

# Adjuvant chemotherapy: an autoethnography

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**Abstract** Adjuvant chemotherapy is given after surgery for early stage cancer. It aims to cure. Though potentially toxic, it has dramatically improved survival for some cancers. This paper offers an autoethnographic exploration of three kinds of strangeness that I encountered during a 12-week course of adjuvant chemotherapy for early breast cancer: the material strangeness of what was done to me; the lived-body strangeness of receiving chemotherapy (which makes people sick to make them well) and the existential strangeness of reconstructing my broken narrative. In a discussion, I consider four aspects of autoethnography of deep illness against which this account and its telling might be judged: ethnographic legitimacy (does it meet the standards of analytic social science?), autobiographical legitimacy (is it compelling as literature?), existential ethics (am I, the wounded storyteller, protected from harm?) and relational ethics (have I discharged my duties towards those implicated in the text and its interpretation?).

**Keywords** Autoethnography · Breast cancer · Narrative · Chemotherapy

## Background

I am a doctor and a social scientist. When I was diagnosed with breast cancer, I sought narratives. What I found both overwhelmed and disappointed me.

The cancer narrative has traditionally served to do biographical work for someone adapting to life-threatening illness (Mathieson and Stam 1995). Prominent themes in breast cancer narratives are receiving bad news, fear and uncertainty,

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coming to terms with a bleak prognosis, coping with disfigurement and compromised sexuality and living with terminal illness. This ‘tragedy’ genre, focused on an individual woman’s disease course and structured around its inexorable progression, remains pervasive in research, lay literature and the media alike.

Alternative framings of breast cancer challenge this dominant genre. Feminist narratives question the ubiquitous war metaphors, depiction of women as victims, depiction of doctors (and surgeons in particular) as heroic, technologisation of cancer management and fetishisation of the female breast; they emphasise instead the sometimes brutalising experience of breast surgery (Cobb and Starr 2012), the possibilities of a more ecological coexistence between the body and cancer (Garrison 2007) and the queering of survivorship through bald pride, rejection of reconstructive surgery and the energising power of women’s support networks (Lorde [1994] 2006). Biopolitical narratives depict breast cancer as disempowering whole populations, not just individuals, and seek to surface and confront prevailing discourses (“...a pinkwashing and infantilizing of diagnosis and the experience of breast cancer; a politics of sentimentality that makes breast cancer palatable through the conventions of the commodity, thereby obfuscating the terror and death that accompany the disease”) (Ehlers and Krupar 2012, pp. 1–2). Postmodern and postfeminist narratives depict the breast cancer experience as ambiguous, fluid, multi-vocal and collectively shaped, and highlight the new narrative possibilities that have emerged through hypertext and social media (Ehlers and Krupar 2012; Pitts 2004).

These narratives overwhelmed and disappointed me. Once I started to look for them, breast cancer stories were everywhere, vying for legitimacy and demanding that I frame *my* story similarly. They disappointed me because none actually fitted my story. Often evocative and sometimes theoretically elegant, they shared two critical limitations. First, they treated breast cancer as a single disease and took little account of its medical heterogeneity. Second, they seemed to overlook recent significant improvements in breast cancer prognosis. Before I could tell my experiential story, I had to anchor it in a medical (‘evidence-based’) narrative of what kind of cancer I had and how it was likely to progress, with and without treatment (Greenhalgh 1999).

Forty years ago, a woman diagnosed with breast cancer in the UK had a 40% chance of surviving ten years. Today, that figure is over 80% (and improving year on year), due to both better treatment and earlier diagnosis. Forty-four percent of newly diagnosed breast cancers in the UK are Stage 0 or 1 (smaller than 2 cm, confined to the breast and with clear margins when removed); the 5-year survival rate of these very early cancers exceeds 99% (Cancer Research UK 2016).

Whilst this still leaves a significant proportion whose cancer is locally advanced or disseminated at diagnosis, tens of thousands of women in high-income countries every year now experience the sequence of bad news—a diagnosis of breast cancer—and then (a few weeks later, when the results of staging, grading and molecular profiling become available) good news—that their prognosis is, in the words of my own oncologist, “excellent”.

But to get to that excellent prognosis, women with very early breast cancer must pay a substantial price. They are expected to choose either what many would classify as mutilating surgery (a mastectomy) or breast-conserving surgery followed



by a course of radiotherapy. The majority, whose tumours express oestrogen or progesterone receptors (denoted ‘ER+’ or ‘PR+’), will be advised to take hormone-blocking medication for several years, with (among other side effects) life-changing implications for fertility, libido and identity. Some, whose tumours over-express the protein ‘HER+’ (a growth factor traditionally associated with rapid proliferation and poor prognosis), will be offered ‘molecular targeted therapy’ against that growth factor. Most women will be offered adjuvant (that is, preventive) chemotherapy to poison rapidly dividing cells.

