TITLE: Future disability projections could be improved by connecting to the theory of a dynamic equilibrium

ABSTRACT

Objective

Projections of future trends in the burden of disability could be guided by models linking disability to life expectancy, such as the dynamic equilibrium theory. This paper tests the key assumption of this theory that severe disability is associated to proximity to death whereas mild disability is not.

Study Design and Setting

Using data from the GLOBE study, the association of three levels of self-reported ADL disability with age and proximity to death was studied using logistic regression models. These regression estimates were used to estimate the number of life years with disability for life spans of 75 and 85 years.

Results

The prevalence of disability incrementally increased with approaching death with 12 percent per year for moderate disability to 19 percent for severe disability. However, no association was observed for mild disability. A ten year increase of lifespan was estimated to result in a substantial expansion of mild disability (4.6 years) compared to a small expansion of moderate (0.7 years) and severe (0.9 years) disability.

Conclusion

These findings support the theory of a dynamic equilibrium. Projections of the future burden of disability could be substantially improved by connecting to this theory and incorporating information on proximity to death.

Keywords: activities of daily living; age factors; longevity; projections; proximity to death

Running title: Improving projections of disability

Word count: 2584 words

INTRODUCTION

The coming decades, the human life expectancy is likely to further increase [1, 2]. The issue whether this increase of life expectancy will correlate with either compression of disability [3] or expansion of disability [4, 5] has been subject of debate ever since the publication of Fries' seminal paper on compression of morbidity [3]. A more definitive answer is urgently needed to prepare future health care systems to cope with the health effects of ageing of the population.

Aiming at insight in whether the total burden of disability can be expected to increase or is more likely to decrease in the future, projection methods have been applied that were based on past trends of disability [6, 7]. Unfortunately, application of these methods involved some difficulties. Past trends of disability were often not unambiguously pointing towards one direction and therefore constituted a weak basis for projections [6, 8]. Furthermore, studies do not present univocal methods to extrapolate trends, as it is not clear to what extent past trends will keep pace in the future [6, 7]. And, as far as we know, the association of increasing life expectancy and trends in disability have not been investigated explicitly.

The extent to which gained life years will be spent in disability will greatly be determined by the relative part of disability in the population that is specifically related to end of life processes and will therefore shift to older ages as life expectancy increases. Assuming that most severe disability is reserved to the end of life [9-11] but that mild disability mostly occurs independent to the end of life processes, it is to be expected that with increase of life expectancy, most severe disability will shift to older ages, but that mild disability will mostly expand . This scenario, which is expressed in the theory of a dynamic equilibrium, is graphically represented in figure 1

[12]. Severe disability is fully dependent on proximity to death and, consequently, with increase of life expectancy, the onset of severe disability equivalently shifts to older ages. Mild disability is fully dependent on age and, therefore, the onset of mild disability does not change as life expectancy increases. The years spent in severe disability did not change, whereas the years in mild disability expanded.

The current paper aims to assess whether the theory of a dynamic equilibrium [12] provides a valid framework for projections of the future burden of disability. We will test the key assumption of this theory that the occurrence of severe disability is associated to proximity to death whereas the occurrence of mild disability is not. Based on estimates of associations of disability with age (time since birth) and proximity to death, we will calculate to what extent the life-time burden of mild, moderate and severe disability will expand in the hypothetical case of a ten year increase of lifespan.

METHODS

Study population

We used data from the GLOBE study, a prospective cohort study investigating the explanation of inequalities in health in the Netherlands [13]. 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 sub sample at baseline was 52.6 years and 34% of the subjects had mild, moderate or severe ADL disability. 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 26% compared to 11% among non-disabled subjects.

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, 572 had incomplete data on ADL disability. Information was missing for only one item of ADL disability in 226 cases. In these cases, we imputed the missing item with the value of the preceding year or (for 1991) the next year. In total 13,519 questionnaires with information on ADL disability were available.

Disability measure

Disability was measured by means of 10 ADL items. The 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’. For each item, subjects were asked whether they were able to perform the actions ‘without difficulty’, ‘with minor difficulty’, ‘with major difficulty’, ‘only with help’. Mild disability was defined as at least one item answered with ‘with minor difficulty’, moderate disability as at least one item answered with ‘with major difficulty’ and severe disability as at least one item answered with ‘only with help’. Overall disability was considered as at least one item answered with any of these three categories.

Data analysis

The variables ‘mild disability’, ‘moderate disability’, ‘severe disability’, ‘overall disability’ and ‘proximity to death’ were created for the six waves of data collection separately. The four disability variables indicated whether mild, moderate, severe and overall disability was reported at the time the data were collected. ‘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. Information on age and sex was obtained from the baseline 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 and logistic regression analyses were applied. Regression models were fitted including ‘age’ and ‘proximity to death’. The models were adjusted for sex and overall, mild, moderate and severe disability prevalence were used as dependent variables. The wald chi square value was used as an indicator of goodness of fit.

