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The 14th World Congress of Bioethics: Some personal reflections

ALASTAIR V CAMPBELL

Abstract

These reflections on the 14th World Congress of Bioethics in Bangalore stem from the author's personal and family connections with India and from his participation in all fourteen of the world congresses since the foundation of the International Association of Bioethics in 1992. The very wide scope of the meeting could be seen in two ways, as confusing and chaotic, or as richly diverse and enlightening. Emphasising the latter aspect, this paper argues that the powerful emphasis on health for all and on care for the marginalised in society has a crucial lesson for the bioethics community worldwide.

Introduction

I may be in the unique – or at least, unusual – position of having attended all fourteen of the World Congresses, since the inaugural one in Amsterdam in 1992. Moreover, I was fully involved in the planning and delivery of two of them – In London in 2000, and in Singapore in 2010. In light of this, and of the fact that I have also served as the President of the IAB, perhaps I am well placed to assess the impact and importance of the Bangalore Congress.

There is another relevant factor to mention by way of introduction. My family has very strong links with India. My grandfather, Thomas Vincent Campbell and my grandmother,

Florence Campbell, were medical missionaries in the rural area north of Madras (now Chennai), and they founded a hospital which exists to this day. My father and mother met and married in Madras – Dad was a Professor of English at Madras Christian College. My brother and two sisters were born in India and spent the early years of their childhood there. Thus, India is in my blood, as it were, though I did not manage to visit it for any length of time until 2012, when I gave a series of lectures in different cities in South India, and was able to visit the Campbell Hospital in Jammalamadugu. On the wall there is a picture of my grandfather, 'TV' Campbell, honouring him as the founder of the hospital. But to me, the much more important connection is with my grandmother, Florence, who is not even mentioned! Yet she was one of the earliest women medical graduates in Britain and she did outstanding work as a doctor in India, most especially with women and children in the rural communities. I have visited India several times since that first tour, and have participated in several National Bioethics Conferences. Hence, these reflections on the World Congress, held in conjunction with the Indian National Bioethics Conference, are obviously coloured by my fascination with this vast country, by my deep admiration for my Indian friends and colleagues, and by my awareness of the major problems and challenges which have to be confronted in this setting.

Scope

As with all other world congresses the scope of this meeting was very broad, although the overarching theme was justice in health care – 'health for all'. This broad scope was clearly inevitable given the fact that Bioethics itself is extremely diverse, and that in order to ensure a viable number of participants a wide range of papers have to be accepted, provided they are up to a reasonable standard academically. The result is, of course, a dizzying set of parallel sessions, with

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To cite: Campbell A. The 14th World Congress of Bioethics: Some personal reflections. *Indian J Med Ethics*. 2019 Jul-Sep;4(3) NS:226-8. DOI:10.20529/IJME.209.027

Published online on May 16, 2019.

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the impossibility of any one person gaining a perspective on the whole. (Thus, these reflections must be seen as wholly subjective and unavoidably impressionistic.) The scope was also greatly increased by several other factors: a large number of pre-conference events; the merging of the World Congress with the biennial meeting of the National Bioethics Conference; the conjunction, plus overlap, with the Feminist Approaches to Bioethics Network conference (a collaboration I pioneered at the London Congress of 2000, and which has continued ever since); and an integrated series of events and exhibitions on the theme of Bioethics and the Arts. One could view all of this as sheer chaos and confusion, or as amazing richness and diversity! I lean to the second more positive view, and I draw a parallel with the mixed reactions of foreign visitors to experiencing, for the first time, life in an Indian city outside the sterile and wholly unreal environment of the international airport where they have landed or the five-star hotel they may choose to stay in. The experience can be overwhelming, but also amazingly stimulating, opening one's eyes to the everyday lives of millions of our fellow human beings and to the challenges they face.

Themes

As I have already mentioned, the overall theme of the Congress was justice in healthcare. Gross inequalities in access to healthcare and to the living conditions essential for good health are a well-known worldwide problem, which has been explored in most the previous congresses. But in this meeting, there was an urgency and vividness evoked by the Indian context, with moving examples of discrimination, marginalisation and neglect of whole groups on the basis of ethnicity, caste or gender. For me the most dramatic example of this was a paper on the health hazards of sanitary workers, an oppressed caste compelled to undertake the (illegal) task of cleaning out the public sewers. But there were numerous other examples of overwhelming injustice, perpetuated by the incompetence, greed and corruption of the authorities supposedly responsible for the wellbeing of all citizens. In contrast with this dark picture of hopelessness, were many inspiring accounts of the commitment, perseverance and courage of health activists and health advocates confronting these problems on a daily basis. When seen in this context, the efforts of bioethicists in the West to describe justice in healthcare seemed pallid, ineffective and 'academic' in the worst sense! We have a huge amount to learn from our Indian colleagues.

This central theme of the Congress was greatly enriched by the interweaving of different forms of artistic expression - music, theatre, dance, and various visual presentations. One especially striking exhibit was called 'Talking Hands', a series of photographs posted at strategic places on the route between the different buildings in the campus. This location meant that virtually all conference participants would see them from time to time as they moved from one session to another. A written description cannot really convey their emotional impact, but what they did was to confront one with the many ways in which people suffer from marginalisation, discrimination

and indifference in our modern world. The artistic events in the main lecture theatre had a different but equally powerful impact, when drama, dancing, singing and drumming conveyed, not only the richness of Asian culture, but also the recurrent themes of suffering, despair, compassion, and hope common to all cultures, East and West.

Issues

A number of key issues for Bioethics were highlighted in this culturally diverse and intellectually challenging Congress¹. None of these issues is new to the field, but they stood out very strongly in this meeting, thanks to the stress of the organisers on the centrality of socio-political challenges.

