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Manuscript title: DISABILITY occurrence and proximity to death

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ABSTRACT

Purpose

This paper aims to assess whether disability occurrence is related more strongly to proximity to death than to age.

Method

Self reported disability and vital status were available from six annual waves and a subsequent 12-year mortality follow-up of the Dutch GLOBE longitudinal study. Logit and Poisson regression methods were used to study associations of disability occurrence with age and with proximity to death.

Results

For disability in activities of daily living (ADL), regression models with proximity to death had better goodness of fit than models with age. With approaching death, the odds for ADL disability prevalence and incidence rates increased 20.0% and 18.9% per year, whereas severity increased 4.1% per year. For the ages younger than 60, 60-69 and older than 70 years, the odds for ADL disability prevalence increased 6.4%, 16.0% and 23.0% per year. Among subjects with asthma/COPD, heart disease and diabetes increases were 25.1%, 19.5% and 22.72% per year. Functional impairments were more strongly related to age.

Conclusions

The strong association of (ADL) disability occurrence with proximity to death implies that a substantial part of the disability burden may shift to older ages with further increases in life expectancy.

INTRODUCTION

Life expectancy in Western societies has shown substantial increases during the 20th century. In the Netherlands, between 1950 and 2005, life expectancy increased with 6.8 years in males and with 8.9 years in females [1]. Worldwide, comparable increases in life expectancies occurred [2,3]. This trend is not expected to come to an end in the near future. Instead, the average length of life is expected to further increase with approximately 5 years between 2005 and 2050 [2-5].

One of the key issues in public health is whether these extra life years gained will be years in good health or, otherwise, will be spent in ill health or disability [6-8]. The alternative scenarios for future trends in disability occurrence are crucial not only for chances of individual lifelong well being [9], but will also influence future demands for health care recourses [10,11].

The future burden of disability among elderly populations may expand at a relative low pace if disability occurrence among the elderly would, along with the increasing length of life, shift towards ever older ages. The possibility of such a concomitant shift is suggested by end-of-life studies showing that trajectories of functional decline may be linked to the end phase of life [12-19]. As life expectancy increases, trajectories of disability can be expected to at least partially shift to older ages. It is uncertain, however, to what extent this would happen. For this, it is important to assess to what extent disability occurrence is related to proximity of death (time to death) on the one hand and to age (time since birth) on the other hand. To our knowledge, the two dimensions of age have not been compared with regards to their relationship to disability occurrence. This paper aims to assess whether disability occurrence is related more strongly to proximity to death than to age.

This paper is linked to recent health economics research that assessed the extent to which increase of life expectancy is likely to increase with health care spending. Several studies determined the association of health care costs with age and proximity to death respectively [11,20-22]. It was found that health care costs were in part determined by proximity to death and that, hence, population ageing is likely to have a more moderate effect on health care spending than was previously assumed [11,20-22]. The outcomes of our analysis may help to assess whether similar effects may be expected for disability occurrence.

METHODS

Study population

We used data from the (GLOBE) study, a prospective cohort study investigating the explanation of inequalities in health in the Netherlands [23]. The study comprised a baseline postal survey in 1991, conducted among a stratified random sample of 27,070 inhabitants of the city of Eindhoven (40%) and surrounding municipalities (60%). The age range was set at 15-74 years with overrepresentation of 45 years and older. Institutionalized persons were excluded in Eindhoven but not in the surrounding municipalities. The response to the baseline questionnaire was 70.1% (n=18,973).

A subsample (n=3,968) of the initial cohort was invited for an oral interview and received annual follow-up questionnaires until 1997 (except for 1996). The subsample overrepresented subjects suffering from asthma/chronic obstructive pulmonary disease (COPD), heart disease and diabetes mellitus. The response to the oral interview was 72.2% (n=2,867). All analyses in the current paper were based on data from the subsample.

The mean age of the subsample at baseline was 52.6 years and 8% of the subjects was disabled in their activities of daily living (ADL). At the moment of the last administrative follow-up in 2004, 16% of the sample had died. Among subjects being ADL disabled at baseline this was 37% compared to 14% among non-disabled subjects (table 1).