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.

Using the different regression models, we estimated age-specific prevalence rates for mild, moderate, severe and overall (sum of mild, moderate and severe) disability for life spans of 75 and 85 years. The age-specific prevalence rates were summed to estimate the total number of years that a person might expect to live with disability over a life span of 75 and 85 years respectively. These number of years are called Life Expectancy with Disability (LED). For both life spans, we also estimated the proportion of all years with disability occurring in the last and in the last five years of life.

RESULTS

Table 1 shows increases of the prevalence of overall, mild, moderate and severe ADL disability per year of age and per year closer to death, as well as the goodness of fit of the models. The raise of the prevalence of disability per year closer to death incrementally increased from -2.42 for mild disability to 12.04 for moderate disability to 18.79 for severe disability. The association of mild disability with proximity to death was not significant. The goodness of fit of the models increased with the level of severity from 152 for mild disability to 215 for severe disability.

Table 2 shows calculated LEDs for mild, moderate and severe disability for lifespans of 75 and 85 years and percentages during the last and last five years of life, based on the respective regression models. A ten year increase in life span resulted in 4.6 extra years in mild disability, 0.7 extra years in moderate disability and 0.9 extra years in severe disability.

Percentages of LED occurring in the last year of life ranged from 1.4% for mild disability to 12.6% for moderate disability to 23.6% for severe disability, for life spans of 75 years. Increase of life span did not strongly affect these percentages. The percentages of LED occurring in the last five years of life showed a similar pattern but were higher.

Figure 2 visually represents the calculated prevalence of mild, moderate, severe disability for life spans of 75 and 85 years. Increase of life span resulted in a strong shift of the burden of disability to older ages, especially for moderate and severe disability. 13% of LED^{mild} was spent during the 10 years that were gained, as compared to 75% and 94% for $LED^{moderate}$ and LED^{severe} respectively. Age specific prevalences of disability at younger ages generally declined.

DISCUSSION

Summary of results

Based on our results, the hypothesis that the occurrence of severe disability is associated to proximity to death and the occurrence of mild disability is not, was confirmed. Based on the associations with age and proximity to death and assuming a ten year increase of lifespan, we showed that mild disability greatly expanded but that moderate and severe disability showed much lesser expansion. Current findings support the theory of a dynamic equilibrium [12].

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 regression estimates with estimates in which missing disability values were imputed from last available observations. The new estimates hardly differed from the original one. This indicates that bias related to sample attrition is probably small.

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, especially for moderate and severe disability.

The use of self-reported measures of the different levels of 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. Again, especially moderate and severe levels of disability may have been influenced, because these levels are more likely to occur close 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, also in view of an increases of health care costs during the last years of life [14-17], it seems unlikely that reporting tendencies alone would explain much of this strong increase in disability occurrence.

In the paper in which Manton introduced his theory of a dynamic equilibrium he stated that slowing down the progression rate of a disease would lead to a longer life, an increasingly longer period spent in disease, but a relatively constant number of years spent in "highly morbid" state. While Manton did not define this "highly morbid" state, we applied a distinction according to the severity of disability. Similar distinctions have been applied by other researchers [18]. In our calculations, mild disability showed rapid expansion while the occurrence of moderate and severe disability shifted towards older ages with increase of lifespan. This shift resembles that trends in the 'highly morbid state' that Manton postulated.

Comparison with past trends

Between 1990-2003, life expectancy has increased with approximately 1 year in females and 2.5 years in males [19, 20]. In accordance to the theory of a dynamic equilibrium, one would expect an increasing life expectancy in mild disability but much smaller increases for more severe disability. In addition, if disability occurrence would be strongly related to proximity to death, one would expect increasing of life expectancy to be related to decreasing age specific disability prevalence rates (instead of constant prevalences; see figure 2).

Although the evidence is not completely unambiguous, generally, stable or decreasing age specific disability prevalence rates were observed for a variety of disability indicators [6, 8]. Simultaneous trends of increasing life-expectancy and decreasing age specific disability rates were also found for the US, Japan and various European countries [6, 21-23]. Thus, evidence from the Netherlands as well as in other countries generally support the expectation of decreasing age specific prevalence rates.

