A COMPARATIVE ANALYSIS OF THE ATTITUDES OF BULGARIAN AND ROMANIAN STAKEHOLDERS TOWARDS LIVING ORGAN DONATION

Mihaela FRUNZA, Assya PASCALEV, Yordanka KRASTEV, Adelina ILIEVA

The online version of this article can be found at: www.rcis.ro, www.doaj.org and www.scopus.com

Published by:
Expert Projects Publishing House

On behalf of:
„Alexandru Ioan Cuza” University,
Department of Sociology and Social Work
and
Holt Romania Foundation
REVISTA DE CERCETARE SI INTERVENTIE SOCIALA
is indexed by ISI Thomson Reuters - Social Sciences Citation Index (Sociology and Social Work Domains)
A Comparative Analysis of the Attitudes of Bulgarian and Romanian Stakeholders towards Living Organ Donation

Mihaela FRUNZA¹, Assya PASCALEV², Yordanka KRASTEV³, Adelina ILIEVA⁴

Abstract

Recently, the European Union has specifically funded several research and cooperation projects aiming to expand living donation in Europe. The project Living Organ Donation in Europe (EULOD) aimed at identifying and analyzing barriers to living organ donation in Europe, and formulating best practice proposals. Statistics show that Romania and Bulgaria have been ranking last among the EU countries in combined organ donation rate and the number of transplants per million population. Two focus groups were conducted in Bulgaria and Romania as part of scientific Work Package 2 of EULOD. The focus groups included major stakeholders such as transplant coordinators, nephrologists, medical lawyers and patients’ representatives. English translations of the focus group transcripts were coded in NVivo 9, and analyzed by a team of researchers. Particular attention was paid to the ethical and legal issues identified in the participants’ answers. Both the Bulgarian and Romanian participants emphasized the merits of their respective legislation regulating living donation. Respondents remained skeptical about the possibility of implementing Samaritan donation and of offering financial compensations for living donors and, considered them as steps towards organ trade. The Bulgarian participants identified financial obstacles as a major barrier to organ transplantation, whereas the Romanian stakeholders were more concerned about the institutional barriers. The similarities and differences between the two countries show that measures designed to foster living donation in Europe need to take into account the specific contexts and the unique cultural, moral, political and legal characteristics of the relevant countries.

Keywords: living donation, transplantation, ethics, law, trust, Romania, Bulgaria, EU

¹ Babes-Bolyai University, Department of Philosophy, Cluj, ROMANIA. E-mail: mihafrunza@gmail.com
² Bulgarian Center of Bioethics, Sofia, BULGARIA. E-mail: apascal2003@gmail.com
³ Bulgarian Center of Bioethics, Sofia, BULGARIA. E-mail: yordanka.krastev@bio-ethics.net
⁴ Bulgarian Center of Bioethics, Sofia, BULGARIA. E-mail:adelina.ilieva@bio-ethics.net
Introduction

Due to the positive outcomes for recipients and relatively low risks for donors, living organ donation (LOD) has been promoted as a viable alternative complementing deceased donation. Many countries have established living donor programs in parallel with deceased donor ones, and some of them have reported notable donation rates of kidneys from living donors, comparable to the rates from deceased donors. For instance, in 2010 in the US there were 6,276 kidney transplants from living donors (19.8 per million population (p.m.p)) out of the total of 16,898 kidney transplants (2010 International Donation and Transplantation Activity). In absolute numbers, there were 7,943 deceased donors and 6,558 living donors (for all organ types). In the same year, in European Union (EU) there were 3,616 kidney transplants from living donors (7.2 p.m.p.) out of the total of 18,246 kidney transplants (2010 International Donation and Transplantation Activity, 2011). In recent years, EU has funded several research and cooperation projects aimed at stimulating living organ donation, e.g. ELIPSY (2009-2011) EULID (2007-2009), EULOD (2010-2012). The latter project, Living Organ Donation in Europe (EULOD), aimed at identifying and analyzing the best practices in promoting living organ donation.

This article is based on research conducted as part of the scientific Work Package 2 of EULOD project. It had several goals: “1) collecting data and obtaining an overview of living unrelated donation practices in Europe; 2) gaining insight in how pre-transplant psychological screening and post-transplant follow-up for living unrelated donors is organized; 3) gaining insight in attitudes and perceptions of European health care professionals towards living donation; 4) identifying possible legal, ethical and financial considerations of health professionals that act as a barrier towards living donation; and 5) identifying strategies for implementation of screening and care for living donors.”

