Before Consent. Living Donors and Gender Roles

Ma Teresa López de la Vieja

Catedrática de Filosofía Moral Universidad de Salamanca tlv@usal.es

Antes del consentimiento. Donantes vivos y roles de género

ABASTRACT: The article analyzes some data concerning gender differences in living organ donation, to argue in favor of a fair distribution of live donors. (1) Consent is a basic requirement in organ donation for transplants. However, reports about kidney transplants are very explicit, there is a gender imbalance. Live donation saves lives; it exemplifies altruism and real concern for others. But the answer to these messages seems different in women and men. (2) Gender issues have to be addressed, because social expectations could bear heavily on individual preferences, as the donors' distribution indicates. (3) How have unequal rates of living organ donation been approached? Could the actual imbalance be a question of communication, health or altruism? Recent donation campaigns and common ideas about health differences and attitudes could be examined from a gender point of view. (4) After exploring three arguments about the gender gap (communication, health, and altruism), the suggestion here is that the solution should not be discouraging potential female donors but encouraging a fair distribution of donors. (5) To conclude, gender perspective is pertinent to confront the imbalance in living donation, because social roles and conventional ideas about the "gift of life" usually precede individual consent.

RESUMEN: El artículo analiza algunos datos sobre la diferencia de género en la donación en vivo, para argumentar en favor de la distribución equitativa de donantes. (1) El consentimiento es básico en la donación de órganos para trasplantes. Sin embargo, los informes sobre trasplante renal son explícitos: existe desequilibrio de género. La donación en vivo salva vidas: ejemplifica el altruismo y el interés por los demás. Pero la respuesta al mensaje es diferente en mujeres y hombres. (2) Las cuestiones de género han de ser tenidas en cuenta, ya que las expectativas sociales pueden pesar sobre las preferencias individuales, tal como indica la distribución de donantes. (3) ¿Cómo abordar entonces las tasas desiguales en donación? La distribución poco equilibrada de donantes ¿es un problema de comunicación, de salud o de altruismo? Campañas recientes a favor de la donación e ideas comunes sobre diferencias en salud y en las actitudes pueden ser examinadas desde el punto de vista de género. (4) Una vez considerados los tres argumentos sobre la brecha de género (comunicación, salud y altruismo), aquí se sugiere que la solución no ha de ser disuadir a las potenciales donantes sino ir a una distribución equitativa de donantes. (5) En conclusión, la perspectiva de género es pertinente para cuestionar el deseguilibrio en la donación en vivo, ya que papeles sociales e ideas convencionales sobre el "don de la vida" suelen preceder al consentimiento individual.

Keywords: Bioethics, gender, organ donation, transplants, altruism, equality

PALABRAS CLAVE: Bioética, género, donación de órganos, trasplantes, altruismo, igualdad

Introduction

This article analyzes some data concerning gender differences in living organ donation, specifically in kidney donation, to argue in favor of a fair distribution of live donors. To support the gender approach of this issue, norms on informed consent and, especially, some data about the gender gap in living donation are relevant. (1) Firstly, informed consent is, and should be, a basic requirement in donation for transplants. However, recent data and several reports about kidney transplants in Spain are very explicit; there is a gender imbalance. Figures about donors' distribution are similar in other countries. Live donation saves many lives; it exemplifies altruism, solidarity or real concern for others' wellbeing. But the usual answer to this message, in several countries and cultural contexts, has been and still seems quite different in women and men.



Received: 28/10/2016 Accepted: 21/12/2016 **DILEMATA**, año 9 (2017), nº 23,

(2) Gender issues have to be addressed here, because social expectations, traditions, and conventional ideas about women roles as caregivers could bear heavily on individual preferences, as the donors distribution indicates. Eventually, who are the donors? The current data are very eloquent. (3) How have unequal rates of living organ donation been approached? Could the actual imbalance be a question of communication, health or altruism? Recent donation campaigns and common ideas about health differences and attitudes could be examined from a gender point of view, in order to confront and, at last, to provide valid arguments against the imbalance in distribution of living donors. (4) After exploring three possible arguments about this topic (communication, health, and altruism), the suggestion here is that the solution to the present gap should not be discouraging potential female donors but encouraging a fair distribution of donors. (5) To conclude, gender perspective is pertinent to confront the imbalance in living donation, because social roles and conventional ideas about the "gift of life" usually precede individual consent.

1. Live donation. Norms and data

".....an organ or tissue may be removed from a living donor only after the person concerned has given free, informed and specific consent to it either in written form or before an official body.

The person concerned may freely withdraw consent at any time".

(Council of Europe, 2002, art. 13)

According to the Additional Protocol to the Convention on Human Rights and Biomedicine, rights and freedoms of donors or potential donors have always to be protected as well as recipients' rights, without discrimination (art. 1). The shortage of tissues and organs for transplants usually requires policies and specific actions to increase organ donation; so, it has to be promoted (art.19). Informed consent is essential before removing an organ or tissue from donors; this principle obviously includes persons not able to consent. In order to protect them, the procedure should incorporate the authorization of a representative or authority (art. 14). In sum, donors have to be competent, free from coercion, suitable for donation – medically and psychosocially suitable -, well informed, and willing to donate, as recommended by the document of 2000, the Statement on the Live Organ Donor. This document offered some practical guidelines concerning live donation, for physicians, care providers, and, certainly, for potential donors (Live Organ Donor Consensus Group, 2000, Premise). Again, the well-being of donors and respect of their autonomy was the first concern of the authors of this set of recommendations. Concretely, for kidney donations – where more activity has been reported, around 41.6% of organ transplantation (GODT, 2016, 1) -; in 2004, another document insisted on the consent process and on the guarantee of voluntary decisions (The Ethics Committee of Transplantation Society, 2004).

