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COMMENTARY

Organ donor families should be free to meet their recipients under controlled conditions if both sides wish, Italian National Committee for Bioethics says

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Abstract
On 27 September 2018 the Italian Committee for Bioethics (ICB) adopted an opinion regarding the possibility of an exception to the anonymity obligation when both parties agree and have signed an appropriate informed consent form. According to the IBC any contact between the donor's family and recipient must be managed by a third-party body pertaining to the National Health Service, established to guarantee strict control over the expression of consent in order to avoid any risk of inappropriate behaviour. The paper traces how Reg and Maggie Green, on holiday from California, donated the organs of their seven-year old son, Nicholas, to seven Italians after he had been shot in a carjacking on the Salerno-Reggio Calabria highway in 1994. Reluctant as a foreigner to propose a change in Italian law that effectively prevents the two sides from contacting each other, Reg Green held back for 22 years until, at age 87, he began a public campaign to voice his concern that the law was hurting transplant families rather than helping them.

Key words
- ethics
- healthcare legislation
- organ donation
- organ transplantation

INTRODUCTION

Article 18 of Italian Law no. 91 of 1 April 1999 [1], establishes the "Duties for personnel working on retrieval and transplant activities". Subsection 2 of this article states that "Sanitary and administrative personnel working on retrieval and transplant activities should guarantee the anonymity of the data of the donor and of the recipient". Current regulations in Italy therefore require absolute anonymity between the family of the deceased organ donor and the recipient/s.

The National Transplant Centre (Centro Nazionale Trapianti) of the Italian National Institute of Health (Istituto Superiore di Sanità) asked the Italian Committee for Bioethics (ICB, Comitato Nazionale per la Bioetica) for its opinion regarding the possibility of an exception to the anonymity obligation "when both parties agree and have signed an appropriate informed consent form".

On 27 September 2018, the ICB adopted the opinion "Anonymity of organ donors and receivers (requested by the Italian National Transplant Centre)" [2].

The ICB analyses the various arguments in favour of anonymity and identifiability, making a distinction between before and after the transplant. The ICB concludes that identification could be possible if both parties express an intention to come into contact with one another.

According to the ICB, anonymity is essential during the initial stage of organ donation in order to guarantee equality, in order to observe stringent clinical criteria and priority on the list and to avoid possible organ trafficking. However, the ICB believes that, after a suitable period, it is admissible from an ethical point of view and following an explicit declaration of consent, to allow each party to be informed of the other's identity, in order to allow them to make contact with one another and meet.

This calls for a new law that caters for this possibility, whilst guaranteeing the observance of the guiding principles of organ transplantation (privacy, gratuity, justice, solidarity and benefits). According to the ICB, any contact between the donor's family and recipient must be managed by a third-party body pertaining to the National Health Service, established to guarantee

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strict control over the expression of consent in order to avoid any risk of inappropriate behaviour. The ICB suggests that the Italian National Institute for Health draw up a template consent form valid for the entire country. The information that the two parties must be given most importantly includes the fact that being informed of the donor's identity is not a right, but a possibility that is ethically justified at certain conditions that must be stringently established and confirmed.

In the following paragraphs Mr. Reg Green, the father of Nicholas, describes his experience and his engagement. The history that sprang from Nicholas' tragedy is enlightening on the possible impact of the new approach suggested by the ICB.

A LONE CAMPAIGN BEARS FRUIT

I am the father of Nicholas Green, a seven-year old American boy who was shot during an attempted carjacking on the Salerno-Reggio Calabria highway in 1994 and whose organs and corneas were donated to seven very sick people, four of them teenagers, two of them on the point of death.

Nicholas was a magical little creature who looked for the best in everyone and nothing has been quite the same since he died. But my wife, Maggie, and I have never had a moment's doubt about our decision and, if we had had any doubts, they would have been banished by the first sight of his recipients four months after the transplants at a ceremony arranged by the Bonino-Pulejo Foundation in Messina. It was one of the most fulfilling experiences of our lives.

When the recipients came in the hall as a group, with just their immediate families, it was like a small army – some smiling, some tearful, some ebullient, some shy. Did one little body do all this? I asked myself. For the first time I fully understood the power of transplantation.

