

EUROPEAN SOCIETY OF ORGAN TRANSPLANTATION



MAIN CONCERNS DUE TO TRANSPLANTATION AMONG EUROPEAN SOLID ORGAN RECIPIENTS

A survey by European Society of Organ
Transplantation

Summary

In collaboration between ETAHP, ELPAT and EDTCO with the aim of establishing a solid platform and interaction with the European Transplant Patient Organizations (ETPO) a survey was launched during April 2020. A total of 351 responses from 54 % women, 45 % men and 0.6 % non-binary was received regarding the patients' top five main concerns due to their transplantation and in relation to their donor. The majority had received a kidney. The most prominent concerns were graft rejection/graft failure and infections followed by side-effects of the medication. Regarding the donor the main concerns were thoughts of the deceased donor's family followed by the wellbeing of the living donor and specific questions about the deceased donor. The findings will act as a foundation for targeting the content of various meetings in collaboration with ETPO for many years to come.

The inside perspective of being an organ recipient

How bad will I really get? Or just "can I join this and that, or is this food something I can't eat?" or ""How can I get a job when I only manage halftime" or maybe the thought ""what will my partner think if I say this routine is to protect my health? Will he/she understand, or will he/she think that I am a neurotic psychopath?" ""How much work out is good and how much are too much?" ""Am I going to tell the hostess at the party that I can't eat this and that or should I just skip this get-together?" "Can I go to work today when there is flu-season?" "Can I by any means discuss vaccination for the flu season with parents of kids I'm around a lot?" "What will my family or friends say, or my transplant-community, if I for ones do take this tasty pastry that I shouldn't eat because it's in the open air?" "Can I really pick this specific career choice?" "What if I pick this choice and I end up dead?" "What if people don't understand why I am acting the way I am concerning my health?" "My medication might not be available forever, ESPECIALLY when 2019 autumn they started making it troublesome to get specific medication in Sweden. There is ALL and everything. All the time and completely different ranges. Totally limiting, And the fact that there are NO SPECIFIC GUIDELINES. In the transplant community I hang out, there is a multitude of different specific advices that different people got. Some people can eat sushi or have kids, and some got doctors saying ABSOLUTE NO to those things? The only thing that seem certain for everyone is ""Do not eat grapefruit!!!

Acknowledgements

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Introduction

The European Society of Organ Transplantation (ESOT) would like to create a platform for mutual understanding, learning and collaborative partnership between the European Transplant Patients Organization (ETPO) and European Donation and Transplant Professionals. We wish to understand the needs of organ recipients and incorporate them into the research studies and educational activities conducted via ESOT for the improvement of patients' knowledge and life satisfaction.

During the last ESOT Congress of 2019 in Copenhagen, the kick-off of the Advisory Board Meeting of ETPO was held on Saturday September 14th to bring ETPO representatives, patients and ESOT Sections (EDTCO, ETHAP & ELPAT¹) together. The aim was to produce a series of statements that will serve as a path to a dialogue between patients and the medical and caring community. The purpose of this is to define the next steps we can jointly take towards giving a voice to the patient network and to help shape the dialogue with the stakeholders. A total of 19 patient groups from all over Europe were represented in Copenhagen. The initiative has been positively welcomed and supported by all the patient networks that were contacted, including those who were unable to attend.

We aim to start this initiative by gaining a greater understanding of organ recipients' main concerns in their everyday life in relation to organ transplantation and to their donor. We would like ESOT and ETPO to work together to propose and share solutions and successful initiatives to meet the challenges of organ donation and transplantation in Europe.

We can learn about the lived experiences of organ recipients by obtaining their inner perspective by means of self-reported concerns. There are both an outer and an inner perspective. The former represents the perspective on organ transplantation based on pathophysiology, while the latter involves the patient's view of transplantation and its consequences for her/his daily life. The outer and inner perspective can also be termed the professional and the personal understanding of transplantation. These perspectives differ from each other in four respects: the focus on the current situation, attitudes towards transplantation, relevance, i.e. what is important and perception of time. Both outside and inside perspectives are important and valid, but it is essential for clinicians to be aware of the different perspectives and above all their own personal attitude. From the professional point of view, the focus on symptoms and establishing diagnosis can be considered a puzzle solving process that ends when the diagnosis is confirmed. However, from a patient perspective, while the diagnosis might explain the symptoms, it can also involve feelings of losing control and being plunged into an

