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Similar dynamics of terminal functional decline in nursing home residents with and without dementia

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Abstract

Background: This study investigates the functional health trajectories at the end-of-life in nursing home residents with no dementia, mild-to-moderate dementia, and severe dementia.

Methods: 45,803 deceased residents (mean age 87.49ys ± 7.14ys, 67.6% female, no dementia (N=18,993), mild-to-moderate dementia (N=14,687), and severe dementia (N=12,123)) from 357 nursing homes across Switzerland were included in this retrospective cohort study. Activities of daily living (ADL) scores of the Resident Assessment Instrument – Minimum Dataset (RAI-MDS) were used to assess functional health. Multi-phase growth models spanning 24 months prior to death were calculated as a function of dementia status and severity.

Results: The functional health trajectories follow a nonlinear pattern with a long period of mild decline with a mean ADL score change of -0.118 points per months (95% CI -0.122 to -0.114) for the no dementia group, followed by a significant terminal drop (mean ADL change of -1.528, 95% CI -1.594 to -1.462) two to three months before death (transition point at -2.221, 95% CI -2.306 to -2.136). Residents with dementia had a steeper preterminal decline (-0.026, 95% CI -0.32 to -0.20 for mild-to-moderate dementia, - 0.056, 95% CI -0.062 to -0.051 for severe dementia) and less terminal decline (0.274, CI 0.211 to 0.337 for mild dementia, -0.230 to 0.336 for severe dementia). However, the transition point and the pattern of decline were similar across the dementia groups, though proceeding at different levels.

Conclusion: The dynamics of terminal functional health decline in nursing home residents with and without dementia are similar.

Keywords

End-of-life, Trajectories, Terminal decline, Nursing home, Long-term care, RAI-MDS, Dementia, Functional health

INTRODUCTION

An increasing number of people are dying with Alzheimer's and other dementias, many of them in long-term care facilities (Badrakalimuthu and Barclay 2014). Although dementia is considered a terminal illness, little is known about the causes and dynamics of dying with dementia (Mitchell et al. 2009; van der Steen 2010). Knowledge about end-of-life health trajectories (see recent systematic review (Cohen-Mansfield et al. 2018) is important for patients and their relatives and could support the recognition of the terminal phase and appropriate care planning. Various approaches exist to define and quantify health status.

A common approach in end-of-life research is the

concept of functional health, which focuses on the most relevant functional abilities for everyday life of a person and is usually measured by dependency in activities of daily living scales (ADLs) (Morris et al. 1999; Lee et al. 2009; Hjaltadóttir et al. 2011; Vossius et al. 2018). Dependency in ADLs is a key feature of dementia and common in long-term care. As a result, specialised ADL scales were developed for this population (Morris et al. 1999). In addition, low-functional health has repeatedly been reported as one of the key factors for institutionalisation and mortality in both individuals with and without dementia (Abicht-Swensen and Debner 1999; Flacker and Kiely 2003; Porock et al. 2005; Gaugler et al. 2007; Lee et al. 2009; Hjaltadóttir et al. 2011; Thomas et al. 2019; Nuutinen et al. 2019). In people without dementia, trajectories of functional health typically follow a nonlinear pattern with accelerated decline in the last months of life, albeit with some differences depending on the condition or disease (Teno et al. 2001; Lunney et al. 2003; Chen et al. 2007; Gill et al. 2010).

In dementia, the terminal phase is usually associated with lower levels of functional health and has been described as 'progressive dwindling' (Murray et al. 2005; van der Steen 2010), but very few studies examined and quantified patterns of functional decline in dementia (Chen et al. 2007; Gill et al. 2010). They have found rather distinct end-of-life trajectories with persistently poor functional health during the last year of life and much less (Chen et al. 2007) or even absence (Gill et al. 2010) of terminal decline. However, in both previous studies the dementia group has been restricted to cases with severe dementia, so there is no information about trajectories of people dying with mild or moderate dementia. In addition, the exact pattern of trajectories and onset point of terminal decline are not known for both populations with and without dementia. This study aims to close a gap in knowledge by studying trajectories of functional health in a large sample of Swiss nursing home residents. In a retrospective cohort study, we modelled the trajectories of functional health, as measured by ADL function, from 24 months prior to death as a function of dementia status and severity (mild-to-moderate versus severe).

METHODOLOGY

Study population and data source

This retrospective cohort study used routine healthcare data of the Swiss version of the Resident Assessment Instrument – Minimum Data Set (RAI-MDS) V2.0 (Morris et al. 1995; Anliker and Bartelt 2015) of 105,834 nursing home residents in Switzerland, with cohorts for the years 1998 to 2014. Data was available for 357 nursing homes out of 16 of 26 cantons across Switzerland, representing about two-thirds of the eligible nursing homes using the RAI-MDS (Anliker and Bartelt 2015). The dataset was arranged by the local distribution and administration company of the RAI system, Q-Sys AG, St. Gallen, after obtaining the anonymised data from each participating nursing home. As the analysis was based on anonymous routine care data, no approval from the local ethics committee was required (cantonal ethics committee Zurich declaration of no objection 103-2015, KEK-ZH-Nr. 2012-0102). This dataset has been used in a previous publication on cognitive trajectories (Hülür et al. 2019).

For this study, deceased residents aged ≥ 65 with at least one RAI-MDS assessment in their last 24 months of life were included (N = 53,424). Residents suffering from disabilities with persistently high dependency levels such as cerebral palsy (N = 192), paraplegia (N = 202), hemiplegia (N = 2,599), quadriplegia (N = 239), or limb amputation (N = 275) were excluded from analysis, as well as those receiving tracheostomy care (N = 167) and comatose residents (N = 76) (total N = 3,295). Lastly, those residents with missing values in any of the predictor variables (dementia diagnosis (N = 3,889) or any of the covariates in the full model (N= 4,164), were excluded from analysis (total N = 4,326).

