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ARTICLE

Life beyond life: Perceptions of post-mortem organ donation and consent to donate—A focus group study in Italy

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Abstract

Objectives: Many factors such as personal and cultural beliefs, misinformation, fear of death and inadequate will registering procedures can influence post-mortem organ donation. The present study aimed to explore the perceptions, beliefs and information around post-mortem donation and will expression in different groups of the Italian population, to orient future interventions and raise awareness.

Design: Qualitative research with focus groups.

Methods: A total of 38 focus groups involving 353 participants including the general population (young adults: 18–39, mature adults: 40–70), local and hospital health professionals, critical area health professionals (emergency room and intensive care), registry office employees and opinion leaders, were conducted in six regions from different parts of Italy between June and November 2021. Thematic analysis was conducted with the use of Atlas.ti9.

Results: Five overarching themes were identified: dilemmas regarding donation, resistance to donation, facilitators of donation, difficulties in terms of will expression and proposals to encourage will expression. Possible facilitators were having personal and professional experiences with organ donation, feeling useful for society, having reliable information and trust in the health care system. Potential barriers to donation were doubts and fears about brain death, bodily integrity concerns, religious beliefs, misinformation and distrust in the health care system.

Conclusions: These results highlighted the significance of a bottom-up perspective with regard to identifying the personal perceptions and beliefs with regard to donation, underlining the urgency of creating tailored interventions to sensitize different groups of the population in terms of promoting an informed choice and a culture of donation.

KEYWORDS

focus group, health psychology, organ donation, perception, qualitative research, transplantation

What is already known on this subject?

- Increasing the number of potential organ donors is among the primary goals of the National Healthcare Systems.
- Doubts, fears, false beliefs and misinformation about organ donation could limit citizens' consent to donate.
- A positive attitude towards organ donation does not necessarily results in the registration of consent to donate.

What does this study add?

- Updated and comprehensive knowledge with regard to perceptions of post-mortem organ donation and consent to donate in Italy.
- The additional inclusion of novel and specific groups of population (opinion leaders and registry office employees).
- Suggestions for person-centred interventions to encourage informed consent to donate.

INTRODUCTION

Organ donation can be defined as an intentional, conscious, free and anonymous act that is essential for organ transplantation, the elected medical treatment to cure patients facing severe chronic or acute organ failure (Linden, 2009). There is a wide variation between countries in terms of rates of consent to donate and transplantation; as well as in the legal systems that define the modalities and laws to regulate this process. Two systems are the most commonly used to regulate organ donation. The first is *opt-in*, defined as an 'explicit consent' system which requires all residents in a specific country to express their intention to donate their organs post-mortem to proceed to the donation (examples of countries adopting this system are the Netherlands, Germany and Ireland). The second system, *opt-out*, is defined as the 'assumed consent' system. This requires all residents of a specific country to express only their opposition to post-mortem organ donation, assuming that every citizen is a donor unless they explicitly express their opposition (examples of countries adopting this system are Spain, Austria, Sweden, Belgium; Poland and Portugal; Etheredge, 2021).

To date in Italy, the law regulating organ donation (Law 91 of 1999) is based on tacit consent but has met many difficulties in its actuation. In practice, to become a donor, it is necessary to explicitly express your intention to donate. If the person has not expressed such an intention, the closest relatives or executor must report a person's will about the organ donation in the event of his or her death. Looking at the statistics of consent to donate while renewing their identity card in 2022 in Italy, 44.7% of the population had not expressed their will to donate, and of those who had expressed their will, 68.2% gave their consent, and 31.8% were opposed (Sistema Informativo Trapianti, 2021). To date, more than 8000 people in Italy are on a waiting list to receive organ transplantation (Centro Nazionale Trapianti, 2022).

From a psychological point of view, post-mortem organ donation represents a topic regarding which the majority of the population reports a positive attitude (Boulware et al., 2002; Brug et al., 2007; Moloney et al., 2019; Morgan et al., 2008; Rumsey et al., 2003), describing it as 'the gift of life' (Moloney & Walker, 2002), as an 'act of charity' (Lauri, 2009) or as 'continuing physical or spiritual survival after death through one's organ recipient' (Morgan et al., 2008). However, this positive attitude does not necessarily result in an effective and registered expression of will (Brug et al., 2007; Moloney et al., 2019; Morgan et al., 2008; Rumsey et al., 2003). Previous studies have analysed the factors associated with consent to donate and have found that the quantity and quality of information that a person has with regard to organ donation is not associated with the intention to become a donor (Brug et al., 2007; Morgan et al., 2008). Fears and doubts can translate into resistance to donation. For example, many people report concerns regarding their bodies when talking about organ donation; the fear of the body being 'ruined', and the desire to maintain the body intact after death (Lauri, 2009) are influential aspects in the decision not to become a donor (Miller et al., 2020; O'Carroll et al., 2011; Shepherd & O'Carrol, 2014). The more people are attached to their body's integrity, the less it is probable they express their will to donate their organs after death (Morgan et al., 2008). In line with this, two studies (Lauri, 2009; Moloney & Walker, 2002) have identified that many people report religious expectations and beliefs regarding the importance of not compromising their body after death through organ donation. More specifically, religion and spirituality are inversely associated with the willingness to become donors (Boulware et al., 2002). Interestingly, these data are in contrast to the position of most religious institutions that, at the present time, have explicitly supported donating or receiving an organ (Bruzzone, 2008).

Fear of death and connected doubts can negatively influence consent to donate, or orient the individual to the decision to oppose donation, for example doubting that a deceased person is actually deceased, hoping that it might awaken 1 day, lacking information and/or having misleading ideas regarding brain death, a lack of trust in the health care system ('doctors can be wrong') and magical thinking (e.g., 'miracles can always happen!') (Anker & Feeley, 2010; Moloney & Walker, 2002; Reynolds-Tylus et al., 2019; Skowronski et al., 2020). Lack of trust in the healthcare system has been reported as an important factor influencing the decision to donate (Feeley et al., 2014; Miller et al., 2020), fearing especially that health care professionals might declare someone deceased inappropriately or prematurely, in order to extract the organs (Lauri, 2009). When thinking of organ donation, people report fearing that their organs could be given to a recipient not deserving/worthy of such a precious present (Miller et al., 2020).

Some studies (Conesa et al., 2006; Pugliese et al., 2001) have focused on the specific population of health care workers, identifying their doubts, uncertainties and difficulties regarding organ donation, more specifically reporting having to face difficulties when it comes to introducing the idea of organ donation to relatives of the deceased, and in explaining brain death (Pugliese et al., 2001).

