synapse optometry

Matters arising…

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NB: Please complete 'Morals versus Ethics' before you start this article, which follows on from it.

Matters arising…

Meetings often have an agenda item called matters arising, which I thought would fit our purpose perfectly. This issue will dive deeper into some of our questions from our previous issue: Morals versus Ethics. Please make sure you have completed it or you may feel a little lost as you work through this one.

In that article we agreed that morals are our **personal**, individual set of values that help us to distinguish right from wrong, and that they develop under various influences, shaped by our perceptions, experiences and our psycho-social environment. They can change, but generally do so slowly.
Ethical rules were developed to maintain a cohesive society. They reflect and summarise our **communal** response to our physical and socio-political environment. As individuals, we may have been central to developing the rules, e.g. if they are for our book club or for the complex that we live in. We may have agreed to them, without being involved, or they may be imposed by an external authority, e.g. the HPCSA's regulations or a speed limit.

Behaving in a way that is different from our morals and ethics has different consequences. Behaviour contradicting our morals are likely to result in guilt and shame, while flaunting ethical rules will result in sanction or punishment from the community they are meant to maintain, or an authority created to enforce the rules. If your families have developed a tradition of spending alternate Christmases with your family and your partner's family, you may get the silent treatment or an outcry on your family WhatsApp group if you announce that you're going on a silent retreat instead. See, not all ethical transgressions are illegal. (I'm about to spend my first Christmas with my family in 22 years and I'm thinking fondly of a silent retreat when I get back. The point is that ethics is about the group, not the individual.)

Generally our morals and ethics are going to be somewhat aligned, since ethics reflect what is acceptable to the community at the time. However, there are historical medical research examples where they may not have been. Despite the Nuremberg Code (1947), several questionable research

projects continued into the 1970's. Stateville only shut down in 1973 and Willowbrook in 1971.

Mentally challenged children were more likely to be accepted into the Willowbrook school if their families agreed to their participation in a hepatitis research. By today's standards we're likely to consider this coercion, rather than consent, but we must also be careful of assessing our past actions by our present knowledge and attitudes – called presentism.

How does Willowbrook differ from the waiting lists at retirement homes now? One is more likely to get in if you agree to buy life rights rather than full title of the property. Is that also coercion?

In the patient's best interests

But returning to Willowbrook's hepatitis experiments: Are potentially dangerous experiments ever acceptable? Under what circumstances? Are they acceptable when the participant will not see any benefit themselves? Fighting to get access to experimental mRNA vaccines for his squamous cell carcinoma, terminally ill author Jake Seliger is hoping for a cure, and also wants his experience to be scientifically valuable, and for his experience not to be in vain. Regulators like the FDA are in a difficult position, particularly in the uber-litigious USA. The remotest side effect of a potentially lifesaving treatment will be laid at their door by the legal fraternity, perhaps representing the family, or by the press, so they cross their t's dot their i's and drag their feet to maintain the public trust and avoid law suits.
Just 3 years ago we were (well, I was) desperate for the COVID vaccines, already available and approved in other countries. SAHPRA's slow administrative process before making it available to the public here

reminded me of the early days of ARVs when the state couldn't afford it so we denied its efficacy. Should we be allowed access to experimental treatments? Do patients feel safer with their choices limited by regulators? Or should they be allowed to decide for themselves? They certainly did when it came to taking Ivermectin.

The US FDA is responsible for '*protecting the public health by ensuring the safety, efficacy, and security of human and veterinary drugs, biological products, and medical devices; and by ensuring the safety of [the] nation's food supply, cosmetics, and products that emit radiation…. [The] FDA is responsible for advancing the public health by helping to speed innovations that make medical products more effective, safer, and more affordable and by helping the public get the accurate, science-based information they need to use medical products and foods to maintain and improve their health.*'

Many believe that we are overregulated in almost every sphere, not just healthcare. The time factor is significant for the likes of Jake Seliger, who may not live to see a cure that he could have benefited from, or at least aided in. On the other side, if authorities are seen to rush a product to market, whatever we learn with the luxury of time (afterward) can come back and haunt them.

Here's an example: The American Journal of Ophthalmology describes a large study in the South Korean National Health Insurance Service which compared over 5 million people who had had at least one of 4 types of vaccination, with 2.7 million who had not been vaccinated. During the follow up period of 180 days, 0.29% of the vaccinated group had episodes of non-infectious uveitis, compared with 0.14% in the unvaccinated group. Does knowing this after the fact lead patients to believe that their healthcare is

underregulated, or does it remind them that all medications have side effects?

