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Organ donation and transplantation in Mexico. A transplantation health professionals' perspective

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Abstract

Objective. We aimed to explore organ donation and transplantation in Mexico from the point of view of transplantation health professionals. Materials and methods. A qualitative study was carried out. Twenty six organ transplantation health professionals from seven states of Mexico participated. Semi-structured face-to-face interviews were conducted mainly in hospital settings. Critical discourse analysis was performed. Results. According to participants, living organ transplantation offers benefits for recipients as well as for donors. Several factors influence the field of transplantation negatively, among them the scarcity of resources that impedes the incorporation of new health personnel, as well as conflicts between transplantation teams with diverse health professionals and authorities. Conclusion. Besides increasing economic resources, transplantation health personnel should be sensitized to find solutions in order to avoid conflicts with different health professionals. Studies on organ donation and transplants also should include other social actors' viewpoint.

Keywords: organ transplantation; health personnel; qualitative research; Mexico

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Resumen

Objetivo. Explorar la donación y trasplante de órganos en México desde la perspectiva del personal de salud de trasplantes. Material y métodos. Investigación cualitativa. Participaron 26 profesionales de trasplantes en siete estados de México. Fueron realizadas entrevistas semi-estructuradas en los hospitales. Se hizo análisis crítico del discurso. Resultados. Según los participantes, el trasplante de vivo relacionado ofrece beneficios para el receptor y donador. Diversos factores inciden negativamente en el campo de los trasplantes, la carencia de recursos económicos impide la incorporación de nuevo personal, así como los conflictos entre los equipos de trasplantes con otros profesionales de la salud y autoridades. **Conclusión**. Es necesario aumentar los recursos económicos y sensibilizar al personal de salud de trasplante para evitar conflictos con los diferentes profesionales de la salud, así como realizar más estudios que incorporen la perspectiva de otros actores sociales.

Palabras clave: trasplante de órganos; personal de salud; investigación cualitativa; México

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Organ transplantation is often considered one of the most significant advances of modern medicine, especially of biomedicine, and one of the miracles of present-day science. This being so, most countries have developed policies, programs and actions regarding organ donation and transplantation. However, most of them are struggling to achieve the expected success; one of the most notable obstacles is the scarcity of organs. Consequently, while the number of patients on waiting lists continues to grow, the number of organ transplants remains virtually constant.

The stagnation in cadaveric organ transplants makes it necessary to explore different avenues in this field. One proposed topic is to examine the situation of health professionals who are key components of the process, particularly those related to transplantation teams, organ procurement and policy makers.³ According to some authors, health professionals' knowledge, perceptions and attitudes can become either facilitators or barriers to organ procurement and transplantation⁴ and can even influence the public's attitudes toward donation.⁵

Nevertheless, few studies have been conducted in Mexico and other Latin American countries on what transplant staff think, say or do regarding the organ donation and transplantation process. ⁶⁻⁹ Besides, most studies have been carried out in developed countries, using quantitative approaches and focusing on knowledge and attitudes of health personnel. ¹⁰⁻¹⁶ This means that they provide no insight into how these professionals perceive, experience and act in this field.

In such context, the examination of transplantation health personnel could be an interesting object of study for several reasons. Among these, they are seen as central figures in the organ donation and transplant process, which is why they are invited to express their opinions regarding problems and achievements in the field. For all these reasons, the aim of this study is to begin filling this gap by exploring the transplantation health personnel's point of view regarding organ donation and the transplantation process.

Materials and methods

We conducted a qualitative study since this is an ideal strategy for exploring the discourse of social actors regarding the organ donation and transplant process. This article reports the findings related to health care personnel who work in organ transplantation, also known variously as transplant teams, health professionals working in transplants, or transplant professionals.

The study was carried out in seven northwestern Mexican states. Transplant teams were identified once

the hospitals that were licensed to do organ procurement and transplantation were identified. Using a purposive sample, ¹⁷ 26 individuals who participated in organ transplantation teams were selected and invited to participate. All of them worked simultaneously in the public and the private sector; however, most transplants were done in the former. Amongst those who participated: eight were transplant surgeons, eight nephrologists, two urologists, one internist, five nurses and two social workers. Two of them worked in the state of Aguascalientes, five in Guanajuato, four in Jalisco, two in Nayarit, seven in San Luis Potosí, four in Sonora and two in Zacatecas; 17 were men and 9 were women.

