

## How Do I Betray Thee? Ethical Journalism in Reporting Cancer

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I will start with a slightly tweaked quote from Elizabeth Barrett Browning: 'How do I betray thee? Let me count the ways'. We always feel very guilty, we who work in cancer, because I think we skew things very badly for everybody else.

Cancer has this status, as somehow being the thing to be scared of. But of course there are many, many things that people suffer from and people have to live with the consequences. In fact it's completely normal for us to be ill and have to cope with long-term chronic illness and that is one of the things we do very badly.

It's very easy in cancer to come up with all sorts of ludicrous things are written and I'm not going to do a lot about, but Figure 1 shows a recent one. It is the *Sunday Express*; along the spectrum of absurdity, perhaps the *Sunday Express* is quite far out.



Figure 1

There are two stories on this front page. One of them does a fair amount of harm and the other one is about red-hot Kate wows at wedding, which doesn't do too much harm to anybody. This is standard stuff and what I am going on about is not so much this story as the whole genre of cancer drug stories: science, high-tech, masquerading as something to do with health, tends to be a very common thing.

The reality of cancer drugs is that we're really not doing that well at all. For most people cancer drugs are not curative but reading stories like this you'd never guess that. Things haven't changed as much as one would have liked over the last 50 years.

A lot of people who have cancer at an advanced stage will not be cured by a drug. A lot of people who are treated for early cancer don't need drugs but they'll get them anyway because you don't really know who does and who doesn't. All the drugs have shifted things a little bit. But not a lot. They've shifted them with quite a high price to pay in terms of the side effects. That's not to say that we're not grateful and if I needed them I would definitely want them. It's just they do not merit stories like this. And it matters, because it skews the picture we're giving to people.

The words tell you this drug, Kadcyra, is not a bad thing, but it's certainly not a holy grail. As far as I'm concerned, and I do try to tell this to clinicians and researchers, when you talk about holy grail what patients are looking for is to live. So you want some extra life; but that is not a holy grail.

No side effects? No side effects it says. But these are the common side effects:

- The most common side effects with Kadcyra (which may affect more than 25% of patients) are haemorrhage (bleeding including nose bleeds), increased blood levels of liver enzymes called transaminases, fatigue (tiredness), pain in muscles and bones, and headache. The most common serious side effects are pyrexia (fever), thrombocytopenia (low blood platelet counts), vomiting, abdominal pain (stomach ache), nausea (feeling sick), constipation, diarrhoea, dyspnoea (difficulty breathing) and pneumonitis (inflammation of the lungs).

There is also a risk of:

- Hepatotoxicity: Serious hepatotoxicity has been reported, including liver failure and death in patients treated with KADCYLA. Monitor serum transaminases and bilirubin prior to initiation of KADCYLA treatment and prior to each KADCYLA dose. Reduce dose or discontinue KADCYLA as appropriate in cases of increased serum transaminases or total bilirubin
- Cardiac Toxicity: KADCYLA administration may lead to reductions in left ventricular ejection fraction (LVEF). Evaluate left ventricular function in all patients prior to and during treatment with KADCYLA. Withhold treatment for clinically significant decrease in left ventricular function

FDA warning taken from Genentech (Roche) site

<http://www.gene.com/medical-professionals/medicines/kadcyla>

An utter lie, in other words. A complete lie you're getting on that front page. Very typical side effects include one from this Roche drug, which lists liver failure and death. 'No side effects' does not include people ending up dying from it. Reductions in left ventricular ejection fraction: this is typical of that particular drug and can leave you with a chronic heart condition or it can kill you. A lot of the time this is chronic, there's nothing you can do because the heart doesn't recover and you lead a very disabled life. It matters. These things really matter.

That was a harmful front page. What we're talking about here is risks and benefits. You've got to be accurate if people are going to take informed decisions.

I described this as a genre because we are feeding stuff all the time about this and it's giving a very misleading picture. People are misunderstanding the reality of where we are with cancer drugs.

I thought I would count the ways we betray.

#### *Betraying people with cancer*

We betray people with cancer. Because we give a very false impression of the risk-benefits and if you're having to make a decision you need to know and they are difficult decisions and they should be taken seriously. Some people decide one way, some people decide another. But it does not help to have that sort of thing, to say 'This is God's own gift'.

Cost is a very big issue here and all over Europe. It is not the duty of the doctor or the press to keep quiet about drugs that we cannot get access to. This happens to be one of them – the Kadcyła holy grail was torn down by NICE. NICE said for the price that would have to pay it would displace more health benefits than it would give. That is their judgement. It is absolutely the job of journalists to question NICE judgement. But the reality is that for cancer and for other diseases for a long time there have been more drugs available that might benefit and make a tiny bit of difference that matter to a very small group of patients but we don't know which ones. There have been more of those than we can afford to fund for more than 10 years I would say. That is the case in most developed countries.

#### *Betraying people who could benefit but can't get access*

Let's not pretend that's not the case. It is up to us as a group to discuss where our priorities lie. It's up to the press to look at where society's priorities lie and to give patients who need access to those drugs a voice, and to give other people access who need access to other things including palliative care. People with cancer do understand that because they're like us: we all know that we cannot all of us be the only priority.

It is not fair and not right to do front pages that imply that you've got this magic thing NICE is denying you. They are not denying you a magic thing – by no means. These are the most vulnerable people in a very difficult situation. It is criminal negligence to do things like that, it is not helpful to anybody.

