Facing death and grief: revolution needed

Despite growing public interest in death, support for end-of-life care and bereavement remains inadequate. We urgently need a revolution: a community centred, public health approach to the social processes of dying and mourning, backed by properly funded palliative care, writes **Lucy Selman**

Over 600 000 people die each year in the UK, leaving more than six million grieving. On the surface, attitudes to death seem to be shifting: witness the rise of death and grief cafes, festivals and annual awareness events, and the formation, in 2018, of a national association of end-of-life doulas.

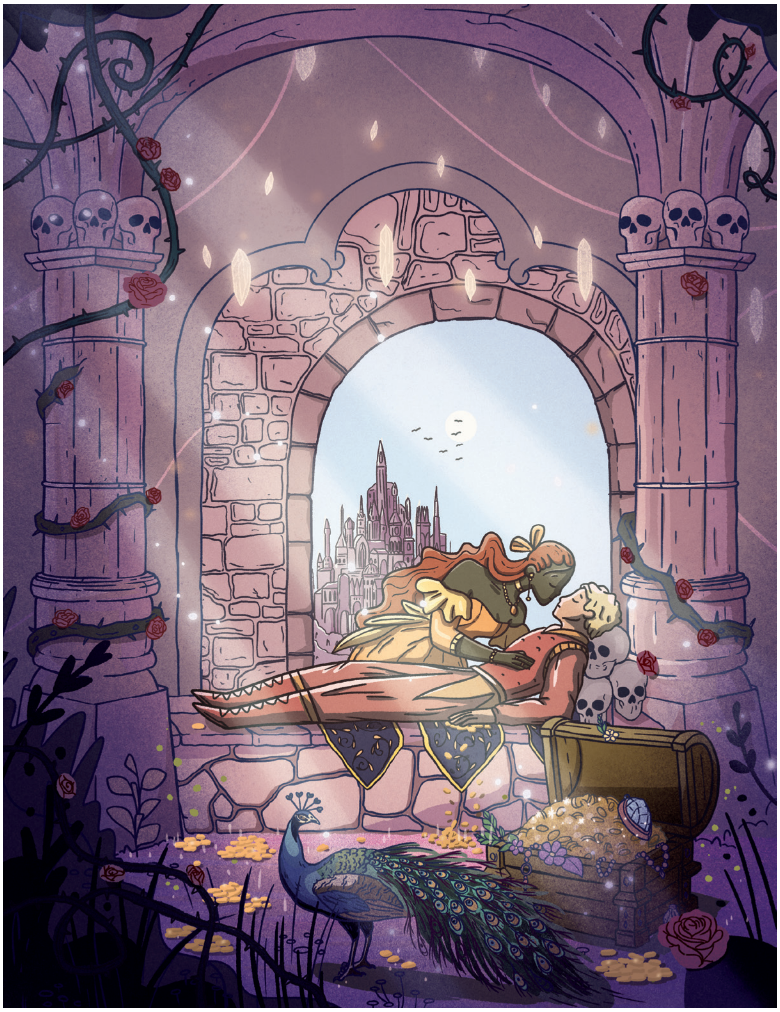
But beneath the surface are major gaps in public knowledge and confidence around death, meaning that the practical, emotional, and spiritual wishes of dying people often remain unexpressed and unfulfilled. Meanwhile, futile medical interventions at the end of life persist as a global failure.

Death is as natural a process as birth, yet much of society refuses to see it that way. This discomfort shows in our behaviour: we avoid seriously ill or bereaved people, and we shy away from discussing our own end-of-life wishes with family, friends, and health professionals. These attitudes are deeply intertwined with cultural and systemic issues, from harmful misconceptions about grief to the medicalisation of dying.

Recent debates on assisted dying have put an intense spotlight on the failures of our attitudes towards and systems for end-of-life care and bereavement support, and the MP Rachael Maskell has announced a commission to improve palliative care. It's a timely and vital move, but the commission must tackle the wider structural issues that shape how people die and grieve. Just as social determinants—income, employment, housing, education, disability, and social support networks—shape our health in life, they also shape how we die.

Without a far reaching and integrated public health approach to end-of-life care and bereavement we will only ever be tinkering at the edges of a complex system.

Seriously ill and dying people spend only about 5% of their final year of life in the direct care of health services, with friends, family, and community members without healthcare training providing much of the remaining support. Between 75% and 90% of home based care at the end of life is provided by unpaid carers, often family. It is time to shift focus and put families and communities front and centre in the management of dying, bereavement, and grief. But for this role they need comprehensive resources, education, and support.



ROWENA SHEEHAN

Death is as natural a process as birth, yet much of society refuses to see it that way

Talking about dying…

Covid-19 forced a global reckoning with mortality, deeply personal for many people. A 2021 survey by funeral directors Co-op Funeral Care suggested a shift in attitudes: 20% of adults felt more comfortable talking about grief, 47% reported increased compassion towards people in grief, and 54% felt more conscious of their own mortality. But this awareness has not led to action: only 14% of UK adults have actually spoken to anyone about their end-of-life wishes.

Many people struggle to make informed decisions around end-of-life care because medical jargon and processes are so opaque. Mistrust of healthcare providers is another barrier. Nearly a third of UK adults doubt their end-of-life preferences would be respected, making them less likely to express their wishes.

…and grieving

Conversations after a death are vital too, but grief is a uniquely challenging topic. Support of family, friends, and communities is fundamental but is too often lacking. Many of us fear "saying the wrong thing" and don't know how to offer support; a quarter of us avoid talking to someone who is grieving, compounding their isolation.

Embarrassment and fear of causing offence may stem from stigma or misguided ideas about grief. For example, the outdated psychoanalytic idea that grief happens in "stages" and is time limited is often contrary to experience. Cultural norms also shape grief: in the US "prolonged grief disorder" is a diagnosis for intense grief after 12 months, while in Egypt tearful grieving years after a death is considered healthy.

That there is a hierarchy in grief is also a common view. This could reflect societal efforts to control or compartmentalise grief, but sanctioning some forms of loss response while disenfranchising others, as often happens when a baby dies before birth, can lead people to compare their grief to that of others and worry they're grieving too much or too little. Such mixed societal expectations mean bereaved people can believe they are failing, abnormal, or unworthy of support, preventing them from expressing their feelings or asking for help.