Instruments and measures

The RAI-MDS was developed to improve the quality of care in long-term care in the US (Morris et al. 1990). It has become a widely used instrument for care planning and reimbursement that is applied in a large number of countries around the world, including Switzerland.

The Swiss version of RAI-MDS V2.0 (Anliker et al. 2007) is used by approximately one-third of the nursing homes in Switzerland (Anliker and Bartelt 2015). The RAI-MDS shows high levels of reliability for most of the MDS items, in particular for the ADL domains (Hawes et al. 1995; Sgadari et al. 1997; Morris et al. 1999; Poss et al. 2008). The assessments include information on a variety of residents' health characteristics (for example, disease diagnoses,

functional health, cognition), and are completed by specialised clinical professionals and physicians. A full assessment extends over a period of two weeks and is completed at admission and every subsequent year or whenever care needs change significantly. Furthermore, an abbreviated assessment is performed six months after each full assessment.

The primary outcome of this study, functional health, was assessed with the ADL index of the Swiss RAI-MDS, which is a 15-points (range 4-18) scale based on the residents' performance in the following four basic ADLs: bed movement, toilet use, transfer, and eating. Each ADL is evaluated in terms of dependency and need for help, resulting in a scale ranging from 1 ('independent and no help needed') to 5 ('complete dependency and help from 2+ persons needed', or 'no activity at all') for each of the four ADLs except eating which has a maximum score of 3 points. The RAI-MDS ADL scales show high internal consistency (Morris et al. 1999), which is also true for the present ADL scale with Cronbachs $\alpha > 0.9$ throughout the different measurement time points. The scale represents the residents' dependency in ADLs, in other words increasing ADL dependency results in higher ADL scores. In order to better illustrate the functional decline at the end of life we reverse coded the scale for our analysis, in other words lower scores now represent lower functional ability.

The classification of dementia status (no dementia, mild-to-moderate dementia, severe dementia) was based on the dementia diagnoses in the RAI-MDS (in other words, the items *Alzheimer's disease* or Dementia other than *Alzheimer's disease*), the ADL index, and the Cognitive Performance Scale (CPS) (Morris et al. 1994; Anliker et al. 2007). The CPS is a 7-point scale (range from 0-6 with 0 = 'intact' and 6 = 'very severe impairment') to evaluate the cognitive impairment of nursing home residents. It has a performance similar to the Mini Mental State Examination (MMSE (Folstein et al. 1975)) (Morris et al. 1994; Hartmaier et al. 1995; Paquay et al. 2007). According to the literature (van der Steen et al. 2006), mild-to-moderate dementia was defined as having any of the two dementia diagnoses and a score <5 on the CPS and <10 on the ADL index in the last MDS assessment before death, whereas severe dementia was defined as having any of the two dementia diagnoses with a CPS score ≥5 and an ADL score ≥10, respectively. Although ADL information was used to define dementia, the RAI-MDS ADL index has been demonstrated to adequately cover change in ADLs in both moderate and severe dementia (Carpenter et al. 2006).

Nevertheless, we additionally fitted the analytic models with other classifications of severe dementia, which provided similar results and so are not reported in this paper.

Statistical analysis

Following good practice in the terminal decline literature (Gerstorf et al. 2014), multi-phase or 'spline' growth models (Cudeck and Klebe 2002; Singer and Willett 2003; Cudeck and Harring 2007; Ram and Grimm 2007) were fitted for functional health over time-to-death for the last 24 months of life. Multi-phase growth models are comparable to linear mixed models, which are especially appropriate for longitudinal designs, as random (individual) effects can be modelled in addition to the fixed effects (for example, dementia group or time to death). In addition to that, multi-phase models allow for a free estimation of different types of trajectories and, in particular, of any existing transition or change points between different trajectories. As the known end-of-life trajectories show distinctive patterns for the last few months of life (Lunney et al. 2003; Gill et al. 2010), the analysis included measures for each month before death. Because residents usually are assessed at longer time intervals and have different numbers of time points, an accelerated longitudinal design was applied, which is based on both cross-sectional and longitudinal data. Here, the mixed models approach is particularly appropriate because it allows handling unbalanced designs and missing data under the assumption of missing at random (MAR). For the multi-phase growth models, different equations are formulated for the time period before and after an estimated change or transition point k (see Appendix for equations and formulas). Both a model with several covariates and a dementia only model were calculated (see Appendix). Although model convergence was given for all models, the models with covariates resulted in violation of second-order optimality condition, which could not be eliminated through fitting process. However, effects of covariates on the trajectories were negligible, so we only report the results from the model without covariates. Description of covariates, model description, and results from the full model with covariates can be found in the Appendix.

For the current model, individual-specific inter-

cepts at change point, β_{0i}, change point, t_i, and the two slopes, β_{1i} and β_{2i}, were modelled as a function of dementia status and severity. In addition to the sample-level associations (fixed effects, *ys*), the model estimates the residual unexplained individual differences (*us*) that are assumed to be multivariate normally distributed, correlated with each other, and uncorrelated with the residual error, e_{ti}. Despite the large dataset with multiple observations, the models could not be estimated with random effects for both the slopes and the change point.

With the focus on identifying the transition to the last phase of life it was more important for us to allow for within-group variation in onset time of the terminal phase. As a consequence, we decided to remove the random effects for the slopes. The random effect variance-covariance matrix was parameterised using (squared) standard deviations. The models were fit with the SAS (SAS Institute Inc., Cary, NC) PROC NLMIXED statement (Littell et al. 2006). Due to the large sample size, significance level was set to α = .001.

