Fear of dying in an ethnically diverse society: cross-sectional studies of people aged 65+ in Britain

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ABSTRACT

Aim To examine fears about dying in an ethnically diverse population sample, and a more homogeneous population sample, aged 65 and over.

Methods Personal interviews with people aged 65+ living at home responding to two Office for National Statistics Omnibus Surveys in Britain, and two Ethnibus Surveys of ethnically diverse populations in Britain.

Results Ethnically diverse respondents were more likely than British population respondents to express fears about dying on all measures used. Respondents in both samples with better, compared with worse, quality of life had significantly reduced odds of having extreme fears of dying (ethnically diverse sample, OR 0.924 (95% CI 0.898 to 0.951); British population sample, OR 0.981 (95% CI 0.966 to 0.996); both $p<0.001$). In the latter sample only, older age was protective (OR 0.957; 95% CI 0.930 to 0.985; $p<0.001$), whereas in the Ethnibus sample, having a longstanding illness (OR 2.024; 95% CI 1.158 to 3.535; $p<0.05$) and having more relatives to help them (OR 1.134; 95% CI 1.010 to 1.274; $p<0.05$) increased fears about dying.

Conclusions Enabling older people to express fears about dying is likely to be important when planning supportive end-of-life care. Practitioners should not assume that fears about dying are the same in different social groups, or that extensive family support is protective against such anxiety. Older people from ethnic minorities had more anxieties about dying than others, and were more likely to express fears the more extensive their family support. These findings have implications for commissioners and practitioners of primary and secondary care.

INTRODUCTION

Most people, particularly those dying from cancer, prefer to die at home.[1 2] Paradoxically, we increasingly die in hospitals and other institutions; fewer than a fifth of deaths in most developed countries, including the UK, are home deaths.[3 4] If current trends continue, by 2030 less than 10% of the population will die at home.[4] On the other hand, most of the healthcare that we receive in the last year of life is provided in primary care settings,[5] although for older age groups, institutional care plays an increasing role.[4]

The most rapidly increasing group of those who die are elderly. The proportion of deaths in the 65+ age group increased from 64% in 1974 to 83% in 2003. By 2030, over 86% of deaths will occur in this age group—with 44% of all deaths to people aged 85 years or over.[4] Older people are also the age group for whom home death is least likely in the UK (cancer and non-cancer deaths), and for whom home death rates are falling most rapidly.[4–6]

One factor probably driving increasing hospitalisation of death is fear. Occasional fears about death may be common among older people in poor health,[7] but barriers to home deaths include concerns about the quality of care, symptom and pain relief, reluctance to burden/availability of children, or for them to provide intimate care, and reluctance to have strangers intruding in one's home.[8] Such fears, including loss of control over one's final days,[9] are likely to increase as fewer people have close experience of death, accelerating hospitalisations.

Criteria for a 'good' death, although partly subjective, include: comfort, freedom from pain, retention of control, autonomy, independence, dignity and treatment as an individual and with respect.[3 10–12] Implicit in these definitions is an avoidance of the negative corollaries and fears associated with dying. Thus, understanding the fears that relate to dying are important in understanding how a 'good' death may be achieved. End-of-life strategies in several countries,[13] including the UK,[3] emphasise public and professional education to reduce fears and increase the proportion of home deaths. The latter will only be successful if underlying fears and concerns are understood and addressed. However, there is little population-based research, with most studies addressing specific groups, such as those already in receipt of palliative care services. Such information could facilitate policy makers and clinicians in addressing service shortfalls and providing realistic reassurance and information. There is a particular need to investigate the beliefs and needs of ethnic minority populations, since there is evidence that services for patients from ethnic minorities with life-limiting illness are often wanting, despite the existence of robust diversity policies.[14] A systematic review of the issues around access to palliative care services for ethnic minority populations[15] highlighted the paucity of research. However, there are indications that healthcare professionals perceive ethnic minority groups to have supportive informal care systems, which may lead them to delay referral or offer limited access to services.[16 17]

This study aimed to examine fears, including extreme fears, of the process of dying in both homogeneous and ethnically diverse population samples aged 65+ in Britain.