Medicalisation…

The medicalisation of death has shifted the process away from homes and communities and into healthcare. Dying has become a clinical process, sidelining emotional, social, and spiritual dimensions once integral to end-of-life experiences. The loss of religious and communal rituals in the global north has deepened our distance from death. The funeral business has commercialised mourning, and grief has become professionalised—the remit of trained counsellors. As a result we may not recognise and accept when death is near and may be more fearful of death and its aftermath.


ARNO MASSEE/SPL

The loss of religious and communal rituals in the global north has deepened our distance from death

Healthcare professionals also struggle to face death and the limits of what medical science can achieve, not least because it means facing their own mortality. But, when clinicians avoid discussing death and patients' preferences for the end of their lives, patients and their families lose crucial opportunities to connect, prepare, and make informed decisions. Clinical education and training must ensure that future clinicians have generalist palliative care skills, know when to consult specialist palliative care, and, crucially, are unafraid and supported to have tender conversations about dying, the bedrock of person centred care.

▶ bmj.com

Death doulas could lead end-of-life care

Non-medical, community based practitioners could have a central role in demedicalising and deinstitutionalising dying to help people navigate the holistic care they need, writes **Marian Krawczyk**

…and deprioritisation

End-of-life care hasn't just been medicalised, it has been deprioritised. Healthcare systems and education focus on cures and life extension, sometimes at the expense of quality of life and compassionate care for dying people.

In the UK around 90% of dying people would benefit from palliative care, but 25% don't get it. Demand is set to rise 25% over the next 25 years as lifespans increase and health conditions grow more complex, yet the sector is already critically underfunded. Just a third of UK hospice funding comes from the state, with the remaining £1bn raised annually through charity shops, fundraising events, and donation.

This funding gap sends a clear message: care for dying people is less valued than aggressive treatments and high tech medical advances. (It's surely no coincidence that 9 in 10 of the clinical and care workforce in UK hospices are women, reflecting a long history of "women's work" being undervalued.)

Patchwork funding leaves rural and other underserved communities with glaring gaps in care, especially for children. As demand for palliative care rises, the case for proper government funding for end-of-life care provision in care homes and the community, including hospices, grows more urgent.

In the meantime, stark inequities exist in access to hospice, palliative, and bereavement services. Marginalised communities face the greatest number of hurdles in accessing support when compassion is most needed. Ethnic minority groups, in particular, encounter language barriers, inadequate outreach, and a shortage of culturally competent providers. Thirty per cent of people from ethnic minority groups but just 17% of white people say they don't trust health professionals to provide high quality end-of-life care.

To close such gaps, hospice and palliative care services and interventions should be co-produced with, and for, underserved communities. Access to advance care planning, for example, can be improved through use of participatory, arts based methods and by collaborating with trusted community organisations to ensure that information and support are culturally appropriate and accessible in multiple formats and languages.

A public health approach

Access to services and interventions, though necessary, is nowhere near enough. Death, dying, care giving, and bereavement are essentially communal events and need to be reclaimed as such. This demands a shift from needs assessment and service provision to genuine cross-sector partnerships with local authorities, social care, the voluntary and community sector, and communities.

We must harness and support community assets—the social, cultural, and natural resources embedded in our communities—and prioritise relationship based approaches to care. Partnerships between healthcare, social care, local authorities, the voluntary sector, and communities aren't new. Since 2022 every integrated care board in England has had a legal duty to commission adequate palliative and end-of-life care services, including bereavement support.But provision varies across boards.


HENNY ALLIS/SPL

Debate continues over what effective integration should look like and what it needs. Critics argue that it risks shifting responsibility for health inequities to the community. Others argue that overcoming barriers to integration, such as the funding precarity faced by community organisations, improves service provision and reduces health inequities through building neighbourhood resilience and collective capacity.

Within palliative and end-of-life care, community models such as the Compassionate Cities charter offer a formalised framework to support public health approaches, but it can be a challenge to shift a system to community engagement and development after a prolonged focus on service provision.

Death and grief literacy

The media play a key role in public understanding but often sensationalise or sanitise end-of-life experiences. In dramas, for example, CPR is often presented with unrealistic outcomes that reinforce misconceptions. Rarely shown are the experiences of elderly patients with multimorbidity—the majority in real hospitals—whose outcomes after CPR are notoriously poor.

Clinicians can model acceptance of dying, build trust, and show the public that it is safe to ask questions

Promoting literacy in death and grief is a key part of a public health approach. Arts and culture offer vital entry points into what can be challenging topics. Most UK children will be bereaved, yet grief and death are largely absent from lessons. Grief education should be made a core part of the national curriculum, now under debate in parliament.

Clinicians too have a critical role in reshaping attitudes and so must build their own death and grief literacy. By discussing end-of-life care openly and challenging common misconceptions, they can model acceptance of dying, build trust, and show the public that it is safe to ask questions and voice doubts and fears. Care must be emotionally aware, culturally sensitive, compassionate, and person centred—and this must be reflected in clinical education. Clinical leaders must acknowledge the emotional weight of dealing with death and grief and offer support, encouraging sharing, peer support, and remembrance. By making space for grief and vulnerability in professional life we nurture the human side of being a clinician.

Changing societal attitudes to death and grief demands bold, multifaceted action. We need proper state investment in hospices, palliative care, and bereavement support and a determined effort to close access inequities. This must go hand in hand with a public health approach that is rooted in collaboration, integration, and the recognition of community strengths. But none of this will succeed without death and grief literacy: the knowledge, skills, and confidence to face mortality with our eyes open.

Perhaps the final, and hardest, piece of the puzzle is the courage to reach out to one another when it matters most.

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bmj.com

End-of-life care needs decolonising

Rich knowledge and practices of community and family based care for dying people in formerly colonised countries should inform a reimagination of palliative care globally, say **Christian R Ntizimira and colleagues**

HENRY PEACH ROBINSON: FADING AWAY, 1858/V&A

OPINION Anita Hannig

Demedicalising dying

Medicine must accept death as a natural part of life

Over the course of the 19th century, across North America and Europe, death slowly migrated from the home to the hospital and came to be viewed as a medical event, and no longer primarily a religious one.