[Insert table 1 about here]

Attrition and item non response

The maximal number of questionnaires that could have been obtained during follow up of the GLOBE subsample was six waves time the 2,867 initial respondents = 17,202 questionnaires. However, 3,337 questionnaires were not returned during follow-up, leaving a total of 13,865 questionnaires.

Among questionnaires that were returned, 403 had incomplete data on disability as measured by the Organization for Economic Co-operation and Development (OECD) indicator and 572 had incomplete data on ADL disability. Information was missing for only one item on OECD disability in 192 cases, and in 226 cases for ADL disability. In these cases, we imputed the missing item with the value of the preceding year or (for 1991) the next year. In total 13,654 questionnaires with information on OECD disability were available and 13,519 with ADL disability information. Information on the presence of asthma/COPD, heart disease and diabetes was missing for, respectively, 50, 39 and 62 subjects.

Measures

As the study results may depend on the type of disability used [24,25], we used different disability measures, including a measure based on 10 ADL questions, and a functional limitation measure based on 8 questions of the OECD indicator of long-term disabilities [26]. ADL items were 'walking down/up stairs, moving outdoors, leaving/entering house, sitting down/getting up from chair, moving on same floor, getting in/out of bed, eating/drinking, getting (un)dressed, washing face/hands and washing completely'. OECD items were 'able to have conversation with 1 person, able to have conversation with 3 persons or more, reading small letters, recognizing faces, biting/chewing food, carry 5 kilo for 10 meter, bending/take something from ground, walking 400 meter'.

For each ADL and OECD item, subjects were asked whether they were able to perform the actions 'without difficulty', 'with minor difficulty', 'with major difficulty', 'not able to perform/only with help'. Disability was defined as having at least one item answered with 'with major difficulty' or 'not able to perform/only with help'. In sensitivity analyses, we also applied an alternative cut-off point to define prevalence cases, as those who had at least two (instead of one) items with 'with major difficulty' or 'not able to perform/only with help'

Information on age, sex and presence of asthma/COPD, heart disease and diabetes mellitus was obtained from the baseline survey. Table 1 presents baseline characteristics of all respondents and of those who died during follow-up.

Data analysis

The variables ‘prevalence’, ‘incidence’, ‘severity’ and ‘proximity to death’ were created for the six waves of data collection separately. ‘Prevalence’ indicated whether disability was reported at the time the data were collected. An individual was considered ‘incident’ if disability existed in the year of observation but was absent in the preceding year. For all cases of disability, ‘severity’ was calculated by counting the case in which respondents reported having ‘much difficulty’, ‘no/just with help’. ‘Proximity to death’ was calculated as the difference between the moment of death, available from linkage to population registers, and the moment of the survey.

For all statistical analysis, Stata 10.0 was used. Generalized Estimating Equations (GEE) models were used to account for the interdependence of observations from one individual. Prevalence data were analyzed using logistic regression analysis, while incidence and severity data were analyzed using Poisson regression. Dependent variables were ‘prevalence’, ‘incidence’ and ‘severity’ and independent variables were ‘age’, ‘proximity to death’ and ‘sex’. A dichotomous variable was added to the models indicating whether or not subjects had died during follow-up, and to capture differences in disability between those who died and those who survived until the end of follow-up. Consequently, the relationship of disability to proximity to death could be estimated only from subjects who died during follow-up.

Stratifications were applied according to age (younger than 60, 60-69 and older than 70 years) and presence of a chronic disease (asthma/COPD, heart disease and diabetes mellitus). To indicate the goodness of fit of the models wald chi2 values were calculated.

RESULTS

Figure 1 presents ADL prevalence, incidence and severity rates by 5 year age groups and by time to death. Disability prevalence increased from around 0.05 up to 0.35 in the oldest age category of 80-84 years. In relationship to proximity to death, disability prevalence increased from 0.12, 12 years prior to death, to 0.38 in the year prior to death. Increases of disability incidence were more pronounced with approaching death as compared to increasing age. The maximum value of disability incidence was 0.10 at the highest age group as compared to 0.26 within the year prior to death. Increases of severity also were more pronounced with approaching death. Severity was especially high the last four years prior to death.

