# PhD Research Progress

## The Association Between Quality of Death and Family Structure and Other Potential Factors.

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# Introduction - Aging

**Proportion of population aged 65 and above (older adults)**

**=**

**aging rate**

>7% = aging society

>14% = aged society

>21% = super-aging society e.g. Japan

According to World Population Prospects 2022,

The aging rate is growing **more rapidly** than the population below 65 years old across the world.

Which means….

1. 10% in 2022 → 16% in 2050.
2. The number of older adults will be **twice** the number of children under age 5

= Almost **equivalent to** the number of children under age 12

UN (https://www.un.org/en/global-issues/ageing)

# Introduction – End-of-life

**End-of-life Care** (NIH)

- **Definition:**
  - Support and medical care given dur
    the time surrounding death. (usua
    < six months)
  - At hospital, facility, home, etc.
- **Care needed before death:**
  1. Physical comfort
  2. Mental and emotional needs
  3. Spiritual needs
  4. Practical tasks (≈ Activities of Daily Living (ADL)).

V.S. **Palliative Care**
For people at any stage of serious illness, even as early as the day of diagnosis, are still pursuing curative treatment.

**Quality of Dying and Death (QODD)** (Patrick DL et al, 2001)

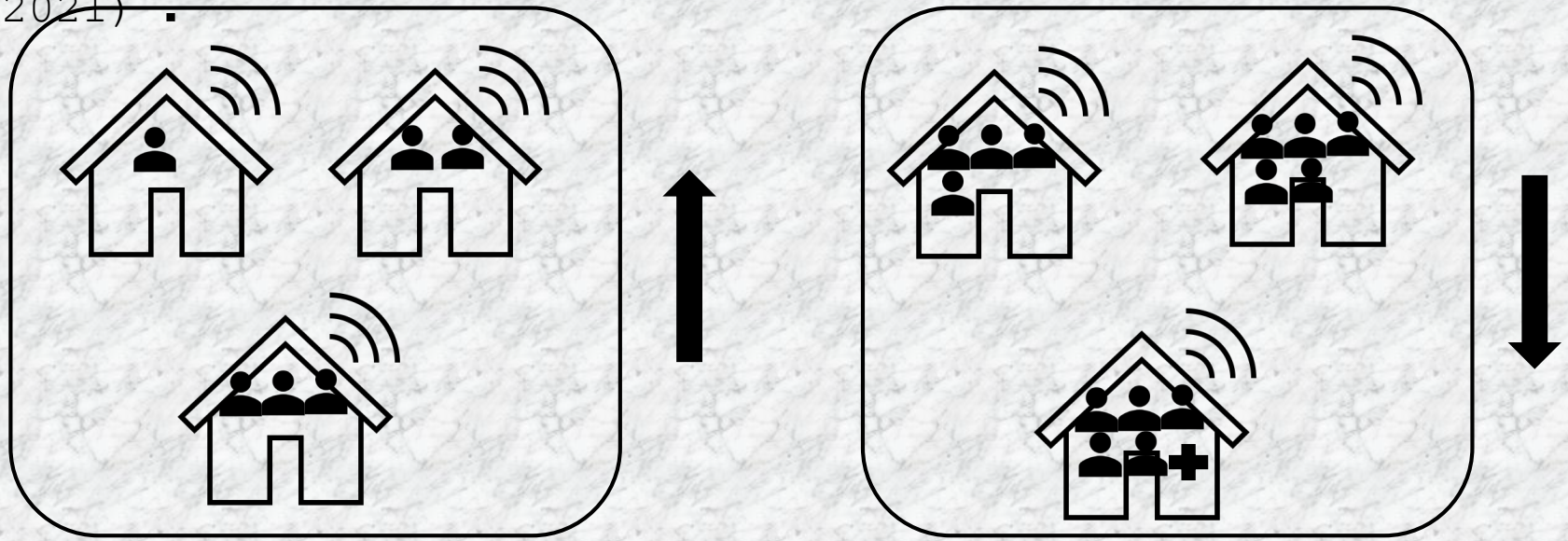
The degree to which a person's preferences for dying and the moment of death agree with observations of how the person actually died, as reported by others.