While the medicalisation of dying has alleviated physical, emotional, and spiritual suffering and sometimes has extended lives, something meaningful has been lost along the way. We have increasingly become detached from the social and spiritual importance of death and reluctant to accept it as a natural part of life. Despite the strides made by hospice and palliative care in demedicalising death, overtreatment of dying people in the US and Europe is widespread. Medicine should adopt a more compassionate approach that rehumanises dying, rather than focusing on extending life at all costs.

Initially conceived as refuges for poor people, hospitals gradually became places of healing—and for dying. With the rise of professional medicine in the US and Europe, doctors came to treat death first and foremost as a medical concern. In 1800, the US had just two hospitals, but by 1909 this number had soared to over 4300. Doctors soon considered it their professional obligation to remain with patients with incurable conditions until the end, ministering hope and whatever limited medicines they had available.

What began in the 19th century as an early sense of duty to tend to the dying eventually led to the wholesale medicalisation of death that we see today. Medicalisation describes a process by which ordinary aspects of human existence such as death or grief become redefined as medical problems. Once death fully entered the jurisdiction of medicine, doctors felt compelled to provide treatment for it.

Today, medical mastery over death seems to have become a goal in itself. Death is increasingly seen as a failure, rather than a natural stage of life. With the growing use of ventilators—originally developed for intensive surgeries—and devices that replace the heart's beating function, medicine now has an unprecedented ability to manipulate death. In the US, this seemingly endless capacity to stretch life is fuelled in part by a fee-for-service model, which incentivises doctors to pursue costly, life prolonging treatments. Currently, a quarter of Medicare's spending is on patients in their final year of life.

Clinicians are uniquely positioned to advocate for compassionate, home based, end-of-life care

More widely, unrealistic expectations of medicine and pressure from families lead to requests for life prolonging treatments that might not be in the patient's best interests. All this compounds the challenges that dying patients face today: professionals who approach the topic of dying with euphemisms and families wholly unfamiliar with what dying looks and feels like.

Since the 1970s, hospice and palliative care have driven a critical paradigm shift away from harmful life extending measures, focusing instead on accepting and easing the process of dying. But they remain far too siloed and stigmatised, especially in hospice care. In the US, patients lose access to their primary care doctor when they enter a hospice—a troubling, quiet signal that, since cure is no longer possible, the duty of care is over. The medical community should reinject humanity into the process of dying and retrain its focus to accompany dying people with care.

Medical professionals have an integral role in shaping societal attitudes to dying. Beyond their role as healers, clinicians are uniquely positioned to advocate for compassionate, home based, end-of-life care and advance care planning—ensuring that every patient's voice is heard and their wishes honoured. By expertly guiding families and patients through the dying process and explaining the importance of letting go and saying a proper farewell, doctors can foster a greater acceptance of death. Comprehensive training in palliative and end-of-life care is essential to equip them with the confidence and compassion needed to fulfil this role. A deeper awareness of our mortality, coupled with a better understanding of patient rights, could improve everything from grief counselling to hospice care.

Anita Hannig, visiting research scholar, Brandeis University, Waltham, MA, USA

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Why I founded a death cafe

Susan Bewley, emeritus professor in obstetrics and women's health, tells **Kathy Oxtoby** why she hosts tea parties with a difference

Every few weeks Susan Bewley meets with people, often strangers, to drink tea, eat cake, and discuss death. She hosts a death cafe—a group directed discussion of death with no agenda, objectives, or themes.

For Bewley, musing on death has added more pleasure to her life. "I've been enjoying things more exquisitely—the smaller things in life—whether it's literally smelling the roses or being more present, in nature and in relationships," she says. The death cafe has also "added more detail, texture, and nuance to what I believe about death," she adds.

Death cafes were started in the UK by Jon Underwood, based on the work of Swiss sociologist Bernard Crettaz. An international social franchise—there are more than 18 500 death cafes in 90 countries—the objective is "to increase awareness of death with a view to helping people make the most of their (finite) lives."

Bewley is an emeritus professor in obstetrics and women's health at King's College London, a retired obstetrician, and retired forensic sexual offences examiner. She finds the death cafe to be "a safe space to explore death, get over the taboos, and use conversations about death to reflect on living well in the little time we've got."

"Being in a room of strangers means that in some ways you're freer to say anything—or nothing—with no expectations to weigh upon you," she says.

At the age of 60 Bewley decided to spend a year doing 60 new things, which included thinking about death. "I wanted to 'prepare' and address unfinished business," she says.

She discovered death cafes on the internet. "I thought I'd like to go to a death cafe and find a neutral space to talk about preparing for death. But all the cafes were far away. I had a lightbulb moment and decided I'd better set one up."

While out dog walking, she discussed the idea with a friend, and, along with two other local people, they started a death cafe in a community centre in London two years ago, using guidance from deathcafe.com.

It makes me think, see, and feel things differently

RICHARD H SMITH

HOW TO MAKE A CHANGE

- Find some likeminded people
- Find a venue—although death cafes can also be run online
- Visit one or two different death cafes to get a flavour of their differences and similarities
- Guidance on how to set up a death cafe is available on the website deathcafe.com

Death cafes are non-commercial and not-for-profit but attendees can make donations. Many are run monthly. They are self-organised, grass roots initiatives that differ in the way they are run, with their own characteristics, and can be large, small, and even online.

At the death cafe Bewley helps run, after introductions are made, two or three topics are chosen, which could relate to current news or one of the rituals around death. People take part in informal discussions over tea and cake, and the four founders facilitate in turn.

The death cafe is a discussion group rather than a grief support or counselling session. "In a way they are more powerful for being 'ordinary,' and not having anyone who is an expert," she says. "As a facilitator I have to be careful not to be a doctor and avoid taking charge. I have to restrain myself from thinking I know better. When facilitating I try to make people welcome and comfortable, and make sure people do not interrupt each other and that those who haven't spoken get the opportunity to do so," Bewley says.

Discussions are thought provoking and inspiring. "People share stories and advice on the practical aspects of death. They might talk about suicide or the last holding of a demented parent's hands. It makes it terribly real for everyone to hear experiences. People are often close to tears, but there's also laughter, recognition, and deep listening," she says.