Since 1979, the Spanish legislation has defined the main conditions for organ procurement and transplants (López del Moral, 2010); definitively, donors' consent has to be informed and formalized (Ley 30/1979, art.4). In 1999, the Spanish Decree on this subject was more specific about how to set donor's consent, insisting not only on formal aspects but also on its use and implications for clinical procedures (Real Decreto 2070/1999, art.9). Since the nineties, the Spanish coordinated system has been valued as a model, thanks to its national organization, thanks also to the communication strategy, and, above all, to the donors answers (Matesanz, 2008, 11-26). Kidney donation exemplifies the functioning of this system and the altruistic response of live donors (Casares, 2010), in spite of the fact that the Spanish model has been more focused on deceased donors (Oppenheimer, 2008). In 2016 this model is still considered very successful, because of the high rates of organ donation for transplants. The worldwide data of the previous year are unequivocal about these rates (IRODAT, 2016, Council of Europe, 2016, GODT, 2016, 16). However, this model still shows some weak points which need to be examined (Rodriguez-Arias, Wright, Paredes, 2010).

Live donation rates are still quite moderate in Spain, higher in other countries like Turkey and Costa Rica. International figures of kidney live donors are similar, with more activity registered in Turkey and the Netherlands (IRODAT, 2016, GODT, 2016, 6-7). On principle and in every country, allocation and distribution of organs for transplants should be equitable, justified, and transparent (WHO, 2010, 7). But looking closely at the figures – particularly for kidney donation –, the main profile of living donors (Manyalich, Paredes, Vilardell, 2008), male and female, speaks openly of an unsettled issue, the *gender distribution of donors*.

To summarize, well informed consent – a legal valid permission (WHO, 2009, 9) - is and should be required for medical interventions, including organ removal for transplants. In fact, the World Health Organization considers it the first guiding principle in this area. The allocation and distribution of organs have always to be guided by ethical norms and clinical criteria (WHO, 2010). Currently, the normative framework seems rather clear, at national (Real Decreto 2070/1999, art. 4, Real Decreto 1723/2012, art. 3) and international level. At the same time, there is a basic question, raised by the available data about living donation and their normative implications: the actual gender distribution of donors.

2. Gender imbalance

In 2015 and according to the annual statement the ONT - the Spanish organization for transplants -, 58.7% of deceased donors were male, 41.3% female (ONT, 2015, 4). Between 2010 and 2014, the majority of kidney donors – 64% of the living donors – were female. Male donors were 36%. However, the main recipients of organs for transplants were also male. Indeed, these recipients were 60% versus a 40% of female (ONT, 2015a, 9). Actually, in 2014 there were 270 female living donors and 135 male donors. How have these rates been explained? ONT dossier has not included any comment. Previously, the national report of 2014 concerning kidney transplants for pediatric recipients stated that 68% were female living donors (32% male). Among these recipients – children or adolescents that increased their life expectancy, thanks to the transplant - 68% were male and 32% female (ONT, 2014). Moreover, 63% of reported donors were the patient's mother, the 21% was the father, and the 16% other relatives. These figures seem utterly explicit; so, they are worthy of some accurate analysis, not only in Spain, but also in other countries.

In fact, the data about gender differences in live donation in Europe are very similar. For instance, since 2002 in Italy, the national system of information (SIT) has registered the transplant activities. The gender impact on live donation and transplantation was considerable in this country, because two thirds of the organs have been given by women, while the majority of recipients were male (Puoto et. al., 2016). According to the official report of 2016, the examining of social and cultural factors – rather than biological aspects – would explain why there are significantly

more female than male living donors. (Ministero di Salute, 2016, 69-72). So, gender imbalance does exist. Do these data reflect conventional roles and traditions still powerful in Southern Europe? Again, the figures speak out about a systematic bias in very different backgrounds. Since 2000, the data collected in Germany showed a considerable gap between female and male living donors; differences were also relevant in organ recipients. Thus, some practices have to be reviewed, in order to assure equitable ratios in donation. Moreover, in a very conventional model of relationships and family it is possible that expectations and some imaginable pressures could affect donors' voluntariness (Biller-Andorno, 2002, 2011).

In Switzerland, the records from 1993 to 2003 about living kidney donors and recipients display comparable rates, with more women willing to donate – 65% - than men. The information comes by the National Health Registry. Presumably, financial risks and the weight of traditional roles – women as caregivers vs. men as economic provider – exert their influence on this outcome related to the unbalanced distribution. (Thiel, Nolte, Tsinalis, 2005) In fact, in countries like Germany, Belgium, the Netherlands, and Austria, a particular notion of family, general expectations, and conventional gender roles are still influential on the willingness to donate. Considering that individual responsibility and moral duties affect differently to women and men, the allocation of organs for transplant is unbalanced. (Schicktanz, Schweda, Wöhlke, 2010). In Norway the experience is equivalent, because of the predominance of female to male live donation. Once again, males compose the majority of kidney recipients, 62. 7%. Data from the years 1985 to 2002 had been collected by the National Renal Registry (Oien et. al., 2005). The stunning gender disparity is visible in this field. Could it be a singular European experience?