RESULTS

The final sample included the longitudinal data of 45,803 deceased residents (mean age at death 87.49 ± 7.15) with a mean number of 3.03 (± 1.56) observations per resident (range 1-11). The mean distance from death at the last RAI-MDS assessment was 2.71 ± 2.44 months, with 31,272 (68.3%) residents having at least one assessment in their last 3 months of life.

A summary of the sample's characteristics is displayed in Table 1. All trajectories were characterised by a long period of mild decline, followed by a terminal phase of accelerated decline (Figure 1). The model estimates are reported in Table 2.

Table 1. Characteristics of deceased nursing home residents

	No dementia (N=18,993, 41.5%)	Mild to moderate dementia (N=14,687, 32.1%)	Severe dementia (N=12,123, 26.5%)	Total (N=45,803)
Age at death, M* (SD)	87.18 (7.60)	87.75 (6.60)	87.65 (7.00)	87.49 (7.14)
Female sex (%)	66.9	66.0	70.8	67.6

* M = Mean. SD = Standard deviation

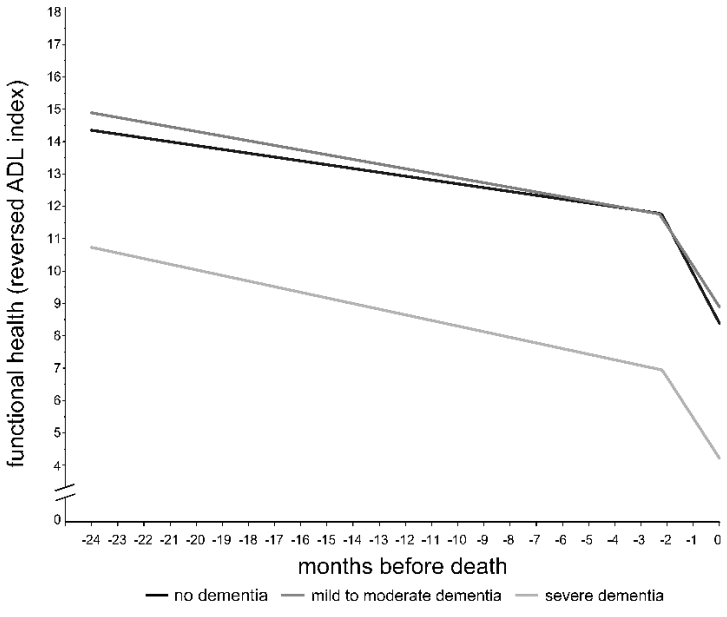

Figure 1. Trajectories of functional health (reversed RAI-MDS ADL index) in nursing home residents with no dementia, mild-to-moderate dementia, and severe dementia. The figure shows the estimated trajectories from the multiphase model. Transition points were estimated -2.22 months before death for the no dementia group, -2.29 for the mild-to-moderate dementia group, and -2.19 for the severe dementia group. Estimated pre-terminal and terminal slopes were -0.12 and -1.53 points per months (no dementia), -0.14 and -1.25 (mild-to-moderate dementia), and -0.18 and -1.25 (severe dementia). ADL = Activities of daily living.

Table 2. Multi-phase model for functional health (reversed ADL*) over time to death, including dementia status. †

Parameter	Estimate	SE‡	p-value
Fixed effects			
Intercept, y_{00}	11.7822	0.0397	<.001
Pre-terminal slope, y_{10}	-0.1180	0.0019	<.001
Terminal slope, y_{20}	-1.5281	0.0337	<.001
Transition point, y_{30}	-2.2207	0.0434	<.001
Mild to moderate dementia*intercept, y_{01}	-0.0131	0.0594	.825
Mild to moderate dementia*pre-terminal slope, y_{11}	-0.0256	0.0028	<.001
Mild to moderate dementia*terminal slope, y_{21}	0.2741	0.0320	<.001
Mild to moderate dementia*transition point, y_{31}	-0.0704	0.0652	.280
Severe dementia*intercept, y_{03}	-4.8394	0.0619	<.001
Severe dementia*pre-terminal slope, y_{12}	-0.0563	0.0028	<.001
Severe dementia*terminal slope, y_{22}	0.2830	0.0270	<.001
Severe dementia*transition point, y_{32}	0.0349	0.0638	.584
Ratio terminal/pre-terminal slope no dementia (y_{20}/y_{10})	12.9518	0.3514	<.001
Ratio terminal/pre-terminal slope mild to moderate dementia ($(y_{20}+y_{21})/(y_{10}+y_{11})$)	8.7361	0.2500	<.001
Ratio terminal/pre-terminal slope severe dementia ($(y_{20}+y_{22})/(y_{10}+y_{12})$)	7.1459	0.1753	<.001
Random effects			
SD§ deviation intercept	3.9952	0.0178	<.001
SD§ deviation transition point	2.2309	0.0527	<.001
Correlation intercept, transition point	-0.5812	0.0068	<.001
Residual variance	4.9044	0.0251	<.001
AIC‖	722114		
Pseudo R-Squared	.7917		

* ADL = Activities of daily living. † Intercept centred at the transition point. Residents with no dementia served as the reference group.
‡ SE = Standard error. § SD = Standard deviation.
‖ AIC = Akaike information criterion.

The transition point for the reference group without dementia was estimated around two months before death (y_{30} = -2.22). Terminal decline (y_{20} = -1.53) for this group was almost 13 times (y_{20}/y_{10} = 12.95) larger than pre-terminal decline (y_{10} = -0.12). Both residents with mild-to-moderate dementia and severe dementia had a steeper pre-terminal decline (y_{11} = -0.03 and y_{12} = -0.06), and less terminal decline (y_{21} = 0.27 and y_{22} = 0.28). However, terminal decline was still more than 8 times ((y_{20} + y_{21})/(y_{10} + y_{11}) = 8.74) larger in the mild-to-moderate and 7 times ((y_{20} + y_{21})/(y_{10} + y_{11}) = 7.15) larger in the severe dementia group compared to pre-terminal decline. The transition point to the terminal phase of both dementia groups did not differ from those without dementia, but residents with higher functional health showed earlier transition points to the terminal phase (r = -.58). As expected due to the classification of severe dementia, residents with severe dementia had lower functional health (y_{03} = -4.84). Except for the intercept, estimates of the dementia groups were similar.

