Bioethicists and priority of health resources in the Brazilian public health system

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Abstract

The aim was to know and to analyze the criteria raised by bioethicists about setting priorities for the Brazilian health system in view of resources shortage. A qualitative exploratory study through semi-structured interviews with 21 bioethics college professors, directors and former directors of the Sociedade Brasileira de Bioética (Brazilian Society of Bioethics) and regional administrations, in the period of July 2007 – February 2009. The major part of the discourses noted the importance of limiting resources in a shortage situation and was opposed to the use of resources toward actions that fit into the *medicine of desire* concept. In addition, they show a conflicting positioning, sometimes equity-oriented, prioritizing the most unprotected individuals, and sometimes oriented by the maximization of benefits. The conclusion shows the existence of a moral pluralism that makes it difficult to decide about what would be a fair health system, making necessary an exhausting dialogue in order to achieve possible consensus.

Key words: Health policies. Bioethics. Health system.

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The universalist systems, funded in needs caring, undergo through intense changes due, mainly to costs pressure, resulting from several factors, among which aging of populations, unabated increment of costly technologies, and epidemiological changes with arise of new pathologies and aggravation of health.

Bioethics has been guiding its reflection, since 1990s, toward the topic of justice, particularly distributive justice. One understands that there is agreement among several ethics currents that fair distribution of goods, obligations, and duties must be done, there is evidence of the diversity in interpretation involving the principles of equality, equity, freedom, and efficacy – which in concrete situations may come to conform into opposing alternatives[1].

This work departed from the premise that it is competence of bioethics, targeted to health sector daily problems, to reflect on values that must preside guidance fair decision-making about priorities of health needs to be met and, by chance, limits to be set in cases of shortage of resources. Therefore, we elected to know and analyze criteria collected by bioethicists on setting priorities for the Brazilian health system in face of shortage of resources.

Methodological path

It is a qualitative research, with exploratory feature, with analytical-descriptive guidance. The choice for qualitative approach is due to potentiality of understanding cultural values. 21 semi-structured interviews were undertaken, in the period of July 2007 and February 2009, with university bioethics professors, working in public or private schools in the field of Health Sciences from different regions of the country. Interviews, carried out by researcher himself, were recorded in magnetic means and, later, integrally transcribe. Responses from three interviewees were gotten in writing after submission of form, via internet, due to personal difficulty in setting up an interview.

The following open questions were made to all interviewees**:** knowing that there are not resources to contemplate all health needs: i) which should be prioritize? ii) Should or must some of health needs be left without been met? which ones? iii) do you understand that there should be limiting of resources to any social group, age group, or any pathology or health aggravation?

A convenience sample was built comprised by directors and former directors of the Brazilian Bioethics Society (SBB), and some of its regional administrations (period of 2005-2008) – Rio de Janeiro, Pernambuco, and Sao Paulo –, all with scientific work in bioethics logged in the CNPq Curriculum. SBB, established in 1995, currently congregates the larger portion of Brazilian bioethicists, and it aims at gathering people from different training at university level, interested in fomenting discussion and dissemination of Bioethics. There was diversification in categories of involved professionals from the realm of Medicine, Dentistry, Nursing, Anthropology, and Theology.

It was sought, in interviewees' discourses, to reach central ideas describing feelings that were present in their speech, and to present similar or complementary meaning. Some key expressions will be presented in the text for each of the central ideas found, consisting in *literal transcriptions of part of declaration that allow rescuing of the essential discursive content of segments diving the declaration*[2].

According to CNS/MS 196/96 Resolution guidelines and standards, which regulates ethics in research involving human beings in Brazil, and it was demanded from each of the research subjects the free and clarified consent to participate in the study by

signing a free and clarified consent term (TCLE). Initially, interviewees were informed by email on the character of the research, its objective, and procedures to be observed, and the possibility of refusal. Anonymity and confidentiality of data were ensured, as results are presented without any possibility of nominal identification. Interviewees were numerated sequentially (E1, E2... E21).

Results

Some of the central ideas were prevalent in collected discourses, and they are presented next.

It is difficult to prioritize/limit scarce resource in health

Some of bioethicists' discourses show difficulty to set criteria that prioritize resources in the health system.
(E4, E6, E9, E12): "*This will be a discussion that we are going to face; and not all, but many in our generation, who discuss bioethics, have great difficulty in discussing this*" (E.6).

It is valid to limit resources

Nevertheless, despite difficulty, it was justified the moral validity in making choices in which personal limitations occur (E5, E6, E17, E21):
"*I understand that this is inevitable. I believe that, in some way, discussion on limiting attendance, obtaining medication, products or services, in some way, with any type of social basis will be unavoidable*" (E.6).