Factors that are positively associated with the intention to donate organs are being familiar with the theme (Brug et al., 2007; Feeley et al., 2014), knowing a donor or a recipient (Alvaro et al., 2005; Rumsey et al., 2003), perceiving the donation as an act to save someone's life (Hyde & White, 2010), having a mechanistic vision of the body (Lauri, 2009), being open and involved in discussions on the topic (Morgan et al., 2008), perceiving that organ donation can be a positive experience also for the donor in terms of being proud of oneself and knowing that a part of one will be living even after one's death (Cohen & Hoffner, 2012).

Departing from the current debate on the Italian regulations with regard to organ donation, the varying regulations in European countries, and the many questions that are still open from the previous literature, such as the comprehension of brain death, the transparency and fairness of the organ allocation system, and the modality of consent to donate, the present research aims to explore, in the Italian population, the perceptions, knowledge, fears and doubts regarding after-death organ and tissue donation and consent to donate. This is the first study to involve different population groups involved in the donation process, such as the individuals who are required to make a choice, registry officers who are required to ask the question with regard to donation, health care workers and opinion leaders who have a key role in the process of decision making. Obtaining knowledge from different perspectives may allow us to develop a more complete picture of the situation. In addition, the results of the present study might offer insights into the barriers to donation and the facilitators which can be useful when it comes to planning innovative models of information and awareness-raising for the professional components and the social stakeholders involved in organ donation and transplantation processes, particularly in regions with a higher prevalence of opposition and a lower prevalence of will declaration.

METHODS

Participants

The research involved a total of 353 participants with a mean age of 45.45 years (ranging from 18 to 77). The participants' personal details are reported in Table 1. As regards their consent to donate, 178 participants (50.4%) reported having expressed their will already, 169 (47.9%) did not and 6 (1.7%) did not specify if they expressed their consent.

The participants in the population group were recruited departing from lists of names identified by the Regional Transplant Centers with the cooperation of various local institutions, associations and organizations and through word of mouth. Health care professionals and registry office employees were contacted by their institutions. Opinion leaders were identified and contacted by the Regional Transplant Centers among influential people (show people, politician, bishops, influencers) on the national territory. The participants were contacted by telephone or e-mail and received an invitation letter and an informed agreement form with regard to participation and data processing. No incentive was proposed. The researchers examined the composition of each group to verify, within a single group, gender balance and to obtain the representativeness of different ages. Six/seven focus groups were conducted in each of six regions, each with a different group of participants and a mean number of 11 participants per group, in line with the suggested number of participants in a focus group discussion, which is usually between 5 and 10 (Krueger, 2014) and with a slight variability between regions due to differences in the acceptance rate to participate in the study. See Table 2 for group composition details. Donors and organ recipients were excluded from the research to ensure that discussion in the focus group was not influenced by the experiences of directly involved people.

The study was conducted in accordance with the Declaration of Helsinki and approved by the Ethics Committee of the School of Psychology of the University of Padova (protocol no. 3749).

Data collection and analysis

Three researchers from the University of Padua conducted 38 focus groups between June and November 2021 in six Italian regions. Each meeting lasted approximately 90 min, in line with the suggested duration of a focus group discussion, which is between 1 and 2 h (Krueger, 2014). Although flexible, the discussion followed a common trace given by the interview guide, adapted for the different groups, as reported in Appendix 1.

Each focus group was audio- and video-recorded with all the participants' informed consent and subsequently transcribed verbatim. The same researchers conducted a thematic analysis of each transcript (Braun & Clarke, 2006) with the aid of Atlas.ti 9. The detailed analysis process is reported in Table 3.

RESULTS

Five overreaching themes were identified from the analysis of the focus groups' data as summarized in Table 4, together with the related themes and subthemes. Quotations from some of the participants

TABLE 1 Participant's details.

Gender	*n*	%	Education	*n*	%	Civil status	*n*	%
Male	144	40.8	Middle school diploma	19	5.4	Married or Cohabitant	202	57.2
Female	208	58.9	High school diploma	35	9.9	Widowed	13	3.7
Not specified	1	0.3	Technical school diploma	49	13.9	Divorced	14	4.0
			Bachelor's degree	46	13.0	Separated	14	4.0
			Master's degree	84	23.8	Single	98	27.8
			Postgraduate	105	29.8	Total	341	96.5
			Other	9	2.5	Missing	12	3.4
			Not specified	6	1.7			
Total	353	100		353	100		353	100

TABLE 2 Groups' characteristics.

Group of belonging	Groups' number	Participants' number	%	Region of origin	*n*	%
Local healthcare personnel (LH)	5	55	15.6	Tuscany	46	13.0
Critical area healthcare personnel (CAH)	6	56	15.9	Abruzzo	47	13.3
Young Adult population (YA)	6	55	15.6	Piedmont	78	22.1
Adult population (AP)	6	57	16.1	Campania	80	22.7
Opinion Leaders (OL)	4	27	7.6	Lombardy	47	13.3
Registry office employees (RO)	6	48	13.6	Puglia	55	15.6
Hospital healthcare personnel (HH)	5	55	15.6			
Total	38	353	100		353	100

TABLE 3 Details of the analysis process.

1.	Two researchers read the focus groups' transcripts and familiarized themselves with the data
2.	Two researchers independently identified preliminary codes and themes
3.	Two researchers compared and discussed the preliminary codes and themes
4.	A researcher codified all the material, starting from the agreed preliminary codes and themes
5.	Another researcher reviewed the preliminary codes and themes
6.	The two researchers discussed and refined codes and themes with a third researcher and agreed on the final ones
7.	The transcripts were read again to verify that the identified themes could be found in the data
8.	Three researchers discussed the findings and themes and agreed on an interpretation of the data

are given in the text. Participants are identified with a code consisting of the number of the participant within the group (e.g., P1); letter M or F indicating the gender (Male, Female); the group to which they belong (YA; AP; OL; LH; CAH; HH; RO as illustrated in Table 2); the group's region.

Dilemmas regarding donation

By analysing the meanings attributed to donation, researchers identified an overreaching theme describing several dilemmas which may play a role in deciding whether or not to donate organs.