We conducted semi-structured individual interviews, most of them at public hospitals, from June 2010 to June 2014. The interviews averaged one hour in length. We used an interview guide developed based on the literature review and on consultations with members of the transplant teams. The interviews were divided into four parts: general introduction, topic's broad exploration, focusing on the topic and synthesis/closure. The interviews began with open-ended questions, such as: Could you tell us the history of the hospital transplant team? What happened with those involved after the donation and transplantation process was activated?

We transcribed the interviews following a standard format, and subsequently organized the data using the Ethnograph V 6.0 program. One of the authors (AM) processed the data, but all authors participated in reviewing the materials, coding and identifying emergent topics and themes, as well as selecting interview excerpts to quote in order to illustrate these themes. A critical discourse analysis (CDA) was performed. 18 CDA involves the development of a theory that reveals the relationship between discourse and social structure. It relates how discourse, being a historically situated social practice, is modeled and determined by the macro and micro structures in which it is embedded, but at the same time contributes actively and creatively to the construction, maintenance and transformation of the social order. Critical approaches not only describe practices related to the discourse, but also enable symbolic, relational and structural aspects in the area of health care to be explored.

This study complied with the ethical principles set out in the Declaration of Helsinki. Participation was voluntary and under informed consent. The principles of respect for autonomy, self-determination and confidentiality of information were observed. The project was evaluated and approved by the respective ethics committees—one at the University of Guadalajara, and three at the public hospitals where the participants worked.

Results

The respondents' discourse focused more on organ transplantation than on donation. They convey a seemingly contradictory view on transplants in Mexico: they acknowledge the progress and achievements of recent years, but they also highlight specific problems that have adverse effects on the program as a whole and on specific aspects. They cite many reasons for their favorable view of transplant programs and actions. For them, these programs have not only been well received by local people, but have also been recognized abroad. In support of Mexico's international reputation, they cite the fact that the country has one of the highest rates of transplants in the world, particularly living related donor transplants, as well as the fact that they were invited to support programs in Central American countries. One participant expressed with pride,

"...The living related transplant program has been very successful in the hospital, being at full capacity...the program is (also) recognized internationally as having the highest rates of transplants in the world. This means that we have a highly qualified transplant team..." (Male, transplant surgeon, public hospital)

A number of ideas support the work they do; namely, images of the superiority of living related donation over cadaveric donation, as well as advantages and benefits of transplants over dialysis. According to them, living related donation is the best choice among renal therapies, since it offers advantages over cadaveric donation for both transplant recipients and donors. Besides, it is better for recipients because they live longer than those who receive an organ from a deceased donor, the wait is shorter, the complications are less, and the probability of survival is higher. Donors, in turn, benefit from being under ongoing medical supervision, which ensures the detection and diagnosis of diseases that could be missed if they had not donated. A transplant surgeon states:

"...The advantages are obvious and have been reported in many studies. Recipients of an organ from a living related donor live 7 to 15 years longer and have fewer complications than those who receive a cadaveric organ. There are even advantages for the donor, because they have more contact with doctors and more frequent check-ups. This means that their (health) problems will be diagnosed..." (Male, transplant surgeon, public hospital)

Members of the transplant team are also perceived as committed, sacrificing and capable of carrying out

remarkable feats in adverse circumstances. Following them, such situation ensures the success of the program in spite of the adversities and limitations in the institutions where they work. One respondent emphasizes certain what she considers to be inherent characteristics of these professionals:

"...It is not only a trained but a highly motivated team... They are not paid as much as the (Spanish) surgeons. In fact, when the Spaniards come, they are surprised at how many transplants are done here..." (Female, nephrologist, public hospital)

For these participants, rejection of the transplanted organ is due to reasons beyond their control; they claim that it is due to negligence on the part of recipients, or of their family members who do not help them take proper care to preserve the transplanted organ. For this reason, some of them suggest increasing the cost of transplants to patients so that these will put more value on the organ, since many do not make enough efforts because the organs that they receive are free of cost,

"...We should require more commitment from the patients...You see patients who stop coming (to appointments), neglect taking their medicine, and eventually lose the organ. You worked hard to support them, you got them social health care, but they failed to appreciate the effort made in so many ways to get them their transplant..." (Female, social worker, public hospital)

According to these professionals, several circumstances affect transplant programs negatively. Some problems are structural and others are relational, as described below. The first problem relates to lack of funds. This is reflected in a variety of ways, such as staffing shortages. One issue frequently mentioned is the insufficient number of human resources –transplant surgeons, nephrologists, and other staff–, as well as the refusal to hire more personnel on the grounds of not having financial resources. Such shortages cause wear and tear in existing personnel, as illustrated by the following comment:

"...transplant surgery is extremely stressful and tiring. Anyone who does not have at least two or three transplant groups will be unable to maintain a healthy program. Eventually you wear out. The time when we were on continuous call, we ended up very exhauste,d and we were saying, 'My God, I thought (transplants) were a blessing, but in the end it was hell'..." (Male, transplant surgeon, public hospital)

This situation is made even worse by the fact that the staff is limited by working arrangements that are not compatible with their duties in the transplant program. In other words, the hospitals do not have appropriate job positions for these staff, and therefore they do not receive the proper recognition, schedule flexibility, or remuneration for their work. One-participant commented on the topic noting the complexity of the situation:

"...we need trained personnel to obtain and preserve organs for the transplant teams. The team has to have enough members that they do not suffer fatigue...because if I am called up on a Saturday or Sunday evening or on a holiday, (then) they do not want me for a full day, and then they want me to do this and that..." (Male, urologist).

The shortage of financial resources also has a visible effect on hospital infrastructure. Members of the transplant team report shortages of available beds, equipment and basic materials necessary to ensure the success of transplants, especially in public hospitals. One professional referred to these limitations pessimistically:

"...it's very difficult to find a (hospital) bed ... Our kidney donor came in on Monday at nine-thirty, and didn't get a bed until six in the morning the next day. In other words, she had to sleep sitting up. So the infrastructure shortage is too much for us, there is nowhere to put the patients..." (Female, nurse, public hospital).

Two other structural issues emerge in the transplant teams' discourse. One is the lack of a universal access to renal therapies, and the other relates to the role of primary health care. The issue of access refers to the Mexican health care system, due to its fragmentation and to the lack of a universal and free access to health care. From the participants' perspective, this results in the scarce existing resources not being optimized. The primary health care service, on the other hand, is failing to make early diagnoses or to provide suitable care, which leads to delay in the treatment. One respondent notes in this regard:

"...from the political point of view, transplants have high visibility. (The administrators say) 'in my state there are so many (transplants)... we are in the first place' and everyone is impressed. Nevertheless, the problem is that you are not healing; the point is to do prevention, to educate the public. You shouldn't let it get to the point of kidney failure..." (Male, transplant surgeon, public hospital)

On the other hand, transplant professionals are constantly interacting with different people, such as administrators, health care staff, and even with lay people. However, these relationships are not always on the best of terms, nor are they examples of cooperation, and this can end up creating conflicts and adversely affecting transplant programs. One of the conflicts mentioned by respondents refers to professional jealousy on the part of some members of the team, a problem that ultimately interferes with team building. An example is the conflict between surgeons and neurologists, because each of them thinks that they are the most important figure in the transplant program. One participant expressed it thus:

"We did not make progress because there are usually very big egos in these programs in the surgical group and in the nephrology group; but (the egos) in the surgical group are bigger. These people practically ask for a red carpet to be rolled out for them to walk into the OR... Maybe because it's so difficult, they act like magicians... Sometimes the result is that the different groups can't help each other..." (Male, nephrologist, public hospital).

Another conflict involves differences between health care professionals on topics such as brain death. This has led, for example, to members of transplant teams having conflicts with neurologists or neurosurgeons when these refuse to make a diagnosis of brain death, due to the legal implications this may have. One of them says in this regard:

"...The biggest conflict in hospitals where there are transplant programs begins when neurologists and neurosurgeons... refuse to sign death certificates because they are afraid; they say they have to talk to the public prosecutor first... The main enemies of donation and transplant programs in this country are inside the hospitals, not outside..." (Male, transplant surgeon, public hospital)

Members of the transplant team also refer that they often have conflictive relationships with other people in the hospital. One such case is intensive care staff, especially those who are in charge. Such conflicts arise from differences in standards of care, as well as care and handling of potential donors. This is how one participant commented on this issue;

"...There is still a bit of a problem in intensive care. Sometimes the head of intensive care refuses to accept potential donors... For example, sometimes they say 'I won't admit them; my criterion for intensive care is that I'm not going to admit someone who is not going to get

out alive.' 'All right,' we say, 'they're not going to live, but then they could become a potential donor.' 'Then you treat him,' they answer. 'No, sir,' we say; 'we can't treat him because he's not legally dead'..." (Male, nephrologist, public hospital)