# Introduction - China

**Aging**

- Became an aging society in 2000.
- The aging rate was 13.5% in 2020 (China Population Cen
- The aging rate is projected to be above 28.7% by 2055 (Zha

**Household size is shrinking** (China Statistical Yearbook 2021) :



It is more and more difficult to take care of older family members within the household.

So, the whole society needs to collaborate

# What's known

**Domains of QODD:** (Hales S et al., 2010)

(1)physical; (2) psychological; (3) social; (4) spiritual and existential experience;

(5) the nature of health care; (6) life closure and death preparation; and (7) the circumstances of death.

**So, a good death would be**:

1. Minimal pain and symptom management
2. Having dignity and autonomy
3. Having family and social support
4. High quality of life
5. Having emotional and spiritual support.
6. Having the chance to prepare and plan
7. Receiving cultural and religious considerations

**Limited and unequally distributed end-of-life care resources in China** (Zhang Y, Lu JH, 2017).

- Lack of awareness of QODD

# What's known – Factors related to QODD

1. Most individuals at the end of life want to be surrounded by family in familiar settings and have a chance to say their goodbyes (Bauchner H & Fontanarosa, 2016 ).
2. Cancer (Addington-Hall & Karlsen, 1999), frailty (Gu et al., 2007), and the presence of chronic diseases (Gibson & Schroder, 2001) all lead to a lower QODD level.
3. Social support and the psychological status of the individual can significantly impact the QODD (Gibson & Schroder, 2001).
4. Emotion ties with family, understanding and accepting attitude toward death, and guilt for burdening family members affect the QODD to some extent (Du P, 2013).
5. The more pathological symptoms, the lower QODD level. The greater the accessibility, affordability, and specialization of end-of-life care, the higher QODD level (Zhang Y, Lu JH, 2017).
6. Chinese older adults have a cultural tradition of living at home and are used to living in familiar family environments, and aging at home is the common choice for the majority. Older adults with deteriorating health status are more likely to live with their children or others [7].
7. Most healthy older adults are financially independent, while most unhealthy older adults depend on family members for support.

(TBC)

# What's unknown

1. Minimal pain and symptom management.
2. Dignity and autonomy. →In China, it is still normal for family members to choose not to tell the patients about the severity of the disease, especially when they are older adults.
3. Having family and social support.
4. High quality of life.
5. Having emotional and spiritual support.
6. Having the chance to prepare and plan. → Advanced Care Planning (ACP) is not popoular yet.
7. Receiving cultural and religious considerations.