The death cafe is an extraordinary, ordinary setting in which Bewley says she has learnt a lot. "Every time I come home from the death cafe my life has been enriched by that hour and a half I've spent with other people. It makes me think, see, and feel things differently, and is so rewarding."

Bewley's working life revolved around "that other great ritual: birth. And there are connections between birth and death," she says. For Bewley, the death cafe is a space to reflect on her professional relationship with death. "For me, it's a bit about letting go of the career as well," she adds.

She recommends setting up or visiting a death cafe as something doctors might enjoy and benefit from. "You see the best in people," she says. "It's beyond the curative and professional attention. It's about the unpaid, meaningful, caring connections you can make. It's constantly intriguing. It's raw and straightforward. There's no agenda, targets, resolution, or problem solving. It's talking and listening—that simple."

Bewley hopes clinicians will look at the death cafe website and if they're curious, dip their toe in. "There's a need for tea, cake, and conversations about death," she says.

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ORIGINAL RESEARCH Population based cross sectional study

Alzheimer's disease mortality among taxi and ambulance drivers

Vishal R Patel,[1 2] Michael Liu,[1] Christopher M Worsham,[1 3] Anupam B Jena[1 3 4]

Objective To analyse mortality attributed to Alzheimer's disease among taxi drivers and ambulance drivers, occupations that demand frequent spatial and navigational processing, compared with other occupations.

Design Population based cross-sectional study.

Setting Use of death certificates from the National Vital Statistics System in the United States, which were linked to occupation, 1 January 2020-31 December 2022.

Participants Deceased adults aged 18 years and older.

Main outcome measures Among 443 occupations studied, percentage of deaths attributed to Alzheimer's disease for taxi drivers and ambulance drivers and each of the remaining 441 occupations, adjusting for age at death and other sociodemographic factors.

Results Of 8 972 221 people who had died with occupational information, 3.88% (348 328) had Alzheimer's disease listed as a cause of death. Among taxi drivers, 1.03% (171/16 658) died from Alzheimer's disease, while among ambulance drivers, the rate was 0.74% (10/1348). After adjustment, ambulance drivers (0.91% (95% confidence interval 0.35% to 1.48%)) and taxi drivers (1.03% (0.87% to 1.18%)) had the lowest proportion of deaths due to Alzheimer's disease of all occupations examined. This trend was not observed in other transportation related jobs that are less reliant on real time spatial and navigational processing or for other types of dementia. Results were consistent whether Alzheimer's disease was recorded as an underlying or contributing cause of death.

Conclusions Taxi drivers and ambulance drivers, occupations involving frequent navigational and spatial processing, had the lowest proportions of deaths attributed to Alzheimer's disease of all occupations.

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Introduction

Deaths attributed to Alzheimer's disease have doubled over the past three decades and will likely increase as the population ages.[1] We aimed to evaluate Alzheimer's disease mortality across various professions by use of population based US mortality data including data for occupation.

Methods

Mortality data were obtained from the National Vital Statistics System, a population based registry of all deaths in the US. Additionally, death certificates included a field for reported the occupation in which the decedent spent most of their working life.

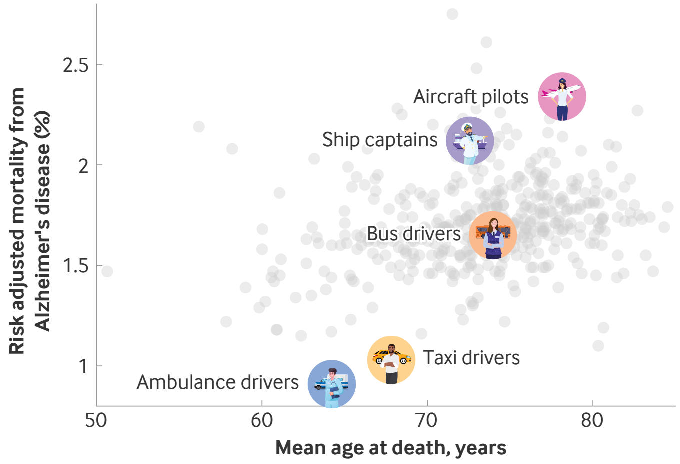
Our final dataset included 443 occupational groups. We focused on taxi drivers and ambulance drivers as occupations involving extensive day-to-day navigation, with often unpredictable, real time navigational demands. All other occupations formed a comparison group. Bus drivers, aircraft pilots, and ship captains were used as a more specific comparison group because these are transportation based occupations, but they rely on predetermined routes. We excluded people with unknown occupational data (4.8% of population studied), students attending high school or college, and occupations with fewer than 250 overall deaths per year.

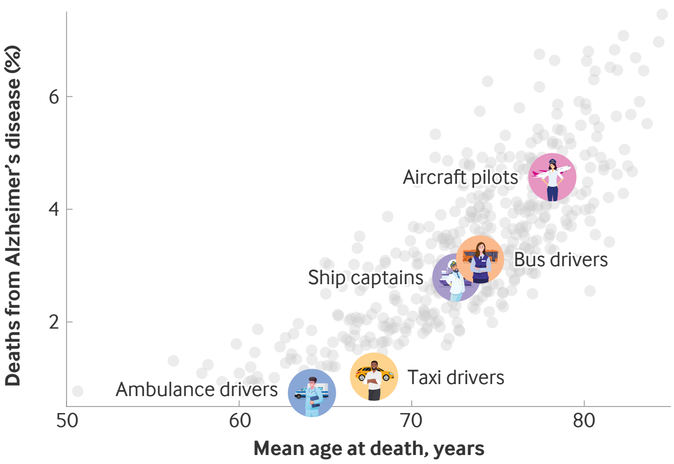
The primary outcome was the percentage of deaths for each occupation with underlying cause of death from Alzheimer's disease (ICD-10 code G30).

