

Willingness to donate organs – an anonymised survey in the emergency department

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Summary

BACKGROUND: In Switzerland, 519 patients received an organ in 2020. In total, 2124 patients were on the donor organ waiting list in 2020. There are many more people who need an organ than people willing to donate one. Therefore, 43 organs had to be imported from outside of Switzerland and this number was still not sufficient. This disproportion of patients needing an organ and available donor organs is the subject of ongoing discussion. A solution to this problem might be provided by a popular initiative proposing that every single resident of Switzerland should be an organ donor, unless a person explicitly rejects organ donation. We surveyed the patients in a single tertiary care emergency department (ED) to determine whether they had an organ donor card or were registered in the Swiss National Organ Donor Registry (NODR), the frequency of willingness to donate organs and which factors were associated with being an organ donor.

METHODS: In a prospective anonymised survey during July 2019, we enrolled patients who visited a Swiss tertiary care ED, during one week from 8:00 to 18:00, two weeks from 14:00 to 23:00 and one week from 23:00 to 8:00. The patients completed a written, standardised and self-administrated questionnaire during the waiting time in the ED. Descriptive, uni- and multivariable logistic regression analysis were performed.

RESULTS: We enrolled 307 ED patients, of whom 62 (20.2%) were donor card holders or were registered in the Swiss NODR. Of these, 53 (85.5%) would be willing to donate organs. The remaining nine (14.5%) were not willing to donate an organ; the reasons for this were very heterogeneous. In contrast, the two leading reasons for willingness to donate organs were: to help after death (94.3%) and to free relatives from the task of making the decision (43.4%). From the 245 (79.8%) participants who did not have an organ donor card or were not registered, 84 respondents (34.3%) lacked knowledge of this topic, 65 (26.5%) had not yet thought about the topic and 51 (20.8%) had not yet had time to take care of this issue.

Blood donation (odds ratio [OR] 2.1, 95% confidence interval [CI] 1.1–3.9; $p = 0.018$) or receiving a transplant in the past (OR 6.1, 95% CI 1.3–29.1; $p = 0.023$) and having a university degree (OR 1.8, 95% CI 1.0–3.2; $p = 0.049$)

were factors associated with being an organ donor card holder.

CONCLUSIONS: Only one in five ED patients had a fully completed organ donor card or were registered in the Swiss NODR. Of these, the great majority were willing to donate organs. Most of the ED patients who did not have an organ donor card or were not registered in the NODR lacked knowledge and information about the topic, had not yet thought about it or had not had time to deal with this issue. Factors such as a positive history of blood donation, organ transplantation in the past or having a university degree were associated with having an organ donor card. In order to increase the willingness to donate organs in the future, it is of immense importance to provide better information and more details and knowledge about this important topic.

Introduction

At the end of 2020, about 1.5% of Swiss residents were registered in the National Organ Donor Registry (NODR) [1, 2]. More than 50% of the registered people were female and they had a median age of 42 years [1]. Despite the COVID-19 pandemic and the resulting delay in surgery and transplants across the country, there were 146 deceased people who donated organs in 2020 [1] and, therefore, eleven persons fewer than the year before [1]. The number of living organ donors was significantly lower (83 vs 110) in 2020 than in 2019, probably as a result of the pandemic [1].

In 2020, 519 patients received an organ in Switzerland [1]. In total 2124 patients needed an organ and were on the waiting list in 2020 [1]. Seventy-two patients on the waiting list died owing to the organ shortage in 2020; most of them were waiting for a liver transplant [1]. There were many more people who needed an organ than people willing to donate one. Therefore, 43 organs (9%) had to be imported outside from Switzerland, mostly from France, and this number was still not sufficient [1]. This disproportion of patients needing an organ and available organs is the subject of ongoing discussion.

Currently, it is not mandatory for Swiss citizens to donate their organs after death, even if they did not express their opposition during their lifetime. In Switzerland, there is a so-called opt-in policy for deceased organ donation. In

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the opt-in system, individuals need to clearly express their preference for organ donation. Unfortunately, many Swiss people do not have an opinion on organ donation and therefore have not expressed their preferences in an organ donor card or the National Organ Donor Registry. Therefore, there is an organ shortage and a possible solution will be decided by a federal referendum on a proposal that every single Swiss resident should be a regular organ donor, unless he or she explicitly rejects organ donation (so-called opt-out policy). The Federal Council has made a counter-proposal, which states that the relatives can continue to refuse organ donation despite the new opt-out policy if the wishes of the deceased are not documented [3]. For this, the term "extended objection solution" is used. At the beginning of May 2021, the National Council approved the counter-proposal and thus the paradigm shift in organ donation [4]. After the parliament approved the Federal Council's indirect counter-proposal, the initiative committee conditionally withdrew the initiative at the beginning of October 2021. Thus, the referendum period for the indirect counter-proposal runs until end of January 2022. If there is no referendum, the indirect counter-proposal will be accepted without a popular vote [22]. With the background of the current organ shortage and political discussions, we evaluated among the emergency department (ED) population whether they have an organ donor card or are registered in the Swiss NODR and which factors were associated with being an organ donor.

Materials and methods

In a prospective anonymised survey, we consecutively enrolled patients who visited a Swiss tertiary care ED in July 2019. The time period for patient enrollment was set a priori as follows: during one week from 8:00 to 18:00, two weeks from 14:00 to 23:00 and one week from 23:00 to 8:00.