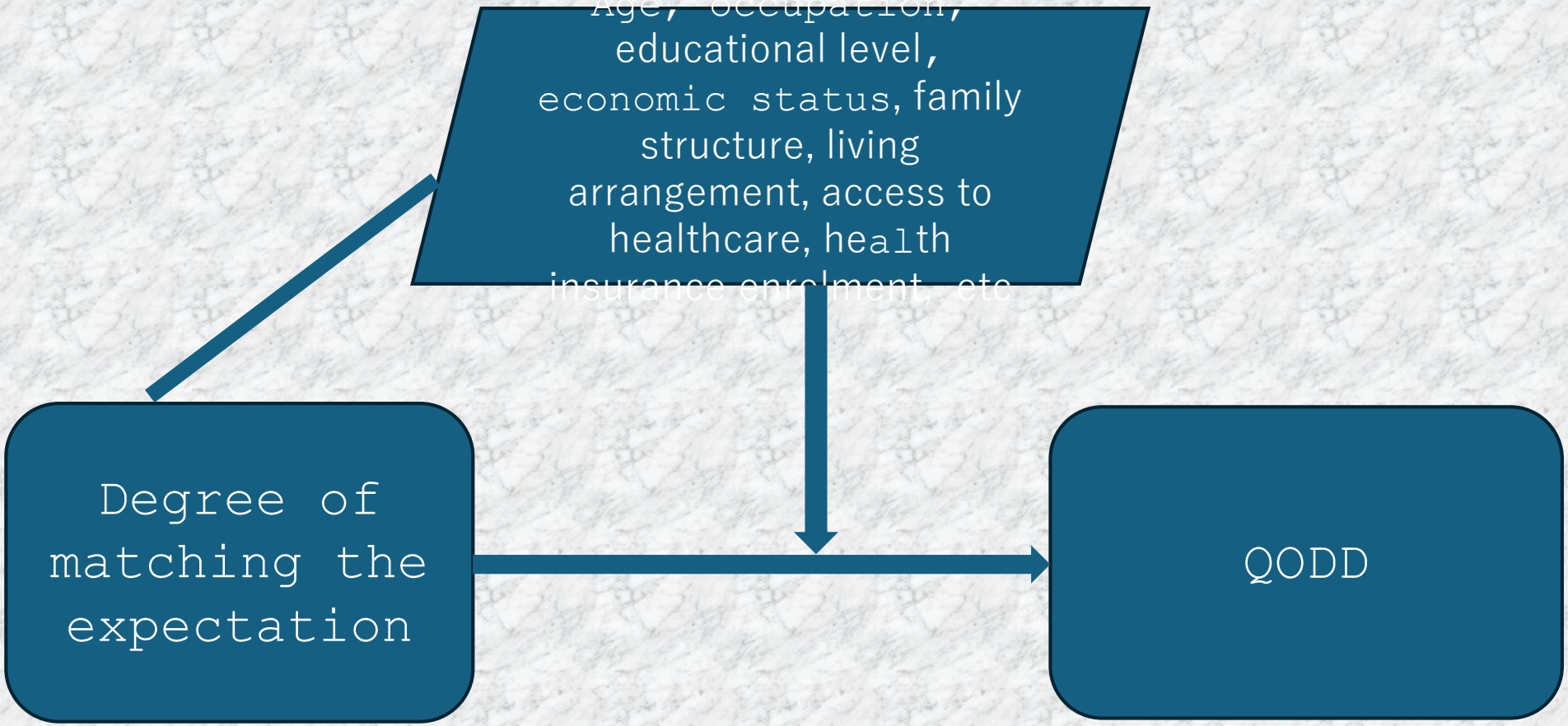
# Research questions & Objectives

**Do older adults who prepared* for their end-of-life and better quality of death in China?**

*preparation = having an expectation of end-of-life care.

- **What are the expectations of older adults in their end-of-life?**
  - What is the living arrangement they want?
  - Who do they want to live with?
  - …
- **Who is the most vulnerable? Should we direct the resources to them?**
  - Singe households?
  - Low-income household?
  - Rural residents?
  - …
- **Who is the most wanted caregiver?**
  - Family members?
  - Medical professionals?
  - Trained caregivers?
- …

# Conceptual Framework



# Methods – Dataset

## Chinese Longitudinal Healthy Longevity Survey (CLHLS) Series

Center for Healthy Aging and Development Studies of the National School of Development, Peking University.

**Target population:** older adults in China
(Including 19.5 thousand centenarians, 26.8 thousand nonagenarians, 29.7 thousand octogenarians, 25.5 thousand younger elders aged 65-79, and 11.3 thousand middle-aged adults aged 35-64.)
**8 waves:** 1998, 2000, 2002, 2005, 2008-2009, 2011-2012, 2014 and 2017-2018.
**Site:** Randomly selected about half of the counties and city districts in 23 Chinese provinces.

**Information collected:**
**Survivors:** Family structure, living arrangements and proximity to children, activities of daily living (ADL), the capacity of physical performance, self-rated health, self-evaluation of life satisfaction, cognitive functioning, chronic disease prevalence, care needs and costs, social activities, diet, smoking and drinking behaviors, psychological characteristics, economic resources, and care giving and family support among elderly respondents and their relatives.