It is suggested some criteria to limit resources

It was found manifestations specifying procedures that should be excluded, among others, invoking the medicine of desire and high cost procedure (E18, E19, E 20, E 21): "*Medicine of desire should be out*" (E.19); "*What can be set aside are the assisted reproduction techniques. I believe that the health system cannot invest in a so expensive technique in prejudice to a vaccination campaign*" (E.20).

One should not limit health care in reason of age or specific social groups

The majority of interviewees' manifestations was unfavorable to rationing health care based in criteria related to age or social groups (E1, E5, E8, E10, E11, E16, E21): "*In any way. To leave aside indigenous and elders groups is inadmissible. There are not resources to all, but there must be technical and ehtical criteria, and under ethical stand point, any group should be set aside*" (E.21).

One should prioritize the most destitute

Discourses favorable to scarce resources been prioritized to people considered as destitute were recorded. This consideration fundamentally happened because of unfavorable social and economic positions and those considered

as exclusive users of the Single Health System (SUS) (E8, E18, E20, E21):

> *"Actually, the State is not able to provide the right to health to all citizens. Nevertheless, it is possible to offer more equitable access, offering more to who needs it more"* (E.18);

> *"I believe that if you are user of the public health system, solely and exclusively, perhaps you should have a bonus in the outlining of resource, and if you were user of a private system, consequently you would have money to bear with some cost, you could be passed over, roughly speaking"* (E.20).

One should maximize benefits

Manifestations guided for maximization of benefits and beneficiaries were found as well (E2, E5, E7, E12, E13, E21):

> *"I advocate a utilitarian decision, that is, the decision to where resource goes it the one that should benefit the larger number of people for the longest period, bringing the best consequences. The decision, priority should be giving through epidemiological data; quantitative"* (E.21).

> *"I have an opinion that may be very polemic. In some situation that benefit just one person, however, involving large sums of money; unfortunately, this person will have to seek a solution for herself"* (E.7).

Should one limit resources through victims' culpability?

The issue of making victims culpable, in decisions on scarcity of resource, was mentioned also in two currents – positive and negative (E7, E14): "*What matters, finally, she decides to have her non-healthy habit, and perhaps she should have to pay na over tee, because she will cost more to the health system*..." (E.14);

> *"Am I not going to benefit who has liver cirrhosis because he is guilty for his disease, or am I not going to benefit those who have lung cancer because he smoked? I don't think so! We have to analyze it with prudence, in order to things be reasonable, but one may not exclude anyone in this issue"* (E.7).

Discussion

Despite majority of discourses have pointed to validity of setting priorities and that one should limit resources in scarcity situation, some of the manifestations showed to there is major difficulty in such task. To decide between right and wrong, between fair and unfair, causes anguish, that is, decision of ethical nature lead to anguish situations for moral agents due to uncertainty of validity of choices. That is why many prefer that others decide in their place, giving up on making autonomous decision [3].

The sanitary reality does not make feasible the option not to decide, as we have resources for health care, even if they are insufficient for all necessities

or for everybody, carrying a moral obligation to make them available, even if decision results in ethical conflicts. This is the case of the recent pandemic (H1N1) regarding which the Brazilian sanitary authority had the difficult task to decide who should have priority in getting vaccines and medication, when one knew that everyone could receive them [4].

It was found, in analyzed discourses, opposition to use of resources targeted to action that fall into denomination of medicine of desire (esthetical surgeries, and assisted reproduction procedures). These were pointed as possible excluding ones in the supply of health care, understood that the objective is to reach results of more psychological than physical nature, and this option should not be considered in the same way to other needed activities for treatment of diseases or other health aggravations.

The results showed also that interviewees assume standings, sometimes guided by equity, understood as protection of the destitute, sometimes for maximization of benefits, following the ethical principle of public usefulness[5,6]. This was observed as well in previous studies carried out in different contexts [7,8].

The stands funded in equity accept that it would be fair that the democratic State guided resources distribution benefiting those more unfavorable in society, the poorer ones, the most vulnerable, those without conditions to afford attendance of their health needs via liberal market models.

It is fit to remember that the *disfavoring* concept may be evaluated through several points of view, such as gender, age, conditions of health aggravation, pathology, eminence or danger of death, or physical or mental disability, and not only social and economic reasons, what, sometimes, makes difficult to implement equity concept. One should stress that in our universalist health system, restriction of procedure or scarce care for people who have alternatives to SUS, that is, they are associated to institutions designed as complementary health, of private nature, would collide in the necessity of changing governing legal norms.

In parallel, differing from equity notion, one finds the utilitarian thought that call us to reflect that resources should be guided to satisfy collective or individual needs, maximizing beneficial results to those involved direct or indirectly in the action. Discourses conform with Boitte statement [9], who understand that maximization of benefits from scarce resources has as merit to provide greater efficiency in resources allocation, but it may cause risk of negative discrimination of people who have lesser probability of contributing to higher health level of collectivity – as pointed by one of the discourse found in the research.