It is well known that donation rates vary greatly among the EU member states (Lennerling et al., 2013). Statistics show that Romania and Bulgaria consistently rank last in EU with lowest combined donation rate for transplantation and the number of transplants p.m.p. While low in comparison with most EU countries, the transplantation rates in Bulgaria and Romania are similar to the neighboring countries from the Balkan region (Spasovski et al., 2012: 1). The rates of living donation are slightly different, with Romania having higher numbers of living donors, but remaining below the EU average (see Table 1).
Table 1. Comparison between transplants from Romania and Bulgaria

<table>
<thead>
<tr>
<th>Year</th>
<th>Country</th>
<th>Total number of kidney Tx</th>
<th>Rate (p.m.p.)</th>
<th>Kidney Tx from Living donors</th>
<th>Rate (p.m.p.)</th>
<th>Total number of Liver Tx</th>
<th>Rate (p.m.p.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>Romania</td>
<td>108</td>
<td>4.70</td>
<td>86</td>
<td>3.74</td>
<td>8</td>
<td>0.35</td>
</tr>
<tr>
<td></td>
<td>Bulgaria</td>
<td>82</td>
<td>10.25</td>
<td>30</td>
<td>3.75</td>
<td>0</td>
<td>0.00</td>
</tr>
<tr>
<td>2001</td>
<td>Romania</td>
<td>166</td>
<td>7.55</td>
<td>129</td>
<td>5.73</td>
<td>12</td>
<td>0.55</td>
</tr>
<tr>
<td></td>
<td>Bulgaria</td>
<td>21</td>
<td>3.00</td>
<td>17</td>
<td>2.42</td>
<td>0</td>
<td>0.00</td>
</tr>
<tr>
<td>2002</td>
<td>Romania</td>
<td>175</td>
<td>8.33</td>
<td>151</td>
<td>7.19</td>
<td>16</td>
<td>0.76</td>
</tr>
<tr>
<td></td>
<td>Bulgaria</td>
<td>29</td>
<td>4.14</td>
<td>13</td>
<td>1.85</td>
<td>0</td>
<td>0.00</td>
</tr>
<tr>
<td>2003</td>
<td>Romania</td>
<td>166</td>
<td>7.90</td>
<td>150</td>
<td>7.14</td>
<td>13</td>
<td>0.61</td>
</tr>
<tr>
<td></td>
<td>Bulgaria</td>
<td>34</td>
<td>4.85</td>
<td>16</td>
<td>2.28</td>
<td>0</td>
<td>0.00</td>
</tr>
<tr>
<td>2004</td>
<td>Romania</td>
<td>189</td>
<td>9.00</td>
<td>168</td>
<td>8.00</td>
<td>16</td>
<td>0.76</td>
</tr>
<tr>
<td></td>
<td>Bulgaria</td>
<td>34</td>
<td>5.00</td>
<td>21</td>
<td>3.00</td>
<td>1</td>
<td>0.14</td>
</tr>
<tr>
<td>2005</td>
<td>Romania</td>
<td>182</td>
<td>8.70</td>
<td>163</td>
<td>7.80</td>
<td>11</td>
<td>0.50</td>
</tr>
<tr>
<td></td>
<td>Bulgaria</td>
<td>33</td>
<td>4.70</td>
<td>23</td>
<td>3.28</td>
<td>8</td>
<td>1.85</td>
</tr>
<tr>
<td>2006</td>
<td>Romania</td>
<td>204</td>
<td>9.70</td>
<td>165</td>
<td>7.90</td>
<td>20</td>
<td>0.90</td>
</tr>
<tr>
<td></td>
<td>Bulgaria</td>
<td>32</td>
<td>4.57</td>
<td>2</td>
<td>0.28</td>
<td>10</td>
<td>1.57</td>
</tr>
<tr>
<td>2007</td>
<td>Romania</td>
<td>222</td>
<td>10.60</td>
<td>152</td>
<td>7.20</td>
<td>31</td>
<td>1.50</td>
</tr>
<tr>
<td></td>
<td>Bulgaria</td>
<td>27</td>
<td>3.85</td>
<td>16</td>
<td>2.28</td>
<td>7</td>
<td>1.00</td>
</tr>
<tr>
<td>2008</td>
<td>Romania</td>
<td>227</td>
<td>10.80</td>
<td>112</td>
<td>5.30</td>
<td>43</td>
<td>2.10</td>
</tr>
<tr>
<td></td>
<td>Bulgaria</td>
<td>17</td>
<td>2.42</td>
<td>11</td>
<td>1.57</td>
<td>9</td>
<td>1.28</td>
</tr>
<tr>
<td>2009</td>
<td>Romania</td>
<td>203</td>
<td>9.67</td>
<td>113</td>
<td>5.38</td>
<td>32</td>
<td>1.50</td>
</tr>
<tr>
<td></td>
<td>Bulgaria</td>
<td>32</td>
<td>4.57</td>
<td>15</td>
<td>2.14</td>
<td>13</td>
<td>1.85</td>
</tr>
<tr>
<td>2010</td>
<td>Romania</td>
<td>212</td>
<td>10.10</td>
<td>88</td>
<td>4.19</td>
<td>51</td>
<td>2.43</td>
</tr>
<tr>
<td></td>
<td>Bulgaria</td>
<td>48</td>
<td>7.00</td>
<td>12</td>
<td>1.71</td>
<td>15</td>
<td>2.14</td>
</tr>
</tbody>
</table>