# Methods – Exposure variable

**Before death**

| | | |
|---|---|---|
| F14. What kind of social services are available in your community?<br>1 Yes 2 No | 1 personal daily care services<br>2 home visits<br>3 psychological consulting<br>4 daily shopping<br>5 social and recreation activities<br>6 legal aid<br>7 health education<br>8 neighboring relations<br>9 others(please specify)_____ | ○ |
| F15. What kind of social services do you expect to be provided by your community?<br>1 Yes 2 No | 1 personal daily care services<br>2 home visits<br>3 psychological consulting<br>4 daily shopping<br>5 social and recreation activities<br>6 legal aid<br>7 health education<br>8 neighboring relations<br>9 others(please specify)_____ | ○ |
| F16. Which living arrangement do you prefer?<br>(to be answered by interviewee only) | 1 living alone (or with spouse), no matter how far children live<br>2 living alone (or with spouse), but it is better that children live nearby<br>3 coresidence with children<br>4 institutions (elderly center, elderly home, etc.)<br>5 do not know | |

Score = sum (matching expectation ① + matching expectation ② +… )

**After death**

| | |
|---|---|
| 3 Main living arrangement in year prior to death? (choose one answer only) | 1. Nursing home<br>2. Alone<br>3. With old spouse only<br>4. with married child (including grandchildren)<br>5. Other relative<br>8. Other (please note) _____ |
| 4. Place of death | 1. home 2. hospital 3. institution<br>4. other (please specify) _____ |
| 10. Did the deceased elder get timely treatment when he/she was ill before dying? | 1.yes 2. no 3. was not ill |