¹ EDTCO: European Donation and Transplant Coordination Organisation; ETHAP: European Transplant Allied Healthcare Professionals; ELPAT: Ethical, Legal and Psychosocial Aspects of Organ Transplantation

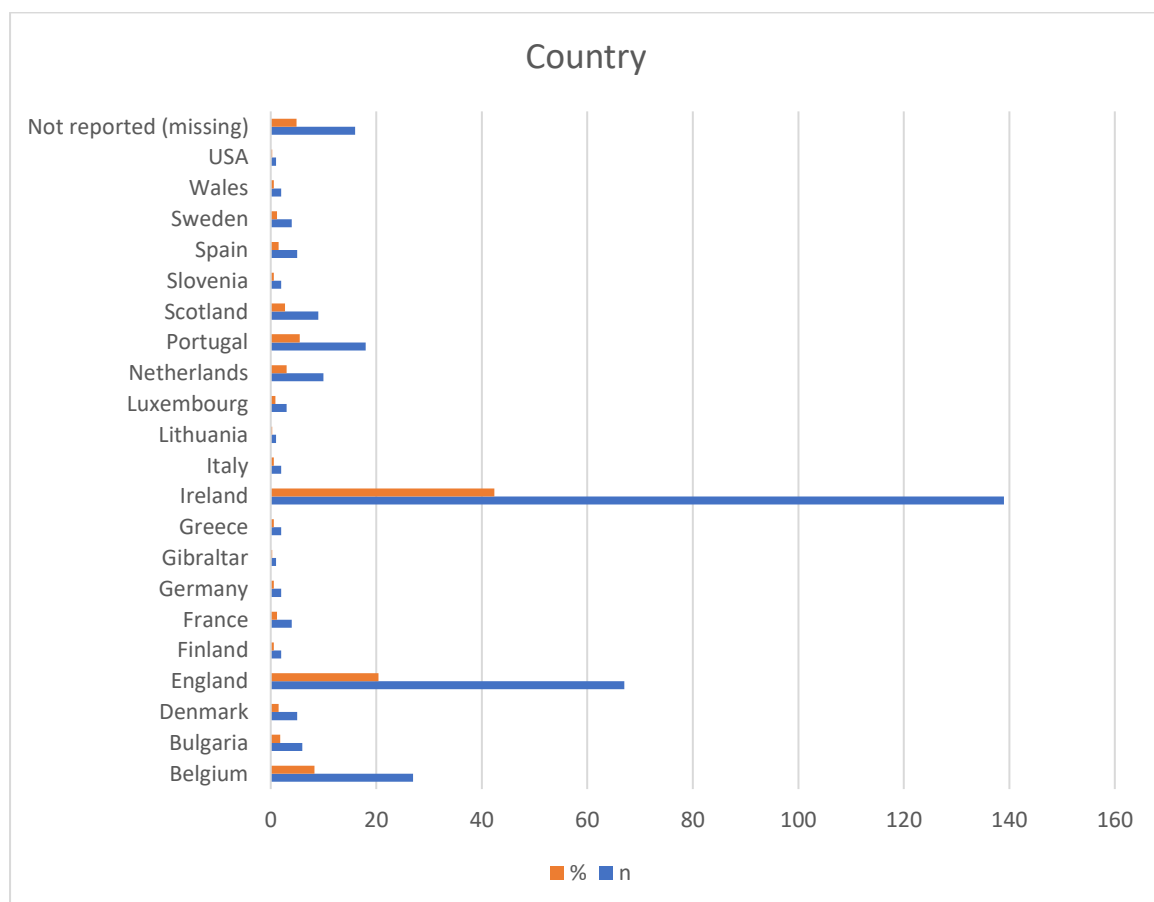
unknown world that necessitates extensive adaptation. Patients view the disease in terms of consequences for daily life and interpret its meaning in different ways.