The table above reveals that, although living donation rates for kidneys in Romania have been constantly higher than in Bulgaria, the numbers of living donors are decreasing, whereas the living donation rates in Bulgaria have varied widely over the last decade.
Figure 1. Donation rates for kidneys of all EU countries, 2010. Blue bars represent the total kidneys transplant rate, while red bars represents the rates of transplant from living kidney donors.

Figure 2. Liver donation rates for all EU countries, 2010

Source: International Donation and Transplantation Activity for 2010, data based on the Global Observatory on Donation and Transplantation.
From Figure 1 we can see that both Romania and Bulgaria are in a cluster of countries with a moderate activity of living kidney transplants (compared with countries with rates higher than 10 p.m.p (such as the Netherlands, Cyprus, Sweden, Denmark UK). In the case of liver living transplants (Figure 2), only a handful of countries have significant transplant rates (such as Belgium, Germany or Sweden), and the rate in both countries is comparable with the EU average.

Figure 3. Kidney transplants from living donors compared to total number of transplants, Romania 2000-2010.

Figure 4. Kidney transplants from living donors compared to total number of transplants, Bulgaria, 2000-2010.
From subsequent figures, we see that, in absolute numbers, the proportion of living kidney donors decreased in Romania from figures ranging between 80-90% of the total number of kidney transplants in the period 2003-2006 towards 40-50% since 2007 (Figure 1). In Bulgaria, the proportion of living donors fluctuated between 2000 and 2005, then dropped dramatically in 2006 (to the lowest proportion of 6.25% of the total kidney transplants), then varied between 25-60% (Figure 2). In the case of living liver transplantations, the low donation rates are more difficult to interpret and they are comparable with the EU average (most values are subunitary, and the EU average in 2010 was 0.48).

The goal of this paper is to understand the factors contributing to the low living donation rates in Romania and Bulgaria on the basis of the opinions and attitudes of the stakeholders. How did the stakeholders interpret the low numbers of living donors in the two countries? Why are there so few living donors? Did the stakeholders believe that there were specific barriers contributing to the low numbers of living donations? What suggestions did they have for improving the situation and stimulating the increase the number of living donors? The input of stakeholders was important for clarifying several aspects connected with the transplant activity: the reasons for the low donation rates in the two countries, the perceived barriers for living donor transplantation, as well as getting access to the insiders’ view of living organ donation. For a detailed account of other aspects concerning transplantation from living donors, especially the Romanian case see (Gavriluta & Frunza, 2012 a,b; Frunza, 2009).

Methodology

As part of the scientific Work Package 2 of EULOD, a series of focus groups were conducted in four EU countries with relative low LOD rates. This paper presents the results from the focus groups conducted in Bulgaria and Romania in the summer of 2011, while the analysis of all the focus groups was published elsewhere (Pascalev et al., 2013). In the case of Romania and Bulgaria, each group consisted of six participants, who were health care professionals involved in transplantation (physicians, transplant coordinators), a lawyer with specialty in medical law and members of patient organizations involved in organ donation and transplantation. A total of twelve participants took part in the focus groups, which were facilitated by two facilitators. The focus groups used a uniform protocol and a list of eight questions aiming at identifying possible barriers to LOD (legal, ethical, medical, religious, financial, institutional, and social). All potential participants were informed of the purpose of the focus group and their oral consent was obtained beforehand. The focus groups were conducted in the participants’ native languages in order to ensure maximum freedom of expression and accuracy of meaning. The discussions were audio-recorded, transcribed verbatim and
translated in English. The focus group data was de-identified and each participant was assigned a unique coded identifier. The transcripts were analysed qualitatively by the authors using a combination of manual and a software-assisted coding (NVivo 9).