METHODS

Independent population surveys were conducted in 2007—8:

1. Face-to-face interview survey with people aged 65+ responding to the Office for National Statistics (ONS) Omnibus Surveys (www.ethnicfocus.com). ONS Omnibus is a rolling face-to-face interview survey with adults aged 16 +, living at home, based on a stratified random sample of postcodes across Britain (62% response rate).

2. Face-to-face interview survey with people aged 65+ responding to the Ethnibus Surveys (www.ethnicfocus.com). Ethnicity was defined for this study in terms of racial groups. Ethnibus is a monthly nation-wide, rolling quota survey of the main ethnic minority communities living in the UK. Ethnibus targeted the common ethnic groups for this study: Indian, Pakistani, Caribbean, Chinese people aged 16+, living at home, based on a statistically robust sample of ethnic minority populations in Britain (70% response rate).

While 41% (162) of the Ethnibus respondents spoke English as their main language, the remainder could speak some or fluent English. Ethnibus interviews were also conducted by trained, multilingual field-workers. They had been fully briefed by the research team about the aims of the study, the questionnaires and each questionnaire item in case of query. The wider aim of the study was to test the reliability and validity of the survey questionnaires in a British and an ethnically diverse sample; these results have been submitted for publication. The intent was to test the questionnaires in English speaking populations representing the population of Britain and ethnic diversity.

Power calculations were conducted for the proposed research which showed that 300 people in each sample would have 89% power, at 5% level of significance, of detecting the significant differences hypothesised. To ensure sufficient respondents aged 65+ from each survey source, two Ethnibus and two ONS Omnibus Surveys were commissioned.

RESPONSE RATES BY SURVEY
Ethnibus

The Ethnibus Survey was based on focused enumeration and stratification random sampling to ensure that samples are representative of the population. For sampling, Ethnibus used census information on ethnicity across postal sectors, and listed the postal sectors according to concentration. Systematic random sampling was then used to ensure an even spread of postal sectors with different concentrations. The number of addresses selected within the sector was proportional to the size of the ethnic concentration—for example, a high-concentration sector would yield a high number of interviews. These addresses form the starting point of the focused enumeration procedure.

Ethnibus targeted the following, most common, ethnic groups: Indian, Pakistani, Caribbean, Chinese people. Sample boosting on the doorstep was used to include greater numbers of people aged 65 and over. Interviews were obtained until the target of 400 was achieved (200 per wave agreed, two waves required to achieve 400). The response rate among people aged 65+, using this method, was 70%, with refusers simply not wishing to participate (no further details available).

ONS Omnibus sample

The ONS Omnibus Survey conducted face-to-face interviews with approximately 1200 adults aged 16 or over, living in private households in Britain, each month. The sampling frame used for Omnibus Surveys was the British Postcode Address File of 'small users' (all private household addresses). A new sample of 67 postal sectors was selected for each month and stratified by region, the proportion of households where the head of household is in the National Statistics Socio-Economic Classification (NSSEC) categories 1—3 (ie, employers in large organisations, higher managerial occupations, higher professional employees/self-employed), and the proportion of people who were aged over 65. The postal sectors were selected with probability proportional to size.

The combined response rate for the two ONS Omnibus Survey waves of all adults was 62% (2256 achieved interviews out of the 3660 eligible base; 589 of these respondents were aged 65+). This represented 61% (1130 achieved interviews out of the eligible sample (1864)) in wave 1 (December 2007; 288 of these were aged 65+—100% were administered our module) and 63% (1126 achieved interviews out of the eligible sample (1796)) in wave 2 (January 2008; 301 of these were aged 65+—100% were administered our module); 1% (23) of households at wave 1 and 1% (14) at wave 2 were households not known to be eligible: combined rate 23+14/3660=1%. Of the eligible households, 30% refused to participate (553) in wave 1 and also in wave 2 (540); the combined refusal rate was 553 +540=1093/3660=30% (no further details of refusers provided). There was no contact with 8% (158) in wave 1 and 6% (116) in wave 2; combined no-contact rate 158+116=274/3660=7%. ONS interviewers identified 589 eligible respondents in subsequently sampled households who were aged 65+ during the Omnibus interviews in December 2007 and January 2008, and administered our module to all of them (100% agreement to participate). They were representative of the population of Britain in relation to age and sex when compared with population estimates from the last census. Responders were broadly representative of mid-year population estimates in terms of age and sex.