The participants considered organ donation as a relevant dimension, but at the same time one that is neglected in public discourse. Some participants explained the lack of attention to the topic by claiming that organ donation is something you do not think about spontaneously, except when it touches you. Organ and tissue donation was therefore described as 'far from everyday life' and featured by several as a taboo subject. In fact, not only is it a neglected topic, but it is a topic people do not want to talk about because it is associated with uncomfortable images such as death, pain, and body disintegration. In response to this, some participants underlined the need for making organ donation an everyday discourse.

Participants often spoke about donation in association with life or death. Several participants argued that consent to donate on organ donation often implies a reflection on one's death, and many consider death as a taboo subject. In contrast, for others, donating can give meaning and relief to grief, as it is intrinsically linked to the life of someone else (the recipient). For many, donating is connected as much as to life and rebirth as it is to death and loss.

TABLE 4 Overarching themes, themes and subthemes.

Overarching themes	Themes	Subthemes
Dilemmas regarding donation	The importance of donation vs. donation as an 'unpopular' theme	Donation as an essential thing
		There is an organ shortage
		It's not talked about
		You don't think about it until it touches you
		Donation as taboo
		It should become something to talk about everyday
	Donation as death vs. donation as life	The fear of facing death
		An act that gives meaning and relief to the loss
		Continue to live in someone else
		How to combine death and life?
	Expecting something in return vs. donating for a greater good	Opposing as an act of selfishness
		If you don't give, you don't receive
		Act of unconditional love
		Act of civil and social responsibility
	Guaranteeing self-determination vs. being forced	Freedom of choice
		Respect my will, that of the family member, and the deceased
		A private and complex choice
	Not looking like a bad person vs. choosing what's best for me	Fear of making a negative impression
		Making excuses
	To know the identity of the donor and the recipient	To know or not to know who the donors are?
		Do the recipients deserve the organ?
	Expressing yourself in life vs. leaving the choice to family members	The weight of responsibility
		Adding another pain
Resistance to donation	The riddle of death	Brain death: this unknown
		Am I really dead?
	The integrity of the body	Fear of wasting the body
		Ensure the integrity of the body
	Ignorance and false beliefs	How does the donation work?
		Where do my organs go?
		False myths
	The lack of trust in the system	They take you off of life support
		Political and economic interests
	The culture of the 'We are not ready yet'	'Out of Date' Religious Beliefs
		Saying yes brings you 'bad luck'
	The identification of groups of resistance	Young people are more likely to donate
		Older people are less likely to donate
		The older you get, the greater the approvals
		The middle age group is less likely to donate

(Continues)

TABLE 4 (Continued)

Overarching themes	Themes	Subthemes
Facilitators of donation	Experience and familiarity with the topic	Having direct experiences
		Professional experiences
		Indirect personal experiences (TV series, movies, theatre)
	The culture of the 'critical sense'	Trust in health care personnel and the donation process
		'Faith and science can coexist'
		An 'atheistic' vision of the body
	Personal motivation	Emergency makes you proactive
		The need for an incentive
Difficulties in consent to donate	Modalities of consent to donate	Little time and wrong place
		The unpreparedness of registry staff
	Lack of information	Accessibility of information
		Little clarity with regard to the bureaucratic and legislative aspects of consent to donate
		Arriving 'unprepared' at the choice
	Difficulties regarding communication	Doctors–Donor's family communication
		Registry office's employee–citizen communication
		The Media: between disclosure and fake news
Proposals to encourage consent to donate	Greater information at a local level	Targeted interventions within categories of population
		Raising awareness through testimonials
		Continuous advertising and campaigns
	Sources of information	Using social media
		Involving institutional experts
	Locations/methods of consent to donate	The right time and place
		More support when choosing

Participants expressed the motivation for organ donation in different terms. Some participants argued that people who decided not to donate their organs are selfish. Others reported that those who oppose becoming donors should not have the right to receive an organ in the event of need: 'Do you want to receive organs if you're sick? Yes! Then you must also donate yours!' (P1, F, RO, Piedmont). In contrast, for many, donating is an act of unconditional love towards others and a conscientious gesture towards one's community, a matter of civil and social responsibility.

The freedom of choice when it comes to consent to donate was widely discussed. Most participants claimed that everyone should be free to choose how to dispose of their body, and therefore should not be judged for their choices. On the contrary, for others, donating should be an obligation. The importance of defending oneself from external interferences, remaining faithful to one's wishes, and respecting those of others was also underlined, because donation is a 'private' (i.e., concerning the single individual) and a 'complex' (i.e., implying different personal aspects such as family, religion and health) choice. Nevertheless, choosing to not donate can imply a negative judgement on the part of others, thus putting people in the difficult position of having to admit their choice, and generate a conflict between what they want and what they think they should do. This situation could result in finding excuses to motivate one's opposition to donation, or in the decision not to express one's will.

Another dilemma dealt with the possibility of knowing the identity and meeting the recipient of a family member's organ. This option could facilitate the consent to donate but also lead to a problematic attachment to that person and an invasion of privacy. Moreover, a dilemma concerning the organ recipients was if they had to deserve it or one should donate regardless of the recipient's history and characteristics because donating means ‘giving’ without regard to the merit of the recipient.

> I just hope that […] someone is worthy of it in a certain sense […] I always hope that these are people who have perhaps given a lot in life, have suffered a lot, and having an organ can truly be a lifesaver for them, people who deserve it.
>
> (P8, M, HH, Abruzzo)

The responsibility with regard to the choice to donate was also debated in terms of expressing one's will while alive or leaving this choice to their relatives. The health care professionals pointed out that the latter alternative can put health professionals in the difficult position to ask families for the consent to donate in a painful moment. This difficulty might lead health care personnel to omit this question, resulting in one less opportunity for organ donation.

Resistance to donation

The participants discussed fears and doubts concerning death assessment, brain death, coma and organ explant practices. While some participants knew the meaning of brain death, several, including health care professionals, did not have a clear idea of its definition. Indeed, health care professionals expressed the need for a training on the process of organ donation and the definition of brain death. The lack of information with regard to brain death was accompanied by a series of scientifically incorrect beliefs (e.g., a brain-dead patient is still alive). These beliefs, although categorically denied by science, remain present among several participants.

> Rarely, but very rarely it can happen that the heart is still beating then somehow the brain activity can start again. It is very rare. So I'm very much in favor, I'd just really like to be dead before they remove my organs.
>
> (P14, M, YA, Piedmont)

Some of the participants described medical practices related to transplantation as brutal, bringing up concerns regarding the explant procedures and the ruining of the body. Many highlighted the importance of the body's integrity after death: ‘When I used the term fear, the first thing that came to my mind was the fear that one day my body may no longer be whole, even when dead’. (P2, F, AP, Campania). The concept of integrity is often, though not always, associated with religious values (e.g., resurrection, afterlife, etc.).