For each occupation, we calculated the percentage of deaths due to Alzheimer's disease and the mean age at death in years (ie, average life expectancy). We accounted for the person's age at death.[9] We then used multivariable logistic regression at the individual level to estimate risk adjusted percentages of deaths from Alzheimer's disease for each occupation, adjusting for age at death, sex, race and ethnic group, and educational attainment. Mortality odds ratios from the multivariable model were also ranked from lowest to highest across occupations to facilitate identification of occupations with the lowest risk of death from Alzheimer's disease. Chief executive was arbitrarily chosen as the reference group in regression models. We used four tests to assess the robustness of our comparisons.[10]

Results

We identified a total of 8 972 221 people who had died who had occupational information. Of the selected navigational occupations, lowest mean age at death was 64.2 years (standard deviation 14.7) in ambulance drivers and 67.8 years (14.5) in taxi drivers. These occupations were of predominantly men with the exception of bus drivers. Other than aircraft pilots, most people in navigational occupations had a high school education or less.





Of all people studied, 3.88% (348 328/8 972 221) were identified as having an underlying cause of death from Alzheimer's disease. The unadjusted percentage of deaths from Alzheimer's disease was 1.03% (171/16 658) among taxi drivers and 0.74% (10/1348) among ambulance drivers; and was 3.11% (1345/43 295) for bus drivers, 4.57% (387/8465) for pilots, and 2.79% (117/4199) for ship captains. Notably, deaths from underlying cause of Alzheimer's disease were lower for taxi and ambulance drivers than for other occupations with a similar mean age at death.

The two occupations with the lowest adjusted percentage of deaths from Alzheimer's disease were ambulance drivers (0.91% (95% confidence interval (CI) 0.35% to 1.48%)) and taxi drivers (1.03% (0.87% to 1.18%)). By contrast, the adjusted percentage of deaths from Alzheimer's disease for the general population was 1.69% (95% CI 1.66% to 1.71%), P<0.001, for comparisons to ambulance drivers and taxi drivers. Similarly, across all occupations the adjusted odds ratio of death from Alzheimer's disease was lowest among taxi and ambulance drivers (odds ratio 0.56 (95% CI 0.48 to 0.65) for both categories combined relative to chief executives).

Ambulance and taxi drivers consistently had the lowest proportional Alzheimer's disease mortality when restricting our analysis to individuals who died aged 60 years or older and when Alzheimer's disease was specified as either an underlying or contributing cause of death. The pattern of lower Alzheimer's disease mortality was not observed in other occupations related to transportation with fewer navigational demands such as aircraft pilots and ship captains. The adjusted percentage of deaths from Alzheimer's disease for bus drivers was 1.65 (95% CI 1.56 to 1.74) (P<0.001 for comparisons to ambulance drivers and taxi drivers, respectively), for pilots was 2.34 (2.11 to 2.58) (P<0.001 for comparisons to ambulance drivers and taxi drivers), and for ship captains was 2.12 (1.73 to 2.50) (P<0.001). Finally, the pattern of low Alzheimer's disease mortality among taxi and ambulance drivers was not observed when forms of dementia (vascular and unspecified) other than Alzheimer's disease were evaluated, suggesting the possibility of changes mediated by the hippocampus in taxi and ambulance drivers lowering Alzheimer's disease risk.

Discussion

This population based study in the US found that taxi and ambulance drivers, whose occupations require substantial navigational memory, had the lowest Alzheimer's disease mortality of all occupations. One hypothetical explanation of this notable finding is that these occupations are associated with neurological changes (in the hippocampus or elsewhere) that reduce Alzheimer's disease risk.

Consistent with our findings, a landmark neuroimaging study showed that taxi drivers in London, UK, developed enhancing functional changes in the hippocampus, while a follow-up study of London bus drivers did not show the same hippocampal changes, possibly due to the pre-determined nature of bus drivers' routes. If a hypothetical link between hippocampal changes in taxi drivers and future risk of death from Alzheimer's disease exists, our findings among US taxi and bus drivers are consistent with studies of hippocampal changes (or lack thereof) among their London counterparts.

Our study design has several limitations that limit causal inference and result in the possibility of other explanations, including unmeasured confounding from biological, social, or administrative factors.

Our large scale findings suggest a potential link between the demands of taxi and ambulance driving and reduced Alzheimer's disease risk; however, this study design does not permit interpretation of a causal effect between occupations and risk of Alzheimer's disease mortality or neurological changes in the hippocampus.

Patient and public involvement Patients were not involved in the design of the study; see full paper on bmj.com for details.

ROWENA SHEEHAN

Ethics of posthumous scholarly authorship in the sciences

David Nunan and **Jeff Aronson** suggest that formal criteria are needed to determine eligibility of deceased authors and for dealing with associated ethical problems

Posthumous authorship poses problems in multiple ways in different disciplines. Max Brod, Franz Kafka's literary executor, published *The Trial*, *The Castle,* and *Amerika* after Kafka's death, despite Kafka's instructions to burn his unpublished works. These works have enriched the literary corpus and have influenced many writers since, but the ethical problem is of concern.

Other notable literary cases include the posthumous publication of letters of Jane Austen, causing distress to members of her family, and Ted Hughes's publication of Sylvia Plath's poems in a disputed edition amid controversy about her suicide. By contrast, posthumous publication of J R R Tolkien's papers by his son Christopher seems to have raised no difficulties.

However, despite interest in posthumous literary publication, little has been written about it in scholarly science. Calls for a clear policy[1] have not resulted in uniform comprehensive guidelines, and occasional online discussions have shown that there is no consensus about how deceased colleagues should be credited in publications: some advocate coauthorship; others acknowledgment only.[2 3] Nor are there clear guidelines on how an author's death should be noted.