[Insert figure 1 about here]

Table 2 presents wald chi2 values that express the goodness of fit of regression models with, respectively, age, proximity to death and these two factors combined. For OECD disability prevalence and incidence, goodness of fit values were higher for the age model (350 and 129) as compared to the proximity to death model (220 and 80) indicating a closer relationship of OECD disability with age. ADL disability, on the other hand, showed goodness of fit values higher for models with proximity to death (309 and 198) as to models with age (187 and 64), indicating that

ADL disability was more closely associated with proximity to death. For severity of disability, goodness of fit values were the highest for models with proximity to death, for both OECD and ADL disability.

The regression coefficients in table 2 show that increases of both OECD and ADL disability prevalence were higher with increasing proximity to death (7.1 and 20.0) as compared to increases with age (4.3 and 4.7). Increases of incidence and severity were also higher with increasing proximity to death as compared to increases with age, for both ADL and OECD disability.

An additional analysis, defining disability as having at least two (instead of one) items with ‘much difficulty’ or ‘no/just with help’, showed goodness of fit values of 350 (age model) and 220 (proximity to death model) for OECD prevalence and 187 (age model) and 309 (proximity to death model) for ADL prevalence and values. Thus, using a more strict definition of disability showed more clearly a stronger association with age for OECD disability and a stronger association with proximity to death than with age, for ADL disability.

[Insert table 2 about here]

In table 3, goodness of fit values are presented for models with age and proximity to death among groups of patients with asthma/COPD, heart disease and diabetes. Similar estimates are also presented for people without any of these diseases. For all groups with a chronic disease, the prevalence of ADL disability showed a better fit with proximity to death than with age. For the prevalence of OECD disability in heart disease and diabetes patients, the goodness of fit was similar with age as with proximity to death, whereas for asthma/COPD patients the best fit was with age. With approaching death, increases of prevalence of ADL disability varied from 19.5 in heart disease patients to 25.1 in asthma/COPD patients. Increases in OECD disability prevalence varied from 4.6 in heart disease patients to 11.6 in asthma/COPD patients. Increases with age were lower and varied from 4.7 to 6.3 for ADL disability and from 4.0 to 4.4 for OECD disability.

[Insert table 3 about here]

Figure 2 presents estimates of the prevalence of ADL disability over the last twelve years of life for asthma/COPD, heart disease and diabetes patients calculated from regression models including proximity to death, age and sex. For the calculations, a constant age of 70 years was assumed and sex was set as the average of values for male and female. The dichotomous variable indicating whether subjects from the original dataset had died at the end of follow-up (1) or where still alive (0) was set at 0.5. From 12 years prior to death to the year prior to death, disability prevalence increased from around 0.10 up to 0.48 in diabetes patients, up to 0.54 in patients with heart disease and up to 0.60 in patients with asthma/COPD.

[Insert figure 2 about here]

Table 4 presents wald chi2 values that express the goodness of fit of regression models for different age strata and for males and females separately and combined. For ADL disability prevalence, goodness of fit values were higher for the oldest age category (110), as compared to the youngest age category (67). The goodness of fit for OECD disability was better for the youngest age category (172) as compared to the oldest age category (24). This pattern was not different for males and females.

The regression coefficients in table 4 show that increases of the prevalence of ADL disability with approaching death were stronger in the oldest age category (23.0) as compared to the youngest age category (6.4), also for males and females separately. Increases of OECD disability were also higher for the oldest age category (7.5) as compared to the youngest age category (6.3).

[Insert table 4 about here]

Figure 3 presents estimates of the prevalence of ADL disability over the last twelve years of life for age strata younger then 60 years, 60-69 years and older than 70 years, calculated from regression models including proximity to death, age and sex. For the calculations, a constant age of 55, 65 and 75 years was assumed for the respective age categories. Sex and the value indicating death at the end of follow-up were set identical as was done for figure 2. From 12 years prior to death to the year prior to death, disability prevalence increased from below 0.15 up to 0.25 for ages younger than 60 years, up to 0.39 for ages 60-69 years and up to 0.59 for ages older than 70 years.