Most of the participants claimed not to have enough information about donation practices, which sometimes raises doubts concerning the destination of one's organs. Some participants feared that their organs would be ‘wasted’, while others raised doubts about the correct use of the organs (e.g., the ‘black market’). Although some participants considered themselves adequately informed about organ donation, most of them showed that their knowledge of the subject is studded with false beliefs which can prevent donation.

The participants expressed a general sense of distrust with regard to the health care system, politics, and organ donation policies, as well as doubts and fears regarding the ‘real intentions’ of the doctors who deal with the verification of death and the explant process. Some expressed a fear that doctors may ‘let the patient die’, to export the organs: ‘There is a fear that everything necessary is not being done to save the patient’. (P12, F, HH, Piedmont) Others, including health professionals, claimed that organ donation is led by secondary political and economic interests:

> Obviously as a human being, the lack of trust immediately takes over, because if the message is "they will kick your ass if you lose a donor," it immediately makes me think that the interest is something else.
>
> (P3, F, CAH, Tuscany)

Many participants pointed to a series of cultural aspects such as 'outdated' religious beliefs and superstitious beliefs about death as potential barriers to donation: 'It's like buying your coffin before you die'. (P2, F, CAH, Campania).

Finally, many participants identified young people as being the most likely to agree to post-mortem organ donation, and old people being less inclined to donate. However, for many, the middle age group was the least likely to donate.

Facilitators with regard to donation

According to the participants, having direct or indirect experience of organ donation could raise people's awareness of organ donation, and provide the necessary tools to make an informed choice and express one's will: 'Recently in our village a very young girl died, and her organs were donated, so we talked about it' (P8, F, AP, Tuscany).

Professional experience with the donation process can raise awareness among those who work in critical contexts; however, some health professionals working in the donation field stated that they are against donation. The participants underlined the importance of TV series and movies with regard to donation in that these can foster empathy with the characters and increase interest in the topic.

The participants identified some cultural aspects (e.g., solidarity fostered by religion, education, tradition, etc.) that could facilitate donation by fostering the creation of a 'critical sense' that allows making informed choices regarding organ donation. Trust in science and the health care system is often described by participants as 'fundamental' for organ donation: 'I imagine that whoever ascertains these things is certainly aware and knows what he is doing. So, in short, I trust the doctors'. (P14, M, YA, Piedmont).

For some participants, religious values and trust in science co-occurred. According to them, in fact, 'faith and science can coexist', facilitating consent to organ donation. For others, a facilitator to donation was related to not feeling attached to their bodies, contrary to concerns with regard to body integrity raised by others.

For many, feeling useful to the community and having an important and active role in society could act as a facilitator for donation. Some would like information such as the number of people on transplant waiting lists or the number of donors currently available, to be publicly disclosed in order to raise awareness in the population, and favour the consent to donate, since in emergencies, humans become more proactive.

Only a few participants reported knowing about and having checked information on the Transplant Informative System's website. A minority of the participants argued that to encourage organ donation, it would be necessary to propose a concrete incentive directed to the donor or his family.

Difficulties with regard to consent to donate

There are many difficulties that could act as potential barriers to the consent to donate. First of all, the methods and places of consent to donate (e.g., registry office, a corridor of a hospital, etc.) are mostly described as being inadequate.

Most of the participants argued that there is too little information about the modalities of consent to donate and that information is not always accessible to the public. Most people reported having doubts about the bureaucratic and legislative aspects of consent to donate, and not having the medical-scientific knowledge necessary to understand the information on organ donation presented in brochures or online.

Participants reported communication difficulties that could translate into barriers to the consent to donate with regard to organ donation. In particular, several health care professionals argued that they are not adequately trained in communicating with the patients' families. Many of them recognized the strong emotional impact of that moment and often find difficulty being in charge of communicating the death and proposing a donation (when patients have not expressed their will).

Most of the participants argued that being asked that question at the registry office while renewing their ID, often leaves the citizen 'displaced'. Many people do not know that this question will be asked and are called to choose without ever having thought about the topic, highlighting the importance of preparing the citizens for making such a choice. Moreover, the participants claimed that the lack of a sufficient amount of time prevents people making an aware choice: 'In my opinion […] those are important decisions to be made and I think those 5 minutes aren't enough to think about it'. (P5, M, YA, Tuscany).

Difficulties related to communication between registry employees and citizens are also underlined. Several registry office employees revealed that they often feel uncomfortable asking citizens this question and that they are not sufficiently trained on organ donation to allow them to fulfil their role.

> I find myself a little uncomfortable with people I already know that could misunderstand me […] it can be a person who does not speak Italian, it can also be a very old and disabled person. I always ask myself: do I ask him the question? Or do I not? And this makes me uncomfortable.
>
> (P11, F, RO, Lombardy)

The role of media has been reported as a suitable information source for many; however, for others, it is reported as a tool with many risks of fuelling disinformation about organ donation.

Proposals to encourage consent to donate

The participants shared many suggestions with regard to promoting and spreading the culture of donation, proposing strategies and methods for informing and sensitizing the population by planning targeted interventions that take into account age, culture and religious differences, and that are specific for families, workers and university students.

Several participants emphasizing the need for more persistent communication, arguing that campaigns carried out only one or a few days a year are not effective when it comes to raising citizens' awareness. Moreover, they highlighted the importance of testimonials: 'In my opinion, the testimony of both the patient who received the organ and the (donor's) relatives, is pivotal, because it touches emotional chords that only they can touch'. (P6, M, HH, Puglia).

The participants discussed the best means of informing citizens about the value of donations. Some supported and promoted the use of social networks as a powerful means of dissemination; others considered social networks as inadequate, preferring other channels that could entrust the subject only to reliable and expert figures. These participants tend to oppose the use of social media and the involvement of non-expert figures such as influencers. 'I wouldn't want Fedez to tell me. I wish there was someone a little more authoritative or someone from the Institute of Health'. (P5, F, CAH, Campania).

The participants proposed places and moments suitable for them to express their will, such as general practitioners' offices or during mandatory vaccinations. Others wish to express their will online, a solution that is already available in Italy, even though most of the participants were unaware of it.

