

FAMILY AUTONOMY AND PATIENT RIGHTS TO HEALTHCARE IN AN ‘ASIAN VALUES’ CONTEXT

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A parallel can be made between the human rights discourse and the global bioethics discourse along two axes: 1) the ongoing relativist-universalist debate in both fields, 2) the overlap of the two discourses on the issue of the right to treatment as an issue of access. This article links the issue of right to treatment with an analysis of patient autonomy. In bioethics, it has been suggested that the Western individualistic notion of patient autonomy is inappropriate in Asian societies with a socio-centric construction of personhood and decision-making, where the family rather than the individual patient tends to make decisions on treatment. Based on a narrative analysis of physician's perceptions of ethical dilemmas in a major tertiary hospital in New Delhi, India, we examine the concept of family autonomy. Six different narrative configurations of patient versus family autonomy are identified and contrasted. The analysis shows that while family autonomy is a common practice in treatment decision-making, it is problematic as a normative ethical principle to guide clinical practice because it poses yet another barrier to treatment for the patient, and because this practice often conflicts with the patient's wishes and with what is best for the patient according to a medical assessment.

Rather than pursuing an idealised 'Eastern' or 'Asian' concept of family autonomy as a 'culturally appropriate' replacement for the concept of

patient autonomy (problematic in itself as it may be), it is suggested that the conflicts between patients, relatives and physicians in everyday clinical practice reflect existing power disparities among the three types of actors, and that these are exacerbated by poverty and insufficient availability of resources at institutional and societal levels.

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. Universal Declaration of Human Rights, Article 25.1

While it is not difficult to agree that health as a human right is not 'respected' or 'adhered to' in most countries in the world, it is much more difficult to agree on what this exactly means, or how health as a human right should be monitored, or even understood. This issue is further complicated by the claim of the universality of human rights. The human rights charter is increasingly part of a globalising agenda and used to legitimise powerful political interventions at national and international levels. Cultural relativists have attacked the human rights charter for being 'universal only in pretension, not in practice, since it is a charter of an idealist European political philosophy', a critique that can conveniently be used to challenge the human rights charter for conservative political purposes.

In 1993, in the so-called Bangkok Declaration, a number of Asian countries confirmed their general respect for the fundamental principles laid down in the Charter of the United Nations and the Universal Declaration on Human Rights. Thus, the Bangkok Declaration 'Reaffirm[s] the interdependence and indivisibility of economic, social, cultural, civil and political rights and the need to give equal emphasis to all categories of human rights'. This confirmation is balanced by a passage that serves to introduce cultural relativism to the human rights principles. There is a certain tension on this issue in the Declaration as a whole. In the relevant passage (§8), the countries behind the Declaration

... recognize that while human rights are universal in nature, they must be considered in the context of a dynamic and evolving process of international norm-setting, bearing in mind the significance of national and regional particularities and various historical, cultural and religious backgrounds.

The Bangkok declaration thereby provides a strong political statement that feeds what we would call the 'Asian values discourse'. The Asian values discourse maintains an East-West dichotomy concerning issues of rights and their underlying rationality. In particular, a contrast, if not a conflict, has

been pointed out between Western values of individuality (including the human rights related focus on individual rights) and collective, socio-centric cultural values in the 'East'. Recent contributions answer in the negative the question of whether there are 'such things as Asian values, understood as a common social morality embraced by that half of humanity living in Asia today' (Jacobsen and Bruun 2000, 4). However, much classical anthropological work supports the notion of family-based, socio-centric notions of personhood, identity and decision-making (Marriot 1976; Östör, Fruzzetti, and Barnett 1995; Daniel 1987, to give a few examples), and a wealth of medical anthropological work also points to the importance of the role of family in patient treatment. A PubMed database search on 'anthropology' 'family' and 'hospital' gives a total of 857 titles (March 2004), 91% of which have been published after Kleinman's influential work on 'Patients and Healers in the Context of Culture', where this topic is given considerable importance. Recently, socio-centric culture has even been constructed as a significant risk factor in the pathology of bulimia in North India.

