Going Public: Performing Dying in the Second Decade of the 21st Century

Michael Brennan

Liverpool Hope University, UK

Abstract

It is now more than a decade since the death of celebrity television personality Jade Goody—a high water mark in public dying comparable to the watershed moment in public mourning marked by the death of Diana, Princess of Wales, a decade or so earlier. As Walter (2009) has noted in this journal, Goody’s very public and highly mediated dying will not be the last. With that in mind, this article analyses the sociological significance of public dying in the decade following Goody’s death—the ‘tens’ of the 21st century. It does so chiefly by focusing on a number of high-profile instances which gained significant media traction, using these to examine the ways in which dying is both performed and made meaningful in contemporary 21st century culture. The argument presented operates on the assumption, following Goffman (1959), of life—and by extension, dying—as performance.

**Keywords**

Body, Cancer, Dying Role, Identity, Illness, Media, Performance, Pathography, Public Dying, Self

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Corresponding author:**

Michael Brennan, Liverpool Hope University, Hope Park Campus, Liverpool L16 9JD, UK.

Email: brennam@hope.ac.uk

‘I’m stuck with that—“look at me, I’m over here, I’m dying.” It’s a performer's attitude’ (Clive James, BBC *Front Row,* 2018).

**Introduction**

Since the very public dying of Jade Goody from cervical cancer in 2009, first-person narrative accounts of living with, and dying from, cancer have continued to proliferate. Beyond published pathographies in book or epistolary form documenting lived experiences of illness and dying, there now exists a rich variety of first-person accounts available in a range of media—radio, television, podcasts, popular magazines, blogs, video diaries and social media. As Walter (2009) has observed, this seemingly challenges the sequestration thesis within sociology, rooted in the assumption that death and dying in modernity have been comprehensively pushed behind closed doors and out of public view.

It also seemingly challenges sociological assumptions that illness and dying are a cause for embarrassment (Elias 1985) and stigma (Goffman 1963). More than this, it suggests that where confessional accounts of private and deeply personal experiences, including illness and dying, were once shocking and revelatory, they are now so widespread and commonplace as to appear almost banal, even trite. The cultural dynamics of contemporary culture are now such, that the injunction to conceal has been inverted and replaced by the impulse to put ‘everything out there’, whether on reality television or through social media. In the ‘new normal’ of the 21st century, it now seems creditable to put the most discreditable information about ourselves into the public domain in the service of impression management.

Too extensive to list in full, the second decade (hereafter ‘tens’) of the 21st century has given rise to a plethora of first-person accounts of illness and dying. These chiefly include mediated accounts by well known public figures and celebrities but also extend to ordinary people who achieve notoriety through their public sharing of experiences on social media. Having tracked pathographies over the last decade, this article analyses the sociological significance of a number of high-profile cases, examining what they tell us about contemporary culture. It does so by weaving these cases (from Christopher Hitchens at the start of the decade, through Jenny Diski in the mid ‘tens’, to Clive James at the end of decade, and others besides) into a thematic discussion based on emergent ‘family resemblances’ between the cases considered. This is followed by a discussion of the power implications resulting from the structural (in)ability of certain groups to curate their own dying and cultural afterlives.

Perhaps a measure of the banality of public dying in the 21st century is the shock generated by the deaths of celebrities whom we did *not* know were ill/dying because they did not reveal their diagnoses publicly. Singer-songwriter David Bowie, comedian Victoria Wood, and actors Alan Rickman and Helen McCrory are recent, UK born, exceptions to the tendency towards public dying.

**New public dying**

Public dying, much like public mourning (Walter 2008), can be distinguished, ‘new’ from ‘old.’ The latter refers to traditional, duty-bound public expressions of grief for a monarch or figure of authority, often based on hierarchy and deference; the former to spontaneous grieving for celebrities or public figures with whom members of the public have identified, and forged an affective relationship, but not necessarily met in person. Like grieving, dying in public is not new. Elias (1978), for example, has reminded us how common death was in the middle ages, taking place openly, in public; the dying routinely mocked by their survivors. Traditional deathbed scenes and *ars moriendi* tradition of devotional Christian literature instructing the dying on how to die well remind us also of a time when dying was both visible and publicly accessible. It is thus only in the modern age that death, like violence and other animal impulses, has been ‘confined to barracks’ as part of a civilising process (Elias 1982: 238)

After a prolonged period of absence, theorised sociologically as sequestration (Mellor 1993; Mellor and Shilling 1993), and against which Jade Goody’s dying provided a hypothetical test (Walter 2009), death, and indeed dying, are back, and appear to be ‘having a moment’ (Clark 2018). Pushed out of sight and out of mind, medicalised, and confined to private spaces in modernity, death and dying in late/post/reflexively modern, information-based, consumer societies are highly visible and hugely accessible (Woodthorpe 2010). What helps make them so is modern media, providing the tracks on which public dying runs and the platforms by which it is viewed. In this respect, a more precise term for describing the images, narrative accounts and representations of people in the throes of terminal illness is ‘public mediated dying’ (Penfold-Mounce 2020a).

Technology in the 21st century has changed the way people mourn (Walter et al 2012). It is also changing the way people die. The increased accessibility and portability of media have opened up new possibilities for sharing one’s experiences, extending inclusion to individuals and groups otherwise excluded from the traditional means of literary production, including those whose health is severely compromised but whose condition is sufficiently ambulatory so as to allow them to share their experiences using social media. Cancer dominates accounts of public mediated dying. With an extended, and sometimes very long dying trajectory, blogs, video diaries, and social media sites such as Twitter, Facebook and Instagram provide unprecedented opportunities for sharing deeply personal experiences: from initial diagnosis, through daily updates on pain/pain management, treatment regimens and their side-effects, to valedictory messages to followers, friends and people within a person’s social network.

While media interest in death, and dying in particular, is not necessarily new, what is new are the niche possibilities opened up by the proliferation of media. Sociological references to ‘the’ or ‘mass’ media now appear rather quaint in light of the ‘narrowcasting’ opportunities made available through the social media outlined above and video sharing platforms such as YouTube, which also permit online sharing and social interaction in the form of comments posted beneath videos by viewers.

The contemporary media ecology is marked in particular by a symbiosis between various media, new and old, mainstream and niche. In the context of public mediated dying, mainstream media may provide the major platform from where a person’s illness and dying are first announced—as for example in the case of UK journalist Steve Hewlett, who used his cancer diary in the *Observer* newspaper and BBC Radio 4’s *PM* programme to talk openly about his cancer.[[1]](#footnote-1) This is often then picked up and shared on other, less mainstream media (especially social media), which in turn may generate further traffic and ‘trending’ on social media sites. Alternatively, in the symbiosis between contemporary media, mainstream media increasingly report instances of public dying that have their genesis and primary locus in more ‘narrowcast’ social media, which, once picked up and reported by mainstream news media, may generate further public interest as part of an ongoing reciprocal news cycle. The instances of UK vlogger Emily Hayward, who shared her dying on YouTube and Instagram, and U.S broadcast journalist Scott Simons, who charted his mother’s dying from her ICU bedside via Twitter, are two examples that fit this category. Aspects of social life, including dying (and the experiences surrounding it) that were, in modernity, once experienced largely ‘backstage’ are clearly now increasingly performed ‘frontstage’ (Goffman 1959).