DISCUSSION

Our study is the first to quantify the nonlinear pattern of end-of-life trajectories in functional health of nursing home residents and to explore the effect of dementia status and severity on rates of change and time of transition to terminal decline. Independent of dementia status and severity, functional health remained relatively stable with only mild decline for most of the time during the last two years of life, followed by a steep decline (up to 13 times larger than before) in the last two to three months before death. Although residents with dementia showed steeper decline in the pre-terminal phase and less steep terminal decline in the last months of life, terminal decline was still at least seven times larger than in the pre-terminal phase. Dementia status or severity did not significantly affect the transition point, so the onset of terminal decline occurred in the same timing pattern in all groups.

Our results confirm previous findings on end-of-life trajectories in subjects dying from various causes without dementia that describe pronounced and

accelerated terminal decline before death (Teno et al. 2001; Chen et al. 2007; Klijs et al. 2010; Gill et al. 2010). Our findings also indicate for the first time that even residents with severe dementia show substantial change in functional health before death. Our study therefore somewhat contradicts two previous studies reporting less pronounced or absent accelerated terminal decline in people dying with severe dementia (Chen et al. 2007; Gill et al. 2010). This may be explained by our approach of trajectory analysis of monthly rates of change as compared to assessments with larger intervals (Chen et al. 2007) or using only rough estimates of ADL function (Gill et al. 2010). In addition, the study population of Gill et al. (Gill et al. 2010) was confined to community-dwelling residents and the nursing home residents with severe dementia in the study of Chen et al. (Chen et al. 2007) tended to be older and more disabled, possibly reducing the range for change. So, the effect of terminal decline could have been previously underestimated for this population. Our findings are unique with regard to the population of residents with mild-to-moderate dementia and the long relatively stable phase of up to two years prior to the acceleration of decline. Previous studies were restricted to severe dementia and were using shorter observation periods of maximally 12 months (Chen et al. 2007; Gill et al. 2010).

The study has several strengths and limitations. The major strengths are the large dataset of routine healthcare data and the use of an internationally established assessment instrument. The RAI-MDS offers a standardised instrument developed and validated for the purposes of nursing home settings. The instrument shows an adequate to excellent level of reliability, in particular for the ADL domains (Hawes et al. 1995; Sgadari et al. 1997; Morris et al. 1999; Poss et al. 2008). ADL scales based on the RAI-MDS also show high internal consistency (Morris et al. 1999) and are adequately change-sensitive even for residents with severe dementia (Carpenter et al. 2006). Use of ADL measures based on the RAI-MDS is in line with World Health Organization recommendations to measure functional impairment and disability (Morris et al. 1999). The wide distribution of the RAI-MDS permits rapid replication and implementation in similar settings, and comparison of different populations or healthcare systems. Furthermore, our study is the first to use multi-phase growth modelling, the most adequate statistical approach to quantify the different periods of functional change before death. The study dataset can be considered as representative for the RAI-using nursing homes in Switzerland, at least for the German and Italian speaking parts of Switzerland with high coverage of the RAI system (Anliker and Bartelt 2015).

There are a number of limitations that need to be addressed. While our findings describe the typical situation of long-term care residents, we do not know whether they apply to non-institutionalised persons with dementia. Persons with dementia in nursing homes appear to differ from those dying at home (Mitchell et al. 2004). In nursing home residents, terminal functional decline in dementia could be more pronounced, as the nursing homes might be better able to stabilise functional health in the pre-terminal phase. Future research needs to address if our results apply to other populations or healthcare settings by comparing different populations that are assessed with RAI instruments. Although our findings help to understand the course of dying by describing the prototypical scenario in which functional health develops towards the end of life, not every single person with dementia in a nursing home will follow this course. The predictive utility is limited due to the individual variability that cannot be explained on the basis of available data. In addition, the analytic model was based on both cross-sectional and longitudinal data because of the data structure with different individual assessment time points and number of assessments. As a consequence, our findings cannot be directly implemented in the RAI-MDS. Finally, the dataset is confined to Switzerland. We do not know in how far variations in the design of nursing homes, number and qualification of staff and the culture of care may influence terminal trajectories (for example, emphasis of palliative care over 'conventional' medical care approaches).

Our findings indicate that nursing home residents with and without dementia can expect to face a long phase with only mild functional decline, in other words relative stability in their functional health, before death becomes immanent and their functional health declines sharply. Our study has broad implications for stakeholders, care practice and research. Life in a nursing home is often feared and seen as a state of severe and progressive dependence and impairment. Our study shows that functional stabilisation is possible, even in residents suffering from severe dementia. Knowledge about the chance for stabilisation and the relatively short dying phase could attenuate fears with regard to nursing home placement. Knowledge about a typical

dying phase in a nursing home could furthermore help to prevent unnecessary and burdensome medical interventions. In addition, our results have methodological implications. Poor levels of functional health have repeatedly been reported as one of the most important factors associated with mortality in long-term care in both residents with and without dementia (Abicht-Swensen and Debner 1999; Flacker and Kiely 2003; Porock et al. 2005; Lee et al. 2009; Hjaltadóttir et al. 2011). Our findings imply that instruments to predict health or mortality should consider the dynamics of trajectories rather than absolute levels of functional health. This includes predictive models for non-cancer patients, for which the needs and timing for palliative care are not well understood (Coventry et al. 2005). Previous studies using rough estimates for change already indicated an advantage of including functional change in tools for mortality prediction in long-term care (Hirdes et al. 2003; Yeh et al. 2014)10. However, since the drop in functional health occurs only two to three months before death, the use of such tools for prediction over longer time periods would appear to be limited. Our results may furthermore have implications for the biological understanding of the dying process. From developmental psychological research, it is known that accelerated decline occurs in various health-related domains, such as cognition, well-being, and subjective health status, usually described as 'terminal decline' or 'terminal drop'. The dynamics of this decline seem to be driven by time to death, rather than age or specific disease (Wilson et al. 2012; Gerstorf and Ram 2013). Our study is the first that observed terminal decline in functional health in people dying with dementia that is comparable to the pattern seen in people dying without dementia. So, our results point toward the existence of similar end-of-life health dynamics in residents with and without dementia, which may reflect the natural process of dying.

