

## ORGAN ALLOCATION FOR TRANSPLANTATION: RELATIONS BETWEEN EQUITY CONCEPTS AND ETHICAL PRINCIPLES

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### ABSTRACT

Democratic and liberal societies must consider justice and equity in their distributions, chiefly in a context of social and economic inequality. Principles of distributive justice are stressed to their limits in life and death situations such as organ allocation for transplantation. This article addresses theoretical aspects of the equity and health equity concepts and tries to relate them to ethical principles used to guide the selection of allocation criteria. In order to identify desirable structural elements of a fair allocation system, the following were analyzed: John Rawls' theory of justice as fairness, the health equity concept developed by Amartya Sen and ethical principles mentioned by Nikola Biller-Andorno and Roberto Andorno. It is suggested that the interaction between the equity concept and a set of ethical principles (equal opportunity, efficient distribution and compassion) need to be considered in the selection of transparent and consistent criteria for organ allocation.

Key-words: health - equity - organs - transplantation  
ethical principles

### RESUMO

Sociedades democráticas e liberais devem considerar a justiça e a equidade em suas distribuições, principalmente num contexto de desigualdade social e econômica. Decisões associadas à vida ou à morte, como a alocação de órgãos para transplante, representam situações-limite para princípios de justiça distributiva. O artigo aborda aspectos teóricos dos conceitos de equidade e de equidade em saúde e busca relacioná-los a princípios éticos utilizados para orientar a seleção de critérios para a distribuição de órgãos. Para identificar elementos estruturais desejáveis em um sistema justo de alocação de órgãos, são analisados: a teoria de justiça como equidade de John Rawls, o conceito de equidade em saúde desenvolvido por Amartya Sen e princípios éticos mencionados por Nikola Biller-Andorno e Roberto Andorno. É sugerido que a interação entre o conceito de equidade e um conjunto de princípios éticos (igual oportunidade, distribuição eficiente e compaixão) precisa ser considerada na seleção de critérios de alocação de órgãos que sejam transparentes e consistentes.

Palavras-chave: saúde - equidade - órgãos - transplante  
princípios éticos

### Introduction

Allocating organs for transplantation is frequently associated to scarcity, representing extreme situations for the application of distributive justice and equity related concepts. Those are critical decisions, since their consequences may determine the difference between life and death (KOCH, 2002).

Organ scarcity is a phenomenon common to many countries and is associated to growing transplantation waiting lines (WORLD HEALTH ORGANIZATION, 2007a).

According to the Organ Procurement and Transplantation Network - OPTN (2007a) there were 97,000 persons waiting for an organ in the USA in September of 2007 (75% were waiting for a kidney). In Brazil, according to the national transplantation program, there were 69,000 persons in the waiting line in 2006 and 49% were waiting for a kidney; 39% for a cornea and 10% for a liver (BRASIL, 2007).

The World Health Organization - WHO (2007a) has expressed concern about the called "transplant tourism", when persons

travel to poorer countries to get an organ transplantation. This institution has also indicated (WHO, 2007b) that the access to transplants are higher in Europe and North America than in countries of Latin America, Asia and, chiefly, Africa.

However, regional inequalities in access to organs were also detected in the most economically developed countries, mainly among citizens of most vulnerable social groups, such as: USA (OPTN, 2007b), Scotland (ONISCU et al., 2003), France (ROUDOT-THORAVAL et al., 2003), United Kingdom (RUDGE et al., 2003), Australia (CHAPMAN; GRAEME, 2003) and Spain (MIRANDA et al., 2003). The problem caused by organ scarcity has produced intense debate for more than 20 years (MELTZER, 2003).

Organ scarcity is a problem for transplant programs around the world. The growing number of chronic diseases, the technical development and the overall dependence of human donors increase the demand for organs.

Principles of distributive justice (including equity) and ethical principles are stressed to their limits in scarcity. Transplant programs are challenged to increase organ donation, but also to promote a fair and efficient allocation, since democratic and liberal societies must consider justice and equity in their distributions; chiefly in a context of social and economic inequality. The contributions of the theory of justice as fairness (John Rawls) and of Amartya Sen (about health equity) were applied in this study to the problem of organ allocation, considering also the integration with ethical principles.

