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ABSTRACT

Background: The global burden of disability is rising. Understanding the hierarchical structure of activities of daily living (ADL) and the disability trajectory of elderly people is pivotal to developing early interventions. Purpose: We aimed to determine the hierarchical structure of the ability to perform ADL and further describe the disability trajectory of the elderly before death.

Methods: A longitudinal item response theory model (LIRT) was constructed from 28,345 elderly participants in the Chinese Longitudinal Healthy Longevity Survey, in which ADL were measured by the Katz scale for up to 20 years from 1998 to 2018, until the participants' death. The disability values estimated from the LIRT were fitted to a mixed-effects model to examine how the disability trajectories varied with different demographic characteristics. Results: The difficulty parameters showed that ADL losses began with bathing-partial ($\kappa = -1.396$, SE=0.003), then toiletingpartial, bathing-total, dressing-partial, transferring-partial, dressing-total, feeding-partial, continence-partial, toileting-total, feeding-total, transferring-total, and ended with continence-total ($\kappa = 3.647$, SE=0.013). Disability trajectories varied with sex ($\beta = 0.041$, SE=0.001), place of residence ($\beta = 0.010$, SE=0.001), and marital status ($\beta = 0.144$, SE=0.001). Females, people who lived in urban areas, and those who lived without a spouse had poorer disability status. Conclusion: Losses in the ability to perform ADL have a hierarchical structure. Demographic characteristics affect disability trajectories among the elderly Chinese population.

KEYWORDS
Introduction

The proportion of the global population older than 60 years of age will nearly double by 2050 as life expectancy increases and birth rates decline[1]. However, longer survival times do not necessarily entail extended periods of good health. With advancing age, the elderly are prone to contracting degenerative diseases, leading to a decline in their ability to live independently[2]. Estimates predict 55 million elderly people will be living with a disability in China by 2025[3]. As such, disability causes a heavy burden on both the family and society[4]. Timely, research-based, and effective interventions to improve the utilization of care services are urgently needed to mitigate the burdens caused by disability.

Scientists generally interpret disability as the loss or limitation of a person’s ability to perform activities of daily living (ADL), which is an important indicator of individual health. Researchers use the Katz Index, CARS scale, and Lawton scale for disability assessment[5, 6]. However, the total score of these scales may have low discrimination among people of varied disability status. Moreover, the total score can also lead to a floor or ceiling effect. To minimize this deficiency, American psychometrician Lord[7] and Danish statistician Georg Rasch[8] proposed a new test method called Item Response Theory (IRT). In IRT, disability among the elderly can be regarded as a potential continuum—avoiding floor and ceiling effects[9]. Among the different IRT models, longitudinal item response theory (LIRT) is applied to data collected over prolonged periods. The LIRT method reduces bias when estimating trajectory rates of decline[10]. For example, Marc et al.[11] developed a LIRT model to characterize cognition over time, and it effectively captured the multifaceted nature of cognition and its longitudinal trajectory. For disability, which is also a
progressive disease, LIRT is also applicable.

People found that ADL are hierarchical in nature[9, 12]. Some researchers have applied LIRT and linear mixed models to capture the hierarchical structure of ADL and changes in disability trajectory over time by taking into account the correlation across multiple measurements in each individual[9, 13]. As a general consensus, older adults tend to lose the ability to perform activities requiring lower extremity strength earlier than activities that require upper body strength[14-16]. Scientists have observed a pattern in the loss of ADL: females experienced an initial loss of their ability to walk independently outside the home, followed by the inability to independently groom, bathe, dress, toilet, and feed themselves, while males experienced a similar pattern, except that the inability to dress occurred second[17]. In addition, disability trajectories change dynamically over time. Although controversial, some research reports that disability change is sex-specific and influenced by education level.

This study aimed to use LIRT and mixed-effects model to study the hierarchical structure of ADL losses and the disability trajectories of people over 60 years of age in China. The outcomes of this study will provide a reference to develop effective interventions for older people living with a disability.