[Insert figure 3 about here]

DISCUSSION

Summary of results

The concept of proximity to death dependence has widely been applied in the health economical field and has led to important new insights in expectations of future health care expenditures. Previous research suggested that disability occurrence is also partly related to approaching death. However, no previous study compared age and proximity to death with regards to their associations with disability occurrence. Our results showed that ADL disability was more strongly related to proximity to death than to age, also within specific patient groups and among different age groups. Functional impairments, as measured with the OECD list, were however more strongly related to age.

Evaluation of data and methods

Our data has some limitations that need proper attention. If non-response during follow-up was related to disability occurrence, this may have influenced the estimation of proximity to death parameters. To evaluate this possibility of attrition bias, we compared mortality during follow-up between non-responders and the rest of the study population. Age-standardized mortality among non-responders was 12.9% versus 16.4% among the rest of the population. The lower mortality ratio among non-responders could be indicative of a lower disability prevalence among this group. In order to evaluate whether this might have biased our estimates of proximity to death dependence, we compared the original prevalence plots with plots in which missing disability values imputed from last available observations. The new plots hardly differed from the original plots. The relatively unchanged plots indicate that bias related to sample attrition or item non response is probably small.

Opposite to the (small) effect of attrition in our study, exclusion of part of the institutionalized population from the baseline survey could have been associated with a lower prevalence of disability due to exclusion of the relatively more disabled nursing home population. As admission to a nursing home occurs often at the end of life, exclusion of the institutionalized might have led to some degree of underestimation of the proximity to death dependence of disability.

The use of self-reported measures of disease and disability might have led to some information bias. This would particularly be problematic if, independent from the status of disability, reporting behavior was related to proximity to death. With the available data, these effects cannot be studied, and, as far as we know, no studies exist that describe such effects. One could imagine that being in the last phase of life could both positively (by increased relativism) and negatively (by increased pessimism) affect one's perception and reporting of disability. If the latter, pessimistic tendency were to predominate, this could in part explain the relationship with proximity to death observed in this study. Nevertheless, as the significant increases of health care costs the last years of life [11,20-22] are to at least some extent related to disability occurrence [27,28], it seems unlikely that reporting tendencies alone would explain much of this strong increase in disability occurrence.

Comparison to previous studies

Our finding that disability prevalence increases as death approaches is in general agreement with a substantial amount of literature reporting terminal trajectories of functional decline at the end of life [12-19]. Similar to our results, trajectories of functional decline were also reported among terminal patients with different diseases [12,17,19], e.g. COPD, diabetes and cerebrovascular accident [19]. In line with our finding of a stronger association of disability prevalence with proximity to death at older ages, it was found that disability rates prior to death were higher at increased ages of death [15]. Hubert et al. [29] found increasing disability scores with approaching death as from 10 years prior to death. As with our finding of a relationship over 12 years of time, their results suggest that death casts its shadow remotely over life.

In the health economics field, the principle of relating health care expenditures to proximity to death has been applied for more than 20 years [28]. International studies found that health care expenditures during the last year of life are four to six times higher than expenditures for survivors [22,27] and ten times higher compared to expenditures five years earlier before death [21]. In the Netherlands, 10% of total health expenditure has been found to be associated with health care use during the last year of life [20]. To compare, we calculated the share of lifetime ADL disability burden (prevalence times severity) that occurred during the last year of life and during the last five years of life, assuming an 80 years lifespan. We estimated that 18% of the lifetime disability burden would occur during the last year of life and 66% of the burden would occur during the last five years of life. This suggests that ADL disability burden is at least as strongly related to the end of life as health care costs.

Interpretations of other findings

A remarkable difference was observed between the dominant proximity to death dependence of ADL disability on the one hand and the dominant age dependence of functional impairments (as measured in the OECD measure) on the other hand. This difference may perhaps be explained to the different physical domains that these scales represent: ADL mainly represents the locomotory domain, and functional impairments also represent visual, auditive and lingual domains. Ageing is associated with degeneration and lack of maintenance and repair of physiological and metabolic systems [30-32]. As a result of damage to these systems, disability can occur, and, if a life maintaining system is involved, chances for death increase. As compared to ADL disability, functional impairments as measured in the OECD list may be more associated to damage to systems that are not life maintaining (e.g. hearing and vision) and that therefore are more dependent on age.

