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Kidney transplantation in Alagoas: a bioethical view regarding the vulnerability of those in need

Carlos Adriano Silva dos Santos¹, William Saad Hossne², Marcio Fabri dos Anjos³

Abstract

Although there is a growing need, the quantity of kidney transplants in the state of Alagoas is very small. The objective of this study was to analyze if the public health managers contributed to the increase of vulnerability of patients who need kidney transplants in Alagoas. The sample consisted of public health managers from the Secretariat of Health in the state of Alagoas; the coordinator of the organization for the procurement of organs and tissues; the transplantation team coordinator; physicians from nephrology clinics, from mobile emergency medical services and from critical care unities; and the representative from the Alagoas Chronic Renal Patients Association. Fourteen research participants pointing failures in the administration of programs and resources for transplantation. The study concludes that those who need kidney transplants in Alagoas are even more vulnerable due to shortcomings in the management of public health.

Keywords: Bioethics. Ethics. Philosophy. Kidney transplantation.

Resumo

Transplante renal em Alagoas: olhar bioético sobre a vulnerabilidade de quem precisa

Apesar da necessidade crescente, a quantidade de transplantes renais realizados no estado de Alagoas é muito baixa. O objetivo do estudo foi analisar se os gestores contribuíram para o aumento da vulnerabilidade de pacientes que necessitam de transplante renal no estado. A amostra foi composta por gestores da Secretaria Estadual de Saúde; coordenadores da organização de procura de órgãos e tecidos; equipes de transplante; médicos de clínicas de nefrologia; médicos dos serviços de atendimento móvel de urgência; médicos das unidades de terapia intensiva; e o representante da Associação dos Renais Crônicos e Transplantados de Alagoas. Resultou em 14 participantes que apontaram falhas gerenciais nos programas e recursos voltados ao transplante. Concluiu-se que necessitados de transplante renal em Alagoas são mais vulneráveis devido a falhas na gestão pública de saúde.

Palavras-chave: Bioética. Ética. Filosofia. Transplante de rim.

Resumen

Transplante de riñón en Alagoas: mirada bioética acerca de la vulnerabilidad de quien lo necesita

A pesar de existir necesidad creciente, la cantidad de trasplantes renales realizados en el estado de Alagoas es muy baja. El objetivo de este estudio fue analizar si los agentes de salud pública han contribuido con el aumento de la vulnerabilidad de pacientes que necesitan trasplante de riñón en Alagoas. La muestra estuvo compuesta por gestores de la Secretaría de Estado de Salud de Alagoas; coordinadores de la organización de búsqueda de órganos y tejidos; miembros de equipos de trasplante; médicos de clínicas de nefrología; médicos de los servicios de atención móvil de urgencias; médicos de las unidades de cuidados intensivos; y un representante de la Asociación de Renales Crónicos y Trasplantados de Alagoas. En total fueron 14 participantes, los cuales apuntaron fallas de gestión en los programas y recursos dedicados al trasplante. Se concluyó que los pacientes necesitados de trasplante renal en Alagoas se encuentran más vulnerables debido a fallas en la gestión pública de salud.

Palabras clave: Bioética. Ética. Filosofía. Trasplante de riñón.

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Declararam não haver conflito de interesse.

Chronic kidney disease (CKD) stems from progressive disease that will extend until the loss of renal function. If it evolves, the disease culminates in permanent incapacity to maintain the normality of the internal environment of the patient. With complete kidney failure, the therapeutic alternative is to replace renal filtration by peritoneal dialysis, hemodialysis or even organ transplantation¹. Renal transplantation (RT) is the “light at the end of the tunnel” for patients who need it, the so expected improvement in quality of life². In some regions of Brazil, renal transplantation has become routine, but in others there is a shortage of supply and/or lack of demand, leaving patients in a state of complete vulnerability.

There are about 3,400 chronic kidney patients in Alagoas and 11 nephrology clinics. In 2013, there were 186 patients with an estimated need for transplantation, of whom only 22 received transplantations³. In the twelve years between 2002 and 2013, the number of transplants was irregular, with a decreasing number of surgeries, always among the last placements in the region, even losing to states with a smaller population. Alagoas is one of the Brazilian states with the lowest rate of renal transplantation. In 2013, the Brazilian Registry of Transplantation (Registro Brasileiro de Transplantes)⁴ concluded its annual report on Alagoas stating the following:

State has a marked decline in the transplant program at all stages. It faces difficulties in the formation of a technical implantation team for the organs and tissues procurement organization (OPO) - stage II, low notification rate and a high rate of family refusal (77.7%). It does not fulfil organ donations and, consequently, transplantations. It is in disarray with the growth of the transplant programs of the states of the northeast region, such as Ceará and Pernambuco. Not even corneal transplantations meet the estimated need. It needs support to prioritize the reactivation of organ donation and kidney and corneal transplantation programs and, as a follow-up action, the creation of a liver transplantation program⁴.

