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Life before death: Trends in health at the end of life, 1997-2009

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Abstract

Larger shares of the population are reaching older ages than ever before in the nation's history, inviting the question of whether trends are moving towards healthier, and not just longer, lives. In this paper, I use data from the 1997-2009 National Health Interview Surveys linked to death records to investigate trends in three health outcomes at the end of life among respondents who died between taking the survey and 2011. I consider trends in disability, mental health, and self-reported health, stratified by those dying within a certain amount of time from the baseline interview. I use a regression framework to estimate annual change in health outcomes while controlling for secular changes in the characteristics of death cohorts. I additionally examine the characteristics of individuals who experience either short or long periods of poor health prior to death. Preliminary results suggest little change in end-of-life health across the study period.

Introduction

The share of the population over age 65 in the United States is larger than ever in the nation’s history, and is projected to continue to increase (Ortman et al. 2014). At the same time that more people are reaching age 65, the number of years we can expect to live above this age has also grown, climbing 15% in 3 decades (16.8 years in 1984 vs. 19.4 years in 2014) ("National Center for Health Statistics" 2017). Given that older age can be marked by chronically poor health, whether these added years are healthy is an important concern. Years of good health enable older adults to actively participate in their communities, families, and the labor market—while extending time lived in declining health can place strain on caregivers, families, and social safety nets. It is no surprise that as mortality is delayed to older ages, a body of research examining not just the quantity, but also the quality, of added years has flourished.

Results from these studies are of interest to many: government statisticians projecting social security costs, health care workers who treat and advise older patients, family members who plan at some point to take care of an older relative, and, of course, older adults themselves, concerned about their future quality of life. Even those of us many years from older age may still like to know: are the trends moving towards healthier, and not just longer, lives? And, importantly, how can one achieve a long and healthy life?

In this paper, I consider trends in three health outcomes at the end of life health: the presence of disability, a respondent’s quality of mental health, and a respondent’s overall self-reported health. I use a novel approach to consider trends in health by respondents’ time to death, measured both in years and as a proportion of total life remaining.

Background

Below, I consider existing research on trends in later life health. Although some patterns emerge, overall trends are difficult to discern, given variation in studies' examined time frames, sampled populations, definitions, and analytic approaches. Finally, I highlight limitations of existing research.

Has morbidity compressed?

Morbidity is compressed when the age at morbidity onset is postponed by more than life expectancy increases (Fries 1980). But how is "more" measured? "More" can indicate that onset is postponed by more years than life expectancy increases (absolute compression), but it can also mean that the proportion of life lived in good health has increased (relative compression). Furthermore, what is the appropriate age range to consider? Although it is common to estimate compression over the whole life span, many papers also consider compression above certain ages, such as 65 or 85 (Cai and Lubitz 2007; Crimmins et al. 2016). Findings can be sensitive to all of these choices.

Whether to examine absolute or relative compression, and across what ages, can be a philosophical question. Is an increase in the number of years lived in poor health always unacceptable? Or is it "worth it" if the number of years in good health increases by even more? For example, is it preferable to die at age 100, having lived 10 years with morbidity, or to die at age 80, after 8 years with morbidity? In both scenarios, 10% of total life is spent disabled. Does our choice change if we consider that 29% of life above age 65 is spent disabled in the former example, and 53% in the latter? Because these questions are difficult to answer, studies should consider both absolute and relative compression, across a variety of age ranges.

Findings also vary depending on the health outcome considered. In the U.S., studies that consider trends in disability, most often using IADL or ADL limitations, typically document compression, while those examining the prevalence of chronic conditions find expansion (see, e.g., Chatterji et al. 2015; Christensen et al. 2009; Crimmins and Beltran-Sanchez 2011). Given that the threshold for absolute compression is higher than for relative compression, more studies document the latter than the former.

Beltran-Sanchez et al. (2016) find that the prevalence and count of several chronic conditions among 50-60 year-olds in the U.S. increased between 1992 and 2004—as did the likelihood of developing cancer, diabetes, or arthritis in the years preceding death. However, a working paper by Cutler and colleagues (2013) documents that trends in disease prevalence in the years before death have changed little over time. Dementia may be an exception: decades-long trends in dementia morbidity indicate compression due to delayed onset and a shortened survival period after diagnosis (Dufouil et al. 2018). Although cause of death is not systematically related to a particular disability trajectory in the last year of life, advanced dementia is the largest exception: nearly 70% of individuals dying from advanced dementia have persistently severe disability in the year preceding death (Gill et al. 2010). Declines in the prevalence of cognitive impairment (Langa et al. 2008; Murabito et al. 2008) may foreshadow future compression.

