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**Dispatches from the dying:  
Pathographies as a lens on consumption *in extremis***

**Darach Turley and Stephanie O'Donohoe**

**Introduction**

For Bury (2001:264), 'universal, cultural and individual levels of human existence are tied together with narrative threads'. Consumer researchers have long acknowledged this, drawing consumption stories from interviews, comics and novels, and personal introspection (Belk 1987; Brown, 1995; Gould 1991).

For all their salience in everyday life, stories acquire particular urgency in extremis. Serious illness and impending death are common yet extraordinary circumstances that cause physical and emotional havoc, trailing 'narrative wreckage' (Frank 1995) in their wake. Individuals experiencing such adversity 'often feel a pressing need to re-examine and re-fashion their personal narratives' (Bury 2001: 264). Telling stories of illness and loss, Frank suggests, is a way of reclaiming agency, transforming fate into experience, and crystalizing or rebuilding disrupted identity projects.

Many such stories are crafted in conversation, and the consumer research literature has been enriched by studies drawing on interview accounts with people facing serious, life-limiting or life-threatening illness (Kates 2001; Pavia & Mason 2004; Botti et al 2009; Dunnett et al 2011; Tian et al 2014). Prior to undertaking interviews with women about breast cancer, Pavia and Mason (2004) read published memoirs as they sought to orient themselves to this sensitive topic. In this chapter, memoirs of illness and dying move from this supportive, orienting role to centre stage, just as they appear to have done in the publishing industry.

Pathographies are a form of popular culture, a genre of autobiographical literature describing an author's experiences in facing or witnessing serious or terminal illness, or grieving for the loss of a loved one (Hawkins 1999). There appears to be considerable consumer demand for musings on mortality; Lane (2000) notes that '[t]he death memoir was the cultural and publishing sensation of the past decade'. Challenging views of death as taboo in Western culture, O'Neill (2012) asks '...how many times does a taboo have to be broken before we stop calling it a taboo? Because writing about one's own malady, especially if it's cancer, is actually pretty commonplace these days'. O'Neill (2012) attributes the popularity of pathographies to a morbid, disease-obsessed and titillation-seeking culture; others attribute it to more profound reader concerns and point to the hundreds of letters from readers thanking authors for the consolation or inspiration of their words and for sharing their own stories of illness, dying and loss (Small 1998; Armstrong-Coster 2012; Berman 2012).

Illness narratives not only offer accounts of how disease affects individual lives; they may also offer important insights into 'the links between identity, experience and "late modern" cultures' (Bury 2001). Such links are central to the consumer culture theory agenda (Arnould and Thompson 2005). Clearly, the authors of pathographies do not set out to foreground consumption issues. Nonetheless, we suggest that deep and detailed accounts of serious or terminal illness, particularly when furnished by accomplished writers, offer a powerful lens for examining the role of consumption and consumer culture in extremis – how consumers in distressing circumstances use an array of goods and services in their struggle to make sense

of illness and loss. As extended, uninterrupted narratives of illness trajectories, these accounts also minimise the risk of researcher-led fragmentation (Gilbert 2002).

In this chapter, we highlight the contribution of pathographies to understandings of consumption *in extremis*, using as exemplars two influential cancer memoirs written by British journalists. We suggest that these authors' journalistic training, coupled with the heightened sensitivity bestowed on them by illness and decline, suffuse their memoirs with deep insights into the interplay between markets and mortality.