All included patients were 18 years or older and had completed an anonymised, written, standardised and self-administered questionnaire while waiting in the ED. Patients were excluded if they were less than 18 years old, had language barriers, refused to participate, had cognitive impairments and diseases, which might yield unreliable answers, or were unable to read and/or write.

A final ethical approval was not required after submission of the study proposal to the local ethics committee owing to anonymisation and according to the legal requirements in Switzerland.

Survey settings

The anonymised survey was performed in a tertiary care ED with an annual load of more than 45,000 adult patients suffering from various disorders of different severities. The ED offers a full interdisciplinary and inter-professional emergency service around the clock. The service area of the ED is the greater region of Zurich and covers highly specialised services for patients with an indication for centre transfer, such as cranio-cerebral trauma or transplant patients, in almost the entire German-speaking area of Switzerland.

The prospective and anonymised survey was conducted by a medical Master's degree student in collaboration with

and under the supervision of a senior ED epidemiologist. Because of limited staff resources, the Master's student conducted the survey on a regular basis from Monday to Friday. However, in order to include as representative a patient population as possible, participants were interviewed in the first week from 8:00 to 18:00, during the following two weeks the enrollment was performed from 14:00 to 23:00 and in the fourth and final week from 23:00 to 8:00. The Master's student made the initial contact with every ED patient in the waiting area of the ED and checked the in- and exclusion criteria in all ED patients. After the ED patients had agreed to participate in the survey and signed the informed consent form, they completed an anonymised paper-based, standardised and easily self-administered survey. The questionnaire could be completed independently in less than 15 minutes. If there were any questions or support was needed, the student was always available.

The survey was based on a previously developed and validated questionnaire and was adjusted to our national circumstances [5]. For this reason, some questions were added, for example, on the knowledge of the existence of the National Organ Donor Registry or on the upcoming national referendum on the new transplantation law. Furthermore, a qualified English translator and the native English-speaking Master's student independently translated the questionnaire in a forward (from English to German) and afterwards in a backward (from German to English) translation procedure to ensure that the proper meaning of the survey questions was being conveyed.

The questionnaire included some person-related parameters such as age, gender, nationality, family status, religion, level of education, presence of any chronic diseases and previous organ donation (appendix). The survey focused on the knowledge and availability of organ donations and organ donor cards, and on knowledge of a National Organ Donor Registry and whether organ donation had been discussed with family members and/or the general practitioner. Furthermore, the reasons for deciding to donate or not to donate an organ, as well as the absence of an organ donor card, were assessed. Additionally, we asked about the willingness to donate living organs, reasons if living donation was not considered and who would benefit from living organ donation. The survey also included other questions, such as how participants would decide if a family member died and the question of organ donation came up. Finally, participants were also asked whether they would accept organ donation if they needed an organ for medical reasons.

Endpoints

As a first endpoint, we examined the frequency of organ donor card holders or being registered in the Swiss NODR. Secondly, we evaluated the frequency of willingness of organ donation and factors associated with being an organ donor.

Statistical analysis

Parameters were tested for normality with the Kolmogorow-Smirnow test and performed quantile-quantile plots of dependent variables. In the case of normally distributed parameters, means and standard deviation (SD)

were reported. If the parameters not normally distributed, medians and interquartile ranges (IQRs) were expressed.

The primary endpoint (prevalence of organ donor card holders or registration) as well as all categorical variables and question answers were presented as proportions.

To identify potential factors associated with having an organ donor card or being registered in the Swiss NODR, a stepwise backward multivariable regression model was used. After identifying potential factors, a uni- as well as a multivariable logistic regression analysis, adjusted for potential confounders such as age, gender (male/female) and the presence of any underlying chronic disease (no/yes), was run. The potential confounding factors were a priori defined according to the literature and clinical expertise.

For all results, we reported point estimates, 95% confidence intervals and p-values (<0.05 considered significant). We conducted the statistical analyses using the statistical program STATA SE (version 16, Stata Corp., College Station, Texas).

Results

During the survey period, the Master's student evaluated in total 1141 potential participants during his ED presence in July 2019. In the first selection step, 709 patients had to be excluded according to the exclusion criteria (fig. 1). Finally, 432 ED patients were evaluated in a second step for potential participation and further 74 patients (17.1%) needed

to be excluded because of factors such as: language barrier, which were not obvious in the first step of exclusion, or lack of adequate time because of short waiting time in the ED, or recommendations by the care team not to conduct the interview due to serious or even life-threatening health conditions. Furthermore, 51 patients (11.8%) were excluded because they rejected to participate in the survey (fig. 1).

Finally, 307 ED patients were enrolled, of whom 62 (20.2%) were organ donor card holders or were registered in the Swiss NODR. Of these, 53 (85.5%) would be willing to donate organs. The remaining nine participants (14.5%) with an organ donor card were not willing to donate an organ; the reasons for this were very heterogeneous.

The entire survey population included 129 females (42%) and had a median age of 41 years (IQR 28–59). More than every fourth participant (26.7%) suffered from an underlying chronic disease and seven patients (2.3%) had experienced an organ transplantation in the past. Four of these seven transplant patients had an organ donor card and were willing to donate organs. Five patients (1.6%) already had a history of stem cell or bone marrow donation (table 1).