Methods

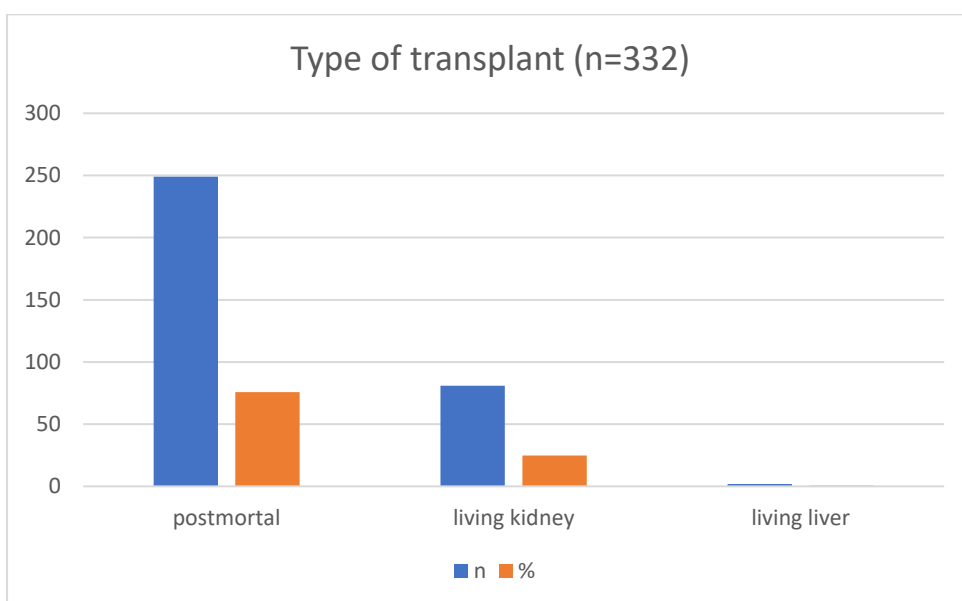
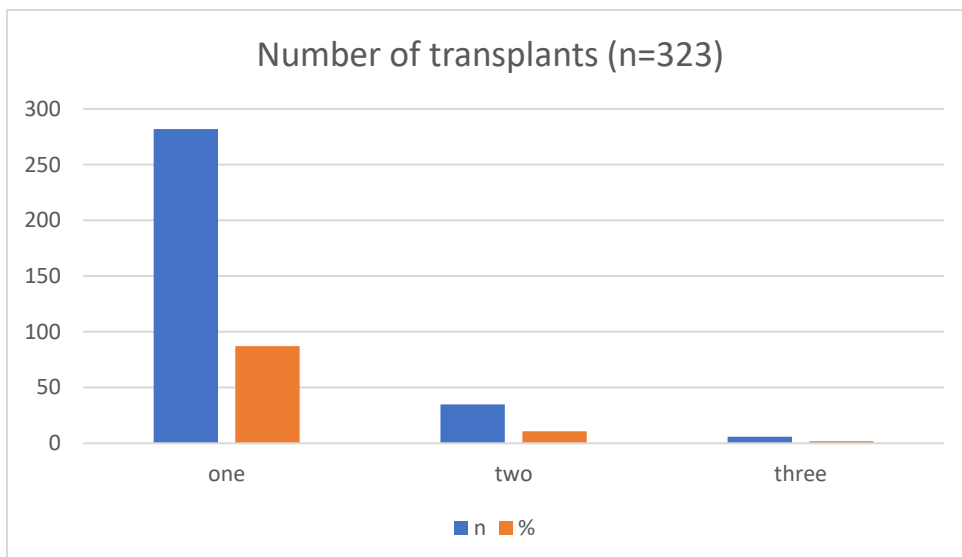
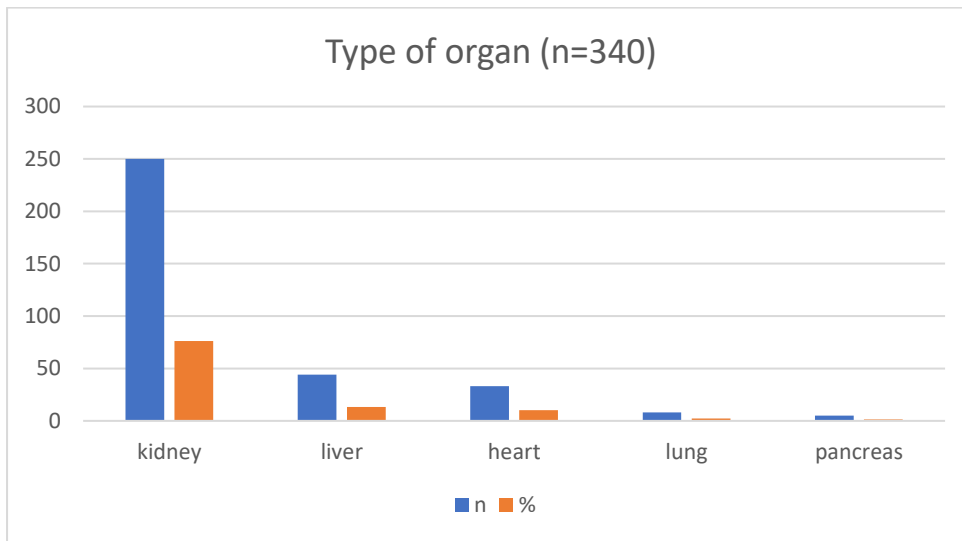
The survey was sent to different patient organizations within the ETPO network in a digital format. The survey included demographic questions regarding gender, age, type of organ, number of transplants and whether they got the graft from a deceased or living donor. These initial questions were followed by a request to list the top five concerns due to their transplantation and the top five concerns in relation to their donor. Additional questions concerned what the expected from the transplant professionals.

