Inquiry Into Terminal Decline: Five Objectives for Future Study

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Notions of terminal decline propose that late-life change is primarily driven by processes closely tied to pathology and mortality rather than chronological age. We use the rationales of longitudinal research as outlined by Baltes and Nesselroade (Baltes, P., & Nesselroade, J. [1979]. History and rationale of longitudinal research. In J. R. Nesselroade & P. Baltes (Eds.), Longitudinal research in the study of behavior and development [pp. 1–39]. San Diego, CA: Academic Press) as a framework for organizing research on terminal decline. In doing so, we note that there are relatively robust descriptions of terminal decline across a variety of different domains, as well as the extent of interindividual differences in the levels of function, rates of change, and timing of terminal decline (research rationales 1 and 2). However, there is much more to learn about the interrelations among change in different domains, the underlying mechanisms of change, and the factors that contribute to interindividual differences in change (research rationales 3–5). Needed are new study designs and analytical models that better address the structural, temporal, and causal interrelations that contribute to and protect against terminal decline.

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for longitudinal research (Baltes & Nesselroade, 1979). Placing the empirical inquiries within this framework, we highlight what is known about terminal decline and highlight areas in need of further study (for conceptual advances, see Baltes & Smith, 2003; Gerstorf & Ram, under review). We focus primarily on terminal decline in well-being, a central indicator of quality of life that has both cognitive–evaluative components (e.g., satisfaction with life overall or with particular domains, such as health and family) and affective–emotional components (e.g., positive affect, negative affect, and depressive symptoms).

**Rationales for Longitudinal Research**

Baltes and Nesselroade (1979) outlined five rationales for longitudinal research that can be used to organize research questions and knowledge about developmental change. The first rationale is direct identification of intra-individual change (p. 23). From a purist perspective, the objective is to describe how a characteristic of an individual changes over time. Given compromises made when designing our studies and analyses, we often end up asking a more assumptive question, for example, how does the typical individual’s well-being change during late life? The second rationale is direct identification of interindividual differences in intra-individual change (p. 24). Here, the objective is to describe the degree of across-person heterogeneity in development. For example, does terminal decline manifest differently across individuals? The third objective is analysis of interrelationships in behavioral change (p. 25). Here, the goal is to represent the constancy and change of the individual in more than one attribute so as to examine the wholistic nature of the individual. For example, how does the typical individual’s well-being, cognition, and health change during late life? The fourth objective is analysis of causes (determinants) of intra-individual change (p. 26). The objective is a time-ordered study of explanatory determinants to establish linkages between outcomes and specific antecedents. For example, is an individual’s late-life change in well-being the consequence of an overburdening of self-regulatory processes? The fifth objective is analysis of causes (determinants) of interindividual differences in intra-individual change. This objective extends the second objective by establishing how across-person differences in the intensity, timing, or patterning of causal factors lead to differences in development. For example, are differences in rate of late-life change in well-being the consequence of specific genetic characteristics or environmental exposures?

**Developmental Inquiry into Terminal Decline**

We organize theoretical and empirical work on terminal decline within the five rationales for longitudinal research. Along the way, we highlight areas of inquiry that are relatively well established and areas that need further elaboration.

**Describing Terminal Decline**

**Initial Descriptions.** —To describe the typical person’s terminal decline, we and others have applied a variety of growth models to data obtained from participants in large-scale longitudinal studies who have since died. Articulating terminal decline as mortality-related development that ends in death, year-to-year changes in function are examined in relation to time to death rather than time since birth. In the cognitive domain, substantial evidence suggests that numerous cognitive abilities show pronounced deteriorations in proximity to death (Bäckman & MacDonald, 2006). For example, Wilson, Beckett, Bienias, Evans, and Bennett (2003) reported that cognitive decline in episodic memory, working memory, perceptual speed, and visuospatial ability sharply accelerates late in life, amounting to an average loss of more than a full SD in the 3.5 years before death (e.g., global cognition: change of 0.619 units evaluated in terms of the study sample’s baseline SD = 0.502 units, i.e., effect size units). For the typical person, markers of both age-sensitive fluid abilities (e.g., perceptual speed) and relatively age-insensitive crystallized abilities (e.g., word knowledge) exhibit late-life decline, with some evidence that fluid abilities show the steepest decline (for discussion, see Ghisletta, McArdle, & Lindenberger, 2006).