Participants having an organ donor card or being registered in the NODR were more often Swiss (64.5% vs 55.1%), singles (54.8% vs 40.4%), more often had a university degree (59.7% vs 44.9%) and reported more often not belonging to a religious community (45.2% vs 32.7%)

Table 1:
Patients' characteristics.

		Survey participants, n = 307	Neither organ donor card holder nor registered, n = 245 (79.8%)	Organ donor card holder or registered in the NODR, n = 62 (20.2%)
Age* (yrs.), median (IQR)		41 (28–59)	41 (29–59.5)	37 (28–55)
Gender, female (%)		129 (42%)	98 (40%)	31 (50%)
Chronic disease (%)		82 (26.7%)	66 (26.9%)	16 (25.8%)
History of organ transplantation (%)		7 (2.3%)	3 (1.2%)	4 (6.5%)
History of blood donation (%)		130 (42.4%)	98 (40%)	32 (51.6%)
History of previous stem cell or bone marrow donation (%)		5 (1.6%)	2 (0.8%)	3 (4.8%)
Sociodemographic parameters				
Nationality (%)	Swiss	175 (57.0%)	135 (55.1%)	40 (64.5%)
	Others	118 (38.4%)	97 (39.6%)	21 (33.9%)
	Double nationality (incl. Swiss)	14 (4.6%)	13 (5.3%)	1 (1.6%)
Marital status (%)	Single	133 (43.3%)	99 (40.4%)	34 (54.8%)
	Married / in partnership	131 (42.7%)	110 (44.9%)	21 (33.9%)
	Divorced	27 (8.8%)	22 (9.0%)	5 (8.1%)
	Widowed	15 (4.9%)	13 (5.3%)	2 (3.2%)
	Missing answer	1 (0.3%)	1 (0.4%)	0%
Highest achieved education (%)	Compulsory schooling	33 (10.7%)	28 (11.4%)	5 (8.1%)
	Vocational training	125 (40.7%)	105 (42.9%)	20 (32.3%)
	University degree	147 (47.9%)	110 (44.9%)	37 (59.7%)
	Missing answers	2 (0.7%)	2 (0.8%)	0%
Religion (%)	Christian	160 (52.1%)	129 (52.7%)	31 (50%)
	Muslim	17 (5.5%)	17 (6.9%)	0%
	Buddhist	4 (1.3%)	2 (0.8%)	2 (3.2%)
	Hindu	4 (1.3%)	3 (1.2%)	1 (1.6%)
	None	108 (35.2%)	80 (32.7%)	28 (45.2%)
	Others	14 (4.6%)	14 (5.7%)	0%

IQR: interquartile range; NODR: National Organ Donor Registry

compared with participants without an organ donor card or were not registered in the Swiss NODR (table 1). Further sociodemographic results are shown in table 1.

The majority of the organ donor card holders (79%) had a paper-based organ donor card. Whereas 14.5% were registered in the National Organ Donor Registry, 6.5% were registered either digitally as well as on the traditional system by holding a paper-based card. A minority of 67 participants (28.4%) of the total survey population were aware of the existence of the new National Organ Donor Registry. Of all, 257 participants (83.7%) knew what organ donation or an organ donor card is and had already discussed the topic with family members in 50.2% (n = 154) and with primary care physicians in 11.9% (n = 36) (table 2). Organ donor card holders discussed this issue more often with family members and primary care physicians (table 2).

Among the sub-population of those who were willing to donate organs, the two leading reasons for the willingness to donate organs were: to help after death (94.3%) and to discharge relatives from the task to take the decision for them (43.4%). Further reasons are presented in table 3.

From the remaining 245 participants who did not have an organ donor card or were not registered, the majority (34.3%) had a lack of knowledge in this topic, 26.5% have not yet thought about it and 20.8% had not had time to deal with this issue. Further reasons are shown in table 4.

Factors associated with a higher likelihood of having an organ donor card or being registered were a positive history of regular blood donation (odds ratio [OR] 2.1, 95% confidence interval [CI] 1.1–3.9; p = 0.018), a university degree (OR 1.8, 95% CI 1.013.2; p = 0.049), and having received an organ transplantation as a patient in the past (OR 5.6, 95% CI 1.225.5; p = 0.027) (table 5).

Table 2:
Knowledge and information about the organ donation.

	Survey participants, n = 307	Neither organ donor card holder nor registered, n = 245 (79.8%)	Organ donor card holder or registered in the NODR, n = 62 (20.2%)
Know what an organ donor card is (%)	257 (83.7%)	197 (80.4%)	62 (100%)
Spoke with family members about the topic of organ donation (%)	154 (50.2%)	99 (40.4%)	55 (88.7%)
Spoke with a doctor about the topic of organ donation (%)	36 (11.9%)	21 (8.7%)	15 (24.2%)

NODR = National Organ Donor Registry

Table 3:
Reasons for organ donation.

Why have you decided to donate your organs?	Willing to donate organs, n = 53 (17.3%)
A way to help after my death	50 (94.3%)
I want to spare my family/friends the stresses of having to decide on my behalf	23 (43.4%)
Motivated through fellow humans	11 (20.8%)
I want to be able to decide what happens to my body after my death	10 (18.9%)
Public discourse	7 (13.2%)
One day I'll be in need of organs myself	4 (7.5%)
Religious reasons	2 (3.8%)
Others ¹	8 (15.1%)

More than one answer was possible; ¹ Others were reasons for positive organ donation such as organ transplantation in the family or own experience.