Our finding that the prevalence of disability is more strongly associated to proximity to death in males as compared to females may be explained by the fact that females tend to suffer to a larger extent from non-lethal chronic disabling conditions like arthritis and back complaints [33-36] whereas lethal disabling conditions like cardiovascular disease and cancer are more common in males [33-36].

Implications

Current projection models of the future prevalence of disability either assume that age specific prevalence rates are constant or that past trends in age-specific disability prevalence rates will continue at the same rate in the future [37]. Scenarios for health care expenditures show that age based models overestimate future expenditures as compared to models that take into account dependence on proximity to death. The latter models project about 10% less increase. [20]. Our preliminary estimates for the Netherlands suggested that disability burden are about equally related to the last year of life as health care expenditures. This would imply that projection models that would take into account this dependence on proximity to death would modify future projection to a similar extent as projections of health care expenditures.

Estimating to what extent past disability trends will be prolonged in the future remains a difficult exercise. In order to improve projections, we strongly recommend incorporating proximity of death parameters in future projection models. This would enable to directly relate future disability occurrence to expectations of increasing life expectancy [2-5] and could therefore lead to importantly improved estimations. The different results for ADL disability and for functional impairments, plea for incorporation of multiple domains of disability in projections of future trends in disability burden.

Declaration of interest

The authors declare that there are no conflicts of interest.

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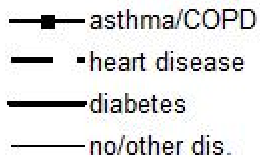
Legend figure 2



Legend figure 3

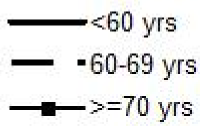


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Table 1

Baseline characteristics of respondents and deaths during follow-up

	Respondents						Deaths before end of follow-up					
	No. subjects	%	Mean age	SD	No. with ADL disability	%	No. among all subjects	%	No. among baseline ADL disabled	%	No. among baseline ADL non-disabled	%
All	2867	100	52.6	14.1	241	8	468	16	88	37	380	14
<60 yrs	1888	66	45.4	0.3	112	6	128	7	22	20	106	6
60-69 yrs	748	26	64.7	0.1	92	12	222	30	45	49	177	27
>=70 yrs	231	8	72	0.2	37	16	118	51	21	57	97	50
Asthma/COPD	588	21	53.1	0.7	75	13	147	25	33	44	114	22
Heart disease	446	16	61.4	0.4	71	16	178	40	40	56	138	37
Diabetes	262	9	60.2	0.6	36	14	92	35	20	56	72	32

Table 2

Goodness of fit and regression coefficients of models relating disability to age and proximity to death

		Goodness of fit (wald chi2)			Regression estimate (% increase per year)			
		age	proximity to death	age + proximity to death	age	95% CI	proximity to death	95% CI
Prevalence	ADL	187	309	359	4.7	3.7, 5.7	20.0	14.8, 25.4
	OECD	350	220	424	4.3	3.7, 4.8	7.1	3.7, 10.7
Incidence	ADL	64	198	214	2.7	1.6, 3.8	18.9	10.4, 28.0
	OECD	129	80	169	2.9	2.4, 3.6	11.2	4.9, 18.0
Severity	ADL	22	44	50	0.6	0.1,1.2	4.1	1.9, 6.3
	OECD	77	162	181	0.8	0.5, 1.2	4.7	3.4, 6.1

Note. Separate sex-adjusted models were fit for ADL and OECD disability. Goodness of fit is represented for three separate models, the regression estimates come from one model with ‘age’ and ‘proximity to death’.

Table 3

Goodness of fit and regression coefficients of models relating disability to age and proximity to death, stratified to chronic disease

		Goodness of fit (wald chi2)			Regression estimate (% increase per year)			
		age	proximity to death	age + proximity to death	age	95% CI	proximity to death	95% CI
Asthma/COPD	ADL	66	107	126	5.7	3.8, 7.6	25.1	16.4, 34.5
	OECD	101	78	128	4.4	3.3, 5.6	11.6	5.4, 18.1
Heart disease	ADL	46	86	94	4.7	2.1, 7.4	19.5	11.9, 27.6
	OECD	43	44	62	4.1	2.3, 5.9	4.6	-1.1, 10.7
Diabetes	ADL	25	39	45	6.3	2.8, 9.9	22.7	10.1, 36.7
	OECD	24	23	35	4.0	1.8, 6.2	9.0	1.0, 17.7
No disease	ADL	47	51	76	3.8	2.4, 5.1	11.0	1.4, 21.6
	OECD	145	48	155	4.0	3.2, 4.7	3.5	-2.9, 10.4

Note. Separate sex-adjusted models were fit for ADL and OECD disability. Goodness of fit is represented for three separate models, the regression estimates come from one model with ‘age’ and ‘proximity to death’.

