An Ethical Approach to Health Journalism in the Netherlands

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I work for *Analysing News*, which is the equivalent of the BBC in the Netherlands. A tax paid, public broadcaster.

Pompe and Fabry: A Case of Funding Withdrawal

I would like to take you through two issues I covered in the last 2 years. The first one is on the reimbursement of very expensive drugs for two rare diseases – Fabry disease and Pompe disease – which use infusions (Figure 1). The therapy for Pompe disease costs in the Netherlands between 300 and 700,000 Euros, roughly £200-600,000 per patient per year. The other for Fabry disease is about half of that but still very expensive.

Figure 1

Compared with the whole budget of health in the Netherlands this is pretty much nothing, Pompe patients cost about 50 million Euros, Fabry patients about 35 million a year, on a budget of 90 billion. If someone forgot to include it in the budget I don't think anyone would realise it was missing.

I got hold of a draft report of an authority inviting a minister, who was deciding on the reimbursement of any drug which is allowed on the market. In this draft, there was a proposal to stop the reimbursement of these two therapies after a 4-year period. It was decided to have an evaluation of the drug and reimbursement after 4 years. But there was a border crossed with this draft. Never before had this authority proposed to stop reimbursement from a therapy there is no

alternative for. There is one drug for each of these diseases. The Fabry one is made by two different companies who came in the market on exactly the same day and were both allowed. It's the only therapy that can be prescribed. You eventually die from this disease.

Other drugs that weren't reimbursed any more include new cancer drugs but you have plenty of others which are. This is really a very big difference.

We first reported on this after we had the draft for 5 weeks. This took as long not because we wanted to wait so long but we tried to convince patient organisations, and the very few doctors treating these people, because all Pompe patients go to Rotterdam University Hospital, all Fabry patients go to Amsterdam University Hospital, and all are treated by two doctors. We tried to convinced them, the authority, the industry, everybody to co-operate and comment on this report.

Everybody refused for different reasons. Patient organisations were afraid they would be considered to have leaked the report to us, which they hadn't. The source was someone in the health world who as a citizen was infuriated by this proposal and found it a sign of a lack of civilisation to put it mildly.

In the end after 5 weeks we decided with or without them to publish. We went to broadcast this on a Sunday evening, and advised people so they could call their patients and tell them this was going to go out. Partly they did, partly they didn't so some patients had a very bad Sunday evening watching the 8 o'clock news and seeing themselves being sentenced. Because most of the time these proposals become law.

The next morning I had a mother of two Pompe patients in the north of the country who asked me how I dared to say that these therapies are not value for money and don't do that much for patients, which is true. The doctors say these are not very good therapies and they could be better, especially for the price we are paying for them.

The mother told me the story of her two kids. One was diagnosed at 4 years, when his legs were already paralysed, and his sister who was born at the moment of his diagnosis, who got the drug right away. She was a totally normal kid. So I asked the mother whether she would like to share her experience of the drugs with us and with the country and she agreed. The moment she did that I was pretty convinced that this draft wouldn't make it to law and I was happy that I could contribute although that was my private opinion which I didn't put in my reporting.

Price Differences

We published 5-7 stories in the summer of 2012 because we discovered a range of price differences. Fabry therapy was more or less the same in most countries, except Germany where it was suddenly about 60,000 Euros more expensive and that's not because Germany is so far away from the plant where it's made. It's for unknown reasons. Then we discovered that the Myozyme drug was far more expensive in the Netherlands, twice at least, as in the USA. The doctor treating the patients told me that we have in the Netherlands a special population getting the drug, more adults than

children. Whereas in the USA it's the other way around. Weight is an important factor in price of the drug, you just need more when you are bigger.

