Pathways through Dependency and the Effects on Old Age Mortality

How do markers of disability trajectories affect survival in the dependent population in Spain?

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Abstract

The exceptional increase of human life expectancy entails the question whether gained life years are spent in good health. Research on the relationship between demographic aging and population health generally suggests improvements in functionality and quality of life for elderlies with chronic diseases and mild disabilities. The situation for more severely disabled individuals, however, has not changed significantly. We aim to examine structural differences in survival within the population in dependency by certain pathway marker of their disability experience in the context of Spain. By applying newly linked data sources, we are going to identify two markers of transition biographies for individuals who receive personal assistance for activities of daily living and estimate how different pathways affect their survival after age 50. We use stratified Cox PH models to estimate mortality hazards for the dependent population. Preliminary results suggest a survival advantage for those experiencing a late onset of disability and a low severity score after onset of disability.

1 Introduction

Despite the opportunity for millions of people to enjoy longer lives compared to previous generations [1–3], the exceptional growth of average human life lengths entails the jarring question whether gained life years are generally spent in good health. While disability prevalence rates are growing as consequence of ongoing population aging, the quality of life after onset of disability has seemingly improved for people with mild disabilities. The situation for the oldest-old and those with severe disabilities, on the other hand, has not changed substantially in terms of quality of life and social participation [4–8]. The only small improvements in the situation of latter group has led to concerns about the explosion of health care costs as these individuals are prone to being dependent on personal care or assistance for activities of daily life [9, 10]. The avoidance or prolongation of such a state of dependency is not only interesting from macro-economical perspective but most importantly related to an increase in the quality of life for the individual. The other end of a period of old age dependency is often marked by death. Recovery from a situation where a person above age 65 requires care are rare, an observation which sparked theories interrelating population health and mortality.

In 1980, James Fries proposed the concept of morbidity compression, which he related to the postponement of chronic disease and disability onset closer to the age of death for a person. Fries stated that chronic illnesses, which account for more than 80% of all deaths, are inescapably linked with eventual mortality [11]. These chronic illnesses and disabilities are thus identified as markers for possible compression or expansion of morbidity [11]. His framework and the adaptations to it, like dynamic equilibrium [12], laid the basis for assessments on whether additional life years are spent morbidity-free or not [13]. When describing morbidity trends for populations over time, we combine various individual life course trajectories that range from individuals with fatal heart attacks at age 50, to those who live up to 100 and die asymptotically from multiple minor diseases or defects [14]. For this aggregation, it is often equally necessary to accept the assumption of linear decline, which basically disallows recovery once a an individual reached a state of disability. At an individual level, we know surprisingly little about how the onset of disability is related to mortality and even less about how it has developed due to medical and social progress.

Most uncertainties about future scenarios and even todays assessment regarding the onset of morbidity are rooted in the difficulties to define and measure health and disability. While death is a clearly defined concept and information on deaths are routinely collected at statistical offices, it is far more complicated to assess health. Even if it is solely defined as absence of disease or chronic condition, when diagnosed many conditions can range from mild to incapacitating. Thus, we would need to pick a threshold value to distinguish a healthy from a sick person. Such an exercise becomes increasingly difficult the larger the variety of considered conditions [15]. Instead of counting diagnoses, the use of impairments of functioning at activities of daily living (ADL) and instrumental activities of daily living (IADL) have been established as proxy for morbidity at older ages [16–18]. Most commonly, ADLs include bathing, dressing, eating, transferring, and toileting while IADL

refers to periodic routines often including meal preparation, shopping, housekeeping, laundering, using the phone, managing medications, managing money, and using transportation [19].

A life course transition, which might be less important from a purely medical standpoint, is the onset of dependency or care need. The loss of independence due to old age disability is often closely linked with the onset of severe problems in the performance of the aforementioned daily activities. Entering dependency can be an extremely challenging life course transition as it is often linked to the loss of autonomies and perceived loss of quality of life [20]. Dependent individuals were found to be less socially involved and have state low satisfaction when asked about their quality of life [21, 22]. Although the onset of such severe problems has generally been postponed to higher ages, fast increasing life expectancy has led to longer average time spans spent in a state of dependency [23].