Table 4

Goodness of fit and regression coefficients of models relating disability prevalence to proximity to death, stratified to age categories

		Goodness of fit (wald chi2)			Regression estimate proximity to death (% increase per year)					
		male + female	male	female	male + female	95% CI	male	95% CI	female	95% CI
All	ADL	343	204	176	19.1	13.9, 24.4	27.0	19.1, 35.3	14.2	7.2, 21.6
	OECD	394	218	194	7.8	6.0, 9.7	7.3	2.9, 11.9	6.6	1.2, 12.4
<60 yrs	ADL	67	40	28	6.4	-3.2, 17.0	9.5	-3.3, 24.0	3.1	-10.9, 19.3
	OECD	172	83	92	6.3	-1.3, 14.5	5.4	-4.4, 16.2	8.0	-3.8, 21.1
60-69 yrs	ADL	66	62	19	16.0	8.3, 24.3	24.3	12.8, 37.0	6.6	-3.6, 17.9
	OECD	38	42	9	6.4	1.1, 11.9	7.1	0.6, 14.1	6.3	-2.6, 15.9
>=70 yrs	ADL	110	73	53	23.0	13.9, 32.7	38.1	21.4, 57.1	17.2	6.2, 29.3
	OECD	24	20	9	7.5	1.6, 13.6	10.0	1.7, 19.0	7.0	-1.6, 16.3

Note. Separate age and sex-adjusted models were fit for ADL and OECD disability. Goodness of fit and regression estimates are represented for separate models including both males and females, males only and females only.

Figure 1 Prevalence, incidence and severity of ADL disability by age and time to death