Measures

Measures included the WHOQOL-OLD[18] sub-scale on death and dying. These items were: How concerned are you about the way in which you will die? How much are you afraid of not being able to control your death? How scared are you of dying? How much do you fear being in pain before you die? Each item has a 5-point response scale from 'Extremely'/'an extreme amount' to 'Not at all'. The sub-scale is summed, after reverse-coding where necessary, so that higher scores reflect better quality of life (QoL).

Also included was the Older People's Quality of Life Questionnaire (OPQOL), which contains 35 items, on 5-point response scales, covering social relationships and participation, independence, control over life, freedom, home and neighbourhood, psychological and emotional well-being, financial circumstances, religion and culture. Items are summed, after reverse coding where necessary; higher scores reflect better QoL. Items were derived from statements from older people about QoL in qualitative and survey research.[19] Cronbach's alphas for the OPQOL in the samples presented here all exceeded the 0.70 thresholds. Measures of health, social and psychological circumstances were included.[20]

Statistical analysis

χ^2 Tests and Spearman rho correlations were used to examine associations with fear of death and dying. Logistic regression was conducted to examine independent predictors of extreme fears of dying, given that occasional fears may be common.[7] For this, responses to the four dying items were recoded and dichotomised as: Extremely/very much afraid=1, Moderately/not very/not at all=0. This 'extreme fear' measure was the dependent variable.

Independent variables were entered in order of their theoretical importance. The level for statistical significance was $p<0.05$; tests for multicollinearity were satisfied. Multivariate analyses were adjusted for socioeconomic status. Religion was asked about in the Ethnibus survey only, and analyses were adjusted for religion in that sample.

The primary a priori hypothesis was that better QoL would be associated with reduced fears about dying. The rationale was that positive feelings about one's life (eg, as a 'good life') were likely to reduce anxieties about the challenges of later life (eg, about dying). Remaining associations tested were based on a priori hypotheses—for example, that having more help and support would alleviate stress, and thus reduce fears about dying; that older age and being faced with ill health and longstanding illness would increase fears about dying, given its potentially greater imminence.

RESULTS

Characteristics of samples

Thirty-eight per cent (152) of the Ethnibus sample were Indian, 29% (117) were Pakistani, 22% (86) were Black Caribbean and 11% (45) were Chinese. Most (94% (555)) of the ONS Omnibus sample were white British, 2% (12) were white other, and three people were Indian Asian. Just over half of each sample were women (52% (207) of Ethnibus and 55% (324) of ONS Omnibus respondents). Reflecting the younger demography of ethnic minority groups in Britain, 91% (363) of the Ethnibus sample were aged 65<75, compared with 55% (326) of the ONS Omnibus sample; the remainder were aged 75+. More Ethnibus respondents were married/cohabiting than widowed (58% (230) vs 49% (285) of the ONS respondents). Fewer Ethnibus respondents than ONS respondents were owner occupiers (52% (208) vs 73% (429)). Almost a third (30% (118)) of Ethnibus respondents lived in households with four or more people aged 18+, compared with 1% (5) of ONS respondents; and just 5% (19) of Ethnibus respondents lived alone, compared with about half of the ONS sample (48%, 286). The Ethnibus sample also had larger family networks: 64% (256) had four or more relatives who would help them practically, compared with about a third of ONS respondents (35% (176) and 34% (89), respectively). All differences reported above were significant using the χ^2 test, at least at the 0.01 level.

Attitudes to death and dying

Significantly more of the ethnically diverse Ethnibus sample (55% (220)) than of the ONS British population sample (13% (73)) had the worst QoL death and dying sub-scale scores. In addition, more Ethnibus than ONS respondents expressed one to four extreme fears about death (77% (310) vs 41% (229)) (table 1). These differences between samples were not explained by Ethnibus respondents being more likely to be younger.