The aggressive management of very early breast cancer is not without controversy. Both sociologists and doctors have argued that women in this group are over-diagnosed and over-treated (Davis 2008; Gøtzsche 2012). These authors have a point. Some Stage 0 disease, detected through mammographic screening, might never turn into invasive cancer and some (though not all) Stage 1 cancers have an extremely low risk of recurrence after removal (Kent et al. 2015). A key aim of current research is to achieve more accurate profiling of very early breast cancer, enabling closer targeting of surgery, radiotherapy and chemotherapy (‘slash, burn and poison’) to those most likely to benefit (Scharl et al. 2015). But for now, almost everyone with early breast cancer faces a significant sojourn in the world of the sick.

## Early breast cancer: a personal narrative

With the epidemiological context sketched, I can begin my personal narrative. In May 2015, I bled from my left nipple. An initial biopsy was reported as “no evidence of malignancy”. A mammogram showed no lump but some areas of calcification—a finding that may be benign, especially when found incidentally in screening mammograms (Gøtzsche 2012). But mine was no innocent, screen-detected anomaly, since nipple bleeding is a ‘red flag’ sign. A deeper biopsy was unambiguous—I had invasive breast cancer, with poor prognostic features: a high cell proliferation index, lymphovascular invasion and over-expression of the HER+ growth factor.

Alarmed by these descriptors and concerned about the risk of heart damage from left-sided radiotherapy, I immediately opted for a full mastectomy. A week after it, I learnt how my cancer would be formally coded and classified: Stage 1b (meaning that, apart from a pea-sized tumour, my entire breast was clear of cancer and it had not spread to my axillary lymph nodes), Grade 2 (moderately differentiated—the middle grade of three), ER–, PR– and HER+.

Even though my cancer was small and apparently localised, it had already eaten into my blood vessels and lymphatic system, perhaps seeding tiny secondary tumours of rapidly proliferating cells. Without further treatment, there was a significant chance that sometime in the future, it could recur—perhaps in my bones, lungs or brain. As I interpreted the pathology reports for my non-medical husband, my unfolding narrative took on some ominous literary features: risk, hidden danger and suspense. This was, in Frank’s (1998) terminology, deep illness. We needed to consider the treatment options carefully.



Oncology is one of the most organised and systematic branches of medicine, boasting a weighty evidence base from large, multi-centre randomised trials and long-term observational studies (since cancer patients tend to be placed on registers and carefully followed up until death) (Mukherjee 2011). The injectable monoclonal antibody drug trastuzumab (usually referred to by its trademarked brand name, Herceptin®), for example, was recently described as “one of the most significant discoveries in breast cancer therapeutics” (Baldwin and Cook-Deegan 2013). It has no impact on most (HER-) breast cancers but produces dramatic regression in rarer HER+ cancers.

Here was an epic twist to my narrative: because of a relatively recent scientific breakthrough in cancer genetics, my “poor prognosis” cancer now turned out to have the most treatable of all molecular profiles—and the very protein that made it “highly proliferative” also made it highly sensitive to the drug. I celebrated the irony.

Herceptin®, whose side effects are relatively mild, is not given alone. It comes as part of a package with chemotherapy, because that is how it was tested in early clinical trials. In these trials, women with HER+ breast cancer were given a combination of two or three highly toxic chemotherapy drugs alongside Herceptin®, and survival rates were good. But the trials focused mostly on women with more advanced cancer. Tolaney et al. (2015) tested a gentler chemotherapy regimen (a single drug, paclitaxel, given weekly for 12 weeks) in over 400 patients with Stage 1 HER+ breast cancers. None developed serious side effects. Three years later, only six had any evidence of recurrence and none had died from breast cancer.

Aside from the fact that Tolaney et al.’s study had included no control group (since a no-treatment comparison was considered unethical in aggressive HER+ disease), I could not have asked for stronger evidence that 12 weeks of paclitaxel, along with a year’s course of Herceptin® injections, was the best and safest treatment for my particular cancer. I described the regimen to friends as a “no-brainer”.

## Autoethnography of chemotherapy: method and theory

Autoethnography has been defined as “*writing about one’s own experiences for specific academic purposes*” (Richards 2008, p. 1718). Whilst it is open to the charge of excessive subjectivity and even narcissism (Roth 2009), the fact that a number of leading social scientists have published autoethnographies of their own cancer journeys (Blaxter 2009; Frank 2002; Riessman 2015; Stacey [1997] 2013) is testimony that the approach has credibility in this context. In her account of treatment of a muscle sarcoma, for example, Cathy Riessman addresses the core narrative themes of temporality (illustrated by her cancer’s fragmented beginning, troubled middle and uncertain ending); identity (by reflecting on how her illness had changed her and how she strove to rebuild that self once treatment was complete) and audience (by asking for whom was she writing her account, and why) (Riessman 2015).

I did not initially plan to write about my cancer at all. I withheld the news of my diagnosis from most of my work colleagues and many of my friends and relatives; I did not share it on social media and I felt no desire to blog about it. I was minded not



to add to the multiplicity of breast cancer narratives in the sociological literature. My mastectomy experience, for example, was unremarkable: I went to hospital one day and came home the next, with an implant where my left breast had been and little in the way of disrupted self-image. But as I lived the ordeal of adjuvant chemotherapy, I felt a growing urge to capture that experience as data and subject it to a research gaze.