However, while various health-related domains seem to show terminal decline with early transition several years before death (Wilson et al. 2012; Gerstorf and Ram 2013), terminal decline in functional health manifests itself as late loss that typically occurs just months or weeks before death. Eventually, there could be important implications for care practices and health systems. Knowledge about the dynamics of functional health at the end of life helps to optimise healthcare provision in the terminal phase, including the practice of providing palliative care for people dying with dementia. Moreover, stabilised in functional health or basic ADLs has been discussed as a quality marker in long-term care (Morris et al. 1999). It needs to be further explored whether effective stabilised of functional health can be used to compare different healthcare settings and systems in terms of quality of care, in particular for residents with dementia.

Future studies should try to identify predictors that explain more of the variability in end-of-life trajectories and better discriminate between those residents with terminal decline in functional health and those without. In addition, specific factors associated with immediate functional decline that increase mortality should be investigated. Future studies should also investigate end-of-life trajectories in other health domains and analyse the reciprocal effects of different health trajectories to identify the directional relationship between different health parameters.

CONCLUSIONS

The nursing home population has a relatively stable functional health in the last two years of life until they enter a phase of rapid decline two to three months before death. This terminal decline occurs independently of dementia status or severity, presumably indicating disease-independent mortality processes.

Our findings may help to better distinguish between different stages at the end of life and to better identify the onset of the terminal phase in nursing home residents with and without dementia. Therefore, our results improve the understanding of the dying process and have broad implications for optimising end-of-life care in nursing homes.

DECLARATIONS

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Conflict of interest: all authors report no conflicts of interest.

Ethics approval (include appropriate approvals or waivers): as the study was based on anonymous routine care data only, the requirement for ethics approval was waived by the cantonal ethics committee Zurich (declaration of no objection 103-2015, KEK-ZH-Nr. 2012-0102).

Availability of data and material: for verification purposes, the dataset is available from the corresponding author upon request.

Authors' contributions: NT: data preparation and data analysis, interpretation of data, drafting the manuscript. DG: supporting data analysis, revising manuscript. SE: interpretation of data, revising manuscript. HG: interpretation of data, revising manuscript. CR: study design and conception, revising manuscript. MM: study design and conception, revising manuscript. HW: study design and conception, interpretation of data, revising manuscript FR: study design and conception, interpretation of data, revising manuscript. All authors contributed important intellectual content to the manuscript. All authors approved the final version of the manuscript.

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Supplementary Appendix

Formulas and equations of the multi-phase 'spline' models

The multi-phase or 'spline' growth models were specified as:

$$functional\ health_{ti} = \beta_{0i} + \beta_{1i}(time_{ti} - k_i) + e_{ti}\ .$$

$$when\ timetodeath_{ti} < k_i \qquad \textbf{(Eq, A, 1)}$$

and

$$functional\ health_{ti} = \beta_{0i} + \beta_{2i}(time_{ti} - k_i) + e_{ti}\ .$$

$$when\ timetodeath_{ti} \geq k_i \qquad \textbf{(Eq, A, 2)}$$

The equations Eq. (A.1) and Eq. (A.2) represent the functional health of resident *i* at time *t* as a function of the individual-specific intercept β_{0i} at a person-specific change point k_i, the individual-specific slopes β_{1i} and β_{2i} for functional change per month before and after the change point k_i, and the residual error e_{ti}.

For the model with dementia status as predictor, individual-specific intercepts at change point, β_{0i}, change point, t_i, and the two slopes, β_{1i} and β_{2i}, were modelled as a function of dementia status, as follows:

$$\beta_{0i} = \gamma_{00} + \gamma_{01}(mild\ to\ moderate\ dementia_i) + \gamma_{02}(severe\ dementia_i) + u_{0i} \quad \textbf{(Eq, A, 3)}$$

$$\beta_{1i} = \gamma_{10} + \gamma_{11}(mild\ to\ moderate\ dementia_i) + \gamma_{12}(severe\ dementia_i) \quad \textbf{(Eq, A, 4)}$$

$$\beta_{2i} = \gamma_{20} + \gamma_{21}(mild\ to\ moderate\ dementia_i) + \gamma_{22}(severe\ dementia_i) \quad \textbf{(Eq, A, 5)}$$

$$k_i = \gamma_{30} + \gamma_{31}(mild\ to\ moderate\ dementia_i) + \gamma_{32}(severe\ dementia_i) + u_{3i} \quad \textbf{(Eq, A, 6)}$$

The γs in equations Eq. (A.3) - Eq. (A.6) represent sample-level associations and the *u*s the residual unexplained individual differences that are assumed to be multivariate normally distributed, correlated with each other, and uncorrelated with the residual error, e_{ti}. In addition, estimates for the ratios between terminal and pre-terminal slopes were calculated for each of the three groups. The mean levels (± SD) of functional health (reversed activities of daily living (ADL) index) for the last 24 months are displayed in Table A1.