In contrast to the rising prevalence of most chronic conditions, Manton and colleagues (2006) find that the prevalence of chronic disability among adults 65+ between 1982 and 2005 initially declined at 0.6% annually, before accelerating to annual declines of 2.2% in later years. These declines outpaced mortality improvements, suggesting both absolute and relative compression. Other work has documented that the prevalence of ADL limitations among older adults decreased from just over 30% in 1995 to 26% in 2004; the trend in IADL limitations, however, was flat during this period (Freedman et al. 2008). Trends in biological age, estimated using biomarkers of aging, indicate that aging is occurring more slowly in recent years (Levine and Crimmins 2018).

Other findings also support compression, but less definitively. The increase in active life expectancy above age 65, for example, was driven by declines in disabled life expectancy, rather than increases in the age at onset, as predicted by compression theory (Cai and Lubitz 2007). Crimmins et al. (2009) find that both total and disability-free life expectancy at 70 rose 0.6 years between 1984 and 2000: although this indicates relative compression (the proportion of life with a disability is decreased), it is equilibrium in the absolute sense (the number of disabled years remained unchanged). Observed patterns also vary by the age range considered. Between 1970 and 2010, the percentage of total life lived with a disability increased, but decreased above ages 65 and 85 (Crimmins et al. 2016).

Fries et al. (2011) write that compression of morbidity "is not inevitable," but can occur in "specific settings and at specific times." Indeed, results are sensitive to choices such as study design and the definitions used (Chatterji et al. 2015). The definition of compression matters. Patterns also vary by population subgroups, varying across such stratifying characteristics as sex, race, and socioeconomic status. The morbidity compression documented by studies cited above was especially concentrated among white men (Sole-Auro et al. 2015). Women report higher levels of disability and chronic illness than men (Case and Paxson 2005)—a relationship that may be strengthening. Between 1988 and 2010, men experienced larger declines in biological ages (Levine and Crimmins 2018) and also had longer active life expectancy during part of that period (Cai and Lubitz 2007). Male gains in overall life expectancy, fueled by age- and sex-specific changes in smoking, obesity, and medication use, may account for some of this phenomenon (Cai and Lubitz 2007; Levine and Crimmins 2018).

Patterns also differ by race and socio-economic status. At the end of the 20th century, racial and socio-economic differences in healthy life expectancy were larger than the well-documented differences in overall life expectancy (Crimmins and Saito 2001). In an analysis considering trends in disability-free life expectancy among black and white men and women of varying levels of educational attainment, Sole-Auro et al. (2015) find that recent gains in life expectancy between ages 60 and 90 “were concentrated in disabled years for most population groups.” Although disabled life expectancy increased for both black and white groups between the late 1980’s and 1990’s, disability-free life expectancy increased only for white men. As a result, racial differences in disability-free life expectancy widened among men. Socio-economic differences within groups also widened for all expect black women. These patterns are apparent even at very old ages. Among centenarians, men are healthier than women, whites are generally healthier than non-whites, and those with higher levels of educational attainments have better cognitive function (Ailshire et al. 2011). These subgroup-specific findings, which are in contrast to work finding disability compression among the overall population of older adults (Crimmins et al. 2016), suggest a less favorable picture of trends in morbidity.

Limitations of past research

Below, I outline three approaches for expanding on existing research on morbidity trends: conceptualizing morbidity more broadly, paying careful attention to population heterogeneity, and applying a more precise treatment of age.

Although most studies on morbidity compression emphasize the role of functional limitations, this emphasis may not be necessary (Beltran-Sanchez et al. 2014). Given that disability is shaped by environmental context, in addition to individual-level factors, trends in ADL and IADL limitations may reflect environmental changes rather than changes in “innate morbidity” (Crimmins and Beltran-Sanchez 2011). Of course, time trends in disease diagnoses, an alternative to a focus on functional limitations, are also influenced by changes outside of innate morbidity, such as evolving diagnostic thresholds and advances in early detection. It may be useful to expand the standard scope of morbidities: some work has already considered trends in self-rated health and diminished vision and hearing (Christensen et al. 2009). Other aspects of well-being, such as mental health, should also be considered. As outlined above, within-population differences by sex, race, and socio-economic status are important for further developing a nuanced understanding of morbidity trends. Work in this area has already begun (Ailshire et al. 2011; Crimmins and Saito 2001; Sole-Auro et al. 2015), and should continue.