**Methods and rationale**

The cases that form part of the analysis in this article are not exhaustive. They are nevertheless made up of instances of public mediated dying that gained significant media traction in the UK (and Anglophone world) in the decade spanning 2010-2019. Global media are today such that stories—including instances of public dying—that originate, or are first reported, in one national jurisdiction, often cannot be contained within it but are diffused and/or accessible to media users worldwide. Writing as a UK-based academic, the accounts considered here are taken from within the media orbit within which I reside. While media are today global, often transcending national boundaries, our ‘media surround’ is still, nevertheless, circumscribed by national jurisdiction (turning on my TV or radio will still, in the 21st century, provide nationally inflected news stories in ways that extend to the focus given to particular public figures who have ‘gone public’ with their dying).

Significance here is understood as accounts of public dying which, as media events, possess a certain magnitude by virtue of their intensity and ability to speak across temporal and locational boundaries (Kear and Steinberg, 1999: 2). Selected on the basis of their magnitude and media take-up, the cases considered here should not be mistaken as representative or reflective of all communities and nationalities’ experiences of (public mediated) dying—though they do nevertheless approximate representativeness of coverage, drawn as they are from a wide range of well-established media sources. Instances of public mediated dying in the UK in the 21st century—especially those reported in conventional/mainstream media—lack ethnic diversity: they are overwhelmingly white, predominantly female and reflect historic and continuing inequalities of power and resources (Hamilton et al 2022).

The cases discussed below come from the author’s own research and collection of news (and social) media stories of public dying archived over the last decade (2010-2019). Some of these (including Christopher Hitchens, Jenny Diski and Steve Hewlett) are drawn from previous research using detailed and ‘granular’ textual analysis (e.g. Brennan 2022, Brennan 2018). Others are discussed using a combination of secondary media reporting of persons who have shared their experiences of dying publicly, their first-person interviews with mainstream media, and their direct messaging via social media. Taken together, they provide a panoramic sweep as part of a socio-cultural analysis of public dying in the second decade of the 21st century. To be clear, this article does not deploy standard sampling techniques but is a qualitatively oriented/theoretically framed article in which the cases considered are interwoven within a thematic discussion.

The cases considered are also deliberately limited to persons who died within the ‘tens’, even though their illness trajectory—and point at which they first began narrating their experiences of illness/dying publicly—may have begun *before* the turn of the decade. In many cases, the discovery of symptoms/onset/diagnosis of illness (often reported shortly thereafter) marks the beginning of public mediated dying and culminates either in death or inability to ‘perform’ one’s dying publicly due to weakness/ill health. Even where the discovery of symptoms/onset/diagnosis of illness does not mark the point in time at which the public performance of dying begins, in accounts told retrospectively, it often provides a significant ‘moment’; a transitional/transformational point within the narrative by which one passes from the ‘kingdom of the well’ into the ‘kingdom of the sick’ (Sontag 1978: 3).

Time (and the selection of cases from the ‘tens’) is significant here because it allows us to track changes in the mediated forms by which people narrate and perform their dying in technological-culturally calibrated conditions. While many of the instances of public mediated dying discussed below do not necessarily originate in, or have social media as their chief locus, they nevertheless rely upon social media for their circulation and distribution within other media such as TV, radio, and newspapers. The ‘tens’ are significant here because, while social media platforms such as Facebook, Twitter and YouTube were launched in the ‘noughties’ (2000-2009), they came of age, achieved peak popularity/usage, and have undergone upgrades in functionality—such as the capacity for live streaming—in the ‘tens’ (only Instagram and Tiktok of the current crop of major social media platforms were launched in the ‘tens’).

**Identity, the body and performance of self**

Serious, long-term illness (including dying), disturbs our sense of self, our assumptions about the world and our place within it. In sociological terms, such disturbance has been theorised as ‘biographical disruption’ (Bury 1982) provoked by a ‘critical situation’ (Giddens 1979) in which a person’s taken-for-granted expectations about the lifecourse and the social roles they are expected to play have been cast into doubt. Illness and dying disturb our ‘ontological security’ (Giddens 1991), and with it our ability to find meaning in the world, often in ways that are directly related to identity. Added to the sense of ‘social fading’ that often accompanies serious illness and dying, as a person’s participation and presence in everyday social life becomes diminished (and potentially erased from public memory), is the risk that a person’s identity may itself become ‘mortified’ (Goffman 1961, 1963), subsumed under a new master status or metanarrative in which a person comes to be defined by their illness/dying.

‘Going public’ with one’s illness/dying (especially by those already in the public domain) may help resist such victim status by normalising illness/dying as an everyday part of life. It may also provide an antidote to social fading by enabling continuing bonds (Klass et al 1996) between the famous and their publics, delaying/preventing a ‘second death’, while allowing for their lives (and deaths) to live on as part of the cultural afterlives of death (Englund 2002; Penfold-Mounce 2018, 2020b).[[2]](#footnote-2) The extent to which one’s posthumous identity is secured is not, however, universal but clearly indexed to one’s access to various forms of capital (symbolic or otherwise) that reflect inequalities of gender and class in ways related to the body (Penfold-Mounce 2020b).

Sociological discussions of illness and dying are prefigured by considerations of the body. Not only does the body place material limits on human experience (Seale 1998), but the illness and pain sometimes visited upon it threaten a separation of body and mind in ways that are perceived as enemies of the self, having betrayed a person’s biography founded upon good health and wellbeing (Howarth 2008: 181). Writing, talking about, and what we might call collectively, ‘performing’ (Goffman 1959) illness and dying in public—albeit in mediated ways—are part of cultural discourse (they are by their very nature, *discursive*)and may help restore and even enhance a sense of self and identity imperilled by ontological insecurity. Public performance (as discursive practice) in the face of illness/dying may also serve as an attempt at asserting agency, mastery and control when both are in short supply; for resisting a loss of self (Charmaz 1983). Aggressive treatments like chemotherapy are notorious for robbing the body of energy and diminishing a sense of self.

Understood as performance, public mediated dying of the sort discussed here can be seen as an attempt to close-up the gap between a person’s identity and others’ perception (and designation) of them as cancer victims, following a diagnosis of cancer. Performance as it is understood here does not simply amount to narcissistic or self-obsessed bids for attention or publicity—characterised caustically by Julie Burchill as the ‘I’m dying I am’ genre or by Decca Aitkenhead as ‘emotional pornography’ (Small 1998), but can be understood as part of the ‘body work’ (Shilling 1993) required to resist the separation of self and social identity precipitated by illness/dying. This fragmentation of identity precipitated by cancer may lead to attempts to preserve the fabric of social identity threatened by illness or lead to attempts to refashion identity in the face of annihilation.

The case of Clive James, Christopher Hitchens, Jenny Diski and Steve Hewlett (among others) represent the former: attempts at ‘writing’ or ‘speaking through’ the pain of cancer in ways consistent with their personal and professional identities as writers; while the cases of UK family doctor, Kate Granger, and UK personal trainer and vlogger, Emily Hayward, suggest that cancer served as a stimulus to the refocusing of goals and repurposing of identity.

Granger, a GP from East Ardsley in Yorkshire, used the liminal period between her diagnosis with a rare form of cancer and eventual death in 2016 to not only speak publicly about her experiences but also to fundraise for a local cancer charity (raising £250,000 for Leeds Cancer Charity Centre) and launch a campaign, ‘Hello, my name is’, to help reform and improve ways healthcare professionals treat patients with terminal conditions.[[3]](#footnote-3) Granger was treated brusquely by a doctor who informed her that her cancer had spread but did not introduce himself or make eye contact with her. Granger’s campaign and public dying gained significant traction via social media, where, using the hashtag ‘Hello my name is’, she garnered 47,000 followers, winning the backing of 400,000 doctors, nurses, therapists and porters across 90 NHS organisations (BBC News 2015).