Findings

The responders represented a wide range of European countries where the majority were from Ireland followed by England and Belgium (figure 1). There were 54 % women (n=177), 45 % men (n=148) and 0.6 non-binary (n=2). The response rate regarding demographic data varied.



The majority had received a kidney and one transplant.



The first and foremost main concerns in everyday life

The aspects below are divided into the main themes included in the answers regarding the number one concern and are presented hierarchal based on prevalence.

1. Aspects pertaining to the graft (n=90)

Graft rejection (n=60)

Graft loss/organ failure (n=22)

Uncertainty about how long the graft will last (n=8)

2. Aspects pertaining to the risk of infection (n=60)

The risk of infections was a major concern (n=56).

These concerns involve how to avoid infections and sick people or persons with poor hygiene. Also fear of becoming severely ill due to infections and be hospitalized, not being able to work due to the risk of infections. Further few mentioned specifically the threat of Covid-19 and lack of information about Covid-19 (n=4).

3. Aspects pertaining to the immunosuppressive medication (n=30)

Adherence to medication (n=17) e.g. have my medications near, remember to take my medication as prescribed and never run out of pills.

Consequences of the lifelong immunosuppressive therapy including long-term effects of steroids (n=13)

4. Health and Quality of life (n=20)

These concerns involve how to stay healthy and safe (n=13) as well as to maintain quality of life (n=3) and not becoming ill (n=2), healing time and recovery (n=1) and mental health (n=1).

5. Symptoms and complications (n=10)

Fatigue or exhaustion was a concern (n=5). Complications such as fear of going back to dialysis, need a new bowel surgery, or a recurrent bile duct blockage, restrictions regarding fluid intake, diabetes, impaired strength or overall physical decline.

6. Exercise, diet, love, fertility, pregnancy and social life (n=11)

These concerns, mainly expressed once for each concern, involved getting enough sports or getting injured while doing sports (being a karate instructor), nutrition, experiencing no love, fertility/pregnancy (n=3), balance social life with social distancing, getting access to regular follow-up. Finally, one participant worried about if he/she made the donor's family proud.

The second most prominent main concerns

The aspects below are divided into the main themes included in the answers and are presented hierarchal based on prevalence. At second place there is a wider spread of aspects that cause concerns or distress. Mainly each concern is mentioned by one participant or to a less extent.

1. **Getting infected including Covid-19 (n=29)**
2. **Lifestyle, self-care and going back to work (n=29)**
 - Eating healthy and food restrictions (n=5)
 - Drinking enough fluid (n=5)
 - Ability to work (n=3)
 - Financial distress (n=3)
 - How to keep fit (n=3)
 - Having enough energy (n=2)
 - Exercise and potential restrictions (n=2)
 - Keep weight (n=2)
 - Keep the kidney well (n=1)
 - Keep on the top of things (n=1)
 - Sun exposure (n=1)
 - Decreased lifestyle (n=1)
3. **Graft rejection or graft failure (n=26)**
4. **Setbacks and complications (n=24)**
 - Malignancies (n=5)
 - Getting sick and hospitalized (n=5)
 - Accidental injury, damaging the kidney (n=5)
 - That the basic disease will return (n=3)
 - Going back to dialysis (n=3)
 - Frailty (n=2)
 - Sepsis (n=1)
5. **Side-effects of the immunosuppressive medication (n=15)**
6. **Uncertainty in chronic illness (n=6)**
 - Uncertainty about one's own performance (Am I doing enough?) (n=2)
 - How to know what the dangers are (n=1)
 - Anxiety (n=1)
 - How long will it last? How long will my life last? (n=1)
 - How to recognize a rejection (n=1)