It seems rather a general situation. In other contexts, living donation usually follows the same pattern. Studies conducted in the United States about this issue and the data collected by the Organ Procurement and Transplantation Network (OPTN) confirmed the disproportion in renal female-to male live donation for transplant was considerable between 1988 and 2016. (OPTN, 2016, https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/#). Evidently, cultural and psychosocial factors mattered, not only clinical criteria (Kayler et. al., 2003, 2002) For instance, in China, published data refer donors, recipients, and gender mismatch – women were more willing to donate, more men received organs-, with several consequences for clinical practice. In this context, cultural and traditional social roles could dispose

39-56

the perception of altruism and the sense of responsibility; the financial impact of donation is also important. (Ge, Huang, Yuan, Zhou, Gong, 2013)

In this panorama, there is an exception, though. In Iran, during the period between 1998 and 2002, 78% of kidney living donors were male. Programs of the national system offered them some incentives, including awards and gifts for donors; later, reports reflected the male predominance and, of course, a clear imbalance in the distribution of donors. For related living donors, the situation was quite different; the figures about parental kidney donation – 23. 1% female, 10% male donors - were like in the European countries. Presumably, mothers were supposed to volunteer to give organs to their children in need of transplants, believing that sacrifice could be part of their responsibilities as mothers. (Ghods, Nasrollahzadeh, 2003).

Definitively, cultural and social perspectives become relevant in order to approach this issue. Thus, the general conclusion is quite evident; gender bias in donation and transplants does exist worldwide and it bears heavily on kidney donation. It is an outcome of a binary system that assigns gender roles and different responsibilities to agents. Perhaps only specific actions and some stimuli, always due incentives, would alter the usual distribution of living donors.

2.1 Gender distribution

"Gender" refers to the personal and social construction of identity. It is connected with socialization processes, roles, and cultural traditions rather than with biology (Chodorow, 1995). For this reason, it exposes structures, expectations, stereotypes, and power positions in every society. Eventually, distribution of roles doesn't depend on natural characteristics but on social and historical phenomena. In consequence, social asymmetry and the subordination of women depend more on gender constructions than on sex characteristics. Thanks to this notion, gender, critical analyses are able to disclose the historical and cultural roots of this patriarchal system (Scott, 1986). Being a binary system, it usually models different aspects of both, the public sphere and of the private one. In this line, the common data about distribution of donors - male and female - reveal how social, cultural, and historical differences still permeate individuals' decisions about health and quality of life. The evidences concerning the distribution of donors - especially of kidney donors - are so abundant that gender bias should somehow be taken into account.

Why do women seem more willing than men to volunteer and to assume the many risks of live donation? (Steinman, 2006) Beyond medical aspects, psychosocial factors – including some indirect and cultural pressures or a partial sense of duty (Csete, 2008) - would clarify the question of the predominance of women as candidates for living donation. As it happens with race, gender difference affects many decisions concerning health (Boulware et. al., 2002). For this reason, the disparity exposed by data from several countries unveils the complex symbolism and cultural significance of donation as a gift exchange. It has really a material, emotional, and moral merit which has to be encouraged. But, how fair is this exchange? When could it become a burden or just a tyranny of the gift? (Fox, Swazey, 1992, 31-42).

The so-called "gift of life" exemplifies altruistic behavior, generosity, and solidarity; it has indisputable medical, social, and moral value. So far, this message has a different echo in donors, though. The rates of living organ donation indicate gender imbalance. A close consideration of social roles will prove that relationships and unbalanced power are crucial, before donors could even think of giving informed consent. In this sense, the available information about the distribution of donors shows that, several times and in too many countries, this kind of exchange requires real sacrifices (Scheper-Hughes, 2007). The data about the gender gap require some reflection. Which medical needs would actually justify the sacrifice of others? Are there some limits? Besides, as a voluntary decision, living donation represents supererogatory actions; they are far beyond duty. Thus, giving organs for transplants and putting personal health or life at great risk could not be either duty or self-sacrifice.

For instance, the WHO guidelines mentioned the question of undue influence or coercion on living donors (WHO, 2010, Principle 3). At the same time, the general criteria were only efficacy, quality, and safety, in spite of the fact that, years before, gender mainstreaming had been adopted by this same organization; the WHO stated that gender is becoming determinant for health (World Health Organization, 2001). In 2011, the practical guidelines for donation and transplantation provided by the Spanish Transplant Organization included a work methodology and some indicators to improve effectiveness, quality and safety. These recommendations were fundamental for a good practice in the field, but they could have also mentioned equity in addressing possible donors (ONT, 2011). The general protocol for altruistic donation refers to informed consent but it only mentions medical and psychosocial evaluation of potential donors (Ministerio de Sanidad, Política Social e Iqualdad,

39-56

ONT,). In Spain, a specific legislation was passed in 2007 to promote gender equality in every area, including health care. Ley Orgánica 3/2007)

To summarize, so far, available data, reports, and laws didn't draw enough attention to the gender dimension, in spite of the distinct figures about distribution of donors, especially in kidney live donation. For this reason, the usual imbalance still deserves a closer examination. On the one hand, this complex and many-sided issue would require multiple analyses, not merely criticism. On the other, three general arguments had envisaged only some aspects of the issue, like an imperfect or biased communication, different life and health expectancies for women and men, and also the moral angle of donation: living donors' altruism. How sound were these arguments? Were they based on enough evidences? Let's consider the three arguments.

