

Cancer Care, Money, and the Value of Life: Whose Justice? Which Rationality?

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ABSTRACT

Cost-containment in oncology is a moral issue. While economists use the word “rationing” to describe all limitations on resource utilization that result from human choice, the ordinary language distinction between allocation and rationing is morally meaningful and can help oncologists to determine their proper moral role in cost-containment. It is argued that oncologists should not be required to ration at the bedside, nor should they be given financial incentives to practice frugally, nor should they be subjected to a variety of bureaucratic mechanisms to control costs indirectly. In addition, it is argued that the fact that treatments have a price does not logically imply that patients have a price. Cost-effectiveness analysis is often suggested as a means of deciding how best to allocate resources, but some of its many ethical limitations are discussed. The alternative is an open, public, participatory process about how to ration care, abandoning the formulaic pretenses of cost-effectiveness analysis, but with a commitment to reason, good will, and common sense. Oncologists would then be free to advocate for their patients within the constraints imposed by this public process.

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INTRODUCTION

The father of modern economics, Adam Smith, held the chair of moral philosophy at the University of Glasgow (Glasgow, United Kingdom). I note this because while many people contrast economics with ethics, the fields are intimately linked. Decisions to distribute resources will always be moral decisions, informed (at least implicitly) by concepts of justice. An overriding question, from the perspective of the clinician, is how to reconcile two seemingly contradictory moral premises.¹ (1) Human life is priceless, and to think otherwise is to detract from the dignity of the patient. (2) All resources are finite and society must decide how best to distribute health care resources.

A CASE

To illustrate, consider a hypothetical case. Mrs Jones, a 48-year-old mother of two and president of the local teacher's union, has metastatic breast cancer that is refractory to standard treatment. Last year, it was reported that patients whose cancers are positive for the *AGR* mutation may respond to fungceptin, a new anti-*AGR* factor purified from a mushroom that grows in northern Sri Lanka. The

AGR mutation is rare, but Mrs Jones' tumor carries it. Treatment with fungceptin conferred, on average, a 4-month survival advantage over salvage chemotherapy. That period would be long enough for Mrs Jones to see her oldest child graduate from high school. Unfortunately, the Tamil Tiger insurgency in northern Sri Lanka makes it very difficult to obtain the mushroom, and there is no synthetic form. Myco-Logics Pharmaceutical Corporation has obtained a limited supply, but is charging \$250,000 for a single course. Should Mrs Jones receive this treatment? Should anyone receive the treatment? Who should decide? Using what criteria?

SOME DEFINITIONS

Many of those writing about the ethics of health care financing conflate the words “allocation” and “rationing.”² Quantitatively oriented 21st century economists regard all decisions not to use potentially beneficial interventions as rationing, heedless of the circumstances or motives. This does not mean, however, that the ordinary language distinction between allocation and rationing carries no clinical or moral weight. Traditionally, acts permitted under the conditions of scarcity that characterize the correct use of the word rationing would be considered immoral under the con-

ditions that constitute allocation. It therefore seems morally wise to maintain the distinction.

Allocation refers in a general way to all decisions to apportion resources. The word simply suggests that “someone in authority has determined how the quantity is to be divided among the group he represents or controls.”²³ One may allocate a surplus, bonus, regular, or scarce supply. Allocation decisions in health care are decisions to apportion health care resources within a community. The National Institutes of Health budget is an allocation. The number of flu vaccine doses ordered by one’s group practice is an allocation. Deciding how to apportion the winnings from a jointly purchased lottery ticket is an allocation.

Rationing refers to a very particular type of allocation decision. The word rationing carries a sense of restriction due to scarcity and a justification for that restriction based on appeal to the common good. In the *Oxford English Dictionary*, one important sense of the noun ration means, “an allowance, share, portion, of provisions or other supplies; especially an officially limited allowance for civilians in time of war or shortage.” ‘Ration’ is “specifically used for a method of sharing or distributing some scarce commodity when demand exceeds supply. It usually (but not necessarily) suggests a method of distribution based on need.”²³ I therefore define health care rationing as a decision: (1) to withhold, withdraw, or fail to recommend an intervention; (2) informed by a judgment that the intervention has common sense value to the patient; (3) made with the belief that the limitation of health care resources is acute and seriously threatens some members of the economic community; and (4) motivated by a plan of thereby promoting the health care delivery needs of unidentified others in the economic community to which the patient belongs.