### **A pathographical lens on mortality and the marketplace**

1998 saw the publication of two books that began as newspaper columns by well-established, popular British journalists documenting their response to progressively more pessimistic cancer diagnoses. Offering insights into lives lived in the knowledge of possible and then certain impending death, their devastating accounts are leavened with wit and gallows humor. Ruth Picardie's *Before I Say Goodbye* (1998), published posthumously, incorporates her seven eponymous newspaper columns documenting the ten months before she died aged 33; her breast cancer, initially misdiagnosed (Boseley 2011), spread to her liver, lungs and brain despite several rounds of chemotherapy. It also includes email correspondence between Picardie and a small group of friends, postscripts from her husband and sister, and a selection of letters from readers of her column. John Diamond's *C: Because Cowards Get Cancer Too* bears witness to a throat cancer diagnosis in his mid-forties, enduring chemotherapy, radiotherapy and surgery that cost him his tongue, his voicebox, and his broadcasting career, but still seeing his prognosis plummet from a 92% chance of survival to imminent death. Occasionally incorporating extracts from his newspaper columns, Diamond offers a more detailed, sole-authored account of declining health than does Picardie's book.

The publication of these two books was the point where 'cancer commentary took off' in Britain (O'Neill 2012). Indeed, journalism professor, former newspaper editor and colleague of Diamond, Roy Greenslade (2011), argues that '[t]heir work, and the resulting publicity that it generated, was praised by doctors and resulted in enormous, and positive, feedback from the public'. As discussed below, many of the experiences recounted by Picardie and Diamond were inextricably linked to the marketplace. Some of their stories resonate with Pavia and Mason's (2005) account of consumers *with* cancer, but others were written as consumers *of* cancer treatment.

### ***Consuming treatment***

Dunnett et al (2011) document how a multiple myeloma support group enabled its members to reclaim a degree of agency and become skilled healthcare consumers. As Lupton (1997:374) notes, the increasingly popular notion of 'the patient qua consumer', like that of the reflexive actor, assumes an individual who is 'actively calculating, assessing and, if necessary, countering expert knowledge and autonomy with the objective of maximizing the value of services such as health care'. Gielser and Veresiu (2014:841-2) refer to a process of 'consumer responsabilization' through which consumers 'are reconstructed as free, autonomous, rational, and entrepreneurial subjects who draw on individual market choices to invest in their own human capital...'. Various sociological studies highlight the interpersonal complexities of health encounters as well as the 'tensions, ambivalences and contradictions' that are often involved (Lupton 1997). Indeed, when parents confronted tragic end-of-life decisions in neonatal intensive care units, those who were 'empowered' to make the choice

themselves appeared to suffer more than those who saw medical staff decide to withdraw life support (Botti et al, 2009). These issues are foregrounded in our two pathographies.

Both Picardie and Diamond found themselves navigating the UK healthcare system, four-fifths of which is run under the auspices of the NHS, the world's largest publicly funded health service (Nuffield Foundation 2014). NHS treatment is, with few exceptions, offered free at the point of use to all permanent UK residents (NHS 2013). It coexists with a private healthcare system which is generally accessed by individuals through private health insurance schemes, although individuals may pay directly for particular consultations or treatments. In practice, the relationship between public and private health provision is complex, with personnel, equipment and buildings often shared between the two systems.

Although both books were written around the same time and in the same metropolis (London), they present us with contrasting health-consumption profiles as each author takes a different path through the UK healthcare system. In market positioning terms, the profiles of our two authors could be plotted on the twin axes of public versus private healthcare, and orthodox versus alternative medical regimes.

John Diamond remains resolutely in the orthodox/private quadrant for most of his book. His distaste for all things complementary was due primarily to his conviction that, in scientific terms, they simply do not stand up, a conviction reinforced by a brief and futile dalliance with an alternative practitioner as a thirty-something bon-vivant suffering the effects of excessive tobacco and junk food intake. Electricity-disrupting allergens were prescribed on the basis of tests which Diamond identified as fundamentally flawed. By the time he comes to write CBCGCT he is in his mid-forties, has been diagnosed with throat cancer and has pinned his hoped-for bodily survival unapologetically to the mast of orthodox medicine. His stance on alternative medicine at this point is 'roughly where the Pope stands on getting drunk on the communion wine and pulling a couple of nuns' (p.98).