The concept of equity is related to a notion of justice (as in Aristotle), which has experienced change over time. The equality of persons and consideration of their relative

situation are central aspects of equity. Sen recognized that demands for equality are plural and that many conceptions of justice are possible according to the demand emphasized. Rawls valued the equality of basic individual liberties and of primary goods, accepting social differences only if they were for the benefit of the most disadvantaged. Even though he did not consider health as an explicit primary good, he changed the perception of inequality through the association with liberties. Sen offered a new perspective since he highlighted the capacity of individuals to transform resources into results and effectively function in society. Sen's health equity concept is multidimensional and relates to total justice, not only to distribution of health services.

These theories, however, cannot be directly applied to organ allocation, since they were developed to explain the general functioning of a fair society. Ethical principles are needed, because specific cases may consider: equal opportunity, efficient distribution and compassion (as mentioned by Nikola Biller-Andorno e Roberto Andorno).

Transplant programs have integrated these principles in many different ways. From the standpoint of a Rawlsian societal fairness it is needed that, once selected by the free members of society, the principles must be expressed by transparent criteria and consistently applied by the institutions. According to Sen, it would also be necessary to pay attention to the real conditions to have access to available organs (for example: access to health care).

Some theoretical aspects of the equity and health equity concepts are discussed and then a discussion is presented about the relation of such concepts and

ethical principles applied to select organ allocation criteria.

### Equity and health equity concepts

Equity and health equity concepts have been largely used by organizations dealing with health policy, as observed in documents elaborated by WHO (2007c), World Bank (MUSGROVE, 1999) and Inter-American Development Bank (2004). However, conceptualize health equity is not an easy task. For example, the WHO's working program for 2006 to 2015 has indicated the need to approach social injustice and its effects on health and also to make the health equity concept clear, since it is a guiding principle for the institution's activities (WHO, 2006).

The word "equity" (from Greek, *epieikeia*) has been used since Antiquity, but its meaning has changed since then. In considerations about equity and justice, Aristotle (1979) considered equity better, since the equitable would be fairest, but not fair according to law, but as a corrective of the legal justice. In this context, one would recur to equity when the generality of the law were not applicable to particular cases. In the Bible, *epieikeia* was used to denote clement and merciful treatment.<sup>1</sup> The linkage of equity to a notion of justice may have inspired the creation of the English system of courts of equity and of courts of law. Courts of equity were created in England during the XIV century to correct injustices caused by the application of the common law (GILLEN, 2006). This kind of court existed in that country until 1873 and has influenced the judiciary system of English speaking countries (GILLEN, 2006).

Equity has been studied by economists, mainly with respect to the

distribution of the tax burden among citizens. At the beginning of the XX century, Edwin Seligman (1908) studied the theory and practice of progressive taxation. In this kind of analysis there are usual references to two types of equity: horizontal and vertical. Horizontal equity is the principle by which persons in similar circumstances should pay similar amount of taxes, while vertical equity indicates that persons in different circumstances should be treated differently, so that those with more economic capacity should pay more taxes (ELKINS, 2006). This economical reasoning was adapted for application in other areas, such as health policy. According to the glossary of the *European Observatory on Health Systems and Policies - EOHSP* (2006), equity is the principle of being fair to all, with reference of a well defined and recognized set of values. The same glossary presents a complementary definition which includes the concepts of horizontal and vertical equity.

Célia Almeida (ALMEIDA, 2002, p. 30) studied the equity concept, considering the contributions of Norberto Bobbio (2000, 2002), and she indicated that this concept is dependent of a historical course, linked to the idea of equality. Even though this relation cannot be denied, establishing a strict conceptual dependence between equality and equity may conceal some specific characteristics of the equity concept and make difficult to consider situations where absolute equality may be unfair, according to the social context.

Almeida (2002) suggested that the meaning of equity has varied throughout time and that is one of the reasons why it is so difficult to get a consensual definition. Currently, the State, as the provider and financier of the public welfare, understood equity as equality of opportunities of access to resources, according to needs (ALMEIDA,

2002). Almeida recognized the need to identify coherent and consistent principles of justice, including the political aspect which is associated to the “degree of inequality (and of conflict) that a society is willing (or can) endure” (ALMEIDA, 2002, p. 35).

Since principles of justice are fundamental to the equity and health equity concepts, the non consideration of these principles would reduce the discussion to a mere verification of inequalities. It is not the case that such verifications are irrelevant, but it must be clear that the detection of inequalities is one step that generally precedes the equity analysis. For example, the Black Report (1980) identified health inequalities in the United Kingdom (WHO, 2007c), offering elements for later discussions about health inequity.

