growing research interest in the disablement process [2] and the availability of longitudinal data has contributed to an increasingly nuanced picture of disability. From intra-individual comparisons of disability at two points in time, it is now widely acknowledged that disability can both increase and decrease over time [3 – 5]. Follow-up studies covering a longer time span bring forward increasing evidence that improvements in functioning are not necessarily persistent and are quite often followed by decline [6 – 9]. Moreover, it has been shown that changes in disability are not necessarily gradual, but include non-linear patterns such as progressive decline [10] and fluctuating patterns [9].

Until recently studies usually focused on either the level of disability or a single aspect of the time course of disability, such as the direction of change (increase vs. decrease), the linearity of change (linear vs. non-linear patterns of change), or the variability of disability (fluctuating vs. non-fluctuating). Persons

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were, for instance, classified into a group with and a group without (serious) disability or into a group who maintain their level of function and a group showing decline. However, distinguishing patterns ('trajectories') which reflect specific combinations of different aspects of the level and time course of disability, could provide a far more comprehensive overview of disability in the population, and could do justice to the heterogeneity within the group of disabled persons. This is important for assessing the burden of disability and the need for care, as well as for enhancing our understanding of the disablement process.

To date, only a few studies have looked at trajectories of disability, and most of these studies focused on specific trajectories, i.e., catastrophic vs. progressive decline in Activities of Daily Living (ADL) [10], trajectories at the end of life [11] or included only the most frequent trajectories [7,12,13]. Two recent studies described trajectories of disability present in the elderly [14] and oldest-old [15] population. The study of Romoren and Blekeseaune [15], documented a wide variety of trajectories of ADL disability before death on the basis of detailed and complete follow-up data on disability among 434 Norwegian octogenarians. However, half of these trajectories included only one person, and in condensing these trajectories into four main groups all variations in the time course of disability got lost. The study of Deeg [14], based on a larger sample of 3107 Dutch subjects aged 55–85, distinguished eight different time courses of functional limitations, and examined their association with chronic conditions. While this study nicely documents different course types of functional limitations present among the elderly and their association with chronic diseases, the classification was based on only three assessments, spaced by three years, of a limited set of functional limitations (climbing stairs, cutting own toenails, and use of own or public transport), and excluded subjects with incomplete information.

The present study combines a large sample size with detailed information on disability from up to six measurements during a six-year period. This allowed us to look at trajectories of disability and death in the adult and elderly population, taking into account the level, direction and linearity of change and variability of disability over time, and without excluding subjects with incomplete follow-up information. As chronic disease figures prominently in the disablement process, we examined the effect of four disabling diseases, next to age and sex on trajectories of disability. The objective of this study was (i) to identify trajectories of disability, (ii) to determine the relative frequency of each of these trajectories, and (iii) to assess the relationship of these trajectories with age, sex and the presence of four disabling chronic diseases.

Material and methods

Population

We used data from the GLOBE study – GLOBE being the Dutch acronym for Health and Living Conditions of the population of Eindhoven and surroundings [16]. The study started in 1991 with a postal survey and an oral interview among a stratified sample of 27,070 Dutch nationals between the ages of 15 and 74 years living in the city of Eindhoven (40% of all respondents) and surrounding municipalities (response rate 70.3%). Persons living in institutions were included in this sample, except for Eindhoven where the institutionalized population only comprises residents of homes for the elderly. Persons aged 45 and up were overrepresented. The response rate was 70.1% ($n = 18{,}973$). About five months later, 3,968 respondents drawn from the postal survey were approached for an oral interview. Subjects who, based on a check-list of chronic diseases in the postal survey, reported to have asthma/chronic obstructive pulmonary disease (COPD), heart disease, severe low back complaints or diabetes mellitus were overrepresented in this sample to increase the power of the survey. The response rate was 72.2% ($n = 2{,}867$). These respondents were included in the analyses presented in this paper.

Between 1992 and 1995, follow-up data were collected from the same population by postal surveys, and in 1997 by both a postal survey and an interview. During this period 26 subjects were lost to follow-up, 14 emigrated abroad and 248 refused to participate any further in the study. The response rate varied between 84.5% ($n = 2{,}422$) in 1992 and 71.0% ($n = 2{,}024$) in 1995 and was 71.4% ($n = 2{,}046$) in 1997. As death was an outcome in our study, the percentage of subjects for which we had outcome information (i.e., responders and deaths) ranged from 85.4% in 1991 to 75.9% in 1995 and was 79.3% in 1997. Table I shows the recruitment of study subjects and questionnaires for each stage of the analyses.

Data

Long-term Disability was measured using the Organization-for-Economic-Cooperation-and-Development questionnaire [17] and a questionnaire with additional items on ADL and mobility [18]. The disability items used in the present study include: Physical performance (walking a quarter of a mile (400 m), carrying an object of ten pounds (5 kg),

Table I. The total study population, the number of subjects who died, subjects with no, complete or partial missing information and the number of valid questionnaires.