7. **Miscellaneous**

General health restrictions (n=6). Problems with blood pressure and blood tests, cancelled health appointments and exhaustion. Also, how to ensure good communication with the transplant team and lack of contact persons for medical questions. Finally, less friendships and lack of medicines.

The third most prominent main concerns

The aspects below are divided into the main themes included in the answers regarding the third most prominent concern and are presented hierarchal based on prevalence. At the third-place aspects pertaining to the chronicity of being an organ recipient and the long-term aspects are more visible.

1. Lifestyle, self-care and going back to work (n=33)

- How to keep fit, cope with physical activity, enough exercise? (n=10)
- Ability to work and earn living, the professional work future (n=8)
- Diet and keeping weight (n=6)
- Loss of mobility and independence (n=2)
- Reduced quality of life (n=2)
- How to handle a pregnancy (n=2)
- Have a good life style (n=1)
- Sun exposure (n=1)
- Play sports (n=1)

2. Side-effects of the immunosuppresses and symptom management (n=32).

This theme includes the fear of negative long-term effects of the immunosuppressive medication and the wish for as few side-effects as possible. Also, the problems when side-effects occur e.g. arthritis, neuropathy, tremor, hypertension, mood swings, sleeping problems, itching at night, nightmares and erectile dysfunction leading to difficulties managing symptoms.

3. Uncertainty: Graft rejection, graft failure and how long it all will last (n=30)

This theme involves a lot of uncertainty regarding the function of the graft, if it will fail or if it will be rejected. Also, there are explicit concerns regarding how long it will last and disease recurrence, i.e. the disease that caused the need for a transplant, will return. What happens if I get cancer? Kidney recipients typically fear going back to dialysis while the other organ recipients refer to being sick again. Two respondents explicitly express the unknown and death as their second main concern.

4. Getting infected including Covid-19 (n=24)

This theme is about feeling vulnerable and wondering how to avoid infections in general and in particular the fear of sepsis. The specific concerns regarding Covid-19 include the fear of being infected by the virus, if one is doing enough safety precautions, if one will survive the virus and if there will be lack of medicines due to the pandemic.

5. Setbacks and complications (n=20)

- Various illness e.g. stroke, diabetes (n=10)
- Malignancies, specifically skin cancer (n=6)
- Accidental injury, damaging the kidney (n=2)
- Not feeling better than before the transplantation (n=1)
- Pain at the place of the graft (n=1).

6. Adherence to medication (n=6)

This concern stem from the question: Did I take my medicines?

7. Psychosocial aspects (n=10)

This theme involves how to manage elevated stress e.g. financial distress, the lack of understanding from others, social problems and how to lead a so-called normal life. There was also a specific concern regarding if the organ recipient's disease would be inherited by his or her children.

8. Issues related to the transplant clinic and follow-up (n=8)

Check-ups and clinical appointments (n=3)

Cooperation with the transplant team (n=3)

Increased anxiety every time a blood test is taken (n=1).

Wondering how the level of creatinine can be lowered when it is high (n=1).

The fourth most prominent main concerns

In this area the concerns are clearly linked to the fact that organ transplantation is a chronic condition demanding rehabilitation and adaptation.

1. Life style and quality of life (n=38)

- Healthy eating, diets, weight and to drink enough fluid (n=17)
- Exercise and sports, how to stay in shape (n=7)
- Lack of information about travelling (n=3)
- Losing quality of life (n=2)
- Make sure I live my life (n=2)
- Poor wellbeing after transplantation (n=1)
- Not being eligible for a second transplantation (n=1)
- Dealing with radiotherapy (n=1)
- Disease recurrence (n=1)
- Take care of fistula (n=1)
- Sun protection (n=1)
- Sexuality as a major concern (n=1)