#### *Betraying people treated for cancer who may not need it*

There's an awful lot of these. Not because they don't have cancer but because people who are cured by cancer are largely cured by surgery and radiation therapy. Drugs then play a marginal role. If I was in that situation I would probably if it was recommended to go for drugs say yes please. It's an

insurance policy. It does matter, but for some people where they really are in such a low-risk category it really doesn't make sense.

If you get cancer you will constantly be faced with options about what you do and you have to make wise choices because there are consequences from being treated as well as from not being treated. If you have a low-risk cancer and people never talk about that, then it's not necessarily the best thing to take drugs like that which could do this sort of damage. That's not a helpful front page for those people.

#### *Betraying people with mental health problems*

This is a chronically under-covered issue. It is very under the radar. If there was ever a need for good journalism it is to bring into public perception very common things that we all suffer from that never surface. Any other problem disease that is suffering from a lack of attention because cancer comes and does its little dance and everybody goes for that and we are really taking the lion's share of both the money for treatment and also for research.

#### *Betraying people who may get cancer (all of us)*

We're doing this because we're making out that progress is all about the high-tech. Very often the drugs. That's actually completely inaccurate. The progress in cancer, a lot of the really important stuff, has come from very different sources. Better care. Better organisation. Better ways of combining things. Better oversight. Better data. Better support, so we don't kill people with the treatments we give them. All sorts of different things. One of the things I like to talk about is that we do a lot less damage to people, including the surgery and the other things than we used to.

There's a huge disconnect between the improvements we would now get from the treatments for cancer compared with 20 years ago, and it is not the drugs. But you would not see that reflected in newspapers – so that is a betrayal. Because if the focus is in the wrong place that is where the attention, the investment, the status, the power, everything goes into the drug stuff. Which is not really delivering as much as the other stuff.

What about the nursing care? It has been shown to make a huge difference but it never gets this sort of attention so it doesn't get the investment and so this is another betrayal.

#### *Betraying people who may get dementia (all of us)*

There are areas that just don't get the resources that they could have.

Cancer is all about genetics. Well, probably so. It's skewing the research budget and there is no reason why certain groups of patients ignored, under the radar, no one invests in them, whereas they do in others. So that is a betrayal of the real spectrum of diseases that we are all likely to suffer from.

#### *Betraying people living with incurable cancers*

And who are living with the effects of having been treated for cancer. It is the chronic conditions, it is having to live while you are alive, being supported to live, which gets overlooked. We all learn as we go along, particularly in this area, and one of the things that I have been learning a lot about is the way that we all think that when people are diagnosed with incurable cancer they become terminal cancer patients who need a dignified death: death, death, death. They are a kind of marked people. I think there is a huge betrayal of these people. I think that these are some of the 'invisibles' of this world.

One of the first interviews I ever did in this job was with an Italian who had run the first ever out event cancer trials, which is when you have been treated with surgery you don't think that you have been cured so just in case they give you chemotherapy. He had had a stroke and found it very difficult to find the words and I was interviewing him in English. That was quite a challenging interview and I have tremendous respect for him for doing it. He was an incredibly good medical oncologist, and was prepared to do an interview with me under those conditions.

I asked him what he thought of giving chemotherapy to people who are basically well. He explained that they knew the disease does come back and that the earlier you catch the disease the more likely you are to have an impact so we gave this again. I asked him why the surgeons did not want to know – for years, the surgeons would not touch this idea. He said it was a matter of prestige. They did not want to hear that they were not curing patients. I said they must have seen them but he replied that they never did. Because they went from surgery, they came back 2 years later and they came back to medical oncology. The people who were in charge of treating cancer did not want to accept what a high rate of failure they had because these people were utterly invisible.

I think there is a big movement nowadays amongst people with breast cancer particularly who are living with breast cancer that is incurable, who are having a go at all the breast cancer campaigns. All the advertising campaigns tend to run by people who have been cured or who have early breast cancer so they are not in that situation. They say the campaigns are making them feel like failures. The campaigns are all about defining success as cure; they feel like they are an embarrassment.

I look at what we do and I look at what the press does generally and it is true. We'll talk about 'hospice people', we'll talk about dying a dignified death. But what we don't do is talk about living with incurable cancer, and this will go for many diseases.

I think we need to do an awful lot more of that. These people are the same people as they were without incurable cancer but they now have incurable cancer. So they have this horrible clock ticking. We all have one of those; it's just they can see theirs more visibly in addition to having to suffer the effects of the disease and the treatment. This is what we do badly. I think we need to do an awful lot more of the day-to-day things that matter.

The story I am most proud of having published was one on what constitutes a success when you are dying of cancer, when you've got incurable cancer. We talked to people about what mattered, what they looked for from their doctor and how the difference between a success and failure in terms of what the doctor could do for them. One of the things that stuck in my mind is a woman whose

husband died of melanoma. She said people don't realise the extent to which it's the little things that matter. We don't do those very well. We do these big things but that's not the stuff that people are living with and I think we can do that better. Radio can help with this: we've suddenly discovered radio. Radio does these little things that matter, probably as well as any other medium.

### **A Journalist's Hippocratic Oath**

Accept the responsibility for the consequences of how you report. This is controversial: should journalists be held accountable for what we write? Yes we should!