Stephen Sutton and the politics of the deathbed smile

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Yasmin Gunaratnam [1] 2 June 2014

In the political economy of modern dying, Stephen's Sutton's death from cancer - wrapped up in cheery charity fundraising - made headlines, while the worst ever Turkish mining disaster went under the radar. Part of Transformation's liberation series [2].

In the UK, thousands of people, including celebrities and Prime Minister David Cameron, commemorated Stephen Sutton’s indomitable spirit in the face of terminal bowel cancer. The
nineteen-year-old had raised millions of pounds for charity.

He seemed to embody his motto: "Cancer sucks, but life is great".

The national outpouring [9] of grief for Sutton’s death happened to coincide with UK Dying Matters awareness week [10] and the launch of two new studies that showed a less rosy picture of British death.

A Comres study [11] identified an overwhelming reluctance among the public to talk about or to plan for death. The National Care of the Dying Audit for Hospitals [12] found that less than half of patients in hospitals were told of their prognosis in the last hours of life. Relatives felt as if they had little emotional support. Specialist palliative care was often unavailable at the weekends.

The patterning and extent of difficult end of life illness experiences are not easy to discern in the public discourse, especially when it comes to negativity or emotional chaos. Aside from Breaking Bad [13] - a drama about how a terminal cancer diagnosis turns an etiolated chemistry teacher into a violent crystal meth cook - how often do we see the damage that disease and dying can intensify or unleash on bodies, relationships and communities?

Over three decades ago, Susan Sontag [14] highlighted the workings of a moral economy that valorised individual responsibility and a psychology of positive thinking for people with cancer. The danger for Sontag was that such social airbrushing could end up putting “the onus of the disease on the patient”. If your cancer returned or you ended up dying from it, you were obviously not trying hard enough.

The allure of the positive psychology illness makeover projects goodness onto the public persona of dying people and their carers. This is crafted by the media [15] and instrumentalised - often unwittingly - by self-help resources [16], charities and death rights activists.

Studies of the Anglophone media have found that the portrayal of people with cancer is mired in a ‘cancer heroics [15]’, with an emphasis on emotional resilience for women and pugnacious fortitude for men. In the business of generating income, charities in the field of illness and death face the difficult ethics of riding the wave of media attention while not exploiting a death or public emotions.

“People don’t just give to a cause, they give to a person in many cases, and they give to a personality”, communications expert Peter Gilheany said in a radio interview [17] following Sutton’s death.

In this eclipsing of cause by personality, deeper concerns emerge about the politics of the deathbed smile.

If happy dying is an increasingly desired modern necro-comportment, it is also true that the upbeat and well-prepared dying make exemplary neoliberal citizens and patients. In contrast to ‘bed blockers [18]’ and disabled ‘benefit cheats’, the resilient cheer of deathbed striving is contagious, offering an existential shock absorber and an occasion to reiterate a sense of national belonging and pride.

The happy death and its promise of order and control is emblematic of what feminist scholar Lauren Berlant [19] calls ‘cruel optimism’, where hope and aspiration can palliate dissent and deflect attention from the violations of structural inequalities and injustice.

We remain relatively ignorant, perhaps intentionally so, of some of the darker realities of illness and dying, both in the UK and globally [20]. Premature mortality [21] rates are high in the North of England, associated with poverty and the decline of manufacturing industries. There is uneven access [22] to specialist palliative care for those from ethnic minorities and for people with diseases other than cancer.

Rising numbers of older people are dying alone, and there is inadequate government support for so called ‘pauper’s funerals [23]’. The average cost of a funeral has been estimated at £7,622 [24]; a
rise of nearly 80 per cent since 2004.

Alongside these localised inequalities are shifting geopolitical divides. Death for many of us in the west is increasingly characterised by forward planning, from will making to organ donation and advance care plans [25]. With the development of bioinformatics [26], such as risk indicators and gene mapping [27] for some hereditary diseases, the more recent drive is to outsmart our health risks and micro-manage future uncertainty, prompting some critics to suggest that more or us are living in an ever-expanding and hopeful ‘prognosis time [28]’.

Yet it is the very normalisation of risk, injury and premature death for the sake of profit that marks the lives and deaths of the poor.

“Let’s please not pretend such incidents do not occur in mines,” Turkish Prime Minister Recep Tayyip Erdogan said in a press briefing [29] after his visit to Soma. “This is part of the nature of this business.”

There have been 1,308 deaths in accidents [5] in Turkish mines since 2000. Figures show that 10.4 per cent [30] of all workplace accidents in 2013 were in the mining and quarry industries, linked to poor working conditions.

There is complexity as much as complicity in the contemporary allure of the deathbed smile. As more people use social media to document their experiences of illness, dying and bereavement, we are offered a real-time intimacy and a humanizing of certain deaths, but at a safe distance.

What is less discernible is how a range of slow motion injuries set in train by poverty, economic exploitation and industrial and environmental disasters play out across the bodies and the life course of those on the social margins. These are injustices that the eco-critic Rob Nixon has called ‘slow violence [31]’. Writing about environmental destruction and hazards, Nixon sees slow violence as deferred and hidden. This is a violence “of delayed destruction that is dispersed across time and space” Nixon writes, “an attritional violence that is typically not viewed as violence at all.”

The challenge for political critique and activism is that unlike the spectacle of digital dying or the industrial catastrophe, the pernicious nature of incremental attrition is that it is a part of the reproduction of daily life. It can be rationalised not only by industrialists and the state but also by workers and communities themselves.

Not easily incorporated into rights based agenda, this mundane violence is barely noticeable. It is something that we might recognise in hindsight with the same astonishment that the speed-up of timelapse photography offers as we watch a flower unfurl, bloom and then wither before our eyes.

Social media may be transforming how we encounter death, but it is the naturalising of disparities of risk and insecurity that continues to characterise the political economy of modern dying.

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