Results and Discussions

The importance of trust

One of the topics that emerged as focal point in the qualitative analysis was the issue of trust in the medical system. According to Oxford Dictionary, trust can be defined as “firm belief in the reliability, truth, or ability of someone or something” or as “the state of being responsible for someone or something” (http://www.oxforddictionaries.com/definition/english/trust). While most definitions underline the link between trust and responsibility, the definitions are not very good in capturing the multiple meanings and different uses of “trust” in various applied fields, and especially in the field of healthcare. Recently, the issue of trust in the healthcare system has become the subject of numerous articles in the social sciences (Abelson et al., 2008). One of the most comprehensive explorations of the place of trust in bioethics can be found in Onora O’Neill’s, book Autonomy and Trust in Bioethics (O’Neill, 2002). Although O’Neill does not offer a definition of trust, she juxtaposes it with autonomy. While autonomy plays a central role in the development of Western medical ethics, trust remains marginal and is rarely mentioned. O’Neill notes that the loss of trust becomes increasingly a problem of medical practices, which undermines autonomy: “From the patient’s point of view, however, the most evident change in medical practice of recent decades may be loss of a context of trust rather than any growth of autonomy. He or she now faces not a known and trusted face, but teams of professionals who are neither names nor faces, but as the title of one book aptly put it, strangers at the bedside” (O’Neill, 2002a: 20).

From a practical point of view, this general mistrust towards the physician as a stranger is amplified by the mistrust in healthcare institutions documented by opinion polls. A poll conducted in the EU in 2006 showed that only 69% of the EU citizens trusted their doctors (Medical Errors, Special Eurobarometer, 2006). The results included also figures from then candidate countries Bulgaria and Romania. In these countries, the numbers showed an even greater level of mistrust: In Bulgaria, only 35% of respondents trusted their doctors. In Romania 58% of respondents worried that they are going to suffer from a medical error, compared with the EU average of 40%. Concerning the likelihood that a patient could suffer from medical errors in the hospital, 80% of Bulgarians and 63% of Romanians
ranked higher than the average of 47% for the EU (Medical Errors, Special Eurobarometer, 2006).

More recent figures show a similar level of mistrust. In 2011, a national opinion poll presented by Sofia News Agency Bulgarian reported that only 5% of Bulgarian patients trust the healthcare system, while “at total of 75% of Bulgaria’s patients are convinced that the healthcare system in the country is not functioning properly” (Guineva, 2012). In Romania, the figures are similar: a 2011 study showed that only 6% of respondents from the general population trusted the public healthcare system (*** 2011).

The issue of trust was raised also by the two focus groups studied by EULOD. We explored the occurrences of trust and its related vocabulary (synonyms and antonyms) in order to observe the level and dimension of the issue perceived by our respondents. Although the topic of trust was not specifically mentioned by the moderators, it emerged as focal point in both groups, a fact that deserves to be addressed. The focus group participants in both countries acknowledged the lack of trust in the transplantation programs. They believed that institutional barriers impeded the advancement of LOD and transplantation.

“Because there will always be doubts. This one is your cousin, why to him and not to the other... again we reach the point that there is distrust in the system in Bulgaria” (P5, Bulgaria).

“Because one of the reasons is that there are huge suspicions related to the health system in general and to the transplant section in particular” (P1, Romania).

Trust as a concept was found in a multiple occurrences. In our further analysis we discovered a variety of situations affected by the lack of trust. For example, Romanian focus group informants identified mistrust of population in transplant program, mistrust of patients in dialysis, mistrust of doctors towards the donors, and mistrust of priests towards the donors. These multiple occurrences add to the picture of general mistrust in the health system (*** 2011), especially since the respondents voicing it are parts of the health systems (physicians, patients representatives).

Mistrust of population in transplant program

In this example, a transplant specialist conditions the acceptability of the transplant program according to the type of relation between donor and recipient. Admits that the trust in the system is very low and could be undermined by the perspective of Samaritan donation (which is not forbidden by law, but is non-existent in practice):
“Now let’s go back to the good Samaritan, in Romania, as my colleague said, I believe that if we tried, if we tried only to bring into discussion such a system, the transplant program would be completely terminated. That small amount of trust we still have in the health system” (P1, Romania).