**Performance-Based Function.** —Recently, evidence is accumulating that objective measures of function in the sensory, physical, and health domains also exhibit terminal decline. For example, Wilson, Segawa, Buchman, and colleagues (2012) found that motor ability (as measured via manual strength, dexterity, balance, and gait) declined an average of 1.4 SD in the last 2.5 years (change of 0.117 units per year evaluated relative to the study sample’s baseline SD = 0.21...
units). However, terminal decline trajectories are not uniform across all domains. Functioning in some domains and as measured by specific tests is more prone to terminal decline than functioning in other domains and measures. Our own work from the Berlin Aging Study (BASE; Gerstorf, Ram, Lindenberger, & Smith, 2013) suggests that typical rates of terminal decline ranged from more than 1.5 SD decline (evaluated relative to the study sample’s baseline SD) during the last 10 years for close vision to less than 0.5 SD decline during the last 10 years for the body mass index. As elaborated later, we note that examinations of terminal decline have tested linear and quadratic forms of change rather than more complex higher order polynomial or exponential functions.

Subjective Function.—Self-report measures of more subjective aspects of function, such as well-being and social participation, also exhibit terminal decline. Of note, evidence of steep mortality-related declines stands in stark contrast to a myriad of reports that multiple facets of well-being remain, on average, relatively stable across adulthood and old age (Diener, Lucas, & Scollon, 2006). Recently, however, several studies have reported that the prevailing “stability despite aging-related loss” picture of the typical person’s well-being does not hold during the final phase of life (Berg, Hassing, Thorvadsson, & Johansson, 2011; Diehr, Williamson, Burke, & Psaty, 2002; Gerstorf, Ram, Röcke, et al., 2008; Palgi et al., 2010; Schilling et al., 2013; Vogel, Schilling, Wahl, Beekman, & Penninx, 2012). Results from our own work in the BASE indicate, for example, that although the typical participant’s decline in well-being was relatively minor when tracked over age (−0.33 SD per decade; Figure 1A), rapid deteriorations were evident when tracked over time to death (Figure 1B), particularly for people who died after age 85 (−1.12 SD per decade). Our work suggests that terminal decline is ubiquitous across subjective domains, with significant declines noted for cognitive–evaluative and affective aspects of well-being, perceived control, subjective health, social activities, and loneliness (Gerstorf et al., 2013). Although generally not as steep as for the more performance-based domains, some subjective domains appear to exhibit greater decline than others. In the BASE data, typical decline in the last 10 years of life was more than 1.5 SD for social activities and less than 0.5 SD for emotional balance (as measured via the Positive Affect and Negative Affect Schedule [PANAS]; Watson et al., 1988). In sum, there is converging evidence that the typical person’s late-life change can be described as terminal decline.

Two Phase Change.—The terminal decline concept also implies that people transition from a preterminal phase of relative stability or minor decline into a terminal phase of rapid decline that ends with death. However, the theoretical descriptions lack specificity about when the transition occurs. For example, Birren and Cunningham (1985) noted that “cognitive and social slipping” may occur some “months to years” prior to death (p. 21) but did not provide any more specificity about timing. In recent years, several studies have used multiphase growth models to describe the typical person’s transition into the terminal phase (Hall, Lipton, Sliwinski, & Stewart, 2000; Johnson, Storandt, Morris, & Galvin, 2009). For example, in studies of terminal cognitive decline, Sliwinski and colleagues (2006), Wilson and colleagues (2003), and Wilson, Beck, Bienias, and Bennett (2007) provided evidence for two phases of decline and located the transition from preterminal to terminal phases of decline between 2 and 6 or even 8 years before death (see also Sliwinski et al., 2003; Thorvaldsson et al., 2008). Applying similar methods to reports of well-being obtained in large national panel studies (e.g., the U.S. Health and Retirement Study and German Socioeconomic Panel, SOEP) also provided evidence for two phases of decline, with a transition between 3 and 5 years before death (Gerstorf, Ram, Mayraz, et al., 2010). For example, as illustrated in Figure 2A, the typical German participant entered the terminal phase around 4 years before death after which the rate of decline steepened by a factor of 3 and declined almost a full SD (effect size units) for the last 4 years of life. Taken together, there is growing evidence that the phenomenon of terminal decline manifests as multiphase change in cognitive, well-being, and other domains of functioning.