As a high profile journalist with a loyal and concerned following, he received an array of rosaries, crosses, juju images of cancer, prayer leaflets, and obscure journal references for naturopathy and iridology from solicitous readers and 'committed alternativists'. These kindnesses did not deter him from continuing the public polemic in his newspaper column against what he considered to be the unscientific, misleading, and ultimately deleterious nature of the belief systems that underpinned them. He penned scathing ripostes to irate readers who berated him for perpetuating one of orthodox medicine's greatest scams by beginning a course of radiotherapy.

Diamond's choice of private over public healthcare system seems to have been a matter of pragmatism over principle. He had seen his father wait two years for an angiogram with the National Health Service before paying for it privately. On the day his father did so, Diamond took out BUPA (private health) insurance for himself. The trajectory of his book is one of an ambivalent private patient dealing with an array of consultants, surgeons, therapists, and nurses as a paid-up BUPA member. This is the world where dropping consultants' names is the stuff of health consumption entrées and social capital. One of the notable features of 'going private' for him is that this system shrouds the whole process of disease and dying with the architectural, sartorial, and decorative veneer of non-medicalised everyday life. Consultants sport pin-striped suits, medics wear 'Calvin Klein lab coats' and nurses pose in air-hostess uniforms. Hospital room fittings and ersatz framed posters remind him of a hotel chain. Specialists show a practiced ability to dissemble, mollifying clients by pasteurising

their 'rooms' of any distasteful or disturbing contaminants. Surgeries morph into sitting rooms or studies:

God forbid that a Harley Street consulting room should look like a doctor's office; they are laid out as old-fashioned drawing rooms or studies: a leather-topped oak desk, a couple of button-back chairs, some anodyne reproduction paintings ... And there in the corner, hiding away, will be a tray full of stainless-steel specula or a discreet X-ray light box or a tasteful little ultrasound machine, as often or not stored behind doors in the way they store TV sets in the Home Counties (p.20).

Diamond submits to this dissembling and domesticated *mis en scene* in return for prompt access to the world of 'I need it now' medical ministrations. He admits to harbouring lingering reservations about it, especially 'if anything went wrong', since in his view private institutions come 'second best in extremis'. Occasionally, he finds himself back in the public health domain, highlighting the tensions involved for patients who straddle or indeed cross the delicate fault lines between both health provision sectors. One evening, for example, he found himself in a public ward in St. George's hospital, having waited all day to be admitted for the removal of a cyst. Reflecting on his irate interaction with a staff nurse, he notes:

...I feel so crass doing the 'What the hell do I pay BUPA all that money for if I can't have a room to myself' shtick in front of a row of patients who have probably been hanging around for months on waiting lists hoping to get a bed in the NHS lottery. But anger overcame crassness... (Diamond 1998:30)

In contrast to the studied argumentation of Diamond's discourses on medics and medicine, Picardie's allusions to her illness and symptoms tend to be brief and often brutal. By the time she came to write the first e-mail reproduced in her book, she was already receiving chemotherapy for breast cancer, misdiagnosed two years previously (Boseley 2011). So, a somewhat jaundiced view of orthodox medicine is hardly surprising, as is her openness to complementary alternatives. From the outset she leaves both friends and readers in no doubt that she is 'going public'. Over time, however, a sizeable portion of the savings accruing from this principled stand is spent on alternative therapies. Far from being an unquestioning evangelical devotee, Picardie acknowledges that heterodox regimes boast their fair share of quackery, snake-oil peddlers, and 'money grabbing wankers'. Her descriptions of encounters with alternative practitioners and their adherents are shot through with humour, wry scepticism, irreverence, and fulsome admissions that she's 'clutching at straws', admissions that beg the question why she engaged with this collection of complementary purveyors for so long. Patronage of particular complementary therapies is fickle and promiscuous, with new options shared by word of mouth among her circle of friends. Her investment in these alternative alternatives seems predicated primarily on the belief that she owes it to herself, and those she loves (including her toddler twins) to at least give them a try.

