A rejoinder to ‘Concepts of health, ethics, and communication in shared decision making’ by Lauris Kaldjian

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Lauris Kaldjian has long reflected and taught on healthcare, addressing what it can and cannot achieve and how it can best be pursued. His efforts over the past decade to make explicit his moral reasoning in a public space have been creative and most helpful for those interested in medical professionalism. In his recent article in Communication & Medicine (Kaldjian 2017), he has brought the topic of shared decision making within the scope of his pen.

The particular achievement of this article is to relate communication in specific healthcare encounters to wider considerations about the goals of care. Kaldjian makes clear that any proposed medical intervention must be – and is in fact – located within a narrative and therefore within a context that relates to the concept of human flourishing. This active placing of case-bound specifics within a broad conceptual framework shows practitioners how decisions about a case are related to the beliefs and values of those involved: patient, practitioner and family. If patients or families disagree with the healthcare professionals about what should be done, the discussion can seek to account for these differences in perspective in terms of the contrasting conceptual frameworks of the various parties. This allows any differences in perspective to be discussed within a framework of mutual respect and, to at least some extent, be explained.

The asymmetry in the doctor–patient relationship is important – indeed, it is inevitable – and is not to be condemned. Patients seek medical care precisely because of the knowledge, skill, and experience of the practitioner that they lack: we cannot regard this as A Bad Thing. The framework developed by Kaldjian helps us to be constructively explicit about these differences in perspective and to reflect jointly upon why any differences have become manifest. A practitioner can give the patient information, which is often regarded as something ‘neutral’, although there are occasions where it may be intended as advice, as in the context of HIV (Silverman 1997: 154–181). If such information is also received as advice, it may lead to a change in action. If an important treatment decision is to be made, then the practitioner may make a clear recommendation or even seek to persuade the patient to act in a certain way. Within the context of genetic counselling, for example, the often non-directive stance may change to a frank recommendation within a ‘shared decision’ model of the consultation, where genetic testing has clear implications for the management of disease risk (Elwyn et al. 2000). These steps progressively ramp up the force of what is being said but the practitioner and the patient may not agree. In such cases, we can say that the decision being made is ‘unshared’.

A practitioner will wish to act in the best interests of the patient. The professional’s view of this will often coincide with the patient’s views of his/her own best interests, so the practitioner’s
beneficence and the patient’s autonomy will map comfortably onto each other. However, where there is a mismatch, it can be discussed in terms of the goals of care and even human flourishing. Relating these different conceptual levels to each other gives us a vocabulary with which to explore and discuss such differences, which will – one hopes most fervently – help to avoid the experience of patients or families feeling that they have not been listened to and engaged with respectfully.

At the very heart of medicine, and as presented by Kaldjian, is the integration of two modes of thought which have been contrasted with each other in many different ways. Kaldjian talks about the biostatistical and the wellbeing approaches. He relates these to the doctor’s twin tasks of understanding both the patient and their disease, and the contrast between attending to disease and attending to illness. Mishler (1984) would have framed the task as being to operate in both the world of medicine and the patient’s life-world. It is the physician’s task to integrate these two spheres of existence, the subjective and the objective, attending sensitively to the patient’s subjectivity in the light of an objective understanding of the patient’s biological (pathological) predicament.

Of course, many physicians fail to ride both tigers with complete success but at least they should be striving to achieve this balance. It is better for a physician to fail, having honestly tried, than to accept defeat in advance by narrowing the scope of understanding of a patient’s disease that s/he strives to achieve by fitting it, in Procrustean fashion, to a conceptually inadequate framework. Thus, while one can contest what counts as evidence, it is essential for physicians to operate within a sound evidence base and not to be lured away by the various appealing distractions of homeopathy, the medical traditions of ancient cultures or the various contemporary schools of complementary and alternative therapies that make a claim to take a holistic, integrated view of people but close their eyes to the complexity of biological reality. By pre-judging the type of solution to be applied, these approaches are not open to the ongoing search for progressively better understandings of disease and, where effective treatments can be devised, for progressively better therapies.

Kaldjian discusses the potential mismatches between practitioner and patient/family. When the parents of a preterm neonate demand that ‘everything possible’ be done, at the point where the professionals regard this as futile, they will have probably failed to appreciate the distinction between the biostatistical and wellbeing conceptions of health. Maintaining arterial oxygen and blood pressure as close to ‘normal’ as possible may achieve little for the infant except deferring the moment of death by a few days or weeks while possibly inflicting pain and distress. Engagement in a respectful discussion about the underlying meaning of health may be much more productive – much more likely to lead to an agreed resolution – than allowing a conflict to deepen, so that one party takes recourse to a court of law, seeking to have a decision imposed. Recourse to the law cannot always be avoided but it must be the very last resort because of the damage it can inflict on the different parties and on the relationships between them.

Conversely, physicians may be too enthusiastic to achieve a very precise diagnosis of the condition affecting their patient or to attempt an innovative (even experimental) treatment, while patients or family members may value attention to their illness ahead of a more detailed mechanistic understanding of the disease. The physicians may need to curb their enthusiasm if the process has become too burdensome for the sick individual, the time having arrived for all parties to accept palliation rather than persisting in a heroic but misplaced, doomed quest for a cure.

When the difference in perspective between patient and professional is not about medical investigation or treatment but about the transmission or generation of information – as it often may be in the context of genetic counselling – Kaldjian’s approach is also helpful, indicating an appropriate way past a disagreement about the correct course of action. If a parent asks me to test their young child for Huntington’s disease, for example, I may regard that as ethically inappropriate as this investigation should be chosen by the individual him/herself as a competent adult. The difference in perspective can be discussed and explained with respect, even if agreement is not reached. Likewise, I may wish to recommend that a patient or the parent of an affected child pass important information about their serious genetic disorder to other members of the family, if it may be relevant to them. Genetics
health professionals generally aim to promote their patients’ autonomy and to practise non-directively in relation to decisions about reproduction or predictive genetic testing. However, they will make clear recommendations about genetic testing if it is important in ensuring best medical care. They will also promote open communication about genetic conditions within the family and discourage the genetic testing of children where it is not important in ensuring access to necessary healthcare, because this approach to the management of genetic information respects the autonomy of the wider family. The affected individuals(s) may be reluctant to do this but discussion can help them understand what is at stake for their relatives if they do not pass on the information. The genetic counsellor’s stance may be regarded as directive at a communicative/informational level, and not at the level of medical intervention (Sarangi 2010).

Kaldjian has helped us all – patients and health professionals – by providing a vocabulary that integrates the different ways of looking at and evaluating the available and often contrasting conceptions of health, illness and disease as they arise in different contexts.

References

Elwyn, G., Gray, J. and Clarke, A. (2000) Shared decision making and non-directiveness in genetic counselling. *Journal of Medical Genetics* 37 (2): 135–138. [https://doi.org/10.1136/jmg.37.2.135](https://doi.org/10.1136/jmg.37.2.135)


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