Deciding that Mrs Jones should not receive fungiceptin because there isn’t enough money to go around and that the resources ought to be spent instead on cancer prevention is a rationing decision.

Justice, in the narrow sense that concerns us here, refers to the fair distribution of resources. Allocation decisions can be made justly or unjustly, and rationing decisions can be made justly or unjustly. Among the questions to be asked when judging whether a scheme of allocation or rationing is just are (1) who decides? and (2) using what criteria?

WHO DECIDES?

Many health care policy analysts and ethicists have argued that because of its complexity, the only point in the system at which one could effectively ration health care would be through the individual practitioner.⁴ Rationing by broad policy is held indiscriminate—the equivalent of clear-cutting. Bedside decisions could be tailored to precise situations—the equivalent of pruning.⁵ Some advocates appeal to practitioners’ sense of the common good as a motive for bedside rationing, arguing that physicians must learn to balance the needs of society and of the individual patient at the bedside.⁶ Although physicians may feel uncomfortable with this responsibility, proponents argue that physicians should be brave enough to take on this further responsibility as part of their civic and medical duties.⁷

Reasoning that physicians would be unlikely to be motivated to ration resources by appealing to their sense of the common good,

managed care organizations designed systems of incentives to induce physicians to be frugal at the bedside.⁸⁻¹⁰ These incentive programs include capitation, withholds, economic profiling, and bureaucratic barriers such as preauthorizations, formulary restrictions, and retrospective denials.

WHY BEDSIDE RATIONING IS WRONG

Bedside rationing by physicians has been extensively criticized.^{11,12} I have argued that bedside rationing is morally unjustified for two main reasons.¹³ First, it violates Aristotle’s formal principle of justice, that similars should be treated similarly, because similarly situated patients would necessarily be treated dissimilarly if rationing were left to the whims of individual practitioners. One oncologist might judge the costs of fungiceptin to be too high. Another might judge 4 months of increased survival to be too little. A third might judge the gain to be worth the cost. Given such arbitrariness, it would seem unjust that Mrs Jones’ treatment could be rationed by one doctor and not by another. Second, it would seem empirically difficult in an “open” system of health care financing (such as that in the United States) to demonstrate that saving money by not treating a given patient would benefit any other patient. The money would more likely be converted into additional corporate profit or squandered on an unproven intervention. Thus, the moral justification for bedside rationing seems based on an empirically flawed premise.

FINANCIAL INCENTIVES TO PHYSICIANS

Programs giving physicians financial incentives to practice frugally share all of the problems of asking physicians to engage in bedside rationing, but add additional moral problems.¹³ First, they disguise the decision maker, making it appear that the decision to withhold care is being made by the oncologist. In fact, the insurance payer has made that decision and is simply trying to manipulate the practitioner to carry it out. Second, appealing to the oncologist’s self-interest undermines the spirit of professionalism, which requires an altruistic motivation to be genuine. At its most pernicious, a system of financial incentives to withhold care creates a moral stress test for clinicians, requiring them to violate their self-interest in order to do their jobs and help their patients. Third, such financial incentives engender distrust. Patients are troubled if their physicians are paid to do less.¹⁴⁻¹⁶ For reasons such as these, capitation and withholds have largely disappeared as mechanisms for inducing physicians to change their allocation decisions, despite the great enthusiasm with which these programs were initially introduced.^{17,18}

MARKETS

Pure market-based approaches to making allocation decisions are a possible alternative, but pure markets in health care are intolerable to nearly everyone. There are libertarians who suggest that the good thing about markets is their flexibility and respect for freedom, so that if one has cancer and loses one’s insurance one can sell one’s kidney to pay for chemotherapy.¹⁹ Most persons, however, would consider such a

scenario a *reductio ad absurdum* refutation of any claim that an unregulated market in health care is just.