3. Three arguments

- "A. Living donors
- 1. The person in charge of the donation process shall ensure that the donor has been properly informed of at least those aspects relating to the donation......
- 5. Information must be given on the necessity for requiring the applicable mandatory consent, certification and authorisation in order that the tissue and/ or cell procurement can be carried out" (Directive 2004/23 EC, Annex)

The European directive of 2004 insisted on information as basic condition for donors' consent; Members States are responsible for the measures to provide this information and also to protect the collected data, the coding, etc. (arts.13, 14). Information could also be essential to get the message about the need of organs for transplants and, eventually, volunteer and increase donation rates. For this reason, the recent Spanish legislation regulates activities and campaigns to encourage voluntary donation of cells and tissues (Real Decreto 318/2016, arts.1, 4). Regarding information about organ donation, the national campaigns are promoting the donor's card as the first step for potential donors. It is a document not legally valid, but it gives evidence of personal wishes and concern about others' health. The current statistics about a longer life could invite to donate organs for transplants, before and after death. At the same time, there are enough data about different

life expectancy for women and men, not to mention the existing information about the real answer of related and non related living donors. Thus, the campaigns to promote donation and the donor's card would take these differences into account, because eventually communication, health expectancy, and altruistic attitudes have considerable weight on the common outcome, the live donation rates.

1. Information for donors is always decisive, as the European directive stated for cells and tissue procurement. In relation to potential organ donors and the public in general, it is also vital. The question is how neutral could this information and the whole communication process be. In the first place and according to a special European survey, women 'attitudes are more favorable and they are also more open to family discussions about the organ donation - 44% women, 36% men (Eurobarometer, 2010, pp.7-10) -; some studies about people interested in discussing the topic and willing to donate had similar outcome. Women were positive about becoming a donor, more than men, perhaps because gender roles dispose arguments, narratives, and, especially, individual attitudes toward donation and transplant (Thompson, Robinson, Kenny, 2003). In this sense, donation campaigns should take the different roles into account, because communication \(\frac{1}{2} \) is always a process connected with relationships, contexts, and also social views. Gender becomes significant because it is constructed by culture and it is also part of social prescriptions. So, communication is actually shaped by values and practices, including gendered values and biased practices (Wood, 2013, 13-38). For instance, in Spain a recent national campaign appeals to health and altruism, to promote the donor's card. The message seems guite direct, saying that: "You are perfect for others" (ONT, http://www.eresperfectoparaotros.com; Mediaset, <a href="http://www.eresperfectoparaotro www.mediaset.es/12meses/campanas/eres-perfecto-para-otros/). The campaign is directed to everyone; to persuade that donation means solidarity, a generous decision. However, praising donation is different from persuading potential donors. For encouraging them, male or female, the message would require another style of communication about a health problem and the shortage of organs for transplants. As an advertisement, this campaign uses sport as metaphor – winning a competition - when addressing the message to potential donors as altruistic and cooperative persons. Moreover, regional campaigns, videos and cartoons in favor of donation (Coordinadora de Trasplantes de Aragón, ONT, 2010; Tiempo extra, 2015) seem directed mostly to women. For instance, the stories have female characters, from

the death donor to the person who has to assume the decision about donation, also the potential recipient of organs, are women, and the role of caregiver is played by a woman. In sum, these forms of communication eventually reproduce traditional gender roles. How could they be appealing for individuals who don't ever question the conventional male roles?

- 2. Health. A recurrent argument to explain why there are more female than male living donors – especially in kidney donation - invokes the data on the unequal life expectancy for women and men. In fact, data prove that on average there is almost six years difference; in Spain, life expectancy average for women in 2014 was 85.58 years-old, while it was 80.0 years-old for men (Instituto Nacional de Estadística 2015, 270-272; Instituto de la Mujer 2015, http://www.inmujer.gob.es/estadisticas/ consulta.do?area=7). However, according to the Spanish official statistics, access to health services and health expectancy are less favorable for women than for men. For instance, the usual stay in hospitals is similar in female and male young people, but it radically changes when they are twenty years old, because women stayed less time in hospital than men (Instituto de la Mujer, 2015, http://www.inmujer.gob.es/ estadisticas/consulta.do?area=7). The situation only reverses with people in their seventies or in their eighties. Probably, because who is taking care of others, for decades, has to change some preferences: the own health could not be a priority. In sum, living longer doesn't exactly mean getting better care or having better health. In Spain and between 2008 and 2013, health expectancy was somewhat higher for men (Instituto Nacional de Estadística, 2015, 283, 288-289). European statistics showed analogous figures: life expectancy is higher for women in five years (Eurostat, 2015, 46-67), however, health and quality of life expectancies were different. In fact, life additional years usually mean developing an activity with severe limitations. These data about health register an evident gender gap, in spite of the general opinion about female as healthier donors than the male ones. Thus, adequate assessment and information about the actual context are necessary to determine the acceptability of every donor, because voluntary consent could be compromised by other factors (Biller-Andorno, Agich, Doepkens, Schauenburg, 2001).
- 3. Altruism. The argument based on the women conception as responsible, concerned, and altruistic agents takes for granted, by the one hand, that traditional socialization is still in force everywhere; by the other hand, that care giving is a value in itself.