**Method**

**Study Population**

The Chinese Longitudinal Healthy Longevity Survey (CLHLS) provides health status information of elderly people in 23 Chinese provinces from 1998 to 2018. The project collected data about individual demographic characteristics, lifestyle, physical and mental health, and survival status[18]. The research protocol was approved by the Duke University Institutional Review Board.
(Pro00062871) and Peking University Biomedical Ethics Committee (IRB00001052-13074). All studies were conducted in accordance with relevant guidelines and regulations, and all participants or their legal representatives gave written informed consent. To fully reflect the natural developmental processes of disability status before death, we built a dynamic queue spanning 1998-2018. Then we selected participants older than 60 years with exact times of death for inclusion in the analysis. Individuals with incomplete covariate information were excluded.

**Disability Status Assessment**

Our study used the Katz scale to assess daily living ability. The Katz scale precisely evaluates the ability to perform specific ADL, including bathing, dressing, transferring, feeding, toileting, and continence, using a three-point scale (no limitation, partial limitation, or total limitation) of task performance. The Chinese version, which has been extensively tested in pilot interviews, yields reliable and valid responses[19]. Participants who refused or declined to answer a question were handled as missing cases.

**Model Construction for the Hierarchical Structure of ADL**

In light of the Katz scale’s ordered categorical responses, a graded response model (GRM), proposed by Samejima [20], was chosen as a generic IRT building block to relate each test item to the potential trait. In the GRM model for hierarchical reactions, every item has three parameters: (1) Two difficulty parameters (κ_{partial} and κ_{total}) which define the thresholds for change (from no limitation to partial limitation and from partial to full limitation, corresponding with κ_{partial} and κ_{total}, respectively). In the disability severity continuum, items with a small κ indicate that older people are more likely to lose this ability. In this study, the difficulty parameters revealed the hierarchical structure of the ADL. (2) An item with a higher discrimination parameter (α) means that it is more
capable of positioning individuals at the closest disability level.

To achieve the dual goals of identifying the difficulty and discrimination parameters of the Katz scale and assessing declines in the ability to perform ADL, we chose a LIRT model for data analysis[11]. Each individual’s response score to a specific item (i) at a given time (t) was recorded as $Y_{s,t,i}$, and the corresponding disability status of the individual was $\theta_{s,t}$ (every six items correspond to the same $\theta$, and a larger $\theta$ indicated a more serious disability status). In this study, the response category of every item was $K = 3$, and its cumulative probability was expressed as $P_{s,t,i,K} = 1$.

$$p_{s,t,i,k} = P(Y_{s,t,i} \leq k | \theta_{s,t}) - P(Y_{s,t,i} \leq k - 1 | \theta_{s,t})$$

$$\text{Logit}(p_{s,t,i,k}) = \log\left(\frac{p_{s,t,i,k}}{1 - p_{s,t,i,k}}\right) = \kappa_{i,k} - \alpha \theta_{s,t}$$

Where $\kappa_{i,k}$ is the difficulty parameter of item $i$, and $\alpha_i$ is the discrimination parameter of item $i$. $k$ corresponds to the selected category of the individual. For the longitudinal aspect of the model:

$$\theta_{s,t} = \gamma_{0,s} + \gamma_{1,s} \times t, \quad \gamma_{1,s} = \gamma'_{1,s} + Z_s \beta.$$  
$Z_s$ are the baseline covariates, including sex, age, years of education, place of residence, and marital status. $\beta$ refers to the regression coefficients of the covariates. Age and years of education were zero-centered and standardized for model fitting.

We cast the model in a Bayesian framework and then implemented it with Markov Chain Monte Carlo (MCMC) methods. The posterior 95% credible intervals of each parameter are displayed with posterior credible intervals (Q2.5, Q97.5). A weak information prior distribution was adopted in all parameters except $\gamma_{0,s}$ [21], which used an independent $N(0,1)$ prior distribution. The slope $\gamma_{1,s}$ selected a hierarchical prior distribution. The mean value of $\gamma_{1,s}$ was described by $\mu$, which represents the average level of ADL decline over time.
Disability Trajectories

To determine disability trajectories, the time between interview and death was taken as the independent variable (t) and the disability level (θ) of the elderly, obtained in the aforementioned LIRT, was taken as the dependent variable (scale to [-3,3]). We used a mixed-effects model to analyze changes in function over time. The model is shown below:

\[ \theta_{is} = \eta_i + \eta_s t_i + e_{is}, \quad e_{is} \sim N(0, \sigma^2) \]

\[ \eta_i = \beta_i + b_i \]

\[ \eta_s = \beta_s + b_s, \quad (b_i, b_s) \sim MVN(0, \Sigma) \]