To achieve improvements in the situation of dependent individuals, it is necessary to understand the different pathways, stages, and impact factors predicting a state of dependency. It is furthermore important to disentangle how such pathways relate to mortality risks after onset of dependency [cf. 24, 25]. Such research can not only help us to predict future care need more precisely but allows us to test hypothesis about the evolution of the relationship between health and mortality.

In this study, we aim to examine how different pathological transition paths after onset of old-age disability affect survival in the dependent population. Applying a newly linked data source, we are able to follow up individuals from the largest Spanish survey on disability and dependency situation and examine how different disability marker and sociodemographic characteristics affect survival after onset of dependency. The following sections of this work are structured as follows. First, we describe the two linked data sources. Second, we define disability and provide two core markers of the disability experience, the onset age and the severity score. Third, we examine the differences between the total population and those who receive personal care for at least one activity of daily living (ADL). Fourth, we explain our statistical model for the survival analysis and describe the results. Last, we conclude the findings and give an outlook for further improvements and future research.

2 Methods and Materials

2.1 Data

Initiated by the National Institute of Statistics (INE), the National Survey on Disability, Personal Autonomy, and Dependency (EDAD, Spanish: *Encuesta sobre Discapacidad, Autonomía personal y Situaciones de Dependencia*) is a one of the biggest national survey study with focus on health, disability and care in Europe. Stratified samples for this cross-sectional study were drawn in a two-stage process. The initial sampling stage, based on 3,843 census tracts, was adjusted in size to allow for more variation by single autonomous region. The second step included the drawing of households from the selected census sections. The final sample consists of 96,075 households and 258,187 individuals aged 0 to 104. Information was collected through face-to-face

List of ADLs and IADLs to define the disability status

Activities of daily living (ADL)

- Body position Changes/Getting in or out of bed
- Walking indoor
- Walking outdoor
- Using public transport
- Bathing/showering
- Basic hygiene
- Urination (bladder control)
- Toileting (bowel control)
- Dressing
- Eating

Instrumental Activities of Daily Living (IADL)

- Shopping
- Preparing meals
- Housework

Figure 1: Activities included in the assessment of disability (ADL, IADL)

interviews between November 2007 and February 2008 (overall response rate 97%). When a household member aged 6 or older was identified as disabled according to the INE definition, the person or, if applicable, her care giver were invited to answer an individual questionnaire directed at health related topics and personal experiences with disability. A second survey stage was aimed at sampling individuals from health institutions and nursing homes [26].

In collaborative action, the INE department for socio-demographic statistics linked the majority of the individuals in EDAD to administratively collected, longitudinal mortality and exposure data for the period between 2008 and 2018. Mortality records were extracted from annually updated statistics for natural population movement (MNP, Spanish: *Estadística de defunciones. Movimiento natural de la población*) and linked through a personal identifier. Exposures are based on yearly updated data from the civil register (Padrónimiento) and allow us to capture migration movements.

2.2 Assessing disability and dependency

In contrast to previous, nationally representative surveys, EDAD is oriented towards the assessment of how individuals with disabilities and care need handle their daily life and how they are integrated in everyday social processes [27]. Building on the International Classification of Functioning, Disability and Health (ICF), the questionnaires are directed towards how personal and technical support contribute to social participation. Instead of medical examinations the respondent is asked about limitations in activities of daily living. Where possible, these limitations are traced back to an underlying disease or functional limitation [28].

For the following analysis, we classify a person as disabled if she has experienced difficulties to perform in at least one of the following activities. We consider 10 activities of daily living (ADL), including body position changes, walking indoors, walking outdoors, using public transport, bathing, basic hygiene, urination (bladder control), toileting (bowel control), dressing and eating. The ADls are extended by a list of three instrumental activities of daily living (IADLS). These are shopping, preparing meals, and housework. Figure 1 gives an overview about the selected items.