Why DO the regulators such as the FDA and SAHPRA continue to extend their scope and focus? Admittedly, we do sometimes discover side effects even after products have come to market but in general, medications have become safer in recent years. The last product withdrawals of a widely used products were rofecoxib (Vioxx) and valdecoxib (Bextra), withdrawn in 2004 and 2005 respectively due to increased cardiovascular risk. I remember that one of my patients bought up all the stock she could get, and appeared very serious when she told me she would rather face the risk of a heart attack than the pain she had suffered before these medications had become available and changed her life.

"Books give us perspective; their stories allow us to feel seen and provide us with the opportunity to learn from each other's lived experiences. Diverse stories deserve to be told, and readers deserve the autonomy to choose what books they read."

Nihar Malaviya
CEO, Penguin Random House Publishers

believing that a problem persists even

Who should decide what children read?

Penguin Random House (PRH) takes on US book bans with Banned Wagon Tour. The publishers are on a mission to fight US book bans that limit the fiction and non-fiction titles that children have access to. Their 'Banned Wagon Tour' will be handing out free copies of banned books at bookstores in communities affected by censorship as it passes through Georgia, Tennessee, Louisiana and Texas. PRH selected 12 titles, including books for young readers that deal with themes of racism and queerness, and classic novels like The Kite Runner, The Handmaid's Tale and The Bluest Eye. The Banned Wagon is a partnership with the Freedom to Read Foundation, Pen America and Little Free Library. According to PEN America, 1477 books were challenged or banned in the US in the 2nd half of 2022, possibly a sign of increasing state paternalism. By taking a proactive stance, this initiative appeals to a consumer base that expects brands to have a purpose and act accordingly.

when it has become less frequent. Levari et al show experimentally that when the 'signal' that we are searching for becomes rare, we naturally respond by broadening our definition of the signal, and therefore continue to find it even when it is not there. '*When blue dots become rare, participants start calling purple dots blue, and when threatening faces become rare, participants start calling neutral faces threatening. When unethical requests became rare, participants began to see innocuous requests as unethical even they were forewarned about it and even when they were instructed and paid to resist it.*' This peculiarly robust phenomenon is called 'prevalence-induced concept change.' It has broad implications that may help explain why people whose job is to find and eliminate problems in world, believe they're intractable, and they can't tell when their work is done.

So we've acknowledged that medications have been approved that have had side effects, but there are also the medications that we never hear about or get to use that may help the likes of Jake Seliger and those yet to be diagnosed. Regulators refuse such patients the opportunity to test new drugs, ostensibly for their own safety and protection, and in alignment with current ethical guidelines. These same regulators existed, as did the Nuremberg and Belmont codes of ethics when the Stateville, Willowbrook and Tuskegee projects continued. We have countless rules and codes of ethics, and apparently an emerging consensus on how ethical principles ought to guide healthcare delivery, yet we continue to hear about unethical practices. Are the codes not effective or are we experiencing the very prevalence-induced concept change that Levari describes? What do you think?

Moral Distress

We know that moral distress in the health professions arises when we know the right thing to do, but institutional constraints prevent us from taking this action. I'm sure most of us have experienced it: When parents insist on antibiotics for their child who has a cold and we understand the importance of antibiotic stewardship. Or when a medical aid refuses to pay for something

that we consider clinically necessary, but cover other less critical procedures because it's a selling point. Can you think of an occasion where you have experienced moral distress?

I have one from many years ago that haunts me to this day: A toddler came in after cataract surgery. Let's call him Joe. He had been born with cataracts, which had gone undetected at the post-natal check at the private hospital where he was born, as well as subsequent assessments at 2 weeks and 12 weeks. Although his mother was a minor (17 years old), she was fortunately on her father's comprehensive medical aid, so Joe's care was covered. His great-grandmother, who worked at a school for the blind, recognised the cataracts. The family first explored traditional medicine options, and surgery was only performed when baby Joe was about 7 months old so the risk for amblyopia was high. Still, we enthusiastically got the best refraction, the most suitable frames, the thinnest and safest lenses we could and had his spectacles made. There was no time to waste – the sooner he started wearing the glasses, the better his chances of developing useful vision would be.

