Persistent problems in the Dutch health care system: learning from novel practices for a transition in health care with the UPP framework

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Preface and acknowledgements

An issue often mentioned in the preface of a dissertation is the amount of stress experienced in the final phases of the process. This dissertation is no exception to that rule. In this case however, it is not a mere factual statement, but an illustration of the core message of this book: there is much to gain in terms of health improvement when health is not perceived as a purely biomedical issue.

In 2010, when the official end date of my project was nearing, I developed a chronic sore throat. This sore throat probably had to do with a mild, but persistent, tonsil infection. This in itself was nothing special, but the inflammation of the throat over time became a fever inducing factor in itself. I felt ill most of the time, and every couple of weeks I had to stay in bed with the flue. Doctors I consulted, mostly general practitioners, but also friends working in health care, in general said that a tonsillectomy might be the only option, since the complaints had become chronic. This was however not favourable because of my age, they added, so a watchful waiting approach was appropriate. As a result, I tried to fight the symptoms by wearing a scarf most of the times. Multiple pictures were taken of me soaking up a summer’s sun while packed in winter garments. In bed I tried to cover my throat all night to keep it warm, and I sometimes slept with a high collar.

In the spring of 2011 I was fed up, ready to undergo the tonsillectomy. And only then it dawned on me that my complaints might be completely stress related. Not on a mental-physical level, as in that negative thoughts or stress can weaken the immune system, but on a much more basic physical level. What if, I figured, the computer-work-induced tension in my shoulder and neck muscles would simply limit the blood flow to the tonsils, making it difficult for my white blood cells to reach that area, leaving a fertile breeding ground for all kinds of viruses and bacteria? Medical practitioners were not impressed by my hypothesis and suggested antibiotics treatment as second option. However, being a biomedical scientist by training, I wanted to test my hypothesis first.

Initial experiments were more than promising. When focussing on the tension in my shoulders, neck and throat, with the aim to relax the muscles, my tonsils immediately started to warm up and soften. In just two days the complaints were gone. Inspired by this success I now focus on relaxing my shoulder muscles whenever I get a sore throat, after which the complaints disappear as by magic.

The obvious question is: why had no medical professional been able to explain this dead simple trick to me? I am hoping this thesis will provide insights that help answer this and related questions.

My interest in this particular field goes back to my training as biomedical scientist, with a specialisation in neurology. As a student, I
gradually became interested in the question what the medical progress I was being trained to contribute to was doing for the people who were at the other end of the development process: the patients. The more I learned about how certain molecules interact with cancer genes, how medical trials are conducted, how far away lab work is from the clinical reality, let alone the social reality, the more I started to wonder how appropriate the questions are that we learned to investigate. Whose problem are we solving? Scientific articles generally start with a vague introduction into a health problem, and then quickly turn to the particular knowledge gap that maybe, somehow, somewhere in the future, will contribute to solving an actual health problem.

This interest, without being aware of it, led me in 2002 to a challenging internship at the department of Medical Technology Assessment at the UMC St. Radboud in Nijmegen. I was researching the case of Taxoids; a group of rather expensive medicines used to treat mammalian and ovarian cancer. Treatment was always palliative, and this new medication had in a clinical trial proven to be able to prolong life with approximately three months. On average, that is. In other words, after an average five years of having a deadly disease, it was possible for patients with this type of cancer to gain another statistically significant three months. Taxoids however can have severe side effects, meaning these last three months of life would be spent in a state of absolute misery.

I interviewed medical practitioners, representatives of insurance companies, pharmacists, policy makers, and patients. They all had different problem definitions relating to this recently introduced medicine. Some were concerned about the high costs, others about conflicting medical protocols. To most respondents, however, it was of primary importance that the treatment would be available to all patients: money should never withhold treatment. The patients I interviewed, surprisingly, were the only group voicing a different opinion: they were wondering whether there could have been different options, such as reimbursing a last trip to a tropical beach with family, instead of the medication. Or maybe a social worker to help the relatives cope with the impending loss. This left a deep impression on the young student I was. In the years that followed, my interests took me all over the place, but when a PhD position opened up for investigating issues of quality in health care, I did not hesitate.

The years at the A(I)SSR were both massive fun and deeply unnerving. Coming from a biomedical background, the social sciences and the accompanying academic discourse was a mystery to me. Only slowly I accustomed, although I feel I will never fully make the transition. Coping with this was made so much more enjoyable because of the people in the institute. In random order, I would like to thank Ana, Elmar, Daphne, Matthijs, Paul, Lutz, Alex, Erica, Mihai, Corina, Jasper, Marii, Apostolos, Benno, Jill, Valentina, Bouchra, Luc, Francisca, Malini, Judith, Marcel, Marten, Amalinda, Victor, Michiel, Nynke, Marieke, Sanneke, Anick, Silke, Marlous, Heidi, Katharina,
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