Table 4:
Reasons for neither having an organ donor card nor being registered.

What are the reasons you don't have an organ donor card?	Neither organ donor card holder nor registered, n = 245 (79.8%)
Not informed well enough or even no knowledge	84 (34.3%)
Haven't thought about this topic yet	65 (26.5%)
Haven't had time to take care of it yet	51 (20.8%)
Organ(s) are also damaged	34 (13.9%)
Don't want to decide yet	30 (12.2%)
Bodily integrity	15 (6.1%)
My family already knows my wishes	14 (5.7%)
Afraid of misuse of organs	12 (4.9%)
I'm too young	10 (4.1%)
Family/friends should decide on my behalf	9 (3.7%)
Worried I will not receive all medical therapeutic options if I decide to donate my organs	7 (2.9%)
I don't remember why	5 (2.0%)
Religious reasons	4 (1.6%)
My wish doesn't count anyway	3 (1.2%)
No advantage for me/family	2 (0.8%)
Others*	22 (9.0%)

More than one answer was possible

* Others were reasons for not having an organ donor card e.g., infection, taking regular medicaments and not being from Switzerland with plan to go back to the country of origin.

In addition, the study population was asked about living organ donation (table 6). More than one third of respondents (34.9%) had never thought about this possibility and 27 participants (8.8%) had never heard about living organ donation (table 6). One hundred and twenty-nine participants (42.0%) were willing to be living organ donors. Organ donor card holders were more likely to be willing to be living organ donors (61.3% vs 37.1%) than no organ

donor card holders (table 6). The majority of the respondents were willing to be living organ donors for close family members such as a child or grandchild (38.4%), spouse (34.5%) or parents (31.3%). A lower willingness to donate organs was found for friends (25.7%) and for unknown persons (17.9%) (table 6).

Table 7 presents survey results on how the respondents would decide about organ donation in the event of a relative's death. If the will of the deceased were not known, almost 60% of the respondents would choose (31.9%) or most likely choose (27.0%) to donate an organ. A clear group difference emerged, in that organ donor card holders or those who are registered would be less likely to decline the organ donation.

The decision to answer the question was easier if the will of the deceased was known and the person was willing to donate an organ. In this case, 75.9% (n = 233) of respondents decided in favour of organ donation and 10.7% (n = 33) were more likely to donate. Organ donor card holders or those who are registered were significantly more likely to be in favour of organ donation when asked this question (table 7).

If the deceased person did not wish an organ donation after death, 20% of the respondents decided to donate the organs of the relative after all. Almost one in three of the organ donor card holders would even decide against the wish of the deceased (table 7).

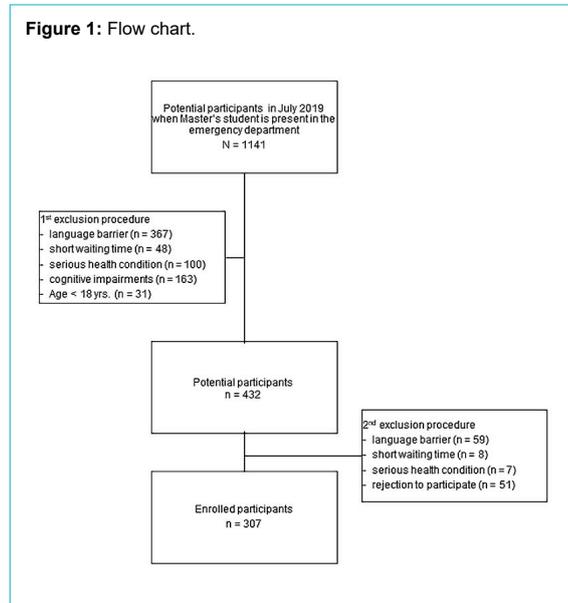


Table 5: Factors associated with a higher likelihood of having an organ card or being registered in the National Organ Donor Registry

	Neither organ donor card holder nor registered, n = 245 (79.8%)	Organ donor card holder or registered, n = 62 (20.2%)	Unadjusted OR (95% CI, p-value)	Adjusted OR (95% CI, p-value)
History of previous organ transplantation (%)	3 (1.2%)	4 (6.5%)	5.6 (1.2–25.5, 0.027)	6.1 (1.3–29.1, p=0.023)
History of previous blood donation (%)	98 (40%)	32 (51.6%)	1.6 (0.9–2.8, p=0.10)	2.1 (1.1–3.9, p=0.018)
Having a university degree (%)	110 (44.9%)	37 (59.7%)	1.8 (1.01–3.2, p=0.044)	1.8 (1.003–3.2, p=0.049)

OR: odds ratio; CI: confidence interval. Results are adjusted for possible confounders such as age, sex and the presence of underlying chronic diseases (yes/no).

Table 6: Living organ donation.