Lastly, many participants underlined the need to have psychological- and medical-scientific support when it comes to making a choice:

> I would like to speak to a person, a doctor, because whether (the question) it is expected or unexpected unless one is firmly convinced about organ donation, it is a very difficult decision, and I would like psychological support.
>
> (P5, F, YA, Lombardy)

DISCUSSION

The results of the present study have shown that deciding on organ donation involves complex choices that can be described in terms of personal dilemmas. Moreover, the focus group discussions have pointed out the barriers and facilitators to donation, the difficulties associated with consent to donate, and some proposals to reduce the gap between the attitude towards organ donation and consent to donate.

A personal and complex choice

In line with other studies (Moloney et al., 2019; Moloney & Walker, 2002), when discussing organ donation, the participants in this study identified several dilemmas that may lead to differing attitudes. As other studies also pointed out (Lauri, 2009; Moloney et al., 2019; Moloney & Walker, 2002) the participants often conceptualized organ donation in negative terms when it referred to the donor's experience (e.g., 'organs as ripped from the body'). Conversely, when the focus was on the recipient, some of the participants revealed a positive view of donation as a 'gesture for society' or an 'altruistic act'. These results offer two main interpretative insights. First, they show how organ donation can be configured in moral terms, in which agreeing to donation is characterized as pro-social behaviour (Cohen & Hoffner, 2012; Lauri, 2009). Second, they suggest that a possible strategy with regard to promoting donations could be to use a communication frame that draws attention to the recipient, and highlights a collective dimension of giving, rather than to the donor and an individualistic dimension.

Another dilemma implied in the attitude towards organ donation dealt with its construction as being linked to life or death. In line with Morgan et al. (2008) some participants considered donation as a way for the donor to continue living through someone else (i.e., the recipient), but, in line with the findings of Alvaro et al. (2005), most of the participants highlighted the fear of facing death as a barrier to donating, because some people withhold their permission or oppose organ donation to avoid thoughts of their death. This result suggests that strategies to encourage consent to donate should convey a message that focuses more on life than on death.

In line with Moloney and Walker (2002), the value of freedom of choice and respect for the deceased's wishes was widely discussed by our participants. For many, leaving the responsibility of this choice to others (e.g., family members, other executors, etc.) carries the risk of not respecting the wishes of the individual. In this regard, the participants repeatedly emphasized the importance of family discussion and confrontation with respect to their choices regarding donation. In fact, creating opportunities for discussion on the topic of donation is an important aspect that can facilitate the consent to donate and spread a culture of donation. In-depth interpersonal exchange on the topic can depower the beliefs, doubts and fears that negatively influence people with respect to choosing to donate. Bringing the topic 'to the light' through conversation and discussion may enable people to adopt a less 'fearful' stance towards donation (Morgan et al., 2008). However, Miller et al. (2020) underscore the importance of perceived negative expectations with respect to one's decision to donate. Our participants described occasions when they perceived judgement and stigma from friends and family members regarding their decision to donate. Such negative experiences thus appear to decrease people's intention and willingness to discuss their decision to donate with friends and family members.

Another dilemma concerns the worthiness of the recipient. In line with Miller et al. (2020), some participants reported the fear that one's organ could be assigned to an unworthy recipient, and argued that stepping out from anonymity and sponsoring one's personal story could help others become familiar and empathetic with the topic, encouraging a more positive consent to donate (Hyde & White, 2010; Petrini et al., 2020). However, it should be noted that in Italy, this is prohibited by law. Others argued the importance of maintaining anonymity to safeguard both the recipient and the donor's family as already pointed out by other researchers (Dobbels et al., 2009; Petrini et al., 2020) who claim the importance of preventing unfortunate episodes caused by the inevitably unbalanced relationship between the two parties.

Barriers and facilitators

The second overarching theme describes the resistance to donating identified by the participants. Although the medical definition of brain death appears to be accepted among the participants, this concept generates fear and doubt. This result is in line with Anker and Feeley (2010). Some participants are uncomfortable with the idea that in some cases organs are removed while the heart is still beating. Coherently with Moloney and Walker (2002), some health care professionals highlighted that the deceased's relatives—noticing the presence of physiological functions in the patient (e.g., heartbeat)—often perceive the deceased as being still 'alive'. In this regard, in line with Pugliese et al. (2001), the health personnel participants complained about a general lack of information regarding organ donation, and requesting greater training, in particular with regard to the topics of understanding brain death and communication with the family.

Many of the health care professionals who participated in this study stated that they have never or only rarely taken university courses related to organ donation. The Spanish model, which has been found to be extremely effective in increasing consent for organ donation (Matesanz, 2003), involves the management of donation by highly experienced coordinators. This similarly occurs in Italy but risks making all the other health professionals feel excluded from the donation process (so much so that they do not know how to give explanations when asked by a patient). One way to ensure that these professionals could therefore be adequately trained on the subject may be to include specific training related to organ donation in university courses of the major health professions. Alternatively, it could become one of several mandatory training and alignments for health professionals. This way the training could offer tools for the communication also in other aspects relating to the end of life, which is crucial to promote trust in the health care relationship (Cipolletta & Reggiani, 2021).

All groups raised concerns related to the body, a topic that is widely discussed in the post-mortem donation literature (Hyde & White, 2010; Lauri, 2009; Miller et al., 2020; Moloney & Walker, 2002; Morgan et al., 2008). In particular, the importance of after-death bodily integrity was underlined. Furthermore, participants discussed the fear that the body could be disfigured by explant practices, and this can constitute a barrier to organ donation. On the contrary, several participants who spoke in favour of donation did not identify themselves with their cadaver, thus proposing a scientific view of life and body as a facilitator for donation (Lauri, 2009; Moloney et al., 2019).

In line with this need for trustworthy information, the participants identified a lack of information as a potential barrier to donation. This result may appear to contrast with those of some other studies (Brug et al., 2007; Morgan et al., 2008), suggesting that the amount of information that a person possesses regarding the donation process does not influence (or influences only weakly) choice when it comes to expressing one's will. This contradiction may be overcome by considering that the simple increase in knowledge about donation and how to express one's consent—often the main objective of campaigns to increase the registration of organ donors—might have no beneficial effect on the actual intentions of individuals. In fact, doubts and fears related to medical errors and brain death, which may be attributable to misinformation, can act as barriers to donation (Skowronski et al., 2020).