\( \theta_{is} \) was the elderly individual’s potential disability at time \( t \), \( \eta_i \) was the intercept when \( t \) is equal to 0, and \( \eta_s \) reflects the changes in \( \theta_{is} \) over time. In this process, \( t \) was regarded as level one, \( s \) was regarded as level two, and all covariates (sex, place of residence, marital status, sex*place of residence, age, years of education, sex*marital status) were included in the model as adjustment factors.

The LIRT method was performed on Open BUGS and the mixed-effects model was conducted on MLwin. Pre and post data processing were completed in R 3.5.3. The Open BUGS software used thin=1 and 1000 iterations after 4000 burn-in.

Results

Demographic Characteristics

After excluding 45 individuals with incomplete covariate data (the missing ratio was 0.15%), 28 345 participants were included in this study. The median elapsed time between the initial (baseline) and final visit was three years (range: 0-19 years). Females accounted for about 60% of the study population (Table 1). The average age was 91.3 years, ranging from 60 years to 122 years.

Regarding years of education, 70.7% of participants had never been to school, and more than 90.6%
had a low level of education—less than five years. Most participants (63.1%) lived in rural areas, with the remaining 36.9% in urban areas. Approximately 80% of participants did not live with a spouse.

The Discrimination Parameters

Table 2 shows the posterior distributions of the discrimination parameters. The posterior means of the ADL items were ranked from toileting, transferring, dressing, feeding, bathing, and continence (range: 1.125 to 4.124).

The Difficulty Parameters

The hierarchical structure of declining ability to perform ADL, provided by the estimated difficulty parameters, is presented in Table 3. Firstly, with a range between -1.396 and 3.647, we confirmed that ADL loss began with bathing\_partial and ended with continence\_total. Regarding some key points, bathing\_partial (location value, -1.396 (standard error (SE), 0.003)) and toileting\_partial (-0.904 (SE, 0.006)) were observed in succession. The last item for which the elderly needed partial help was continence. Next, bathing was the first task to be restricted at the total level of limitation (-0.374 (SE, 0.003)). Finally, at the end of the structure, we found total limitations in feeding (3.440 (SE, 0.004)), transferring (3.454 (SE, 0.008)), and continence (3.647 (SE, 0.013)).

The Effect of Covariates on the Rate of Decline

Table 4 displays the regression coefficients of the baseline covariates for the individual slopes $\gamma_{1,s}$. Sex, years of education, place of residence, marital status, and age showed significant associations with the slopes. The value can only be interpreted in relative terms (cannot indicate the risk of disability), such that males, older age, fewer years of education, urban residence, and living without a spouse promoted a faster decline. The posterior mean of the slope parameter $\mu$ was 0.857
(2.5% and 97.5% quantiles [0.824, 0.891], SE=0.003), indicating that individual disability increased by 0.857 units per year.

Disability Trajectories in the Mixed-Effects Model

Disability trajectories varied with sex ($\beta=0.041$, SE=0.001), place of residence ($\beta=0.010$, SE=0.001), and marital status ($\beta=0.144$, SE=0.001). Females, people residing in urban areas, and living without a spouse had a poorer disability status. The further cross-group analysis in Figure 1 shows that, compared with males living in rural areas (mean=−0.219, SE=0.001), the disability status of males living in urban areas (mean=−0.163, SE=0.001), females living in rural areas (mean=−0.124, SE=0.001), and females living in urban areas (mean=−0.085, SE=0.001) became progressively worse. In Figure 2, compared to males living with a spouse (mean=−0.265, SE=0.001), the disability status of males living without a spouse (mean=−0.249, SE=0.002), females living with a spouse (mean=−0.164, SE=0.001), and females living without a spouse (mean=−0.099, SE=0.001) became worse in sequence. Detailed disability statuses and cross-group characteristics are displayed in supplementary materials Table S1. After a brief fluctuation in the 15-20 years before death, the function shows deterioration from the 15th year.