Many studies examine trends in morbidity by comparing recent and more distant age-matched cohorts. However, age is an inherently flawed variable, given increasing life expectancy. Is a 50-year old woman in 1980, who can expect to live 30.6 additional years, is not comparable to a 50-year old in 2015, who can expect to live 33.4 additional years ("National Center for Health Statistics" 2017)? Possibly not, since it would unclear if differences between these women are due either to changes in morbidity (what we aim to study) or changes in mortality. A partial solution is to compare individuals with the same number of years of life remaining using a retrospective approach (Beltran-Sanchez et al. 2016; Cutler et al. 2013; Sanderson et al. 2016; Wolf et al. 2015). In the above example, it would be more appropriate to compare a woman who had 30.6 years of additional life remaining in 1980 (she would be 50), to a woman who also had 30.6 years of life remaining in 2014 (she would be roughly 53). This variable, sometimes termed “years of life left”, offers only a partial solution: although age is now comparable over time, it can only measure absolute compression, not relative.

The distinction between absolute and relative compression is important. If the mean age at death has increased by more than the age at morbidity onset is delayed, it is possible for the years lived with disability to increase in an absolute sense, but the time spent with disability to decrease in a relative sense. Relatedly, a postponed age at onset can still be associated with morbidity expansion if age at death is postponed by less. Converting “years of life left” into “proportion of life left” is one way to consider relative compression, while accounting for changing mean ages at death. Of course, the “proportion of life left” cannot be used to assess absolute compression. These two measures must be used together to gain a fuller picture of trends in morbidity.

Data & Methods

To investigate trends in end-of-life health, I use data from the cross-sectional National Health Interview Survey (NHIS) for years 1997-2009. Respondents in the NHIS are linked to the National Death Index, allowing for mortality follow-up. I restrict the sample to adults who were 50+ at survey time and who died during the mortality follow-up.

This study has three analytic aims. The first is to examine trends in health stratified by those dying within a certain amount of time from the year of interview. The second aim is to examine these trends in a regression framework, controlling for secular changes in the characteristics of death cohorts. Nested models will be used to estimate what percent of annual change in a certain health outcome is due, for example, to changes in the age distribution. The third aim is to examine the characteristics of individuals who experience either short or long periods of poor health prior to death.

I consider three health outcomes. The first is a set of disability measures: whether a respondent needs help with any IADL's, as well a respondent's number of ADL limitations[1]. The second outcome is a measure of self-rated health. Third, I also consider a respondent's score on the Kessler Psychological Distress Scale (K6). The measure is a composite of 6 questions asking how often in the last 30 days a respondent felt nervous, hopeless, fidgety, sad, worthless, or that everything was an effort. Answers are given on a 4-point Likert scale and summed to create the K6 score, ranging from 0 (no psychological distress) to 24 (maximum psychological distress).

Analyses are stratified by time until death. This measure is operationalized in two ways—"years of life remaining" and "proportion of life remaining"—and all analyses are performed twice, once for each measure. While the former measure is an absolute measure, the latter is a relative measure that depends on a respondent's age at death. Using both measures is important to distinguish between absolute and relative compression.

Covariates include a respondent's age, sex, educational attainment, and race/ethnicity. The portion of the analysis that examines the characteristics of respondents who experience short/long periods of poor health prior to death will also include additional individual-level characteristics such as cause of death, nativity, marital status, home ownership, smoking status, and variables related to healthcare utilization. Given the male/female health survival paradox, all analyses will be performed separately for males and females.

All analyses are performed in Stata 15, using survey weights adjusted for mortality follow-up. The questions on IADL and ADL limitations were asked of all adults; this portion of

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[1] The NHIS does not collect information on specific IADL limitations, but rather whether a respondent needs help with any of them.

the analysis uses the general mortality weights. Self-rated health and questions related to the K6 were only asked of sample adults; this portion of the analysis therefore uses mortality weights for the sample population.