Chronicling her cancer journey by posting videos on YouTube and Instagram, Hayward shared her intimate experiences of diagnosis, treatment and wider experiences of pain mixed with positivity—of medical appointments, chemotherapy and regular updates for followers on social media.[[4]](#footnote-4) Hayward’s overriding message in approaching illness/dying was one of positivity and defiance; her Twitter bio was ‘Full time cancer fighter, vlogger, fitness fanatic’ (https://twitter.com/emilyhaywardpt).

**Frames and discourses**

A useful framework for understanding public mediated dying in the 21st century lies in the sociology of Erving Goffman and social theory of Michel Foucault. Goffman’s (1974) development of frame analysis helps to understand the ‘frame’ through which public dying is experienced and perceived; namely, in this respect, the public dying frame. As a means of organising social experience, ‘frames’ serve as both guide to action and framework for understanding a social phenomenon, event or *form* of social interaction, telling us how to perceive, and behave within, a particular social situation. Performance in the public dying ‘frame’, again using Goffman’s ideas, is always reliant upon a supporting cast of others—in this instance, journalists, TV and radio interviewers (who engage the person occupying the dying role in a dyadic relationship), as well as the wider public audience who support the performance through positive feedback and messages on social media.

Foucault’s work on the other hand helps us to understand the linguistic tropes associated with the public dying ‘frame’; to situate the death talk underpinning narratives of public dying within a particular linguistic genre or discourse. Discourse of this sort is, in a very literal sense, a conversation (Thompson and Owen 2017); and conversations like this, about the end of life, have been encouraged in the last decade or so as part of a policy agenda in which talking about death and dying have been actively promoted by charity/campaign groups such as Dying Matters: as ‘good for our wellbeing, [...] good for those around us, and [...] good for society’ ([www.hospiceuk.org](http://www.hospiceuk.org)).[[5]](#footnote-5)

Discourse of this sort, in a Foucauldian sense, can also be seen to operate in a more insidious way, serving to regulate and authorise particular styles of dying while disavowing others. Could it be that certain styles of dying are discursively established—normatively—as if representative of *all* dying, thereby creating a ‘regime of truth’ around dominant forms of public mediated dying? Many of the instances of public mediated dying in the ‘tens’ speak explicitly about ‘normalising’ death and dying, about removing the stigma, silence, fear and misapprehensions surrounding it. But could it also be, that in attempting to ‘normalise’ dying, other forms of less heroic and sanguine dying—that is, dying that does not conform to these ideals—are marginalised and closed down as possible alternatives?[[6]](#footnote-6)

There is a parallel here with the danger identified by Walter (1996) in terms of grieving: that particular styles of grieving, at particular moments in historical time—whether involving a detachment or ongoing relationship with the deceased—become established as ‘clinical lore’ in ways that dictate how people *should* grieve; and in this instance, how they *should* die. There is another sense in which Foucault’s ideas are useful here—and that is in helping us to understand writing, talking about, and performing dying publicly as a technology of the self; a means for achieving better self-understanding and self-care.

**Confronting cancer**

First-person accounts of illness and dying in the ‘tens’ are dominated by cancer. My analysis of public mediated dying in this period reveals a recurrent theme: namely, an explicit attempt to confront cancer and the status it has acquired in contemporary culture. Much of this clusters around resistance to the prevailing imagery of cancer, the fears it generates in the public imagination, and sense of passivity associated with it—especially that of cancer victimhood. In performing public mediated dying, we can see here how the dying role—as distinguished from the sick role (Parsons 1951) from which people are expected to recover (but in the dying role cannot)—is reframed in ways both positive and consistent with the dying person’s identity. Public dying functions here as inspirational example and transferable public duty (Steinberg 2016b).

In lieu of religious frameworks to interpret the meaning of death and dying in contemporary society (Walter et al 1995), media continue to play a significant role in helping to frame how these deaths should be understood. But they do not do so alone. Rather, in the new media ecology, media (both new and old) work in combination with the performative agency of individuals themselves who, like the ‘citizen journalists’ that new mobile technology first helped usher in the ‘noughties’ of the 21st century, contribute and shape media content.

Several of the pathographies considered here from the ‘tens’ make confronting cancer an explicit part of the way their dying is performed. In a valedictory interview given to the BBC in 2010, writer, journalist and well-known controversialist, Christopher Hitchens, told Jeremy Paxman that, against the bogus cures and myths with which it has been propitiated, ‘he had set his face to demonstrating’ that cancer is ‘a malady like any other that will yield to reason and science—and that’s what I’m trying to spend my time vindicating’ (BBC *Newsnight* 2010).[[7]](#footnote-7)

Hitchens takes issue with the term ‘battle’, a well-worn media trope used to describe people suffering from (‘battling’) cancer. Instead, Hitchens insists that cancer feels more like it is *battling* *him* (and for the most part, not like fighting at all), describing the passivity that comes from the ‘kill or cure’ venom of chemotherapy mainlined into his veins every few weeks. Like Hitchens, who expressed his frustration with the hackneyed terms for describing living with cancer, many others who performed their dying publicly during the ‘tens’ share their frustration with the language and discourse surrounding it.

Kate Granger, who published two pathographic books before her death in 2016 (*The Other Side* and *The Bright Side)*, used Twitter to confront cliched metaphoric talk around cancer, tweeting for example about how ‘cancer is a journey not a battle or fight’. ‘Dark’ (or ‘gallows’) humour provided another tactic by which Granger confronted cancer, using it to disarm the terror surrounding cancer and the fear of dying. In common with other instances of public mediated dying in this period, Granger’s confrontation with cancer involves reframing it by attempting to remain positive throughout her cancer ‘journey’.

Death positivity is also evident in the public mediated dying of former UK New Labour strategist, Philip Gould, who, in a short 8-minute film ‘When I Die’ and pathographic book, *When I Die: Lessons from the Death Zone,* spoke candidly about freeing himself (and by extension, others) from the fear of death by re-framing its meaning as something positive.[[8]](#footnote-8) American based British neuroscientist, Oliver Sacks, also spoke publicly and in positive terms, about his dying, reframing the loss of sight in one eye following his diagnosis with uveal melanoma as—quite literally—giving him a new perspective on life.[[9]](#footnote-9)

We also find ‘confrontation’ with cancer in the public mediated dying of UK journalist and broadcaster, Rachael Bland, who, in chronicling her experiences of breast cancer over a two-year period, claimed that her chief aim in talking about cancer was to help demystify it: ‘to punch it square in the face’ (Hayward 2018).[[10]](#footnote-10) The BBC Radio 5 podcast ‘You Me and the Big C’ she co-hosted with Deborah James[[11]](#footnote-11) and Lauren Mahon (both of whom have also had cancer), was part of an attempt to normalise cancer by creating a safe and supportive space for talking about it in ways that might help others re-frame it in more positive ways, and in so doing, change wider perceptions and the public conversation about it. Attempts at ‘normalisation’ here extend to the aim of creating ‘a space where you feel like you’re sitting down with girls like you, having a cup of tea, talking about it like it’s *Eastenders’* (ibid.).

‘Normalisation’-as-confrontation is also evident in the public mediated dying of UK actress, Lynda Bellingham, who in TV appearances, newspaper interviews, and her pathographic book, *There’s Something I’ve Been Dying To Tell You*, sought to challenge the stigma surrounding colorectal cancer (with which Bellingham was diagnosed) and wider inflammatory bowel diseases.[[12]](#footnote-12) Here again, humour, this time scatalogical, is used to confront the stigma and embarrassment that lead to silence around the subject.