As limitations in an activity of daily life can range from minor difficulties to impossible, the degree of severity

can help to further specify the actual situation of a person in disability. Among the countless ways to rate severity, we aim for a method that was facilitated by the set-up of the survey. When a person stated to experience a limitation in the interview, there would be a categorical follow-up question to assess the extent of the same limitation. The three categories are 1. the activity can be performed with "moderate difficulty" (*"Con dificultad moderada"*), 2. the activity can be performed with "severe difficulty" (*"Con dificultad severa"*), or 3. the activity cannot be performed. Although these categories may not be strictly ordinal, we rate severity by score based on these categories. For all 13 limitations that we consider, we either rank the categories and give one point for the lowest level of severity, two points for severe difficulties and three points when an individual states it cannot perform the activity. Summing over all 13 disability, our severity score ranges between 1 and 39 points, with higher scores indicating a higher level of disability. Although not statistically sophisticated, it was proven that the method leads to a reliable assessment of severity [29, 30]. For the difficulties to interpret numerical values of the score, we categorize the severity based on the ICF suggestions [31]. Someone with a score of four (first quartile) and lower is considered as "low", while people with a score up to nine (Median) are considered to have a moderately severe limitation. Everyone above score above nine is understood to be highly limited. As the score is solely based on information from the survey year, we are not able to observe changes in the severity over time which limits the concept validity. A second potential pitfall with any cross-sectional measure of severity is the selection upon the criteria. If there is a relationship between severity and age-specific mortality, we observe an already selected population. Due to their greater mortality risk at any time, individuals with high levels of severity have a lower chance to survive to the higher ages.

2.3 Characteristics of the Study Population

To assure that we observe disability patterns representative of those commonly experienced by older people, we restrict the sample to all non-institutionalized individuals with disability, as defined above, and an onset after age 50. Second, for the analysis of survival of the dependent population, we extract only individuals who stated they were dependent on a personal care giver in 2008. Our working sample contained 6648 cases (4560 female, 1979 male). As dependency often occurs very late in life, selected individuals are substantially older than the total population. Their median age in 2008 is 78 for men and 80 for women compared to 65 (women) and 64 (men) in the total population aged 50 or older. Further descriptive statistics comparing the two groups are provided in Table 1. The values indicate that the older age structure of the dependent population also causes the ages at death to be higher and more concentrated around the mean. The average onset age of disability in the dependent population is 71 years for both sexes, only a slight difference compared to the overall sample, where men experience the onset on average at age 70. Table 2 and Table 3 provide an overview over further characteristics related to disability. Naturally, the dependent population is relatively unhealthy, as for example indicated by the average number of disabilities and diseases (comorbidity). In contrast to the health measures, the distribution of sociodemographic variables does not vary substantially between the two samples. While the majority of men is married (76%), the women in our study are mostly widowed (49% compared to 42% in

Table 1: Descriptive comparison between the total population and the dependent population

	N (% of total)	Mean Age	St. Dev.	Median Age a. D.	Mean Age a. D.
Females					
Total Pop 50+	41715	66.39	11.04	79	78.15
Population Dep. 50+	4560 (10.9%)	78.67	9.54	83	82.32
Males					
Total Pop 50+	36770	65.01	10.43	75	73.78
Population Dep. 50+	1979 (5.4%)	77.18	9.63	80	79.54

marriage). A large proportion of our subjects does not have completed a formal degree (59.4% females, 48.8% males), while twice as many men in our study have a secondary or university degree (19.8%) compared to their female counterparts (11.3%). Educational levels and civil status are expected to vary with age as partners which is accounted for in the following survival analysis. Information on income is not taken into account, due to the large amount of missing information.