Studies for the Netherlands estimate that between 1989 and 2000 a gain in life expectancy in males from 14.3 to 15.3 years at age 65 was accompanied by an increase of years in mild disability from 3.7 to 6.2 years, while the number of years in moderate and severe disability decreased from 5.1 to 4.5 years [24]. Similar patterns were observed for females [24]. Research from other countries showed similar results. In the US, between 1992 and 2002, a half year gain in life expectancy at age 65 was accompanied with constant expectations of years in IADL and moderate ADL disability and a decrease of life expectancy in severe ADL disability from 2.1 to 1.7 years [25]. In New Zealand, between 1981 and 1996, life expectancy at age 65 increased from 13.3 to 15.5 in males and from 17.2 to 19.0 years in women. During the same period, the life expectancy with major mobility restrictions in male remained 0.8 years, but life expectancy with moderate mobility restrictions more than doubled from 0.7 to 1.6 years. In females, the life expectancy with major mobility restrictions moderately increased from 2.0 to 2.6 years, whereas the life expectancy with moderate mobility restrictions sharply increased from 1.2 to 2.7 years [26].

Implications for modelling future developments in disability

Together with evidence from past disability trends the results from the current paper provide empirical support to the theory of a dynamic equilibrium. This theory may provide a useful framework for projecting changes in disability occurrence in relationship to increases in life expectancy. Prediction models could connect to this framework by incorporating information on proximity to death. Using a proximity-to-death term would allow the modelling of a shift disability towards older ages when life expectancy increases. To further connect to the theory of a dynamic equilibrium, prediction models should distinguish for different levels of severity of disability.

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Table 1
Increase of the prevalence of mild, moderate and severe ADL disability per year of age and per year closer to death and goodness of fit of the regression models

	increase with age (% per year with 95% CI)	increase with proximity to death (% per year with 95% CI)	goodness of fit (wald chi2)
overall disability	3.86 (3.33-4.39)	9.77 (6.94-12.51)	422
mild disability	2.71 (2.20-3.21)	-2.42 (-5.82-0.87)	152
moderate disability	3.19 (2.20-4.18)	12.04 (7.50-16.36)	182
severe disability	9.45 (7.24-11.70)	18.79 (12.58-24.57)	215

Table 2
Life years in mild, moderate and severe disability for life spans of 75 and 85 years and percentages of disability occurring the last and last five years of life

		mild	moderate	severe	total
years in disability	75 years lifespan	11.6	2.4	0.8	14.8
	85 years lifespan	16.2	3.1	1.7	21.0
	absolute increase	4.6	0.7	0.9	6.2
% in last life year	75 years lifespan	1.4	12.6	23.6	4.4
	85 years lifespan	1.3	12.0	21.3	4.5
% in last five life years	75 years lifespan	7.1	50.2	75.3	17.8
	85 years lifespan	6.4	48.9	72.7	18.0

Figure 1
Effects of increasing life expectancy on LED ^{mild} and LED ^{severe} according to the theory of a dynamic equilibrium

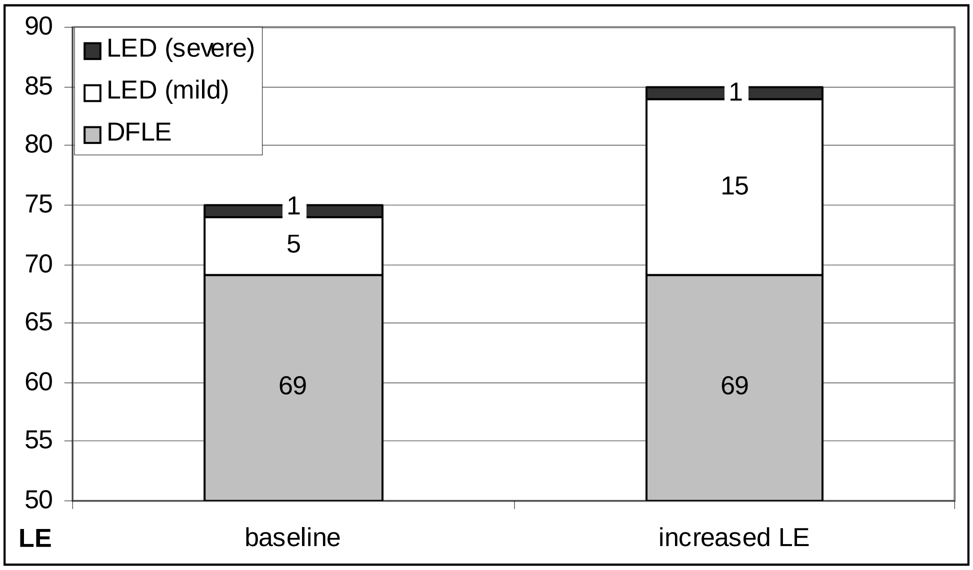

Figure 2
Age-specific prevalence of ADL disability by level of severity for life spans of 75 and 85 years. Estimates derived from regression models