Samaritan donation, or more accurately “unspecified donation” (Dor et al., 2011) represents a type of transplantation where the recipient donates anonymously to the waiting list. Although in Romania it is not specifically forbidden, the specialists believe that the mere possibility of discussing the subject would undermine the trust in the health system. This can be related both to the low probability of finding available living donors for unspecified donation and to the effects of this type of donations for the transplant system in general. Unspecified donation is a topic that could attract media attention in a sensationalist way, and this is something professionals are trying to avoid, because it can provoke damages. We can read critical articles in sensationalist journals each time a celebrity performs a transplant, one recent example being the case of a well-known actor (Alexa, 2013).

Mistrust of patients in dialysis

“We were very lucky: there was a saving meeting downstairs, at the clinic, when the dialysis patients met professor and even with people with transplants of until eight years old. And this convinced many of us them to run from dialysis to transplant” (P6, Romania).

In this example, a former dialysis patient tells a personal story of how he discovered transplantation as a better alternative than dialysis. Dialysis and transplantation are perceived to be in a conflicting relation, as competing for the same patients (the patients run from one system to the other). Transplant program appears not necessarily as more safe/ trustworthy per se, but rather as a better alternative than dialysis.

Mistrust of doctors towards the donors

Here, a transplant specialist explains the role of the ethics committee in the approval of donation. We can note the insistence on possible negative factors (“suspicions”) on behalf of the commission members. This insistence might be due to an effort to clear up all possible types of rewards a donor might unreasonably expect, yet the effect is of negatively emphasizing the suspicions towards would-be living donors.
“If one of the three does not agree or has suspicions that there is any kind of reward of any type, gift, which is not only material reward, even if the donor receives a new job or he is provided with the accommodation or ... any kind of suspicions, automatically advises against donation of the pair” (P1, Romania).

**Mistrust of priests towards the donors**

Transplant patient depicts a situation in which a priest formulates doubts about the donation process.

“I have an aunt who said that they were told in the church, the preacher said that he, we agree with this (with the transplant), only that they have a suspicion. Precisely what the doctor said at the beginning. What if they give money?” (P6, Romania).

In this case, the reference is more imprecise (a third person – an aunt of the participant – who heard something in church). It is not clear who was suspected for providing the money – the donor himself, the doctor, the recipient – and certainly no kind of objective proof is mentioned in this narrative. However, this type of personal narratives, even if vague and subjective, more at the level of gossip, do have an impact on how such a phenomenon is perceived. Similarly, the Bulgarian focus group participants mentioned respectively mistrust of doctors towards lawyers, mistrust of doctors towards the political system and mistrust of patients in the state.

**Mistrust of doctors towards lawyers**

In some examples, transplant specialists question the capacity of legal representatives to protect them from abuses of the Ministry of Health and false allegations from patients. The lack of cooperation between doctors and lawyers is based on lack of knowledge and on fear. The issue of fear is very indicative of the lack of trust and, thus is partially irrational and hard to change. Although the issue of doctors’ mistrust towards lawyers specifically surfaced in the focus group from Bulgaria, the two aspects – of mistrust and of legal system – were apparent in the Romanian focus group as well (see below the section “Counting on the law”). It has to do with respondents’ inability to understand and operate with the subtleties and nuances of a law that circumvents their relation with patients. This particularity of having a law that dictates and restricts who can and cannot be a patient (a living donor) is a unique feature of transplant legislation.

“This is the principle. But what I wanted to say is that there is mistrust between doctors and lawyers” (P5, Bulgaria).
“Unfortunately, the lawyer can hardly support the full legality of the procedure if he does not rely on the doctor and if the doctor is not sufficiently informed” (P5, Bulgaria).

“... So from now on the reason for that fatal outcome will be important, but what should we do then? Are we legally protected as doctors?” (P2, Bulgaria).

“As long as big hospitals, the Ministry included, are deprived of legal specialists, who are to protect their interest and who are familiar with health care, there cannot be such a team – no way” (P6, Bulgaria).

“This is a large obstacle for transplantation, namely the lack of teams comprising doctors and lawyers. And that doctors’ fear of lawyers” (P5, Bulgaria).

**Mistrust of doctors towards the political system**

Patient representative explains the frustration by the way politicians handle the healthcare system:

“What happens at the moment is unfortunately unprecedented compared to the past few years. The healthcare system is collapsing. This deprives them [transplant professionals] of faith, and deprives us [patients] of faith” (P6, Bulgaria).