		Survey participants, n = 307	Neither organ donor card holder nor registered, n = 245 (79.8%)	Organ donor card holder or registered in the NODR, n = 62 (20.2%)
Willing to be a living organ donor (%)	Never thought about this	107 (34.9%)	93 (38.0%)	14 (22.6%)
	Never heard of this	27 (8.8%)	23 (9.4%)	4 (6.5%)
	Yes, I would be willing for certain people	129 (42.0%)	91 (37.1%)	38 (61.3%)
	I am not willing to donate organs while alive	44 (14.3%)	38 (15.5%)	6 (9.7%)
Which organs for living organ donation* (%)	Bone marrow / stem cells	119 (38.8%)	81 (33.1%)	38 (61.3%)
	Part of liver	96 (31.3%)	65 (26.5%)	31 (50.0%)
	Kidney	95 (30.9%)	68 (27.8%)	27 (43.5%)
Whom willing to donate organ* (%)	Child/grandchild	118 (38.4%)	85 (34.7%)	33 (53.2%)
	Partner	106 (34.5%)	73 (29.8%)	33 (53.2%)
	Spouse	96 (31.3%)	62 (25.3%)	34 (54.8%)
	Grandparents	64 (20.8%)	41 (16.7%)	23 (37.1%)
	Other family members	104 (33.9%)	70 (28.6%)	34 (54.8%)
	Friends	79 (25.7%)	50 (20.4%)	29 (46.8%)
	Unknown person	55 (17.9%)	37 (15.1%)	18 (29.0%)

* More than one answer was possible.

NODR: National Organ Donor Registry

Nearly three quarters of participants had confidence that medical staff would pursue all therapeutic options and not stop any treatment too soon simply because the patient is an organ donor (table 7).

More than 80% of participants (n = 251) would accept organ donation for themselves should they need an organ. This also applied to respondents who did not have an organ donor card at the time of the survey (table 7).

Finally, the participants were also asked about their opinion on the upcoming federal referendum regarding the amendment of the transplantation act by changing the current system from an opt-in to an opt-out policy. If federal referendum had been held at the time of the survey, 198 respondents (64.5%) would have opted for a change in the law. Especially, holders of an organ donor card or those who are registered in the Swiss NODR supported the amendment significantly more often (83.9% vs 59.6%) than those without an organ donor card or registration. At the time of the survey, 51 participants (16.6%) had not yet made an opinion.

Discussion

In summary, only one in five ED patients had a fully completed organ donor card or were registered in the Swiss NODR. Of these, the great majority were willing to donate organs. Most of the ED patients who did not have an organ donor card or were not registered lacked knowledge and information about the topic, had not yet thought about it or had not had time to deal with this issue. Factors such as blood donation and organ transplantation in the past or

having a university degree were associated with being an organ donor card holder.

In many European countries, opt-out policies with presumed consent for deceased organ procurement are common strategies to address the organ shortage for years. Such countries are for example Austria or Spain. The positive impact of an opt-out policy on organ availability is well illustrated by the example of Wales. In early December 2015, Wales introduced a soft opt-out policy for organ donation, where consent for organ donation was presumed unless the person had opted out. The impact of the Welsh opt-out policy was highlighted by Madden et al., who reported that the likelihood of consenting to organ donation was 2.1 times higher in Wales than in England [6]. The convincing results of the opt-out policy in Wales led England and Scotland to also introduce the opt-out system in May 2020 and March 2021, respectively, in the hopes of addressing organ shortages. The UK Organ and Tissue Donation and Transplantation Activity Report 2020/21 described an increase in opt-out registrations across the UK, with two million people on the organ donor registry by March 2021 [7]. Other European countries, such as Switzerland or Germany, have the opt-in policy that the removal of organs and tissues after death is only permissible if the deceased people consented to it during their lifetime or if the relatives consented on their behalf. Which organ donation model (opt-out or opt-in) is the more effective is still controversial. There is some literature clearly supporting the opt-out policy because this system leads to a larger pool of organs for transplantation [6, 8–11]. On the other hand, there is also some literature that disagrees with the opt-out regulation [12–16]. Owing to this contro-

Table 7:

The decision about organ donation in the event of a relative's death.

		Survey participants, n = 307	Neither organ donor card holder nor registered, n = 245 (79.8%)	Organ donor card holder or registered in the NODR, n = 62 (20.2%)
If you were asked to decide on a relative's behalf whether their organs can be donated and their will is not known, what would you decide?	No	47 (15.3%)	44 (18.0%)	3 (4.8%)
	More likely no	55 (17.9%)	47 (19.2%)	8 (12.9%)
	More likely yes	83 (27.0%)	64 (26.1%)	19 (30.6%)
	Yes	98 (31.9%)	70 (28.5%)	28 (45.2%)
	No answer	24 (7.8%)	20 (8.2%)	4 (6.5%)
If you were asked to decide on a relative's behalf whether their organs can be donated and you knew that their will was to donate their organs, what would you decide?	No	18 (5.9%)	16 (6.5%)	2 (3.2%)
	More likely no	9 (2.9%)	8 (3.3%)	1 (1.6%)
	More likely yes	33 (10.7%)	32 (13.1%)	1 (1.6%)
	Yes	233 (75.9%)	176 (71.8%)	57 (91.9%)
	No answer	14 (4.6%)	13 (5.3%)	1 (1.6%)
If you were asked to decide on a relative's behalf whether their organs can be donated and their will was to not donate organs, what would you decide?	No	182 (59.3%)	150 (61.2%)	32 (51.6%)
	More likely no	45 (14.7%)	36 (14.7%)	9 (14.5%)
	More likely yes	28 (9.1%)	23 (9.4%)	5 (8.1%)
	Yes	39 (12.7%)	25 (10.2%)	14 (22.6%)
	No answer	13 (4.2%)	11 (4.5%)	2 (3.2%)
Do you believe there is a certain risk associated with the will to donate organs in the sense that the medical staff might not pursue all therapeutic medical options?	No	141 (45.9%)	109 (44.5%)	32 (51.6%)
	More likely no	86 (28.0%)	66 (26.9%)	20 (32.3%)
	More likely yes	40 (13.0%)	34 (13.9%)	6 (9.7%)
	Yes	14 (4.6%)	13 (5.3%)	1 (1.6%)
	No answer	26 (8.5%)	23 (9.4%)	3 (4.8%)
If your life could only be saved by means of organ transplantation, would you accept an organ?	No	25 (8.1%)	21 (8.6%)	4 (6.5%)
	More likely no	20 (6.5%)	19 (7.7%)	1 (1.6%)
	More likely yes	59 (19.2%)	51 (20.8%)	8 (12.9%)
	Yes	192 (62.5%)	144 (58.8%)	48 (77.4%)
	No answer	11 (3.6%)	10 (4.1%)	1 (1.6%)