Today's market-based US health care insurance system often uses bureaucratic mechanisms for controlling costs—closed formularies, required preauthorizations, and retrospective denials. Though widely accepted, these mechanisms also raise moral questions. Consider how the required standard that must be met before altering clinical practices has changed. Physicians traditionally thought it morally wrong to change the standard of care without first proving that the proposed change was safe. Now insurers regularly change practice policy and then ask for proof that anyone has been hurt. This change has gone largely unnoticed. Yet it would seem morally preferable to prove safety and efficacy prior to policy changes, just as one does before the introduction of new antitumor regimens.

Consider, for example, the new uses of closed formularies. Are closed formularies actually best for patients? Formularies often now make within-class substitutions of one drug for another that the manufacturer has agreed to supply to the insurer or to the hospital at a lower price in exchange for exclusivity. However, clinicians cannot reasonably be expected to know everything there is to know about every drug on the market. Wise clinicians once averred that it was better for patients if their physicians knew two drugs within a class very well (in case patients might tolerate one better than the other), and perhaps have a third in reserve.²⁰ Such advice can no longer be followed, however. Instead, it is now better for physicians to know all drugs superficially. No one has studied the consequences of such changes for patients. Thus, if Mrs Jones becomes neutropenic and septic after fungiceptin treatment, her oncologist might be forced to treat her with an antibiotic he or she has never prescribed before. Complicating matters, since formulary-approved drugs are often changed annually on the basis of price, patients are often switched from one chronic medication to another. It may take a long time after each switch to adjust the dose of these medications. The profile of interactions between these new drugs and the oncologic agents that the patient requires might change. If the moral goal of medicine is to do what is best for patients within the bounds of reason and necessity, letting private entrepreneurs introduce untested policy changes seems unwise.

Another market mechanism to try to control health care costs is through the introduction of cost-sharing by patients. It is argued that health care financing is subject to the inaptly named phenomenon of moral hazard: when care is underwritten by third-party payers, patients are insulated from the true costs of care and therefore behave in a manner that is economically irrational—their demand for health care goods and services increases disproportionately.²¹ To mitigate this moral hazard, many insurers are now increasing deductibles and copays, subjecting patients, at least in part, to the true costs of care. To the extent that this practice helps to control health care inflation and reduce overly exuberant demand for marginally beneficial treatments, this seems like a reasonable thing to do. However, concerns about justice arise. The poor and lower-middle classes simply may not be able to afford to share these costs, and therefore health care will be distributed according to ability to pay rather than based on need or expected benefit, and many would consider such an arrangement unjust. One might argue that as long as the cost-sharing were set low enough so that all patients who needed a drug such as fungiceptin

could afford it, the justice issue would be solved. However, lowering the burden of cost-sharing enough to make it just and fair might also make that cost-sharing arrangement ineffective as a remedy for moral hazard, raising questions about whether it is empirically possible to be just as well as effective in a cost-sharing arrangement.

GOVERNMENT

The alternative approach to controlling health care costs is through government intervention. This approach has its own drawbacks. Making allocation decisions through governmental processes makes the affair political and therefore susceptible to phenomena such as interest-group lobbying, which might lead to unjust patterns of distribution. Nonetheless, even without direct across-the-board government involvement in US health care, interest groups already exert enormous influence. One might argue that their influence would be greater in a government-rationing scheme, but not that this influence would be avoided by “keeping government out it.”

Health care allocation by government might also be slow and perhaps inefficient. Governmental approaches would necessarily rely on broad policies (“clear-cutting”) rather than bedside decisions tailored to specific circumstances (“pruning”). Yet, some inefficiency might be the price that must be paid in exchange for a more just system. Even so, it is not certain that governmental decision making would be any more inefficient than the current system. Government has no monopoly on bureaucracy—private insurers often use bureaucratic barriers as a means of controlling costs. And the costs of private insurance bureaucracy can be quite high. Under Canada's system of national health insurance, 17% of the costs of health care are administrative. The US figure is 31%.²²

HOW SHOULD ONE DECIDE?

The question of whether there is any way to reconcile the premise that each patient is priceless with the premise that allocation (or even rationing) decisions are a necessary part of health care, however, is not resolved by deciding on one of these cost-control schemes.

PRICING LIFE?

