Dying at “a great age”
– end of life care issues:

“Older old” people’s attitudes and preferences regarding care towards the end of life care

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BACKGROUND

• Demographics ... Living longer means dying older

• Crucial questions for shaping end-of-life care services:

  How does being very old affect attitudes towards death, dying and care towards the end of life?

  What are the preferences of very old people approaching death?

• Preferences and experiences of ‘older old’ people, or even their carers, are rarely heard
AIM

• To inform policy, planning and practice by exploring these questions with a representative sample of ≥95-year-olds and their family and / or formal carers
METHODS

• Topic-guide explored:
  – attitudes towards very late life, dying and death
  – preferences and concerns re care at the end of life
• Majority consented to audio-recording
• Topic-guided interviews transcribed in full
• Extracts from usual interviews also transcribed
• Field notes if no recording, correspondence, etc
• 112 source documents – huge qualitative dataset
• Framework analysis facilitated by NVivo software
RESULTS

3 broad themes identified:

Context, beliefs & outlooks

Attitudes towards dying and death

Preferences concerning end of life care
Context, beliefs & outlooks
- Everyone dying
- Euthanasia
- Outlook on life
- Being ready to die
- Medicalisation of death
- Being not ready to die

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Attitudes towards dying and death
- Thoughts about dying
- The manner of dying
- Talking about death
- Talking about funerals

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Preferences concerning end of life care
- Preferences regarding life-saving treatment
- Admission to hospital at the end of life
- Family members’ wishes for their relatives
- Family members’ understanding of their older relatives’ preferences
- Planning
- Discussing end of life care preferences
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1) Context, beliefs and outlooks

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)
1) 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
1) Context, beliefs and outlooks

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)
1) Context, beliefs and outlooks

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)
1) Context, beliefs and outlooks

• 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.

(3403)

• 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)
1) Context, beliefs and outlooks

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

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

(2999)
1) Context, beliefs and outlooks

Euthanasia & the medicalisation of death

• Some informants raised the topic of euthanasia

• Remembering mother visiting friend with dementia:

  “When she had her marbles, she said ‘Gordon, 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)
1) Context, beliefs and outlooks

- Ability to act diminished as desire to die increased:

  *Mother would quite willingly go somewhere.*  *If you offered her to go to Switzerland [...] she’d go.*  *She’s been ready to do that for a long time.*

  (1077-daughter)
1) Context, beliefs and outlooks

- Another 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’ [...]”

... but had considered the legal repercussions:

  “Well, someone would be assisting, wouldn’t they? If they gave her something to end her life”

  (1162-daughter)
1) Context, beliefs and outlooks

- One 98-year-old could not
  
  “...see any point in keeping people [alive]”

(2999)

- Her niece confirmed:
  
  “She will come out every now and then
  with ‘You look after us too well’”

(2999-neice)
1) Context, beliefs and outlooks

• There was talk of the medicalisation of dying:
  “in hospitals death is not something they want, so they will over-medicalise because it’s better than doing nothing”
  
  (0142-care home deputy manager)

• Relatives questioned the logic of some medical practice (medicalisation):

  I was annoyed [...] the doctor gave her her pneumonia injection, seeing that she had no quality of life... [she] was ready to go.

  (3403 daughter-in-law)
2) Attitudes towards death and dying

Thoughts about dying

• Most were not afraid of death:

  “I’m not afraid of dying [...] at my age anything can happen” \( (0645) \)

• Some even longed for it:

  \( \text{Sometimes I say ‘I hope I won’t wake up tomorrow’} \) \( (3346) \)

• Absence of fear rooted in positive experiences of others’ deaths
2) Attitudes towards death and dying

- Negative experiences of death led to worry ... especially about the process of dying:

  “She found my mother’s end quite distressing, because my mum ... [pause] was not herself for quite a long time before she died, and then was in hospital for a long time, and then was in the home. [...] And I think she worries that she’s going to be like that when the end comes.”

   (2882 - niece)
2) Attitudes towards death and dying

- Worries about impacts their death might have on others...emotional, loneliness, financial:

  “He’s accepted the fact that he’ll have to die. And that when he does I’m going to be left alone - which he doesn’t like the idea of.”

  (3185 - wife)
2) Attitudes towards death and dying

- Some stated explicitly that they didn’t think about death, or preferred not to discuss it:

  “I don’t think about dying. I sit and wait for that to happen” (2804)
2) Attitudes towards death and dying

• For most dying was seen as inevitable and beyond their control:

   "If it happens we’ve had our lives."