Let me just pause here to remind you that

1. This child (well, both Joe and mother are children, but I mean baby Joe now) is protected by 2 sections of the Constitution. Firstly, section 27(1) gives every South African the right to access healthcare services, and section 27(2) obliges the state to take reasonable legislative and other measures, within its resources, to achieve the progressive realisation of, amongst others, health care rights. Second, section 28, which deals with children specifically, gives them the right to basic health care services (section 28(1)(c)).
   Note the difference: Section 27(2) covers the right to **access** only, and section 28(1)(c) describes a **right to actual** services.
2. Since the Constitution was adopted we have seen several pieces of legislation that expand and clarify the rights enshrined in the

Constitution. However, Notice 657 of 1994 which relates to the National Health Act, predates the Constitution, and had already provided for free health services for pregnant women and children under the age of 6.

3. Cataracts are a prescribed minimum (PMB) condition. What does that mean? Annexure A of the General Regulations of the Medical Schemes Act provides a list of prescribed minimum benefits (PMBs); conditions that Medical Schemes are obliged to cover. This includes the diagnosis, treatment and care of
    - any emergency medical condition;
    - a limited set of 271 diagnosis and treatment pairs (DTPs), and
    - 26 chronic conditions

    The purpose of creating PMB conditions is so that a patient arriving at a hospital with a life threatening condition cannot be refused care because their medical aid benefits have been 'exhausted' for the year. Neither can treatment be refused for conditions like diabetes and hypertension, or as in young Joe's case, cataracts. The treatment extends to vision correction for an aphakic patient after the surgery.

Surely a child protected by all this legislation would receive the best care. What could go wrong? Well, plenty, as it turns out. His medical aid refuses spectacles for children as a matter of course. Yes, you know the one. They rejected, even for this prescribed minimum benefit condition, for which they are obliged to pay, and had already paid for the cataract surgery. They asked for, and rejected my motivation because his prescription was too high for such a young child, they felt. I explained again, this time with a letter from the ophthalmologist, which took some time as well because he could not understand why a motivation was required at all. They had paid for his cataract surgery so surely they know that he would be requiring glasses? Of course he has a point, yet here we are. Meanwhile, the glasses are ready, sitting in their little case, so I've agreed to let them go because the child's neurological visual development relies on him wearing them as soon as

possible, and as much as possible. The mom brings him in, and we fit the glasses, complete with a little elastic band to secure them in place. He is just the happiest baby, all smiles. I explain that they must be worn every waking moment. I turn away to pick up the case and she's taken them off. She thinks it's best not to let him wear them all the time in case he breaks them. After all, they haven't even been paid for yet. I had to go to my office so the people in our waiting room wouldn't see me cry. My ethical code prevented me from changing the prescription when the medical refused to pay – that would have been fraud. In terms of the National Credit Act, I'm not supposed to allow them to leave before the glasses have been paid for, because I'm not an authorised credit provider, let alone release them to a 17-year-old mom who doesn't have the legal capacity to contract in terms of section 17 and 18(3)(b) of the Children's Act, as well as the common law. So I turned to the regulators and emailed a complaint to the Council for Medical Schemes. They auto-responded and referred the matter to the medical aid, which has 30 days (working days, not calendar days) to respond. Meanwhile I'd tried Carte Blanche and the newspapers. Nobody seemed to share my outrage that this child had to wait almost 30% of his life for the entities that 'protect' him to sort out their admin and pay for his glasses. The CMS finally responded with a back-slapping email shortly after the medical aid had paid to say how pleased they were that they problem had been resolved and that they were closing the case. No doubt they consider this a success story. Joe's much older now, and he's functionally blind. He will always be a financial burden on his family and society. Would his vision have been better if he'd got his treatment sooner? Perhaps not, but I never got to try. In terms of my morals, I want to do the best I can for children because they need protecting, but institutional constraints prevented me in this case… so, moral distress.

The experience left me cynical of regulators and the media, so I can understand why Barlem and Ramos say that moral distress 'obstructs the process of moral deliberation [and] compromises advocacy and moral sensitivity, which results in ethical, political and advocational inexpressivity and a series of physical, psychical and behavioural manifestations.' This accurately describes my reaction, except instead of a reduction in moral sensitivity, I experienced a period of heightened awareness of my own and others' morals. I found it confusing, draining and depressing, plus I'm sure I was perfectly boring to my friends in the acute stages of my obsession. Having well-intended laws and ethical guidelines are not enough when they're not applied, adhered to or enforced by the powers-that-be.

In Issue 10.5 we talked about changes in women's rights to abortion after Roe v Wade was overturned in 2022.
Roe v Wade had been the precedent-setting case that allowed US women access to abortions since 1973, overnight changing the ethical code. It appears that these rights are just as poorly protected in the EU.