Sociological accounts of chemotherapy have tended to focus on its dramatic dark side. Riessman's autoethnography, for example, includes this story-fragment (2015, p. 4): "*I had had a disastrous response to inpatient chemotherapy, losing consciousness in a series of 'cardiovascular events' after several days of 24-h chemo infusion therapy, which was ultimately aborted*".

Isabelle Baszanger's (2012) sociological and historical analysis of chemotherapy questions its use in repeated cycles in terminal cancer in an effort to stave off death. She asks "*At what point does medicine reach its own limits and the limits of life itself?*".

Kirsten Bell (2009) reviewed a sparse qualitative literature on the patient experience of chemotherapy, "*a highly feared form of treatment that is often popularly depicted to be worse than the experience of cancer itself*" (p. 169). She found that chemotherapy's dangerous side effects were often perceived by cancer patients as evidence that it was 'working'.

My own experience of chemotherapy was less dramatic. As a recipient of one of its lighter-touch regimens, and benefiting from palliative management (in the sense of using drugs and other tested strategies to prevent or reduce side effects, not of anticipating death), I encountered few problems beyond my own initial anxieties. I never lost my hair, and I continued working (on some days from home) throughout the treatment period. It was unpleasant, but not unbearably so. Yet there was a strangeness about chemotherapy that invited exploration. And as far as I was aware, the undramatic story of non-life-threatening, short-course adjuvant chemotherapy had not previously been explored in the sociological literature.

I formulated a research question—"What is the nature of chemotherapy's strangeness?" To address it, I repurposed various materials I had already collected: emails and photographs sent to friends, my symptom diary, leaflets, a cookbook. I approached some close academic friends (initially, two doctors, a nurse, a sociologist and a bioethicist) to give me feedback on drafts, which I anticipated would—in Denzin's (2013) words—"embrace vulnerability with purpose". I called these friends my 'interlocutors' and sent them numerous drafts of my story, which they duly commented on.

As I organised my materials into something that could be called a dataset, I explored the literature for a suitable theoretical lens. Strongly resonant with my experience of chemotherapy as high-tech, coldly clinical but also caring and hopeful was Annemarie Mol's *The Logic of Care* (2008). In a genre that has been called 'performative' (that is, focusing on what people do) and 'post-actor-network-theory', Mol surfaces through ethnography how human creativity can harness the material properties of technologies to generate both care and cure. In the same tradition, Jeanette Pols (2012) has challenged the dualism that pits cold care (rational, technical, detached, patient as object) against warm care (human,



relational, ethical, patient as subject). Care, she suggests, is necessarily both warm *and* cold—and hence embodies a potentially productive tension. Both these authors depict how the patient’s experience of illness, and the diagnosis and management of disease by professionals, are part of wider networks—the scientific establishment, professional regulation, cultural discourses, information technology infrastructures, social media and much more—within which technologies are made to ‘work’ (or not) and identities (patient, nurse, doctor) are situated and enacted.

I was also attracted by theories of the sociology of the lived body. These hold that illness produces ‘dys-ease’ (a disruption of the taken-for-grantedness of bodily perceptions and motor intentions), demanding both an explanation and work to restore a sense of normality (or, if that is impossible, to compensate for its absence) (Leder 1992). The bodily sensations of illness (pain, nausea and so on) are real and have pathophysiological origins, but are also socio-culturally framed—and hence shaped by wider discourses and social institutions. As Ricoeur (cited in White, this volume) has said: “*one’s own body is ... the mediator between the intimacy of the self and the externality of the world*” (Ricoeur 1992, p. 322); it follows that chronic poisoning of the physical body will tend to generate a profoundly distorted narrative.

Finally, I wanted my study to connect with the mainstream literature in narrative sociology, which views illness as biographical disruption (a “broken narrative”) and considers the autobiographical narrative, written for (or told to) an audience, as an important means of reconstructing the self (Frank 2000; Riessman 2015). As Bakhtin’s work in particular has demonstrated, the study of narrative includes both analysis of the story itself (narrative as noun) and analysis of how it is told—and to whom (narrative as verb) (Bakhtin 2010). Particularly where deep illness is concerned, the illness narrative is not merely a text but an unfolding encounter between the wounded storyteller and his or her audience(s) (Frank 1998).

## Findings: the strangeness of chemotherapy

The three theoretical lenses introduced above—performative, lived body and what I have called existential (that is, concerned with the repairing of a broken narrative in dialogue with an audience)—helped me make sense of three empirically overlapping but analytically distinct components of my dataset: what was done to me, what I experienced myself, and my reflections on how I came to construct my narrative. I consider these in turn.

