Thieme

Organ Donation in Germany – An Analysis

SUMMARY

In 2018 the number of organ donors in Germany increased by about 20 % compared with 2017 – from 797 to 955. However, this increase occurred after a long decrease in the rate of organ donation in the years 2010–2017. In that period the number of organ donors per year fell by more than one-third from 1296 donors to 797 [1]. This had dramatic consequences for the prognosis of patients with end-stage organ failure: 1500 fewer organ transplantations were performed in 2017 compared with 2010. As each organ transplantation prolongs life by an estimated average of 4.3 years, this implies a loss of more than 6000 years of patient life for 2017 alone [2]. For patients with end-stage chronic kidney disease, for instance, the decline in organ donation rate is critical: the waiting time has increased considerably, and waiting 10 years or more for a kidney transplantation becomes the norm rather than the exception. This has considerable implications for potential kidney recipients. First, the prognosis of the patient after transplantation is strongly dependent on the time spent on dialysis, so that waiting times of 10 years or more lead to a significant survival disadvantage. Second, while waiting for the kidney, the potential recipient has a significant risk of becoming unfit for transplantation owing to rapid progression of vascular calcification, effectively preventing the potential kidney recipient from receiving an organ for transplantation. However, the decline in organ donation between 2010 and 2017 is only one facet of the problem in Germany: even at its peak, the number of organs donated in Germany was relatively small compared with international standards [3]. Unfortunately, in the public discourse, the two distinct problems of the low organ donation rate per se in Germany and of the decline in organ donation over the years 2010–2017 are not distinguished and discussed separately.

Many reasons have been advanced for the decline in organ donation in the period from 2010 to 2017 [4], but obviously it has to be linked to some temporally related development or event. The underlying legal framework of organ donation cannot be blamed for the decline, since that legislation has been in place since well before the period considered. In fact, a major improvement of the legal framework in 2012 introduced a declaration-based decision model wherein every person in Germany aged 16 and older is now regularly asked by his or her health-insurance carrier to declare and document whether they would be willing to donate organs. Therefore, it is surprising that an opt-out regulation for organ donation is frequently proposed as a potential solution in the context of the recent decline in organ donation. The fact that the German organ donation system is based on an opt-in regulation cannot be the reason for the decrease of organ donation, since the system was not significantly altered between 2010 and 2017 (the declaration-based decision model is still an opt-in regulation). The organ allocation scandal of 2012 (▶ **page 21**) is offered as another explanation for the recent decline, the reasoning being that the scandal produced uncertainty among the public that decreased the acceptability of organ donation. However, the decline in organ donation had already started before the scandal and no general decrease in the acceptability of organ transplantation by the general public was revealed in the annual surveys subsequent to the scandal [5] (▶ **page 21**). Furthermore, the percentage of respondents stating that they had an organ donor card actually rose from 17 % in 2008 to 36 % in 2018 [6]. Taking these considerations together, there is no evidence that any population-based causes are responsible for the recent decline in organ donation in Germany and other reasons have to be considered. The goal of our study was to analyse the reasons for the decline in organ donation in recent years [4]. We first hypothesized that the number of patients with severe irreversible brain damage had declined between 2010 and 2017 as a result of progress in medical therapy. If so, the number of potential organ donors had to decline consequently. Our second hypothesis was that potential organ donors were not recognized or reported for organ donation by the treating physicians.

Development of potential organ donor numbers in Germany

To investigate the changes over time in numbers of potential donors – that is patients with severe irreversible brain damage who possibly could become an organ donor – we carried out a nationwide survey of all hospitalizations from 2010 to 2015. We analysed the hospital billing data from 112 172 869 hospitalization events compiled as specified by the appropriate German law (§ 21 KHEntgG) and used the DSO-Transplantcheck analytical algorithm to investigate the number of potential donors. The DSO-Transplantcheck is a programme with a four-step analysis process:

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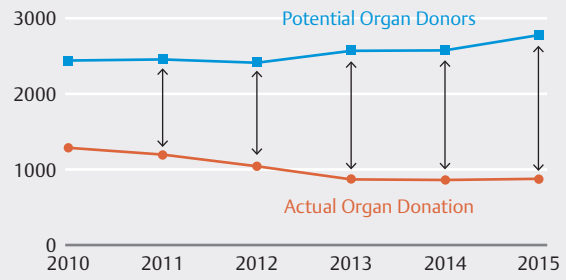
- Step 1: Selection of all hospitalizations per year for which the documented reason for discharge was death.
- Step 2: Selection of patients who died with a main or subsidiary diagnosis that can be presumed to have led to severe, irreversible brain damage.
- Step 3: Exclusion of patients for whom at least one coded diagnosis contraindicated organ donation.
- Step 4: Exclusion of patients for whom invasive ventilation was not billed.

Others have shown that the algorithm reliably identifies all cases in which a diagnosis of irreversible loss of brain function would have been possible [7]. Although the sensitivity of this process is high, it lacks specificity. However, from prior investigations it can be assumed that at least 10 % of the identified potential donors can become actual organ donors [8]. Our analysis showed that from 2010 to 2015 the number of potential donors increased by 13.9 %, while the rate of organ donations declined by 32.3 % (▶ **Fig. 1**). Therefore, the hypothesis that the decline in organ donation in Germany is caused by a decline in the number of potential organ donors is not supported.