2. Co-morbidity, symptoms, complications (n=25)

- Metabolic complications: Heart problems, hyper or hypo tension (n=4)
- Chronic rejection (n=3)
- Fear of dialysis (n=3)
- Diabetes (n=3)
- Cancer (n=2)
- Pain (n=2)
- Tiredness and sleeping problems (n=2)
- Fear of re-transplantation (n=2)
- Not being eligible for a second transplantation (n=1)
- Dealing with radiotherapy (n=1)
- Disease recurrence (n=1)
- Take care of fistula (n=1)

3. Medication related issues (n=15)

- Side-effects of medication (n=10)
- Availability of medicines (n=3)
- Changes in medication (n=1)
- Forget to take medication (n=1)

4. Family life and social adaptation (n=14)

- Ability to work or not getting a job due to transplantation (n=5)
- Lack of understanding from others (n=4)
- Normalizing of family life and being able to contribute to family life (n=3)
- Social interaction (n=1)
- Partner's wellbeing (n=1)
- Will I be able to have more children? (n=1)

5. Infections and viruses (n=10)

- Catching an illness from anyone, infections (n=6)

- Covid-19 (n=4)

6. Dealing with psychosocial challenges (n=8)

- Uncertainty about graft survival (n=2)
- Overall uncertainty (n=1)
- General stress (n=1)
- Finances (n=1)
- Mental health (n=1)
- No counseling post transplantation (n=1)
- Worry about the living donor(n=1)

The fifth most prominent main concerns

1. **Psychosocial aspects and family (n=20)**
 - Uncertainty about the future (n=5)
 - Economy (n=4)
 - Family concerns (n=3)
 - Negative impact on labor (n=2)
 - Hobbies, friends and family around (n=1)
 - Worry about the donor and their family (n=1)
 - Bad thoughts and fear of death (n=1)
 - Wish to speak to someone who understands (n=1)
 - Mental health (n=1)
 - Ineffective coping strategies (n=1)
2. **Co-morbidity, symptoms, complications (n=19)**
 - Cancer (n=3)
 - Graft rejection (n=2)
 - Diabetes (n=2)
 - Pain (n=2)
 - Fatigue (n=1)
 - Lack of information regarding signs of graft rejection (n=1)
 - Return to dialysis (n=1)
 - Tiredness and sleeping problems (n=1)
 - Needing re-transplantation (n=1)
 - Chemotherapy (n=1)
 - Take care of fistula (n=1)
 - Kidney problems (n=1)
 - Hospitalizations (n=1)
 - Always have a cold or headache (n=1)
3. **Life style (n=17)**
 - Healthy eating, diets, weight and to drink enough fluid (n=8)
 - Exercise and sports, how to stay in shape (n=5)
 - Can I travel? (n=3)
 - Hygiene (n=1)
4. **Infections and viruses (n=7)**
 - Always avoid infections (n=5)
 - Covid-19 (n=2)
5. **Body, mind and soul (n=5)**
 - Being mindful (n=1)
 - Body confidence (n=1)
 - Making difference if I can (n=1)
 - Ability to contribute to society (n=1)
 - Be happy (n=1)

MAIN CONCERNS IN RELATION TO THE DONOR

The first and foremost main concerns related to the donor

The aspects below are divided into the main themes included in the answers regarding the number one concern and are presented hierarchal based on prevalence.

DOD= Deceased organ donor

LOD= Living organ donor

Concerns of the DOD's family, their grief, feelings and well-being (n=41)

- Did the donor family receive my thank you letter? (n=3)
- Grieving their loss(n=3)
- Do they know I'm healthy? (n=1)
- Do they know that the organs of their deceased family member were used? (n=1)
- I hope that they don't know if the organ I received fails. (n=1)
- I am worried to be tracked down by the DOD's family. (n=1)
- What if my donor's family don't think I am good enough to receive this gift (n=1).

Concerns regarding the deceased donor (n=37)

- The disease of the donor and if he/she was healthy while living (n=12).
- Who was the donor as a person? (n=9)
- Cause of death involving the reasons for dying, a hope that the death wasn't painful and that he/she didn't suffer (n=8).
- Age of the donor (n=4).
- The gender of the donor(n=1).
- To get a disease from the DOD (n=1)
- To be the correct match (n=1)
- Hoping that thorough testing was performed of the DOD before donation (n=1)

Concerns of the LOD's welfare and health now and in the future (n=32)

Includes the health overall and the fact that the LOD only have one kidney left. If he/she will need a kidney in the future or if the function of the remaining kidney will deteriorate.