Unresolved Issues.—Terminal decline is, by definition, a within-person process. However, the descriptions in the literature (including our own) rely on sample-level averaging to describe the typical individual’s change. Inference to any specific individual rests on strong, untested assumptions that all individuals follow the same pattern of change. The currently available data are typically too sparse to track incremental change reliably at the individual
level. The yearly or longer intervals between assessments constrain our ability to relax linearity, single transition point, and homogeneity of (error) variance assumptions. Thus, it remains an open question whether each individual’s late-life changes do follow the two phase pattern. For example, current models of terminal decline describe the end of life as an incremental change process of relatively smooth, directional changes initiated after a distinct, qualitative transition out of the preterminal phase. Alternatively, late-life change may manifest as a stability maintenance process that governs...
how individuals maintain physical, emotional, and cognitive function after perturbation. The models of terminal decline currently do not consider nondirectional fluctuations in function, at any time scale (e.g., larger variation from one day to the next).

To verify that a wider range of possible patterns of...
change is not being missed (Ram & Gerstorf, 2009), intensive studies that follow individuals at monthly or even weekly intervals are needed.

Describing Individual Differences in Terminal Decline

We have thus far only reviewed descriptions of the typical person’s terminal decline. Here, we review research on individual differences in terminal decline. As seen in Figure 1, there are substantial individual differences in both levels and in rates of late-life change in well-being. Some people experience dramatic declines, whereas others’ well-being remains stable. As with other phases of life, differential development is ubiquitous (Rutter, 1997). For example, our own work in the BASE suggests that while, on average, emotional balance was stable between ages 70 and 100, the 95% confidence interval (CI) in the rate of change ranged from −0.59 SD decline per decade to 0.45 SD increase per decade (Gerstorf et al., 2013). Notably, the bulk of findings highlight differences in linear rates of change. However, there is evidence that terminal decline is also somewhat homogenous. For example, among deceased participants of the SOEP, 69% exhibited decline in the last 5 years of life (Gerstorf, Ram, et al., under review). Of note, having too few repeated measures for each individual has often precluded examination of interindividual differences in nonlinear change.

Also difficult to extract have been interindividual differences in the transition into terminal decline. Almost all multiphase models of terminal decline have relied on the very strict, if not unrealistic assumption that all individuals enter the terminal phase at exactly the same point in time (Figure 2A). This assumption has been necessary for model parameter estimation with the sparse longitudinal data of seven or fewer repeated measures per person that are typically available in longitudinal panel studies. The SOEP data provided a unique opportunity to relax the assumption and estimate two-phase growth models with individual transition points for participants with long sets of repeated measures, 12 or more annual well-being reports (n = 400; Gerstorf, Ram, Estabrook, et al., 2008). With this setup, we confirmed the typical transition into terminal decline as somewhere between 3 and 5 years before death (Figure 2B) and also confirmed that there are substantial individual differences in the timing of the onset of terminal decline in well-being. Some people entered the terminal phase earlier (e.g., 7 years before death), whereas others entered later (e.g., 2 years before death), and still others did not ever enter terminal decline. Additional research is needed to disentangle whether the latter individuals died from some “random” accident or because the repeated measures were not frequent enough to capture late-onset terminal declines (<1% of deceased participants provided data within their last 12 months).