In view of this situation, the objective of this study was to analyze, in the light of bioethics, whether public health managers contributed to the increased vulnerability of patients with CKD who require kidney transplantation in Alagoas.

Methodology

The article was based on a qualitative study, carried out through an open, structured, face - to

face interviews, whose objective was to analyze, based on bioethical references, the problems pointed out by managers, health promoters and institutions - *institutional subjects* - and patients with the disease - *ethical subject*. Each participant in the research was questioned about factors that impeded the performance of renal transplantation in patients who had in this procedure the only possibility of a definitive clinical solution for their disease. All interviews were recorded and, as soon as they were analyzed, destroyed. Inclusion criteria incorporated individuals who acted as institutional subjects who participated directly in the decision making regarding the care of patients who needed renal transplantation, as well as representatives of patients with chronic renal failure in the state of Alagoas.

As shown in Figure 1, it was initially intended to include 21 institutional representatives in the study as research participants. Of these, 14 were included and seven were excluded. The reason for this exclusion was the refusal to respond to the questionnaire by four possible interviewees and the request to be excluded from the study by three participants, although they were listed to participate in the study and had signed the ICF. With the exclusion of these people, we were unable to interview three coordinators of intensive care units (ICU), one person responsible for a transplant team and three medical coordinators of a nephrology clinic. Those excluded were part of three private hospitals that provide services to the Brazilian Unified Health System (Sistema Único de Saúde - SUS).

The study was carried out in public and private health services, the chronic kidney patients' association and the Health Secretariat in the State of Alagoas. It counted on a sample of 14 participants, distributed as follows: representatives of the research teams; nephrology services medical coordinators; ICU medical coordinators; medical coordinators of the Mobile Emergency Medical Services (Serviços de Atendimento Móvel de Urgência - SAMU); Representative of the Association of Chronic Renal and Transplant Recipients from Alagoas (Associação dos Renais Crônicos e Transplantados de Alagoas - ARCAL); the secretariat of health; and the superintendent of health care. The main variable was the increase in the vulnerability of patients with CKD, caused by a failure to manage programs and resources for renal transplantation in the state.

The following guiding questions were adopted for the survey: 1) what are the factors that limit the realization of a transplant?; 2) what could be done to solve the problem?; 3) what is the

opinion of the interviewee regarding the national data on transplants in the state of Alagoas? This last question refers to the aforementioned conclusion regarding transplantation in the state as disclosed in the Brazilian Registry of Organ Transplantation⁴, the official publication of the Brazilian Association of Organ Transplantation (Associação Brasileira de Transplante de Órgãos - ABTO). Having conducted the interviews, we interpreted the responses that were raised using Engers' content analysis method⁵.

The first stage consisted of reading what was said by the interviewees. The second step was to distribute the responses of each interviewee in relation to each question raised, so that vertical analysis of the grouped information could be performed. In the third stage, what each respondent answered to each question was horizontally analyzed. The fourth step consisted in the synthesis of what was explained in the previous steps, establishing the grouping of the data. The fifth and final stage was about the categorization of the data so that one could reflect on the information obtained.

Results and discussion

At the time of the interviews, regardless of the item to be questioned, there was always the aspect of the ethical subjects being vulnerable to some degree. Not only because of the condition of the disease they were burdened with, but also because of the shortage, omission or neglect to which they were exposed by those who had the obligation to protect them. This premise is explicit in Hossne⁶, when he calls attention to the fact that:

... human beings are always vulnerable; they may or may not be in a situation of vulnerability. Therefore, human beings are always vulnerable; their vulnerability may or may not manifest itself. It is a question of moving from a latent situation to a manifest situation; from a situation of possibility to a situation of probability, from potentially being vulnerable to being vulnerable. These oscillations accompany all situations involving Bioethics⁶.

The same author also comments that the vulnerability can be that of the individual or the system, thus reaching other elements that can present several fragile points. *Therefore, when discussing the vulnerability of the patient or research subject, it is indispensable to reflect on the*

vulnerability that can affect the various links in the system and not only the vulnerability of the patient or research subject⁷.