Marcelo Medeiros and Debora Diniz (2007) analyzed paradigms of equality and equity, considering the application of principles of distributive justice in the practice of social policies. According to these authors, equality is based on the equal treatment of individuals and equity considers the inequalities among individuals to define allocations and determines that the objective of a public allocation is to revert unfair inequalities when they exist and to treat all equally when there is no inequality (MEDEIROS e DINIZ, 2007, p. 4). They related equality to the morality of rights and used as examples the foundations of the French and American Revolutions (MEDEIROS e DINIZ, 2007). The paradigm of equity was exemplified by John Rawls conception of distributive justice and by the rule proposed by Karl Marx: to each according to their needs and from each, according to their capacities (MEDEIROS e DINIZ, 2007, p. 4).

Studying the liberal thought, Silvia Porto (1995) identified three approaches to

social justice: the contractualism of Rousseau, the classical utilitarianism and the reflection done by Rawls in his Theory of Justice. The Rawlsian approach tried to identify universal principles in the values of justice common to democratic societies in their many contexts. Such approach used Kantian based principles of justice, which emphasized equity. That is why this approach was prioritized in this discussion.

Rawls' theory (1997, 2000, 2003) is based on moral obligations, rationally justified by principles that one should agree, if also in agreement with the premises. The fair moral procedures would be applied to societal institutions. Rawls deduced principles of justice considered acceptable by members of society at the moment they decided how the institutions - basic structure - should work in a liberal and democratic context. His theory follows the contractualism tradition, presupposing that the fair functioning of institutions will favor equity in the distribution of social resources.

The author enunciated two principles of justice, which interact with each other to promote justice as fairness. The first principle values the basic liberties, which should be equally accessible to all. Basic liberties are considered essential for the individuals to play their role in society and search their development by their own means. The second principle, hierarchically inferior to the first one, deals with economic inequality and with equality of opportunities. According to it, social and economical inequalities should satisfy two conditions: be associated with open positions available to all and be of greater benefit to the least privileged members of society (RAWLS, 1997; RAWLS, 2003).

Some societal resources, objects of the social contract, were called as primary

goods. They are related to things that each rational person presumably desires and include: rent and richness, basic liberties, freedom to move, choice of occupation, positions of responsibility and the social basis of self-respect (RAWLS, 2003). The allowance of inequalities which are in favor of the least privileged is called the “difference principle” (RAWLS, 1997), a mechanism to attenuate inequality. It is presumed that this theory accepts inequality as something natural and unavoidable and for this very reason it is needed to look for ways to improve the situation of the least privileged.

Rawls principles of justice are of great appeal to modern democratic societies, since they contribute to the debate of equitable distribution of collective resources independently of moral doctrines, allowing the integration of persons with varied ideologies about how society should be constructed. Besides that, they approach economic inequality, a structural characteristic of capitalist societies, which requires mechanisms for improvement of the situation of the least privileged. Rawls considered that both principles were not related to moral perceptions of well and purpose, rejecting association of his theory with the classic utilitarianism; which was considered by him as a teleological theory, related to an end: the majority’s well being (RAWLS, 1997).

The works of Rawls and of his critics have contributed to the debate about justice and equity (NOZIK, 1991; SANDEL, 1984; DWORKIN, 2005; KYMLICKA, 2006; SEN, 1995). Robert Nozik (1991) defended a distributive principle of justice based on the fair right to possession, historically established. This right would be justified by the principles of acquisition and of property transfer and also, if needed, by the correction principle. The last one should be used to correct injustices

in the application of the others principles. Nozik expressed that Rawls’ theory is incapable to produce this kind of conception since it focalizes on final result of distributions and don’t considers the historical process (NOZIK, 1991).

Michael Sandel (1984), from a Hegelian communitarian standpoint, which values ethical systems, a substantive notion of “well” and, consequently, societal values system, directed strong criticism towards Rawls’ principles of justice, which try to avoid moral values in considering what is fair. According to Sandel (1984), Rawls’ conception of individual morality is utilitarian and his criticism of utilitarianism is limited to the application of his maximization principle on collectivities.

