Older old people
towards the end of life
– well-being, preferences and care

Public Health @ Cambridge
14 June 2017
Murray Edwards College
Old age is getting older

- Increasing longevity
  - multiple generations are on the increase but ....
  - many old people do not have any family / none nearby

- What does this mean for mental health and wellbeing towards the end of our increasingly long lives?
“Older old” people

What does that mean?

... ... What does the term “older old” age mean?

... ... What does it mean to live to be so old?
“Older old” people

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... ... ... What does it mean to live to be so old?
In the UK

In the last ½ of last century:
• % aged >85 rose 5-fold

In 3 decades 1995-2025:
• number of people aged >80 is set to increase by almost ½
• number of people aged >90 is forecast to double

Over the last decade
• the number of centenarians has risen by 65% to 14,570

Dept. Health National Service Framework for Older People (data for England)
http://www.dh.gov.uk/assetRoot/04/05/82/95/04058295.pdf
Office of National Statistics (2016)
Estimates of the very old (including centenarians), UK: 2002 to 2015
2 out of every 3 of the world’s “oldest old” people (UN: 80+) will live in developing regions by 2050.

“Older old” people

What does that mean?

... ... ... What does the term “older old” age mean?

... ... ... What does it mean to live to be so old?
The Cambridge City over-75s Cohort (CC75C) study

www.cc75c.group.cam.ac.uk
Cambridge City over-75s Cohort (cc75c)

- Population-based study
- 7 general practices
- n=2610 aged ≥75 interviewed in usual residence 1985 -1987
- 95% response rate

Study participants were originally enrolled through GP lists from practices geographically and socially representative of the whole city of Cambridge.
Data collected - 1

Interview data:

- Cognitive function, psychiatric diagnosis
- Socio-demographics, social networks, informal/formal support, service use
- Depression, anxiety, subjective well-being
- ADL, activities, physical health, medication

See questionnaires on website: http://www.cc75c.cam.ac.uk/documents/questionnaires
Data collected - 2

Other assessments included:

• Genetics (in early study waves)
• Brain imaging [MRI] (in early sub-samples)
• Neuropathology (brain donation programme)
• Bone health [QUS] (in survey 6 falls study)
• Functional tests (in survey 6 falls study)
• Hearing, eyesight (from survey 3 onwards)
Depressive symptoms prevalence

CC75C Survey 2 (n=1180 aged >77 years old)

Only 6% described themselves as feeling depressed most of the time but 21% admitted that they sometimes felt life was not worth living
Negative mood was not uncommon: slightly more so ≥90
Measurement issues…

Have you lost interest in things you used to enjoy?
   “I can’t do the things I used to enjoy any more”

Do you have more difficulty making decisions than you used to?
   “I never have to make any decisions these days”

Have you preferred to be on your own more?
   “Well, I’m always on my own now…”

How do you feel about the future?
   “I don’t have much future at 98, do I?”
In the last year of life

Positive outlook was common, only slightly less so ≥90
Loneliness

Nearly a fifth said they were ‘lonely’ or ‘very lonely’, 42% if include ‘slightly lonely’- 35% of 85/89-yr-olds - 49% of ≥90-year-olds
### Study population samples

<table>
<thead>
<tr>
<th>CC75C Study</th>
<th>Survey 1</th>
<th>Survey 2</th>
<th>Survey 3</th>
<th>Survey 4</th>
<th>Survey 5</th>
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<th>Survey 7</th>
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<tbody>
<tr>
<td>Year 0</td>
<td>Year 2</td>
<td>Year 7</td>
<td>Year 10</td>
<td>Year 13</td>
<td>Year 17</td>
<td>Year 21</td>
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<tr>
<td>(n=2610)</td>
<td>(n=1177)</td>
<td>(n=710)</td>
<td>(n=446)</td>
<td>(n=233)</td>
<td>(n=110)</td>
<td>(n=44)</td>
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- Cognitive status known (n=283)
- Dementia status known (n=142)

Interviews ≤1 year before death aged ≥85 linked with available death certificate data (n=320)
Increasing dependency

Place of residence when last surveyed in the year before death

Usual address at death

Place of death
Individuals who died aged 85 or older less than a year after interview
Where people died

For everyone except the most cognitively impaired

  a hospital was the most common place of death

For individuals with severe cognitive impairment

  a care home was most common place of death

Most likely to die elsewhere (80%)

  severely cognitively impaired in the community
Usual address at death

Place of death

Cognitive impairment

- None (n=115)
- Mild/moderate (n=64)
- Severe (n=104)
End of life transitions

- Own home (65 years)
  - Own home (4 nights)
    - Residential care home (rehab / respite)
    - Care home with nursing
      - Care home with nursing
        - Acute hospital (2 weeks)
      - Acute hospital (6 weeks)
        - Acute hospital (1 night)
          - (“2 or 3 ‘practice dies’… then rallied again”)
          - Care home with nursing
            - (delirium ?UTI)
              - Acute hospital
                - (fell first night after moving in)
                  - Care home with nursing
                    - (concern re breathing)
Qualitative methods added in later surveys:

Quality of life near the end of life in very old age

Year 21 survey (n=44)
92% of those still alive took part

Qualitative data (n=42)
aged 95 – 101 years old; mean 97; median 97

37 women
5 men

24 at home in community
18 in long-term care
Cognitive function, disability and self-rated health

**Cognitive impairment**
- Moderate: 24%
- Severe: 33%

**Disability**
- Instrumental activities of daily living only: 10%
- Personal activities of daily living: 71%

**Self-rated health**
- Reported as “good” or “very good”: 66%
Qualitative study (n=42)

- Study cohort participants in person: n=33
- Proxy informants interviews: n=39 (closely involved relative/friend/carer)
- Both participant + proxy informants: n=30

Topic-guided interviews:
Themes explored...