**Mistrust of patients in the state**

Transplant patients complain about the fact that the state does not understand the complexity of problems faced by them and is mistreating them:

“[Our] patient organization during the past few years is somehow trying to make the state to take care of its transplanted patients regardless where and why they have been subject to transplantation” (P6, Bulgaria).

The above examples demonstrate the ubiquitous presence of distrust which is not only manifested by patients towards transplantation programs, but contaminates the relations among transplant professionals, patients, and other stakeholders, culminating in the mistrust in the state itself. This migration of mistrust from the government to the public health system and vice versa is well documented in the literature (Abelson *et al.*, 2009: 64). In order to prevent or reverse this phenomenon, careful analysis of the way trust is earned and acquired is needed, as well as its relations with social capital and welfare (Voicu & Voicu, 2011: 75). As O’Neill claims, establishing trust is a hard enterprise because it can easily be granted and lost: “Loss of trust, it seems, is often reported by people who continue to place their trust in others; reported perceptions about trust are not mirrored in the ways in which people actually place their trust” (O’Neill, 2002a:
9). Although the meanings and consequences of mistrust in national health systems may be debatable, the solutions seem clear: “When public trust appears to be on the decline, policy makers take measures to try to restore it.” (Abelson et al., 2009: 63). However, as shown above, trust does not seem to be a goal of the health care system.

**Counting on the law**

One possible escape from mistrust seems to be the emphasis on rules and regulations which, if enforced, could safeguard the stakeholders from the effects of mistrust. It is not surprising that both Bulgarian and Romanian professionals focused on the legislative aspects of LOD, underlining the merits of their legislation in framing and regulating living donation.

“Bulgarian law on organ transplants is a modern law, which is absolutely comparable with the laws in the European countries. This is a European law. Perhaps it is among the few laws in Bulgaria, which are absolutely comparable” (P1, Bulgaria).

“In 2006 a very restrictive legislation entered into force, probably the most restrictive one in the whole Europe, regarding the donation from living donors, (consequently) those scandals with European echoes diminished” (P1, Romania).

Both focus group participants felt the need to compare their national legislation with the general EU framework, which can be explained by the fact that the discussion was taking place in the framework of an EU project. Another possible explanation is that many laws from the two countries had been recently harmonized to conform to the EU framework. Participants from both countries praised the modern character of the law, and Romanian participants viewed the restrictiveness of the law as a positive feature helping to lessen the doubts and suspicions of the public concerning transplantation. The claim that Romanian transplant legislation is the most restrictive one in Europe is debatable. Some EU countries have legislations imposing restrictions that are not present in the Romanian law, i.e., the existence of special kinds of genetic relations between donor and recipient.

However, both types of perceptions could be interpreted as strengthening the position of the transplantation field inside the national health system. In a health care system characterized by mistrust among the population, professionals seem to feel the need to distance themselves from the national realities by emphasizing that the transplantation field is European (i.e. superior), even if the operations take place in Romanian and Bulgarian hospitals.

The Romanian and Bulgarian transplant laws are similar in many respects, although there are some differences concerning the relationship between the donor and the recipient, as well as the required steps for donation approval. In Bulgaria,
the law requires that the recipient and the donor are genetically or emotionally related, while in Romania there are no legal limitations.

“Art. 26 of the Law on transplantation of organs, tissues and cells reads that a donor may be only a person (only but it turns out that these are many persons) who is a husband or wife or a relative of the recipient from a direct or lateral family branch, the range extending up to the fourth generation. Perhaps, this is the greatest degree of relationship, which the law recognizes, more than even in the heritage legislation” (P5, Bulgaria).

“No. These are medical limitations, not legislation limitations, which only the doctors assessing the respective pair may evaluate... the law cannot impose” (P1, Romania).

However, even if the laws differ in the restrictions they impose on the donor-recipient pair, in reality, the situation in the two countries does not differ significantly. Thus, in Romania, unspecified donations or direct specified donations among individuals without an emotional or genetic relation are infrequent (Frunza, 2009). In Bulgaria, such donations are banned but the ban has challenging ethical consequences resulting in unjustified discrimination against certain categories of persons such as orphans who are ward of the state (Pascalev, 2011). Another difference between the two countries is the process of approval of living donations to take place. In the case of Romania, every LOD requires the approval of an Ethics Committee. Romanian respondents noted repeatedly that this requirement was a serious improvement from the previous legislation. Generally, the participants approved of the restrictive character of the law. Bulgarian stakeholders stated that there was no independent Ethics Committee for LOD, and identified its absence as a barrier to LOD.