However, the moral value of this kind of "enforced" altruism is questionable, to the same extent that the conventional and strict division of roles (López de la Vieja, 2013, 123-136). Caring for others to the point of compromising the own health or putting life at risk is not a duty; so, responsibility or concern for others' needs has to be balanced with own needs. In relation to potential donors, it is clear that implicit or explicit pressures should be casted aside. Thus, impartial evaluation and counseling of donors are part of an ethical approach to this issue (Steiner, 2004, 1-12). Even so, the argument about altruism and its limits is basically theoretical, because there is not an actual method to measure how altruist people are. But there are enough data about how much time people dedicate to others, who are the actual caregivers, and who are the living donors. The figures seem eloquent, indeed. For instance, official Spanish statistics about people taking leave of absence to attend to others, especially family members, showed that 84.58% were women (Instituto Nacional de Estadística, 2015, Instituto de la Mujer, http://www.inmujer. gob.es/MujerCifras/Conciliacion/ExcedPermisos.htm). Collected data from 2008 to 2014 were almost identical (Ministerio de Empleo y Seguridad Social, 2016, http:// www.empleo.gob.es/es/estadisticas/contenidos/anuario.htm). In consequence, the list of psychosocial factors to evaluate potential donors should also include accurate information about the actual context. In Spain, the protocol for donor's evaluation refers in general terms to psychological evaluation and, at the same time, to health and well-being of the donors (Ministerio de Sanidad, Política Social e Igualdad, 1-24). But, one again, social expectations about women' answer to others' needs are usually more linked with common stereotypes than to moral considerations, based on previous assessment of individual cases and on relevant circumstances. Supererogatory action is always beyond duty; it is a meritorious and admirable behavior that should not be imposed by any means to others. Then an obligatory or compulsory altruism is a plain contradiction, an oxymoron. Moreover, universal moral answers to others' needs would appeal to every female and male agent. Does a universal moral duty make any sense mainly for the half of humankind?

4. Fair distribution

In every society, the general rule for exchanges is based on reciprocity, "something for something" (Gouldner, 1973, 266-299). A stable society requires cohesion

and some balance between the giving and the returning in interactions. However, societies and agents also have a very different rule, in order to attend the needs, to overcome unequal situations, and, eventually, to survive. Helping others and getting help from others have been ans still are necessary in many circumstances; thus, "something for nothing" has to be complementary to reciprocity in exchanges (Gouldner,1960). Regarding to health, it seems evident how crucial this giving without return could become for everyone. Terms like generosity, responsibility, solidarity, beneficence, or altruism translate this additional social rule into a moral language. But "something for nothing" is quite different from "everything for nothing", because altruistic or generous action is always necessary, worthy, but it is not or should not be equivalent to self-sacrifice (López de la Vieja, 2008)

Organ donation for transplants proves that the second rule, giving something for nothing, is actually essential to saving many lives; for this reason, campaigns, protocols, professionals, and national organizations are promoting organ donation, including living donation. The therapy is a real improvement for many patients. At the same time, risks have to be clearly assessed, informing and to protecting donors, especially living donors. The distribution of organ for transplants is a key issue, but the distribution of donors is also very relevant question, who are these donors?

National and international reports and statistics show the figures, different for female and male living donors. The data indicate that gender gap occurs. Before being a donor, before giving informed consent, social environment and agents' common beliefs have their influence on individual decisions. In fact, agents have different roles and opportunities and, in accordance to this, there are diverse expectations about women and men as potential donors. Eventually, gender socialization has substantial consequences for health. So far, conventional ideas about care giving don't help very much to make visible the main cause of gender imbalance in organ donation. This is already regulated; equal rights are also promoted and regulated in many countries, like Spain. But sometimes women's rights are considered claims, legitimate but only general claims, as moral rights without institutional support (López de la Vieja, 2013, 137-159). Actually, formal and real equality are very different questions.

Organ donation is usually successful in many countries, with guarantees for donors; however, the "gift of life" is a very special form of exchange (Spital, Jacobs, 2007).

The undeniable fact is that donation saves lives (Youngner, 2003). At the same time, there are also disturbing experiences and an evident imbalance that still needs to be evaluated. The gender gap is basically due to traditional views about unequal relationships, women as born caregivers, and family as a singular "bond" for donors and recipients of organs. This bond has to be redefined (Biro, 1998), because stereotypes would compromise the general principle of voluntariness in emotionally related donors (Biller-Andorno, Schauenburg, 2001). Gender perspective makes explicit this reality, offering a different approach to organ donation, where autonomy would be compatible with care or real concern for others. But it is absolutely incompatible with any social pressure on potential donors. So, the gender approach enters a caveat about the gift of life, in its more conventional terms.