Access, treatment, ethics, and culture

In this paper, we shall pursue this discussion on 'Asian values' with a focus on rights to health. Since there is hardly any agreement on the meaning of health as a human right, we would like to suggest a working distinction of *access* to public health services and *treatment*, once access has been obtained. The first implies that people have a right to equal access to healthcare offered by the State, irrespective of gender, age, ethnicity, etc. The second implies that treatment should be offered on the basis of medical evaluation and not according to discriminatory practices based on sex, ethnicity, etc. Unfortunately, often these principles are not adhered to, and one could complicate these formulations through further reflection, but as basic principles they would be acceptable to many people.

There is, however, an important distinction between access and treatment: while an ill person ideally should have access to healthcare facilities – and may claim such access as his or her right – the right to a *particular* treatment does not exist. It means that, in general, a patient can insist on being treated according to the standards of government health services in the society in which she lives, but the patient does not have the right to determine the specifics of this treatment, like whether this or that drug should be preferred. This decision is supposed to be made by the physician on medical grounds, not by the patient. On the contrary, as a right, the patient can only refuse to accept a treatment offered. However, in certain cases, as we shall see, there may be a more effective treatment, which also involves a higher cost for

the patient, compared to a less effective but cheaper or free medicine. In such cases, it is expected that the patient is informed of this situation and decides which drug to use. It may be open to debate, to what extent the right to simply refuse treatment is part of the human rights formulation cited above; one could perhaps see it as the 'right to security ... in case of sickness', i.e., the security that one is not subjected to unwanted treatment.

The discussion of health as a human right represents but one aspect of the global discourse on human rights – which, by definition, are thought to be universal – and their potential relativity in what can be conveniently phrased as local adaptation. There is a parallel discussion on the universality versus relativity of medical ethics. While in practice there is also no consensus on what actually is ethically defensible in medical practice in different clinics, departments and sectors of different countries in the world, bioethics as a discipline dominated by Western European philosophy has formed a certain level of consensus around the four principles suggested by Beauchamp and Childress as having general applicability. These principles are 1) the principle of respect for autonomy; 2) the principle of non-maleficence; 3) the principle of beneficence and 4) the principle of justice. Simplifying the discussion of these principles considerably, the principle of the respect for autonomy primarily has to do with competent patients' right to decide – based on sufficient information to be provided by the physician – whether or not to accept a certain treatment. Beauchamp and Childress' discussion of non-maleficence focuses on the moral obligation to protect incompetent patients, such as children and mentally incapacitated patients, from undue harm caused by the treatment. They suggest that in cases where patients are not capable of autonomous decision-making, the family should be the presumptive authority because 'of expected identification with the patient's interests and intimate knowledge of his or her wishes' (ibid.:179). We shall return to this issue later in more detail in an analysis of implications of family autonomy for patients. The third principle, of beneficence, mainly has to do with the amount of good (versus harm) that a given treatment can possibly do to the patient, and it is directly related to issues of autonomy. However, here we shall not focus on this discussion. Finally, the principle of justice has to do with distribution of health goods and is related to concepts such as fairness and equity. In continuation of our distinction between access and treatment, justice is about access, whereas respect for autonomy is about treatment, i.e., the right to refuse treatment.

This parallel between the rights discourse and bioethics is not limited to similarity of issues. While founded in classical European philosophy, both the human rights declaration and the development of Western bioethics are children of World War II, and though the principle of patient autonomy can

be found in other connections as well, it has been formalised in the aftermath of the medical experiments with concentration camp prisoners in Nazi Germany, particularly with the Helsinki Declaration of 1964 and subsequent revisions. Historically, there has been more attention on medical research, particularly on the testing of new drugs with its uncertainty of outcome and side effects, but in the context of this article, clinical trials could be seen as merely a particular instance of the doctor-patient relationship.

In the field of bioethics, the concept of patient autonomy has given rise to a debate that closely parallels the discussion of 'Asian values' in the human rights discourse. Proponents for the Asian values position claim that the Western perception of the patient as a rational, self-conscious creature, capable of making own decisions on treatment avenues offered, is insufficient and inappropriate and must be replaced with a perception of the patient based on 'Eastern' values. For instance, Confucian philosophy has been promoted as a paradigm for an alternative Eastern medical ethics, where the concept of person is not limited to a rationally behaving individual, but is supplemented with a relational concept of person, where 'individuals are never recognised as separate entities; they are always regarded as part of a network, each with a specific role in relation to others'. One important implication of the Confucian perception of personhood is that the family, rather than the individual patient, is seen as the primary negotiation partner for the physician in the doctor-patient relationship. According to this perception, the physician should 'maintain harmonious relationships among families and help to bring agreement out of conflict, [...] in effect seeking to maximise the long term welfare of the patient' (Tsai 1999:48).