	Number of subjects		Number of valid questionnaires[1]	
Original sample	2867			
No valid questionnaire	7			
At least one valid questionnaire or died during follow-up	2860[2]		13565[3]	
Died during follow-up		226[4]	612	
All six questionnaires valid		1485[5]	8910	
Survivors with incomplete response		1149[6]	4043	
Five valid questionnaires		406		2030
Four valid questionnaires		236		944
Three valid questionnaires		198		594
Two valid questionnaires		166		332
One valid questionnaire		143		143

[1]Including 490 questionnaires with less than 50% missing items in each of the two disability domains; [2]Included in logistic regression analysis of trajectories of disability. This number includes three subjects who died without a valid questionnaire; [3]Used in the PCA to obtain a summary disability score; [4]Grouped into a separate tenth trajectory; [5]Used in the definition of trajectories (trajectory 1–9); [6]Added to logistic regression analysis with multiple imputation (trajectory 1–9).

bending and picking up a shoe), gross mobility capacity (walking up and down the stairs, walking outside (no distance), getting outside) and basic activities of daily living (getting in and out of bed, getting in and out of a chair, dressing; washing hands and face, walking across a room, bathing/showering). Subjects were asked whether they could do these actions and activities with no difficulty, some difficulty a lot of difficulty or whether they needed help/were unable to do. We used information on this broad range of disability items to describe the full spectrum of disability in the population. Principal Component Analysis (PCA, see Method section), indicated that the 12 items could be summarized adequately by one dimension.

The presence of four disabling *chronic diseases* was measured in 1991 by using disease-specific questionnaires on asthma/COPD [19], heart disease [20,21], diabetes mellitus [22] and severe low back complaints [23,24]. Irrespective of whether subjects did perceive themselves as suffering from the particular disease they were asked questions to assess the presence of the particular disease. Based on these disease-specific questionnaires, the study population was found to include 507 subjects with asthma/COPD, 395 subjects with heart disease, 578 subjects with back complaints and 109 subjects with diabetes. Information on *age* and *sex* was available from the 1991 survey, and on *mortality* from yearly administrative follow-up in municipal population registers.

Methods

Identifying trajectories of disability

A three-step approach was adopted to identify patterns ('trajectories') in the level and time course of disability: (i) one individual summary disability score was calculated per year (except 1996); (ii) the individual level and course of disability over time was determined by calculating four aspects of the level and time course of disability (i.e., level, direction, linearity of change and variability); and (iii) persons with similar levels and time courses of disability were grouped into trajectories of disability. A total of 226 subjects who died during follow-up could not be classified in a similar way as the survivors because of the availability of fewer questionnaires, inherent to dying during the interval. In order to represent the entire population, these deaths were not excluded, but were placed in a separate trajectory. For the sake of clarity, we first describe the general procedure to identify trajectories of disability among survivors, which was based on 1,485 survivors with complete information on disability. The specific steps needed to classify survivors with incomplete data ($n = 1{,}149$) into one of these trajectories are described in a separate paragraph.

Assessing an individual summary score of disability per year (step 1)

The answers to the 12 disability questions per individual for each year, ranging from 1 (no difficulty) to 4 (unable to do/only with help) were taken as the starting point. Principal Component Analysis (PCA), indicated that these items could be summarized by one dimension (the first axis presented 58% of the variance, the second axis only 9%). Plotting each of the 12 disability items against the first axis showed monotonous and almost linear relationships for each item, indicating that we could use PCA. PCA was performed on the correlation matrix of the 12 disability items. The summary

scores (object scores in PCA terminology) were scaled from one to four and can simply be interpreted as weighted means of variables, using as weights the scores for the disabilities (i.e., the variable scores derived from the PCA, see Table II). For a person who is unable to do without help all disability items, each disability score is multiplied by four and then added, yielding a summary score of four. Adding the scores (i.e., disability scores multiplied by one) yields the summary score of one for a person without any difficulty.

Characterization of the individual course of disability over time (step 2)

For *each* individual with six complete or completed (see section on incomplete data) questionnaires (in total $n = 1{,}485$), we assessed four aspects of the level and time course of disability, using separate linear regressions for each respondent. The mean individual summary score over all questionnaires, i.e., intercept of linear regression line at the middle of the six-year period measured the level of disability (first aspect). The intercept at the middle of the six-year period was used, because it is not correlated with the slope (the second aspect), and the risk of regression to the mean is smaller, as compared to using the intercept at baseline. The direction of the change (second aspect) was defined operationally as the slope of the linear regression line. A positive slope indicates an increasing disability score, that is, deterioration in functioning, and a negative slope an improvement in functioning. To assess the non-linearity in the scores (third aspect), we added a quadratic term to the regression equation. Non-linearity was measured by taking the difference between the quadratic regression line (parabola) and the straight linear regression line at the middle of the period. A positive difference indicates a convex shape, a negative difference a concave shape. For example, an individual without disabilities throughout the entire period except in the last year has a negative value. For the variability (fourth aspect), we used the standard deviation of the residuals from the parabolic regression.

Table II. Weights for summary score (i.e., variable scores derived from PCA analysis on questionnaires with sufficient* disability information ($n = 13565$).