Discussion

We studied the natural history of disability in the last 20 years of life in the CLHLS cohort. We provided a synthetic hierarchy of the Katz scale’s rating of ADL performance and described the disability trajectories preceding death. As we know, with greater disability severity among the elderly comes a heavier burden on caregivers[22]. Therefore, preventing or slowing the occurrence of disability in the elderly should be a key national focus. Unfortunately, few international studies have examined the history of disability in the elderly. Governments routinely advocate preventive
strategies for health problems, and as such, geriatric medicine must evolve to intervene at an earlier stage of the disability process to be more effective. To date, some research has demonstrated a positive effect of primary prevention on dependence morbidity [23-25]. For the elderly, disability is a primary dimension of health and function, and it acts as an indicator or guideline for developing health policies for this age group[26]. The study provides foundational evidence upon which to formulate early intervention policies for preventing disability in the elderly.

**Item Discrimination**

According to Baker’s[27] guidelines for a normal ogive model, the discrimination value of continence was moderate, and all other items were very high. Poor discrimination refers to a task or activity (i.e., scale items) that prove unresponsive to changes in a particular person’s disability level. In our research, toileting, transferring, and dressing all showed high degrees of discrimination, but bathing and continence were not discriminative. Similarly, other scholars have found the same parameter order (toileting>transferring >dressing) in a two-parameter IRT model[28, 29]. In previous calculations of the parameters between ADL items, it was generally believed that the discrimination of toileting, dressing, and bathing was higher[30, 31]. However, in this study, bathing had a poor discriminatory effect. Saliba et al.[31] divided elderly people aged over 65 years into two groups (65-84 years and ≥85 years) and found that bathing had a smaller discrimination value in the older age group when fitting the model. The very high age range in this study may be why bathing could not effectively distinguish different levels of disability.

**The Hierarchical Structure of ADL**

The continuum of declining ability to perform ADL began with bathing\_partial and ended with continence\_total. As noted in previous publications [17, 32-34], bathing was the first ADL to
deteriorate, which was defined by Katz et al. as the threshold of disability. In this study, the local parameter between bathing\textsubscript{partial} and bathing\textsubscript{total} was only 1.022, confirming that bathing was the first ADL to be lost among the elderly. Scientists report that bathing was the first ADL that both older Americans and Chinese have difficulty performing\cite{14}. However, the bathing task was informative only in the low ability range, so partial and total bathing limitation occurred when the elderly were slightly disabled.

The second ADL to be lost was toileting\textsubscript{partial}. Among the six items explored here, the behavior of the toileting item was peculiar. The distance on the continuum between its partial and total limitation thresholds was much higher (4.252) than the other activities (ranging from 0.759 (dressing) to 3.507 (transferring)). Furthermore, its discriminative ability was very high, showing that the item correctly discriminates between individuals at the two levels of disability.

**Factors Affecting Deteriorating Ability Status**

The Bayesian methodology allowed the longitudinal slope estimates to remain vague for subjects with little (or no) follow-up time. We fitted our model on all participants and concluded that males, greater age, fewer years of education, living in rural areas, and without a spouse were associated with a faster deterioration in the ability to perform ADL. We discovered that older females had a higher level of disability, but their function deteriorated at a slower rate. As a result, there is a larger proportion of dependent women among the elderly population in China. Education has always been considered a factor that slows aging and ability decline\cite{35-37}. The probable reason may be that people with lower education levels might pay less attention to their physical health, not to mention the prevention of chronic disease. In addition, this phenomenon is more common in rural areas. Marital status, as a defining feature of the social environment, has long been
argued to affect an individual’s risk of disability[38]. Marital status has been significantly associated with physical disability[39, 40], and marital closeness moderates the negative psychological effects of high levels of disability on depression, anxiety, and self-esteem[41].

**Disability Trajectories**

The estimated disability trajectories highlighted that the degree of disability became progressively serious as death approached. Trajectories of disability at the end of life are quite variable[42, 43]. In the mixed-effects model, females, living in urban areas, and living without a spouse had worse ADL status. Interestingly, disability status was better in rural areas. It may be that rural medical services are relatively inaccessible, and older adults become frailer at a younger age and die earlier, so the remaining elderly are in better condition[44]. Overall, differentiating among the expected trajectories and related needs would help to tailor strategies and programs to improve elder care prior to death.