Formulas and equations of the multi-phase 'spline' models with covariates

The resident assessment instrument – minimum dataset (RAI-MDS) provides a large number of other factors potentially related to functional health. However, to keep the statistical models as parsimonious as possible, the selection of covariates was reduced to demographic variables (age at death and sex) and those variables directly linked to the functional health scale (training and skill practice in ADLs, the residents' belief in future improvement of at least some ADLs, the staff's belief in future improvement of at least some ADLs, daily variability in ADLs, and the possibility to perform ADLs though only slowly). Within the RAI-MDS, training and skill practice is documented for any of the particular ADLs. Here, only the four basic ADLs related to the ADL index were considered and merged to one single variable of receiving at least one of the four ADL care trainings or not.

To avoid time-varying predictor variables, the independent variables were aggregated, so the residents were classified into a specific group whenever a characteristic appeared in at least one of the available assessments (for example, the resident was classified as receiving training and skill practice when training and skill practice for one of the four basic ADLs was documented at least once during his or her nursing home stay). Finally, age at death was centered at the mean level. A summary of the ADL-related items in RAI-MDS used as covariates is displayed in Table A2.

In the full model with all covariates, individual-specific intercepts at change point, β_{0i}, change point, t_i, and the two slopes, β_{1i} and β_{2i}, were modelled as a function of dementia status and the covariates, as follows:

$$\beta_{0i} = \gamma_{00} + \gamma_{01}(mild\ to\ moderate\ dementia_i) + \gamma_{02}(severe\ dementia_i) + \gamma_{03}(age\ at\ death_i) + \gamma_{04}(sex_i) + \gamma_{05}(care\ training_i) + \gamma_{06}(residents'adl\ belief_i) + \gamma_{07}(nurses'adl\ belief_i) + \gamma_{08}(slow\ adl\ possible_i) + \gamma_{09}(adl\ daily\ variability_i) + u_{0i} \quad \textbf{(Eq, A, 7)}$$

$$\beta_{1i} = \gamma_{10} + \gamma_{11}(mild\ to\ moderate\ dementia_i) + \gamma_{12}(severe\ dementia_i) + \gamma_{13}(age\ at\ death_i) + \gamma_{14}(sex_i) + \gamma_{15}(care\ training_i) + \gamma_{16}(residents'adl\ belief_i) + \gamma_{17}(nurses'adl\ belief_i) + \gamma_{18}(slow\ adl\ possible_i) + \gamma_{182}(severe\ dementia_i * slow\ adl\ possible_i) + \gamma_{19}(adl\ daily\ variability_i) \quad \textbf{(Eq, A, 8)}$$

$$\beta_{2i} = \gamma_{20} + \gamma_{21}(mild\ to\ moderate\ dementia_i) + \gamma_{22}(severe\ dementia_i) + \gamma_{23}(age\ at\ death_i) + \gamma_{24}(sex_i) + \gamma_{25}(care\ training_i) + \gamma_{26}(residents'adl\ belief_i) + \gamma_{27}(nurses'adl\ belief_i) + \gamma_{28}(slow\ adl\ possible_i) + \gamma_{29}(adl\ daily\ variability_i) \quad \textbf{(Eq, A, 9)}$$

$$k_i = \gamma_{30} + \gamma_{31}(mild\ to\ moderate\ dementia_i) + \gamma_{32}(severe\ dementia_i) + \gamma_{33}(age\ at\ death_i) + \gamma_{34}(sex_i) + \gamma_{35}(care\ training_i) + \gamma_{36}(residents'adl\ belief_i) + \gamma_{37}(nurses'adl\ belief_i) + \gamma_{38}(slow\ adl\ possible_i) + \gamma_{39}(adl\ daily\ variability_i) + u_{3i} \quad (\mathbf{Eq, A, 10})$$

The γs in equations Eq. (A.7) - Eq. (A.10) represent sample-level associations and the *u*s the residual unexplained individual differences that are assumed to be multivariate normally distributed, correlated with each other, and uncorrelated with the residual error, e_{ti}. Stepwise model estimation was performed with variable implementation in the displayed order. Interaction effects of the covariates with dementia were tested for all the covariates, but only one interaction (γ_{182}) was reliably different from zero, so the other interaction terms were removed from the final model. In addition, estimates for the ratios between terminal and pre-terminal slopes were calculated for each of the three groups. The covariates were coded using the weighted effects according to their distributions (for frequency distribution of the covariates see Table A2), so the effects represent deviations of the grand mean instead of the group mean or a reference group, which is for example the case when using dummy coding. As a consequence, the models' parameters can be interpreted in terms of controlling for the covariates' effects and not under the specific condition of the actual reference groups (i. e. always the group that is coded with 0). Results of the full model with covariates are displayed in Table A3.

Table A1. Mean levels (± SD) of functional health (reversed ADL* index) over time to death