Tsai's contribution to the discussion is framed within a consciously normative position – he discusses how at least Chinese physicians should behave towards their patients. But contributions to the discussion of Asian values often hold less particular generalisations about something named 'Asian culture'. A recent article in the *Journal of Medical Ethics* begins:

Human-heartedness has been at the centre of Asian civilisation throughout history. Benevolence and compassion are the two magic words in Asian cultures. Asian people are not as individualistically oriented as their counterparts in the West, especially in their demands for self actualisation.

The article goes on to compare something called 'Western culture' with 'Chinese culture' and 'Indian culture', as idealized constructs based on the works of Kant and Konfutse, and on the classical Vedic texts, Caraka Samhita and Susruta Samhita (ibid.). This textual analysis drives the authors to the conclusion that, 'In applying biomedical ethical principles to the actual medical situations in Asia, cultural elements must be considered.

To give a concrete example, the rule of informed consent must not refer to the patient alone. The patient's family should also be consulted before a definite action is taken' (ibid.:53).

It is tempting, not least from an anthropological perspective, to simply dismiss this type of reasoning as an expression of an essentialist and static concept of culture in favour of a dynamic idea of culture-in-the-making (Barth 1987) and culture as knowledge (Barth 1995). Obviously, the generalisation of fragments of classical philosophical discussions written down many hundreds of years ago to something called 'Asian culture' can hardly be justified neither in time nor space. Still, there is enough evidence to suggest that, say, Indian and US American perceptions on personhood are different, even if the kind of essentialist thinking that is characteristic for the Asian values discourse can be refuted. However, the anthropological rethinking of the culture concept forms a useful platform for dissolving the usually futile conflict between universalist and relativist positions in the areas of human rights and bioethics. A central critique of radical cultural relativism in ethics has been that it legitimises any practice that may be explained in terms of culture, be it pharaonic female circumcision – retermed as female genital mutilation in refutation of the relativist perspective – or infanticide in South Asia, or murder of women suspected of witchcraft in Eastern Africa, or rationing of healthcare based on skin colour in South Africa during apartheid, to list some examples mentioned by Kleinman. Yet, culture only works as legitimisation if seen as timeless, space-bound essence. Kleinman dismisses the radical cultural relativism as unacceptable and suggests instead what he calls a constrained and engaged relativism:

The (...) argument is for elicitation of and engagement with alternative ethical formulations, a constrained and engaged relativism; it is for affirmation of differences, not automatic authorization of any standard of practice as ethically acceptable because it is held by some people, somewhere (Kleinman 1995: 63).

Our discussion below of family and patient autonomy in an Indian context may be seen as a contribution to this type of engaged relativism. We wish to explore what family autonomy may mean for the treatment of patients, particularly in terms of access.

Family autonomy in clinical practice

What follows is based on an interview study among physicians at the All India Institute of Medical Sciences (known as AIIMS) in New Delhi. AIIMS is the largest and most advanced public hospital in India, with a total of more than 1,500 beds, more than 95,000 admissions and more

than 1.7 million outpatient consultations in 1998. AIIMS is a tertiary, high-tech urban university hospital with all the facilities that modern technology offers. At the same time, it is a hospital which has long queues in front of the outpatient department every morning, and to which it is extremely difficult to get access as a patient from the street.

The purpose of the study, which was sponsored by the World Health Organisation (SEARO), was to explore perceptions of and stories about ethical dilemmas from a medical perspective, and based on the clinical experience of the participating physicians, in six countries in South and Southeast Asia. The present articles focus on part of the material from the Delhi sub-study. Here, 20 physicians were interviewed three times each on cases and clinical experience that had afterwards 'troubled them in their hearts', as it was coined by the interviewers. This turned out to be an extraordinarily fruitful way to initiate interviews that might otherwise have been perceived as evaluations of their ethical standards. Focus was on stories told, not on their truth-value. However, one should keep in mind that the stories told by the physicians were in general not flattering for themselves. There is no issue of presenting a 'nice picture' of the self in most of the interviews. The doctors seemed to feel a genuine need to share troubling experiences and situations where they might not have taken the right decision according to their own standards. The analysis attempts to look at physicians' thoughts on issues of patient autonomy and the role of the family in this particular 'Asian', i.e. Indian, context. In the sixty interviews, the physicians discuss 145 cases in connection with perceived and felt ethical dilemmas, and 26 have been identified for the present discussion based on the explicit role of family involvement in treatment decision-making. These 26 cases were narrated by 11 of the interviewed doctors, of which four were women, in 28 interviews. The 11 physicians represented a wide range of medical specialisations. All had at least 5 years of professional experience, and seven had more than 15 years' experience.