I started in October by visiting a so-called complementary guru whom I'm sure won't mind being called Dr Charlatan (his swish London clinic closed down overnight; he has now disappeared). First, he got me on the aforementioned supplements ... plus a £275 drink called Yeastone which filled up half the fridge. Then he got my blood analysed by a German professor who advised me that refined sugar was poison and urged me to go on a complicated diet (vinegar bad, trout good, three-day-old eggs best of all). Finally, he got me hooked up with a computer expert-cum-homeopath for a course of 'Bicom' therapy which meant being wired up to a laptop which positively recharged my cells. All this may

sound ridiculous; but when the hospital baldies have told you, aridly, that such-and-such treatment only has a '50:50 survival benefit', you desperately want to lengthen the odds ... the desperate hope of a girl with cancer knows no bounds (76).

Here Picardie rides a roller coaster of complementary therapies, reflexively aware how absurd it all sounds and yet asking her readers to understand why, given the shoddy treatment and sober prognosis she had received from oncologists, she could hardly have done otherwise. Medical bulletins such as the one above lack the rhetorical polemic of Diamond's columns, although reeling off alternative therapies without any mention of positive outcomes can hardly have bolstered their widely contested reputation.

### **Contested control**

Although both authors differ on the optimal health-provision and therapeutic approaches for cancer, they have much in common. Both are unashamed denizens of the risk society (Giddens 1999; Lupton 1997; Giesler & Veresiu 2014), refusing to be cowed when confronted with professional pomposity or the foibles and fallibilities of medics. They seek to exert personal agency in the diagnosis, understanding, and management of their respective conditions. In Diamond's case this goes as far as acknowledging quite openly that his smoking had been tantamount to playing Russian roulette with his immune system.

Both share a passion to know exactly what is going on and see the internet becoming a wellspring of information and empowerment for those living with cancer. The internet's democratic and egalitarian ethos lends itself to untrammelled expression and it is for this very reason that Diamond in particular views it as the site where the battle lines between traditional and heterodox treatments are most vividly evidenced. He was not averse to entering into this online affray; indeed it was precisely when he was trying to familiarize himself with and confront the myriad pseudo-medical, lay, and religious online 'opathies' for his column that he became fully aware of a sleeping giant that lay beneath the surface-level exchanges. The more he browsed, the more he became aware of a vast corpus of scientific research studies on cancer outcomes and, although he was unable to adjudge their relative merit, their collective import for his survival odds was somber and 'really scaring'.

The tensions and ambivalence of a 'consumerist' stance (Lupton 1997) are evident in other parts of Diamond's account. Having made rational choices about orthodox, private medicine, he acknowledges that this requires him to compromise on both comprehension and control over his condition, in contrast to the sense of empowerment afforded the alternative aficionado:

How much better it would be if I could do something for myself ... which would allow me to take control of my cancer. How wonderful it would be to decide for myself which of the dozens of equally valid remedies from around the world was most suitable for my personality, my cancer, my birth sign (p.104).

Picardie also alludes to the 'dark side of empowerment' in medical contexts (Dunnett et al 2011). For those who lack the requisite physical and emotional stamina, empowered consumer health choice can prove a burden rather than a bonus. At the outset of her treatment, she emails a friend who is also seriously ill:

Like you say, the fact that you have done so much research and are making treatment decisions must make you feel good. Have yet to get a web browser and find breast cancer site. Part of me is so exhausted by all the appointments and X-rays and tears that I want to switch off from the subject completely. (p.7)

Nonetheless, she finds herself having to be on guard, alert to the options and obtaining second opinions. Comparing what she knows about chemotherapy regimes at two hospitals, she notes the Marsden reviews treatment after four cycles, 'whereas Guy's seem to let you suffer for the whole whack, regardless of efficacy, unless you take control' (p.7). Concerns about secondary bone cancer lead her to 'shop around', but 'The Marsden pretty much said what Guy's said, so I won't be transferring there' (p.9).