NODR: National Organ Donor Registry

versy, Molina-Pérez et al. performed a systematic review in 2019 [17]. It showed that the consent to organ donation in countries with an opt-in policy is higher than in opt-out countries [17]. Hansen et al. postulated a public campaign that better informs about and sensitises the population to the organ shortage and the possibility of organ donation as the reason for the higher approval of the opt-in strategy [18]. They also showed that enhanced education and better knowledge about the transplantation system is associated with an increased willingness to donate organs [18]. These results are supported by our survey findings. The current survey also showed an increased willingness to donate organs when participants had a university degree. Additionally, the majority of the survey respondents who were not organ donor card holders or were not registered in the Swiss NODR lacked knowledge and information about the topic. In addition, more than one in three did not know about the possibility of living donation, which again indicates that there is a large gap in knowledge and information.

Despite the fact that the opt-out policy seems to provide a larger pool of organs, there are some ethical and legal issues. Organ donation rates in opt-out countries seem to be higher only when the public is less informed about the law and its requirements [12]. This is seen as coercion and disrespect for individual autonomy over the body, mind and spirit, which is a clear ethical problem with opt-out policies [19, 20]. In contrast, proponents of the opt-out strategy argue that with this policy, each individual's freedom of choice and individual responsibility are still preserved, and one can refuse organ donation by registering the refusal in national registries [21]. However, the systematic review by Molina-Pérez et al. showed that people from countries with opt-out policies were insufficiently informed about the possibility of actively excluding themselves as potential organ donors [17]. This is clearly reflected by the current survey result that people who had already been previously transplanted are very well informed about the procedures and are more likely to be potential organ donors, pointing out that insufficient information and knowledge about transplantation is the reason for higher organ donation rates in opt-out countries.

The participants of the current survey were also asked about their opinion on the upcoming federal referendum on the amendment of the transplantation act changing the current system from opt-in to an opt-out policy. The majority of respondents were in favour of a change to an opt-out system, notably over 80% of organ donor card holders or those who are registered in the Swiss NODR. This high level of support for the opt-out policy could be due to the increased public awareness campaign that the opt-out system can solve the problem of organ shortage.

Regardless of which system (opt-out or opt-in) is better, both systems show that regular education, investment in knowledge and training, and the resulting transfer of information to the population increases willingness to donate organs. Hence, we recommend that each individual voter compare the personal pros and cons of each system (current opt-in vs new opt-out) in the upcoming referendum and choose the right option for him or herself.

Therefore, we recommend, whether or not the current system remains or is replaced by the opt-out strategy, that the

general population continues to be informed, that school classes are educated about the issue and that people talk about organ donation. It must no longer be a taboo subject, because only in this way can people develop their own opinion, act on their own responsibility and increase the number of organ donations.

In the last part of the current survey on how the respondents would decide about organ donation in the event of a relative's death, we showed that there can be differences between the respondent's decision and the last will of the deceased person. Especially in cases where the deceased was in favour of organ donation, about 10% of respondents would decide against the wish of the deceased person and refuse organ removal. Additionally, almost 30% of the organ donor card holders would allow organ removal even if the deceased did not wish to donate organs. These survey results may indicate huge problems in communication and acceptance of the decisions among family members, friends and the loved ones. Therefore, each individual should have an advance directive filled out during their lifetime and plan the further procedures by means of advance care planning. The possible donation of organs after death is just as much a part of advance care planning as the wishes about further therapy measures in critical or palliative situations. Furthermore, every single person has the chance, independent of the current transplantation act, to officially register their organ donation willingness (yes or no) in the National Organ Donation Registry. Additionally, close relatives must be informed about the advance care planning, so that in the event of death the close relatives are informed and can act as well as decide based on the will of the deceased person.

Strength and limitations

The survey has some limitations. We were not able to obtain consecutive enrollment (24/7) of all ED patients during the four weeks of observation because of limited staff resources (Master's student thesis). Furthermore, critically ill patients and many patients with language barriers had to be excluded. Nevertheless, the survey results are similar to the existing literature and are therefore generalisable.

A strength of this survey is the prospective design and enrollment of participants during all 24/7 ED work-shifts. Furthermore, the response rate was rather high and the rejection rate was only about 11%. An additional strength is that we were missing information on marital or educational status from only three participants. This success was based on the active one-site ED presence of the Master thesis student and the study team.