Imbalance of power usually makes some agents more vulnerable than others. How to face informed and voluntary consent in uneven exchanges? The only right answers could be non exploitation, protection of rights, and fair consideration of donors (Childress, Liveman, 2006, 263-279). Fairness and justice - a basic principle in bioethics – provide a very strong argument to support organ live donation. It saves lives, but it has significant risks for who are giving something vital for another persons, and for nothing in return. The question is the *fair distribution* of donors.

5. Some Conclusions

"3.1.2. Living donations as complementary to deceased donations
Being complementary to deceased donation, living donation is a real alternative
to improving the availability of organs for transplantation. Member States should
therefore deploy the Action Plan to promote the exchange of best practices on
living donation programmes (Priority Action 3)." (Commission of the European
Communities, 2008)

The European Union has defined its action plan to promote donation, including live donation, in order to increase the organs for transplants, because, so far, the demand is higher than the available organs. Quality and accessibility have to be improved, for the sake of donors and recipients. Safety is also important, to promote altruistic donation and, so, to avoid organ trafficking and malpractice. National programs, reports, legislation, and guidelines insist on the procedures and the guarantees,

because individual decision should be respected. For years, the Spanish model has developed a set of good practices for transplants, based on these criteria, with ample success. Beyond all these institutional efforts, the key factor to increase the rates is the voluntary decision of donors. For this reason, informed consent is essential.

Transplants organization and the effective application of the normative framework for donation and transplants eventually depend on individual decisions. But individuals take their decisions in specific circumstances, involved in network of roles, relationships, and social expectations. They have gender roles, with specific rules. In consequence, their answers to others' needs are usually different. Reports and data systematically collected for years and in several countries prove that contexts and gender distribution of roles actually matter for becoming a donor. Before they give informed consent, the social environment and cultural traditions had drawn the lines. Organ donation exemplifies altruism, especially live donation, because of its risks and consequences. However, the different figures raise several questions, about the gender gap

Certainly, this gap has several causes; there is not a simple explanation for it. For this reason, the different roles and expectations about women and men should be taken seriously. In fact, organ donation represents the complementary social rule for exchanges, the giving of something without return, for nothing. It goes beyond the limits of the common rule, reciprocity or something for something, because in special situations people need help and also being helpful to others. The question is, why some agents are supposed to go beyond the reciprocity rule, something for something, putting at risk their own health? Considered as the gift of life, why does donation become tyranny in some cases and for some agents?

Perhaps, there is a problem of communication in donation campaigns, how and to whom is the message actually directed? Could it be also a question of health and life expectancies? So far, altruist attitudes seem more appealing for some agents, as the worldwide figures about caregivers and donors proved. In any case, report, statistics, and evidences indicate that gender is relevant for these issues. Thus, the unbalance in living donation, singularly in renal donation, requires further analysis.

Organ donation has to be voluntary. For this reason the system has to assure safety and quality in transplants, as well as the respect for individual rights. Apart from these

basic premises, generosity and altruism are not duties. They imply supererogatory decisions and actions, which can be considered morally valuable, excellent but never obligatory. Enforced altruism represents a contradiction; in consequence, social pressures are unacceptable in organ donation. On the one hand, the national and international normative framework is very specific about voluntariness and consent. On the other, doubts are raised by the data collected about unbalanced living donation and their normative implications.

The possible solution to the present gap should not be discouraging potential female donors but encouraging and directing the positive message about the "gift of life" to every agent, putting aside stereotypes and conventional beliefs about gender roles. In theory and in practice, everyone could always be more responsible, generous, concerned by others' needs, as well as more altruistic. Eventually, the distribution of donors would be fair; the organizations and transplant models would be more efficient with a balanced live donation. In conclusion, it is a question of real autonomy and, especially, of justice.

References

Biller-Andorno, N. (2011) "Voluntariness in Living-Related Organ Donation", *Transplantation*, 92, 617-619

Biller-Andorno, N. (2002) "Gender Imbalance in Living Organ Donation", *Medicine, Health Care and Philosophy*, 5, pp 199-204

Biller-Andorno, N., Schauenburg, H. (2001) "It's Love? Some Pitfalls in Emotionally Related Organ Donation", *Journal of Medical Ethics*, 27, 162-164

Biller-Andorno, N., Agich, G., Doepkens, K., Schauenburg, H. (2001) "Who Shall Be Allowed to Give? Living Organ Donors and the Concept of Autonomy", *Theoretical Medicine*, 22, 351-368

Biro, D. (1998) "Silent Bond", New York Times Sunday Magazine

Bosch, J. (1999) "Spain Leads World in Organ Donation and Transplantation", JAMA, 282, 1, 17-18

Boulware, L.E., Ratner, L., Cooper, L, Sosa, A., Laveist, Th., Rowe, N. (2002) "Understanding Disparities in Donor Behavior. Race and Gender Differences in Willingness to Donate Blood and Cadaver Organs", *Medical Care*, 40, 85-95