### The strangeness of what was done to me

Chemotherapy is given in specialist units, often housed in separate buildings from other hospital services, because it is a complex and high-risk procedure and patients are very vulnerable to infection. I had been a doctor for 32 years, but I had never entered a specialist chemotherapy unit until I did so for my own treatment. The following field notes were collated from several of my weekly visits:



The Oncology Centre ('XOC') is a converted town house, opposite a linked hospital. Apart from the fact that most patients are wearing hats or headscarves, the only hint that XOC differs from any other outpatient clinic is a box on the reception desk offering 'credit-cards' bearing this message:

I am a patient receiving chemotherapy. If I present with sepsis and/or fever  $>38^{\circ}\text{C}$ , I require emergency intervention including full blood count, blood cultures, IV fluid hydration and commencement of IV antibiotics.

I made sure I took one.

The core business of XOC takes place in the basement in what is referred to as the 'chemotherapy suite'—a term which for me conjured up comparisons with other kinds of suite (bridal, banqueting, presidential). Common to all is a sense of costly privilege (in this case, an ironic one) and a zealous policing of its threshold. On arrival, you must take your place in the waiting room until summoned downstairs (this means they have prepared your drugs and are ready for you). You will be greeted by a uniformed escort who will bring you through two sets of rubber-sealed double doors and down a corridor displaying leaflets (e.g. 'Coping with Hair Loss', 'Sex and Cancer') to the suite itself.

The main room is large and oval-shaped; its circumference is divided into cubicles known as 'pods', each with three walls and a curtained opening to the central space. White floor tiles, a smell of disinfectant and harsh artificial lighting gives this space the air of an over-sized operating theatre. In the middle is an island, from which staff can observe every patient.

Each pod contains a vinyl reclining chair, like a dentist's chair but with adjustable arm-rests. You will spend hours in this chair, so get as comfortable as you can. But first, offer up your veins to the smiling nurse in the white tunic. Your chemotherapy session will begin with a blood test to check that you are well enough to be made sick.

Nurse Josef dons a disposable white plastic apron and blue plastic gloves. After measuring my temperature, blood pressure and blood oxygen levels, he fixes a tourniquet around my upper arm and studies my forearm carefully. Gently, he strokes and pats one bulging vessel after another, deciding which to select. The vein needs to be strong, since after the blood is drawn, the same cannula will be used to infuse no fewer than nine bags of chemicals, some of which are toxic to vessel walls. Last week's 'good vein' is now a shrivelled relic on my wrist. Josef does not want to inflict a botched line. He suggests, once again, that I might like to have a 'port' implanted beneath the skin to give him ready access for the duration of my treatment. Once again, I decline this intrusion and tell him I don't mind having the needle once a week. He finds a vein he likes, unsheaths the cannula and inserts it skilfully. Dark red blood flushes back. We both smile with relief. He tapes the cannula in place.





The chemotherapy suite runs to a tight timetable. If the blood test confirms that my bone marrow has not taken too hard a hit from the last session, it will now be exactly 45 min until the first bag starts running. Ten minutes before that, they will fit a ‘cold cap’ to freeze my scalp, thereby preventing hair loss. It consists of a padded neoprene outer cap and a gel inner cap that connects to a portable refrigeration unit.

Nurse Debbie, like Josef, wears a neat unisex white tunic and a plastic apron and gloves. She damps my hair, massages in some rich conditioner, saying “mmm, I love the smell of this”, and carefully lines the outer edge of the cold cap with gauze to prevent chafing. Once I have retrieved my ears from under the neoprene and declared the arrangement “comfortable”, she connects up the refrigeration unit and adjusts the temperature to minus 4 degrees for the next two and a half hours.

Each bag is labelled with the drug, its dose, my name and my date of birth. I must read each of these out loud and confirm my consent to receive it before Debbie connects up the bag and runs the tubing through a machine that controls the infusion rate. An alarm will chime if the infusion rate falls, indicating that either the bag is empty or the vein is blocked.

My machine is chiming, but my bag is not empty. Debbie appears within seconds. She examines my arm. “Is it sore?”, she asks, stroking my skin. “No,” I reply. “Your arm is cold, I think your veins have closed up,” she says. “I’ll get a heat pad.” She goes to find a small plug-in heat pad, places it in a soft cotton pillowcase, wraps it round my arm and gently presses. The fluid is soon flowing again.

As I lie here, I see the other patients coming and going. Many are thin, pale and concealing baldness beneath a hat or wig. A few (perhaps attending for the first time) look pink and healthy. Those arriving on the unit look nervous; those leaving (patients and relatives alike) look exhausted. We smile shyly if our eyes meet, but in general this is not a place for socialising.

In sum, the chemotherapy suite is characterised on the one hand by a sterile efficiency and panopticon-like surveillance designed to support the administration and monitoring of dangerous drugs—and on the other hand by a humanising tenderness from front-line staff, who are attuned to the high clinical and psychological support needs of the patients in their care. Most of the nurses are of childbearing (or child-siring) age, so whilst they infuse toxic chemicals into patients by the bagful, they must not let a drop touch their own skin.

