Elements: in this month’s issue

An un-just society—limiting access to medicines for rare diseases

John Rawls, an eminent American philosopher, set out principles for a just society. One of the pillars of his just society was that the greatest benefit of this society should be to the least advantaged. Prof. Tim Cox et al. at the University of Cambridge persuasively argue that in a ‘just society’, as envisaged by Rawls, all of our citizens should be entitled access to life-saving treatment.

It is morally arbitrary as to whether one is born healthy or with a debilitating rare disease, yet patients with rare diseases often have a significant loss of social and economic opportunities combined with potentially restricted access to life-saving therapies. They highlight the inappropriateness of current healthcare economic modeling in defining benefit to society in the context of rare disease and they determine three rules that detail when, and when not, current cost effectiveness modeling should be used in assessing care for patients with rare diseases. It is timely to reflect on why oftentimes life-saving therapies are not universally available to patients with rare diseases.

Adverse events in healthcare—empowering individual accountability

As a practising physician, it is impossible to guarantee that mistakes will not be made in the care of our patients. It is estimated that up to 10% of patients will experience an adverse event resulting in prolonged hospital care. Many of these adverse events within the healthcare system are preventable. Rafter et al., in this issue of the journal, explore the reasons why this occurs and defines how a systems-based approach is required for the development of a safety culture that learns from adverse events.

This approach requires a shift from an adversarial blame culture that incentivizes non-disclosure, to an ethos of safety management built around a ‘just-culture’ to maximize the potential avoidance of future adverse events. A ‘just-culture’ reflects the balance between limiting blame and empowering accountability for individual healthcare workers within the system.

The system within UK currently has a limited ability to learn from its mistakes. This review challenges us as physicians to take a step back and address how the health system can adapt to build a culture of safety in which an integral part of that culture would be the development of robust and globally standardized measurements for adverse events.

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