Table 2: Descriptive Overview about entry and exit ages - Dependent Population (Females)

Statistic	Mean	St. Dev.	Min	Pctl(25)	Pctl(75)	Max
Age 2008	78.66	9.53	50	73	85	102
Onset age disability	70.92	10.97	50.000	61.00	80.00	101.00
Age of first severe disability	71.41	10.78	50.00	63.00	80.00	101.00
Disabilities	4,63	3.17	1	2	7	10
Comorbidity (other conditions)	4.03	2.71	0	2	6	16
Age at death/censorship	85.75	8.57	53.84	81.01	91.93	107.09

Table 3: Descriptive Overview about entry and exit ages - Dependent Population (Males)

Statistic	Mean	St. Dev.	Min	Pctl(25)	Pctl(75)	Max
Age 2008	77.20	9.63	50	72	84	101
Onset age disability	70.44	10.82	50.00	61.00	79.00	99.00
Age of first severe disability	70.58	10.77	50.00	61.00	79.00	98.00
Disabilities	4.79	3.12	1	2	7	10
Comorbidty (other conditions)	3.54	2.53	0	2	5	14
Age at death/censorship	83.24	8.86	53.26	78.01	89.43	108.34

2.4 Statistical Model

We estimate mortality disparities within the dependent population based on previously identified pathway indicators and additional sociodemographic factors with well-documented effects using a Cox proportional hazard (PH) regression. The original model is the most commonly used approach to model censored time to event data, particularly when the interest lies in the relative effects of covariates [32]. Mathematically, the model can be expressed as in the following equation 1 [cf. 33].

$$h(t) = h_0(t) \exp(\beta_i \mathbf{X}_i) \tag{1}$$

, where h_0 is the baseline hazard and $\exp(\beta_i \mathbf{X}_i)$ the non-negative function of covariates. Hazard ratios are obtained through the maximization of the partial log likelihood with respect to $\beta_i \mathbf{X}_i$ [34, 35]. Since only the right-hand side of the formula is maximized, the Cox PH model does not require you to specify the underlying baseline distribution. Given this set-up, it is assumed that covariate effects are proportional over time. As we observe individuals at different ages in 2008, it is necessary to account for left truncation [36]. Such an adjustment is necessary as the time under risk of dying before the start date of the study remains unobserved. In other words, we select individuals based on their survival upon the year the EDAD survey was conducted. We choose to use person years as the time scale in our models to account for left-truncation. In other words, we measure age-specific mortality differences rather than survival over calender time. Cohort and time effects are accounted for by including a second time variable as covariate [37].

3 Results

In this work, a disability experience is captured by two main characteristics, the severity score, which combines information on the number and seriousness of a limitation and the onset age, which places it in the life course. Figure 2 is a display of the frequency distribution of the dependent population by degree of severity and within each level we display the proportion of individuals who have died or survived during our follow-up period. The graph indicates that most individuals are concentrated in the lower end of the score range. The lower the score on the severity scale, it appears, the higher the chance to survive until 2018. In a second exploratory analysis, we compared the probabilities of dying for different ages by the categorical version of the severity score. Group-specific, non-parametrically estimated survival probabilities, displayed in Figure 3, suggest that there are significant differences in age-specific survival between individuals who experience a low or moderate severity in comparison to the ones with a severity score higher than the median level. While the survival experience of this third group is very different until the highest ages, the survival of the other two groups is almost the same. To examine the survival risks in a multivariate setting, we estimated a number of nested Cox Proportional Hazard models. We stratify the models by sex to account for the structurally different health biographies of men and women at older ages. When compared with likelihood ratio tests, the models presented in Table 4 and