   (1523)

• But despite the inevitability, when and how were both unknown
2) Attitudes towards death and dying

Talking about death

- Proxies reported that death was rarely discussed with the older people:
  
  “That generation, they didn’t actually discuss death much, I don’t think, my parents, at all”

  (1162-proxy)

- Conversations might allude to death but tended not to be explicit
2) Attitudes towards death and dying

• Only a few described openly talking about death or the future:

  “The other day [...] she said, “I should think I’ll snuff it soon, don’t you?” I said, “I don’t know, you tell me” and she just laughs [...] You can laugh with her about it. [...] Oh, joking. Oh yes, she’s never morbid.”

  (2804 - daughter)
2) Attitudes towards death and dying

Manner of dying
• Although some said they had “not really thought about [dying]” (1079)
  many explicitly expressed the wish to die:
  - peacefully
  - pain free
  - preferably while asleep

  “I don’t want to be ill. I’d rather go to bed and go to sleep forever. I think that must be lovely” (3400)
2) Attitudes towards death and dying

• So the manner of death was of more concern than its imminence:
  “All I hope is peaceful. I’ve shut my eyes thinking ‘This is it’.” (3346)

• Indeed death coming suddenly was seen as positive:
  “I’d be quite happy if I went [snaps fingers] suddenly like that” (3403)
3) Preferences concerning EoL care

Preferences regarding life-saving treatment

• Most talked readily about EoL care preferences

• Question wording:
  “If you had a life-threatening illness, would you want to receive treatment that would save [your] life or prefer care that would just make [you] comfortable?”

• Some barely hesitated in replying one way or the other – most wanted comfort
3) Preferences concerning EoL care

• Preferences for life-saving treatment were unusual but strong:

  I: If there was something seriously wrong would you want the doctors, you know, to go all out with treatment and so on?
  R: Well yes, I should think so. Yes.
3) Preferences concerning EoL care

• Very common to want “to be made comfortable” (2705, 3124, ...)

• Sometimes linked to quality of remaining life

• ‘Hesitators’... it would depend on circumstances ... (echoed by relatives) ... complexity of uncertainty:
  “I haven’t thought about it. It’s a decision you can’t make unless you’re in that position” (3103)
3) Preferences concerning EoL care

- Decisions likely to be made by others
  - fatalistic or realistic?

- Some chose (pro-actively) to leave decisions to others
  - relatives, health professionals or even God
3) Preferences concerning EoL care

• Older people were more likely than relatives to report having discussed care preferences:

  “I wouldn’t want [...] these terrible things where people go on living and deteriorating. I think they would know my views on that [...] which would not be to continue life [...] I once mentioned to my doctor [...] and he said ‘Well, I’ve made a note on your file saying NO HEROICS’ ”

(2930)

• Written documentation rare – relevance? (only 1 other with any recorded wishes – ignored)
3) Preferences concerning EoL care

Admission to hospital at the end of life

• 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)

• Family members often aware
3) Preferences concerning EoL care

• 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”
3) Preferences concerning EoL care

Family members’ understanding of their older relatives’ preferences

• Often proxies said the older person never discussed care preferences with them but... most felt they had a good idea of preferences

• Definite statements ... uncertainty was rare

• Abhorrence of severe dependency (QoL):
  “I don’t think she’d want to be a vegetable”
  (1079-daughter)
3) Preferences concerning EoL care

- But there were contrasts between older peoples’ and their relatives’ views...

- Daughter:
  (when asked if mother would like treatment that might save her life or care to make her comfortable)
  “I should think probably the latter”
  (1523-daughter)

- Mother:
  “I’d have treatment as long as could” (1523)
3) Preferences concerning EoL care

Discussing end of life care preferences

- Occasional examples of end of life discussions:

  “Annie turned round and said ‘Well, I’d like to talk to the GP about it then’, which is harder because of her deafness [...] because she actually wants an intelligent conversation: ‘If something happens to me tomorrow I want to be involved in that’ ”

  (0142-care home deputy manager)
3) Preferences concerning EoL care

• Specific discussion in families was rare (interview itself a possible prompt, considering how)

• Insights from a care home manager:
  
  o Hospitals tend to ask relatives not patients
  o ‘Tempting fate’
  o Literature would help start conversation
  o Trying group discussions
  o Impact of communication problems
  o Views may change
CONCLUSIONS AND IMPLICATIONS

• ≥95-year-olds are willing to discuss dying and EoLC – but seldom do so

• Families are uncomfortable raising these issues

• Formal documentation of wishes is extremely rare and, given uncertainties, may not be welcome

• Majority wonder ‘why am I still here?’ / ‘ready to die’ – but a minority celebrate survival

• Worries more about dying process than death itself

• Preferring a palliative approach predominated – but these preferences cannot be assumed

• Minimising transitions needs ↑ EoLC in all settings
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Further details
Death and the population’s ‘oldest old’ – attitudes and preferences for end of life care
Jane Fleming, Morag Farquhar, Cambridge City over-75s Cohort (CC75C) study collaborators,
Carol Brayne and Stephen Barclay
PLOS ONE [in press]