In a similar way, they recount conflicts between transplant teams and other surgeons that are due to the limited number of operating rooms available. Such conflict occurs when the latter are forced to postpone scheduled surgeries when a cadaveric donation protocol is activated. One of them explains the situation,

"...The transplant group is hated in all the hospitals because they upset everything...they block up the operating rooms and even more so if it is an explant followed by a transplant ... If it's the liver, everyone goes home that day because no one can do anything else..." (Male, transplant surgeon, public hospital)

One final issue that emerged from the respondents' accounts was the conflicts they have with hospital administrators. These arise because of the administrators' insistence that they increase their number of transplants in order to increase the hospital's indicators and help it stand up to external—e.g. political—pressure. One respondent commented on the issue with a cautionary note:

"...I have felt that transplantation is a government mandate. (They say) 'I want you to do more transplants.' You get pressured by the hospital director who, instead of joining forces, pressures people...I don't know if they get pressure from the media... or from the Ministry of Health..." (Male, internist, public hospital)

Discussion

The purpose of this study, which used a qualitative design and interviews in seven Mexican states, was to explore the discourses of transplantation health personnel regarding the organ donation and transplantation process. In this regard, this report breaks new ground on the field for several reasons. It focuses on the discourse of these professionals in particular, explores the situation in a Latin American country, and uses qualitative methodologies, which are relevant for making the voices of different social actors heard.

According to our results, the discourse of these professionals conveys a number of contradictory images about organ donation and transplantation, among them, that organ transplantation is more important than organ procurement, and that living related donation is a better option than cadaveric donation, under the argument

that it provides benefits to both the recipient and the donor. Similar results were reported in Spain. ¹⁹ Alvarez and colleagues found that 59.2% of nephrologists, urologists and medical coordinators considered that living related donation gives better results than transplants from deceased donors. Nevertheless, such topic has been object of debate. Arias and Felipe²⁰ report that 54% of nephrologists surveyed in Spain held the opinion that kidney transplants from living related donors should be considered only in special cases, such as when patients have been on waiting lists for a long time and suffer from hyperimmunity or clinical problems. For these reasons, the topic should be explored in more detail; for example in Mexico, since more than 70% of kidney transplants come from a living related donor.²

Another finding shows that these professionals have a representation of the cause of the rejection of transplanted organs: they attribute it to insufficient care on the part of recipients and their families. Anderson and colleagues reported similar findings. ²¹ Exploring the opinions of nephrologists in Australia regarding treatment compliance, these authors found that nephrologists claimed that patients did not comply with the medical treatment despite not having a common definition of compliance, the appropriate methods, nor systematic records to prove it. A fact to have in mind is that while Australian patients receive drugs free of charge, half the Mexican population must pay for medicines.

Despite their favorable images of organ transplants -though not of organ procurement-, our results show a series of structural and relational issues that negatively affect the transplant programs. Respondents repeatedly mentioned problems at the structural level, where lack of funds plays a central role. These shortages have been underreported, as most studies on the topic are conducted in developed countries. There are exceptions: Roberti and colleagues⁸ report that, in Argentina, according to transplant team heads, some patients cannot afford repeated trips to transplant centers for pre-transplant evaluation or follow-up visits, a situation that constitutes a barrier for both patients and the donation and transplant teams. Kim and colleagues²² report a similar situation in Korea, noting that limited health insurance benefits partially cover the cost of a kidney transplant and affect the work of the above-mentioned teams.

As in the case of organ donation coordinators, ⁹ transplant personnel face various conflicts that arise in their relationships with health professionals, both medical specialists and administrators. One issue worth emphasizing is the fact that these professionals never portray themselves as at a disadvantage to or under the command of others, even directors. This issue does not seem to have been a focus of interest in the literature on

Hernández-Ibarra LE y col.

health personnel related to organ donation and transplants. Rather than to an absence of conflict, it appears that this gap is due to the fact that most studies usually adopt a traditional approach, employ quantitative methodologies, and focus on these professionals' knowledge and attitudes. The adoption of such approach, therefore, implies the exclusion of such issues as conflict.

The contribution of this study stems from the information provided by the transplant teams. In this regard, they made suggestions on the topic. Dedicated resources and support must be allocated to transplant programs in order to incorporate new personnel. In this regard, team members' shifts should be adjusted to have a better coordination with those professionals and lay people who participate in the process. Health personnel involved in organ transplantation also should be sensitized to find solutions to the conflicts with other hospital professionals. Finally, further studies on organ donation and transplants should include the viewpoints of other social actors involved on the topic.

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