Disability item	Weight for summary score
Washing hands and face	0.1386
Walking across a room	0.1330
Getting outside	0.1042
Dressing	0.1023
Washing whole body	0.0876
Getting in and out of bed	0.0808
Walking outside (no distance)	0.0772
Getting in and out of a chair	0.0768
Climbing stairs	0.0628
Bending and picking up a shoe	0.0494
Walking a quarter of a mile (400 m)	0.0486
Carrying an object of ten pounds (5 kg)	0.0387

Note: The variable score gives the weight of each disability item to construct the summary score; *See Table I.

Grouping persons with similar individual courses of disability into trajectories (step 3)

Using the values of the four aspects, which were based on individual regression lines, we grouped persons with similar levels and time courses of disability into trajectories of disability, by using divisive cluster analysis [25]. We standardized the aspects before clustering ensuring that level, direction and non-linearity of change and variability equally influenced the clustering process. By clustering the four aspects, rather than the original summary scores per wave, we could obtain clusters with a similar variability of disability, regardless of the specific years during which high or low scores occurred. The result consisted of nine clusters among survivors, in addition to one cluster including all deaths. As the number of clusters is always subjective, we compared the results between five and 12 clusters. Distinguishing substantially more trajectories would have resulted in more homogeneous but smaller groups, whereas distinguishing fewer trajectories would have masked heterogeneity within the groups. The plot of the within-cluster variance against the number of clusters showed that adding a tenth cluster resulted in a smaller reduction in variance as compared to the sixth through ninth. We did not reduce the number of trajectories to avoid trajectories with low frequencies, as these trajectories were characterized by severe disability, which we considered relevant for the burden of morbidity and the need for care.

Incomplete data

To handle incomplete data, missing information was imputed at two stages in the analyses. First, when information on less than half of the items was missing, we imputed the value by using the answers to disability questions that most closely resembled the missing disability items. This procedure resulted in an increase of 490 questionnaires over all years, yielding in total 13,565 questionnaires (see Table I). As among these 490 questionnaires, 68% questionnaires missed only one item and 30% missed two or three items, this imputation will hardly have affected the disability scores, and even less the classification

of trajectories. Including these imputed disability items, we calculated a disability score (see step 1). For persons having disability scores for all 6 rounds, we determined the scores on the four aspects using regression analysis (step 2). After this first imputation and excluding 7 persons not responding to any questionnaire, the study population numbered 1,149 survivors with disability scores for less than 6 years (Table I). Often disability scores for only one or two years were missing. Persons with missing questionnaires were more often women, were younger, had lower education, and were more likely to have chronic diseases at baseline. To avoid that excluding subjects with missing questionnaires would reduce the representatively of our results, multiple imputation using a hot-deck algorithm [26] was applied to classify these subjects. First, we randomly selected for each incomplete case 15 complete cases with similar summary scores for the years that were present. Similarity was assessed using the least squares criterion. Next, we randomly selected one case from these 15 'nearest neighbors' and imputed its disability scores for the missing years. Regression analysis on the completed set of disability scores for each person gave the values for the four aspects. Individuals were assigned to the cluster with the smallest standardized mean squared errors between the individual score and the mean cluster score as criterion (Kmeans criterion). By repeating this procedure four times, we made five replicas of the dataset. 621 of the 1,149 subjects were assigned to the same trajectory in all 5 replicas.

Determination of the relative frequency of the trajectories of disability

To determine the relative frequency of each of the trajectories (second research question), we took into account the overrepresentation of persons with one of the four chronic diseases and of persons aged 45 years and over by re-weighting for the sampling design. Since we used multiple imputation to assign subjects with missing questionnaires to one of the trajectories, we obtained five frequency distributions. The five distributions were combined according to Rubin's method [26] into one mean estimate of the frequency distribution and confidence interval adjusted for non-response. The frequency distribution of trajectories was based on virtually all subjects, ($n = 2{,}860$, including 1,149 subjects with incomplete information and 226 deaths).

Assessing the relationship between the trajectories of disability with age, sex and four disabling diseases

Multinomial regression was used to assess the relationship between the trajectories of disability and age, sex and four disabling chronic diseases, respectively (third research question), taking classification into one of the 10 trajectories as the dependent variable, and using trajectory 1 (entirely non-disabled) as the reference category. The major difference with standard logistic regression is that the dependent variable has more than two outcome possibilities (i.e., nominal rather than dichotomous response). Multinomial regression was preferred over repeated pair-wise ordinary logistic regression because it renders overall p-values for the relation between the trajectories and age, sex and the four chronic diseases, respectively. Like standard logistic regression, multinomial regression allows correcting for confounders and it expresses the results as odd ratios (ORs). We took in general the group with the lowest risks as the reference group (OR of 1). Only for age, we used the oldest age group as reference group to avoid that the low prevalence of trajectories associated with disability among the youngest age group would result in extreme large ORs and large confidence intervals. We used normalized weights (with a mean of one) in the regression analyses to take into account the sampling design. Since we used multiple imputation, we ran the regression models for each of the five replicas of the dataset, and calculated one mean estimate and a confidence interval adjusted for non-response [26] and one overall p-value [27].