Experiences of care

Experiences of moving

Contexts, beliefs and outlooks

Attitudes towards dying and death

Preferences concerning end of life care
Themes explored...

Experiences of care

Experiences of moving

Contexts, beliefs and outlooks

Attitudes towards dying and death

Preferences concerning end of life care
Context, beliefs and outlooks

- Death and dying were part of everyday life ... framed their outlook on their remaining life

- Positive take ... being a “survivor” ... rare

- More often ... questioning why they were still here

- Being on borrowed time

- Most accepted they were going to die soon ... long lives coming to an end
Everyone dying

• Majority of contemporaries had died:
  “I mean I’ve got her Christmas card list down to five now” (1077-daughter)

  “She’s been to a lot of funerals in her own old age” (1162-daughter)
Daughter:
We haven’t bought her new clothes for 10 years [...] ‘It’s not worth it dear’ [...] Same for the teeth, [...] she won’t do anything about her teeth [...] 

Son-in-law:
I think the best one was the long life bulb that she gave our daughter ‘Something for you - it’s not worth me having a... 

Daughter:
...a long life bulb!’

(1077-joint proxy informants)
Ready to die

• Most felt ready to die - waiting for it to happen:
  “I’m ready to go. I just say I’m the lady in waiting [...] waiting to go”  (0645)

• Some linked this to the quality of their lives:
  I: Would you say that you enjoy your life?
  R: I’m past it.  (2882)
Living too long

• Some worried about being a burden on others:
  R: I feel I can be a nuisance to people.
  I: Does that worry you?
  R: Sometimes, yes.

• Some felt they had simply lived too long:
  “She sometimes says ‘I’m long past my ‘sell by’ date. What am I doing here?’”
  (2961 - daughter)
Had enough

- Others had had enough... felt they had nothing to live for:

- One 98-year-old could not

  “...see any point in keeping people [alive]”

  R: I wish I could die.
  I: Is that something you think about a lot?
  R: Yes.

- Her niece confirmed:

  “She will come out every now and then with
  ‘You look after us too well’ ”

  (2999-niece)
Wanting help to die

• Some informants raised the topic of euthanasia

• One mother had told her daughter many times...

  “‘Oh, wouldn’t it be wonderful if someone could give me a tablet and I could just go off to sleep [...] I wish there was something that I could be given to end my life peacefully’ [...]” (1162-daughter)

• Remembering mother visiting friend with dementia:

  “When she had her marbles, she said ‘Don’t ever let... If I ever get like that, for goodness sake put a...’ – it was her words, not mine – ‘put a pillow over my head, will you’ ” (2916 - son)
Preferences concerning care at the end of life

• Most preferred to be made comfortable than to have life-saving treatment if seriously ill:
  “I wouldn’t want [...] these terrible things where people go on living and deteriorating.”  (2930)

• Respondents often raised hospital admission spontaneously – again largely negative views... adamant:
  “I should... I should hate, I should hate it. [...] Well... I just wouldn’t like it”  (2916)

• Many recognised hospital admission might happen despite preferences:
  “It would be selfish not to go somewhere where I can be looked after. It’s not fair to them [...] I would have to accept it [...] I should... shouldn’t really like it. [I’d rather] stay put”  (1079)
CONCLUSIONS AND IMPLICATIONS

• Population-based studies are crucial for understanding and planning to meet the needs and preferences of growing numbers of older old people

• These studies are challenging but participants value the opportunity to take part

• Very old people are willing to complete in-depth interviews, including assessments of cognition and mental health

• ≥95-year-olds are willing to discuss dying and end of life care – but seldom do so

• The majority wonder ‘why am I still here?’, are ‘ready to die’, prefer a palliative approach avoiding hospital, but most undergo transitions in place of care at the end of life

• Minimising transitions needs improved EoL care in all settings

• The issues raised urgently need wider social / political debate
THANK YOUs

- funders, past and present
  http://www.cc75c.group.cam.ac.uk/background/grants/

- collaborating GP practices and care homes

- all our STUDY PARTICIPANTS and their RELATIVES and FRIENDS
The Cambridge City over-75s Cohort (CC75C) study

www.cc75c.group.cam.ac.uk

http://www.phpc.cam.ac.uk/pcu/research/research-projects-list/other-projects/oldestoldneareol/

Professor Carol Brayne
Dr Stephen Barclay
Dr Morag Farquhar
+ many, many more over many, many years
Self-rated health in the final year of life
– by age and sex

SRH compared with others of same age
- Poor or very poor health “compared with others the same age” was far less commonly reported than worse health “compared with a year ago”
- Minimal age differences, contradictory sex differences (all NS)

SRH compared with a year ago