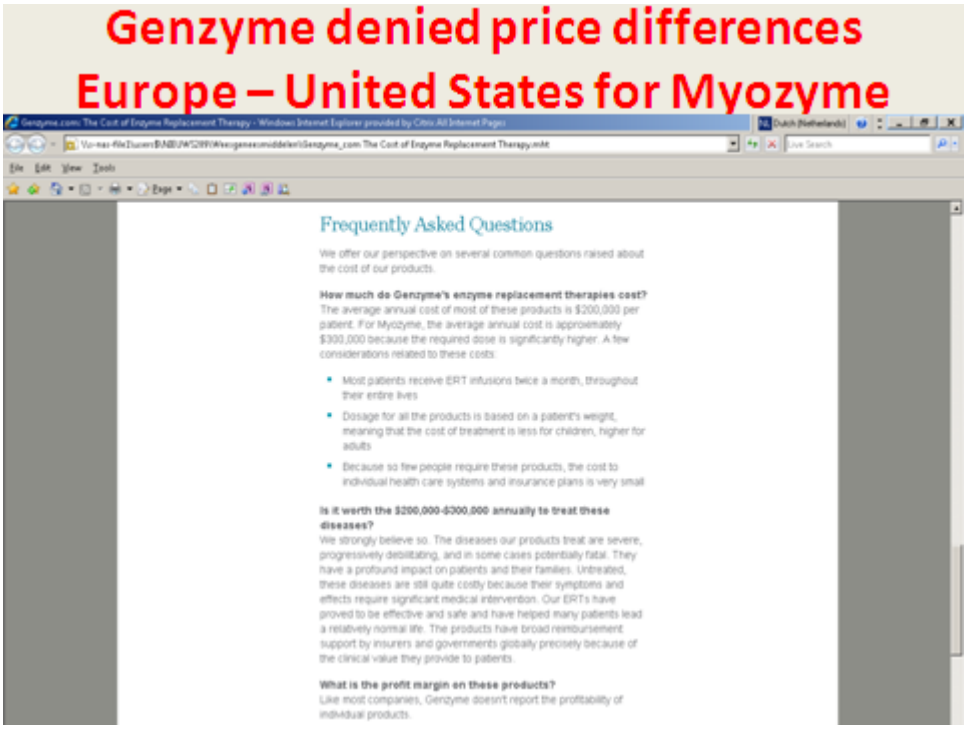

Figure 2

That might be part of the explanation but the strange thing was we published this and then I saw the website of the pharmaceutical company (Figure 2) explaining something about the prices saying that the annual cost of these products is $200,000 per patient. For Myozyme the average adult cost is approximately $300,000 etc. It didn't say anything about children or adults. This was removed immediately from the website which made me suspicious.

The night we published the price difference we got a press communique from the Genzyme who didn't want to talk to us in the report, just saying these were false allegations. The next day we published their website screen shot and we published the new screen shot of the changed website and asked again for comment and they didn't. Then they said we were confusing the matter but we weren't making false allegations any more.

I'm not sure we were completely right on reporting on these price differences. But the fact is that they didn't want to comment and they still do not and say nothing about prices. You have to phone now to have price information so that still makes me very suspicious.

The debate in the Netherlands went on. Zeten is the organisation of the health insurers in the Netherlands. There were 50 and we introduced a market system. There are now four very big companies, who share 95% of the market. And a couple of very little ones who do well in their own town. They decided that they wanted to continue to pay for the therapies. The authority continued to want to stop. In the end we made a report in which we said you have to have more power in

developing this drug, because the whole problem started in 1999 as the European Union took a very good decision. They asked the industry to develop drugs for rare diseases to help out people who have a lot of bad luck being born with a disease very few people have so commercially not interesting. The European Union made it easier for these drugs to come on the market.

The Pompe drug came on the market on the basis of a trial of 41-43 patients. They more or less got what they asked for because it's politically very hard when there is such a drug to say you can't give it to patients. Both university hospitals are seeking ways to co-operate with small biotechnology firms and to make these kinds of drugs together and try to skip the expensive part, not let the industry do it but do it as university hospital do where you would make drugs a lot cheaper as part of the scientific research. They have even thought of bringing it onto the market themselves. There are interesting talks going on in that field.

It finally ended well. The drug is still reimbursed. There are plans to have a special fund with money only for drugs for rare diseases. That's not yet the case but people are still getting the drug and I am very happy we published this story. Although I was in a debate in Berlin presenting a similar talk where some of the patients from the Fabry Foundation said we should not have done it, and still said she would not cooperate even with the current ledge with such a media report.