Recognizing the state of vulnerability of ethical subjects and understanding that not only their illness, but also factors managing public health influence it, it was possible to observe in the results presented six items that clearly demonstrate this condition: 1) lack of commitment to the implantation of an effective transplant program in the state, which is perpetuated over time; 2) failure to administer the old transplantation center and current Organ Procurement Organization (Organização de Procura de Órgãos - OPO); 3) the Ministry of Health's (Ministério da Saúde) lack of technical knowledge regarding transplant programs; 4) lack of structure dedicated to transplantation, both from the point of view of care and from the diagnostic point of view; 5) OPO's operational incapacity; and 6) difficulty in accessing pre-transplant exams for patients from the Brazilian Unified Health System (Sistema Único de Saúde – SUS).

The lack of commitment to the implantation of an effective transplant program in the state seems to be confirmed by the interviewees (to facilitate the ordering of the citations and to guarantee confidentiality, we will identify the interviewees by the vowel "E" followed by a number) when they emphasized: E1 - *"The Secretariat of Health, regarding transplant programs, is still learning to walk. Government enters and leaves government and the managers of the field are not aware about the subject"*. In general, respondents emphasize that it is not only chronic kidney disease that debilitates the individuals as to their physical, mental and spiritual integrity - taking away from them the prospect of healing from a serious condition and that, by essentially depending on others, violates their autonomy⁷ - but also presents another face that should not exist: the omission of the State⁸. The diagnosis of omission by government reveals in the following sentence its painful truth, felt only by those who need renal transplantation: E2 - *"The problem comes from management failure; there was a lack of greater commitment from management and its staff on the subject."* The statement makes it possible to perceive that the managerial problem is not limited only to putting (or not) in practice a certain program; it is necessary to know which program, how to implement it and how much will be available for the maintenance of such proposal.

In addition to the difficulty of implementing welfare programs of this magnitude, there is a lack

of knowledge regarding how to make the practice of this program a source of funds so that the State can maintain it: E3 - *"Our managers do not know what are the resources aimed at transplant programs, nor how they should be sought"*. That is, patients are entirely in the hands of those who do not know how to direct their needs. Foucault's "let live" is lacking^{9,10}, when he relates aspects of biopower. There will be more to "let die".

Although we are no longer in the seventeenth century, when the sovereign defined who would die or live, in direct reference to his omnipotence in the face of the weakness of his subjects, similarly, not guaranteeing access to the means necessary to be able to continue living in a condition dependent on a renal transplant excludes from those who need their rights guaranteed for years to come to make a life and not let die^{9,10}. Especially when we take into account that resources do exist and are guaranteed by the State. By limiting assistance, vulnerability increases. This is what Hossne⁶ comments on when he says that the vulnerability of subjects is not only in them, but in the other elements that make up the care. If a subject is fragile, the vulnerability of the environment also increases his or her intrinsic vulnerability.

And the problem of management failure continues to emerge in the reports as a continuous stream of failures, errors, and omissions. The old transplantation center, which was responsible for the procurement of organs, which did not function or functioned in a precarious way, reflects the lack of attention given to transplantation in the state. Regarding this situation, the interviewees state: E4 - *"For some time SESAU has imposed the non-functioning of the transplant center"*. They explain that for a long time, SESAU's function was only that of "featherbedding" for those who did not want or did not know how to do other activities. And as a consequence of this irresponsibility, those who needed a kidney to continue living had their vulnerability intensified.

This panorama reveals another aggravating condition, which will only distress subjects further, making them increasingly dependent on the environment. Fiametti, citing MacIntyre, adds that *vulnerability and distress, and the ensuing dependence, is a condition and not, as a possibility, a state that happens from time to time. One is not distressed only in some moments. One always is vulnerable, afflicted and dependent*¹¹.

Patients, the ethical subjects of research, are struck not by their own vulnerability, but by the

vulnerability that emanates from some other point of their care. This vulnerability can be caused by the lack of support structure, the incompetence of the institutional subject as manager, or even by the deviation of public resources to serve private interests, as happens when jobs that require the provision of qualified service are destined to people who do not fulfill these requirements⁶. To guarantee assistance, a good relationship between the ethical subject and the institutional subject is important: *good living is not limited to interpersonal relations, but extends to the life of institutions*¹².

During the interviews, many narratives reported the lack of structure dedicated to transplantation, both from a care point of view and from a diagnostic point of view. Most of the interviewees were categorical in stating that it is fundamental to have a hospital unit exclusively dedicated to transplantation, considering the procedure too complex to be associated with other needs: E5 - *"Alagoas must have a hospital unit from the Brazilian Unified Health System (Sistema Único de Saúde – SUS) that is exclusively dedicated to transplantation"*.