Like Rachael Bland (on whose podcast she appeared as a guest), personal trainer and blogger, Emily Hayward, sought to confront cancer by remaining defiant in the face of her illness, helping ‘to put two fingers up to cancer’ (Moore 2019). Her informal, matter-of-fact, and ‘up close and personal’ approach to cancer helped generate a community of followers, many of whom were themselves living with or had survived cancer, and were seemingly able to take inspiration from her predominantly upbeat messages posted on social media.

**Helping others, helping oneself**

The language used by pathographers who have narrated their experiences of illness and dying in the ‘tens’ is frequently that of helping others. New Labour architect, Philip Gould, spoke of facing down his fear of dying by writing/talking about it in ways that might help others going through a similar plight. Kate Gross, also a UK political advisor, who died from colon cancer in 2014 aged 36, shared her experiences of dying in *The Times*, via her blog, and in her book, *Late Fragments: Everything I Wanted to Tell You About This Magnificent Life*, with the express intention of helping others understand what it means for a person to ‘die before their time’ and how to engage with people (and their families) who are dying.[[13]](#footnote-13)

Steve Hewlett’s candid accounts of his experiences of esophageal cancer, especially his experiences of cancer care, can be understood as an attempt to help others navigate the labyrinth of NHS care. Listeners to Hewlett’s interviews with presenter Eddie Mair on BBC Radio 4’s primetime news programme, *PM*, learned valuable lessons, including advice that active involvement in one’s own treatment produces better care. Hewlett’s interviews appeared—if only anecdotally and in the short term—to produce an equivalent of the so-called ‘Jade Goody effect’ (Casey et al, 2013; Marlow et al 2012), helping encourage an uptake of middle-aged men presenting themselves for medical attention with gastrointestinal symptoms in much the same way as Goody’s public dying from cervical cancer in 2009 helped see an uptake of cervical smear tests among young women.

Taken together, the net effect of these pathographers may be, as Goody before them, to serve as informal death educators (Walter 2009), providing valuable insight into what dying is like for people with no experience of it, while simultaneously validating experiences that resonate with people who are themselves dying or may be caring for people who are dying.

Many of those who have narrated their dying publicly have couched their experiences as imparting valuable ‘life lessons’ to others (in ways perhaps not lost on publishers keen to monetize their experiences in the form of book sales). Such life lessons include the tweets (and later book, *Unforgettable: A Son, A Mother, and the Lessons of a Lifetime*) of U.S writer, broadcaster and NPR (National Public Radio) host, Scott Simon.[[14]](#footnote-14) Simon made headline news when he tweeted from the bedside of his 84-year-old mother, Patricia Lyons Simon Newman, following her admittance to the ICU of a Chicago hospital in 2013. Simon’s tweets included ‘life lessons’ on the importance of spending time with the dying and accompanying them on their ‘journey’, both of which appear to serve as an antidote to the loneliness and sense of embarrassment of being in the company of the dying described by Norbert Elias (1985) as a feature of the civilising process.

Such ‘life lessons’ also include the encouragement and advice to reach out to people who are dying by writing to them, because, as Christopher Hitchens put it in his valedictory interview with Jeremy Paxman for a BBC *Newsnight* ‘special’, ‘you’d be surprised...how much difference it can make [and it’s something]…I regret not doing…more often myself’ (BBC *Newsnight* 2010).

Helping others is also manifest in campaign work (such as Kate Granger’s efforts to transform the ways in which dying people are treated by healthcare professionals), in attempts to normalise attitudes towards stigmatised conditions (in, for example, Lynda Bellingham’s openness around colorectal cancer), and in efforts to create a ‘safe space’ in which to talk freely about cancer, pain and (the fear of) dying (as Rachael Bland attempted to do in her podcast ‘You Me and the Big C’).

In helping others, one may also be helping oneself. Publicising one’s own illness (and dying) may be part of an attempt to find a donor (as in the case of UK journalist Sue-Lloyd Roberts, whose public dying was also an appeal to find a stem cell donor as a cure for her myeloid leukaemia).[[15]](#footnote-15) Talking about one's own experiences by people facing death or caring for others who are dying may also bring opportunities for self-reflection; opportunities that arise not simply through vocalising one’s experiences but in and through dialogue with others (and the opportunities this provides for reflection). Third party reflection on others’ dialogue (such as Steve Hewlett’s radio interviews) may also provide insight into one’s own experiences in ways that cannot necessarily be found in intimate relationships in which we are involved (see Brennan 2022). More than this, talking candidly about one’s own dying can perhaps also be understood, in Foucauldian terms, as parrhesia (or frank-speech), in ways that reveal both the intimate connections between self-understanding and self-care (Foucault 1986), but also the moral and social obligations to speak the truth (Foucault 2001)—in this instance, about the lived experience of illness/dying.

**Dying with purpose**

We have seen already how illness and dying disturb biographical continuity (Bury 1982) and threaten ontological security (Giddens 1991). In ways that are of profound sociological interest, the liminal period between a terminal diagnosis and death can be understood as providing a crisis of meaning by disrupting everything a person may have taken-for-granted, including one’s health, sense of identity, and general purpose in life. Religion was once, and for many still is, a primary source of meaning in the face of death, helping to transform it from an event that negates meaning into something meaningful. For sociologists like Max Weber, religion was understood for its capacity to both generate and sustain meaning (Woodhead 2001) as part of the ‘theodicy of suffering’ (Berger 1963).

For those considered here who, in the second decade of the 21st century, have given public voice to their experiences of dying, religion features very little in their accounts. What does, however, appear to give meaning to their experiences is writing, speaking about, and performing their dying. For those already in the public domain (as writers, journalists, actors, senior political advisors), performing one’s illness/dying in this way is not only a means of attempting to exert agency and control in the face of a diagnosis and treatment marked, overwhelmingly in the case of cancer, by passivity and loss of control, but a way of maintaining a thread of continuity with one’s personal/professional identity. Work, like religion and health, provides an ‘anchor point’ for biographic continuity (Pascal and Sagan 2017).

As a vocation, the professional identity of writers (and atheists), like Jenny Diski and Christopher Hitchens, appears as a guiding force that is drawn upon to help give meaning to an event that, for them (as atheists), is utterly devoid of meaning. In her public mediated dying, Diski spoke about her use of humour as a means of dealing with the banality of death and the existential rage generated by the meaninglessness of non-existence.[[16]](#footnote-16) In an interview with David Schneider for the BBC Radio 4 programme *One to One* first broadcast in November 2015, Diski explained how she understood the comfort provided by religion for people of faith but found it ‘bloody distressing’ that she herself could not make sense of it as a non-believer. Instead, Diski claimed that her writing provided a ‘solution’ to the anxiety generated by the thought of death (BBC 2015). For a writer like Hitchens, who had forged a reputation as a celebrity atheist (one of the ‘four horsemen’ of ‘militant’ atheism, together with Richard Dawkins, Daniel Dennett and Sam Harris), his public mediated dying provided the opportunity to reaffirm his atheism in face of the ultimate test, death itself; going on public record (notably in interviews with Anderson Cooper for CNN and Jeremy Paxman for BBC *Newsnight*) to dismiss any rumours of last-minute deathbed conversion.

For those already in the public eye, the prospect of illness and dying raises the spectre of social fading and social death; a mortification of the self that, in philosophical terms, threatens their Being-in-the-World (Heidegger 1927/2000). Dying publicly, in the full glare of media publicity is, for showmen like Clive James (whose extended period of dying between diagnosis and death spanned almost a decade) entirely consistent with the ‘performer’s attitude’ he himself identifies and ‘owns’ in a BBC *Front Row* *Special* interview with Professor Mary Beard broadcast in December 2018.[[17]](#footnote-17) Together with lesser known individuals, such as Kate Granger and Emily Hayward, dying is repurposed (as ‘death positivity’) in ways that give strength and inspiration to others, while at the same time giving new meaning and purpose to pathographers in their being-toward-death (ibid.).