What follows is a narrative analysis of these 26 cases, inspired by the building on the approaches of Good and Mattingly, respectively, and their adoption of the work of Ricoeur in medical anthropology. Directly inspired by Good's analysis of seizure disorders in Turkey, six configurations of narrations of family autonomy were differentiated from the cases: 1) Doctor-relatives alliance; 2) Family autonomy; 3) Family pressure on physician; 4) Family pressure on patient; 5) Patient-relatives alliance; and 6) Patient autonomy respected. We shall discuss these one by one in what follows. Of particular interest for the discussion is the configuration of decision-making among the physician, the patient and the relatives, and its importance for the patient's access to treatment.

Physician-relatives alliance

Physician-relatives alliance refers to a situation where there is general agreement between physician and family about the treatment plan, but where the patient has not been informed about diagnosis and prognosis, and in some cases also not about treatment options. All six cases of this sort concern serious illness – 5 cases of cancer and one case of TB with possible fatal outcome. One case is a 70+ year-old woman who had vulvar dysplasia. There was a suspicion of malignancy so a biopsy was done that showed a carcinoma. The woman had already been operated once for the same problem and did not want to have another surgery, as she did not have any symptoms. She had not been informed of the diagnosis:

The patient was absolutely not willing; we had a tough time, husband, her daughter, then myself. We continued counselling her so it was a tough decision for the patient to accept that she needs a second surgery and at the same time we did not want to tell her that you have a cancer. And I still convinced her that you must get operated, so that was the problem.

Obviously, this narrative construction positions the patient as an ‘opponent’ to the narrating physician. The patient does not accept an operation, about which she has not been informed of the rationale. The physician is the story’s ‘hero’, who intends to save her without having to inform her of an ‘unpleasant’ diagnosis, and the physician’s allies are the informed family members, who also participate in the process of not allowing the patient to refuse the treatment, she has not been informed of. One could call this procedure ‘uninformed discontent’.

In another case, the role of the family in decision-making on treatment was even more pronounced. Before we look at it, we wish to stress that it is not inherently wrong that families are involved in these decisions; some would probably argue that involvement of relatives is particularly appropriate in connection with elderly patients. However, these cases are examples of physicians being troubled with the way things were done, and we have no information of the patient being seen as otherwise incompetent in decision-making. In this case,

There was an elderly man, a 75 year-old male, who had a malignant [brain] tumor [...]. Now the dilemma was whether to operate on him or just give him symptomatic treatment. Because I had explained to the family that even if we operate on him and then give him chemotherapy and radio therapy post operatively, then most likely his life span would not extend beyond one or one and a half years, even after full treatment. And on the other hand, if we leave him without surgery and subject him to supportive therapy then he may survive for about 6-9 months. [...] I gave the prognosis to the family and left the final decision to them whether they would like to go in for surgery, because he was not a very good surgical candidate.

To inform the relatives but not the patient of a severe cancer diagnosis is not particular to 'Asian' countries. As part of the same research project, a questionnaire study was carried out where 415 physicians in eight research centres across South and Southeast Asia were asked, whether they would inform the patient of the diagnosis in a case of colon cancer. Responses showed considerable variation, from a low of 31% in a rural district of Bangladesh stating that they would inform the patient, to a high of 92% at the Christian Medical College in Vellore, South India. These findings suggest a greater willingness to inform of a cancer diagnosis than was shown in a similar study among gastro-enterologists in Europe. Here, countries like Spain (8%), Greece (12,5%) and France (30%) were all lower than rural Bangladesh. Except in Denmark and Sweden, most physicians everywhere would inform a spouse of a cancer diagnosis. On that issue, there was little variation among the Asian centres in the study – from 90% to 98% would inform the spouse.