It was evidenced, still, that interviewees stand unfavorably that age may serve as criteria to ration resources, except for one single discourse pointing as limiting criteria receiving high cost procedures.

The fact of accepting age as one of the factors to set limits for resources seems to mean the understanding that there is a natural limit to human life morally validated; arguable position to be accepted if one takes into consideration the deep changes in age structure of population occurred in the 20th Century. We understand to be different the argumentation that, in certain circumstances, age may be taken as objective criterion in resources distribution. This would be the case when one evaluates that very old people would not have clinical condition to withstand certain medical or surgical procedure, that is, there would not be clinical efficacy.

Finally, some declarations consider the issue of existence of life styles considered as non-healthy as criteria to set limits on use of certain scarce procedures in a process called as *victim's culpability*, as Berlinguer [10] warned already in 1996. Bioethical literature has presented positioning, like that of Lemos [11], who advocate the thesis of validity of an intermediary moral responsibility in order to avoid loss of scarce resources, quoting a liver transplant undertaken in an alcoholic individual should have the obligation for the individual to keep himself abstemious, that is a smoker who by receiving a new lung should be accountable for avoiding tobacco. Nevertheless, it fit Schramm's [12] warning that remind us that more than protection to vulnerable ones, victim's culpability derives from economic and financial reasons and from liberal ideologies, leading that health care be moved from the right to be ensured by the State toward individual duty.

Final considerations

It is fit to highlight that this is a qualitative research, with convenience sample, which does not intend to be representative of the entire Brazilian bioethics, but through its exploratory feature, it intended to present trends that present among main national bioethicists linked to several well-known university institutions. These researchers and professor, who have the possibility to influence, direct or indirectly, health institutions and policies, also work as opinion makers through practice of teaching in graduate courses *lato and stricto sensu* nin the field of Bioethics.

Research outcomes evidence that pluralism of values among interviewed bioethicist is shown in the issue of priority or setting limits for use of scarce resources in the public health system. From the diversity of perspectives and opinions one may infer that difficulties of contemporary world in morally deciding about the issue seem to be marked characteristic of our times. They show, as well, that even among bioethicists, who reflect and discuss value and moralities in their daily work, an exhausting dialogue is necessary between all stakeholders to achieve possible consensus.

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Resumen

Bioeticistas y la priorización de los recursos de salud en el sistema público de salud brasileño

El objetivo fue conocer y analizar los criterios utilizados por bioeticistas sobre el establecimiento de prioridades para el sistema de salud brasileño en virtud de la escasez de recursos. Es un estudio exploratorio cualitativo, realizado de Julio de 2007 a Febrero de 2009, mediante entrevistas semi-estructuradas con 21 profesores universitarios de bioética, directores y ex-directores de la *Sociedade Brasileira de Bioétic*a (Sociedad Brasileña de Bioética) y sus directorios regionales. La mayor parte de los discursos apunta la validez de limitar recursos ante la escasez y son contrarios a la utilización de recursos para acciones que se enmarcan en la denominada *medicina de deseo*. También demuestran posiciones ora orientadas por la equidad, priorizando a los más desfavorecidos, ora orientadas por la maximización de los beneficios. Se concluye que existe un pluralismo moral que acarrea dificultades para decidir qué sería un sistema de salud justo. Así es necesario un exhaustivo dialogo para llegar a consensos posibles.

Palavras-clave: Políticas de salud. Bioética. Sistemas de salud.

Resumo

Bioeticistas y la priorización de los recursos de salud en el sistema público de salud brasileño

Estudo exploratório qualitativo objetivou conhecer e analisar critérios levantados por bioeticistas sobre o estabelecimento de prioridades para o sistema de saúde brasileiro em face da escassez de recursos. Os dados foram obtidos no período de julho de 2007 a fevereiro de 2009 mediante entrevistas semiestruturadas com 21 professores universitários de bioética, diretores e ex-diretores da Sociedade Brasileira de Bioética (SBB) e de suas diretorias regionais. A maior parte dos discursos apontou a validade de se limitar recursos em situação de escassez e contrariedade à utilização dos recursos voltados para ações que se enquadram na denominação de *medicina de desejo*. Também demonstram posicionamentos, ora orientados pela equidade, priorizando os mais desfavorecidos, ora orientados pela maximização dos benefícios. Conclui-se nesta análise parcial pela existência de um pluralismo moral que traz dificuldades para decidir-se sobre o que seria um sistema de saúde justo, do que se pode depreender ser necessário exaustivo diálogo para se chegar aos consensos possíveis.

Palavras-chave: Políticas de saúde. Bioética. Sistema de saúde
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