For the participants, this hospital unit should preferably receive a team of properly trained and remunerated professionals dedicated exclusively to transplantation: E5 - *"It is impossible to have greater commitment to transplantation if professionals divide their occupations with other professional activities."*

It is not easy, when it comes to public health in the State - where basic care is precarious and other health conditions such as hypertension and diabetes are neglected -, to adopt a care policy focused on exclusive situations, such as renal transplantation, while so many other necessities require attention. However, with adequate public health measures aimed at diseases that require high complexity attention, within the imposed financial constraints, it would be perfectly plausible to have hospital units intended for the care of chronic renal patients who need transplantations, simply by ordering measures for the rationalization of expenditures and the applicability of public resources³.

As an example, it is important to mention the case of Spain, which has become one of the largest transplantation centers in the world by adopting a clear-cut policy for the population, structuring teams dedicated exclusively to the subject and building specialized and exclusive hospital units for this purpose. Transplantation became a public health problem of great interest to the Spanish

government, and thus *the Spanish model of donation and transplantation was created (el modelo español de donación y transplante)*^{13,14}.

In the distribution of responsibilities - or rather irresponsibility - is the game of who is to blame for the system's inoperability. It is a summation of events that culminates with the blocking of the care process turnstile for the ethical subject. One of these blockages takes place in the operation of the OPO. Phrases regarding this were frequent in the interviews, such as: E6 - *"There is no effective search for donors; the OPO is incompetent in this matter"*.

On the other hand, the OPO argues that it still has considerable difficulty in receiving from emergency hospitals notification of potential donors. In the state of Alagoas, the two largest emergency hospitals are public and managed by the State Secretariat of Health. The difficulty in obtaining a deceased donor organ is not minimized by the number of transplants performed *inter vivos*. Despite the greater number of surgeries performed with live donors, the number of transplants is very low. In part this is due to the difficulty of patients from the Brazilian Unified Health System to undergo the preoperative exams necessary to be able to undergo renal transplantation: E7 - *"There are patients who wait for about a year to go through arteriography!"*

Hossne⁶ is emphatic in saying that the individual is not vulnerable alone. There are a number of factors that make the situation more difficult and require more attention, not only to identify what is happening, but also to find solutions. Otherwise, the most vulnerable side will also be the most fragile, the ethical subject. Thus, the vulnerability of the other links (of sustentation) implies the vulnerability of the most vulnerable link itself. Therefore, it is indispensable to evaluate,

analyze and heal the vulnerability not only of the final link, but also of all of them⁶. We have seen that situations of managerial fragility that depend on the institutional subject exacerbate the vulnerability of the ethical subjects, who are already undermined by the illness that limits them¹⁵. Finding the reasons that make the individual vulnerable to prevent them will contribute decisively to improving the patient's health. Recognizing vulnerability as a decisive element in the integrity of the individual, without leaving aside the role of autonomy, equity, prudence, otherness and, above all, solidarity, makes it an extremely important reference point in bioethics, a true marker of the one who is exposed^{6,16-19}.

Final considerations

According to the previously described, there is an increasing vulnerability of people with kidney disease and who need transplantations in Alagoas, as evidenced in the interviewees' statements. Still relying on Foucault's^{9,10} concept of biopower, one can see how vulnerable these people are. It is a fact that the non-recognition by the State that a chronic and insidious disease, that afflicts the population, is a public health problem, is an omission of its responsibility to institute global measures of protection for its ethical subjects who are in need. Moreover, according to the biopolitical view of this author^{9,10}, we can add that it fail to reduce morbidity and "to extend life". It was also possible to correlate what professor Hossne thinks with the opinions of the interviewees regarding the bioethical reference of the vulnerability with the vulnerability of those in need in renal transplantation in the State of Alagoas.

This article is part of a doctoral thesis by Carlos Adriano Silva dos Santos, entitled "The patient with chronic kidney disease in face of public health managers and their need for transplantation in the state of Alagoas: a qualitative analysis regarding the bioethical references of vulnerability, equity, prudence and otherness", defended in the Bioethics Post-Graduation Program of the São Camilo University Center, São Paulo/SP, Brazil.

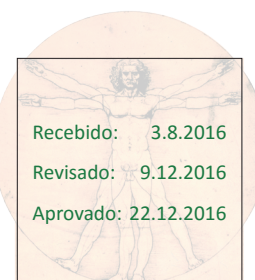
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Participação dos autores

Carlos Adriano Silva dos Santos trabalhou na concepção e planejamento, análise e interpretação dos dados, bem como na elaboração do rascunho. William Saad Hossne trabalhou no planejamento, análise e interpretação dos dados. Marcio Fabri dos Anjos trabalhou na análise dos dados. Todos os autores contribuíram com revisão crítica do conteúdo e aprovação da versão final do manuscrito.



Anexo

Figure 1. Survey sample