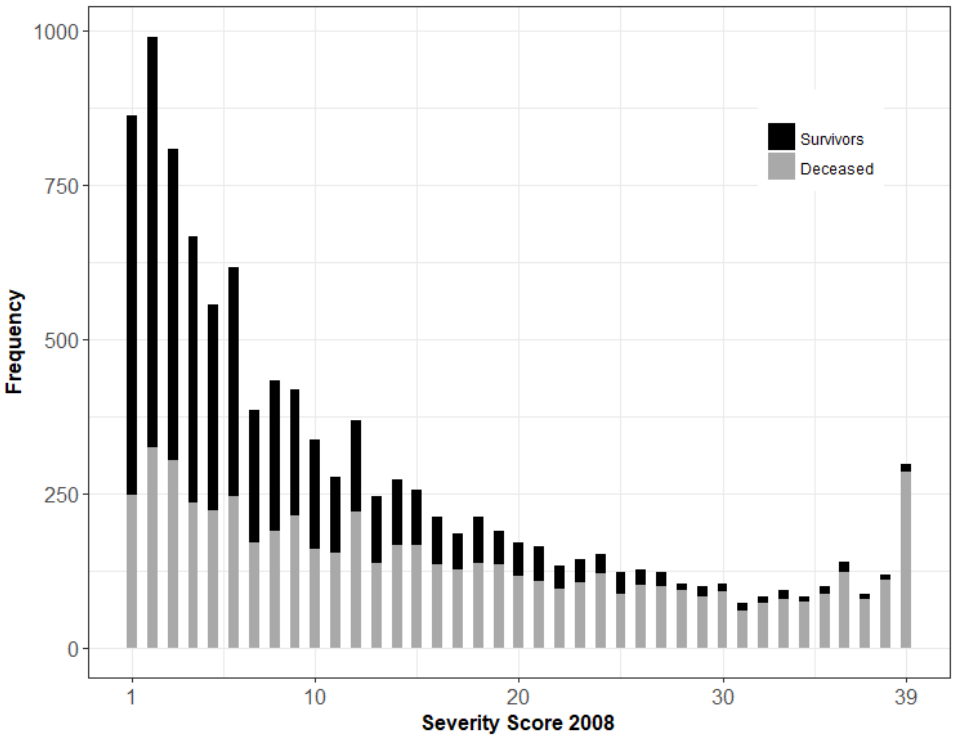

Figure 2: Histogram - Survival by Severity Score

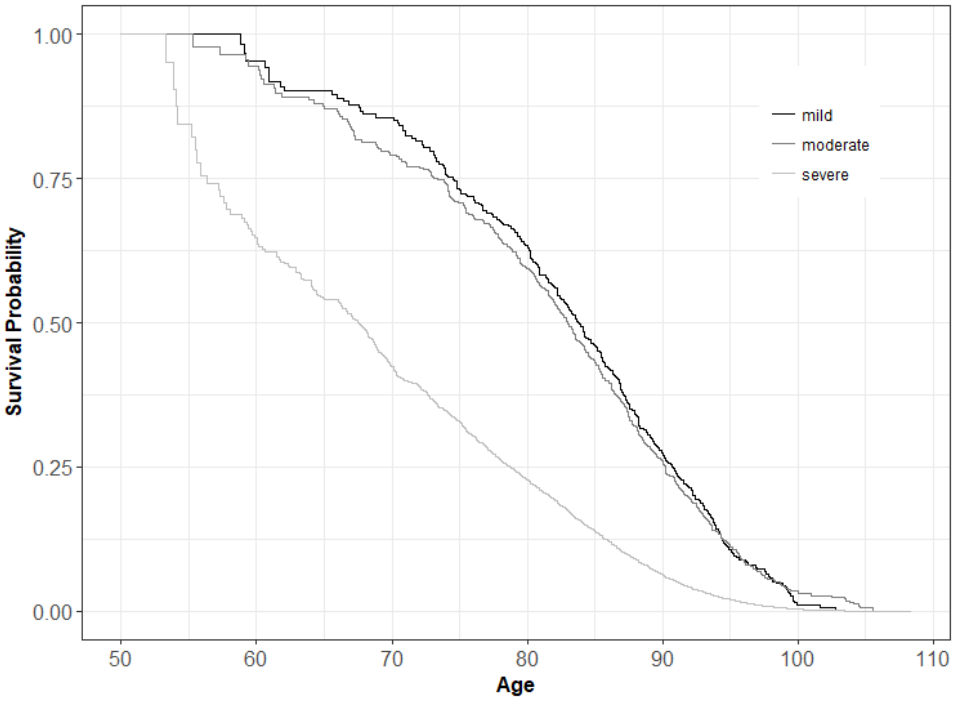

Figure 3: Survival Probability (KME) by Severity category over Age

Table 5 have the best fit, given the covariates we have tested so far. Every successive model step improves the fit in the respective line of nested models. The onset age and high severity in 2008 appear to explain most of the survival differences in the group of women within a dependency situation. Every year the onset of disability is delayed is suggested to reduce the risk of dying by about 0.8 percentage points. In other words, the later the onset of disability the higher is the probability of survival. While the effect is apparent for all models concerning females, there is no such effect for males. The effect of the severity score, on the other hand, appears to be universal. For both sexes it is suggested that being above the median severity score will increase the hazard of dying between 51.4 and 72.1 percentage points. The hazards appear to be higher for men compared to their female counterparts. Another effect that appeared in all tested models is the increased relative risk due to lack of daily activity. Individuals which have stated that the cannot move or be active on a daily basis in 2008 are suggested to experience a 30 to 32 percentage point higher hazard of dying, in spite controlling for severity and onset age. Other variables included in the models are not suggested to have an significant impact, according to conventional assessments of statistical significance.

In spite of the lack of explanatory power, we still want to make the reader aware that we include important predictors of mortality and disability severeness like the occurrence of an accident or fall within the last year. Notably, we tested for various other combinations of variables in this analysis of mortality hazards, including well-documented socioeconomic characteristics. Neither the highest educational degree nor civil status appeared to affect survival in the presence of the severity level and the age of onset of first disability.