Disability prior to death

To examine differences in disability prior to death, a complementary analysis was conducted among those who died during the 6-year period ($n = 226$). Based on the disability scores in the last questionnaire prior to death, or if not available in the second-last, deaths were classified into trajectories with and without disability. A cut-off point of 1.4 was used, reflecting that among survivors the mean disability score was 1.4 or higher in trajectories with at least moderate disability (Table III). When no disability information was available from the (second) last questionnaire, the subject was excluded ($n = 36$). Examining the mean disability scores of these 36 subjects for the preceding years showed that this group holds an intermediate position between the groups with and without disability (data not shown). Even though the classification was based only on the (second) last questionnaire prior to death, almost all subjects classified as non-disabled prior to death were non-disabled during the whole period, and most subjects classified as disabled showed an increase in disability closer to death. Standard logistic regression was used to assess whether disability, as compared to no disability prior to death was associated with age, sex and four disabling chronic diseases.

Table III. Mean values of the four course aspects for each trajectory ($n = 1485$).

Trajectories	$n = 1485$	Mean level	Direction of change	Linearity of change	Variability
1. Entirely non-disabled	918	1.014	0.0004	− 0.0027	0.0222
2. Permanently mildly disabled	230	1.138	− 0.0029	0.0248	0.1663
3. Mild, but increasing disability	106	1.235	0.0466	− 0.0300	0.1719
4. Mild, but decreasing disability	56	1.303	− 0.0415	− 0.0927	0.2612
5. Sudden increase in disability	25	1.419	0.1481	− 0.1094	0.2996
6. Moderately disabled with partial regain in functioning after loss	73	1.444	0.0254	0.1098	0.2893
7. Moderately disabled with strong fluctuations	22	1.572	0.0326	0.0856	0.7867
8. Permanently severely disabled	35	2.053	0.0243	− 0.0506	0.3160
9. Severely disabled with large increase in disability	20	2.229	0.1225	0.1909	0.4532

Results

Trajectories of disability

We identified nine trajectories of disability (Figure 1), in addition to the single trajectory into which all deaths were classified. For the ease of presentation, we ordered the disability trajectories by disability level, ranging from non-disabled (trajectory 1) to severely disabled (trajectories 8 and 9). A person reporting each time only difficulties in carrying an object would just fit within the group of entirely non-disabled. Had this person been unable to carry an object or reported other difficulties, (s)he would have been classified into one of the trajectories with disability. Severely disabled persons reported at least some difficulty on virtually all disability items (including ADLs), or great difficulty or being unable to do several items. Severe disability should be interpreted within the context of the general adult and young elderly population.

Figure 1 shows for each trajectory the mean disability score per year, and Table III presents for each trajectory the mean value of each of the four aspects. Looking at Figure 1 and Table III, Trajectory 1 can be seen to include persons who are non-disabled during the whole follow-up period. The other eight trajectories comprised disabled persons, but with different combinations of the four trajectory aspects. Trajectory 2 comprises mild disability, without substantial change. Trajectories 3 and 4 also include mildly disabled persons, but trajectory 3 is characterized by deteriorating, and trajectory 4 by improving functioning. Trajectory 5 is clearly distinct, as it is characterized by a sudden strong deterioration in functioning (i.e., a non-linear course). Trajectory 6, into which moderately disabled people are grouped who have regained some functioning after a loss, likewise shows a non-linear course. Trajectory 7 also comprises the moderately disabled, but is characterized by much more variability over time. Trajectory 8 includes permanently severely disabled people and trajectory 9 severely disabled people with a large non-linear deterioration in functioning. Trajectory 10 includes all deaths.

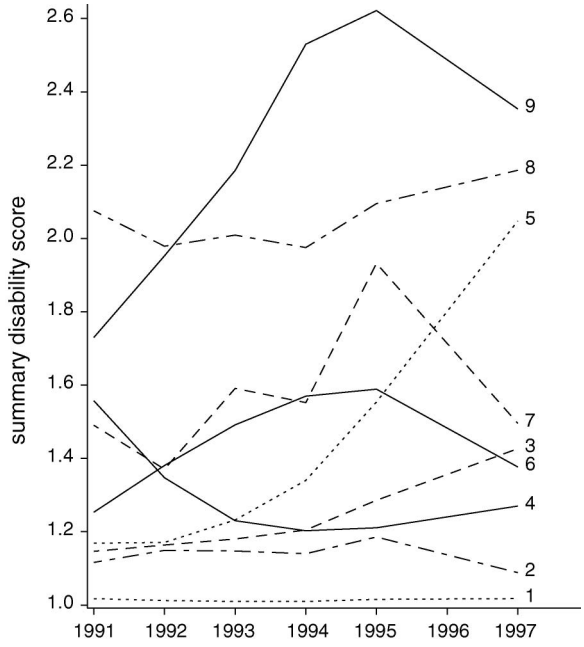

Figure 1. Mean disability score per year per trajectory, ranging from 1 (without any difficulty on all 12 disability items) to four (unable to do or can only do with help all selected disability items). 1 = entirely non-disabled, 2 = permanently mildly disabled, 3 = mild, but increasing disability, 4 = mild, but decreasing disability, 5 = sudden increase in disability, 6 = moderately disabled with partial regain in functioning after loss, 7 = moderately disabled with strong fluctuations, 8 = permanently severely disabled, 9 = severely disabled with large increase in disability.