Conclusions

Only every fifth ED patient had a fully completed organ donor card or were registered in the Swiss NODR. Of these, the great majority were willing to donate organs. Most of the ED patients who did not have an organ donor card or were not registered in the Swiss NODR lacked knowledge and information about the topic, had not yet thought about it or had not had time to deal with this issue. Factors such as a positive history of blood donation, organ transplantation or having a university degree were associated with having an organ donor card.

Regardless of which organ donation system (opt-out or opt-in) is better, with regular education, investment in knowledge and training, and the resulting transfer of information to the population an increase in the willingness to donate organs can be achieved.

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Studivnummer _____

Häufigkeit des Vorhandenseins eines Organspendeausweises bei Notfallpatienten am Institut für Notfallmedizin des UniversitätsSpital Zürich

Allgemeine Informationen

Alter _____

Geschlecht

- weiblich
 männlich

Staatsangehörigkeit Schweiz
 andere: _____

Religion christlich muslimisch anderes:
 buddhistisch keine
 hinduistisch

Ausbildung obligatorische Schule ohne Berufsabschluss
 Berufslehre
 Fachhochschule/Universität

Familienstand ledig geschieden
 verwitwet verheiratet/feste Partnerschaft

Haben Sie an einem/mehreren Organ(-systemen) eine chronische Krankheit?

- nein
 ja falls ja, an welchem?

Haben Sie bereits einmal Blut gespendet?

- ja nein

Haben Sie bereits Organe gespendet?

- nein
 gelistet, noch nicht gespendet
 Knochenmark/Stammzellen
 Niere
 Leberanteile
 anderes: _____

StuDiennummer _____

Umfrage

1. **Wissen Sie, was ein Organspendeausweis ist?**
 ja nein

2. **Haben Sie jemals mit einem (Haus-)Arzt über die Organspende gesprochen?**
 ja nein

3. **Haben Sie mit Nahestehenden (Familie, Freunde) über Ihren Wunsch bezüglich der Organspende gesprochen?**
 ja nein

4. **Haben Sie einen ausgefüllten Organspendeausweis?**
 ja → seit wann? _____ Bitte kreuzen Sie an, in welcher Form:
 Papier digital (App o. Ähnliches) beides
 nein → **Bitte fahren Sie mit Frage 10 weiter**

5. **Haben Sie Ihren Organspendeausweis dabei?**
 ja, in Papierform ja, digital nein

6. **Seit Ende 2018 gibt es im Internet ein nationales Organspenderegister (Achtung, es geht nicht um Ihren **Ausweis!**), in dem Sie Ihren Willen online festhalten können. Wussten Sie davon?**
 ja, und habe es ausgefüllt ja kenne es, habe es aber nicht ausgefüllt nein

Stutiennummer _____

7. «Ich habe einen Organspendeausweis ausgefüllt und...»

... habe mich gegen die Organspende entschieden.

Bitte fahren Sie mit Frage 9 weiter

... habe mich für die Spende aller Organe entschieden.

Bitte fahren Sie mit Frage 8 weiter

... habe mich für die Spende einzelner Organe entschieden, die wären (*Mehrfachauswahl möglich*):

- Leberanteile
- Lunge
- Knochenmark
- Hornhaut (Auge)
- 1 Niere
- Herz

8. Sie haben sich für die Organspende entschieden: Aus welchem Grund?
(Mehrfachnennungen möglich)

um Selbstbestimmung nach dem Tod zu wahren

religiöse Gründe

um Angehörigen die Belastung einer Entscheidung abzunehmen

ich möchte nach meinem Tod mit meinem Körper einem anderen Menschen helfen

Motivation durch Mitmenschen

ich denke, dass ich in der Zukunft selber ein gespendetes Organ brauchen werde

öffentliche Diskussion (z.B. im Rahmen der Volksinitiative «Organspende fördern – Leben retten»)

Sonstiges:

Bitte fahren Sie mit der Frage 11 weiter.

Studennummer _____

9. Sie haben einen Organspendeausweis und haben sich gegen die Organspende entschieden. Was ist der Grund dafür?
(Mehrfachnennungen möglich)

- | | |
|--|---|
| <input type="radio"/> religiöse Gründe | <input type="radio"/> mein(e) Organ(e) sind krank |
| <input type="radio"/> Wunsch nach körperlicher Unversehrtheit | <input type="radio"/> Spende bringt mir oder meiner Familie keinen Vorteil |
| <input type="radio"/> Angst vor Missbrauch der Organe | Aus Altersgründen:
<input type="radio"/> ich bin zu jung
<input type="radio"/> ich bin zu alt |
| <input type="radio"/> Sorge davor, dass nicht alle Therapiemöglichkeiten ausgeschöpft werden, wenn mein Wille zur Organspende bekannt wird | <input type="radio"/> ich weiss nicht mehr, wieso ich mich gegen die Organspende entschieden habe |
| <input type="radio"/> Ich befürchte, dass sonst nicht auf meinen Willen eingegangen wird | <input type="radio"/> Sonstiges:

_____ |

Bitte fahren Sie mit der Frage 11 weiter.