An analogue of more recent existentialist thinking on dying—not as an ending but as a purposive beginning—can be found in Ricoeur (2009). In the existentialist philosophical tradition, self-knowledge is born in the realisation of one’s own mortality. Seen in this light, the intense creative activity of those who—in the liminal period between terminal diagnosis and death—perform their dying publicly, speaks to a rejection of a moribund existence in favour of living fully, in the now, and up to the moment of death. It reflects not only a ‘jouissance for life in the face of death’ (Putt 2011: 240) but a more clearly defined sense of purpose in which life is experienced more vividly in the firmament provided by knowledge of one’s own non-being. Those who narrate their experiences of dying publicly routinely talk of feeling more alive in dying than in life itself; as if giving testimony to the metaphoric notion of how a candle burns brightest just before it is extinguished.

**Community, support and online pushback**

By virtue of being openly shared, personal experiences of illness and dying become public property. In so doing, they invite the possibility of support, but also risk inviting criticism and abuse, especially online. Among those who have shared their experiences publicly, Christopher Hitchens, Steve Hewlett and Rachael Bland have all spoken of being overwhelmed (and gratified) by messages of support from well-wishes, contributing to a perception of community—whether imagined (Anderson 1983) or real. By the same token, they have also been subject to online criticism and abuse, sometimes vitriolic. Bland, for example, was the victim of online trolls who berated her for not fighting her cancer hard enough (Bland 2018).

Messages of support from well-wishers can provide comfort, solace and strength upon which people in the throes of illness can draw. The support provided to individuals whose dying is publicly mediated comes often from individuals whom the dying person does not know and has never met. There are again clear parallels here between public dying and public mourning, not least the social connections and networks that extend over and beyond face-to-face relationships, but also in terms of the antipathy and pushback that public dying, like public mourning before it, generates.

In its milder forms, criticism of public mediated dying may stem from antipathy towards the de-privatisation of emotion and de-sequestering of issues once closeted, including personal experiences of illness, dying and grief. Such opposition to public displays of emotion, especially for those not known to us personally through a face-to-face relationship, was relatively widespread, though not particularly well represented in media discourse, following two watershed moments in public mourning in the UK towards the end of the 20th century: the Hillsborough disaster of 1989 and death of Diana, Princess of Wales, in 1997.

Public reaction to Scott Simon’s tweets during his mother’s lingering death in a Chicago ICU in 2013 provides a particular example of such pushback. Simon’s deathbed tweeting provoked the ire of many, especially in the comments sections of online newspapers in which his tweets were reported. In the talkback sections of online newspapers, many readers objected, claiming that Simon’s tweets were ‘selfish’, ‘exploitative’ and ‘narcissistic’, accusing him of turning a sacred and deeply private moment into public spectacle. One reader asked sarcastically: ‘Couldn’t he have kept a private diary?’ (*Mail Online* 2013). Others doubted that someone so involved in providing a running commentary on his mother’s dying on Twitter could be fully present in the moment of her dying/death.

In its more extreme forms, opposition to public dying is directed less against detraditionalization, and the tendency towards the public sharing of things once considered private, than it is towards the individual doing the sharing. Online trolling of this sort accompanied Christopher Hitchens’ public dying. As controversialist, contrarian and public atheist, Hitchens’ dying attracted the unwanted attention of Christian conservatives (especially in the USA), whose messages to him suggested his cancer of the esophagus was divine punishment for his atheism—direct punishment visited upon the organ with which he was perceived to have blasphemed.

While it is not within the scope of this paper to provide explanations for the online trolling of individuals who share their experiences of dying using various media, it is enough to offer a few preliminary observations. First, that some of the opposition to public mediated dying comes from a lag in public sensibilities outpaced by wider societal shifts and changes in technology that alter how we die and mourn (Walter et al 2012). Second, that some trolling of the dying, while by no means justifying it, owes much to the politics or position that they may have taken on various different issues during their lifetime. As in the case of Hitchens, as atheist, the dying are spared little compassion by their detractors. Third, that people who publicly share their experiences of dying, especially from cancer, may invoke criticism and trolling for a perceived failure to tackle the cancer aggressively enough using conventional medicine or from a failure to adopt alternative remedies and ‘cures’.

**Narratives of illness and dying**

First-person, public mediated accounts of illness and dying are typically organised along narrative lines. As a medium and genre of communication, the formal properties of narrative have been comprehensively theorised, including the tendency to recapitulate past experiences in and as a temporally sequenced order of significant events (Labov 1972; Ricoeur 1984). Stories are always told for a reason and with particular intent. This may be to persuade or create a particular impression in others or—as a technology of the self (Foucault 1997)—to achieve coherence (Bruner 1987; Nash 2005), biographical continuity (Bury 1982), and for creating and maintaining personal identity (Linde 1993). Storytelling may also serve as a vehicle of meaning-making, helping make sense of traumatic experiences and what might otherwise be encountered as ‘an unbearable sequence of sheer happenings’ (Arendt 1968: 104).

As a genre, most of the instances of public mediated dying discussed here share ‘familiar conventions of story and characterization’ (Cohan and Shires 1988: 77). These typically include descriptions of falling ill and feeling that something was wrong (or ‘not quite right’); an epiphanic moment of diagnosis/receiving bad news; experiences of aggressive treatment (such as chemotherapy) and clinical trials; followed by the cessation of treatment and shift to palliative care once all others treatment pathways have been exhausted. Such narratives are routinely accompanied by humour and metaphor—as both coping mechanism and defence, and means of making sense of the senseless. Jenny Diski’s response to receiving a terminal cancer diagnosis, for example, was to quip that it was time to start ‘cooking the meth’—a cultural reference to the popular television series *Breaking Bad*, and one, according to Diski, entirely lost on the consultant delivering the bad news to her. Metaphor, on the other hand, was deployed by Christopher Hitchens to describe his illness journey as a form of deportation and border crossing: from the land of the well to the land of malody (c.f. Sontag 1978).

As we enter the third decade of the 21st century, we have reached a point now where the proliferation of narratives of public (mediated) dying has achieved critical mass. This is only possible in cultural conditions in which certain stories become permissible and where there is an audience willing to hear such stories. It is a far cry from the cultural conditions that gave rise to secrecy, collusion and veiled exchanges between terminally ill patients, their loved ones, and healthcare professionals analysed in Glaser and Strauss’ (1965) ethnographic study of awareness contexts that shaped the experience of dying for many in the mid-20th century. For such stories to be told and heard requires both a fertile environment and support reflective of particular social and historical conditions (Plummer 1995). There are perhaps parallels to be drawn here between the emergence of narratives of public dying and the ways in which the idea of the ‘homosexual male’ could only be inhabited as a lived identity because of new discourses of sexuality that surfaced towards the end of the 19th century (Bristow 1995, Sedgwick 1985).

In post-structuralist terms, discourse and narrative clearly have performative implications. For it is in telling, in the declarative speech act (Austin 1976), that subjectivity is realised, bringing into being that which is spoken or named. Language in this sense is not neutral but helps produce rather than simply describe everyday life (Barthes 1981). By extension, narrative and storytelling help summon and create a sense of self (Riessman 1993). Here in the public dying narratives analysed in this article we see the realisation of identities through the performance of dying; in attempts to ‘own’ and ‘stand-up to’ cancer, and thereby create a new reality and conditions in which cancer can be talked about. Kate Granger and Emily Hayward provide examples in which identity is realised *in and* *through* the performative ritual of telling; while for writers and celebrities already in the public domain, performing dying provides the affirmation of identity and a bulwark against anonymity and social fading.