**Strengths and Weaknesses**

The innovative feature of our study was that it relied on a longitudinal analysis of 20-year follow-up data from a substantial sample of the general elderly population. Moreover, the LIRT and mixed-effects model allowed us to capture the multifaceted nature of disability. The LIRT also allowed us to estimate item and disability distribution parameters, as the data were from a longitudinal cohort study. In addition, the correlation between the subject-specific covariates and the slope of deterioration was embedded in the same model.

Two limitations of this study should be noted. It has been suggested that instrumental ADL (IADL) and ADL have a hierarchical relationship, with older adults first declining in IADL function[45, 46]. However, there were no IADL items in this survey, resulting in the inability to
explore the hierarchy of ADL and IADL disability. Unavoidably, there may also have been investigation bias and survivor bias during the follow-up period.

**Conclusion**

In conclusion, toileting and bathing are promising domains for detecting early signs of disability in the elderly Chinese population. At the same time, toileting and transferring were more discriminative than other ADL. The LIRT method and the mixed-effects model, as applied here in an elderly population, are suitable methods to jointly capture the multifaceted nature of disability and its rate of change. As a result, we found that males, those of older age, fewer years of education, living in rural areas, and living without a spouse often decline faster in their ability to perform ADL. However, females, people who live in urban areas and without a spouse had a lower ability to perform ADL. Therefore, we recommend a reasonable allocation of health resources toward mitigating declining ability and encourage the widowed elderly to engage in more social activities. Furthermore, health interventions are needed to address deficits in the home bathroom environment, especially in developing countries like China.
Abbreviations:
ADL: Activities of daily living; IADL: Instrumental activities of daily life; IRT: Item response theory; LIRT: Longitudinal item response theory; CLHLS: Chinese longitudinal healthy longevity survey; GEM: Graded response model

Declarations:
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2. Authors’ contributions
Study concept and design: Yaofeng Han, Jihui Xue. Acquisition of data: Jihui Xue, Wei Pei. Analysis and interpretation of data: Jihui Xue. Drafting of the manuscript: Yaofeng Han, Jihui Xue. Critical revision of the manuscript for important intellectual content: Yaofeng Han, Ya Fang. All authors read and approved the final manuscript.
3. Ethics approval and consent to participate
The study design was approved by the Duke University Institutional Review Board and Peking University Biomedical Ethics Committee. All participants gave written informed consent.
4. Consent for publication
Not applicable.
5. Availability of data and materials
The raw data is available on website (https://opendata.pku.edu.cn).
6. Competing interests
Not applicable.
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**Table 1** Baseline characteristics of the CLHLS study population

**Table 2** Posterior means and 95% credible intervals of the discrimination parameters for items in Katz scale

**Table 3** Posterior means and 95% credible intervals of the Local parameters for items in Katz scale

**Table 4** Regression coefficients for the individual slopes $\gamma_{ls}$ in LIRT

Note: The binary covariates were coded as sex [1: male, 2: female], place of residence [1: urban, 2: rural], marital status [1: with a spouse, 2: without a spouse]. Years of education and baseline age were zero-centered and standardized for model fitting.

**Table S1** Latent dependency of the elderly with different demographic characteristics

Note: Adjust for age and education levels.

**Figure 1** Twenty-year mean trajectories of disability preceding death grouped by gender*place of residence.

Note: MU means males living in urban, FU means females living in urban, MR means males living in rural, FR means females living in rural. Adjusted for age, marital status and years of education.

**Figure 2** Twenty-year mean trajectories of disability preceding death grouped by gender*marital status.

Note: MY means males living with a spouse, FY means females living with a spouse, MN means males living without spouse, FN means females living without spouse. Adjusted for age, place of residence and years of education.
Figure 1

Twenty-year mean trajectories of disability preceding death grouped by gender*place of residence. Note: MU means males living in urban, FU means females living in urban, MR means males living in rural, FR means females living in rural. Adjusted for age, marital status and years of education.
Figure 2

Twenty-year mean trajectories of disability preceding death grouped by gender*marital status. Note: MY means males living with a spouse, FY means females living with a spouse, MN means males living without spouse, FN means females living without spouse. Adjusted for age, place of residence and years of education.

Supplementary Files

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- TableS1.doc