Ronald Dworkin (2005) agreed with Rawls on the need of fair functioning of institutions to favor an equitable distribution of resources. However, he indicated that equality of resources is more objective than of well being, allowing for comparison among standards of resources distribution. His abstract model of an imaginary auction values individuals freedom of choice, but differently from Rawls’ difference principle it introduces individual responsibility for the consequences of choices and allows for compensation of natural inequalities, through corrections at the initial stage of distribution of resources (DWORKIN, 2005). Dworkin conceived an egalitarian auction in which the State is the auctioneer and everyone is conscious about her (his) situation in society and tries to satisfy their needs and preferences with the available resources. The auction would end when nobody would desire the resources distributed to others. There would be a situation of initial equality, which would allow the individuals to live according to their will, whether developing potentialities,

whether dedicating to extravagant desires; but assuming responsibility for their destinies.

Will Kymlicka (2006) considered that Rawls' theory was one of the first alternatives to utilitarianism and that his first principle of justice is consensual, since the notion that political and civil rights should receive priority is largely shared in our society (KYMLICKA, 2006, p. 68). However, he criticized the fact that the difference principle tries to compensate for social inequalities (through primary goods), but do not offer the same treatment in the case of natural talents inequalities (e.g.: physical disabilities). In that sense, it would be an insufficient reaction to the problem of undeserved inequalities (KYMLICKA, 2006). He also stressed that the difference principle do not distinguishes between chosen and not chosen inequalities, leaving individual responsibility out of consideration. In this case this principle would be an excessive reaction to undeserved inequalities (KYMLICKA, 2006).

Among the critics of Rawls, but still sharing liberal and democratic views, Amartya Sen stands out. Even though he recognized the relevance of the Theory of Justice and presented no objection to the first principle of justice, he criticized the difference principle in the context of the discussion about equality (SEN, 1995). Sen called our attention to the theoretical need to specify the equality space which is object of a particular discussion, since each theory related to equality approaches a specific space in which it is considered essential. Libertarians value equality of rights and utilitarians, equality of individual utilities (SEN, 1995). Rawls theory values equality of basic liberties and of distribution of primary goods and Dworkin values equality of resources (SEN, 1995). Other theories may

value equality of rights, satisfaction of needs, of rent, etc.

An example of demand for equality of rights is observed in the approach adopted by Vera Telles (2001). While trying to identify the causes of inequalities in Brazil, she presented arguments related to social justice. Telles values the conflict as an element which "qualifies justice as a guarantee of an equity that unequal situations always jeopardize" (TELLES, 2001, p. 30). The question of justice and the dispute about the measure of what is fair or unfair represent a field of conflicts, where claims for rights are processed through possible negotiations (TELLES, 2001, p. 30). According to Potyara Pereira (2000), a basic right is deserved to all and is supposed to fulfill "basic needs". This right is inalienable, unnegotiable and unconditional and those who don't have access to them, due to failures of the social system, should be compensated by society (PEREIRA, 2000, p. 35). This view opposes that based on social distribution of only "minimal needs" (PEREIRA, 2000, p.34).

Sen pointed out that equality in one space may walk with inequality in another (for example, equality of libertarian principles may be accompanied by rent inequality); this way, some theories may justify inequality through equality (SEN, 1995). Sen recognized that Rawls has transformed the way we think about inequality. Before him, results had greater emphasis and after, opportunities and freedoms were also considered (SEN, 1995). Nevertheless, Sen stressed that the difference principle focus on the distribution of primary goods emphasizes more the means to achieve freedom than the freedom itself. Even though persons may have similar resources (primary goods), some would have more freedom than others to achieve their life goals (SEN, 1995).

As a solution, he proposed an evaluation of inequality based on achievements and freedoms. This way, individuals would be evaluated not by the primary goods they own, but by their capacity to function in society and, consequently, to achieve well being. Such capacity would derive from a set of *functionings* (situations of existence and desired activities which are constitutive of the well being) that a person had the effective freedom to choose and fulfill his (her) life plan (SEN, 1995). According to Sen, *functionings* may vary since elementary situations, like being well nourished or free from an avoidable disease or from premature death, until complex achievements like self-respect, happiness and participation on community life (SEN, 1995). In this perspective the measurement of resources or of primary goods would be an imperfect indicator to evaluate the freedom which one really has to do this or to be that, since it only tells about means to achieve freedom (SEN, 1995). Sen indicated that we need to advance by considering capacities, through the evaluation of effective freedoms. This allows for consideration of interpersonal variation in abilities to transform primary goods into capacities to search for our goals (SEN, 1995).