This was a very big ethical issue because paying 300,000 or 500,000 Euros for one patient for one year might mean that you can't pay for something else. The issue I would say was at stake was not that should we give reimbursed drugs to people that they need, I would say that's the normal solidarity in the system. That you pay for someone who is ill, not always for itself. But why are these drugs so expensive? Then you have this mantra of the industry which says 'It's at least a billion to develop a drug'. In those drugs, and some are enzyme therapies which were work exactly the same way, the mechanism they use is most of the time is identical, they just put another enzyme in it. You can ask whether you have to pay the price for the development of the mechanism each time. But this is a complicated debate.

Euthanasia: A Case of Medical Error?

The other story I would like to share is about euthanasia. The BMJ got hold of this as well. Where the GP administers a lethal dose of morphine to a dying patient. Euthanasia is under strict rules allowed in the Netherlands. In this case the rules were not adhered to, that was very clear.

We have something else to help people die, palliative sedation. I don't know whether that's the phrase in English. It's with Domicum and morphine, slowly bigger doses, you bring someone into a coma which they won't emerge from. That's allowed when the diagnosis is that someone will live for only 2 more weeks and is suffering severely. The patient in question asked for euthanasia then changed their mind with the doctor. He went to the doctor with his wife and said he wanted to have his euthanasia declaration back and he now wanted palliative sedation because he wanted to die but his wife didn't want him to and their compromise is that they do it slowly so she could get used to the idea of her husband passing away in a coma. It gave her a bit more comfort to get used to it.

There were very clear instructions. The GP was called to the patient and found the patient's situation very bad. He wanted to help him. He went home and he prepared two syringes, both with 1000 mg of morphine, so 2 g of morphine in total, with 315 mg of Domicum.

In reporting this I used a metaphor I should not have used. I said it was enough to kill an elephant, which was what the doctors had told me off the record. I had to tell the story myself all of the time because we had no sources to interview.

The GP gave the Domicum and one of the morphine syringes to the patient who passed away 1 and a half hours afterwards. He had a trainee from the Amsterdam University Hospital and she was asking questions because she had to prepare the syringes. She asked how much she should put in, and the GP told her to go on. She said the GP was going to give him a lethal injection, and the GP said yes, because the patient wants to die. So they had a debate. She was questioning the doctor who trained her which was a strong thing to do.

Afterwards, because he made all kinds of remarks and forbade her to talk about what happened with her university, she decided to report. The university relieved her, checked her out, and decided to report it to the health inspectorate which forced them to name the doctor, and this went straight to the public prosecutor. The police raided the patient's house and the GP's practice. Days after he got severe mental problems, went to a mental institution. He was questioned in the institution with a psychiatrist's consent and his lawyer. When he came out of the institution he committed suicide.

We reported this whole story based on off-the-record sources, and I knew from day one the exact amount of morphine he gave but we couldn't use it because it would lead immediately to my source who was very close to the family.

The first night I talked about this story was on the 10 o'clock news. Half an hour later I was in my care and I had 65 Twitter messages addressed to me. There was a huge mistrust from many doctors in the health inspectorate, the public prosecutor and the MOS. Nobody even started to think that this doctor might have done something wrong. Then the day afterwards we had our first on-the-record interview with the University Hospital and there was a slight change. When we published in the end the doses used there was more change. Those more in support of the GP said they would never have gone to the health inspectorate or public prosecutor without telling him.

That's where this story ends because there is a big inquiry of the health inspectorate on this doctor, the health centre he is working in, the pharmacist who delivered such quantities. After the health inspectorate inquiry will be an inquiry on everybody. Nobody thinks this doctor is a killer. But he was treated as one because it's either euthanasia or palliative sedation or not, and when it's not it's a murder inquiry. In my talks on TV I said the public prosecutor is not treating this as euthanasia; I knew this was a murder inquiry but didn't want to say it that way. So I said this was more like manslaughter or murder.

I did my utmost to be very prudent but wasn't at all! I learned an important lesson from that.