Preliminary Findings

Figure 1 shows trends in IADL and ADL limitations, by years of life remaining. Roughly 40% of women within 0-2 years of dying report needing help with any IADL, compared to 30% of those in their last 3-5 years of life. These trends have remained relatively stable over time. Trends among men are similar, though the percent requiring assistance is much lower: roughly 25% and 13% of those with 0-2 years and 3-5 years of life remaining require help, respectively. As shown in the bottom panel of Figure 1, the mean number of ADL limitations also remained constant over the study period, with women reporting more ADL limitations than men. For those with 0-2 years of life remaining, women report, on average, 0.6 ADL limitations, while men report just under 0.4. For both sexes, ADL limitations appear to develop quickly toward the end of life: while those with 3-5 and 6-9 years of life remaining have a somewhat similar mean number of limitations, that number jumps considerably during the transition from 3-5 to 0-2 years remaining.

Figure 2 shows trends in self-rated health. Individuals nearer to death are less likely than others to report being in good or excellent health, though this number is still surprisingly high. Among men and women alike, roughly 50% of those within 0-2 years of death report being in good/excellent health. Trends in good/excellent health are less flat over time than those for IADL and ADL limitations. While some are constant (women 0-2), some indicate improvement (men 6-9 years) and other deterioration (women 3-5, men 3-5, men 0-2) (though these changes are not always statistically significant). Despite sex differences in self-rated health throughout life, these differences dissipate at the end of life.

Figure 3 shows the mean K6 score of psychological distress. Psychological distress increases toward the end of life, with women in the last 0-2 years of life reporting roughly a mean score of 4, and men just over 3. At all distances from death, women report a higher mean K6 score. Trends are generally flat over time, though reports of psychological stress among women 3-5 years from death somewhat declined over the period, while reports among women 0-2 years from death steadily increased, from a mean of roughly 4 in 1997-1998 to 4.5 in 2009.