Casares, M. (2010) "Aspectos éticos de la donación renal en vivo", Revista Nefrología, 30, 14-22

Chodorow, N. (1995) "Gender as a Personal and Cultural Construction", Signs, 20, 516-544

Commission of the European Communities (2008), Action Plan on Organ Donation and Transplantation (2009-2015): Strengthened Cooperation between Member States, Brussels, COM(2008) 819/3

DILEMATA,

- Coordinadora de Trasplantes de Aragón, ONT (2010), En el lado de la vida, https://youtu.be/r0xc4I
 PX7Y Accessed 15 December 2016
- Council of Europe (2016) "International Figures on Donation and Transplantation. 2015", Newsletter Transplant, vol.21
- Council of Europe (2002) Additional Protocol to the Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin, European Treaty Series No. 186, Strasbourg
- Csete, M. (2008) "Gender Issues in Transplantation", *International Anesthesia Research Society*, 107, 232-238
- Childress, J., Liveman, C. (2006) Organ Donation, The National Academies Press, Washington
- Directive 2004/23/EC of the European Parliament and of The Council of 31 March 2004 on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells
- Directorate General Health and Consumers. Eurobarometer (2010) *Organ Donation and Transplantation, Brussels*
- Eurobarometer (2010) Organ Donation a and Transplantation, Brussels, TNS Opinion & Social
- Eurostat (2015) Key Figures in Europe, Luxembourg
- Fox, R., Swazey, J. (1992) Spare Parts, New York, Oxford University Press
- Ge, F., Huang, T., Yuan, S. Zhou, Y., Gong, W. (2013) "Gender Issues in Solid Organ Donation and Transplantation", *Annals of Transplantation*, 18, 508-514
- Ghods, A., Nasrollahzadeh, D. (2003) "Gender Disparity in a Live Donor Renal Transplantation Program Assessing From Cultural Perspective", *Transplantation Proceedings*, 35, pp 2559-2560
- GODT (2016) Organ Donation and Transplantation Activity. 2014.
- Gouldner, A. (1973) For Sociology. Renewal and Critique in Sociology Today, Allen Lane, London,
- Gouldner, A. (1960) "The Norm of Reciprocity: A Preliminary Statement" *American Sociological Review*, 25, 161-178
- Instituto Nacional de Estadística, Instituto de la Mujer y para la Igualdad de Oportunidades, Mujeres en cifras, http://www.inmujer.gob.es/MujerCifras/Home.htm, Accessed 16 December 2016
- Instituto Nacional de Estadística, Instituto de la Mujer y para la Igualdad de Oportunidades, Mujeres en cifras, http://www.inmujer.gob.es/MujerCifras/Salud/MorbilidadAccidentalidad.htm, Accessed 16 December 2016
- Instituto Nacional de Estadística, Instituto de la Mujer y para la Igualdad de Oportunidades, Mujeres en cifras, http://www.inmujer.gob.es/MujerCifras/Conciliacion/ExcedPermisos.htm, Accessed 16 December 2016
- Instituto Nacional de Estadística (2105) Mujeres y hombres en España, Madrid
- IRODaT (2016) Preliminary Numbers 2015
- Kayler, L., Rasmussen, C., Dyksra, D., Ojo, A., Port, I., Wolf, R., Merlon, R. (2003) "Gender Imbalancd and Outcomes in Living Donor Renal Transplantation in the United States", *American Journal of Transplantation*, 3, 452-458
- Kayler, L, Meier-Kriesche, H., Punche, J., Campbell, D., Leichtmann, A., Magee, J., Rudich, S., Arenas, J., Merion, R, (2002) "Gender Imbalance in Living Renal Transplantation", *Transplantation*, 73, 27, 248-252

