

PATIENT AUTONOMY BETWEEN RIGHT AND DUTY

Patient health education programmes: a cost containment measure — way of controlling the demand.

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Background

Looking at the trends in health care expenditure as % of GDP there is a constant upward trend, conveying the message that the healthcare expenditures keeps raising dramatically (OECD Health Data, 1997). But we are deceived by the way of reporting: if we look at the annual rate of growth of health spending, since the 1990s, it is approximating zero! — Health spending is under tight control since the 1990s: the growth is halted in most EU countries because the governments had learned to control costs.

The 'new', now emphasised, cost containment measures in EU member states, for the (late) 1990s, were budget shifting, rationing and evidence-based purchasing decisions.

With budget shifting, the making of decisions has been decentralized: down to the particular individual: more pharmaceuticals switched to over-the-counter (OTC) status, reduction in number of people and/or diseases exempt from co-payment.

This led to the conscious realisation of everybody involved that all services cannot be funded, and that there is a need for choices. One of the solutions came with the introduction of benefits and exclusion from treatment of those who would not benefit. But! At the same time providing the service/drug for which a person is excluded for the reason of no benefit, if it (service/drug) is paid out of the pocket of that particular individual (negative lists both for drugs and service reimbursement).

Measures included regulation of supply (e. g. prices and volume for drugs), regulation of the proxy, (e. g. influencing the prescriber through information, negative and positive lists, guidelines, budgets, pharmacy schemes), as well as the regulation of the demand through patients, by the

means of cost-sharing, development of a market for OTC products and through health education programmes that encourage more personal responsibility and accountability.

Starting points

In defining healthcare there is a constant interplay between needs, demand and use of services. A need to medical care exists when an individual has a condition for which there is an effective and acceptable treatment: either prevention, care or cure. If the patient with a need decides to seek help, by his behaviour of requesting a service (that will be consumed, used, upon appropriate clinical judgement), the patient creates demand. Therefore, health education programmes for patients are being created, with the idea to modify patient behaviour, influencing the decision process that produces demands, with the main goal of reducing costs of health services.

Theoretical basis

Rights and duties are concepts from deontological theories of ethics. Rights (xrefer) are justified claims to the protection of persons' important interests and rights' objects benefits to the right-holder. Correlative with claim-rights are duties, of subjects to provide the good (benefit) to the right-holder.

Deontological theories claim that the actions are right or wrong *per se*. Moral worth of an action (Kant: The Moral Law, in Paton translation) done from duty (because of the duty) doesn't lie in the purpose of the action, but is determined by the principle of volition, and duty is the necessity to act out of reverence for the law. Translated to an individual: I ought never to act except in such a way that I can also will that my maxime (subjective principle of action) should become a universal law. This is what Kant calls the *categorical imperative*. Any action in accordance with the categorical imperative can be called *autonomous*: action done from duty to behave in this way. All actions done *because of* (some gain or anything else) are done heteronomously, following the hypothetical imperative.

Consequentialists claim that all actions are right or wrong in virtue of the value of their consequences (xrefer). Still, there are consequences that are more desirable and more valuable than others, leading us to the question of the most desirable consequences? Viewing the wider issue, and the individual in the context of the society: the most desirable consequences would be the greatest amount of the consequences altogether.

According to Rawls' *Theory of justice*, modern accounts of justice are based on ideas about human rationality. Rawls states two principles of justice (i) equal right for all to the equal basic liberties (e. g. basic services package); (ii) certain inequalities allowed if they contribute to the greatest benefit of the least advantaged (e. g. children/old people), chosen by autonomous judges behind a veil of ignorance (designed to deny them knowledge of their own position in a social system to which the principles will apply).

Autonomy of patients' decision process

Autonomy is considered to be the right to make decisions. It is crucial for any reform because it provides an instrument that enables response to incentives within the system. So, the first key element in regulating the demand through patients is to increase the degree of autonomy of the patients, making patients responsible for the allocation of resources.

To enable this to happen, the system has to prepare itself to take advantage of the greater autonomy of the patient, organise provision of information to the patient (through health education programmes) and transfer rights to the patient, and align the decision rights and external pressures so that those who make good/bad decisions face good/bad incentives.

But is autonomy in the usual sense of the word, autonomy at all?

According to Kant: no, it couldn't be called autonomy. The patient, when deciding on further actions regarding his health needs is not acting from duty, in accordance with the categorical imperative, but *because of* many things summarized in 'having a health need'.

So, instead of being autonomous and having a right to decide, the patient is acting in accordance of duty, heteronomously, following the hypothetical imperative and deciding whether to seek medical care to get a treatment he knows that exists and is effective for his health condition.

Following the consequentialists' approach, the decision the patient should make regarding the health need he has is not only to request one service / treatment for his condition, but to opt for the service that would provide the greatest amount of gain altogether.

If or applying the principles of justice, autonomous decision making behind the veil of ignorance is required, the patient is not in the position of deciding autonomously: he is well aware of his position: both, regarding his condition and regarding his position within the system. Also, he arrives with an infinite list of criteria for just distribution of the resources for the treatment of his condition.

My position

A colleague once stated that we cannot make rational decisions about ourselves, whether ill or not, and I couldn't agree more.

According to deontologists, there is no autonomy, in patients' decision making, the the idea of health needs complies with the consequentialists theory, still, they demand too much from the patient if asking him to think in the context of the society, and maximisation of gain. For Rawls, the decision making process relies on human rationality, questionable at the time of altered health condition. Furthermore, deciding about oneself, the patient no longer have the privilege of the 'veil of ignorance' a necessity for an autonomous, just decision.

To be able to claim that the patient's decision nevertheless is such, autonomous and just, the system is trying to replace the impossible request of ignorance with knowledge, offering information through health education programmes in exchange for more personal responsibility and accountability.

All knowledge the patient may have, or receive through health education programmes is still structured by his principles of understanding (Kant would say, the *a priori* categories) taking him even further away from a just and autonomous decision.

Therefore, for me, it is not acceptable to leave the decision to, not even — or especially not — to the well-informed and / or educated, patient.

Autonomy in voluntary active euthanasia

Voluntary active euthanasia (VAE) is a case in which a terminally ill person requests the termination of his or her life. The most common argument from the supporters of VAE is the argument of autonomy that obligates the society to respect the decisions of those who elect euthanasia.

Without the wish to start a pro and contra debate, I would only like to consider the permission given.

Presupposition of VAE: the person whose life is to be terminated has given his/her permission voluntarily.

Putting aside my personal belief that a person in a particular situation can not thing rationally to decide on matters concerning him/her, and especially not matters concerning him/her in that particular situation, my problem with the voluntarily given permission in VAE lies in:

How was the permission obtained?

When was the permission obtained?

Was it given in a specific case / time / situation?

These are the questions raised in search of the 'veil of ignorance', a requirement for a autonomous and just decision, here not applicable. The decision again cannot be made nor permission given by the patient: at least not at the time of imminent death threat, caused by the condition.

As much as I cannot agree with the autonomy *pro* argument, I also disagree with the 'slippery slope' *contra* argument, stating that justified practice will soon lead to unjustified.

For me the permission given voluntary can be a patient's wish (further raising the issue: what about people who are incapable of communicating their wishes?), but a health need raised to the level of health demand by the autonomous decision of the patient (here I do not want to raise the issue of cost containment regarding euthanasia)?

References

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