Nevertheless, the participants in the present study underlined contrasting positions with regard to science and its institutions. In fact, on the one hand, scientific institutions are often identified as the only reliable sources of information, while on the other, in line with the current literature (Feeley et al., 2014; Lauri, 2009; Miller et al., 2020), participants identified distrust in health care institutions as a possible obstacle to donation. Distrust could be associated with a general worsening of Italians' trust in health care institutions following the COVID-19 pandemic, as reported by some statistical sources (Bucchi & Saracino, 2021) and studies (Cipolletta et al., 2023), together with the spreading of sensationalized news of organ donation and transplants reported by the mass media or on social media, that are often a catalyst for distrust (Etheredge, 2021).

In agreement with other studies (Boulware et al., 2002; Feeley et al., 2014; Lauri, 2009; Reynolds-Tylus et al., 2019), many participants argued that religion can be a barrier to donation. The topic of religion is disputed. Indeed, it can act both as a barrier and as a facilitator. In the former case, the theme refers to what are considered to be outdated religious beliefs. They often result in the idea that many religions do not allow organ donation. Associated arguments are often linked to the importance of the integrity of the body in the afterlife (Lauri, 2009) and the sacredness of the body. On the contrary, religion can act as a facilitator for some of the values it refers to, namely unconditional love for others, as well as the concepts of charity and goodness (Lauri, 2009). Although several participants supported the influence of religion on the choice to donate, some statistical sources (e.g., European Commission, 2010) show that only a small part of the European population opposes donation due to religious factors (7%), while a higher percentage of people are opposed due to bodily concerns (25%).

During most of the focus groups sessions, several participants identified categories of people who—according to them—are more likely to oppose donation. In particular, the middle-aged group (35–55) is considered to be the most opposed. This perception, however, does not reflect the more recent statistics from the Transplant Information System (2022) which show that middle-aged groups (ranging from 31 to 40 and 41 to 50) present the lowest percentage when it comes to opposition (from 25.8% to 27.2% in opposition) compared with the under 30 age group (28.4%) and those over 70 (from 45.1% to 60.9%). In line with these statistics, many participants perceived older people as being the most resistant to donation and recognized instead young people as more likely to donate. In the process of creating a culture of donation, young people could play an important role in the discussion around donation within their families, fostering a positive attitude and supporting their parents, grandparents and peers in expressing their consent; this should be supported by the implementation of educational and sensibilization campaigns with a specific priority in high schools before the driver's licence acquisition.

The third overarching theme reports the donation facilitators identified by the participants. In line with Moloney et al. (2019), donating was described as a form of 'reciprocal altruism', which not only allows the recipient to lead a better life but allows the donor to continue living through the recipient. Moreover, the perception of being useful to the community and the resulting satisfaction, as well as viewing donation as a gesture of 'disinterested altruism' which only considers the recipient's benefit can, according to research (Cohen & Hoffner, 2012; Feeley et al., 2014), constitute a donation facilitator. Surprisingly, some participants in the present study suggested the introduction of benefits and incentives (e.g., priority in the ranking of transplants, monetary compensation for the family, etc.), highlighting the fundamental value of reciprocity in the context of organ donation.

In line with the previous literature (Alvaro et al., 2005; Brug et al., 2007; Feeley et al., 2014), several participants argued that having experiences related to donation can constitute a potential facilitator of donation. Moreover, in line with Rumsey et al. (2003), most of the participants emphasized the importance of testimonials expressing the wish to meet and talk to people who have received transplants, or with donor family members, as these experiences would allow individuals to approach the theme of donation which is often perceived as 'far' from everyday life.

Strategies to encourage consent to donate

Being specifically related to the Italian context, difficulties concerning consent to donate and proposals suggested by the participants, are not yet reported by the literature on the subject. Little research has been carried out in Italy to determine the potential barriers and facilitators with regard to organ donation. The present research is therefore innovative, not only in terms of the new data collected in the Italian context by different actors in the donation process (e.g., individuals, registry office employees, health care personnel and opinion leaders), but also in terms of the proposals related to policy implementation with regard to intervention strategies. Our citizens' proposals included commercials, public awareness campaigns and events and education and training in schools, universities and workplaces with a type of communication that must be clear and understandable to all. Moreover, receiving training on the death determination procedure could be useful in order to increase trust in the health care system.

As shown in Figure 1, the process of donation choice is characterized by dilemmas and beliefs, as well as by doubts, resistances and practical difficulties. These aspects can take the form of facilitators or barriers to donation. In the former case, the choice will probably lean towards a 'yes', and in the latter towards a 'no'. However, if individuals are torn between the former and the latter, they will risk not making any choice, leaving the responsibility to other eligible persons. Based on the results, together with an information campaign that includes medical-scientific aspects and donor families and transplant patients' testimonials, it would be important to support the individual in the moment of choice (in the hospital, in the registry office, etc.) by providing the opportunity to engage with an expert.

In conclusion, the present study underlines that in order to move from research to practice, it is important to address the challenges related to organ donation and consent to donate by developing and implementing contested interventions that take into account different aspects and perspectives. The complexity of the topic and of the choice regarding one's will with regard to post-mortem organ donation should be addressed with the introduction of collaborative interventions aimed at raising awareness, informing and encouraging individuals to express their will, while at the same time supporting them throughout the process of decision and expression.

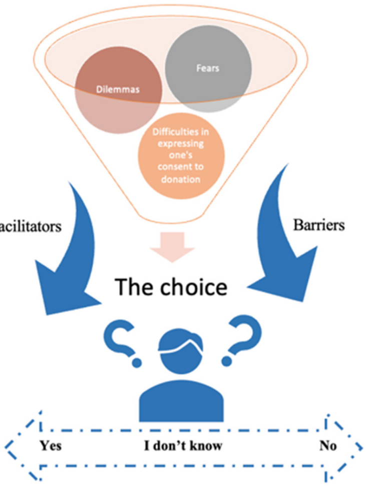

FIGURE 1 Visual representation that synthesizes the meanings with regard to organ donation as reported by participants in the facilitators and barriers to organ donation.

Limitations

The limitations of this study include the risk of recruiting participants with similar beliefs in terms of the degree of sensitivity towards the topic of organ donation, thus potentially selecting individuals expressing positive beliefs about donation. However, the doubts, uncertainties and resistances reported by the participants allow us to think that varying positions were represented. Furthermore, during the focus group discussions the potential influence of social interaction could have played a role in inhibiting the sharing of fears and misinformation to avoid the risk of being judged negatively by others with an overall positive attitude towards organ donation.