Taken together, converging results from several studies suggest that typical late-life change in multiple domains of function (e.g., health, cognition, social, well-being) can be described as terminal decline. Results highlight both the pervasive nature of mortality-related declines and its domain and function specificity. There are also substantial interindividual differences in rates of terminal decline and initial evidence of interindividual differences in onset of terminal decline in well-being. As longitudinal panel studies that assess function in multiple domains extends into many occasion archives, these studies will be useful for identifying interindividual differences in both onset and progression of terminal decline in other domains.

Interrelationships in Terminal Decline

The third objective focuses on the individual as a multivariate entity. In research on terminal decline, the goal is to represent end-of-life change in a multivariate set of characteristics. Thus far, our descriptions of terminal decline have been approached from a variable-oriented perspective, modeling how a single objective ability or subjective feeling changes over time to death (Gerstorf et al., 2013; Sliwinski et al., 2006). Researchers have only recently started to chronicle how multiple attributes change simultaneously. For example, Wilson, Segawa, Hizel, and colleagues (2012) examined interrelations between trajectories of terminal decline in cognitive and motor function. Using correlated growth methods (McArdle, 1988), they found that individuals with earlier onset of terminal decline in one aspect of function (e.g., manual strength) also had earlier onset of terminal decline in the other domain (e.g., cognitive; r = .90–.99). However, associations among rates of decline were not found.

Such findings start to put the pieces of the individual together so as to understand terminal decline as a wholistic phenomena. Unfortunately, ordered sequences of onset across multiple domains are not yet established (Gerstorf & Ram, under review). The typical analysis of late-life data is faced
with several challenges, including sizeable sample attrition, few repeated assessments, long between-wave intervals, and imperfect measurement reliability, which conjointly undermine our statistical power to examine interrelations among trajectories of change. For example, Hertzog, Lindenberger, Ghisletta, and Oertzen (2006) demonstrated that in realistic scenarios where six occasion repeated measures are available for 500 participants, the statistical power to detect the slope intercorrelations is only low to moderate, unless measurement reliabilities are more than .90 (which is often not the case).

An additional limitation is that the correlated growth model concentrates on quantifying between-person associations by examining whether people who are declining more than others in, for example, physical health are also declining more than others in well-being. But, terminal decline is by definition a within-person change phenomenon and our real interest is how end-of-life change in multiple domains is organized within person. Inferring within-person associations (individual level) from between-person associations (sample level) brings with it the risk of ecological fallacy. Alternative approaches would include engagement with data and study designs that provide for more direct examination of within-person associations. For example, we would hypothesize that health and well-being are not closely tethered as long as a person’s health is in reasonable shape (Figure 3). Once the terminal phase arrives and functioning falls below a critical threshold, this weak coupling shifts into a strong coupling and declining health drags down well-being. To examine such hypotheses at the individual level, we need intensive within-person change data with many closely spaced measurements that allow us to track how multiple aspects of cognitive, psychosocial, and health function unfold together in an end-of-life “cascade.”

A complementary route is to move toward considering multiple indicator information at the individual or subgroup level and track how “profiles” of objective and subjective function change with approaching death. To illustrate, Lövdén, Bergman, Lindenberger, and Nilsson (2005) identified different multivariate configurations of cognitive change in the Betula study. One of the groups was characterized by relative stability across time, whereas another group was characterized by a major drop in spatial ability with minor changes in other abilities; a third group of participants experienced a developmental cascade of poor performance in declarative memory, followed by increasing deifferentiation of cognitive performance toward generalized low performance, dementia diagnosis, and death. In future studies, it would be highly informative to identify groups of people who are able to maintain functionality across multiple domains into the last years of life. The insights gained from studying those persons will help us to better tailor diagnostic and intervention efforts to individual profiles of need.