The strangeness of the chemotherapy suite is attributable partly to the highly technical, high-risk clinical environment—but mainly to the paradox that, like the main characters in Kasuo Isighuro’s dystopian science fiction novel *Never Let Me Go*, patients come here to be made sick. In almost all other respects, the suite mirrors a haemodialysis unit: both are high-tech, nurse led, oriented around administering intravenous medication and place strong emphasis on biomarker monitoring and infection control. But in the haemodialysis unit, patients arrive sick





and leave well. Small wonder that the chemotherapy nurses put so much emotional labour into their role.

Importantly, however, the practice of making well people sick is a situated one. The poisoning makes sense in terms of the wider socio-technical network that forms the context for contemporary cancer care—especially the discipline’s long tradition of coding and classification (latterly enhanced by molecular profiling and the new genetics) along with a systematic and dialectical approach to clinical trials (in which the regimen with the current best benefit-harm ratio for each cancer sub-type forms the control arm for the next trial). The network includes the infrastructure for setting and implementing evidence-based standards and a thriving international circuit of conferences at which oncologists, cancer epidemiologists and geneticists (with considerable input from the biotechnology industry) debate the latest findings and plan the next phase of trials.

### **A lived-body strangeness: my experience of chemotherapy**

Evidence-based and in my own long-term interests it might have been, but being made sick was a surreal physical experience, as the extracts from my field notes below illustrate.

#### **DAY 1**

My nine bags of chemicals: Saline (250 ml), an antihistamine (chlorpheniramine, 10 mg), saline again, a powerful steroid (dexamethasone, 8 mg), more saline, another antihistamine (ranitidine, 50 mg), more saline, my chemotherapy (paclitaxel, 140 mg), and, finally, saline. The saline is to ensure that I am fully hydrated and that the drugs don’t mix directly. The first three drugs are ‘pre-med[ication]s’, given to prevent an allergic reaction to the chemotherapy. My brain feels numb. I have a cold-cap headache. I feel drowsy but am unable to sleep. My mouth, nose and eyes become intensely dry, to the extent that my nose begins to bleed. I develop a thumping in my heart and a vague sense of depersonalisation, as if I am not actually in this body or this brain.

Once I am loaded with the pre-meds and well and truly frozen-headed, my chemotherapy infusion begins. On top of the side effects I already have, it brings a more intense headache (inside my head as well as all around it), a sensation of ants under the skin, a further quickening of my heart rate, sweating palms, flushing face and a pervasive feeling of nausea that will last until the day after tomorrow.

My husband has stopped reading out the crossword clues. He waits patiently for another hour while the infusion runs its course, and then for a further hour of cold-capping. Eventually, Debbie comes to remove the cap. My short hair is spiked with icicles. I badly need to pee but when I get up, my knees go weak and my husband has to support me. I make it to the toilet and pass more urine than I thought my bladder could carry. It smells vaguely of solvents. Returning to the main suite, I take a boiled sweet. My mouth is so dry it sticks to my tongue. On my husband’s arm, I stagger along the corridor and up the stairs. One down, eleven to go.



## DAY 2

Awake all night on a steroid high. Thumping heart. Lost all sense of taste and smell. Skin is dry despite moisturiser. Eyes are gritty. Nose keeps bleeding. Feeling sick. And yet, at the same time, I am hungry, craving chocolate, crisps, even bacon [I'm vegetarian!]. What are they doing to me?

## DAY 6

I can't poo. I've had prunes, carrots and three different laxatives. Miserable.

## DAY 11

I am what my mother would call 'run down'. I have ulcers in my mouth, acne on my face, cold sores on my lips and itchy red eyes. My gums and nose ooze blood, though not profusely. I have a vaginal discharge (thrush?) and weeping from my anus. I suspect my immunity is low. As per the advice leaflet, I am already using mouthwash and washing my backside with soapy water after bowel movements (which don't come often). I visit my GP and get anti-virals for the cold sores, pessaries for the thrush, antibiotic nose ointment and artificial tears.

## DAY 12

I have a fever, but only a low-grade one (37.4). If it goes above 37.5, I must phone the hotline. After days of constipation, I now have liquid diarrhoea (and a sore backside). Perhaps I over-did the laxatives; perhaps I have a tummy bug.

## DAY 15

The pre-chemo blood test confirms my white cell count has fallen to an abnormal level, but not low enough to cancel today's treatment. It's scary being infused with yet more of this stuff when I know my bone marrow is failing. But the oncologist is upbeat. "You're doing fine. I would expect your white count to be a bit low. It will plateau out now. Yours is very healthy, considering."

## DAY 22

The oncologist was right, I have been better this week. The ulcers, acne, cold sores, thrush and bowel upset have all cleared up. My bum is better. My blood count is almost back in the normal range.

## DAY 28

The leaflet said I would lose my hair "between 2 and 4 weeks". The hair on my head is still there (thank you, cold cap). But my pubic hair, eyebrows and eyelashes are all falling out. The hairs inside my nose have gone, which explains why my nose has been running for the last month.