- Ley Orgánica 3/2007, de 22 de marzo, para la igualdad efectiva de mujeres y hombres.
- Ley 30/1979 de 27 de octubre sobre extracción y trasplante de órganos
- Live Organ Donor Consensus Group (2000) "Consensus Statement on the Live Organ Donor", *JAMA*, 284, n.22, 2919-2926
- López del Moral, J.L. (2010) "Bases legales de la donación en vivo", Nefrología, 30, suppl. 2, 23-29
- López de la Vieja, M.T. (2013) Bioética y literatura, Madrid, Plaza y Valdés
- López de la Vieja, M.T. (2008) "Organ Donors. Something for Nothing", López de la Vieja, M.T., Velayos, C. (eds): Educación en Bioética. Donación y transplante de órganos. Bioethical Education. Organ Procurement and Transplantation, Publicaciones Universidad de Salamanca, Salamanca, 69-80
- Manyalich, M., Paredes, D., Vilardell, J. (2008) "Donación de vivo para trasplantes. Aspectos generales", Matesanz, R. (ed.) *El modelo español de coordinación y trasplantes*, Madrid, Aula Médica, pp.181-185
- Matesanz, R. (2008) "El modelo español de donación y trasplante de órganos: la ONT", Matesanz, R. (ed.) El modelo español de coordinación y trasplantes, Madrid, Aula Médica, pp.11-26
- Matesanz, R., Dique, M., Sagredo, E., Vega, R. (2008) "Prensa, donación y trasplantes", Matesanz, R. (ed.) El modelo español de coordinación y trasplantes, Madrid, Aula Médica, 215-238
- Mediaset, Eres perfecto para otros, http://www.mediaset.es/12meses/campanas/eres-perfecto-para-otros/ Accessed 16 December, 2016
- Ministero della Salute (2016) "Il genere come determinante di salute", Quaderni del Ministero di Salute, 26
- Ministerio de Empleo y Seguridad Social (2016), http://www.empleo.gob.es/es/estadisticas/contenidos/anuario.htm Accessed 16 December 2016
- Ministerio de Sanidad, Política Social e Igualdad, ONT, *Protocolo de donación renal altruista*, Accessed 16 December, 2016
- Oien, C., Varber, A, Leivestad, T, Pfeffer, R., Fauchald, P., Os, I. (2005) "Gender Imbalance among Donors in Living Kidney Transplantation: The Norwegian Experience", *Nephrology. Dialysis Transplant*, 20, pp 783-789
- Oppenheimer, F. (2008) "El trasplante renal de donante vivo", Matesanz, R. (ed.) El modelo español de coordinación y trasplantes, Madrid, Aula Médica, 187-191
- ONT (Organización Nacional de Trasplantes) (2015) Memoria de actividad
- ONT (Organización Nacional de Trasplantes) (2015a) Trasplante renal con donante vivo. España 2015
- ONT (Organización Nacional de Trasplantes), (2014) Trasplante renal con donante vivo. 2014
- ONT (Organización Nacional de Trasplantes), (2011) Guía de buenas prácticas en el proceso de donación de órganos
- ONT (Organización Nacional de Trasplantes) Eresperfecto para otros, http://www.eresperfectoparaotros.com/ Accessed 16 December, 2016
- OPTN (2016), https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/# Accessed 16 December, 2016
- Puoti, F., Ricci, A., Nanni-Costa, A., Ricciardi, W., Malorni, W., Ortona, E. (2016), "Organ Transplantation and Gender Differences: A Paradigmatic Example of Intertwining Between Biological and Sociocultural Determinants", *Biology and Sex Differences*, 7-35

- Real Decreto 318/2016, de 5 de agosto, por el que se regula el procedimiento de autorización para la realización de actividades de promoción y publicidad de la donación de células y tejidos humanos.
- Real Decreto 1723/2012, de 28 de diciembre, por el que se regulan las actividades de obtención, utilización clínica y coordinación territorial de los órganos humanos destinados al trasplante y se establecen requisitos de calidad y seguridad
- Real Decreto 2070/1999 de 30 de diciembre, por el que se regulan las actividades de obtención y utilización clínica de órganos humanos y la coordinación territorial en materia de donación y trasplante de órganos y tejidos
- Rodriguez-Arias, D., Wright, L., Paredes, D. (2010) "Success Factors and Ethical Challenges of the Spanish Model of Organ Donation", *The Lancet*, 376, 9746, 1109-1112
- Scheper-Hughes, N. (2007) "The Tyranny of the Gift: Sacrificial Violence in Living Donor Transplants", American Journal of Transplantation, 7, 507-511
- Schicktanz, S., Schweda, M., Wöhlke, S. (2010) "Gender Issue in Living Organ Donation: Medical, Social, and Ethical Aspects", Klinke, I., Wiesemann, C. (eds.) Sex and Gender in Biomedicine, Universitätsverlag, Göttingen, 35-55
- Scott, J. (1986) "Gender: A Useful Category of Historical Analysis", *The American Historical Review*, 91, 1053-1075
- Spital, A., Jacobs, Ch. (2007) "The Beauty of the Gift: The Wonder of Living Organ Donation", *Clinical Transplantation*, 21, 435-440
- Steiner, R., Bennett, W., Gert, B. (2004) "Ethical Approaches to Living Kidney Donor Education and Acceptance", Steiner, R. *Educating, Evaluating, and Selecting Living Kidney Donors*, New York, University of California, Kluwer, 1-12
- Steinman, J. (2006) "Gender Disparity in Organ Donation", Gender Medicine, 3, 246-252
- The Ethics Committee of Transplantation Society (2004) "The Consensus Statement of the Amsterdam Forum on the Care of the Live Kidney Donor", *Transplantation*, 78, n. 4, 491-492
- Thiel, G., Nolte, C., Tsinalis, D. (2005) "Gender Imbalance in Living Kidney Donation in Switzerland", *Transplantation Proceedings*, 37, p. 592-594
- Thompson, T., Robinson, J., Kenny, R.W. (2003) "Gender Differences in Family Communication about Organ Donation", Sex Roles, 49, 587-596
- Tiempo extra (2015) https://www.youtube.com/watch?v=zOhUlaeqWMs, Accessed 16 December 2016 United Nations (2015) Human Development Report
- Wood, J. (2013) Gendered Lives: Communication, Gender, and Culture, Wadsworth, Boston
- World Health Organization (2010) *Guiding Principles on Human Cell, Tissue and Organ Transplantation*, WHA 63.22
- World Health Organization (2009) Global Glossary of Terms and Definitions of Donation and Transplantation, Geneva
- World Health Organization (2001) Gender Mainstreaming Health Policies in Europe
- Youngner, S. (2003) "Some Must Die", Zygon, 38, 705-724