Calls for a clear policy have not resulted in uniform comprehensive guidelines

KEY MESSAGES

- No comprehensive guidelines exist for posthumous authorship in scholarly scientific publications
- Death of a contributor raises several ethical questions, and some advocate posthumous acknowledgment rather than coauthorship
- Existing authorship criteria can be used to determine whether a deceased person should be included as an author or only acknowledged
- Requirements for noting an author's death in publications should be standardised and included in established publishing guidelines

The International Committee of Medical Journal Editors (ICMJE) does not mention posthumous inclusion in its guidance on criteria for authorship of published papers.[4 5] Nor do guidelines from the Committee on Publication Ethics (COPE) specifically mention posthumous authorship,[6] although the committee has occasionally commented on specific cases[7] and also reported a case highlighting the possibility of introducing errors that would otherwise have been corrected by the deceased author.[8]

Other important documents on research integrity have been published by the UK Research Integrity Office,[9] Universities UK,[10] and a House of Commons Science and Technology Committee[11]; none, however, mentions posthumous

Ethical and practical problems raised by posthumous authorship, with proposed solutions

Features causing ethical problems	Proposed solutions
Difficulty in determining whether a contributor should be a coauthor or simply acknowledged and how increasing time after death affects that decision	Criteria for posthumous authorship should be included in guidelines; journals should seek a statement from the corresponding author attesting that, to the best of their knowledge, the deceased individual would have met the criteria for coauthorship had they survived and that all the other coauthors agree
Disagreement among coauthors about the inclusion of a deceased contributor's name, either as a coauthor or in an acknowledgment	If, after discussion of editorial criteria, the authors cannot agree, we suggest that a statement should be included in, for example, the list of contributors, acknowledging the posthumous individual and the authors' disagreement
The impossibility of obtaining an individual's posthumous consent to either coauthorship or acknowledgment, or for a coauthor to have posthumously approved the final version	Impose an editorial time limit between the date of death and submission of the relevant publication (say 1 year), after which coauthorship should be converted to acknowledgment
Failure to state that a deceased coauthor did or did not approve the final version	Acknowledgments stating whether approval was obtained should be standard
Failure to acknowledge that a coauthor has died	Publication submission systems, such as ScholarOne, should ask submitting authors to declare whether any coauthors are deceased; the death of a coauthor should be routinely acknowledged, giving the date; the use of a footnoted obelus to mark the names of deceased coauthors (eg, "X died on [date]") should be considered
Death of an author between online and print publication	Acknowledge the death in the print version and if the deceased author was the corresponding author seek a replacement
Prepublication death of an author who has been named as a guarantor of an accepted paper	Ask a coauthor or, in the case of single authorship, a proxy (eg, a colleague), to act as guarantor
The possibility of errors occurring during the posthumous preparation of a single author publication	The death should be acknowledged and a proxy invited to act as guarantor and corresponding author and to check the proofs for errors, with an acknowledgment; otherwise consider withdrawing the publication
Not all of a deceased coauthor's competing interests may be known to the other authors	A separate statement should be included to that effect
Posthumous publication of a foreign language translation of a paper, whether originally published posthumously or not	As in general, publishers should consult at least the corresponding author before publishing a translation or agreeing to its publication, even if they have the right to do so without consultation. A translation should usually preserve the names of the original authors
Inappropriate use of an author's name to enhance the reputation of the work itself or of other coauthors	Impose a time limit after the date of death (eg, 1 year), with possible exceptions if proof of contribution can be provided
Relatives and estates may be surprised by the inclusion of their late relative as a coauthor	Coauthors should consider contacting relatives and relevant estates to inform them
A deceased author's reputation may suffer if their name is included on a publication that is subsequently retracted	The retraction statement should make the deceased coauthor's role clear

authorship. Nor do various documents by publishers and editors dealing with publishing ethics.[12-14]

Two reviews have examined advice given by learned societies (the American Meteorological Society, the American Ornithological Society, the American Physical Society, and Cochrane); journal publishers (BMJ Journals, Dove Press, Elsevier Science, Wiley, Nature Publishing, Oxford University Press, Springer Nature, Taylor and Francis, and Walter De Gruyter); and 16 individual journals.[5 15] Several of those do not specifically address the question of deceased authors, and among those that do there are large variations in what they specify (box 1).[5] Furthermore, there are conflicting views about whether coauthorship or an acknowledgment should be preferred. However, the guidelines discussed in these reviews have not dealt with other ethical concerns arising from posthumous authorship.

Box 1 | Advice on posthumous authorship from 23 societies, publishers, and journals*

- Authorship according to criteria (indirectly implying, but not specifying, ICMJE): n=9
- Obelus ("death dagger") required to mark a deceased author: n=4
- Requirement to mention the deceased in a footnote or contributor statement: n=13
- Corresponding author responsible: n=3
- Family consent required: n=5
- New contact to be appointed if required: n=1
- Editor in chief to arbitrate: n=1
- Deceased individuals should not be authors: n=1
- Acknowledgement an alternative to co-authorship: n=1

*Analysis by Helgesson et al[5]

Extent of the problem

The exact number of publications that feature posthumous coauthors is not known; we estimate it to be at least 10 000 in the biomedical field alone. Jung and colleagues surveyed 2 601 457 peer reviewed biomedical publications during 1990-2020 and found 1439 deceased authors credited with 5477 posthumous publications; they found a 146-fold increase in the number of such authors since the year 2000.[16] However, they underestimated the extent of the problem.[17]

Box 2 | Proposed definition of a posthumous publication

A publication, whether in print or online, for which at least one author has died before the accredited date of publication of the version of record, the deceased author(s) being named in either the main list of authors or the list of members of a contributing group; this includes translations and updates of previously published lifetime or posthumous publications but excludes verbatim reprints and print versions of publications that were published online during the author's lifetime.

First, they searched only in acknowledgment sections for declarations on coauthors who had died. But posthumous coauthors are often not mentioned in acknowledgments. For example, Jung and colleagues identified our late colleague Douglas G Altman as having 36 posthumous publications, but in fact he had 79 by the end of 2020, and we have now identified 103 (data available on request). Altman's death is not always recorded in his posthumous publications.

Jung and colleagues also missed several posthumous biomedical coauthors altogether. These include David L Sackett (three posthumous publications listed in PubMed), Lisa M Schwartz (eight before the end of 2020), and Stanley J Korsmeyer (26). By restricting their search to biomedical authors listed in the Europe PubMed Central database, Jung and colleagues missed publications and scientists listed in other databases. For example, they did not mention the mathematician Paul Erdös, who died on 20 September 1996, leaving many problems in number theory unsolved and projects unfinished; he is credited with at least 73 posthumous items up to 2015 (bit.ly/3D3HtPw).[18] Nor did they include the egregious case of the 1913 Nobel prize winning chemist Alfred Werner, who died in 1919 and was named as a coauthor of a paper published in 2001.[19] We know of no extensive survey of non-biomedical fields.