“There should be a ssethics committee, which is completely independent of the people involved in transplantations, and which is to determine whether a certain living donor is suitable or not[...] This committee is among the places where the living donor may give up and it can say that the waiver is for medical reasons, to ensure there is no tension between the donor and the recipient.[...] each hospital has its own [ethics] committee, which are not involved in this process. They are outstanding professionals” (P1, Bulgaria).

“In order to perform a transplant from a living donor, irrespective of the degree of relation between the donor and the recipient, that is including the first degree relatives, all the pairs have to go through an Ethics Committee in the first place. An Ethics Committee is made up of three members who have no connection with the transplant team: a member which is representative of the College of Physicians, a psychologist and a member of the clinic where the transplants are performed, which does not have any connection to the transplant team” (P1, Romania).
However, the Bulgarian transplant law requires the establishment of an Ethics Committee on Transplantation, however only one such committee exists, at the Council of Ministers level. The law specifies some general attributes of this Committee such as its composition, term of membership, the role of the Committee and the type of its meetings: Article 12.(1) Under Council of Ministers shall be established and Ethics Committee on Transplantation. (2) Committee under paragraph 1 shall consist of nine members and shall include mandatory physicians, psychologists, theologians, and lawyers. The staff of the Committee shall be determined by a decision of the Councils of Ministers on proposal of the Minister of Health, for a period of five years. (3) Persons, conducting activities under article 2, shall not be members of the Ethics Committee on Transplantation. (4) Ethics Committee on Transplantation shall give opinions on deontological and ethical issues in the field of transplantation and shall permit collecting of organs and tissues from persons in cases under this law.”(Law on Transplantation,2005).

Knowledge of the legal requirements of LOD

Another similarity between the two countries was the lack of knowledge of the relevant law by the medical practitioners. Except for a few people specialized in medical law, the transplant professionals in the focus groups were not familiar with the legal requirements of LOD. The Bulgarian respondents provided ample details on this matter.

“I must admit that I am not familiar with the requirements of the legal system. There were no legal issues in my experience with living donation. ... The documents that are prepared are presented to us with the relevant signatures and seals, etc. and we are not personally and specifically engaged with that” (P4, Bulgaria).

“We have carried out only those transplantations, where there were no legal problems. Maybe it is our mistake that we are not completely aware of the legislation. But simply my work is not related to that [awareness of legal requirements]” (P4, Bulgaria).

“And such a thing as an intern who understands medical law does not exist in Bulgaria. I have personal experience” (P5, Bulgaria).

The physicians’ knowledge of the law is not better in Romania. Romanian transplant professionals are not required to study the technicalities of the law, with the exception of the transplant coordinator. The health legislation is subject to frequent changes in Romania (Vlădescu et al., 2008: 168) and empirical studies show that physicians fail to incorporate the relevant legal knowledge in their day-to-day practice (Nanu et al., 2011). Another aspect related to the legislation that was specifically mentioned in the Bulgarian focus group was the high possibility
of lawsuits as a result of unsuccessful operations. This represented a concern for the physicians because they are not familiar with the law.

“Almost with every rejected organ, not to say exitus, there are immediate proceedings begun with a claim, where the claim coincides with the price charged by foreign clinics for re-transplantation. At the moment, we have already 4 lawsuits” (P2, Bulgaria).

“Samaritan Donation” and financial compensations

Participants from both countries were skeptical about the possibility of implementing unspecified donation and direct specified donation with no genetic or emotional relation (the so-called “Samaritan Donation”) (Dor et al., 2011). In answer to the question: “Is it possible that people be allowed to donate organs to people, with whom they have neither emotional nor genetic relation? I.e. only if they want to help someone?”

“I don’t think so. This is a prerequisite for trade in organs. The emotional relationship is not the most appropriate solution – there should be a genetic relation” (P1, Bulgaria).

“The Netherlands is the only country which uses the Good Samaritan system. ..They are the only ones who adopted laws in this sense; in Romania there is no such thing.”(P1, Romania).

“For example, our people, the Romanians, they would rather sell their kidneys, instead of donating them. And so it happens that a transplant can be performed in Romania from a living donor only if the recipient comes with his own donor” (P1, Romania).