Information is important because it is a precondition for patient autonomy. It seems little justified, then, to speak of a special 'Asian' practice in this regard. Perhaps, what seems to be at stake everywhere is that physicians tend to feel it as a burden to give a poor prognosis to a patient, and many or most physicians find it sensible to involve the relatives in this situation.

What also seems to be at stake is a well-known tendency that families play a vital part in hospital treatment not only in Asian countries, but in most settings where hospital facilities do not necessarily work to cover the basic needs of the patient, unless one pays for extras.

Family autonomy

In the second narrative configuration, 'family autonomy', the family rejects a type of treatment even if the patient accepts it, and even if the treatment is otherwise seen to be medically well-advised. Here, we have grouped very different case scenarios. In one case, no family members agree to donate blood for the patient's surgery. In another case, the family decides to replace biomedical treatment with alternative treatment but returns the patient one year later, according to the physician, in a much worse condition. In one case, a wife objects to intensive care for her husband, because her sister had previously died while in intensive care. In yet another case, a man of 35 years is in for an amputation of his leg following a traffic accident, but the family objects and activates their political connections, who make the concerned physicians understand that they are not to proceed with the surgery. When gangrene developed during the ensuing days, the leg was eventually amputated.

The concept of patient autonomy in bioethics implies respect for the patient's decision to reject treatment (REF) B&C. It follows that the concept of family autonomy implies respect for the family's decision to reject treatment, irrespective of the patient's interests and wishes (REF). From the interviews, it is not always clear what the patient's perspective actually was (in part because patients were not interviewed). For example, we cannot determine whether or not the person to have his leg amputated was conscious or not during the decisive moments, which obviously is important. But as a whole, the material shows that the family plays a very important part, more often than not as a necessary actor in the entire treatment process during admission. But families are also very active in the creation of situations which are seen as ethically problematic by the physicians, precisely because there is no necessary overlap of patient and family interests.

Family pressure on the physician

The stories under this heading are about families who do not accept the physician's message that no treatment is available. Often, the stories point to economical rather than medical reasons for not treating. A recurrent theme involves the judgement of the physician that both patient and family are incapable of autonomous decision-making: The family cannot, according to the physician, understand that they should not invest their money in a treatment, when this decision could have unwarranted long-term financial and social consequences. In the following example, the parents of a 7 year old boy with sub-acute sclerosis and encephalitis insisted that the boy be treated with Interferon, a drug costing around USD 200 per injection:

They took the first course and went back home and found that the child has shown some improvement, which is ah ... what ... I feel is quite subjective. Objectively when we re-assessed the child we could not find very significant improvement apart from slight improvement in the frequency of convulsions. Now ah ... they have come back for the second course. Despite the fact that they had sold some of their land. And they are still willing to sell some more of their property to take care of the child. And when we tried to explain to them that look we are not sure how much we will be able to help the child, they are still insisting, that they would like to give treatment to the child even if they have to sell half of their property. They are ready to do that.

The basic issue here is not uncommon, neither in India, Europe or other places: The family members invest their hopes in a treatment that the physician does not deem relevant to pursue; but the non-medical aspects of the story are about poverty and autonomy. The physician hesitates to treat, not because treatment is contra-indicated, but because the family in her mind is not capable of rational decision-making. She sees the family's line of action

as socially invalidating and therefore harmful. She stresses the financial argument in her narrative through a projection of an unwanted future, which also includes gender aspects:

Eventually we know that he is not going to survive. So apart from this, the social structure is like that, that [since] he [is] a boy, probably they are taking more care. Probably this patient, [if she] was a girl, they might have left this child and said no. This will definitely affect the family specially if [in the future] there is another sibling, who is normal. The care of that baby is neglected. Then [...] the attention of the whole family is on one child.

This type of problem was very common in the interviews, but it rarely reached the level of conflict seen in the above example, simply because physicians often chose not to inform patients of treatment options if, in the physician's view, the family would not be able to afford it or be able to protect their own long-term economical interests. Along these lines, the physician in the current case had second thoughts concerning her information of this treatment option:

Now this creates a problem with many of our patients because first, even if there is some [...] treatment there but the outcome is not going to be good ... To tell a patient who is economically not strong, [...] about the treatment, the availability of treatment ... [...] should we do that or not? And at times there have been instances where the patient is so poor that if the cure, ah ... treatment is available, and we know that the outcome is not going to be good ... At times you have to resort to a decision, which is probably not ethical. [...] This kind of problem arises every day not only for neurodegenerative disorders but [...] for other disorders, too.

