
The unholy trinity

GEIR W. JACOBSEN

geir.jacobsen@ntnu.no

Geir W. Jacobsen (born 1945), professor emeritus at the Norwegian University of Science and Technology and editor of the Journal of the Norwegian Medical Association.

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Doctors, patient organisations, and the pharmaceutical and medical device industry – along with the media – may thwart efforts to achieve evidence-based medicine.



Photo: Journal of the Norwegian Medical Association

Numbers count, but some numbers count more than others. For example, the number seven has a special place in the Judeo-Christian tradition. First and foremost, we are familiar with it from the creation story. And seven Sundays passed between the resurrection from the tomb on Easter morning and Pentecost, when the Christian Church was founded. However, the number three, as the expression of the Holy Trinity (Father, Son and Holy Spirit) is the bedrock of Christianity, with the Creed and the sacraments as central parts of the liturgy. Nevertheless, in our earthly world the trinity will not always serve society's best interests.

In the health services we were banished from the Garden of Eden back in the 1980s. The bitter apple that we had to bite into instantly opened our eyes to the fact that sufficient resources were no longer available to cover all needs. The health service research and health economics disciplines emphasised prioritisation, and this taught us about marginal cost and the cost of alternative use of resources [\(1\)](#). What is most intriguing is when the discussion turns towards measures that ought to be prioritised, but without even a glance at what must make way for these. An eight-year-old understands that if she spends all her money on sweets, she will not have any money with which to go to the cinema. When the politicians decided a few years ago to pay attention to the campaign 'Breasts for the people' and earmarked funds to reduce the waiting time for breast reconstruction after breast cancer, adolescents with cleft

lip and palate had to remain politely in *their* queue and wait even longer for treatment than previously (2, 3). Currently the offer of treatment for the rare, serious and disabling disease spinal muscular atrophy has raised the most heated debate. The controversy relates to the high cost of the drug nusinersen (Spinraza) as well as to which patients should have these costs covered by the state. The petition 'Spinraza for all' is only meaningful if one completes the sentence by stating what and who will have to receive less of the common good.

In 1987–88, Statoil was affected by cost overruns in building the Mongstad oil refinery. The term 'a mong' was used for several years afterwards as a synonym for the figure of NOK 6 billion, but the Willoch government footed the bill nonetheless (4). The Storting is currently experiencing a similar overrun on its own refurbishment project, the cost of which has reached NOK 2.3 billion. This means that each metre of the parking tunnel equates to the cost of 86 uncomplicated births in Norwegian hospitals (5).

The unholy trinity consists firstly of committed professionals who operate from within a narrow field of vision. I myself have heard a colleague say: 'Women want to be offered this – so why shouldn't they have it?' Others have stated that it is 'unreasonable that the patient should die without having tried this treatment' (6) or that 'the proportion of people who should be offered bariatric surgery paid for by the state should be extended' (7).

Then there is the matter of a large number of patient organisations that proclaim their first commandment with a varying degree of force: 'Thou shalt not have other priorities than me' – in line with the mission of any organisation that exists to promote its group's interests. The famous Norwegian doctor, Jonas Fjeld, is none other than the hero of a series of novels written in the first half of the last century (8). A paraphrase of his legendary line in this context might be: "'I have (choose disease),' said the patient, and all the other patients moved aside." Diseases that affect many people tend to attract attention. But this requires that the commitment of patients and their relatives, and the possibility to make their voices heard, are not diminished by the disease.

The third actor is an aggressive pharmaceutical and medical device industry. They constantly urge for 'our drug' to be available on reimbursable prescription and fiercely oppose assertions regarding the increased medicalisation of society. Innovation, healthcare industry and welfare technology are among the cliché generator's absolute favourites. Against this backdrop and with their brash style, representatives of the healthcare industry are now gaining access to the boardrooms of some medical faculties (9).

As an addendum to 'all good things come in threes', it is not unusual to hear 'the fourth comes too'. In this case, the press. A patient in her fifties with spinal muscular atrophy was the first to be asked to make a statement on the 18-year age limit for public funding of the Spinraza drug. 'Unfair', was her highly understandable comment. Another tried to put Lars Vorland, director of the National System for Managed Introduction of New Health Technologies, on the spot: 'Can *you* say whether Spinraza has a better effect on a 16-year-old than on a 19-year-old patient?' (10). Obviously he cannot. On the other hand, it is

Vorland's duty to state how the documented effect, adverse effects and prognosis at group level stand in relation to the cost – what Americans call 'Bang for your Bucks'.

In the eyes of the trinity, it is only natural that the patient's healthcare service may come into conflict with the requirement for quality of treatment. The paradox is that 'everyone' agrees that scientifically proven efficacy and evidence-based medicine are the same in practice. If the requirement for quality is put to the test, as may be the case, we are paving the way back to prioritisation of health services according to who shouts loudest.

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