Only a short time before, the healthy bodies we now saw had been gaunt, frightened shadows, shuffling like old men and women, in pain, in and out of hospitals, and never knowing when they went to bed at night whether they would wake up in the morning.

To pick just one of them, Maria Pia Pedalà, 19 years old, who was in her final coma from liver disease on the day Nicholas died. Her doctor told us, "We had given up on her." But instead of dying, she woke up with a new liver, quickly bounced back to good health, married her childhood sweetheart and four years after the transplant had a baby – a boy whom she named Nicholas. After all this time her devotion to our Nicholas still brings tears to my eyes. Maria Pia is now a sturdy woman in her forties and a strong advocate for organ donation and her Nicholas, in a family with a history of debilitating liver disease, is fit enough to be in training as a non-commissioned officer in the navy.

Nowadays none of these relationships would be possible because in 1999 a law was passed that by forbidding health care personnel from divulging any information about families involved in a transplant effectively stops donor families from knowing anything other than the most basic facts about the other side – age, sex, if the transplant operation was successful. As time passes the donor family does not even know if the recipients are still alive.

For many families, that is not a problem: they want to put the transplant behind them and get on with their lives. But for many others it is a nagging feeling of incompleteness, some important piece missing in their lives, and for some it is a chronic state of anguish, as some well-publicized cases show of families going public in their desperate search for their recipients. Many – I'd guess most – recipients too feel there is something missing. They are profoundly grateful to the people who saved their lives and yearn to thank them.

In the United States where I live communication between the two sides is not only allowed but is strongly encouraged because in the overwhelming majority of cases in thousands and thousands of contacts over more than twenty-five years the results have been therapeutic for both sides.

I knew all this but felt that it would be out of place for me to propose changes in the law in a foreign country. I raised the question in private conversations with doctors and health care administrators but no one thought repeal was feasible, most thought it was also undesirable and those who agreed preferred not to get involved in so controversial an issue.

By 2016, however, I realized that at 87 years of age I might not have many more opportunities to bring the topic into the open and so, after more than twenty years of maintaining silence, I took a deep breath and began to contact the media to try to have a national discussion. I was surprised and gratified by the response. I am a journalist myself and was proud of my profession when I found that the media understood instinctively the deep feelings of people involved in these transplant situations.

I had just one partner, Andrea Scarabelli, from Rome who when a university student of 21 was one of many hundreds of Italians who wrote to us when Nicholas died. Andrea became a friend and, now in his forties, has been an invaluable guide in steering me through the complexities of a country I love but am still a foreigner in.

A turning point came when the open-minded *Journal of Italian Nephrology* accepted a paper from me [3-5]. From then on the arguments for relaxing the law were seen not to be the wild ideas of an amateur who did not understand Italian customs but a problem deserving serious consideration. Leading newspapers, magazines and television channels began featuring stories asking what precisely was the justification for keeping the two sides apart.

The campaign began gathering support from the public, the most notable coming from Marco Galbiati, a determined, intelligent and imaginative man from Lecco who in January 2017 was caught in one of those crushingly unforeseeable developments that mark brain death. Skiing with his 15-year old son, Riccardo, Marco reached the end of the slope but Riccardo did not arrive. He was found unconscious on the slope and was rushed to hospital in Bergamo but died two days later.

Devastated, his parents donated his organs and only

a few weeks later, Marco on a night when, as he told me, his desire "to know who the recipients were was particularly strong" decided to start a petition to change the law (I can picture that restless night, can't you?). So far, almost alone and without financial help from anyone, he has collected 46 000 signatures! So much for the argument that this is an issue no one cares about. Now Marco continues as committed as ever, working with anyone who will cooperate with him, to ensure that any new law is fair and efficient. Three eminent Italian transplant surgeons working in top transplant centers in the United States – Professors Ignazio Marino, Cataldo Doria and Cristiano Quintini – spoke up strongly in favor of allowing contacts.