## DAY 51

My toenails have gone soggy; one has fallen off.

In her classic text *Purity and Danger* ([1983] 2003), anthropologist Mary Douglas proposed that all societies carefully define the sacred and the profane, and develop rituals of purification to keep the one from the other. Jackie Stacey ([1997] 2013) draws on Douglas' work to explore the cultural semiotics of the abject in relation to the symptoms of cancer and its treatment. "The abject", in this context, means bodily fluids (blood, urine, faeces, mucus, saliva, sweat, tears and so on) that are out of place



or not controlled even by the enhanced rituals of purification that cancer management protocols encourage us to follow—and thus, in Douglas’s terminology, profane.

Bodily revulsion is a sign of abjection, and as Stacey points out, one of the most elementary and archaic forms of abjection is the loathing of food. Chemotherapy and steroids have complex and conflicting pharmacological effects. With this combination, the nauseous stomach also longs for food, producing a tendency to swing between under- and over-eating, cachexia and bloating, vomiting and gorging. The effects of all these can be far-reaching, since the preparation and communal consumption of food has profound social significance and is closely bound up with cultural constructions of health and well-being.

Dictionary definitions of abject include “hopeless”, “miserable”, “humiliating”, “contemptible” and “feeling or showing shame”. When body fluids are in the wrong place, and/or when the membranes that keep them contained cease to function effectively, “*It [becomes] hard to distinguish human from non-human, self from other, use from waste and life from death*” (Stacey [1997] 2013, p. 83).

Whilst this depiction resonates to a degree with chemotherapy’s distressing effects on my body, it draws the analytic focus to the abject as passively experienced rather than to how the abject can be actively managed and lived with. Save for five or six (of 80) days when I was bedbound with nausea, tiredness or infections, coping with chemotherapy was, for me—and for the nurses, allied professionals and volunteers who spearheaded a proactive programme of support—a performance of ‘tinkering’ (Mol 2010).

At my first chemotherapy session, for example, the pharmacist gave me a ‘goody bag’ containing painkillers, anti-nausea medication, laxatives and other symptomatic remedies to take as needed. The contents were, I was told, the result of much research into the management of chemotherapy’s many side effects. I was encouraged to attend carefully to my bodily symptoms and be proactive in using the drugs. My one bout of severe constipation occurred because I failed to notice or treat a mild bout.

I bought the *Royal Marsden Cancer Cookbook*, written jointly by oncologists, dieticians and chefs. Professionally produced and celebrity-endorsed, it celebrates the aesthetics of food and its centrality in care relationships (families and friends are encouraged to cook *for* someone with cancer), while taking account of physiological issues (e.g. chemotherapy’s effects on appetite are often less severe in the mornings, hence patients may be better able to stomach a hearty breakfast than a heavy supper). Exchange of recipes and tips for successful ‘social’ eating (even when everything tastes of cardboard) were a major theme in the online peer support forum I joined.

The *Livestrong* education programme invited us to develop and exchange strategies to maintain and even increase our physical activity levels. This was presented as ‘complementary medicine’ but reflects randomised trial evidence that in adjuvant chemotherapy, exercise reduces side effects, improves emotional well-being and increases the chance of completing the course (van Waart et al. 2015). The charity *Look Good Feel Better* helps women manage the visible (especially skin- and hair-related) effects of chemotherapy; a fellow patient tipped me off that high-end cosmetics companies donate free samples for its workshops.



In sum, the lived-body strangeness of adjuvant chemotherapy is aptly captured in Stacey's notion of the abject. But in my own experience, it was an abjectness that could, by and large, be actively managed by 'tinkering' with drugs, food, exercise regimens and cosmetics. The actor-network that makes such tinkering possible is extensive and complex; it spans conventional and alternative medicine and includes researchers (who undertake clinical trials of drug and non-drug interventions), clinicians and allied professionals, peer support groups and charities, and a commercial sector devoted to cancer care products.

### An existential strangeness

Arthur Frank (2000) has challenged the popular myth that in autobiography, the self writes the story. In reality, the story writes the self.

I am a woman, mortal, vulnerable. When I developed breast cancer, the different elements of the self I that I had painstakingly presented to the external world all my adult life—my healthy body; my love of endurance sport; my irreverent sense of humour; my persona as a practising doctor who hears (but for professional reasons, does not tell) illness narratives; my achievements in the higher echelons of medical academia—were all profoundly threatened. With the identity of 'cancer patient' newly imposed on me, I found much resonance in Frank's words (2000, p. 135): "*A self that has become what it never expected to be requires repair, and telling autobiographical stories is a privileged means of repair*".