**Determinants of Terminal Decline**

The fourth rationale for longitudinal research centers on identifying the causes of intra-individual change (Baltes & Nesselroade, 1979). In research on terminal decline, time to death serves as a proxy for unnamed mortality-related causal processes. The goal is to identify the processes that explain the rate of change and the timing of transition into terminal decline. It is widely accepted that factors like late-life neuropathology (e.g., Alzheimer’s disease), the deteriorating integrity of neurocognitive control, and a breakdown of overall system coordination each play some role in late-life decline. The analytical objective is to test whether factors such as deteriorating health or worsening cognition relate to both timing and rate of terminal well-being decline. To do so, researchers can apply dynamic models that include markers of

![Figure 3. Illustration of a hypothesis about terminal decline as an integrated phenomenon that governs the coupling between health and well-being for a given individual. The two domains may not be closely tied to one another as long as a person’s health is in reasonably good shape. Once terminal decline set in and functioning has fallen below a critical threshold, this weak coupling may shift into a strong coupling and declining health is dragging one’s well-being down.](image-url)
these factors (though difficult to obtain reliably in situ) as time-varying predictors of repeated measures of individuals’ function. Coupled differential and difference equation models provide tools for assessing how levels and rates of change in one variable predict subsequent changes and/or accelerations in change of another variable (McArdle & Hamagami, 2001). However, similar to correlated growth models, caveats for application to most existing data include low statistical power, sparse data near to death, and reliance on between-person associations for within-person inferences.

Causality is most easily established using experimental designs, but those are not viable or ethical in studying terminal decline. However, it is possible to locate natural experiments. Prospective studies that, although designed for other purposes, collect data on individuals’ experience of specific events can be useful in testing for pre-to postevent changes. For example, Lucas (2007) reported that the onset of disability relates to lasting well-being declines. In our own work, we described the typical well-being changes with the experience of more than 20 critical life events (Gerstorf, Ram, et al., under review). Results revealed that events such as widowhood and disability were accompanied by substantial declines in well-being (loss of 25 and 19 population percentiles, respectively, in the year preceding the event). The widowhood effect, for example, was highly comparable to the rapid losses preceding one’s own death. Though not conclusive, these natural experiments provide evidence that critical life events such as serious physical limitations or bereavement may be among the causal factors that prompt terminal decline in well-being.

Given a focus on establishing causes of intra-individual change, true time series designs, wherein many repeated measures of the same person are obtained, may also be useful (Ram & Gerstorf, 2009). Advances in ambulatory assessment technologies are prompting collection of such data (Hoppmann & Riediger, 2008). Once collected, dynamic models (Molenaar, 1985) can be used to establish within-person causality (Chow, Nesselroade, Shifren, & McArdle, 2004). However, these models are best suited for examining stability maintenance processes (e.g., returns to equilibrium after perturbation) and will need to be adapted to additionally accommodate the incremental changes (e.g., long-term declines) that terminal decline seeks to describe (Ram, Brosc, & Molenaar, in press). Intensive, in situ study of terminally ill or very old persons may help identify these and other proximal causes of terminal decline. Though difficult to implement, such data may be obtained by physicians, nurses, or professional caregivers through regular assessments that are integrated into daily or weekly care routines.

**Determinants of Individual Differences in Terminal Decline**

The fifth rationale of longitudinal research centers on identifying the causes of interindividual differences in intra-individual change (Baltes & Nesselroade, 1979). In research on terminal decline, the objective is to establish why some people transition into and/or experience steep late-life declines, whereas others maintain well-being all the way until death.

A variety of individual factors may influence how mortality-related processes evolve. Such factors range from the genetics, health, and comorbidities to individual resources, attitudes, or behaviors (for a discussion of physiological mechanisms, see Charles, 2010). For example, individuals with particular genetic constellations may be more prone to specific diseases (e.g., Alzheimer’s disease), the accumulation of disease, and/or the extent to which those diseases become mortality-related processes. It has also long been established that aspects of individual’s beliefs and strivings for control are related to well-being (Lachman, 2006). Specifically, control perceptions are known to buffer the impact of stressors on physiological reactivity, to help downregulate negative emotions, and to mobilize social support when needed (for discussion, see Heckhausen, Wrosch, & Schulz, 2010), which in turn foster well-being. In our own work, we found that perceptions of control are linked with higher levels of late-life well-being, with shallower rates of declines, and with a later onset of those declines (Gerstorf, Heckhausen, et al., under review). However, our control measure was obtained several years before people died, so the measure indicates the resources people bring into late life, not necessarily how preserved this resource is late in life. It is also conceivable that goal disengagement becomes increasingly relevant at the end of life because disengagement allows people to let go of the goals that are not attainable anymore.