As observed by Álvaro de Vita (1999), Sen used normative and ideological structures of Rawls' theory to build a conception of distributive justice, without having the scope of a theory of justice (VITA, 1999).<sup>2</sup> However, Sen established a minimal level of resources to be distributed among members of society: the one enough to promote the capacity to function. This kind of concern is typical of the substantive nature of his contributions (SEN, 1995).

The more specific debate about health equity share the challenges presented so far for the general concept of equity. The

Associação Nacional de Pós-Graduação em Saúde Coletiva - ABRASCO (2000, p. 1) accentuated that there is a lack of more precise concepts and empirical evidences about health equity. This institution has also pointed out that broad definitions are packed with ethical values and moral principles which are not given *a priori* and that are generally not operational. However, conceptual clearness about health equity is needed to implement equitable health systems.

Sen (2006) revealed, once again, his preoccupation to link theory to practice by studying the concept of health equity. He considered this concept central for the understanding of social justice, since any conception which accepts the need of a fair distribution of resources and of efficient building of human capacities can't ignore the role played by health on human life and on opportunities that persons have (Sen, 2006).

Using elements of his reasoning about equality, Sen considered health equity as a multidimensional concept, which includes aspects of health achievement and of capability to achieve good health, avoiding strict analysis based only on distribution of health care (SEN, 2006). His view includes also justice of institutional procedures, since it values, for example, non discrimination in offering health services. Besides that, he indicated that the concept should be integrated with broader aspects of social justice and total equity, paying attention to versatility of resources and to the reach and impact of different social arrangements (SEN, 2006, p. 31).

Sen indicated that health equity violations cannot be judged only by observing health inequalities, because such assessment may not offer adequate information. More than revealing differences on distribution of health services, materially relevant violations

need to be associated to avoidable and unfair causes, such as failures in resource allocation policies for health services (SEN, 2006). Therefore, health equity cannot be limited to isolated observation of health or distribution of health services (SEN, 2006). It is not to say that the emphasis on the general and inclusive framework of the concept means disregard for the use of specific criteria for particular ends, since they are useful to clarify specific and concrete questions about equity. The objective was to oppose the excessive valorization of specific criteria present in operational concepts, since broader criteria are also needed to establish relations with total equity (SEN, 2006). According to Sen, health equity is a broad concept and its recognition as such has to precede its limitation by any specific criteria associated to contingent purposes (SEN, 2006).<sup>3</sup>

Other researchers and institutions interested in health policy have elaborated health equity definitions and the analysis of those are useful to expose associated principles. Margaret Whitehead defined health inequity (as a result of discussions carried out by the Health Equity Program of the European office of WHO) as differences which are unnecessary and avoidable, besides those considered as socially unfair (WHITEHEAD, 1992, p. 431). Even though this definition deals with the issue of social justice, it is worth to stress that “unnecessary differences” presuppose the acceptance of “necessary differences”. Curiously, this is the definition generally cited in discussions about health equity. It is possible that a consensus around the health “inequity” concept may be easier to reach by adepts of many justice concepts. Unnecessary, avoidable and socially unfair differences provokes, in general, a common sense of rejection among those who desire a fairer society.<sup>4</sup> On the other side, a

direct approach to conceptualize health equity demands the recognition of an explicit framework of principles of justice, what would make more likely the appearance of disagreements in a plural society.

However, Whitehead also presented a *working definition* for health equity: it implies that, ideally, everyone should have a fair opportunity to develop full health potential and, more programmatically, that nobody should be in disadvantage to achieve such potential, if it can be avoided (WHITEHEAD, 1992, p. 433).

The EOHSP (2006) presented a similar concept, adding that everyone should have geographic and financial access to available resources for health care. This concept values a fair opportunity of access to resources (as a principle of justice), not necessarily based on total equality. It also points to the relational nature of equity, since its determination depends on fairness of resources distribution according to individual socioeconomic characteristics. Both definitions are close to the one developed by Sen with respect to developing a full health potential.

A report from the Knowledge Network on Health Systems of the WHO Social Determinants of Health Committee indicated that the health equity definition includes the concept of fair distribution of health results in the population as well as of health services and of levels of payment for health services (WHO, 2007c). It was also distinguished the redistribution of power to take decisions which affect health and health care (WHO, 2007c). This definition has incorporated elements associated with the promotion of individual capacity to achieve health, as in Sen’s concept. It has avoided the limitation of the concept to health services access criteria and has advanced to incorporate the relevance of political action. However, this

concept looks still centered on the health system, decreasing the emphasis of the relations with other public policies needed to develop individual capacities (even though many of such relations were mentioned in the report).