Attempts to exert mastery and control over cancer in the performative agency of the actor who speaks but is also spoken reveal pathagraphers’ indebtedness to the cultural conditions that help give rise to such narratives. As Butler (1990) reminds us, the repertoires and performative matrix in which speech and doing are located are always fashioned from pre-existing discourse. Seen in this light, their act ‘becomes a citation [as] they repeat an established protocol’ (Butler, cited in Gleeson 2021). If, as Butler suggests, performative speech-acts help to create a new reality, then the contemporary narratives of public mediated dying of the sort discussed here may well reflect but also help to cultivate new ways of being in the face of illness and dying.

**Discussion: Capital, legacies, vanishing points**

While access to the platforms by which one is today able to reach a wider public audience has opened up due to the advent of social media, public mediated dying of the sort discussed here remains, for the most part, culturally bound—the preserve of social groups whose power and privilege is manifested in forms of capital (social and cultural) that enable them to articulate their dying in ways that others cannot. Alert to the possibilities that performances at the end of life might contribute to how the dead are remembered, public mediated dying may be utilised to help to frame the posthumous identities of those with the social/cultural capital and wherewithal to do so—often in ways that may contribute to their cultural afterlives (Penfold-Mounce 2018). Those already in the public domain before their public dying, and with the resources to secure their cultural afterlives, are less likely to fade from public memory than those who came to wider public attention (but were not famous before) through their public dying. In attempting to secure their posthumous futures, those in positions of power/privilege able to publicly choreograph their dying may also be contributing to the perpetuation in death of inequalities that exist in life (Penfold-Mounce 2020).

Within death/bereavement studies of late, there has been growing acknowledgement of the need to decolonise its practices/focus in ways that resist ethnocentrism and recognise the complexity of people’s histories/situations (Hamilton et al 2022). As indicated above, the instances of public mediated dying discussed in this article, while not representative of the UK population as a whole, are nevertheless representative of instances of public dying that have achieved ‘critical mass’ and been widely reported within/across mainstream UK media. Despite antecedents in the United States (Lorde 1980; Kalanithi 2017), those from global majority backgrounds in particular are conspicuously absent from public dying narratives in the UK.

This may perhaps reflect cultural distinctiveness in how particular communities ‘do’ dying, though this seems less plausible an explanation for the absence of Black and Caribbean voices in public dying narratives, especially given the well-established oral/storytelling tradition within African culture. Much more plausible an explanation lies in the *underreporting* of instances of minority ethnic public dying by mainstream media; and/or the *underrepresentation* of people from global majority backgrounds among the literati and those from the arts/entertainment industries from where the majority of those who share their experiences of dying publicly hail—though this too is less convincing given the diversity of voices in contemporary music, drama and the wider arts. A third explanation may lie in the possibility that instances of public dying among individuals from a global majority background may remain ‘stuck’ at the level of media serving particular minority ethnic communities in ways that do not ‘cut-through’ to mainstream media/audiences. Either way, minority ethnic voices remain a vanishing point within contemporary instances of public mediated dying requiring further investigation in ways that are beyond the scope of this paper.

**Conclusion**

Motivations underpinning a person’s decision to ‘go public’ with their experiences of dying vary and, even within a given social actor, are likely to be multiple. Such motivations may include: a desire to help others (by offering a usable template—of fortitude and resilience); to help oneself (as a form of self-care and/or distraction from one’s own precarity, predicament and pain); to challenge prevailing discourses (of the cancer patient as metaphor of hopelessness, tragedy and shame [Steinberg 2016b], or of the unremitting tyranny of positivity of cancer memoirs—and the portrayal of cancer as redemptive/transformative [Ehrenreich 2009, Segal 2007]). They may also be motivated by an interest in monetizing the public sharing of one’s experiences to secure the futures of intimate survivors (as Jade Goody did by selling her story to benefit her sons [Woodthorpe 2010]); and/or to secure one’s own legacy by helping to craft an enduring legacy of how one will be remembered within public memory.

Public performances of the kind considered in this article are performative by virtue of the ‘dramatic engagement’ they invite between the dying self and wider public audience. Any performance demands an audience and is oriented towards others. In the context of public mediated dying, it is in the space between performers (who are dying) and spectators (as participants to the performance) that intersubjectivity is born; a co-production facilitated by global (social) media that enables empathy, compassion and companionship—a shared experience of ‘suffering-with’ (Ricoeur 2009: 17) the dying person as they journey toward death.

As the counterpart to life itself, dying has always been performative. Deathbed scenes of the late Middle Ages were also performances, the *ars moriendi* tradition of which they were a part motivated as much by an attempt to create a favourable impression (and legacy) among survivors as they were by a plea to God for clemency in the afterlife. How dying is ‘done’ has clearly changed (and will continue to evolve), shaped by and in accordance with wider sociocultural and technological changes that influence our performances.

**References**

Anderson, B. (1983) *Imagined Communities.* London: Verso.

Arendt, H. (1968) *Men in Dark Times*. New York: Harcourt-Brace.

Austin, J. L. (1976) *How to do Things with Words.* London: Oxford University Press.

Barthes, R. (1981) ‘Introduction to the Structural Analysis of Narratives’, in S. Heath et al (eds) *Culture, Ideology and Social Process.* London: Batsford.

BBC News (2015) ‘Terminally Ill Doctor Kate Granger’s “My Name is” Campaign Wins Support’, 2 February: https://www.bbc.co.uk/news/health-31062042

BBC Front Row (2018) ‘When Mary Beard Met Clive James’, 21 December.

BBC Newsnight (2010) ‘Paxman Meets Hitchens’, *BBC 2*, 26 November. Retrieved from https://www.youtube.com/watch?v=Y-s9AyNQyCw

BBC (2015) ‘One-to-one: David Schneider with Jenny Diski, *BBC Radio 4*, 17 November 2015. https://www.bbc.co.uk/programmes/b06pb54l

Bland, R. (2018) ‘BBC’s Rachael Bland on Having Terminal Cancer: “The Outpouring of Love was Overwhelming”’, *Huffington Post*, 5 September: https://www.huffingtonpost.co.uk/entry/bbc-presenter-rachael-bland-this-cancer-is-growing-wildly-through-my-body\_uk\_5b88f132e4b0511db3d6b3f3

Brennan, M. (2022) ‘Radiotherapy: Deathtalk on Primetime National Radio—The Steve Hewlett Interviews’, *Mortality*, DOI: [10.1080/13576275.2022.2039603](https://doi.org/10.1080/13576275.2022.2039603)

Brennan, M. (2018) ‘Christopher Hitchens’ Public Dying: Toward a Secular Ars Moriendi?’ *Omega: Journal of Death and Dying*, 77(2): 99-132.

Bristow (1995) *Effeminate England*. Buckingham: Open University Press.

Bruner, J. (1987) ‘Life as Narrative’, *Social Research*, 54: 11-32.

Bury, M. (1982) ‘Chronic Illness as Biographical Disruption, *Sociology of Health and Illness*, 4(2): 167-182.

Butler. J. (1990) *Gender Trouble*. London: Routledge.

Casey, G., Morris, B., Burnell, M., Parberry, A., Singh, N. and Rosenthal, A. (2013) ‘Celebrities and Screening: A Measurable Impact on High-Grade Cervical Neoplasia Diagnosis from the “Jade Goody effect” in the UK’, *British Journal of Cancer*, 109(5): 1192-1197.