Relative frequency of the trajectories of disability

Table IV shows the frequency distribution of the 10 trajectories, both unadjusted ($n = 1{,}711$) and adjusted for non-response and sample design. In general, correction for incomplete information slightly altered the point estimates and narrowed the confidence intervals. We focus on the adjusted

Table IV. Frequencies of the trajectories for complete cases and deaths (absolute numbers and % adjusted for sample design) and for all cases (adjusted for non-response and sample design).

	Complete cases and deaths ($n = 1485 + 226$)		All cases	
Trajectory	# in the sample	% and 95% CI, adjusted for sample design	# in the sample	% and 95% CI, adjusted for sample design and non-response
1. Entirely non-disabled	918	75.0 (71.4 – 78.3)	1363 + 154.8*	74.0 (71.9 – 76.0)
2. Permanently mildly disabled	230	9.3 (7.8 – 11.0)	284 + 120.0	9.8 (8.7 – 11.1)
3. Mild, but increasing disability	106	3.0 (2.3 – 4.0)	132 + 71.0	3.8 (3.0 – 5.0)
4. Mild, but decreasing disability	56	1.8 (1.3 – 2.7)	84 + 37.2	2.2 (1.8 – 2.7)
5. Sudden increase in disability	25	0.6 (0.4 – 1.1)	38 + 20.6	1.0 (0.7 – 1.3)
6. Moderately disabled with partial regain in functioning after loss	73	2.4 (1.8 – 3.3	98 + 61.4	3.0 (2.1 – 4.3)
7. Moderately disabled with strong fluctuations	22	0.9 (0.5 – 1.7)	29 + 23.0	1.2 (0.8 – 1.8)
8. Permanently severely disabled	35	0.6 (0.4 – 1.1)	52 + 22.6	0.9 (0.7 – 1.3)
9. Severely disabled with large increase in disability	20	0.4 (0.2 – 0.7)	26 + 17.4	0.5 (0.3 – 0.8)
10. Death	226	5.8 (4.9 – 7.0)	226 + 0	3.3 (2.8 – 4.0)

*The first figure shows the number of complete and consistently imputed respondents; the second figure shows the mean number of respondents with varying imputations per replica. The sum of the numbers is 2,332 + 528.

outcomes, which relate to a population between the ages of 15 and 74 years, with an age distribution similar to that of the source population of Eindhoven and surrounding municipalities. About 74% of this population is in trajectory 1 'entirely non-disabled'. The second largest group is trajectory 2 'permanently mildly disabled' (9.8%). Trajectory 3 'mild, but increasing disability' includes 3.8% and trajectory 6 'moderately disabled with partial regain in functioning after loss' 3.0%. The remaining trajectories (except trajectory 10) range from 2.2% (trajectory 4 'mild, but decreasing disability') to 0.5% (trajectory 9 'severely disabled with large increase in disability'). The tenth trajectory 'death' includes 3.3%.

Relationship of trajectories of disability with age, sex and chronic diseases

We found a significant overall association with the trajectories of disability and death for age ($p = 0.000$), but not for sex (corrected for age, $p = 0.31$). After controlling for age and sex, heart disease ($p = 0.0008$), asthma/COPD ($p = 0.0001$) and severe low back complaints ($p < 0.0001$) were significantly associated with the trajectories of disability (2 – 10). The overall effect of diabetes was borderline significant ($p = 0.07$).

The ORs (and 95% CI) for each trajectory are presented in Table V. The ORs for sex are corrected for age and those for the chronic diseases are corrected for age and sex. A young age (15 – 39 years relative to age 65 and over) is associated with lower risks of almost all trajectories of disability and death. The extremely small ORs for trajectories 8 permanently 'severely disabled' and trajectory 9 'severely disabled with large increase in disability' indicate that this younger group is relatively unlikely to follow trajectories characterized by severe disability.

People with heart disease, asthma/COPD and severe low back complaints (relative to people without the specific diseases) were found to be relatively more likely to follow any of the trajectories with disability (2 – 9) or to die (trajectory 10), relative to being entirely non-disabled. In general for people with these diseases, large ORs were found for trajectories with severe disability (trajectory 8 'permanently severely disabled' and 9 'severely disabled with large increase in disability'). In addition, some disease-specific associations catch the eye. For heart disease, large ORs were also found for trajectory 4 ('mild but decreasing disability') and 7 ('moderately disabled with strong fluctuations'), while for severe back complaints the ORs for trajectories characterized by a regain in functioning (trajectory 4 'mild but decreasing disability' and 6 'moderately disabled with regained functioning after initial loss) are also relatively large (as compared to trajectory 1). For asthma/COPD, in addition to trajectory 9 (and 8), large ORs were seen for other trajectories characterized by an increase in disability (trajectory 3 'mild but increasing disability' and 5 'sudden increase in disability'). For diabetes, a large OR was seen for death.

Disability prior to death

Of the 226 deaths during the follow-up period, 95 died without at least moderate disability prior to death, 95 with disability, and 36 could not be classified. Adjusted for the sample design, 41% of

Table V. Adjusted odds ratios and 95% confidence intervals (relative to entirely non-disabled) derived from the multinomial logistic regression model, corrected for age and sex.