With that task in mind, I embarked on my search for narratives. But the narratives I found—cancer as death-journey, cancer as political-feminist cause, cancer as cacophony—served only to make my fragile self even more precarious. Before I could rebuild my story, I had to re-tell cancer's story. Using my background as a doctor and my academic training in evidence-based medicine, I wrote the first draft of this paper—in which I crafted breast cancer as a (somewhat uncritical) account of medical success: its dire prognosis transformed over the past four decades through biotechnology research, rigorous clinical trials and rational application of standards and guidelines. Via a subtle literary trope (and unconsciously at the time), I allowed my personal cancer narrative to mirror this dramatic evolution by contrasting the biopsy's "poor prognosis" with my oncologist's pronouncement of "excellent prognosis" a few weeks later.

I focused my autoethnographic 'fieldwork' tightly on the temporary ordeal of adjuvant chemotherapy. After 80 days in this not-too-terrible wilderness, I began to announce through my text, I would be myself again. I considered the focus on light-touch adjuvant chemotherapy to be an original sociological take on the cancer experience. But it was also a uniquely privileged means of repair for the self I desperately needed to rebuild. As my 'patient self' was struggling with the stigma of cancer and being made sick by the treatment, my 'academic self' clung tightly to the powerful story of modern chemotherapy as game-changing wonder-drug.

Thus, with input from the friends I had appointed as interlocutors, I worked on the strangest story I have ever written. I told them that one of my goals was to change the way sociologists think about breast cancer—and specifically, to encourage them to explore a new era of interdisciplinary research that embraced



rather than dismissed recent developments in biomedicine. With a passing nod to the limitations of the evidence base—a single study, without a control group, with a follow-up period of only three years and sponsored by the drug’s manufacturer—I boldly concluded: “I could not have asked for stronger evidence” for my light-touch chemotherapy regimen. I proceeded to analyse that regimen and how I learnt to handle its effects on me.

My interlocutors, mindful of my vulnerability, failed to comment on this. Instead, they congratulated me on a “clear” summary of the background evidence. “You write well”, one added. “Thanks”, I replied.

I wrote as if my life, my very self, depended on it.

## Discussion

One of my goals in writing this paper was to explore how a medical analysis of the epidemiology and molecular biology of a particular cancer can inform and enhance a sociological analysis of how it affects the individual. To date, neither sociologists nor society in general have shown much interest in good-prognosis cancers treated with light-touch adjuvant chemotherapy regimens. Cancer’s place in cultural history as “the emperor of all maladies” (Mukherjee 2011) explains why—as I found to my cost—becoming a cancer patient remains symbolically life-changing, even when the objective survival figures are excellent. As well as learning to tinker in the strange world of the abject to deal with troubling lived-body experiences, I faced a colossal task of repairing my broken narrative.

Several colleagues who looked at earlier iterations of this paper pointed out that a strong theme in its development was control. I shared my story with very few people (initially five, expanding to 16 as the text developed and my confidence grew), and strictly on my terms. As I began to contemplate sharing this story more widely, I encountered what might be called a ‘meta-strangeness’ that stemmed from casting my fellow academics as Bakhtinian audiences for my self-rebuilding story (as one of my PhD students put it, “*the strangeness of a well-known professor turning her research gaze on her own body*”).

This meta-strangeness raises a question with which my interlocutors struggled: how should we judge the work of an academic who uses autoethnography to describe and analyse her experience of deep illness? Below, I consider four criteria—ethnographic legitimacy (does the work meet the standards of analytic social science?), autobiographical legitimacy (is the text compelling as literature?), existential ethics (is the wounded storyteller protected from harm?) and relational ethics (has the storyteller discharged her duties towards those implicated in the text and its interpretation?). Readers of this narrative may or may not agree that these are the criteria against which the work should be judged—and with the extent to which I have succeeded in meeting them.

Anderson (2006) proposes five defining features of analytic autoethnography as a distinct branch of social science: the researcher (a) is a full member in a research group or setting; (b) uses analytic reflexivity; (c) has a visible narrative presence in the written text; (d) engages in dialogue with informants beyond the self and (e) is



committed to an analytic research agenda. My interlocutors were selected from a research group that forms the context for my professional life and work. I am the central character in the text and tell an intimate, first-person narrative. I did not ask to interview the doctors or nurses caring for me as informants, because it seemed ethically dubious to do so (see below) and because I believe that Anderson's phrase "engages in dialogue" should not be interpreted narrowly as privileging the interview. The analytic dimension of this work was important to me, not least because defining and striving reflexively to meet a set of academic standards was a powerful and familiar way for me to achieve control.

Ellis et al. (2011) have challenged Anderson's claim that autoethnographies meeting his criteria for analytic social science count as scholarly whereas those presented in a more literary genre are correspondingly less scholarly. They depict the emergence of critical autoethnography as part of a postmodern turn, commencing in the 1980s, which sought to bring some branches of social science closer to literature and philosophy and liberate them from the methodological rigidity of the natural sciences. Ellis et al. uphold both the 'ethnography' (analytic) and the 'auto' (autobiographical) in autoethnography; they argue that it is possible for an autoethnographic account to be both analytically robust *and* autobiographically robust ("*aesthetic and evocative, engage readers, and use conventions of storytelling such as character, scene, and plot development*").