A related motif for both authors is a studied reliance on self-diagnosis and a resolve to ensure that they listened as carefully to their own bodies as they did to the medics. This is particularly pronounced in Picardie's case, as she recounts numerous 'I told you so' incidents. Indeed her husband Matt describes 'a pattern in which she always knew the bad news before the hospital tests confirmed it' (p.105). At one stage Diamond receives an official all-clear, but, whenever he is asked if he still has cancer admits presciently: 'I feel as if I ought to say that I haven't because the truth is that there is no cancer anyone can find. But when it comes to saying the words, I can't do it. I hedge, and fudge, and bluster' (p.238).

Both authors are at pains to confront their condition by putting a tolerable distance between them and their cancer. The very process of penning a pathography can be viewed as such an enterprise (Hawkins 1999). Both texts are replete with accounts documenting the size, location, and progression of the authors' respective tumours and cancer cells. That these well-informed accounts are couched in conversational terms underscores how normalization can serve as a means of control and empowerment. Diamond's narrative includes particularly vivid examples of exerting control through objectification and externalization. In one instance he asks his radiotherapist for a slide of sections of his cancer and brings a radiotherapy mask home as a souvenir. Later, in an equally fetishistic vein, he uploads as a screen-saver a photograph of a squamous cell cancer of the neck. Finally, given his experience in broadcasting, he agrees to the BBC making a documentary featuring his undergoing and recuperation from major surgery - all in the hope 'that by rendering the cancer an objective spectacle I could distance myself from it' (p.214).

The contestation for control between cancer and patient is played out in quite a number of additional arenas in both books. On some occasions the pendulum swings in cancer's favor as when Diamond finds himself in a hospital waiting room and comes face to face with a plethora of *momento mori*: leaflets on how to register a death, contact details for religious ministers when death is imminent. These sober reminders were disconcerting enough without his being further ambushed by a barrage of glossy magazine headlines: an article on weekend breaks titled 'When you've got to go GO'. Other headlines leap out of pieces on the mundanities of travel, cooking and wine: 'A GRAVE SOLUTION, NO HOPE OF RETURN, HEAVEN CAN'T WAIT' (31). When it came to double-entendres, the darker side seemed to win out every time.

If cancer commands attention and colours perception in this way it can also impose itself on the individual in more tangible and explicit ways. Daily routine in both narratives becomes dominated by rosters of consultations with medics, dosage regimes for medication, and dates

of hospital appointments and discharges. 'My whole life seems to have been taken over by illness' complains Picardie before detailing her diary for the following week; Thursday is her only day off. Cancer also exercises control by imposing itself on their physical surroundings and both authors proffer multiple lists of pharmaceutical prescriptions, patient paraphernalia, and cancer accoutrements, goods that are increasingly populating and dominating their personal living space. Diamond hammers home this point by devoting over three pages of his book to rattling off a litany of his 'latest collection of cancer victim takeaway gear'. At one level such exhaustive inventories betoken consumers essaying to manage their illness by auditing what exactly is going on, at another they mirror in external matter the physical progression of the cancer within.

### **Accommodating cancer**

One notable feature of both books is the juxtaposition of harrowing detail and what might appear banal consumption-related stories. This may reflect the role of everyday consumption in keeping those facing serious illness woven into the fabric of everyday life (Mason and Pavia 2005). Indeed, when a friend worries that she should purge her messages of such things, Picardie emails 'PLEASE keep the so-called trivia coming: the last thing I want to do is spend 23 (instead of 22) hours a day thinking about cancer' (p.17). For Picardie and Diamond, however, consumption also seemed to be used to acknowledge and respond to the progress of cancer, especially as it led to changes in their physical appearance.