Charmaz, K. (1983) ‘Loss of Self: A Fundamental Form of Suffering in the Chronically Ill’, *Sociology of Health and Illness*, 5(2): 168-191.

Clark, D. (2018) ‘A Moment for Dying and Death’, *Discover Society*, 6 February: https://archive.discoversociety.org/2018/02/06/focus-a-moment-for-dying-and-death/

Cohan, S and Shires, L. (1988) *Telling Stories*. London: Routledge.

Elias, N. (1978) *The Civilising Process*, vol 1. Oxford: Blackwell.

Elias, N. (1982) *Power and Civility*. New York: Pantheon Books.

Elias, N. (1985) *The Loneliness of the Dying*. Oxford: Blackwell.

Englund, L. (2022) ‘The Afterlives of Death: Gratitude and Gratefulness in End-of-life Writing by Jenny Diski and Oliver Sacks’, *Mortality*, published online 27 January: <https://doi.org/10.1080/13576275.2022.2031942>

Ehrenreich, B. (2009) *Smile or Die*. London: Granta.

Foucault, M. (1986) *The Care of the Self: Volume 3 of The History of Sexuality*. New York: Pantheon Books.

Foucault, M. (1997) Technologies of the Self, in P. Rabinow (ed) *Essential Works of Michel Foucault.* London: Penguin.

Foucault. M. (2001) *Fearless Speech.* Edited by Joseph Pearson. Los Angeles: Semiotext(e).

Giddens, A. (1979) *Central Problems in Social Theory.* Basingstoke: Macmillan.

Giddens, A. (1991) *Modernity and Self-Identity: Self and Society in the Late Modern Age*. Cambridge: Polity.

Glaser, B. and A. Strauss (1965) *Awareness of Dying*. Chicago: Aldine.

Gleeson, J. (2021) ‘Judith Butler’, *Guardian* 7 September: https://www.theguardian.com/lifeandstyle/2021/sep/07/judith-butler-interview-gender

Goffman, E.. (1959) *The Presentation of Self in Everyday Life.* New York: Doubleday.

Goffman, E. (1961) *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. Garden City, NY: Doubleday.

Goffman, E. (1963) *Stigma: Notes on the Management of a Spoiled Identity*. New York: Simon and Schuster.

Goffman, E. (1974) *Frame Analysis: An Essay on the Organization of Experience.* Cambridge, MA: Harvard University Press.

Hayward, A. (2018) ‘Rachael Bland Obituary’, *Guardian*, 7 September: https://www.theguardian.com/society/2018/sep/07/rachael-bland-obituary

Heidegger, M. (1927/2000) *Being and Time*. Oxford: Blackwell.

Hitchens, C. (2012) *Mortality*. London: Atlantic Books.

Howarth, G. (2008) *Death and Dying: A Sociological Introduction*. Cambridge: Polity.

Kalanithi, P. (2017) *When Breath Becomes Air.* Harmondsworth: Penguin.

Karpf, A. (2013) ‘The Cancer Memoir’, in Burke, J. (ed.) *The Topic of Cancer* (pp. 177-211). London: Routledge.

Kear, A. and Steinberg, D. L. (1999) ‘Ghost Writing’, in Kear, A. and Steinberg, D. L. (eds.) *Mourning Diana*. London: Routledge.

Klass, D. Silverman, P. and Nickman, S. (Eds.) *Continuing Bonds*. London: Routledge.

Labov, W. (1972) ‘The Transformation of Experience in Narrative Syntax’, in W. Labov (ed) *Language in the Inner City*. Philadelphia: University of Philadelphia Press.

Linde, C. (1993) *Life Stories.* New York: Oxford University Press.

Lorde, A. (1980) *The Cancer Journals*. Aunt Jute Books.

Mail Online (2013) ‘Devastated National Radio Host Scott Simon Documents his Mother’s Final Days in a Series of Moving Tweets from Her Hospital Bedside Drawing in 1.2 Million Followers’, 29 July: https: https://www.dailymail.co.uk/news/article-2380632/Scott-Simon-NPR-host-documents-mothers-final-days-series-moving-tweets-hospital.html

Marlow, L., Sangha, A., Patnick, J. and Waller, J. (2012) ‘The Jade Goody Effect: Whose Cervical Screening Decisions were Influenced by her Story?’ *Journal of Medical Screening*, 19(4): 184-188.

Mellor, P. (1993) ‘Death in High Modernity’, in D. Clark (ed) *The Sociology of Death.* Oxford: Blackwell.

Mellor, P. and Shilling, C. (1993) ‘Modernity, Self-Identity and the Sequestration of Death’, *Sociology* 27(3): 411-32.

Moore, A. (2019) ‘Sharing My Life and Death Online’, *Mail Online*, 14 April: https://www.dailymail.co.uk/home/you/article-6886795/Sharing-life-death-online-YouTubers-document-journey-incurable-illness.html

Nash, C. (2005) N*arrative in Culture*. London: Routledge.

Parsons, T. (1951) ‘Illness and the Role of the Physician: A Sociological Analysis’, *American* *Journal of Orthopsychiatry*, 21(3): 452-460.

Pascal, J. and O. Sagan (2017) ‘Being-in-the-World of the Sociological Imagination: Understanding Living with and Beyond Cancer’, in N. Thompson & G. Cox (eds) *Handbook of the Sociology of Death, Grief and Bereavement.* London: Routledge.

Penfold-Mounce, R. (2018) *Death, the Dead and Popular Culture.* Bingley: Emerald.

Penfold-Mounce, R. (2020a) ‘Mortality and Culture’, in T. Holmberg et al (eds) *Death Matters: Cultural Sociology of Mortal Life*. Basingstoke: Palgrave.

Penfold-Mounce, R. (2020b) ‘Value, Bodily Capital, and Gender Inequality after Death’, *Sociological Research Online*, 25(3): 490-506.

Plummer, K. (1995) *Telling Sexual Stories*. London: Routledge.

Putt, B. (2011) ‘Learning to Live Up to Death—*Finally*: Ricoeur and Derrida on the Textuality of Immortality’, *Philosophy and Social Criticism*, 37(2): 239-247.

Ricoeur, P. (1984) *Time and Narrative*, in 3 vols. Chicago: Chicago University Press.

Ricoeur, P. (2009) *Living up to Death*. Chicago: Chicago University Press.

Riessman, C. (1993) *Narrative Analysis,* Qualitative Research Methods 30. London: Sage.

Seale, C. (1998) *Constructing Death: The Sociology of Dying and Bereavement*. Cambridge: Cambridge University Press.

Sedgwick, E. (1985) *Between Men*. New York: Columbia University Press.

Segal, J. (2007) ‘Breast Cancer Narratives as Public Rhetoric’, *Linguistics and the Human Sciences*, 3(1): 158-163.

Shilling, C. (1993) *The Body and Social Theory*. London: Sage.

Small, N. (1998) ‘Death of the Authors’, *Mortality*, 3(3): 215-228.

Sontag, S. (1978) *Illness as Metaphor*. Harmondsworth: Penguin.

Steinberg, D. L. (2016a) ‘Bowie, Diana and Why we Mourning in Public’, *The Conversation*, 16 January: https://theconversation.com/bowie-diana-and-why-we-mourn-in-public-53396

Steinberg, D. L. (2016b) ‘The Bad Patient: Estranged Subjects of the Cancer Culture’, *Body and Society*, 21(3):115-43.