Many commentators have argued that it is simply a pious aphorism to say that human beings are priceless.²³ Everything, from an economic perspective, has a price—a maximum amount of money and effort one will expend in order to obtain or preserve it. From this perspective, it is an admirable sentiment to suggest that the dignity of patients is a value that is beyond price, but such a sentiment is literally false. Therefore, in a world of finite resources, the best way to distribute health care is to ask how much we are willing to pay to preserve a life, and then allocate resources accordingly. This procedure should be practiced whether one is a practicing oncologist rationing fungiceptin at the bedside, an insurer making coverage decisions, or a government official deciding which new treatments to fund. One cannot avoid “pricing life.”

This argument appears convincing, tough minded, and even scientific. It is an old argument in philosophy. But it rests on a logical mistake.

Thomas Hobbes once wrote that “The value or worth of a man is, as of all other things, his price; that is to say, so much as would be given for the use of his power. . . . The public worth of a man, which is the value set on him by the Commonwealth, is that which men commonly call dignity.”²⁴

The competing view is that of Immanuel Kant, who wrote, “Whatever has reference to general human inclinations and needs has a market price; . . . but that which constitutes the condition under which alone something can be an end in itself, has not merely a relative worth, ie, a price, but an intrinsic worth, ie, dignity. . . . Hence morality and humanity, insofar as it is capable of morality, alone have dignity.”²⁵

Does the fact that there is a limit to how much one is willing or able to pay to preserve a human life logically imply that humanity has a market value rather than a priceless dignity? The answer is no.

The fact that treatments have prices does not mean that people have prices. There is no logically necessary connection between the absolute value of an entity and the price one is willing to pay to maintain or repair it. This is not true merely with respect to human beings and the practice of medicine. One may justifiably claim that Giotto’s fresco on the ceiling of the Basilica of San Francesco in Assisi was a priceless work of art, yet still declare that the efforts and costs involved in restoring it by gathering the millions of pieces into which it was smashed by the 1997 earthquake are more than one could humanly be asked to pay. Likewise, the fact that one remunerates a rabbi for officiating at a wedding does not mean that this is the price of God’s blessing. Only the most crass sort of economic reductionism would support such claims. As the philosopher Bernard Williams once put it, we still think it immoral to say, “Every man has his price.”²⁶

The humanity of our patients is priceless. Their value is what we call their intrinsic dignity.²⁷ Respect for that dignity is the foundation for all efforts to reach out to help the sick. It is the foundation on which we assign patients rights. This value, the dignity of the patient, is not reducible to dollars and cents. Logically, concern for quality of life depends upon recognizing the dignity of life. The intrinsic dignity of the patient, which is the value the patient has simply because he or she is human, is the condition for the possibility of making judgments of quality of life. It is not part of any calculus. It is neither a benefit nor a burden. It is not a QALY (quality-adjusted life-year).

The dignity of the patient commands respect, and respect requires, at the very least, justice. Knowing that all patients have this intrinsic worth that we call dignity, a worth that calls forth the professional skills of oncologists, but realizing that the resources are finite, by what criteria should such resources be allocated in a just system of health care?

COST-EFFECTIVENESS ANALYSIS

Some would argue that this should be done by cost-effectiveness analysis (CEA), especially when it is adjusted for quality of life.²⁸ But CEA is not a morally neutral way to make allocation decisions. It is not rationality itself. Rather, it represents a particular view about the rational that prizes efficiency over fidelity and outcome over process. It assumes one can commensurate everything that human beings value

in monetary terms. As MacIntyre states, CEA has the argumentative form of utilitarianism.²⁹ Thus, every ethical argument that can be mounted against utilitarianism can be mounted against a plan to distribute health care resources by CEA.

One set of problems with CEA is that its prescriptions are often at odds with our sense of justice. CEA prescribes the decision that maximizes the average outcome, but is indifferent to the distribution of that outcome. So, presuming equal cost, if 150 patients would live 1 day longer with the money saved by withholding fungiceptin from Mrs Jones, a drug which would be expected to extend her life by 120 days, CEA would prescribe that Mrs Jones should not receive the fungiceptin. But is this just? Is it fair? Is it really rational?