Chinese people expressed the lowest levels of fear, although caution in interpretation is needed because of their smaller base numbers (table 2).

Better QoL was associated with reduced fear of dying in each sample. For the four death and dying items (item 6, concern about the way of dying; item 7, fear about not being able to control one's death; item 8, scared of dying; and item 9, fear of being in pain before death), the respective Spearman rank correlations with the OPQOL were: 0.135, 0.396, 0.310 and 0.020 (not significant with item 9: pain) for Ethnibus and 0.129, 0.120, 0.130 and 0.111 (all $p<0.01$) for ONS Omnibus. Age was significantly associated with each death and dying item for the ONS, but not the Ethnibus sample; the ONS correlations (rho)

with age were: 0.158, 0.158, 0.162 and 0.164 for items 6—9, respectively, in the ONS sample (all $p<0.01$): older age reduced fear of dying. Age differences between the samples did not explain differences in fears about dying.

In the Ethnibus sample only, having more relatives who would help with practical tasks if needed increased fear of dying and its processes on three of the four items: Spearman rho for items 6, 7 and 8, respectively, were: -0.128 ($p<0.05$), -0.134 ($p<0.01$), -0.136 ($p<0.01$) and -0.072 (not significant with item on pain). Number of people to turn to in a personal crisis showed similar patterns, again in the Ethnibus sample only. Poorer self-rated health status, having a longstanding illness, and difficulties walking 400 yards were all associated with increased fear of dying per se (item 8), in the Ethnibus sample only: Spearman rho, -0.113 for self-rated health, -0.098 for longstanding illness, and -0.123 for ability to walk 400 yards (all $p<0.05$).

In the Ethnibus sample, there was a significant inverse correlation between being in the Indian ethnic group and greater fear of not being able to control one's death (Spearman rho, -0.102, $p<0.05$). Chinese people were significantly less likely to express fears about dying than the other ethnic groups, on three of the four items: Spearman rho for items 6—8, respectively, -0.066 ($p<0.01$), -0.208, -0.166 ($p<0.01$), and 0.021 (not significant) for item 9 (pain).

Table 1 Attitudes to death and dying by sample

WHOQOL-OLD death and dying items	Total Ethnibus sample	ONS Omnibus sample
6. How concerned are you about the way in which you will die?		
A little/not at all	32 (126)	74 (424)*
Moderate amount	33 (134)	15 (87)
Extreme amount/very much	35 (140)	11 (63)
7. How much are you afraid of not being able to control your death?		
Slightly/not at all	30 (118)	67 (383)*
Moderately	27 (109)	15 (86)
Extremely/very	43 (173)	17 (101)
8. How scared are you of dying?		
Slightly/not at all	38 (151)	81 (465)*
Moderately	29 (117)	11 (66)
Extremely/very	33 (132)	8 (45)
9. How much do you fear being in pain before you die?		
A little/not at all	16 (66)	48 (278)*
Moderate amount	32 (126)	18 (100)
Extreme amount/very much	52 (208)	34 (193)
WHOQOL death and dying QoL sub-scale score		
18—20 (Highest possible QoL)	2 (9)	35 (197)*
15—17	15 (58)	29 (161)
12—14	28 (113)	23 (129)
<11 (Lowest possible QoL)	55 (220)	13 (73)
Expressed EV fear on 1—4 death and dying items		
0 (No EV fear on any items)	23 (90)	59 (331)*
1	28 (114)	23 (127)
2	23 (90)	10 (55)
3	16 (65)	5 (30)
4 (EV fear on all four items)	10 (41)	3 (17)
No of respondents	400	560—6

Values are % (n).
* $p<0.0001$, differences between Ethnibus and ONS Omnibus (χ^2 test).
EV, extreme/very much; ONS, Office for National Statistics; QoL, quality of life.