Over the course of her book, Picardie loses much of her hair; initially she asks her friends to send her hats, and makes multiple hairdresser appointments, first to cut her hair into a manageable bob, and then, once clumps start falling out, to have her head shaved. Weight gain from treatment and her response to treatment is a constant theme in Picardie's book; she impishly ascribes the extra weight to eating opportunities such as the chocolate biscuits at the cancer support group and the sandwiches eaten to kill time in hospital. She accommodates her changing girth by entering into 'fashion bimbo' mode:

...yesterday bought pair of linen trousers (elasticated waist) and linen shirt from Hobbs (my new favourite shop, though size 16 jacket was too tight) and new pair of (brown, three strap) Birkenstocks. What is happening to me? But it is such good therapy (p.26).

Diamond, on the other hand, loses a considerable amount of weight. He too decides to take action. On finding that most of his clothes were now two sizes too large, he chooses not to behave as men are supposedly wont to behave; he purchases a £299 leather jacket on impulse on his way home from a hospital appointment.

What sort of world was this where a man with cancer couldn't buy himself a leather jacket? ... It was bad enough that I had cancer without having to have cancer and be dressed in clothes two sizes too big. And, what the hell, we could pay the Amex bill next month.' (p.118).

Both refer to being cheered by what Picardie labels 'retail therapy'; indeed both report some delight in making various purchases which in their 'normal' lives they would have considered extravagant or excessive. There may have been more than a momentary psychological fillip at play here, however. Accommodating to physical increments or decrements by changing one's wardrobe, by not throwing in the towel, can be seen as an instance of turning a physical loss into a psychological and morale gain. Refusing to continue wearing ill-fitting clothes can



thus represent an attempt to neutralise at a sartorial level what cancer was doing to their appearance at a physical level. It may also be read as an act of defiance, following the poet Dylan Thomas's command to '[r]age, rage, at the dying of the light'.

Other consumption accounts suggested however a more measured, gentle going into Thomas's dark night. Pavia and Mason (2004) refer to 'green banana' syndrome among cancer sufferers, reflecting a degree of anxiety about tempting fate by investing in products that presume a longer lifespan than they might be granted. Towards the end of both these books, however, the authors *know* their fate is sealed and goods have more to do with the duration and tone of time remaining than any hope of recovery. Picardie muses whether her jar of face cream will see her through to the end and Diamond's last words in his book refer to acceptance of impending death rendered through an act of consumption:

As I write this we have just returned from buying a basket for the spaniel we are due to collect in a couple of days time. A friend e-mailed me when she heard this to tell me about how it's a denial of what's happening and what's about to happen. It isn't at all: I know what's happening. But a dog is a happy thing, and it will be happy for me for whatever time I've got left and as happy as things can be for the family when I've gone (p.256).

## Conclusion

Accounts of dying date back to the medieval and renaissance eras, when the Church sought to instruct the faithful into the ways of a good death, drawing on examples of those who departed this world in a state of grace (Hawkins 1999). In our contemporary consumer culture, Berman (2012: 295) suggests that end-of-life memoirs constitute 'a secular example of the long tradition of *ars moriendi*, the art of dying', offering readers opportunities to learn from others' experiences so that they feel less isolated and afraid. Clearly, in a crowded market not all pathographies will be written in such a way as to strike a responsive chord with readers confronting illness, mortality or bereavement, but many do reach heady heights in both literary and humane terms.

Perhaps one of the most striking insights offered by Diamond and Picardie is that dying well entails sustaining as good a life as possible, for as long as possible, and that consumption is intimately interwoven into the fabric of that life. Their accounts show two people going about their business, engaging with the marketplace as consumers of cancer care and consumers with cancer, and they illuminate for readers the light, shade and even the routine involved in performing both roles.

The success of pathographies suggests that their detailed, granular accounts may be particularly valuable for future cross-cultural studies of healthcare consumption. They may also lend themselves well to analyses of consumer experiences in the course of particular illnesses or traumatic events, or of how illness or bereavement have been experienced within consumer culture in different eras or for different groups of consumers. Overall, there seems to be a great deal of analytical life in this literary genre devoted to illness, dying and death.

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