Denzin's definition of autoethnography, for example, is "*an imaginative organisation of experience that imposes a distortion of truth*" (2013, p. 13). He proposes five standards of autobiographical truth: sincerity, subjective truth, historical truth, fictional truth and aesthetic truth. My account is sincere in that I did not set out to deceive. It is subjectively true in that I believe it, even though I recognise it as perspectival and serving an important ulterior purpose. I anchored it in historical data (a detailed profiling of my cancer and a verifiable empirical dataset). I sought fictional (that is, literary) truth through my efforts to recruit my readers, build dramatic anticipation and justify the predicted happy ending from the medical handling of the trouble. I worked to make the account aesthetically appealing (and, in particular, to avoid the traps of sentimentality and 'pinkwashing').

When I began this project, I was concerned that my researcher self might ignore the needs of my sick self and that the process of developing an academic analysis could potentially damage the latter. Indeed, I recruited my initial interlocutors with the specific remit of protecting me from my over-analytic academic self. April Chatham-Carpenter (2010) describes how every time she attempted to resume her autoethnographic account of anorexia nervosa (which had been in remission), the illness began to flare up. Sarah Wall's autoethnography of international adoption (2008) compelled her to explore aspects of the adoption of her own child that she had previously chosen not to confront—in particular, the needs and motives of her child's birth mother (with whom she began to identify). In my case, partly because my interlocutors helped me reflect on such dangers and partly because an academic analysis surfaced a hopeful and persuasive narrative, I experienced the process of autoethnographic writing as actively healing, rather than further fracturing, my sick self. The question of existential ethics became progressively less relevant as the text took shape.



My work must also be judged on what Ellis et al. (2011) have called relational ethics—the duties incurred by the autoethnographer towards the characters in, and readers of, the text. In relation to the clinicians in my story, I focused primarily on their material practices (and only to the extent that those practices affected me). It was not my purpose to criticise their actions or explore their perspective. Moylan and Jureidini's (1994) psychoanalytic study of clinicians on a chemotherapy unit (published before the days of light-touch regimens) identified deeply repressed psychic trauma in many staff. They asked, "*What happens inside you when you watch a patient who is clearly suffering as a direct result of the treatments you have given him? The unconscious feelings ... are very frightening; ... issues about sadism, power and control are stirred up*" (p. 232). Whilst these (postulated) troubles were beyond the scope of my study, my decision not to seek interviews with my clinicians was perhaps driven partly by reluctance to scratch the surface of unmet psychic need.

My ethical obligations towards my interlocutors are not so tidily dismissed. If existential wholeness is inherently constituted in relationships with others (Frank 2000), those agreeing to support the narration of a text of deep illness must balance their judgement of its scholarship against the author's need to create a healing fiction. As one of them pointed out, they were being asked to provide both 'cold care' (rational, analytic, my text as object) *and* 'warm care' (relational, ethical, its author as subject). My interlocutors managed this balance skilfully—some by commenting only on 'safe' aspects of my text; some by addressing the less 'safe' aspects sensitively and professionally; some by putting the text aside and asking me how I felt otherwise. I believe some of them were troubled (though none admitted to being traumatised) by the complex role I had invited them to adopt.

The publication process adds another layer of relational ethics. Dashper (2015) has written about how an instruction to "revise and resubmit" her autoethnography served as a significant existential threat. But there is also a converse threat: to what extent might editors and reviewers feel pressurised, consciously or unconsciously, to accommodate the account of a deeply ill academic rather than risk doing damage with a harsh rejection letter? This possibility raises the question of whether the (sick) autoethnographer owes a duty to the editors and peer reviewers *not* to submit unless and until s/he is well enough to face that existential threat.

#### DAY 80

My story is finished. As I sit connected to my last bag of chemotherapy and feel its final wave of nausea pulsing through me, I come to a decision. Sick but made well, I am ready to write my covering letter and hit 'send'.

#### Postscript

It is now two years since my last infusion of chemotherapy. I was indeed made well; a recent check-up showed N.E.D. ("no evidence of disease"). As I explained in the section 'An Existential Strangeness' above, writing and re-writing the autoethnographic account in this paper (including researching the medical evidence and





sending it out to my ‘interlocutors’) served a healing purpose for me during my cancer treatment. Indeed, that was the only reason why I wrote it. Re-reading my text with cancer long behind me, I rediscover a lived-body strangeness that I had long forgotten.

My account of breast cancer as a ‘temporary strangeness’ interposed in a hopeful meta-narrative of medical progress sets it apart from most other breast cancer narratives in the sociological literature, which emphasise—variously—such things as catastrophe, disfigurement, medical insensitivity and feminist awakening. My story reflects, in addition to the perspective of a doctor-become-patient, the extraordinary improvements in breast cancer survival over the past 40 years. I hope that other social scientists will choose to study of the mismatch between what is now often a hopeful prognosis and the discourses that still prevail on breast cancer, based on outdated folk models of an often-fatal disease treated with mutilating surgery and killer chemicals.

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