Table 2 WHOQOL-OLD death and dying sub-scale: summary by ethnic group (Ethnibus sample)

WHOQOL-OLD death and dying items	Indian	Pakistani	Black Caribbean	Chinese
6. How concerned are you about the way in which you will die?				
A little/not at all	31 (47)	21 (25)	37 (32)	49 (22)*
Moderate amount	34 (52)	36 (42)	27 (23)	38 (17)
Extreme amount/very much	35 (53)	43 (50)	36 (31)	13 (6)
7. How much are you afraid of not being able to control your death?				
Slightly/not at all	26 (40)	21 (25)	37 (32)	47 (21)**
Moderately	26 (39)	32 (37)	16 (14)	42 (19)
Extremely/very much	48 (73)	47 (55)	46 (40)	11 (5)
8. How scared are you of dying?				
Slightly/not at all	35 (54)	27 (32)	45 (39)	58 (26)*
Moderately	28 (42)	36 (42)	21 (18)	33 (15)
Extremely/very much	37 (56)	37 (43)	34 (29)	9 (4)
9. How much do you fear being in pain before you die?				
A little/not at all	16 (24)	12 (15)	19 (16)	24 (11)
Moderate amount	32 (49)	39 (45)	26 (22)	22 (10)
Extreme amount/very much	52 (79)	49 (57)	56 (48)	53 (24)
WHOQOL death and dying sub-scale score				
18—20 (Highest possible QoL)	2 (3)	—	4 (3)	7 (3)*
15—17	11 (17)	9 (11)	17 (15)	33 (15)
12—14	30 (46)	27 (31)	28 (24)	27 (12)
<11 (Lowest possible QoL)	57 (86)	64 (75)	51 (44)	33 (15)
No of respondents	152	117	86	45

Values are % (n).
* p<0.01,** p<0.001.
QoL, quality of life.

Logistic regression

Logistic regression was used to examine independent predictors of extreme fears of dying (dependent variable). Variables that correlated significantly with two or more of the death and dying items, or the sub-scale, were selected for entry as the independent variables: OPQOL score; number of relatives who would provide practical help when needed; number of people who they could turn to in a crisis; number of different social activities engaged in during the past month; adjusted for chronic illness (reported longstanding illness, disability, infirmity 1, none 0), age (continuous) and sex (male 1, female 0). Ethnicity was also entered; a dummy variable was created for each ethnic group in the Ethnibus sample (specific group=1, rest=0). Ethnicity in the ONS Omnibus sample was dichotomised, as a few were in ethnic minority groups (white British 1, rest=0). In initial modelling, socioeconomic status was included to adjust for its effects. Religion was asked about in the Ethnibus survey only, and initial modelling also adjusted for religion in that sample. They made no significant contribution to the modelling and were removed in the final models.

In the final models, respondents in both samples with better, compared with worse, QoL (OPQOL scores) had significantly

Table 3 Logistic regression showing independent associations (OR, 95% CI with predictors on extreme fear of dying, adjusted by age, sex and ethnic status[†])

	Ethnibus	ONS Omnibus
Quality of life (OPQOL total; higher scores=better quality of life)	0.924 (0.898 to 0.951)**	0.981 (0.966 to 0.996)**
Actual number of relatives who would help if needed with everyday chores, running errands, odd jobs	1.134 (1.010 to 1.274)*	0.977 (0.934 to 1.023)
In a serious personal crisis, actual number of people could turn to for comfort/support	1.040 (0.955 to 1.133)	1.021 (0.995 to 1.048)
Actual number of different social activities in last month	0.870 (0.718 to 1.054)	1.102 (0.978 to 1.242)
Reported longstanding illness (1 vs none 0)	2.024 (1.158 to 3.535)**	1.323 (0.891 to 1.965)
Age (continuous)	1.015 (0.944 to 1.091)	0.957 (0.930 to 0.985)**
Sex (male 1 vs female 0)	0.843 (0.500 to 1.421)	0.887 (0.615 to 1.279)
Ethnic status		—
Indian (1 vs rest 0)	1.770 (0.776 to 4.037)	—
Pakistani (1 vs rest 0)	2.286 (0.953 to 5.482)	—
Black Caribbean (1 vs rest 0)	1.502 (0.618 to 3.649)	—
Chinese (1 vs rest 0)	0.542 (0.255 to 1.152)	—
White British (1 vs rest 0)	—	0.973 (0.442 to 2.142)