Skepticism about the ethics of CEA does not entail skepticism about the usefulness of engaging in formal decision analysis for individual patients, the value of outcomes, or the value of efficiency. A critic of CEA might very well believe that consequences count, but hold that other things in addition to the net cost-effectiveness ratio ought to be considered to determine the right and just decision. In formal ethical language, one says that nonconsequentialism is not anticonsequentialism.³⁰ For instance, one might use formal decision analysis to help decide whether fungiceptin or some other drug would be best for Mrs Jones. Although one might criticize the expenditure of resources for either drug as unjust, the process of using decision analysis in support of such an individual clinical decision involves no other patients and could not be critiqued as unjust per se. Critics of CEA could also support better outcome studies and research to refine more specific subpopulations (for instance, through pharmacogenomics), while still arguing against CEA as a mechanism for distributing health care resources. Such research might help to tailor specific interventions to specific populations and this might have the happy effect of improving the quality of health care while reducing the cost of health care. However, since the motive is more or less purely the improvement of care for individual patients, such endeavors are not truly CEA.

As Rawls has remarked, “utilitarianism does not take seriously the distinction between persons.”³¹ By always averaging across a population, CEA does not take seriously the fact that one patient may have a higher pain threshold than another or a greater tendency to be depressed. Patient preferences and the uniqueness of each patient yield to the community average.³² Even improvements in quality-of-life measurements would not circumvent this problem, because it is always the average quality of life that is considered in CEA. Nor does selecting a hard outcome, such as “number cured per dollar,” circumvent this problem, because one does not know ahead of time which patients will be cured; and by so structuring the question, one has already superimposed a moral preference for cure over average increased life expectancy that might not be shared by all patients. For these and other reasons, at best, CEA is a highly controversial way to distribute health care resources.

VITALISM OR COMMON SENSE?

At the other extreme, does saying that life is priceless imply that one should never limit any treatments for any reasons? From this vitalistic view, any oncologic treatment that confers any effectiveness, no matter how costly or marginally beneficial, must be given to patients and

COMMON SENSE ALLOCATION DECISIONS

underwritten by third-party payers. One might think this a “straw man” argument, but such thinking is not far removed from clinical reality. Seventy-eight percent of oncologists in a recent survey endorsed the notion that all patients should have access to all effective care regardless of the cost.³³

This refusal to acknowledge limits springs from multiple sources. Some of it is undoubtedly due to oncologists’ own troubles facing death and the finite nature of their craft. Some of it is due to cultural forces in a consumer society in which it has been observed that Americans have come to regard death as one more option—one that most patients would rather not exercise.³⁴ But some of it, I would argue, has been the wholesale abandonment of common sense reasoning in medicine.

One used to hear it said often that a particular study result was “statistically significant but clinically unimportant.”³⁵ Such a common sense judgment is rarely heard today. Researchers, their funders, advocacy groups, universities, and for-profit producers of devices and drugs all have a huge stake in touting the success of their research. These (usually unarticulated) self-interested motives blend almost imperceptibly into expressed beliefs in the incremental nature of medical progress and into population-based arguments that small differences (if the condition is sufficiently common) lead to large net gains in public health. Thus nearly every statistically significant improvement, no matter how small, has come to be hailed as a breakthrough. Cardiologists, for instance, regularly laud the results of studies that demonstrate 1% absolute differences in outcome, despite enormous costs, as “breakthroughs.”³⁶⁻³⁸

In classical epistemological terms, science deals with universals. By contrast, common sense (classically, “art”) deals with individuals. Science relates the data to each other: data to data. Common sense relates the data to us.³⁹ Science is knowing the universe. Common sense is using one’s knowledge of the universe to help decide what to do. The fields of public health and health policy both deal with populations—they are scientific in this sense. But precisely for this reason, health policy decisions often seem to make little sense in the care of individual patients.⁴⁰ Net benefit to the population may not be visible at the bedside.

Clinical medicine is a common sense enterprise. One is concerned, in the practice of medicine, not with universals, but with individuals. In the common sense of clinical practice, we relate the data to our patients. As Aristotle once wisely put it, “The doctor does not treat ‘man’ except accidentally; he treats Callius or Socrates or someone else described in this way, who is accidentally ‘man.’ So, if someone has grasped the principles of a subject without having any experience, and thus knows the universal without knowing the individuals who are contained in it, he will often fail in his treatment; for it is the individual who has to be treated.”⁴¹

So, while a 25% reduction in relative mortality in a study with 10,000 individuals in each arm might be highly statistically significant and a true scientific finding (relating the data to each other), if this reflects an absolute mortality change from 1.0% to 0.75%, common sense (relating the data to us; observing from the perspective of the individual patient), suggests that this is not a real difference. From the perspective of common sense, if a study requires 10,000 case subjects to prove its scientific superiority over standard care, that finding is almost guaranteed to be statistically significant but clinically unimportant.