A further similarity was related to the distrust in almost all types of financial compensation for living donors. Such compensation was associated with payments for organs and was viewed as the first step towards organ trade.

“I think that donation should be a completely gratuitous act. Because the minute one mentions compensation, organ trade takes place” (P1, Bulgaria).

“So, well, this is completely different, the financial chapter; but this means that he cannot receive any type of material benefit, or of any other nature“ (P1, Romania).

Examples from both countries show the same pattern of associating “Samaritan donation” and financial compensations with organ trade. This association has traditionally been formulated by the opponents of Samaritan donation (Epstein & Danovitch, 2008). However, studies by psychologists speak about Samaritan donation as being one of the most altruistic forms of donation (Spital, 2001).
However, if we take into account the financial compensations, following the living donation process, everyone involved in the process seems to benefit from a LOD except the donor itself.

The reluctance towards Samaritan (unspecified) donation can be understood as an expression of generalized mistrust. Thus, one respondent from the Romanian FG had a strong preference for restricting donations to relatives only, and excluding all other types, including donation among emotionally related individuals stating that “there should be a genetic relation”. The underlying assumption is that the blood tie would exclude the possibility of money exchange, which is purely hypothetical. Another participant believed that “our people, the Romanians” (P1, Romania) would prefer to sell their organs rather than donate them. The possibility of financial compensation is rejected on similar grounds:

“[the donor] cannot insure him a job, a place to live, cannot get him a car. OK? So, well, this is completely different, the financial chapter; but this means that he cannot receive any type of material benefit, or of any other nature…” (P1, Romania).

Just as the population in these two countries harbors mistrust towards physicians and the health care system, there is a manifested mistrust of the physicians towards certain categories of donors, particularly those donors who are not genetically and emotionally related to their recipients, and donors who were believed to gain material benefits from the donation.

Financial barriers

The participants of both focus groups spoke about financial impediments: terms such as “money”, “financial”, “economy” were often mentioned and discussed at length, however the criticism was differently focused. The economic hardship of the health care system in general was criticized extensively by the Bulgarian stakeholders:

“In my opinion, the reasons lie much deeper because in principle there is no money for health care…” (P1, Bulgaria).

“You cannot buy low-quality medications, and not to give money for periodical standardized testing. You cannot make a laboratory carry out tests with old reagents and old equipment. You cannot tell the doctor to operate “smoothly” with these medications, because they are the cheapest” (P1, Bulgaria).

Romanian participants concentrated their critiques on the funding system for the deceased donation program:
“Before 2010 additional hours were paid, finally, solutions were found, but now, as there are no solutions to reward the medical staff, except the fact that he equips his department” (P1, Romania).

Looking for solutions

The goal of the EULOD focus group was to identify solutions to the problem of the low rates of LOD in these countries. However, for this to happen, the professionals needed to recognize the importance of the problem. The discussions revealed an interesting difference. The Bulgarian professionals were eager to explore solutions for increasing the rate of living donors, admitting the existence of the problem and attempting to find various explanations for it. The Romanian professionals, however, were reluctant to increase the numbers of living donors. They generally associated a large number of living donors with a higher probability of organ trade, which represented a serious concern for them. The Romanian participants preferred to focus instead on strategies for increasing the rates of diseased donation because it was seen as less morally problematic.

“In Bulgaria, families are small and the law permits living donation for up to fourth generation of the lateral family branch. And due to the fact that it is a first cousin and the fact that families are small – living donation is not in such frequent use” (P1, Bulgaria).

“The donor rate is small for the brain dead donors, not for the living donors... Taking into account the fact that we needed a very high transplant activity, we had to compensate the absence of brain dead donors and this could be achieved only with living donors and we had discussions at the European level – why? Because, obviously, having a very large number of transplants from living donor, the discussions related to organ trafficking were more frequent in Romania than in the rest of the countries. Meanwhile, we started to grow as number of brain dead donors; automatically, the rate from living donors decreased” (P1, Romania).

Conclusion

The comparative analysis of the attitudes of Bulgarian and Romanian stakeholders towards LOD revealed instructive similarities and differences concerning transplantation of organs from living donors. It suggests that measures designed to improve transplantation rates for living donors need to take into account the existing country-specific social realities and the socio-political, economic and psychological practices they intend to shape.
Acknowledgements

The research leading to these results has received funding from the European Commission Seventh Framework Programme (FP7/2010-2012) under Grant Agreement 242177 Living Donation in Europe (EULOD project).

References