A consequence of this problem is that physicians often see poor patients and their families as a group who do not and should not get the same level of information on treatment options, therapeutic efficacy and side effects as other patients and families who are perceived to be able to pay. From the physician's perspective, it may be an issue of protecting poor patients and their families from unnecessary worries and feelings of guilt related to not being able to provide the necessary resources. From the family perspective, they are deprived of the autonomy to decide over the use of their own resources, including the possibility as in the above case to sell off land to be able to afford treatment of a family member, even if the efficacy of the treatment may be in doubt.

Family pressure on the patient

At times, the family puts pressure on the patient to accept a treatment that he or she does not readily accept by his or her own standards. In the five cases identified of this narrative configuration, it is striking that all patients

under pressure are women, and in all cases the pressure is somehow connected to reproductive issues, either directly – like in the case where abortion is not carried out even though going through pregnancy involves considerable danger for the woman – or indirectly – like in the case where treatment is dictated by the woman's chances to get married, as perceived by her parents. In this latter example, family autonomy has fatal consequences for a 20 year-old woman with a liver disease causing portal hypertension:

This is a person who lived about 1,200 kms from here. [...] The father was very keen that the daughter should have the operation done, so that he would get her married off. We were in two minds because there is a doubt whether this would help her out or not help her out. [...] Unfortunately, the daughter was not keen. She was being pressed hard because the father wanted the operation. But she did agree ultimately. On a balance we said 'OK, she is so far off from Delhi. [...] She is going to bleed massively and have a massive vomiting and if she bleeds massively at any point in time she won't reach a hospital'. She was [...] the only child of the family and the parents were quite poor [...]. We went ahead and operated her and she did quite well from the surgical procedure but died a year later of a surgery-related complication. I for one did feel very bad about having played God in a sense and letting the father sort of dictate terms to the daughter who was not very keen on this. In fact, she was very reluctant to the procedure [un]till [after] 2 or 3 repeated visits in the OPD. The father finally convinced her.

Later in the interview, it turns out that what at first was provided as a medical justification – the risk of severe bleeding far from a qualified healthcare facility – is subsequently modified:

She could just have gone regularly for [other treatment options, which] required regular follow up. So obviously, when she would have got married off, the father would have had to tell the husband that look she requires this. She would have required 6-7 sittings over a period of 6-7 months. So these would have gone through before her marriage. But by the time she would have actually got married off, she would have had to have a yearly visit for a repeat endoscopy to check whether she required any further sittings. [...] There was obviously a question of problems associated to a large spleen and repeated bleeds during her pregnancy, but those could have been handled if she came and stayed in Delhi for the last three months of her pregnancy. They would have been handled here.

According to the physician, the father had been worried that it would not have been possible for him to get his daughter married if she would have to return yearly for follow-up checks at the hospital, possible problems during pregnancy and risk of severe bleeding. If the father would not inform of these health problems during wedding negotiations, there was a considerable risk that the woman, once married, would subsequently be thrown out of her husband's household, once the problems surfaced. The father, it

seems, saw the operation, which his daughter did not want, as the solution to his problems with her marriage – presumably also linked to issues of dowry – and he forced the issue.

Patient-relatives alliance

Only in one case of direct relevance to our discussion, patient and relatives agreed on a decision, and, quite atypically, it is not an issue of deciding on a kind of treatment offered, but, on the contrary, to insist on a particular kind of treatment, namely an induced abortion. Abortion is legal in India, and hence it is one of the few exceptions to the rule established earlier, that patients cannot insist on a particular kind of treatment. The female physician, who felt she was placed in an ethical dilemma, also treated for infertility, and some of her patients cannot become pregnant as a consequence of having previously had an abortion. In the particular case, the woman was 22 years old and the couple agreed that the woman should also have the opportunity to pursue her career rather than have a child at that stage. In the end, the abortion was carried out after pressure from a united couple.