	OR and 95% confidence interval (in brackets)								
Variable	Permanently mildly disabled (2)	Mild, but increasing disability (3)	Mild, but decreasing disability (4)	Sudden increase in disability (5)	Moderately disabled partial regain in functioning after loss (6)	Moderately disabled with strong fluctuations (7)	Permanently severely disabled (8)	Severely disabled with large increase in disability (9)	Death (10)
Age[1]									
15–39	0.36**	0.27**	0.14**	0.04+	0.33+	0.41	0.01**	0.01**	0.02**
	(0.23,0.58)	(0.14,0.50)	(0.05,0.38)	(0.00,1.41)	(0.10,1.16)	(0.11,1.47)	(0.00,0.13)	(0.00,0.24)	(0.01,0.06)
40–54	0.59*	0.31**	0.61	0.23**	0.48	0.63	0.15**	0.11*	0.13**
	(0.35,0.98)	(0.15,0.61)	(0.27,1.40)	(0.08,0.69)	(0.18,1.26)	(0.10,3.89)	(0.05,0.46)	(0.02,0.66)	(0.07,0.22)
55–64	0.80	0.51*	0.74	0.19**	0.72	0.61	0.33*	0.15*	0.30**
	(0.50,1.30)	(0.27,0.95)	(0.33,1.70)	(0.06,0.61)	(0.29,1.77)	(0.11,3.23)	(0.13,0.84)	(0.03,0.76)	(0.18,0.51)
Sex[2]									
Women	1.13	1.35	1.54	0.58	1.10	1.51	1.51	2.70	0.58*
	(0.78,1.64)	(0.74,2.45)	(0.88,2.68)	(0.19,1.78)	(0.64,1.90)	(0.53,4.31)	(0.44,5.22)	(0.75,9.75)	(0.37,0.90)
Diseases									
Heart diseaes[3]	4.28**	6.81**	8.52**	7.00**	4.53**	8.43**	18.20**	17.97**	7.16**
	(2.32,7.91)	(3.23,14.35)	(3.76,19.29)	(2.18,22.47)	(2.06,9.95)	(2.48,28.65)	(6.96,47.63)	(5.33,60.62)	(3.78,13.54)
Asthma/ COPD[4]	3.69**	6.38**	5.65**	5.70**	4.26**	2.84	6.96**	16.27**	5.18**
	(2.22,6.15)	(3.13,13.01)	(2.70,11.83)	(1.80,18.07)	(1.60,11.34)	(0.46,17.58)	(2.50,19.34)	(4.65,56.91)	(2.91,9.21)
Back complaints[5]	3.64**	6.74**	7.25**	5.18*	9.91**	5.57**	11.95**	13.15*	4.81**
	(2.34,5.64)	(3.82,11.91)	(3.84,13.68)	(1.50,17.82)	(4.79,20.51)	(1.76,17.60)	(4.64,30.73)	(1.90,90.98)	(2.60,8.90)
Diabetes mellitus[6]	1.25	3.52+	1.94	6.22+	2.97	2.55	4.96+	3.40	8.61**
	(0.27,5.71)	(0.86,14.44)	(0.26,14.40)	(0.76,51.11)	(0.61,14.43)	(0.05,99.00)	(0.82,29.85)	(0.19,60.70)	(3.24,22.90)

+ $0.1 > p > 0.05$; * $0.05 > p > 0.01$; ** $p < 0.01$; [1]Odds ratio relative to 65+; [2]Odds ratio relative to men; [3]Odds ratio relative to no heart disease; [4]Odds ratio relative to no asthma/COPD; [5]Odds ratio relative to no back complaints; [6]Odds ratio relative to no diabetes mellitus.

the deaths (CI: 24–48%) had disability prior to death. Figure 2 shows for the two trajectories prior to death the mean disability score. Persons grouped in the trajectory non-disabled prior to death appeared to be non-disabled during the whole period, while those classified as having disability prior to death showed increasing mean disability scores closer to death. Logistic regression analyses showed that disability prior to death was more prevalent among persons with heart disease, asthma/COPD and low back complaints (corrected for age and sex), but did not differ significantly by age, sex nor by the presence or absence of diabetes (Table VI).

Discussion

Based on six rounds of a population-based longitudinal study in Dutch persons between the ages 15 and 74 years at baseline this study reported on trajectories of disability, and their association with age, sex and four chronic diseases. We identified nine trajectories of disability, each one grouping persons with a similar level, direction and linearity of change and variability of disability. The largest trajectory (74%) comprised of permanently non-disabled people. The other eight comprised of disabled persons who differed with regard to the level and time course of disability, with frequencies varying from 10% ('permanently mildly disabled') to less than 1% ('permanently severely disabled' and 'severely disabled with large increase in disability'); 3% of the trajectories ended in death. About 41% of the deaths experienced at least moderate disability prior to death. Belonging to a disability or death-associated trajectory (2–10) was significantly associated with age, asthma/COPD, heart disease and low back complaints (corrected for age and sex). Although in general, the ORs were highest for trajectories characterized by severe disability, disease-specific associations were also found. For instance, persons with asthma/COPD were relatively more likely to follow a trajectory characterized by increasing disability (as compared to being entirely non-disabled).