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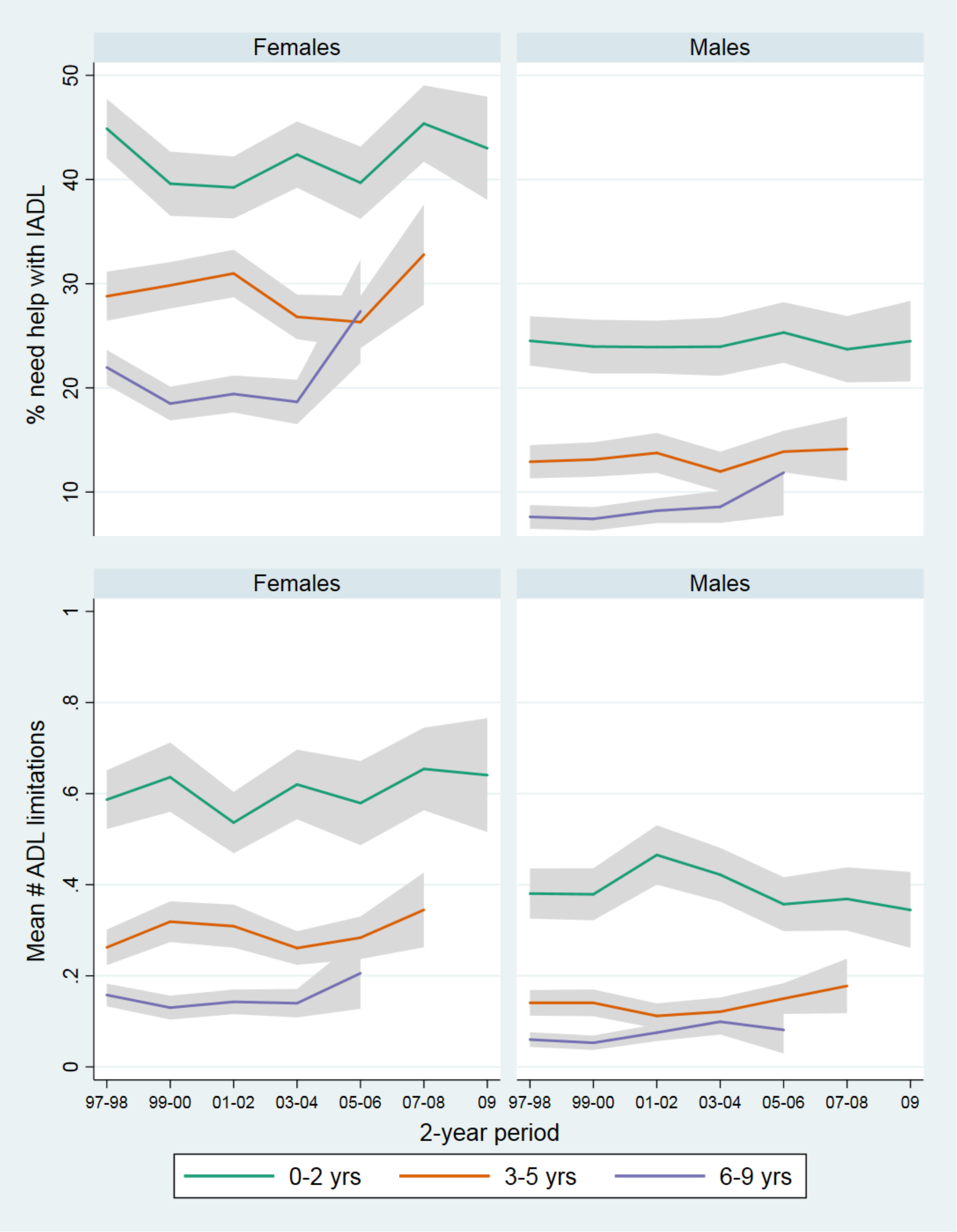
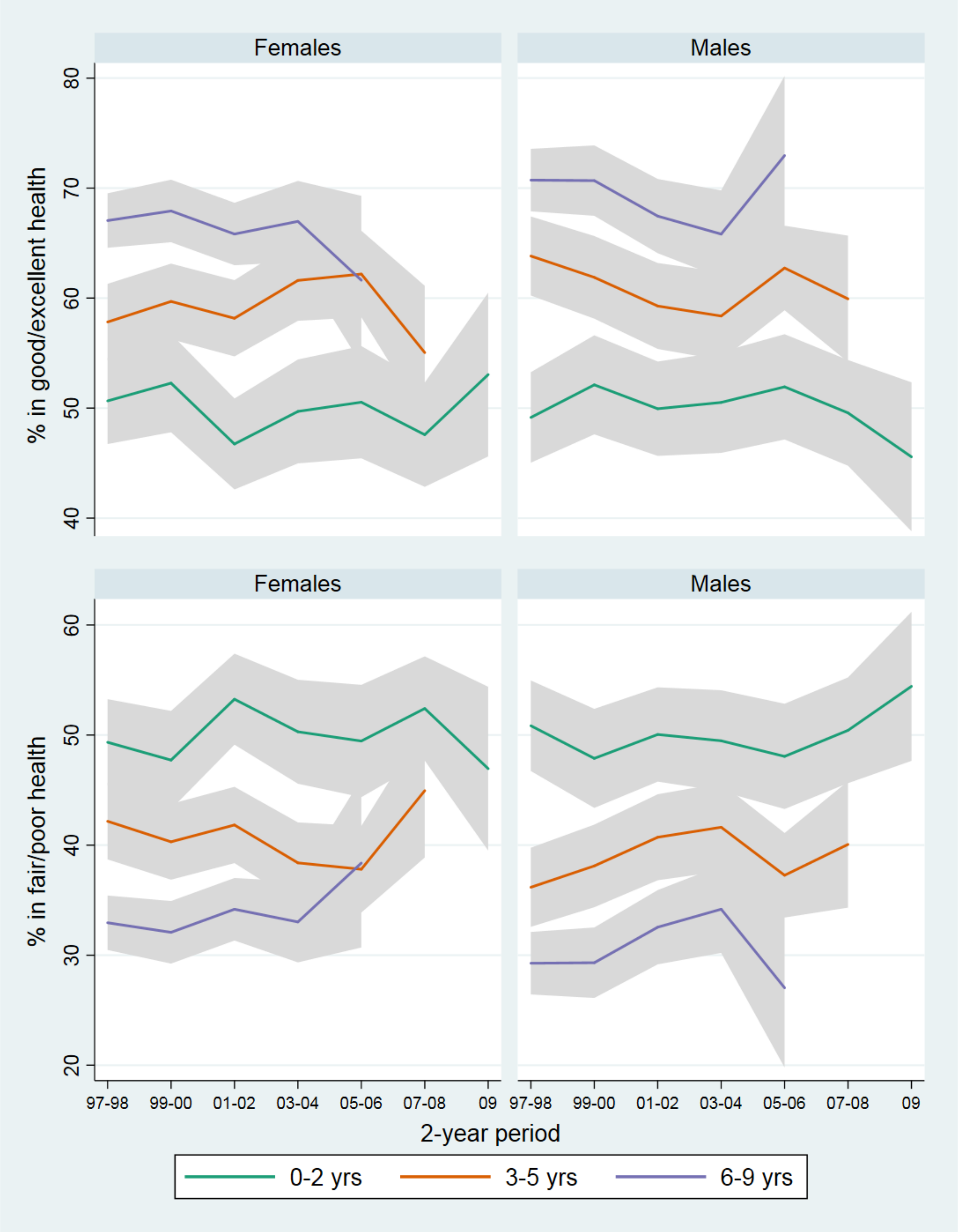
Figure 1. IADL and ADL limitations, by years until death.