According to ABRASCO (2000), two health equity dimensions should be considered: equity in life conditions and is access and consumption of health services. Such distinction would be necessary since many studies have shown that use of health services is not the only factor to affect population health, other variables, such as epidemiological pattern, age structure, biological inheritance and lifestyle are also relevant (ABRASCO, 2000). Consideration of dimensions of equity, others than access to health services, increases the reach of the concept, allowing analysis of health policy interaction with the socioeconomic and political environment. Although the mention of equity dimensions makes this concept close to the systemic and broad concept adopted by Sen, this author has mentioned other dimensions which also need to be addressed, like justice on procedures, non-discrimination and relations to total equity.

The International Society for Equity in Health - ISEH (2006) has defined health equity as the absence of systematic and potentially avoidable differences in one or more aspects of health among populations or socially, economically, demographically or geographically defined groups. This definition has approached health equity by contrasting it with its contrary, avoiding also explicit consideration of subjective values of justice. The absence of a principle of justice, however, may distinguish health inequalities without considering their relevance to social justice, deviating from Sen's broad concept and allowing selection of less efficacious and efficient solutions (based more on the

consequences than on the structural causes of health problems).

The next item approaches the relations between equity and ethical principles applied to allocation of organs for transplantation.

### Equity and organ allocation criteria

International organizations, such as WHO, recommend that only health need must be considered in deciding to whom allocate organs for transplantation (CÂMARA DOS DEPUTADOS, 2004). Consequently, one cannot directly apply an equity principle and allocate organs according only to the social situation of the less privileged members of society. The equality space needs to be well characterized and, at start, be associated to health needs. However, health needs present levels of intensity, not always objective and which require intermediation of ethical principles to promote justice in organ allocation. This way, besides considering principles of justice and the concept of equity, it is also needed to consider the adoption of ethical criteria.

Carlos Ribeiro and Fermin Schramm (2006) identified two strategies for organ allocation: egalitarians and utilitarians. The former offer equal opportunities to all, as would be the case of order of registration in waiting lists and of a lottery. Utilitarian strategies may be related to health and to social conditions. The health related strategy uses criteria associated to health needs and to probability of treatment success. Social utility relates to allocation criteria based on social characteristics, such as: sex, race, age (as in the case of children), lifestyle and existence of a social support network (RIBEIRO; SCHRAMM, 2006). The subjectivity of this strategy demands attention to avoid implementation of biased criteria.

Nikola Biller-Andorno and Roberto Andorno (2001) identified four ethical principles which may be used to allocate organs. The first one is "equal opportunity", similar to the egalitarian strategy mentioned by Ribeiro and Schramm (2006). Considered one of the most simple, it is based on the idea that all criteria would be arbitrary, thus all persons registered on the waiting lists would have the same right to receive organs independently of any additional criteria (BILLER-ANDORNO; ANDORNO, 2001). The authors indicated that the exclusive adoption of this principle is not defensible, since it does not consider special particular needs of individuals.

The second principle is "compensatory justice", by which people who have suffered most or sacrificed most by others would have more right to receive an organ. The third one is the principle of "efficient distribution", which determines that those with greater probability to achieve better results would have preference to receive organs. This may cause discrimination if there is no preoccupation with questions of justice, race, culture and gender (BILLER-ANDORNO; ANDORNO, 2001). The fourth principle is "compassion", sometimes called as urgency criteria, which indicates that those in greater need to survive should be selected, as in the case of imminent death. This principle is generally in conflict with that of efficient distribution (BILLER-ANDORNO; ANDORNO, 2001).

Biller-Andorno and Andorno (2001) recognized that the integration of these principles is not always simple and that maintaining complete objectivity on allocation criteria is not feasible. They recommended the development of a high level of attention on the implicit difficulties of the organ allocation process and a continuous effort to search for the best

possible solution for each person in particular and for society in general (BILLER-ANDORNO; ANDORNO, 2001). They have also suggested attention to non-discrimination, to transparency and to combined use of criteria - based and not based on health need, such as waiting time (BILLER-ANDORNO; ANDORNO, 2001).