CONCLUSIONS

This is the first study to consider the different population groups that are directly involved in the choice and process of organ donation, as well as socially influential people. Until now, little research investigating attitudes and perceptions with regard to organ donation has been carried out in Italy (Burra et al., 2004; Fontana et al., 2017; Pugliese et al., 2001). Moreover, in terms of results this study adds to the current literature a system of dilemmatic issues that characterize the difficulty of this choice. We intended dilemmas as issues usually felt by an individual as equally relevant but often conflicting or opposing. These dilemmas naturally make the choice more complex as it is animated by internal struggles and can often result in a non-choice.

The findings of the present study may have important implications for the development of strategies to encourage consent to donate. It is important to specify that there is no single suitable way to solve the organ supply and demand gap. However, by identifying the facilitators and barriers to donation on the basis of the analysis of individuals' needs, beliefs, fears and doubts, it is possible to implement targeted interventions.

Future interventions should support individual choice by providing reliable information on the donation process, explaining how to express the will to donate, and by using appealing means with regard to information. To make information reliable, it is also important to overcome any distrust with regard to health care institutions, and to identify which institutions are considered reliable and for what reasons. The other way round, sharing scientific knowledge on the part of the medical community may reduce false myths and increase trust in the health care system.

Future research could offer a useful contribution in this respect. Intervention strategies to promote organ donor registration should take into account the barriers to donation identified in the present study, including false myths, the fear of death and body disintegration and, at the same time, use as resources donation facilitators such as experience and familiarity with the topic, trust in the institutions involved and social responsibility.

AUTHOR CONTRIBUTIONS

Sabrina Cipolletta: Conceptualization; investigation; writing – original draft; methodology; writing – review and editing; validation; supervision; formal analysis. **Silvia Caterina Maria Tomaino:** Investigation; writing – original draft; formal analysis. **Alessandra Brena:** Investigation; writing – original draft; formal analysis. **Paola Di Ciaccio:** Conceptualization; writing – review and editing. **Margherita Gentile:** Conceptualization; writing – review and editing. **Francesco Procaccio:** Conceptualization; writing – review and editing. **Massimo Cardillo:** Conceptualization; writing – review and editing.

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CONFLICT OF INTEREST STATEMENT

None declare.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article due to the nature of this research, as participants of this study did not agree for their data to be shared publicly.

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REFERENCES

Alvaro, E. M., Jones, S. P., Robles, A. S. M., & Siegel, J. T. (2005). Predictors of organ donation behavior among Hispanic Americans. *Progress in Transplantation*, *15*(2), 149–156. https://doi.org/10.1177/152692480501500207

Anker, A. E., & Feeley, T. H. (2010). Why families decline donation: The perspective of organ procurement coordinators. *Progress in Transplantation*, *20*(3), 239–246.

Boulware, L. E., Ratner, L. E., Sosa, J. A., Cooper, L. A., LaVeist, T. A., & Powe, N. R. (2002). Determinants of willingness to donate living related and cadaveric organs: Identifying opportunities for intervention. *Transplantation*, *73*(10), 1683–1691. https://doi.org/10.1097/00007890-200205270-00029

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77–101. https://doi.org/10.1191/1478088706qp063oa

Brug, J., Van Vugt, M., Van Den Borne, B., Brouwers, A., & Van Hooff, H. (2007). Predictors of willingness to register as an organ donor among dutch adolescents. *Psychology and Health*, *15*(3), 357–368. https://doi.org/10.1080/08870440008401998

Bruzzone, P. (2008). Religious aspects of organ. *Transplantation*, *1067*, 1064–1067. https://doi.org/10.1016/j.transproceed.2008.03.049

Bucchi, M., & Saracino, B. (2021). *La "seconda ondata" della pandemia cala la fiducia in istituzioni ed esperti*. Observa Science in Society. https://www.observa.it/la-seconda-ondata-della-pandemia-cala-la-fiducia-in-istituzioni-ed-esperti/

Burra, P., De Bona, M., Canova, D., Germani, G., Rumiati, R., Ermani, M., & Ancona, E. (2004). Changing attitude to organ donation and transplantation in university students during the years of medical school in Italy. *Transplantation Proceedings*, *37*, 547–550. https://doi.org/10.1016/j.transproceed.2004.12.255

Centro Nazionale Trapianti. (2022). *Sistema Informativo Trapianti*. https://trapianti.sanita.it/statistiche/liste_attesa_1.aspx

Cipolletta, S., Previdi, S., & Martucci, S. (2023). The healthcare relationship during the second wave of the COVID-19 pandemic: A Qualitative Study in the Emergency Department of an Italian Hospital. *International Journal of Environmental Research and Public Health*, *20*(3), 2072. https://doi.org/10.3390/ijerph20032072

Cipolletta, S., & Reggiani, M. (2021). End-of-life care after the legal introduction of advance directives: A qualitative study involving healthcare professionals and family caregivers of patients with amyotrophic lateral sclerosis. *Palliative medicine*, *35*(1), 209–218. https://doi.org/10.1177/0269216320967280

Cohen, E. L., & Hoffner, C. (2012). Gifts of giving: The role of empathy and perceived benefits to others and self in young adults' decisions to become organ donors. *Journal of Health Psychology*, *18*, 128–138. https://doi.org/10.1177/1359105311433910

Conesa, C., Ramı, P., & Martı, L. (2006). Attitudes of resident doctors toward different types of organ donation in a Spanish transplant El Hospital. *Transplantation Proceedings*, *38*, 869–874. https://doi.org/10.1016/j.transproceed.2006.02.029

Dobbels, F., Van Gelder, F., Remans, K., Verkinderen, A., Peeters, J., Pirenne, J., & Nevens, F. (2009). Should the law on anonymity of organ donation be changed? The perception of liver transplant recipients. *Clinical Transplantation*, *23*(3), 375–381. https://doi.org/10.1111/j.1399-0012.2009.00955.x

Etheredge, H. R. (2021). Assessing global organ donation policies: Opt-in vs opt-out. *Risk Management and Healthcare Policy*, *14*, 1985–1998. https://doi.org/10.2147/RMHP.S270234

European Commission. (2010). Organ donation and transplantation. https://ec.europa.eu/health/ph_threats/human_substance/documents/ebs272d_en.pdf

Feeley, T. H., Reynolds-Tylus, T., Anker, A. E., & Evans, M. (2014). Reasons for (not) signing the state registry: Surveying Department of Motor Vehicles customers in New York state. *Progress in Transplantation*, *24*(1), 97–105.