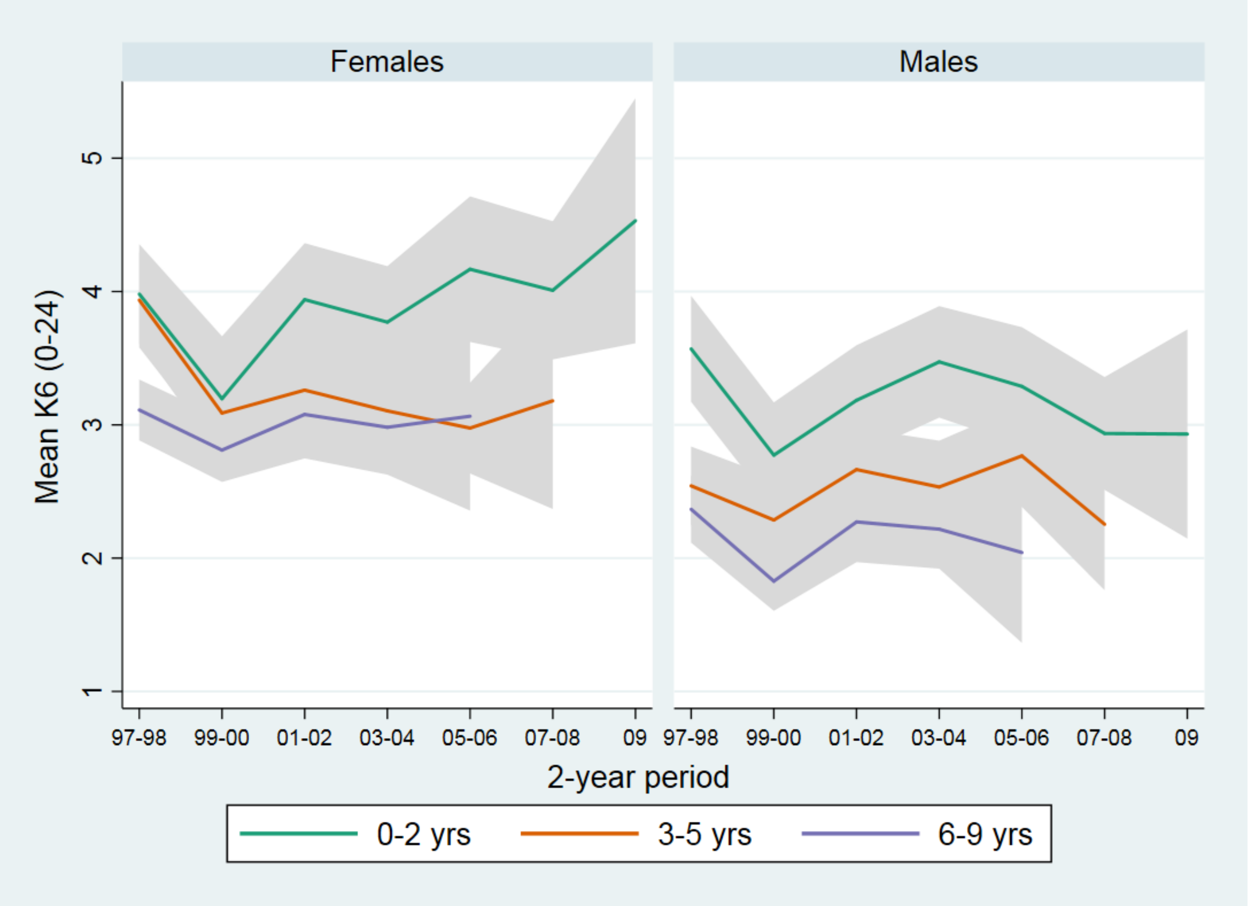
Shaded area indicates 95% confidence interval.

Figure 2. Self-rated health, by years until death.



Shaded area indicates 95% confidence interval.

Figure 3. Indicator of psychological distress, by years until death.



Shaded area indicates 95% confidence interval.