EDITORIAL

We must tackle inequalities in care

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In this third edition of *The Journal of Haemophilia Practice*, Madhuri Kurdi and colleagues from India describe the case of a patient with moderate haemophilia A undergoing surgery [1]. In summary, the patient was posted for elective endoscopic internal urethrotomy and received 800 units of FVIII 2 hours before surgery corresponding to a dose of 13 units/kg body weight. On the third postoperative day he developed haematuria. Additional factor VIII transfusion could not be given because of economic constraints and therefore fresh frozen plasma was transfused. The patient's haematuria receded and he was discharged on the tenth postoperative day. The authors state that this case, who obviously had postoperative bleeding and an unnecessarily long hospitalisation, should have been given a higher preoperative dose (3000 units) and continued treatment postoperatively. The patient could not afford this.

This is a situation that is not unique to India. A glance at the World Federation of Hemophilia website (www.wfh.org) shows that 75% of people with a bleeding disorder receive inadequate care or no care at all. WFH's global survey of factor usage for 2012 shows that the average (mean) global factor VIII use per capita based on countries according to World Bank ratings show a figure of 0.01 IU per capita in lower economy parts of the world, 0.15 IU in lower middle, 1.35 IU in upper middle and 5.36 IU in upper economic countries. The situation is similar for factor IX. These figures tell us that factor concentrates go to parts of the world where a minority of people live and barely at all to those parts with the greatest population. The figures become even more shocking when we look at individual countries. Mean per capita use of factor VIII is 0.002 IU in Ghana and Nigeria, 0.007 IU in Ethiopia and 0.005 IU in Uganda. In fact, in Africa only two countries reach 1 unit per capita (Algeria 1.63 and South Africa 1.02). In contrast, in Europe only 4 out of 24 reported countries have a consumption below 1 IU, and most countries use more than 4 units per capita. Several countries consume 7 IU per capita, with Finland and Sweden both above 10 IU.

It is easy to understand from these figures why the quality of haemophilia care is much higher in richer countries than in most other countries across the globe. Several publications show that the expected median survival of people with haemophilia approaches that of the background male population in the western world [2,3]. This has prompted more focus on how to handle comorbidities in the ageing haemophilia population [4], which creates challenges in haemostatic management even when concentrate availability is high. Prophylaxis is now seen as the best practice in wealthier countries, even if the exact mode of dosing remains to be settled [5]. Surgeries can be performed safely.

Dr Kurdi's case report shows how uncertain the outcome of even a rather minor surgery can be if availability of concentrate is restricted. However, it has been shown that surgery in fact can be managed safely with lower dosing than is usually used in western countries [6]. WFH guidelines also provide dosing recommendations for coverage of surgery depending on which economic setting the health care facility is in. Long term, regular, prophylaxis can also be successfully implemented with much lower doses than commonly recommended as outlined in a paper from Wu et al in China [7].

Irrespective of the feasibility of using different dose ranges in haemophilia during prophylaxis or surgery one has to conclude that the lower the dose, the less is the safety margin. In the case reported here, the margin was too low, and the patient suffered more than necessary. The challenges to improve haemophilia care in the world are tremendous, and it is important to convey to every politician and health care provider, the following.

- Nobody asks to be born
- Nobody asks to become sick
- Everybody deserves the best and equal care.

Every human being has an equal value and the right to a significant life are important principles in the UN's human rights conventions. These principles also permeate the ethical codes that have been adopted by healthcare professionals. Those who work in these professions therefore have the task of promoting implementation of these rights. A provider that tries to get its employees to work in accordance with other principles presents them with serious ethical dilemmas.

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