Thompson, N. and E. Owen (2017) ‘Michel Foucault’, in N. Thompson, N. and G. Cox (eds) *Handbook of the Sociology of Death, Grief and Bereavement.* London: Routledge.

Walter, T. (1996) ‘A New Model of Grief: Bereavement and Biography’, *Mortality*, 1(1): 7-25.

Walter, T. (2008) ‘The New Public Mourning’, in M. Stroebe et al, eds *Handbook of Bereavement Research and Practice.* Washington, DC: American Psychological Association.

Walter, T. (2009) ‘Jade’s Dying Body: The Ultimate Reality Show’, *Sociological Research* *Online*, 14(5): 105-115 doi:[10.5153/sro.2061](https://doi.org/10.5153/sro.2061)

Walter, T. et al (1995) ‘Death in the News: The Public Invigilation of Private Emotion’, *Sociology*, 29: 579-596.

Walter, T. et al (2012) ‘Does the Internet Change the Way We Die and Mourn? *Omega: Journal of Death and Dying*, 64(4): 275-302.

Woodthorpe, K. (2010) ‘Public Dying: Death in the Media and Jade Goody’, *Sociology* *Compass*, 4(5): 283-294.

**Acknowledgements**

My thanks are due to the journal’s editors and to the anonymous reviewers for their instructive comments on an earlier version of this paper.

**Funding**

The author(s) received no financial support for the research, authorship, and/or publication of this article.

**Author biography**

Michael Brennan is Professor and Deputy Head of Sociology of the School of Social Sciences at Liverpool Hope University, UK. He writes widely on the social aspects of death, dying and bereavement; specifically, at the intersection between culture and death/dying/mourning. Recent publications include work on public mediated dying, the materiality of mourning, and the context and clinical implications of social death.

1. Hewlett first disclosed his cancer publicly in a diary for the *Observer* newspaper in October 2016. In the five months between October 2016 and his death in February 2017, Hewlett appeared weekly as a guest on the flagship BBC Radio 4 programme, *PM*. His death was announced on air in February 2017 by its host, Eddie Mair. [↑](#footnote-ref-1)
2. Significant others, including family and friends, routinely participate in the cultural afterlives of those who perform their dying publicly by contributing postscripts/epilogues at the end of cancer memoirs, updating blogs and/or releasing messages on social media following the death of a loved one. For a discussion of this, see Englund (2022), Karpf (2013). [↑](#footnote-ref-2)
3. Granger died in July 2016 aged 34. In the time between her diagnosis and death, she tweeted, wrote two books about dying (*The Other Side* and *The Bright Side*, both published in 2012), newspaper articles (including for the *Guardian*), and gave interviews to BBC Radio 4’s *Today* programme and the *Huffington Post*, amongst others. [↑](#footnote-ref-3)
4. Hayward began tweeting and vlogging about her experiences following her diagnosis with malignant melanoma, aged 17, in 2011. She died in June 2018. Released posthumously by her wife, Aiisha, whom she had married in April 2018, Hayward posted a final valedictory message via Twitter and Instagram on 26 June 2018 announcing her death. [↑](#footnote-ref-4)
5. Dying Matters mass email to promote bestselling author, Kate Mosse, in conversation with Hospice UK CEO, Tracey Bleakley, sent by Imogen Thomas, 1 September 2021. [↑](#footnote-ref-5)
6. Although less common, counter narratives of the experience of cancer as transformative or redemptive do nevertheless exist (e.g. Ehrenreich 2009). For a discussion of these, see Karpf (2013). [↑](#footnote-ref-6)
7. Hitchens first shared his experiences in his *Vanity Fair* column in August 2010 following his diagnosis with Stage 4 esophageal cancer earlier that summer. His last word on dying came in his cancer memoir, *Mortality*, published posthumously in 2012, following his death in December 2011, and contains an afterword by his widow, Carol Blue. In between, Hitchens spoke about his cancer at public events and in interviews with major television news channels including BBC, CNN, PBS and ABC Australia. [↑](#footnote-ref-7)
8. Gould first spoke publicly about his terminal cancer in a Sunday morning BBC TV interview with Andrew Marr broadcast on 18 September 2011. He died shortly after in November 2011. [↑](#footnote-ref-8)
9. Sacks announced his dying in a *New York Times* op-ed essay entitled ‘My Own Life’ in February 2015. He also wrote a valedictory essay, ‘Sabbath’, in the *New York Time*s in the weeks before his death in August 2015. [↑](#footnote-ref-9)
10. Bland died aged 40 in September 2018, having been diagnosed with triple negative breast cancer in November 2016. She tweeted about her cancer, wrote articles about it for the *Daily* *Telegraph* and *Huffington Post*, and co-hosted a BBC podcast about cancer. Bland died two days after she announced on Twitter that she had only days left to live, writing: ‘In the words of the legendary Frank S—I’m afraid the time has come my friends. And suddenly, I’m told I’ve only got days. It’s very surreal…Au revoir my friends’. [↑](#footnote-ref-10)
11. Shortly before this article was accepted for publication, Deborah James announced in May 2022 that she was no longer receiving active care for her cancer and did not know how long she had left. Since being diagnosed with bowel cancer in 2016, James won plaudits for talking publicly about her cancer. Before her death, aged 40, in June 2022, James was awarded a damehood for her fundraising and campaign work in raising awareness about bowel cancer. To date, her fund (Bowelbabe) has raised over £7 million since its launch to raise money for clinical trials and personalised medicine for cancer patients. [↑](#footnote-ref-11)
12. Bellingham died aged 66 in October 2014. She first announced her diagnosis in a piece for the *London Evening Standard* in July 2013. Bellingham spoke publicly about her cancer in a number of media appearances (for BBC Breakfast and BBC Radio 4’s Woman’s Hour) and newspaper interviews (with the *Daily Express*, *Daily Mail* and *Yorkshire Post*). [↑](#footnote-ref-12)
13. Gross began blogging and wrote pieces for *The Times* following her diagnosis with Stage Four colon cancer in October 2012. She died on Christmas morning 2014, her death announced on her blog by her mother. [↑](#footnote-ref-13)
14. Simon began tweeting from his mother’s bedside after she was admitted to hospital on 21 July 2013. She died 9 days later on 30 July 2013, during which time Simon kept vigil by her bedside, sharing their experiences with his 1.3 million followers via Twitter. [↑](#footnote-ref-14)
15. Roberts first announced she was suffering from myeloid leukaemia on the BBC 2 Victoria Derbyshire programme in June 2015 (having been diagnosed four months earlier). During her illness, she blogged and gave interviews to BBC Radio 4’s Woman’s Hour, BBC Radio London and the *Daily Mail Online*. She died in October 2015 aged 64. [↑](#footnote-ref-15)
16. Diski first revealed she had inoperable lung cancer in the *London Review of Books* in 2014, following her diagnosis in August of that year. In between her diagnosis and death in April 2016, she tweeted, gave interviews (including the One-to-One interview with David Schneider for BBC Radio 4), and wrote her final book, *In* *Gratitude*, a cancer diary, which was published shortly before her death and includes an afterword by her daughter, Chloe. [↑](#footnote-ref-16)
17. James died in November 2019 aged 80. He first announced his death was ‘imminent’ in a BBC Radio 4 interview in June 2012. Following this, James began saying his ‘goodbyes’ and chronicling his dying in his reviews for the *Guardian*, and in a series of long form poems, for the *New Yorker*, and in books *Sentenced to Life* (2014), *Injury Time* (2017), and *The River in* *the Sky* (2018). His last television appearance came in a BBC *Front Row Special* with Mary Beard that aired in December 2018. [↑](#footnote-ref-17)