Table 4: Cox PH Regression Models - females

	Dependent variable:		
	Relative risk of dying		
	(1)	(2)	(3)
Onset age	0.992***	0.992***	0.992***
	(0.987, 0.996)	(0.988, 0.996)	(0.988, 0.997)
Moderate Severity Score (ICF)		1.021	0.995
		(0.862, 1.180)	(0.836, 1.154)
High Severity Score (ICF)		1.639***	1.514***
		(1.502, 1.776)	(1.375, 1.654)
Reference: Low Severity Score (ICF)			
Suffers from multiple diseases			1.097
			(1.004, 1.190)
Reference: No multi-morbidity			
Had accident in last 12 mo.			0.965
			(0.867, 1.063)
Reference: No accident			
No daily activity			1.304***
			(1.214, 1.395)
Reference: Moves daily			
Observations	4,560	4,560	4,560
R^2	0.003	0.030	0.038
Log Likelihood	−19,372.320	−19,309.950	−19,290.490
Wald Test	13.950*** (df = 1)	129.620*** (df = 3)	165.510*** (df = 6)
LR Test	13.605*** (df = 1)	138.339*** (df = 3)	177.266*** (df = 6)
Note:			*p<0.1; **p<0.05; ***p<0.01

Table 5: Cox PH Regression Models - Males

	Dependent variable:		
	Relative risk of dying		
	(1)	(2)	(3)
Onset age	1.001	0.999	0.999
	(0.995, 1.008)	(0.992, 1.005)	(0.992, 1.006)
Moderate Severity Score (ICF)		1.083	1.048
		(0.891, 1.275)	(0.855, 1.240)
High Severity Score (ICF)		1.721***	1.548***
		(1.561, 1.881)	(1.383, 1.713)
Reference: Low Severity Score (ICF)			
Suffers from multiple diseases			1.059
			(0.937, 1.180)
Reference: No multi-morbidity			
Had accident in last 12 mo.			1.063
			(0.908, 1.218)
Reference: No accident			
No daily activity			1.324***
			(1.213, 1.434)
Reference: Moves daily			
Observations	1,979	1,979	1,979
R^2	0.0001	0.040	0.053
Log Likelihood	−8,645.392	−8,605.128	−8,591.727
Wald Test	0.120 (df = 1)	75.690*** (df = 3)	101.390*** (df = 6)
LR Test	0.125 (df = 1)	80.651*** (df = 3)	107.454*** (df = 6)
Note:			*p<0.1; **p<0.05; ***p<0.01