The limitations of our study should be noted. The most important threat to the validity of our results is attrition. While disability-induced non-response can

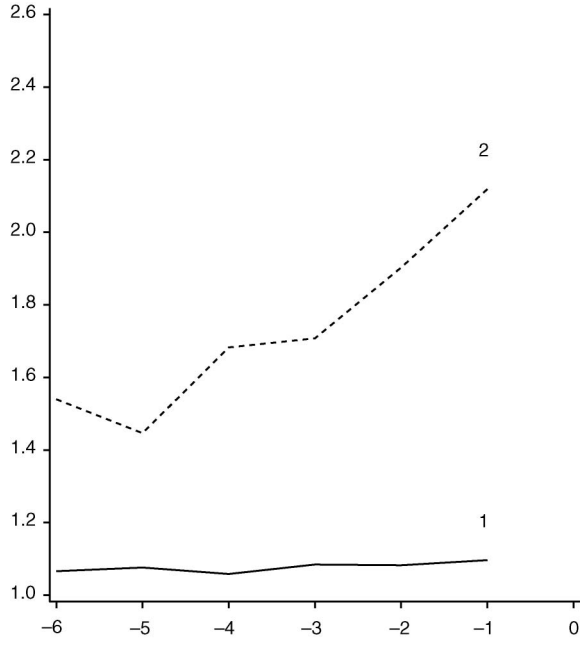

Figure 2. Mean disability score per year for two trajectories prior to death*, ranging from 1 (without any difficulty on all 12 disability items) to four (unable to do or can only do with help all selected disability items). *1 = non-disabled prior to death, 2 = disabled prior to death. Persons with a disability score of 1.4 or higher in the year prior to death, or if not available, in the second year prior to death were classified as disabled. 36 deaths with an unknown history of disability prior to death were excluded. This group had an intermediate position between the two trajectories and had virtually the same mean disability score over all available measurements as the total group; Note: trajectory year 0 is the year of death; −1 is one questionnaire prior to death. Mean values of non-disabled prior to death are based on 19 (6 years prior to death), 30 (5 years prior to death), 35 (4 years prior to death), 54 (3 years prior to death), 74 (2 years prior to death), 61 (1 year prior to death) subjects. Mean values of disabled prior to death are based on 13 (6 years prior to death), 28 (5 years prior to death), 48 (4 year prior to death), 62 (3 years prior to death), 79 (2 years prior to death), 59 (1 year prior to death) subjects.

Table VI. Adjusted odds ratios and 95% confidence intervals for age, sex (corrected for age) and chronic diseases (corrected for age and sex) derived from logistic regression models.

	Non-disabled prior to death	Disabled prior to death vs. Non-disabled prior to death
n	95	95
Age[1]		
15–54	1.00 (reference group)	0.57 (0.28,1.16)
55–64	1.00 (reference group)	1.20 (0.59,2.44)
Sex[2]		
Women	1.00 (reference group)	1.60 (0.86,2.96)
Diseases		
Heart diseaes[3]	1.00 (reference group)	5.94** (2.52,14.0)
Asthma/COPD[4]	1.00 (reference group)	3.57** (1.70,7.49)
Back complaints[5]	1.00 (reference group)	2.35** (1.22,4.54)
Diabetes mellitus[6]	1.00 (reference group)	0.86 (0.31,2.35)

*36 deaths with an unknown history of disability prior to death were excluded. This group had an intermediate position between the two trajectories and had virtually the same mean disability score over all available measurements as the total group; [1]Odds ratio relative to 65+; [2]Corrected for age. Odds ratio relative to men; [3]Corrected for age and sex. Odds ratio relative to no heart disease; [4]Corrected for age and sex. Odds ratio relative to no asthma/COPD; [5]Corrected for age and sex. Odds ratio relative to no back complaints; [6]Corrected for age and sex. Odds ratio relative to no diabetes mellitus.

neither be taken into account nor can be ruled out entirely, it can be argued that by using multiple imputation the bias is minimized. For subjects with missing information, we used previous and later disability scores to select respondents with a similar level and time course of disability. Within this group of 'nearest neighbours' we selected randomly one case and imputed its score(s) for the missing year(s). Even if the imputed disability score(s) would have underestimated the true but unknown disability level in case of disability-induced non-response, the selected disability trajectories will often have been the same or adjacent. In total 2,332 out of 2,860 subjects could be assigned consistently to one of the trajectories. Uncertainty due to missing information is taken into account in the confidence intervals.

Second, our study is based on self-reports of disability and chronic diseases. Given the focus on the time course of disability, our main concern is that changes in disability could reflect inconsistency in response behavior, or a poor validity of the instruments rather than any 'real' change in functioning. There is little information on the stability of disability over time if no real change occurs. However, potential bias is minimized due to the fact that six measurements were included and regression analyses were performed, reducing the sensitivity of the results to incidental misreporting.

The major strength of the study lies in the size and prospective design of the GLOBE study, which provided up to six measurements of several disability items in a relatively large sample of the general population. This allowed us to classify virtually all persons into non-overlapping groups based on information on several aspects of the level and time course of disability, and to examine to what extent age, sex and the presence of four chronic diseases are associated with these trajectories.