Values are OR exp B (95% CI). Extreme fear of dying: 1=expressed extreme/very much fear on 1—4 death and dying items versus rest=0.
* p<0.05; ** p<0.01.
†The final Ethnibus and ONS models were both statistically significant at p<0.001.
OPQOL, Older People's Quality of Life Questionnaire.

reduced odds of having extreme fears of dying (ethnically diverse sample, OR 0.924; 95% CI 0.898 to 0.951; British population sample, OR 0.981; 95% CI 0.966 to 0.996; both p<0.001). In the latter sample only, older age was protective (OR 0.957; 95% CI 0.930 to 0.985; p<0.001), while in the Ethnibus sample, having a longstanding illness (OR 2.024; 95% CI 1.158 to 3.535; p<0.05) and having more relatives to help them (OR 1.134; 95% CI 1.010 to 1.274; p<0.05) increased fears about dying (table 3).

Ethnicity was not significant, although the ORs reflected the patterns reported in the correlation analyses. In particular, Pakistani people had over twice the odds of having extreme fears about death and dying, although the CIs were wide, and Chinese people had reduced fears (see table 3 for details).

DISCUSSION

This is the first study to examine fears about dying in a British population sample aged 65+ (ONS Omnibus) and in an ethnically diverse population sample aged 65+ in Britain (Ethnibus). Over seven in ten Ethnibus respondents compared with fewer (about four in ten) ONS respondents expressed at least one extreme fear of death and dying; 55% of Ethnibus respondents, compared with 13% of ONS respondents, had the lowest death and dying sub-scale scores, indicating poor QoL on this domain. Differences in fear between samples held when age was controlled for.

In confirmation of expectations, higher QoL protected against fears about dying in both samples. In the Ethnibus sample, having larger networks of relatives who could help independently increased fears about dying. Perhaps in this sample, with the largest networks of relatives, the latter led to less efficient and coordinated help. This is consistent with social network theory, which holds that, in a crisis, more integrated, smaller networks of people are more effective than wider networks in coordinating support.[21] The different meanings of illnesses in different cultures may also have played an important role in the fears expressed.[22]

In the Ethnibus sample only, respondents who reported a longstanding illness had just over twice the odds of having extreme fear compared with those with no reported long-standing illness. Minority groups with chronic diseases may find it more difficult than others to access appropriate health services effectively, increasing anxieties. Increased age reduced the odds of expressing fear of dying only among the ONS sample, suggesting that they increasingly came to terms with death, and its processes, with older age.

The strengths of the research were its older population coverage, inclusion of ethnic diversity and good response. However, the research had several limitations. The main method

Current research questions

▶ Do fears about dying vary by sociodemographic group or by having a longstanding illness?
▶ Does social network and support size influence fears about dying?
▶ Can having better quality of life reduce fears about dying?

of sampling sufficient numbers of people in ethnic minority groups is focused sampling in areas where the target groups are concentrated, which detracts from the random nature of national sampling strategies. The English language version of the questionnaire was tested for reliability and validity in both samples (submitted for publication), but it was not translated into other languages spoken. Bilingual interviewers were used instead for the small number who did not speak fluent English. The translation, back-translation and testing for cultural equivalence is a major research exercise in each target group and outside the remit of this research. In addition, the sampling only included people living in the community. The research did not address preferences for place of death, but it did provide evidence about older people's fears, at population level, about dying, not being able to control their death, the way in which they will die, and being in pain. This information is important for practitioners and policy makers when planning how to increase the proportion of home versus hospital deaths, in line with the government strategies to improve end-of-life care. A shift in place of death is only likely when high-quality community palliative care services are uniformly accessible and people's fears are addressed.

Main messages

▶ Over seven in ten of our ethnically diverse sample aged 65+ expressed up to four extreme fears of dying, compared with about four in ten of the ethnically more homogeneous population sample aged 65+; Chinese people expressed the least fear of death and dying.
▶ Having better quality of life had a protective effect against fear of dying, and its processes, in both samples.
▶ Older age was protective against fear of dying in the more homogeneous sample only; in the ethnically diverse sample, having a longstanding illness and having more relatives to help them increased fear of dying.

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