4 Discussion

The onset of care dependence due to disability or disease may be one of the most difficult transitions in ones life time. For the individual, this experience is often linked to a loss of autonomy and quality of life. The ability to perform activities of daily living may be one of these things that are unnoticed or often unrecognized until the point when you lose it. As social, technical, and medical progress improves the lives of many people with limitations and allows them to participate in all social spheres, it becomes more difficult to predict this onset point. While there are better solutions for preventing, treating, or assisting for some of these limitations than for others, the sheer amount of possible conditions and the degrees of severities make it very hard to assess health and predict the onset of dependency.

Our work is an attempt to use a simple classification of the above mentioned variety of conditions and degrees, to predict the other end of a dependency episode at older ages, often marked by death. We want to know how the survival is affected by different characteristics of a disability biography. The way to this analysis was paved by the offer of the Spanish National Institute for Statistics, which offered to link the most complete and representative source for the assessment of disability and situations of dependence to an internal mortality follow-up. In spite of that newly linked data source, we encountered several limitations due to the structure of the data. As there is just one cross-sectional time point from which we obtain information on severity of single limitations and the state of dependence, we cannot assure that these levels may have changed substantial during the follow-up time. Due to the aforementioned social and medical progress, there may have been individuals for whom the severity score has lowered after the survey. The validity of our results may have also been affected by the aforementioned selection mechanism. Since we examine survival difference based on variables which are technically time-dependent and with a hypothetical cohort, it is more than possible that individuals in the study are selected. As mentioned above, we expect to find less individuals with a high severity score in the highest age groups as there mortality risk is higher throughout the life course. Since we decided to only look at the population aged 50 or older, our base population is also selected upon survival to age 50. We try to control for that in our analysis by left truncating the data at age 50.

In spite of the limitations, the results of our mortality analysis confirm the applicability of the score-based assessment of severity. In its categorized form the severity measure is suggested to have a substantial impact on the survival of dependent individuals. There may be more possibilities combine the score into categories, but the ICF based categorization suited us and appears to predict mortality well. The onset age is only found to significantly affect female survival and has to be reviewed. We play with the idea to try different age variables including age groups. As this is work in progress, we will keep adding variables and recode them to see if the fit and the exploratory power improves. We will also run different models which may be better suited to model human mortality, for example, a Gompertz model.

The assessment different trajectories across different health states or markers for different pathways through disability will remain important. From a economical perspective, it may help to better predict future care costs.

If we would, for example, find that a jump in our severity assessment from year a to b will lead to a short episode of dependency and a close death, we would not need to allocate the same resources as for people with a gradually increasing score. At a individual level further assessments of this kind may help to make personal decisions regarding care or even more general how to manage different spheres of life after onset of disability. Even just a better understanding of what to expect in certain (and in this case dire) situations has the potential to contribute to a better quality of life.

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5 Appendix

Table 6: Life expectancy, DFLE, DepFLE for both sexes and selected ages in 2008

	Females			Males		
Age	LE	DFLE	DepFLE	LE.1	DFLE	DepFLE
50	35.576	27.693	29.034	30.161	26.579	27.481
65	21.846	14.860	15.878	17.811	14.613	15.322
75	13.381	7.449	8.159	10.749	7.828	8.393
80	9.723	4.550	5.084	7.843	5.121	5.596
90	4.528	1.152	1.424	3.832	1.559	1.872