Fontana, F., Massari, M., Giovannini, L., Alfano, G., & Cappelli, G. (2017). Knowledge and attitudes toward organ donation in health care undergraduate students in Italy. *Transplantation Proceedings*, *49*(9), 1982–1987. https://doi.org/10.1016/j.transproceed.2017.09.029

Hyde, M. K., & White, K. M. (2010). Exploring donation decisions: Beliefs and preferences for organ donation in Australia. *Death Studies*, *34*, 172–185. https://doi.org/10.1080/07481180903492604

Krueger, R. A. (2014). *Focus groups: A practical guide for applied research*. Sage Publications.

Lauri, M. A. (2009). Metaphors of organ donation, social representations of the body and the opt-out system. *British Journal of Health Psychology*, *14*(4), 647–666. https://doi.org/10.1348/135910708X397160

Linden, P. K. (2009). History of solid organ transplantation and organ donation. *Critical Care Clinics*, *25*(1), 165–184. https://doi.org/10.1016/j.ccc.2008.12.001

Matesanz, R. (2003). Factors influencing the adaptation of the Spanish model of organ donation. *Transplant International*, *16*(10), 736–741. https://doi.org/10.1007/s00147-003-0623-1

Miller, J., Currie, S., McGregor, L. M., & O'Carroll, R. E. (2020). 'It's like being conscripted, one volunteer is better than 10 pressed men': A qualitative study into the views of people who plan to opt-out of organ donation. *British Journal of Health Psychology*, *25*(2), 257–274. https://doi.org/10.1111/bjhp.12406

Moloney, G., Sutherland, M., Norton, M., & Walker, I. (2019). When is the gift given? Organ donation, social representations, and an opportunity to register. *Journal of Community and Applied Social Psychology*, *29*(3), 207–221. https://doi.org/10.1002/casp.2395

Moloney, G., & Walker, I. (2002). Talking about transplants: Social representations and the dialectical, dilemmatic nature of organ donation and transplantation. *British Journal of Social Psychology*, *41*(2), 299–320. https://doi.org/10.1348/014466602760060264

Morgan, S. E., Stephenson, M. T., Harrison, T. R., Afifi, W. A., & Long, S. D. (2008). Facts versus "feelings": How rational is the decision to become an organ donor? *Journal of Health Psychology*, *13*(5), 644–658. https://doi.org/10.1177/1359105308090936

O'Carroll, R. E., Foster, C., McGeechan, G., Sandford, K., & Ferguson, E. (2011). The "ick" factor, anticipated regret, and willingness to become an organ donor. *Health Psychology*, *30*(2), 236–245. https://doi.org/10.1037/a0022379

Petrini, C., Riva, L., Floridia, G., & Mannelli, C. (2020). Anonymity and organ donation: Ethical and policy implications after the opinion released by the Italian committee for bioethics. *Transplantation Proceedings*, *52*(5), 1525–1527. https://doi.org/10.1016/j.transproceed.2020.01.079

Pugliese, M. R., Degli Esposti, D., Venturoli, N., Mazzetti Gaito, P., Dormi, A., Ghirardini, A., Costa, A. N., & Ridolfi, L. (2001). Hospital attitude survey on organ donation in the Emilia-Romagna region, Italy. *Transplant International*, *14*(6), 411–419. https://doi.org/10.1007/s001470100007

Reynolds-Tylus, T., Quick, B. L., King, A. J., & Moore, M. (2019). Illinois Department of Motor Vehicle customers' reasons for (not) registering as an organ donor. *Progress in Transplantation*, *29*(2), 157–163.

Rumsey, S., Hurford, D. P., & Cole, A. K. (2003). Influence of knowledge and religiousness on attitudes toward organ donation. *Transplantation Proceedings*, *35*(8), 2845–2850. https://doi.org/10.1016/j.transproceed.2003.10.078

Shepherd, L., & O'Carroll, R. E. (2014). Do affective attitudes predict organ donor registration? A prospective study. *Journal of Health Psychology*, *19*(10), 1329–1333. https://doi.org/10.1177/1359105313488984

Sistema Informativo Trapianti. (2021). *Dichiarazioni di volontà registrate nel sit (dati al 31/12/2021)*. https://trapianti.sanita.it/statistiche/attivita/2021_D_ATTIVITA_ORGANI_DX-TX_DICHIARAZIONI.pdf

Skowronski, G., O'Leary, M. J., Critchley, C., O'Reilly, L., Forlini, C., Ghinea, N., Sheahan, L., Stewart, C., & Kerridge, I. (2020). Death, dying and donation: Community perceptions of brain death and their relationship to decisions regarding withdrawal of vital organ support and organ donation. *Internal Medicine Journal*, *50*(10), 1192–1201. https://doi.org/10.1111/imj.15028

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APPENDIX 1

Interview guide for the focus group discussion.

DONATION AND TRANSPLANTATION OF ORGANS, TISSUES AND CELLS

Were there any situations in which you had to do with the issue of organ, tissue and cell transplantation?

What feelings does the idea of organ transplant arise in you?

What do you know about organ donation?

As far as possible, do you think you have sufficient and correct information on the subject?

If yes, where and how did you receive/find this information?

If not, where and how would you like to find/receive them?

EXPRESSION OF CONSENT

Have you ever been asked to express your consent about organ donation?

Where and how?

How did you feel when you were asked to express your consent?

What would it be like today to express your consent to organ donation? If you have already done so today, would you confirm your choice?

Have you ever expressed consent for someone else (e.g., children, deceased relatives who had not expressed consent)? In this case, how did you experience it?

What do you think of the current practice for the expression of consent?

PROFESSIONAL ROLE AND WORK EXPERIENCE—FOR REGISTRY EMPLOYEES ONLY

Thinking about your work experience, have you had direct contact with the area of donations?

Have you had the opportunity to talk about the subject of donation with people who turn to you for services?

What do they report? What is your impression?

SOCIAL ROLE—FOR OPINION LEADERS ONLY

From the perspective of your role in society, to what extent are you interested in the issue of organ donation?

Have you ever participated in and/or done activities to raise awareness of the issue?

What could you do?

PROPOSALS

Where and how would you like to be asked to express your consent for organ donation?

What could be done to raise awareness of this issue?

Do you have proposals or ideas to attract the attention of your colleagues and the general population or clarify the subject? Is there a channel that you think is more useful for this purpose or through which you would like to receive more information on this topic?

CLOSURE

Is there anything you would like to add? Any doubts or questions left open?