Patient autonomy respected

Lastly, in one case, patient autonomy was respected. The patient successfully refused a particular treatment in spite of agreement between relatives and physician that it should be carried out. A 75 year-old man had been admitted with a broken elbow that needed surgery and was offered to have an operation for his hernia problem.

He was ready for the surgery for the elbow but not ready for the other surgery. [...] It did involve some discussion with patient, with his son, with his family members and then ... we followed the patients will. He wanted operation only for the elbow.

Q: So it was a difficult case for you?

A: Not surgically. This problem it did take some time, it did involve some discussion because the ... naturally the family members wanted that while he is in the hospital, and is undergoing surgery for one reason, he might get treated for the other problem as well. But the patient did not want it and then again some responsibility does rest with treating doctor because then he has to answer the relations (relatives) that exactly what is the correct (solution) from our point of view. What is medically correct? Should he also undergo surgery for the other problem or not? [...] You can't say that it is a surgical emergency and we have to say well, if the patient does not want treatment for a particular thing, we cannot force it.

*Q: So what was the prognosis of this patient, especially the second problem of hernia? He didn't want this (surgery)?

A: Well theoretically speaking it can create problem any day, but since there was no emergency at that point of time, the surgeon also did not think it necessary to force the patient to undergo an operation for that if presently it was not giving him any problem. This fact was explained to the patient and relatives and everything, and the patient was very insistent.

He refused because he did not have any symptoms from his hernia. While the physician mentions this case as an ethical dilemma, he did not think it was a major such – perhaps because, as an orthopaedist, he was able to solve the medical problem under his direct area of responsibility. The main ‘problem’ in this case of patient autonomy respected, from the physician’s point of view, is that it took time. In a clinical situation where the staff in general and the physicians in particular are working under great time pressure, it seems to be exceptional to allot the necessary time to discuss the nature of the treatment and negotiate the differences of opinion among patient, relatives and physicians.

In the above schematic illustration of the narrative configurations, we have retained the titles of the different plot types, focusing here on the position of patient and relatives in relation to treatment decision-making out-

The six plot types compared

Plot type	Narrative configuration				
Physician-relatives alliance	Family is informed ≡	Family gives consent ≡			Treatment is given or not given
Family autonomy	Family is informed ≡	Family does not consent ≡	Patient is informed ≡	Patient gives consent ≡	Treatment is not given
			----- OR is not informed ≡		
Family pressure on physician	Family is informed, but no treatment is available ≡	Family insist on treatment ≡	Patient is informed ≡	Patient gives agrees with family OR not ≡	Treatment is not given
			----- OR is not informed ≡		
Family pressure on patient	Family is informed ≡	Family gives consent ≡	Patient is informed ≡	Patient does not consent ≡	Treatment is given
Patient-relatives alliance	Family is informed ≡	Family does not consent ≡	Patient is informed ≡	Patient does not consent ≡	Treatment is not given
Patient autonomy respected	Patient is informed ≡	Patient does not consent ≡	Family is informed ≡	Family does not consent ≡	Treatment is not given

come. This is evidently a reduction of some important aspects of narrative analysis, including the desires involved in consenting or not for families, patients and physicians, and narrative time. The matrix is not intended to be a structuralist transformative model, but is a descriptive device intended to provide an overview of the identified plot structures in relation to the question of whether treatment is eventually given to the patient or not.

Based on the matrix, we would like to point out three important observations: 1) *In all cases, the families are informed of diagnosis and/or treatment options.* This means that the first element of informed consent, which is a precondition for decision autonomy and the 'receiver' side of health services, namely information, is generally given to *relatives*, not to patients. 2) *In no case where the relatives refuse to give consent to treat the patient is treatment carried out.* This observation indicates that family autonomy may be generally practiced irrespective of the patient's interests. Hence, as an ethical value guiding medical practice, family autonomy seems to hierarchically overrule the concerns for beneficence and non-maleficence. This is, essentially, why the physicians are 'troubled in their hearts' by these cases. In addition, this practice may also conflict with the principle of justice, since relatives may effectively establish an access barrier to treatment for the patient. 3) *In some cases, where the family consents while the patient refuses, treatment is carried out.* Again, a dilemmatic ethical conflict between family autonomy and the principles of beneficence and non-maleficence troubles the physicians, since these principles are normally mediated by respecting the patient's views on the potential risks and benefits of treatment offered. To treat a patient against his or her will is, of course, no little responsibility to take on, when that patient is not either a minor and considered too young for autonomous decision-making, or otherwise mentally incapacitated to such a degree that somebody else is legally authorised to take decisions on behalf of that person.