They pointed out the allocation principles present on legislation of Germany and France. The German transplantation law, approved in 1997, used a mix of compassion and efficient distribution principles. The transplant centers of that country must decide about inclusion of persons in the waiting list considering the state of scientific knowledge, the urgency and the probability of transplant success (BILLER-ANDORNO; ANDORNO, 2001). The principle of compensatory justice was discussed but it was rejected due to its discriminatory nature. The equality principle was not considered adequate since it does not consider pre-existent conditions, allowing for the reinforcement of previous inequalities (BILLER-ANDORNO; ANDORNO, 2001). This situation exemplifies that the adoption of an egalitarian principle without equity considerations may not be acceptable by society.

In France, the Law n° 94-654 of 1994 formulated general principles about organ transplantation (BILLER-ANDORNO; ANDORNO, 2001). It was created an institution to manage the national waiting list and to establish allocation criteria to be ratified by the ministry of health. A national committee report, presented in 1996, suggested harmonization of existent protocols at the national level and a better geographical allocation of organs (BILLER-ANDORNO; ANDORNO, 2001). The French government modified its regulations in 1996, establishing rules for different organs and four stages of distribution - local, inter-regional, national e

international (BILLER-ANDORNO; ANDORNO, 2001). It was established priority in favor of those in imminent death, with lower chances to find a compatible organ and of children (BILLER-ANDORNO; ANDORNO, 2001). It was recognized the non-resident foreigners right to be included in the waiting list (BILLER-ANDORNO; ANDORNO, 2001).

The USA has also used a combination of principles to allocate organs for transplantation. According to Robert Veatch (1998), the organ transplantation law of 1984 demanded a combination of equity and efficiency principles, but the definition of specific distribution formulas was delegated to the United Network for Organ Sharing (UNOS).

In Brazil, the national transplantation law (nº 9.434 of 1997) and its regulations set a combination of ethical principles: equality (time in waiting list), efficient distribution (biological compatibility and state level privilege on allocation to avoid losses due to delays in transportation) and the compassion principle (imminence of death). It was also added an equity principle at the national level, since it is possible to transfer organs not used in one state to other state.

As observed in the referred cases, each country has adopted a particular set of ethical principles, which guides a supposedly equitable organ allocation system, according to their context and social values. The determination of relative weights of each principle and of priorities (as in the case of children) is a task for each country to decide with transparency. Since so many combinations are possible, it is clear that ethical and distributive justice principles need to be integrated to produce an equitable outcome.

Rawls' theory has a relevant contribution in this debate with respect to

justice of procedures adopted by the institutions responsible for organ allocation. These procedures should guarantee equal opportunities to all (the same conditions) and the correct application of criteria agreed by society and expressed in formal regulations. However, due to its political conception, directed towards the general functioning of the basic structure of society, this theory has as a practical limitation the fact that it was not meant to be applied to solve specific distributive problems. In spite of this, Veatch (1998) questioned if Rawls' difference principle would justify direct organ donation to specific social groups in a waiting list based transplant program. Veatch (1998) suggested that the difference principle would justify direct organ donation, because the individuals standing at the end of the waiting list would benefit and those in front of the recipient wouldn't be damaged, since if there were no direct donation there would be no donation at all. Sen's health equity concept is also useful in this discussion. His preoccupation with social non-discrimination would probably exclude direct donation in a waiting list program, since this kind of donation is discriminatory.

The substantive nature of Sen's contributions offer other helpful elements to the complex task of organ allocation. His systemic approach, for instance, demands that the allocation criteria should be considered according to the health system context and to the individuals' effective capacity to access health services. To promote equity, the health system needs to offer equal opportunity to services in general, not only to transplantation, avoiding inequalities in prevention and treatment of diseases which will require organ transplantation. Such inequalities would place the less privileged in disadvantage. For example, unequal access to renal disease

prevention may generate a context in which the less favored will stand a higher risk to need a kidney transplantation and, consequently, face organ scarcity. Tom Koch (2002) alerted that public policies should avoid the artificial organ scarcity produced by decisions and resources distributions which does not contribute to reduce the scarcity level to the minimum possible.