In addition, individuals’ micro and macro contexts may also operate as resources and constraints for shaping interindividual differences in terminal decline (Lawton, 1982). For example, support of a spouse may act as a resource such that individuals with spouses exhibit less pronounced terminal
decline than those who are widowed. We have argued that physical, social, service, and economic aspects of context may serve as “risk regulators” that up- or downregulate the individual-level mechanisms and behaviors that put individuals at risk for or protect against terminal declines (for discussing selection and socialization effects, see Gerstorf & Ram, 2012). To illustrate, the extent to which declining health drags down well-being depends on the availability of regional resources that may fulfill individual needs. For example, people living in regions in which ambulatory care services are available may remain in their known environment, maintain their daily life routines, and stay connected with family and friends, and thereby maintain well-being into late life. To test these notions, we combined individual data from the SOEP with regional data on German counties and compared two-level and three-level growth models that did or did not take into account that individuals are nested within counties (Gerstorf, Ram, Goebel, et al., 2010). Results revealed that 8% of what were thought to be between-person differences in both late-life level of well-being and rate of terminal decline were actually between-county (context) differences.

One major question is whether 8% are a lot or little. We consider this effect size striking for three reasons. First, following meta-analyses (deNeve & Cooper, 1998), typical correlates of individual differences in well-being levels such as education and personality account for an average of 4% of those differences, whereas the effect size for county differences was comparable to that of individual differences in health (approximately 10%). Second, correlates of individual differences in rate of well-being change are rarely identified, whereas here a broad proxy for context accounts for 8% of those differences. This suggests that we may find specific causal factors contributing to interindividual differences in terminal decline that in the long run could become the focus of interventions. Finally, regional effects on late-life well-being documented in a European nation with small regional differences and obligatory health insurance provide a conservative estimate of the effects operating in more diverse nations, such as the United States. A speculation we hope to empirically address in the future.

Conclusions

The application of contemporary methods to long-term longitudinal data has provided for key insights into both typical intra-individual changes in late-life and interindividual differences in terminal decline. Nevertheless, the growth models used and the data to which they are applied have severe constraints. To name just two: first, time-to-death information is not available until after a person has died. Models that track change over time-to-death work in a postdictive manner in which the proxied mortality-related processes are examined as retroactive cause for the declines that, by definition, ended in death. To test predictive theories with translational value, we need to examine whether and how “terminal-like declines” that may or may not end in death turn into true terminal decline. Second, many models in the field capitalize on the assumption that the passage of years of calendar time (age, time to death, time to/from events, such as disability, etc.) is a reasonable proxy of processes assumed to cause the observed developmental changes. To move several steps ahead, it will be instructive to model directly how these processes evolve. For example, treating disability processes as the cause of intra-individual change, we can examine more directly how accumulating pathology and evolving disability map onto terminal decline.

Research on terminal decline promises to alert society and policy makers to the serious declines often accompanying the end of life and to allocate the resources necessary to alleviate the personal and social costs of those declines. For example, knowing that a person has entered terminal decline may not affect the net sum of health care expenditures but the way those expenditures are made. Through a well-balanced and strictly evidence-based strategy that is tailored to individual needs and contextual requirements, it may be possible to devote those resources toward maintaining quality of life rather than toward extending life for as long as possible. As outlined earlier, the causal mechanisms contributing to terminal decline are so far only poorly understood. To address the research objectives three through five outlined by Baltes and Nesselroade (1979), study designs are needed that provide for intensive within-person assessments examining the structural, temporal, and causal interrelations of intra-individual change (Nesselroade, 1991; Ram & Gerstorf, 2009). Moving in this direction may also help identify possible areas of strength that remain relatively intact late into life. Such information would help tailor intervention programs to help people capitalize on available resources. We are only at the very beginning of understanding the specifics of how these factors operate. To further refine the terminal
decline concept, advanced methods and models from related fields of study can readily be implemented, but the appropriate data are necessary.

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