Studiennummer _____

10. Sie haben keinen ausgefüllten Organspendeausweis. Was ist der Grund dafür?
(Mehrfachnennungen möglich)

- | | |
|--|---|
| <input type="radio"/> religiöse Gründe | <input type="radio"/> mein(e) Organ(e) sind krank |
| <input type="radio"/> Wunsch nach körperlicher Unversehrtheit | <input type="radio"/> Spende bringt mir oder meiner Familie keinen Vorteil |
| <input type="radio"/> Angst vor Missbrauch der Organe | Aus Altersgründen:
<input type="radio"/> ich bin zu jung
<input type="radio"/> ich bin zu alt |
| <input type="radio"/> ich will das (noch) nicht entscheiden | <input type="radio"/> ich weiss nicht mehr, wieso ich mich gegen die Organspende entschieden habe |
| <input type="radio"/> meine Nahestehenden (Familie, Freunde) sollen für mich entscheiden | <input type="radio"/> Ich befürchte, dass sonst nicht auf meinen Willen eingegangen wird |
| <input type="radio"/> noch nicht dazu gekommen | <input type="radio"/> Unentschlossenheit |
| <input type="radio"/> wusste nicht, dass es einen Organspendeausweis gibt | <input type="radio"/> ich fühle mich ungenügend informiert |
| <input type="radio"/> meine Familie kennt meinen Willen bereits | <input type="radio"/> ich habe meinen Willen online im nationalen Organspenderegister hinterlegt |
| <input type="radio"/> noch nicht daran gedacht | <input type="radio"/> Sonstiges:

_____ |
| <input type="radio"/> Sorge davor, dass nicht alle Therapiemöglichkeiten ausgeschöpft werden, wenn mein Wille zur Organspende bekannt wird | |

Studennummer _____

11. In bestimmten Konstellationen kann in der Form der Lebendspende (v.a. Knochenmark/Stammzellen, Niere oder Leber) auch zu Lebenszeiten eine Organspende stattfinden ohne dadurch wesentliche körperliche Einschränkungen zu erleiden.

Haben Sie sich bereits Gedanken darüber gemacht, ob Sie bereit sind, Lebendspender/in zu sein?

Ja, ich habe mir Gedanken gemacht und

- ...wäre bereit, für gewisse Personen Lebendspender/in zu sein (weitere Angaben dazu später)

Bitte fahren Sie mit der Frage 12 weiter

Nein,

- ...ich habe noch nie etwas davon gehört
 ...ich habe mir keine Gedanken dazu gemacht

Bitte fahren Sie mit der Frage 14 weiter

- ...wäre **nicht** bereit, Lebendspender/in zu sein

Bitte fahren Sie mit der Frage 14 weiter

12. Sie haben in Frage 13 angegeben, dass Sie **gewillt** sind, Lebendspender/in zu sein. **Welche Organe wären Sie bereit lebend zu spenden?**

(Mehrfachnennungen möglich)

- Leberanteile Knochenmark/Stammzellen
 eine Niere

13. **An wen wären Sie bereit zu spenden?**

- Partner/in eigenes Kind/Enkelkind
 Eltern Grosseltern
 andere Familienmitglieder Freunde
 Fremde

Bitte fahren Sie mit der Frage 14 weiter

Visum Studienbegleitung _____

Studivnummer _____

Ihre Meinung

14. Im Oktober 2017 hat die Unterschriftensammlung für Volksinitiative «Organspende fördern – Leben retten» begonnen. In den nächsten Monaten darf eine Volksabstimmung erwartet werden. Deren Annahme würde bedeuten, dass grundsätzlich von der Zustimmung zur Organspende ausgegangen wird – ausser der/die Verstorbene hat sich zu Lebzeiten ausdrücklich dagegen entschieden.

«Falls heute die Volksabstimmung «Organspende fördern – Leben retten» stattfinden würde, so würde ich «Ja» stimmen.»

ja

nein

ich weiss
nicht

15. Würden Sie sich für die Spende der Organe eines nahen Angehörigen entscheiden, auch wenn Sie nicht wissen, wie er/sie selber entschieden hätte?

trifft gar nicht
zutrifft eher
nicht zu

trifft eher zu

trifft ganz zu

16. Würden Sie sich für die Spende der Organe eines nächsten Angehörigen entscheiden, wenn Sie wüssten, dass er/sie der Organspende zugestimmt hätte?

trifft gar nicht
zutrifft eher
nicht zu

trifft eher zu

trifft ganz zu

17. Würden Sie sich für die Spende der Organe eines nächsten Verwandten entscheiden, auch wenn Sie wüssten, dass er/sie sich gegen die Organspende zu Lebzeiten geäußert hat?

trifft gar nicht
zutrifft eher
nicht zu

trifft eher zu

trifft ganz zu

18. «Entscheidet sich ein Patient für die Organspende, so besteht die Gefahr, dass die medizinischen Therapiemöglichkeiten nicht ausgeschöpft werden.»

trifft gar nicht
zutrifft eher
nicht zu

trifft eher zu

trifft ganz zu

Studennummer _____

19. «Falls mein Leben nur durch eine Organspende gerettet werden könnte, so würde ich die Organspende annehmen.»

trifft gar nicht
zu

trifft eher
nicht zu

trifft eher zu

trifft ganz zu

Wir danken Ihnen für Ihre freundliche Unterstützung und wünschen Ihnen eine rasche Genesung.

Bei Unklarheiten, die während der Studie oder nach deren Abschluss auftreten, können Sie sich jederzeit an die Kontaktpersonen wenden.