In the case of transplantation, Sen's capacity approach supports that those in waiting lines should have real opportunities to get an organ. Considering a public and universal health system, it would not be admitted the existence of formal allocation criteria not accompanied by the means needed to fulfill them. For example, it would not be equitable the demand for specific pre-transplant lab tests if they were not accessible to all registered on waiting lines. The result would be an unfair inequality, since those with access difficulties to tests would have their waiting time extended, while those with access to private services would get an advantage. Surely, tests requirements should not be abolished, for the benefit of all transplant candidates, but access to tests should be offered to all.

Sen's approach would also support a homogeneous geographic distribution of transplantation centers, the development of special arrangements to overcome specific regional access deficiencies of population groups (by adoption, for example, of a national waiting list), and the removal of any barriers which restrict the effective freedom to develop the individuals' full health potential.

## Conclusions

This analysis suggests that the equity concept is related to a notion of justice,

which would be the main responsible for the variation on the meaning of this word throughout time. However, the basic framework of the equity concept, based on the classic Greek view of treating different people differently (BROWN, 1991, p. 491), has remained stable. Thus, one cannot dissociate the discussion of equality / inequality from that of equity / inequity. Based on Amartya Sen's thoughts, it was perceived that equality spaces are plural and that different conceptions of justice are possible, when different demands for equality are considered. These demands may be associated to (or even justify) inequalities in another spaces.

Rawls' principles of justice are matter of reasonable consensus among liberals, chiefly, with respect to the defense of basic individual liberties and of the justice of procedures adopted by institutions of society. Most of disagreements to this theory are related to the distribution of primary goods through the difference principle. Even though this theory advocates for liberty, equality of opportunities and reduction of inequalities, it is not clear about primary goods level of satisfaction. Health is not even mentioned as a primary good (RAWLS, 2003). Albeit the difference principle admits relevant compensations (like the equitable measures associated with the welfare state), the absence of minimum requirements, may justify distributions which appears to benefit the less privileged but in reality, due to the insufficiency to develop capacities, only maintain a framework of social inequality.

Sen's criticism about the difference principle focus on means inserted a preoccupation with interpersonal variability in the capacity to transform primary goods into results. Sen has established a clear difference between means and the effective freedom to achieve welfare (with choice).

Although the measurement of capacity inequalities it is not methodologically simple, this approach has expanded the practical use of Rawls' theory. With respect to health equity, this approach allows linkage with themes of total equity and social justice, avoiding limitation of discussion on issues of inequalities in levels of health and in distribution of health services.

From the set of health equity concepts observed, which made reference to a principle of justice, it was clear a trend to adopt the principle of fair opportunity and support for the correction of unnecessary inequalities. This pattern is compatible with a liberal conception of justice, such as that proposed by Rawls. It was also observed theoretical advances similar to those proposed by Sen, associated with the development of individual capacities to achieve health. However, if the goal is to implement equitable health systems, there still a need to emphasize in operational concepts: the principle of justice adopted, the multidimensional nature of health equity and its relations with total equity and social justice, according to Sen's systemic view.

About the application of theories of Rawls and Sen to organ allocation for transplantation, it was clear the need to integrate ethical principles accepted by members of society. In practice, each national transplant program adopts a set of ethical principles trying to achieve equitable results. Generally it is used an equality principle (order in waiting list) associated to compassion (imminent death) and efficient distribution criteria (best expected result according to severity and health need). In special situations some priorities are set, such as in the case of children. The weighs each principle receives on allocation varies among countries, but once expressed in formal regulations, they need to be applied

impartially and with transparency to promote justice in procedures and equal opportunity.

Finally, it stands out that for achievement of an equitable access to organs it does not suffice to have formal allocation criteria and procedural justice, it is also needed attention to the effective freedom to mobilize means which will allow a fair opportunity of access to health services in general and to transplant programs in particular.

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## NOTES

<sup>1</sup> The use of the expression “equity” may be observed in texts of the Old and New Testament, such as: Psalms, 99:4; Proverbs, 2:9; Acts, 24:4; II Corinthians, 10:1 and Hebrews, 1:8.

<sup>2</sup> According to Vita (1999), Rawls’ theory is a proposal to balance political values (such as freedom, equality, solidarity) and efficiency.

<sup>3</sup> A contingent purpose may be exemplified by the use of access criteria to health services as the only component of a health equity analysis, without consideration of relations within the health system and with other public policies.

<sup>4</sup> Sudhir Anand (2006) indicated that we have less tolerance to health inequality than to rent inequality, since health is a special good, with an intrinsic value (for our well-being) as well as an instrumental value; while rent is only instrumental.

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