Defining a posthumous publication

Although what constitutes authorship in scientific publications has been widely discussed, we have not found a satisfactory definition of a posthumous publication. It is not simply a publication that appears after a coauthor's death, as our proposed definition shows (box 2).

Box 3 | Suggested classification for posthumous authorship

Class 0: None of the ICMJE criteria is met. This does not merit authorship and perhaps not even acknowledgement

Class 1: Only the first ICMJE criterion is met. This does not merit authorship, merely acknowledgment

Class 2: The first two ICMJE criteria are met. This merits authorship

Class 3: The first three ICMJE criteria are met. This merits authorship

Occasionally an author may be the sole author on a posthumous publication, generally when papers published during the author's lifetime are republished as verbatim reprints—for example, in collections of their work—but occasionally after online publication. The definition takes note of such cases.

Ethical concerns and solutions

The few publications in which posthumous authorship has been discussed have mainly concentrated on the question of whether someone who has died should be credited with authorship or merely acknowledged for their contribution, principally highlighting the impossibility of obtaining posthumous consent to either authorship or acknowledgment.[2] However, there are several concerns beside the question of coauthorship versus acknowledgment, which have not been widely aired (table, on p 387).

These observations raise questions about posthumous inclusion of authors' names in publications. For example, posthumous authors may have contributed to the concept or design of a study (ICMJE criterion 1) but no more than that, or they may have taken part in drafting or revising the manuscript (criterion 2), or occasionally may have approved the final manuscript (criterion 3). The last ICMJE criterion clearly cannot be met ("agreement to be accountable for all aspects of the work").

Helgesson and colleagues[5] made some suggestions for dealing with ICJME authorship criteria, and we build on these to propose a classification that authors could use to decide on posthumous

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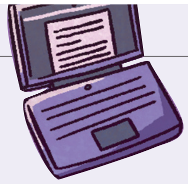
EDITORIAL



BMJ's approach to deceased authors

New guidance aims to improve consistency, reporting, and respect for people who have died before publication of their work

Preparing academic work for publication can be a lengthy process. Occasionally someone may die before the content they have worked on is published. There is no unifying industry guidance from organisations such as the Committee on Publication Ethics (COPE) on how to include deceased people in author lists or in terms of copyright, intellectual ownership, and publication ethics, and there is therefore ambiguity and variation in the approach taken by journals and publishers.

An analysis in *The BMJ* by David Nunan and Jeff Aronson discusses some of the ethical issues and suggests that formal criteria are needed.[1] BMJ is expanding its existing approach to improve consistency, reporting, and respect for individuals who have died before publication of their work. The approach may also reduce instances of inappropriate authorship by deceased individuals.

Variation in approach to deceased authorship makes it challenging to estimate what proportion of published content in the scholarly record is authored by people who had died before publication. Estimates in 2022[2] by researchers who examined the Europe PMC database for articles from 1990 to 2020 identified 1439 authors with posthumous publications. Together, these authors had published more than 38 000 papers during their careers, including more than 5000 after their deaths. The analysis suggested that acknowledgment of deceased authors had increased. In addition, half of the papers were first submitted after the death of the relevant author.

Previously, BMJ's guidance made clear that deceased authors could be listed but offered little practical guidance on how. BMJ journals will continue to publish work from people who have died and who would have been likely to have met the authorship criteria if they were still alive. Our new approach aims to improve the quality and consistency of decision making by authors and editors confronted with such situations.[3] The guidance is pragmatic, author centred, and supports communication between authors, next of kin, and editors. By focusing on the contribution and likely wishes of the deceased person, BMJ aims to reduce the likelihood of disputes.

Several important principles guide our updated approach. Authorship is typically decided by the authors, and this principle remains when one of the authors has died. Judgment on whether a deceased individual is eligible for authorship is primarily a matter for the authors. Journals rarely become involved in determining authorship and are actively discouraged from attempting to intervene in and resolve disputes.[4,5]

authorship depending on the number of ICMJE criteria that the author met (box 3).

We suggest that a footnoted obelus (†) should be appended to the deceased author's name in the list of authors. We recognise that some journals prefer not to do this, but the death of an author, including the date of death, should at least be acknowledged in the notes about contributors. Contributions to such groups as data monitoring committees by a deceased individual should be acknowledged, where relevant.

Deceased authors of online versions of publications published before their deaths, should be credited with authorship when the publication appears in print posthumously. However, their death should be noted (eg, "since this paper was published online, X has died [date of death]"). In the case of a sole author, the publishers should seek a colleague of the deceased author to act as corresponding author and guarantor and to take responsibility for approving the print version.

Our proposals facilitate authorship, in the spirit of the ICMJE criteria, rather than denying it. There should generally be an assumption that the author would have agreed to be named in the list of authors. The extent of the author's contribution should provide some validation of this assumption.

In the case of acknowledgments, it will not generally be known whether the individual would have agreed to the acknowledgment. Confidentiality is unlikely to be a problem when acknowledging the contribution of an individual who has died, but coauthors should be confident that the individual would not have objected to the acknowledgment. In such cases, discussions with members of the deceased author's family or other associates may be helpful.

International consensus required

Posthumous coauthorship is not uncommon and is increasing in frequency worldwide. This suggests the need for internationally agreed uniform methods for addressing a choice between posthumous authorship or acknowledgment, for signalling that an author has died, and for dealing with the attendant ethical problems.

Our view on the question of authorship versus acknowledgment is determined by the extent to which the dead person fulfils the ICMJE criteria for authorship (box 3). Setting a time limit, of say one year, between the time of death and the first submission date of a publication would be a practical way of facilitating decisions.

Both ICMJE and COPE should update their guidance to include posthumous authorship along the lines we suggest, and the approach would ideally be agreed by all publishing societies and journals, to ensure uniformity.

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There should generally be an assumption that the author would have agreed to be named in the list of authors

BMJ supports the ICMJE guidance on authorship. This requires (1) substantial contributions to the conception or design of the work or the acquisition, analysis, or interpretation of data for the work; (2) drafting the work or reviewing it critically for important intellectual content; (3) final approval of the version to be published; and (4) agreement to be accountable for all aspects of the work.[6] However, authors who have died before publication may be unable to fulfil one or more of these criteria. Some flexibility with respect to these criteria is reasonable when the surviving authors consider the person has made substantial contributions to the work. The ICMJE authorship criteria are a poor fit for non-research content, such as comment pieces, though similar principles can be applied.