Potential data for creating the outcome variable

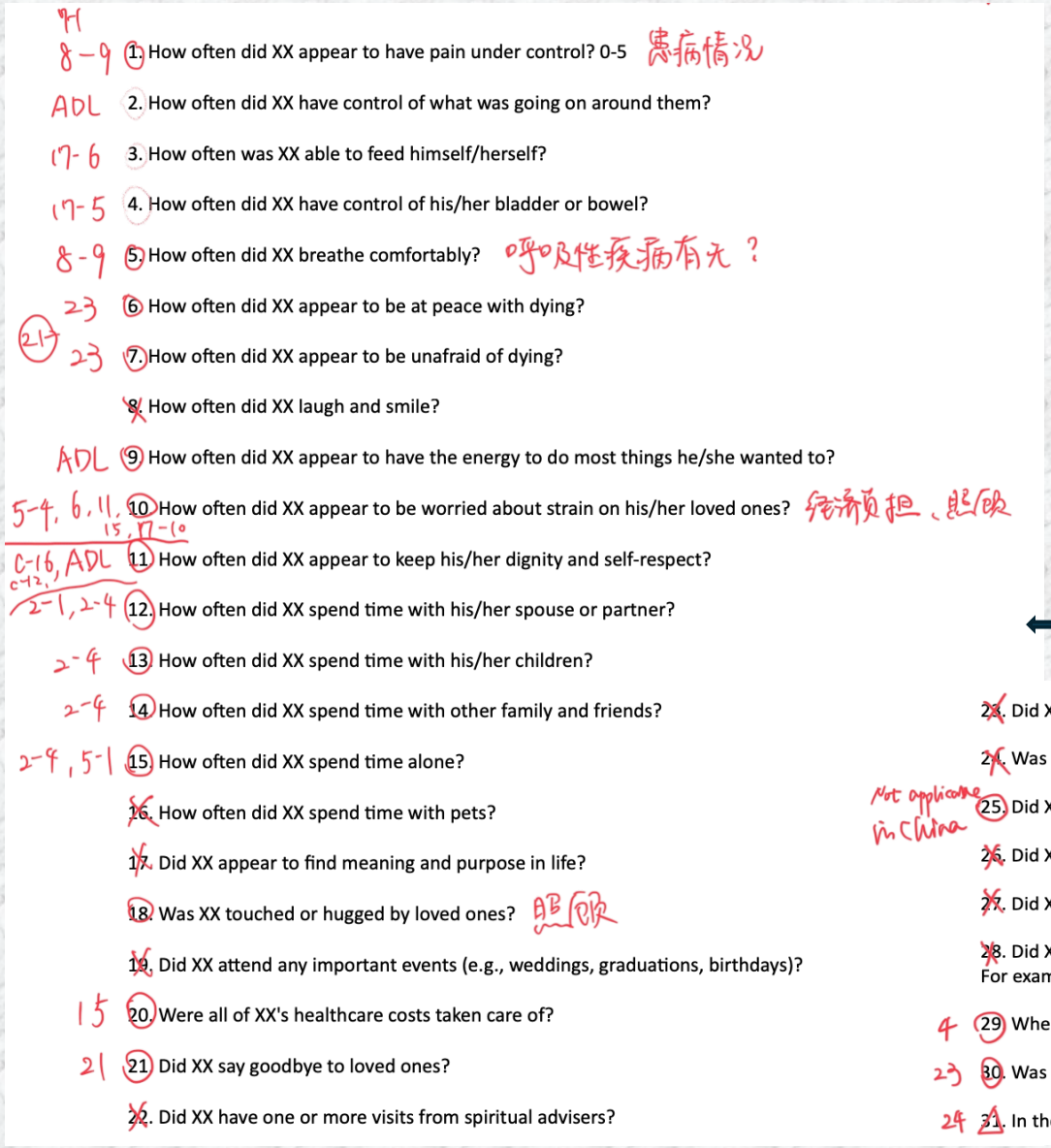
# Methods – Outcome variable

## Quality of death score

- Ideally, using a valid scale if the dataset fits most of the questions in it.

Alternative:
If scales are not applicable, change "the degree of matching expectations" to the outcome and explore the potential factors that affect it.

Quality of Dying and Death Questionnaire(Downey L. et al., 2010)



1. How often did XX appear to have pain under control? 0-5
2. How often did XX have control of what was going on around them?
3. How often was XX able to feed himself/herself?
4. How often did XX have control of his/her bladder or bowel?
5. How often did XX breathe comfortably?
6. How often did XX appear to be at peace with dying?
7. How often did XX appear to be unafraid of dying?
8. How often did XX laugh and smile?
9. How often did XX appear to have the energy to do most things he/she wanted to?
10. How often did XX appear to be worried about strain on his/her loved ones?
11. How often did XX appear to keep his/her dignity and self-respect?
12. How often did XX spend time with his/her spouse or partner?
13. How often did XX spend time with his/her children?
14. How often did XX spend time with other family and friends?
15. How often did XX spend time alone?
16. How often did XX spend time with pets?
17. Did XX appear to find meaning and purpose in life?
18. Was XX touched or hugged by loved ones?
19. Did XX attend any important events (e.g., weddings, graduations, birthdays)?
20. Were all of XX's healthcare costs taken care of?
21. Did XX say goodbye to loved ones?
22. Did XX have one or more visits from spiritual advisers?
23. Did XX have a spiritual service or ceremony before his/her death?
24. Was a mechanical ventilator or kidney dialysis used to prolong XX's life?
25. Did XX have the means to end his/her life if he/she needed to?
26. Did XX clear up any bad feelings with others?
27. Did XX have his/her funeral arrangements in place prior to death?
28. Did XX discuss his/her wishes for end-of-life care with his/her doctor? For example, resuscitation and intensive care?
29. Where did your loved one die?
30. Was anyone present at the time of death?
31. In the moment before death, was he awake or asleep?

◎ 20/31

× Spiritual

△ preparation and planni

# Methods – Analysis (to be studied)

**Secondary data analysis**

Time series analysis.

Panel data

- **Descriptive analysis**: Identifies patterns in time series data, like trends, cycles, or seasonal variation.
- **Explanative analysis**: Attempts to understand the data and the relationships within it, as well as cause and effect.

To be studied: Which model?

# Implication

This study will be beneficial for policy-making in en

reminder

What are the expectations of older adults in their end-of-life
- What is the living arrangement they want?
- Who do they want to live with?
- …

Who is the most vulnerable? We should direct the resources to them.
- Singe households?
- Low-income household?
- Rural residents?
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Who is the most wanted caregiver?
- Family members?
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…

# References


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# Thanks for