Firstly, can Bioethics escape its capture by the affluent societies of the West, whether on the European or American continents? For too long Bioethics scholarship in the West seems to have become seduced by the glamour of high-tech medicine, just the latest example being the controversy over gene editing. This is not to deny the importance of these issues and the need for careful assessment of the ethics of their use, plus the hope that policy makers can receive high quality and unbiased advice about how they should be regulated. However, the major health problems facing the majority of human beings outside the privileged enclaves of high-income countries surely have a much greater moral urgency than these narrowly specialised ethical concerns. This issue of the moral priority of social justice in healthcare has been raised strongly in many IAB congresses over the years (including in several Presidential Addresses), but still it seems to remain masked by the drama of quandary-driven clinical ethics. Perhaps the massive injustices exposed in the Bangalore plenaries, symposia and concurrent sessions, across such a range of topics and geographical areas, will lend a new sense of urgency in the Bioethics community about where our priorities should lie in our own countries.

However, a second issue is raised by this urgent demand for ethical prioritisation. Should Bioethics embrace health advocacy and/or health activism? This question features prominently in India, since so many of the participants in Bioethics conferences and meetings are themselves health activists working in highly challenging areas of social and healthcare. Theirs is a very different world from the enclaves of academia, in which philosophical sophistication and debating skills are often seen as the highest marks of achievement. The two worlds do not mix easily, and more than once in both plenaries and concurrent sessions I heard comments like, "very worthy and important, no doubt, but where is the critical analysis?" To some extent this disagreement about the nature of Bioethics is related to the ongoing debate about "empirical bioethics". Philosophers worry about the naturalistic fallacy, the logically illicit jump from "is" to "ought". Yet Bioethics is surely pointless if it shuns any contact with the real world and its moral complexities, and rests content with hearing good arguments on both sides of every moral dilemma. Needless to say, the 14th World Congress did not, and could not, resolve this fundamental issue. However, it did serve to bring it out into the open, and while there is no possibility of the IAB changing

itself into some sort of health advocacy group – this would be a breach of its Constitution – many who attended the Congress should have been inspired to think again about their role in their own social setting. To what extent can they make a difference, at least to the quality of the debate about justice in health and social care? Can they find a way on influencing national policy? What NGOs might they join, where advocacy and activism are a core activity?

A final issue relates to the interweaving of the Arts into the Congress programme. This has been a feature of IAB Congresses since the one in Australia in 2004, when its President, Paul Macneill, set a powerful example, which has been followed – to a greater or lesser extent – ever since. Bioethics is frequently described as inter-disciplinary, but this is usually referring to the inter-relationships of Philosophy, Theology, Law, Medicine and Social Science in its scholarship. But incorporating the Arts, or, more broadly, the Humanities in its discourse makes a profound change. Such a change opens up the issues of Bioethics to the imagination and the emotions as well as to the mind. This broadening of the discourse was done very effectively in Bangalore, and it gave the lie to the simplistic notion that all that is needed in morality is rational argument. Certainly, we cannot do without rationality, but reason alone cannot help us to be moral agents in the richest sense of that specifically human capacity.

Conclusion

It was a privilege to attend this Congress, as well as a great pleasure to spend time again with my good friends from India (and from many other countries too). But the main personal reflection from this experience is an awareness that we must learn from what we have heard over these days of bombardment with experiences and ideas from all sides. For me the lesson is a simple one: the time is short and we must do our best to make *some* difference in this unjust world. We must seek to counter the gloomy prophecy of W B Yeats in his poem, *The Second Coming*:

*The best lack all conviction,
While the worst are full of passionate intensity. (1)*

It need not be like this! But that is up to us, those of us who claim to be really concerned with Bioethics. Inspiration to make a difference can surely come from these few days in India.

Note:

- ¹ For full range of papers, see: <http://www.worldcongressofbioethics.org/documents/Program.pdf>

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The patient is king: But does the king accept wise counsel?

ANEESH BASHEER

Abstract

Trust is the most important component of the doctor-patient relationship. This relationship has evolved substantially from a sacred paternalistic bond to a very prejudiced, consumeristic link. Changes in legal systems have brought medicine into the purview of consumer litigation and therefore the patient is the king akin to the consumer. In this short paper, the implications of the rights of the patient from a consumer point of view and the issues related to its use/misuse in daily interactions is discussed. How patients could potentially participate in decision making is stressed. At the same time, the fallout of their unnecessary intrusions into the doctor's clinical expertise and advisory capabilities needs to be recognised and tactfully countered to build and maintain trust in the doctor-patient relationship.

Keywords: patient - doctor relationship, paternalism, consumerism, trust, good communication,

The doctor-patient relationship has long been considered special and sacred.⁽¹⁾ A fundamental principle of this relationship is Trust which in turn is built upon warm rapport, good communication and mutual acceptance of each other's strengths and weaknesses.⁽²⁾ This relationship was not built overnight; it has taken centuries of personal sacrifices and professional commitment to win the hearts of ailing men, women and children. A million oaths have been pledged after Hippocrates to ensure that doctors treat their patients honestly, compassionately, selflessly —and most importantly —with no intention to harm. This relationship has been under duress for quite some time, and it has become more relevant than ever to regain trust lest it should crumble forever.

Before the emergence of the four principles of ethics and the rise of evidence-based medicine, patients relied heavily on advice from their physicians to start, stop or change a medicine. It was also considered an unwritten dictum to religiously follow the physician's opinions on what tests may need to be performed to arrive at a diagnosis. Times have changed and patients confront their physicians with a

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To cite: Basheer A. The patient is king: But does the king accept wise counsel? *Indian J Med Ethics*. 2019 Jul-Sep;4(3) NS:228-29. DOI:10.20529/IJME.2019.048

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