But in Italy the medical establishment remained unconvinced, however, and I felt like a voice crying in the wilderness. Or, rather, like Don Quixote with Sancho Panza. What if the two sides met and didn't like each other? We were asked. What if one party wanted a much more intense relationship than the other? What if a donor family told the recipients they needed money and expected someone whose life they had saved to help them out? Suppose the recipient died soon after the transplant.

All those nightmare scenarios are possible, of course. But the actuality is in the statistics: in the tens of thousands of cases where the two sides have communicated in the United States only a small minority have gone wrong. And even then the problem has normally been dealt with reasonably soon.

Partly that is because transplant families have had to deal with far more difficult problems. The thought that they are helpless to deal tactfully with potentially embarrassing situations is to seriously under-estimate them. But in addition a formidable set of rules have been worked out based on decades of experience.

First, no communication is allowed unless both parties express a desire for it. If they do the normal procedure is for one of the families to write an anonymous letter to the other with information about itself. That letter is examined by the hospital to make sure nothing abnormal is in it. It then is passed to the other family. If they do not want to start a relationship, the process ends there.

If that second family does want to reply, however, it does so, also anonymously and also through the hospital. The two sides can continue anonymous correspondence for as long as they wish or they can reveal their identity. Sometimes there is frequent exchange of letters, sometimes just on rare occasions – on the anniversary of the transplant, for example.

Anonymous letters may sound a little dry but imagine the thrill of receiving one from a boy who tells you that before the transplant he could walk to the door of his apartment only by stopping for breath and was receiving blood transfusions twice a week but now has a job and can even play soccer. That's not an imaginary recovery. I know someone who did just that.

In time the parties may decide they want to meet, their hearts beating wildly as the day approaches. Sometimes, as the critics say, the differences between the two sides are too great for them to want to continue but more often, much more often, the two sides seem to melt into each other's arms.

Why not? One side is meeting recipients who have inside them part of the body of someone they themselves loved, the other is meeting people who despite all the temptations to turn inwards in grief or bitterness had the warmth of human understanding to help a perfect stranger, when no one else could. In most cases it is a natural fit.

The people who choose to meet face to face are only a small proportion of those who write to each other – it is after all a step into the dark – but some become best friends, visit each other for Sunday lunch, give each other strength when their spirits droop.

But the clinching evidence comes from the abundant statistics, collected by the organ procurement organizations (OPOs) that are responsible to the US Department of Health for looking after transplant families in their area and work hand in glove with hospitals there that range from small rural institutions to some of the world's best-known transplant centers. There are 58 of them and every one promotes communication between the two sides.

Here are what the CEOs of some of the largest Organ Procurement Organizations from every region in the United States say:

- "In New England, with a total population of 14 million, about 52% of donor families will connect with a recipient within the first two years of their loved one's organ donation". Alexandra Glazier, President and CEO, New England Donor Services.
- "Having the ability to exchange letters between donor families and recipients is profoundly healing and therapeutic for both parties". Kevin O'Connor, chief executive officer of Life Center Northwest.
- Our experience with donor family and recipient communication has been "overwhelmingly positive for all involved". Kathleen Lilly, Executive Vice President of LifeLink Foundation in Florida.
- "Donor families have only one request and that is that we save as many lives as we can with their gift. Those who meet the recipients get a chance to see that promise fulfilled". Kevin Cmunt, CEO of Gift of Hope, whose area includes Chicago, home to two hundred thousand people whose families came from Italy.
- "In the last twenty years in an area that includes 20 million people and 200 hospitals in Southern California no families who met each other have regretted it". Tom Mone, CEO, OneLegacy.

The volume of these communications should also finally put to rest any idea that families are not interested in contacting each other: in 2017 a survey of 35 of the 58 OPOs recorded almost 13 000 letters between pairs of families.

Admittedly conditions are different between the United States and Italy and many practices that work well would have to be modified, but I refuse to believe Italian grief is so much different from American grief that principles that work so well in one would be ineffective in the other. I was delighted to learn that the ICB agreed with the main arguments for allowing contacts to take place under controlled conditions. I hope

we can look forward to an early change in the law and the consolation it will bring to people who have already suffered more than most of us can imagine.

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