Months	No dementia (N=18993, 41.5%)		Mild to moderate dementia (N=14687, 32.1%)		Severe dementia (N=12123, 26.5%)		Total (N=45803)	
	M†*(SD)*	*N*	*M*†*(SD)*	*N*	*M*†*(SD)*	*N*	*M*†*(SD)*	*N*
-24	13.35 (4.54)	812	13.77 (4.20)	732	9.88 (4.56)	808	12.29 (4.78)	2352
-23	13.39 (4.58)	1,321	13.80 (4.24)	961	9.82 (4.68)	1,168	12.30 (4.86)	3450
-22	13.54 (4.55)	1,389	13.57 (4.33)	1063	9.64 (4.49)	1,200	12.27 (4.83)	3652
-21	13.21 (4.64)	1,367	13.61 (4.17)	1177	9.54 (4.49)	1,160	12.19 (4.79)	3704
-20	13.30 (4.68)	1,411	13.65 (4.17)	1149	9.48 (4.58)	1,292	12.12 (4.87)	3852
-19	13.19 (4.56)	1,506	13.44 (4.19)	1250	9.47 (4.51)	1,327	12.06 (4.78)	4083
-18	13.11 (4.65)	1,532	13.51 (4.20)	1241	9.55 (4.43)	1,402	12.03 (4.79)	4175
-17	13.05 (4.65)	1,715	13.45 (4.28)	1362	9.13 (4.40)	1,454	11.92 (4.85)	4531
-16	13.13 (4.65)	1,673	13.32 (4.29)	1379	9.12 (4.36)	1,409	11.83 (4.84)	4461
-15	13.08 (4.70)	1,771	13.12 (4.29)	1418	9.10 (4.34)	1,473	11.83 (4.84)	4662
-14	12.91 (4.69)	1,893	13.14 (4.27)	1619	8.84 (4.35)	1,591	11.71 (4.86)	5103
-13	12.80 (4.59)	1,777	13.11 (4.30)	1514	8.69 (4.14)	1,580	11.56 (4.79)	4871
-12	12.93 (4.69)	2,071	13.05 (4.30)	1620	8.57 (4.10)	1,644	11.62 (4.85)	5335
-11	12.81 (4.67)	2,059	12.83 (4.26)	1709	8.33 (4.03)	1,687	11.43 (4.82)	5455
-10	12.70 (4.65)	2,187	12.67 (4.33)	1860	8.40 (4.02)	1,699	11.42 (4.78(	5746

-9	12.55 (4.72)	2,233	12.54 (4.32)	1902	8.13 (3.99)	1,730	11.24 (4.82)	5865
-8	12.50 (4.71)	2,324	12.48 (4.31)	1905	7.94 (3.85)	1,809	11.13 (4.81)	6038
-7	12.32 (4.69)	2,397	12.53 (4.32)	2108	7.91 (3.74)	1,894	11.09 (4.77)	6399
-6	12.21 (4.73)	2,568	12.30 (4.31)	2058	7.79 (3.70)	1,930	10.93 (4.77)	6556
-5	12.10 (4.73)	2,797	11.98 (4.40)	2387	7.51 (3.58)	2,023	10.77 (4.78)	7207
-4	11.84 (4.68)	2,875	11.79 (4.34)	2441	7.26 (3.39)	2,120	10.52 (4.70)	7436
-3	11.67 (4.74)	3,188	11.48 (4.40)	2581	6.98 (3.14)	2,108	10.35 (4.72)	7877
-2	11.29 (4.68)	3,727	11.17 (4.35)	2988	6.63 (2.82)	2,422	10.01 (4.62)	9137
-1	10.46 (4.62)	4,448	10.63 (4.32)	3235	6.10 (2.30)	2,709	9.38 (4.49)	10392
0	8.70 (4.40)	3,177	9.45 (4.33)	1641	5.47 (1.89)	1,813	8.00 (4.17)	6631

* ADL = Activities of daily living. † M = Mean. ‡ SD = Standard deviation.

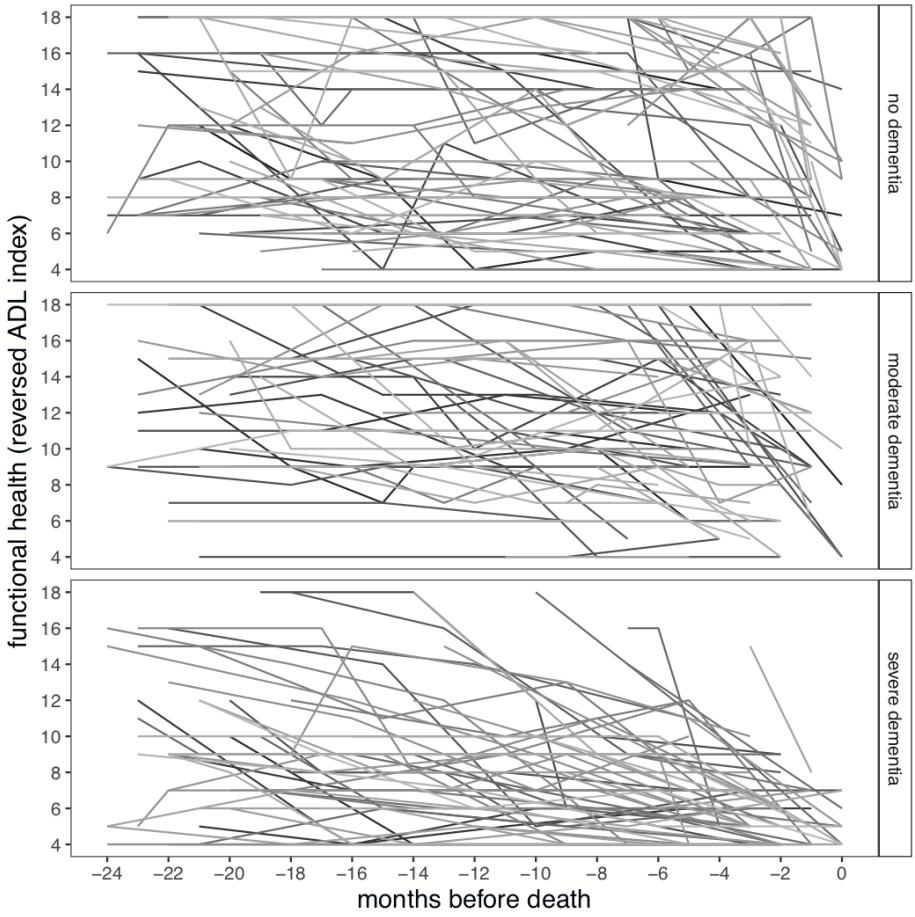

Figure A1. Terminal trajectories of function health (reversed RAI-MDS ADL index) of a randomly selected subsample of 300 nursing home residents. The individual trajectories are displayed as a function of dementia status (no dementia, mild-to-moderate dementia, severe dementia).