Transparency and consistency

When including a deceased person as an author, coauthors should contact the person's next of kin before publication. They should explore the situation to understand the deceased person's likely views on authorship and any concerns they might have had about the final content. Coauthors should consider the deceased author's rights: copyright and moral rights may form part of a deceased person's estate, for example.

By improving the guidance we hope that what may be someone's last work and memory is respected

Reporting of deceased authors will be made more consistent. When a deceased person is listed as an author, their contribution should be described within the contributorship statement.[3] Within this, coauthors should outline any notable duties that the deceased person could not fulfil, such as approving the final published version. If desired, authors may include a few words of tribute in the acknowledgments.

Clearly, a deceased author cannot be the submitting author, corresponding author, or the work's guarantor for academic content. If the person was unable to share or declare their competing interests, coauthors should consult with the next of kin and report the person's interests to the best of their knowledge.

If an author dies after publication, BMJ does not typically amend details of the corresponding author or guarantor. If, in the view of the authors, there is a need to update the contact details shown in the article after publication for correspondence purposes, a rapid response should be posted to the content outlining who should be contacted.

This approach does not cover circumstances in which an author temporarily or permanently lacks capacity. These circumstances will be considered on an individual basis, taking into account the likelihood and trajectory of recovery.

By improving the guidance, reporting, and consistency of BMJ journals' approach to deceased authors, we hope that what may be someone's last work and memory is respected. As is standard, BMJ's guidance will be regularly reviewed, and may evolve over time.

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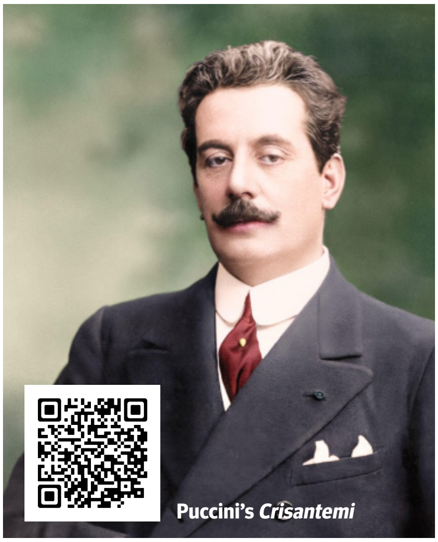
Mendelssohn's *Op 80 requiem*

Leifs's *Vita et Mors*



Puccini's *Crisantemi*

Broken chords

Chamber music can spur us to reflect on the experience of families and friends when a patient dies—but also to celebrate and grieve for loved ones of our own, says **Desmond O'Neill**

To grieve is not only to have loved but also to continue to love, prompting many great artistic creations—from the Taj Mahal, through the heartbreaking novel *Grief is the Thing with Feathers*, to the songs of Nick Cave. Music can reflect and evoke our most powerful emotions.

The philosopher Arthur Schopenhauer noted that "other arts…speak only of the shadow, but music of the essence." Felix Mendelssohn believed music to be more precise than words at expressing human feeling. And music can crystallise burning pain, according to Gustav Mahler.

Celebrated examples of how sung music can elevate texts on grief include Herbert Howells's *Hymnus Paradisi*, written after the death of his son, and Mahler's *Kindertotenlieder* (*Songs on the Death of Children*), based on poems by Friedrich Rückert, who had lost two children. Less recognised is how purely instrumental music can offer subtle and potent channels to combine remembrance, loss, and consolation.

Purely instrumental music offers subtle and potent channels to combine remembrance, loss, and consolation

Chamber music is particularly intimate. Without great splashes of sound, variety of tone, or virtuoso display, we are offered the composer's inmost intentions. Although grief has been expressed in forms such as Bedřich Smetana's *Piano Trio* and Louis Vierne's *Piano Quintet*, string quartets are perhaps the most canonical and revealing form of chamber music, and several have been associated with loss and bereavement.

Mendelssohn provides a striking example arising from the loss of Fanny, his beloved older sister and fellow composer. On hearing of her death he fell into deep depression and subsequently wrote a string quartet as a personal requiem. This final quartet (Op 80), written only months before his own death at age 38, contrasts starkly with his sweet, inventive, and mellifluous earlier string quartets.

In the key of F minor—and privileging the diminished fourth, associated with strong and deep emotions—the work is characterised by agitation and restlessness, with discontinuities and abrupt changes. The slow movement is a deeply personal elegy, whereas the finale is fretful and wild, not yet ceding to solace and catharsis. Mendelssohn's friend Julius Benedict wrote, "It…so completely impresses the listener with a sensation of gloomy foreboding, of anguish of mind, and of the most poetic melancholy."

Equally striking and plangent is the second string quartet of the 20th century Icelandic composer Jón Leifs, a somewhat thorny personality who lived in Germany during both world wars. Much of his work reflected the elemental splendour of his native country, his tone poems *Hekla* and *Geysir* portraying volcanoes and geysers with extraordinary added percussion.

What music speaks to you about grief, and why?
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His quartet *Vita et Mors* (*Life and Death*) was one of four compositions inspired by the drowning of his teenage daughter, Líf, whose name translates as "life." Three movements trace her life: Childhood, Youth, and then Requiem and Eternity.

Childhood, enmeshed with Icelandic rimur song, has increasingly complex structure and energy, parallelling our early development. The central movement carries a sense of maturing and ends with abrupt dissonance, reflecting Líf's tragic fate. Pain, solace, and consolation entwine in Requiem and Eternity, with plaintive violin and anguished harmonies, delicate pizzicati (plucking) like gentle tears, and a hushed ending.

Last is a string quartet by Giacomo Puccini. Written in one night on hearing of the death of his friend Amadeo di Savoia, *Crisantemi* is an exquisite, single movement lament. Lasting barely six minutes, its title referencing the flowers traditional for mourning in Italy, it offers a spontaneous and masterly expression of love and loss.

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