

**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  $\geq 95$ -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

## **Attitudes towards dying and death**

## **Preferences concerning end of life care**

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- Everyone dying
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## Attitudes towards dying and death

- Thoughts about dying
- The manner of dying
- Talking about death
- Talking about funerals

## Preferences concerning end of life care

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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

- 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:

*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 [...] about it. [...] morbid.”*

*You can laugh with her*

*Oh, joking. Oh yes, she’s never*

*(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.*

*(1110)*

### 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 should... [I’d rather] stay put”*

(1079)

### 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:
  - Hospitals tend to ask relatives not patients
  - 'Tempting fate'
  - Literature would help start conversation
  - Trying group discussions
  - Impact of communication problems
  - Views may change

## CONCLUSIONS AND IMPLICATIONS

- $\geq 95$ -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  $\uparrow$  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

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Carol Brayne and Stephen Barclay

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