Abortion in South Africa

I used the example of the right to seek an abortion to illustrate how our morals, once well aligned with our ethical codes, may suddenly be at a mismatch when the laws change.
In South Africa, women may seek an abortion within the first 12 weeks of pregnancy, and up to 20 weeks in specific cases, in terms of the Choice in Termination of Pregnancy Act, 92 of 1996. The Act was assented to shortly before the Constitution was approved, one of the most liberal examples of abortion legislation globally reflecting the halcyon days of a new democracy. The Act was fuelled by the alarming findings of national epidemiological study (1994) on incomplete abortion, as well as international statistics: More than 22,000 women die from complications from unsafe abortions each year in the developing world, and 6.9 million need treatment for complications.

Surely, I hear you say, there must be some consistency in law? Inconsistency is one of the most obvious manifestations of unfairness that we are likely to come across. Indeed, the concept of rule of law requires that laws be applied equally, without unjustifiable differentiation. There are 2 forms of inconsistency:

- Treating the same person inconsistently over time, which is more obvious and easier to prove
- Treating 2 people differently.

Hidden J, in R v Special Adjudicator *ex parte* Kandasamy considered the question whether there is a general public law duty to be consistent. The judge decided that 'consistency, as such, is not a principle of administrative law; the governing principle is whether there has been unfairness such as to amount to an abuse of power.'

Besides their responsibility to follow the rule of law, courts are also expected to exercise their judicial review function to develop the law and lead, or prompt legislative changes. The South African judiciary has been criticized for not doing so sufficiently in the years pre-democracy, and not providing a remedy to the inconsistency of what was legal and ethical on the one hand, and what was moral. Courts can introduce change, as we saw after the Nuremberg trials. (It's how, and whether those changes should be followed that is proving more difficult.)

I'm not suggesting that we should rush to assimilate changing ethical rules into our personal morals without robust internal and external debate. In fact, some dissent and dialogue is probably healthy. Just like the courts, we have

the right and the responsibility to develop society's values. Sproul (2015) uses the term 'statistical morality' for when our normal or regular behaviour becomes the normative.

Statistical morality described in a picture.

Or as my mother used to say: 'Just because all your friends are doing something doesn't mean that you should do it too.' Our (professional) peers may be regulating us now, through the structure of the HPCSA, but there were times where our younger peers talked us into underage drinking, or perhaps worse. And even as adults, which of us hasn't told a lie, or exceeded the speed limit? But just because everyone does it at some point, doesn't mean that in current South African society it is normal to lie or speed. 'Normal' means good and right, and our ethical rules need to define what is right, not what is accepted. Do you agree? It's OK if you don't, but let's 'waste no more time arguing what a good man should be. Be one.' (Marcus Aurelius)

CPD Questions

1. Applying current thinking, experience and wisdom when forming an opinion on historical events is called…

a) Paternalism
b) Positivism
c) Presentism

2. What is the primary difference between morals and ethics?

a) Morals are personal values, while ethics reflect communal rules.
b) Morals are laws, while ethics are personal values.
c) Morals focus on individual actions, while ethics consider societal well-being.

3. Which regulatory authority in South Africa is responsible for ensuring the safety of medical products?
   a) HPCSA
   b) SAHPRA
   c) FDA

4. What is the purpose of Prescribed Minimum Benefits (PMB) in the context of medical aid members/ dependents?
   a) To limit access to medical care
   b) To ensure access to life- and quality of life- preserving medical treatment
   c) To provide more benefits to elderly patients

5. What is moral distress in healthcare professions?
   a) A sense of guilt when making personal decisions
   b) When ethics align with institutional constraints
   c) Knowing the right thing to do but being prevented by institutional constraints.

6. According to the Constitution, who has the right to access healthcare services?
   a) Only adults
   b) Only patients on medical aids
   c) Every South African

7. What does the author's experience with the toddler named Joe illustrate?

a) The efficiency of medical aid in approving healthcare expenses
b) How laws and ethics are consistently applied in healthcare
c) That legislation does not always achieve what it intends to

8. According to the article, what did the judge in the case of R v Special Adjudicator *ex parte* Kandasamy determine about consistency in administrative law?

a) Consistency is a fundamental principle of administrative law
b) Consistency is not a principle of administrative law; the focus is on fairness and possible abuse of power
c) Consistency is only applicable to private individuals, not public institutions

9. What is 'statistical morality' according to the article?

a) When everyone follows the law
b) When typical behaviour becomes the normative
c) A mathematical approach to evaluating moral decisions

10. According to the article, what should ethical rules define?

a) What is legal in society
b) What is accepted in society
c) What is right and good in society

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