Table A2. ADL-related items in RAI-MDS used as covariates

Characteristic	No dementia (N=18,993, 41.5%)	Mild to moderate dementia (N=14,687, 32.1%)	Severe dementia (N=12,123, 26.5%)	Total (N=45,803)
ADL* training and skill practice (%)				
yes	8.7	6.4	14.9	9.6
no	91.3	93.6	85.1	90.4
Residents' ADL* belief (%)				
yes	14.2	9.6	2.8	9.7
no	85.8	90.4	97.2	90.3
Staffs' ADL* belief (%)				
yes	16.0	11.7	5.5	11.9
no	84.0	88.3	94.5	88.1
ADL* daily variability (%)				
yes	38.3	48.9	43.0	42.9
no	61.7	51.1	57.0	57.1
Slow ADL* possible (%)				
yes	41.3	44.3	31.2	39.6
no	58.7	55.7	68.8	60.4

* ADL = Activities of daily living

Table A3. Multi-phase model for functional health (reversed ADL*) over time to death, including dementia status and covariates.†

Parameter	Estimate	SE‡	p-value
Fixed effects			
Intercept, γ_{00}	11.8225	0.0334	<.001
Pre-terminal slope, γ_{10}	-0.1180	0.0019	<.001
Terminal slope, γ_{20}	-1.4597	0.0303	<.001
Transition point, γ_{30}	-2.2037	0.0001	<.001
Mild to moderate dementia*intercept, γ_{01}	-0.2340	0.0591	<.001
Mild to moderate dementia*pre-terminal slope, γ_{11}	-0.0224	0.0029	<.001
Mild to moderate dementia*terminal slope, γ_{21}	0.3533	0.0284	<.001
Mild to moderate dementia*transition point, γ_{31}	-0.3599	0.0777	<.001
Severe dementia*intercept, γ_{02}	-4.6466	0.0616	<.001
Severe dementia*pre-terminal slope, γ_{12}	-0.0649	0.0029	<.001
Severe dementia*terminal slope, γ_{22}	0.3575	0.0225	<.001
Severe dementia*transition point, γ_{32}	-0.2479	0.0699	.001
Age at death*intercept, γ_{03}	-0.0123	0.0028	<.001
Age at death*pre-terminal slope, γ_{13}	-0.0003	0.0002	.0978
Age at death*terminal slope, γ_{23}	0.0069	0.0013	<.001
Age at death*transition point, γ_{33}	-0.0099	0.00002	<.001
Sex(female)*intercept, γ_{04}	-0.1749	0.0123	<.001
Sex(female)*pre-terminal slope, γ_{14}	0.0030	0.0007	<.001
Sex(female)*terminal slope, γ_{24}	0.0288	0.0058	<.001
Sex(female)*transition point, γ_{34}	-0.0394	0.00002	<.001
ADL* training*intercept, γ_{05}	-2.2322	0.0597	<.001
ADL* training*pre-terminal slope, γ_{15}	0.0044	0.0032	.168
ADL* training*terminal slope, γ_{25}	0.1412	0.0269	<.001
ADL* training*transition point, γ_{35}	0.0925	0.00002	<.001
Residents' ADL* belief*intercept, γ_{06}	1.1004	0.0664	<.001
Residents' ADL* belief*pre-terminal slope, γ_{16}	0.0059	0.0040	0.144
Residents' ADL* belief*terminal slope, γ_{26}	-0.1427	0.0307	<.001
Residents' ADL belief*transition point, γ_{36}	-0.0769	0.00003	<.001
Staffs' ADL* belief*intercept, γ_{07}	0.2651	0.0591	<.001
Staffs' ADL* belief*pre-terminal slope, γ_{17}	-0.0144	0.0035	<.001

Staffs' ADL* belief*terminal slope, y_{27}	-0.0674	0.0264	<.001
Staffs' ADL* belief*transition point, y_{37}	0.0172	0.00001	<.001
Slow ADL* *intercept, y_{08}	0.0401	0.0245	.101
Slow ADL*pre-terminal slope, y_{18}	-0.0022	0.0016	. 169
Slow ADL* * terminal slope, y_{28}	0.0130	0.0107	.0226
Slow ADL* * transition point, y_{38}	-0.0277	0.00002	<.001
Slow ADL* * pre-terminal slope*severe dementia, y_{182}	-0.0497	0.0026	<.001
Daily ADL* variability*intercept, y_{09}	-0.0895	0.0220	<.001
Daily ADL* variability*pre-terminal slope, y_{19}	-0.0216	0.0013	<.001
Daily ADL* variability*terminal slope, y_{29}	-0.0370	0.0098	<.001
Daily ADL* variability*transition point, y_{39}	-0.1287	0.00003	<.001
Ratio terminal/pre-terminal slope no dementia (y_{20}/y_{10})	12.3721	0.3627	<.001
Ratio terminal/pre-terminal slope mild to moderate dementia ($(y_{20}+y_{21})/(y_{10}+y_{11})$)	7.8814	0.2604	<.001
Ratio terminal/pre-terminal slope severe dementia ($(y_{20}+y_{22})/(y_{10}+y_{12})$)	6.0260	0.1595	<.001
Random effects			
SD§ intercept	3.9203	0.0182	<.001
SD§ transition point	2.4931	0.0680	<.001
Correlation intercept, transition point	-0.5978	0.0070	<.001
Residual variance	4.8845	0.0251	<.001
AIC||	718922		
Pseudo R-Squared	.7926		

* ADL = Activities of daily living. † Intercept centred at the transition point. Residents with no dementia served as the reference group.
‡ SE = Standard error. § SD = Standard deviation.
|| AIC = Akaike information criterion