Our results confirm outcomes from prior studies showing a large variation in the individual time course of disability [3,7,9,12–15]. A salient point is the fact that the variation in individual trajectories is even bigger than expressed by the ten *common* trajectories and would have been observed as larger if we had smaller follow-up intervals. The trajectory labeled 'mild but decreasing disability' confirms the possibility and substantial probability of improvement in functioning referred to in prior work [3–5]. The trajectories showing non-linear patterns of change (i.e., 'sudden increase in disability', 'moderately disabled with partial regain after loss' and 'severely disabled with large increase in disability') support that besides linear deterioration ('mild, but increasing disability'), non-linear patterns of change occur [6,10,14,28–30]. Finally, the trajectory 'moderately disabled with strong fluctuations', confirms previous findings [6,7,9] that large fluctuations over time may occur.

Less information is available from prior studies on the effect of age, sex and specific diseases on the time course of disability to compare our results against. We found that trajectories were significantly associated with age, but not with sex. Similar to Deeg [14] we found for women significantly lower chances to die, and higher chances to be disabled (OR above 1 for most trajectories), but within the group with at least mild disability the trajectories were not significantly affected by sex in our study. Prior research was inconclusive as to whether the likelihood of changes in function differs by sex, which might partly reflect that many studies fail to account death as a competing risk [7,14]. For asthma/COPD, heart disease and low back complaints, we found strong associations with the trajectories of disability and death (after correction for age and sex). These associations remained when we additionally adjusted for the presence of one of the other diseases (data not shown). The strongest effects were seen for trajectories characterized by severe disability. This is in line with existing knowledge on the disabling impact of these diseases [31,32]. In addition, our results pointed at disease-specific associations. For instance, our results suggest that increasing disability also characterizes asthma/COPD. In contrast with Verbrugge [30] who found that people with COPD experience the most short-term fluctuations, we found no significant effect of asthma/COPD on trajectory 7, which is characterized by large fluctuations. This could reflect that fluctuations in our study are year-to-year fluctuations. For heart disease, the association with a rapid increase in disability in our study confirms findings of Verbrugge. In contrast with her work, we did not find that persons with heart disease were less likely to recover. For diabetes, we only found a significant association with death, but not with the trajectories of disability. This is in contrast with Deeg [14], who showed strong associations of diabetes with trajectories of stable mild and stable severe disability and with death. A possible explanation for the lack of a significant effect of diabetes on the disability trajectories is the small number of diabetics in our study ($n = 109$).

Our findings on disability prior to death confirm that while disability is strongly associated with death, the group who dies is not homogeneous with respect to disability prior to death [11,13–15]. Four out of 10 deaths in the source population of Eindhoven and surrounding municipalities reported moderate or severe disability in the questionnaire(s) prior to death, whereas among the survivors only 7% followed a trajectory that was characterized by moderate or severe disability (Table IV). This information shows that excluding deaths from the

analyses would have resulted not only in an underestimation of the presence of functional losses as was postulated by Deeg [14], but also of most severe health losses due to either disability or death. For the entire population, as well as the subgroups of survivors and deaths, heart diseases, back complaints and asthma/COPD were found to be associated with these most unfavorable trajectories.

Our finding of several distinct patterns in the level and time course of disability, which we summarized in 9 trajectories, forces us to stop viewing disability as a unitary concept. Although other studies are needed to confirm our conclusions, it is certainly plausible that several groups, differing in level and time course of disability, are present in the population. As disability is affected by multiple factors, and the presence of these factors can vary across individuals, (and for some factors over time as well), it is plausible that the disability level and time course differs from person to person. This variability was also reported in prior studies [7,9,12]. We found that age and the presence of heart disease, asthma/COPD and back complaints were significantly associated with the trajectories of disability. However, our data also showed that within disease groups still large variability exists in the level and time course of disability. As postulated by the theory of the disablement process, when chronic diseases occur and progress certain longstanding behaviors or attributes are likely to elevate the chances of disability. In addition, actions taken in response to disease or dysfunction reduce these chances, while others increase them [2]. These include adaptations to disability, including altering the method, environment or frequency of doing tasks [31]. For a fuller understanding of the disablement process, more research is necessary that takes into account these factors and includes detailed information on chronic diseases, including severity.

Our results have important implications. First, the dynamic and non-linear time courses of disability reported in this study suggest that studies based on two points in time often misreport changes in disability as onset of disability or regain in functioning. Improvement or decline, based on two measurements may not reflect persistent change. The problem is even larger than suggested by the results presented here, as the process of data reduction involved some smoothing and we used one-year intervals. Second, the heterogeneity within the 'disabled' population, as reflected by the different trajectories, should be considered. As the burden of disability and need for formal and informal care is likely to differ from trajectory to trajectory, taking this variation into account might improve our understanding of differences in service use and, in the end, help to better adjust the provision of care to different and changing demands. Third, the variation in the level and time course of disability suggest that there may be more possibilities for reducing the burden of disability than previously thought. Our results highlight the need for further research that examines how chronic diseases, treatment and rehabilitation strategies and other non-disease factors affect trajectories of disability.

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