Between utilitarianism and vitalism, is there an alternative way to distribute health care resources justly? Common sense suggests that there is. A common sense approach to resource allocation would argue that when extremely expensive treatments are developed that are statistically superior to their alternatives, but the advantages are clinically unimportant when relating the data to the patient, these treatments can be withheld at the bedside. By my definition, this would not be rationing and ought to be viewed, in principle, as a morally permissible decision that a clinician could make unilaterally without disregarding the priceless dignity of the patient. Nonetheless, one should not underestimate the effort that will be involved to restore a universally shared appreciation for common sense among patients and practitioners.

Treatments that do confer a common sense advantage, however, ought never to be withheld at the bedside. Neither should they be allocated by financial incentives to oncologists, by erecting bureaucratic barriers to their use, or on the basis of ability to pay a market price. Contrary to vitalism, there may be serious reasons why concern for the common good requires that some potentially medically effective interventions be withheld. But common sense also suggests that such decisions ought not to be made by cost-effectiveness analysis.

Ethically acceptable common sense rationing would require the following: (1) the financial exigency that requires rationing must be convincingly demonstrated. It is not immoral for a nation to spend more on health care than on defense, for example, unless the need for defense clearly represents the greater need in a given situation. (2) There should be a large pool of persons included in the rationing scheme (eg, a very large insurance plan, a state, or a nation). (3) There should be a reflexivity condition, such that those who make the rationing decision must themselves be subject to it. Common sense says that rationing for the common good will never be just if one group is deciding to withhold treatment from another group for the “common” good. (4) An open, public, participatory process should be used to decide what will be withheld. Clinicians would be important participants, providing expertise and experience. But patients, payers, the disabled, employers, policy makers, and others will all have important contributions to make. (5) The process should be iterative and revisable. (6) Allocations for science should be sharply distinguished from those for clinical care. Scientific progress need not be lost in a system of health care rationing, but not every incremental, statistically significant, but clinically unimportant result needs to be transformed instantaneously into the standard of clinical care. (7) Morally acceptable material criteria by which to make just allocation decisions must include outcomes, but ought not to be determined solely by outcomes. Material considerations in a just system will include the effectiveness of treatments, their costs, the needs of patients, special consideration for those historically disadvantaged within the system (such as the disabled and certain racial minorities), the availability of effective alternative therapies, and many others. No one should dream of thinking, however, that these considerations can be commensurated into a common currency such as dollars, utiles, or QALYs. Justice is hard to achieve, and no algorithm or equation is sufficient to the task. (8) When in doubt about whether an

intervention should be judged statistically significant but clinically unimportant (which might be always, unless common sense can be restored to medical practice), it should be subjected to the review process. (9) Common sense suggests that it is easier to ration diagnostic interventions than to ration therapeutic interventions, because it is much harder to refrain from offering treatment to people who know they are sick than it is to refrain from telling people how sick they are.

CONCLUSIONS

Cancer care costs money. Deciding how resources should be distributed to treat cancer is always a moral act. In the example, fungiceptin would cost \$750,000 per life-year gained while millions of US citizens go without health insurance. Surely a case could be made to ration fungiceptin. The only question would be how to do so rationally and fairly.

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Individual oncologists should not make rationing decisions at the bedside, nor should they be manipulated by financial incentives. Society has too much at stake in the maintenance of trust between practitioners and patients. Neither market forces nor bureaucratic barriers seem capable of attaining a just distribution of resources. Society can only maintain respect for the priceless dignity of each individual patient, while acknowledging that resources are limited if health care rationing decisions are made through open, public, participatory processes that free oncologists to act as advocates for their patients within the limits set by these processes. If the rationing of oncologic care is necessary (and many would argue that it is), then this sort of process must be engaged. Although not easy, only this form of rationality could bring about a just and fair result.⁴²

AUTHOR'S DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author indicated no potential conflicts of interest.

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