▶ **Fig. 1** Comparison of numbers of potential organ donors and actual organ donations, 2010–2015 [4].

Decline of reporting of potential donors

Hospitals are required by law to report potential organ donors to the German Organ Procurement Organization (Deutsche Stiftung Organtransplantation; DSO). The DSO publishes annually the number of donors reported by the hospitals, and those numbers declined significantly by 18.7 % from 2010 to 2015. Our study showed that the decline in the number of potential donors was even more pronounced: the so-called contact quotient (the percentage of potential donors reported to the DSO) declined by 28.7 % (▶ **Table 1**). Additionally, we were able to show that the contact quotient varied not only regionally but also locally when we compared hospitals directly with each other. In our analysis, direct comparison between different university hospitals revealed a more than tenfold difference in contact quotient: with the same number of potential donors, one hospital reports one potential donor to the DSO and another reports ten. We conclude that there is large heterogeneity in the management of potential organ donors in the different university hospitals. This finding helps to identify the level of the organ donation process at which there are potential barriers and it rules out the notions that there is a rejection of organ donation per se or that the current legal and financial framework inevitably leads to a decline in the number of organ donations. Our study clearly shows that the decline in post-mortem organ donation is due to a deficiency at the level of identification and reporting of potential organ donors. Although we have identified that the barriers for organ donation operate at the level of the donor hospital, we were not able to identify the specific reasons for the decline of the contact quotient in the individual hospitals. Some potential reasons are now addressed by the new law (2. Gesetz zur Änderung des Transplantationsgesetzes – Verbesserung der Zusammenarbeit und der Strukturen bei der Organspende). A very important aspect of this new law is that the contact quotient of each donor hospital will be published, which will increase the transparency of the organ donation activities of each hospital. It should then be possible to purposefully intervene in hospitals in which there is a deficit in the organ donation process.

Low donation rate before 2010

We have identified the recognition and reporting deficit as the reason for the recent decline in organ donation in Germany. The question arises why organ donation in Germany generally is so low compared with the international norm. Until now the low donation rates in Germany before 2010 have been thought to be due to the public's attitude rather than to a recognition and reporting deficit. This conclusion was supported by a DSO analysis carried out between 2010 and 2012, which stated that "the below-average donation rates in Germany are by and large not due to inadequate reporting of potential donors by hospitals" [8]. Our study, however, shows that the hospitals participating in the project at that time were not at all representative of the overall situation in Germany but rather had a significantly higher contact quotient than the nationwide average (▶ **Table 1**). In short, the below-average donation rates seen in the international comparison at that time were already mainly due to insufficient reporting of potential donors. In our study we have per-

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▶ **Table 1** Nationwide analysis of all hospitalizations* [4].

	2010	2011	2012	2013	2014	2015	DSO Project 2010-2012 (Categories A and B)
Hospitalizations	**18 032 903**	**18 344 156**	**18 620 442**	**18 787 168**	**19 148 626**	**19 239 574**	**–**
Deaths, total	405 627	400 051	404 146	415 250	401 204	425 128	–
Deaths with primary or secondary brain damage	65 080	63 652	63 618	65 010	64 544	68 024	22 946
Deaths with an absolute contraindication to organ donation	6456	6566	6485	6688	7045	7281	3011
Deaths without invasive respiratory therapy	34 687	33 007	33 433	33 221	32 235	33 485	6888
Potential organ donors	**23 937**	**24 079**	**23 700**	**25 101**	**25 264**	**27 258**	**13 047**
DSO contacts (n and as % of potential donors)	2760 (11.5 %)	2778 (11.5 %)	2594 (10.9 %)	2221 (8.8 %)	2170 (8.6 %)	2245 (8.2 %)	4141 (31.7 %)
Actual donations (n and as % of potential donors; realization quotient)	1296 (5.4 %)	1200 (5 %)	1046 (4.4 %)	876 (3.5 %)	864 (3.4 %)	877 (3.2 %)	1327 (10.2 %)
Actual donations (as % of DSO contacts; conversion quotient)	47 %	43.2 %	40.3 %	39.4 %	39.8 %	39.1 %	32 %

* Results of the DSO In-House Coordination Project are given for comparison. Category A hospitals are university hospitals; category B hospitals are defined by the presence of a neurosurgical service.

formed a potential analysis that shows that if all potential donors were recognized, the number of organ donations would increase threefold, which means that the organ donation rate in Germany would be 33.8 donors per million inhabitants [4]. Thus, if the existing reporting deficit in German hospitals were uniformly and sustainably rectified, there would be a legitimate expectation that organ donation rates in Germany would rise to international levels [9].

Summary

- The organ donation rate is historically very low, which has been further consolidated by the recent decline in organ donation.
- The main reason for the low organ donation rate can be identified at the level of the recognition and reporting of the potential donors in the individual hospitals.
- If the individual barriers in this process can be identified and corrected, the shortage of organ donation in Germany can be eliminated.

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