Let us at this stage return to the article by Tai and Lin. In their article, they mention a case where a cancer diagnosis with a fatal prognosis is communicated to the relatives but not to the patient, and they comment: 'From a Western individualistic perspective, this collective autonomy violates the principle of autonomy. Not so, however, from the Confucian [i.e., 'Asian'] point of view. Here, the head of the family, in consultation with other members, must decide what is best for the patient for filial piety's sake' (Tai and Lin 2001:52). As has been mentioned, terminal cancer is not a good example as a support for the argument of family autonomy based on 'Asian' values. There is tremendous variation among physicians within countries and in different geographically close countries, and physicians in Europe cannot be construed as a group that are less likely to involve the family, or

more likely to inform the patient of the diagnosis. But even if one would support the suggestion that the family plays a greater role in Asian contexts than would be found for example in Northern Europe – and what we have discussed in this paper could be seen to support this line of thinking – it is not clear what this means for actual treatment. Surely, the examples given in this article provide little reason to accept the harmonious and conflict-free physician-patient-family triangle that is promoted in the Asian values discourse as a Confucian or Vedic ideal and as a marker of the extraordinary generalisation of ‘Asian’ culture. The *descriptive* examples of family autonomy in practice given above suggest that there are real problems involved in replacing patient autonomy with a *normative* concept of family autonomy, as is sometimes presented in the bioethics literature, because family interests often may not coincide with patient interests, and because family decisions may block patient access to treatment, after other access barriers to hospitalisation have been surpassed. The narratives illustrate that family autonomy is not an unequivocal good, nor, perhaps, a necessary evil (as suggested by some of our cases in this article). Does the relatively larger role played by the family in decision-making in India and other poor and/or Asian countries at the descriptive level necessarily turn family autonomy into a useful normative principle for biomedical practice?

Conclusion

This article took as its point of departure the discourse of human rights and bioethics in Asia, which establishes the family as the central unit of autonomous rationality. We went on to suggest a necessary distinction for the discussion of health as a human right between (the right of) access to treatment and (the right of) autonomy to refuse treatment and attempted to set up the normative Asian values discourse for a kind of descriptive narrative test to see what the implications of family autonomy are according to the involved physicians. Perhaps paradoxically, the distinction collapses between justice and rationality – conceptualised here as a distinction between access to treatment and patient autonomy to refuse it – when the principle of family autonomy is introduced. Access to proper healthcare may be hard to get for most people in developing countries, Asian or not. But the principle of family autonomy establishes yet another potential barrier to treatment. As we saw, in no cases were patients allowed to get a treatment they wanted, and which the physician could offer, unless the family gave their consent.

The Asian values discourse is ideologically tied to an outdated notion of culture as essence, tied to place and determining action. In contrast, the

practice of bioethics is constructed by knowledge, that is negotiated and exchanged, and power positions that are created and maintained. In the triangle of physician, patient and relative, the patient is usually the weakest, whereas the dynamic power structure between the other two actors is intensely negotiated to determine the course of action. In this process, the role of the family remains important. But the importance of the family, then, is not linked to a dubious principle of family autonomy as normatively 'good' (or 'bad'). The family remains factually important, because it more often than not has to find the resources to pay for medicine and medical investigations, and because the patient is dependent on family support before, during and after treatment. Rather than transform this into a discursive principle of family autonomy with reference to an idealised cultural framework, we note that patient autonomy seems not to be optional not because East is East and West is West, but rather because poverty in the families and relative lack of resources at the institutional level of the healthcare system increase both the number of ethical dilemmas facing the physicians and the patient's degree of dependency on his or her social network during illness periods, to such a degree that, more often than not, it would simply be meaningless not to involve the family in decisions concerning the treatment. While we believe that the intrinsically Western notion and promotion of the individual as the centre of decision-making, which is the basis for the concept of patient autonomy, is not necessarily universally meaningful, possible or desirable, and that grounded explorations are required to guide a bioethics discourse that is often naïvely ethnocentric, we also suggest that the straightforward acceptance of family autonomy as a normative bioethical principle may be repressive, dangerous and against the interests of the patient.

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