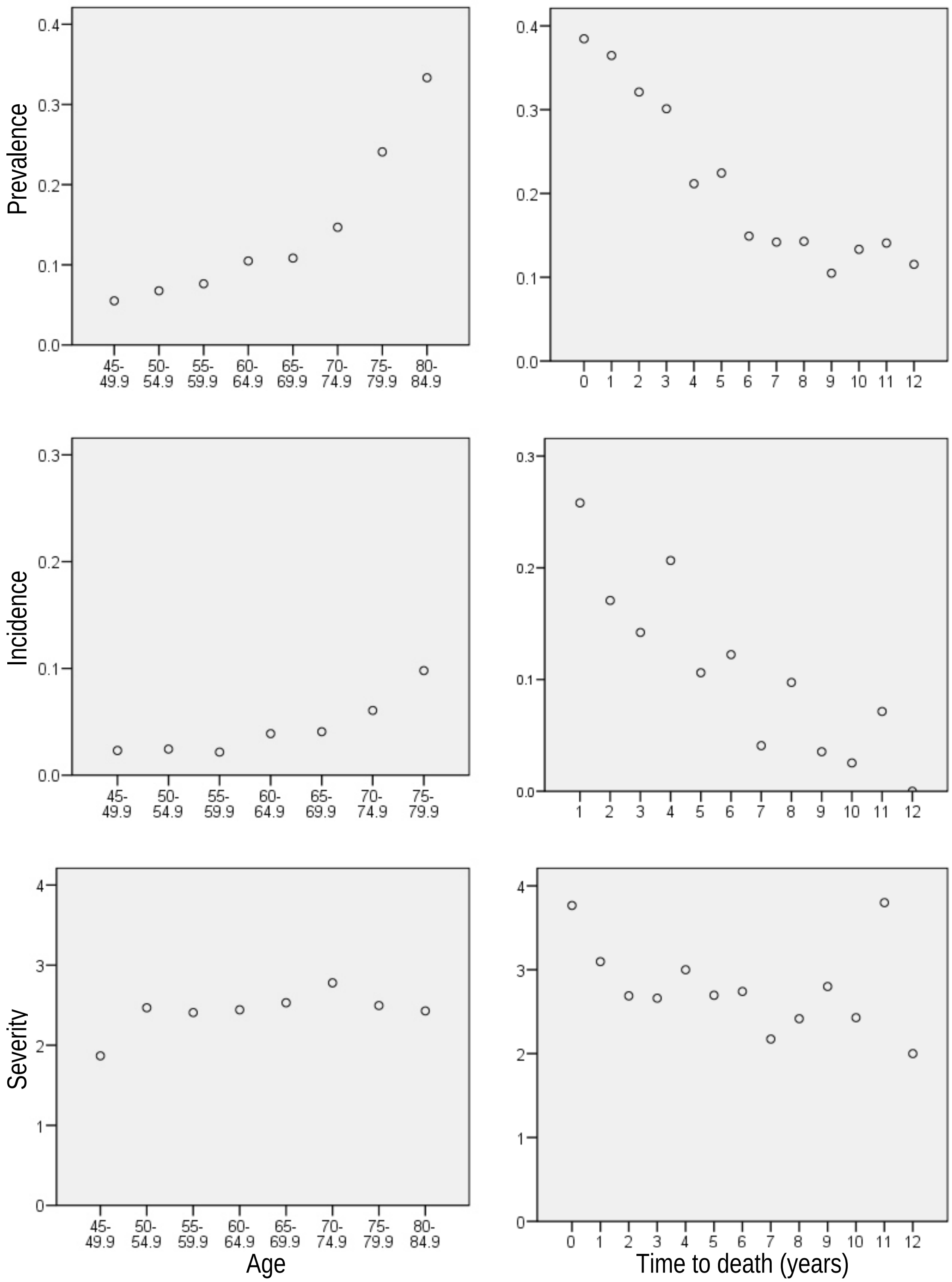

Figure 2 Regression based estimates of ADL disability prevalence by time to death stratified by chronic disease

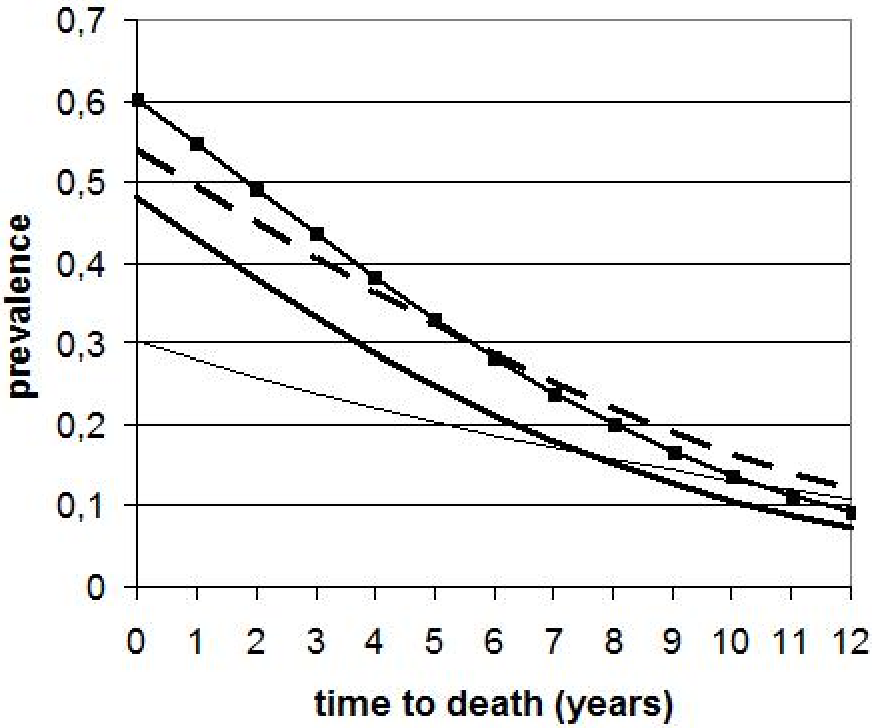

Figure 3 Regression based estimates of ADL disability prevalence by time to death stratified by age