I have no concerns (n=23)

Being grateful and showing gratitude (n=19)

Includes making the most of the gift and being constant grateful, always remember the donor and keep in contact with the LOD.

Feeling guilty and sad (n=12)

Includes feeling guilty of sad that somebody passed away to save your life, that you benefit from someone's death. Am I worth to receive this organ?

Other (n=2)

How long will it last?

The second main concerns related to the donor

The aspects below are divided into the main themes included in the answers regarding the number one concern and are presented hierarchal based on prevalence.

DOD= Deceased organ donor

LOD= Living organ donor

Being grateful and showing gratitude (n=28)

Includes to honor the DOD and being grateful expressed for example praying for the donor. It also asking the following questions: Have I expressed my gratitude enough? For how long should I be grateful? Am I doing enough? Regarding the LOD is meant keeping update of the LOD's health, being concerned about his or her wellbeing, if they are emotionally ok. There was a wish to respect the donor family, to confirm their goodness and to stay healthy as a way to honor the donor. Further a strategy to repay the donor's gift was to give presents to the LOD now and then.

Concerns of the DOD's family, their grief, feelings and well-being (n=18)

Includes a hope that the DOD's family know that the recipient is grateful and that they can find peace. Also, to acknowledge their generosity.

- Grieving their loss(n=4)
- A wish to meet to DOD's family to show the that everything went well. (n=2)
- Did they receive the thank you letter? (n=1)

Feeling guilty and sad (n=13)

This theme involves questions regarding: Have I made the LOD proud? Do I meet the LOD's expectations? Also, guilt for the sake of the DOD but also for causing a painful procedure on the LOD. They wanted to make sure that the LOD doesn't regret the donation and a wish to make their gift count. There was a fear of graft rejection since it meant that the sacrifice made by the DOD would be undone.

Concerns regarding the deceased donor (n=12)

- Who was the donor as a person? (n=3)
- Age and gender of the donor (n=3).
- To get a disease from the DOD (n=1)
- Cause of death (n=1).
- The disease of the donor and if he/she was healthy while living (n=1).
- Alcohol history of the DOD (n=1)
- Transferrable diseases from the DOD (n=1)
- Genetic history (n=1)

No concern (n=11)

Concerns of the LOD's welfare and health now and in the future (n=10)

Includes health costs for the LOD, worrying about the LOS's children not being able to have a kidney from their mother in the future and the LOD's future need of dialysis or transplantation. They hoped that the remaining kidney stays good and that the LOD has access to regular check-ups.

The third main concerns regarding the donor

DOD= Deceased organ donor

LOD= Living organ donor

The themes at the third place were mainly recurrent and therefore divided in three broader themes. The issues brought up were at this point also involved aspects of being an organ recipient in general rather than related to donation and the donor.

Concerns related to the deceased donor (DOD)

As previous described there were ongoing concerns about the age of the DOD, the health condition and fitness of the DOD and if he/she had had an addictive personality or a drug history. Also, there were fear of possible latent diseases in the DOD that would be transmitted. The thoughts of the DOD's family are present and concerns about their grieving process are common. The organ recipients express humility and at the same time guilt, always in dept. They wish to honor the DOD always and make the DOD's family proud while at the same time frustrated by the fact that they can't express their gratitude in person.

Concerns related to the living organ donor (LOD)

In relation to the LOD there are concerns regarding the donor only having one kidney left and that he/she might need a kidney transplant in the future. Also, that pain or possible suffering was caused to the LOD: "he will be left with significant scaring", "hope for minimal discomfort during the donation process". They worry about low energy levels in the LOD and his or her mental health and overall health. The recipients want to assure that the LOD know who brave he/she has been and realizes the magnitude of his or her effort. They repay by helping the LOD and live their life at their best. There were also examples of relational strain between the LOD and the recipient by means of: "The LOD makes me feel like it's still her kidney"

Concerns in relation to everyday life

The themes here are recurrent and not new and involves disease recurrence, general health and lifestyle, effects of aging, getting infected and being worried at every check-up. The inability to fully accept the transplantation was there. Two informants emphasized their will to promote organ donation.

The fourth and fifth main concerns regarding the donor

The themes were recurrent with no new information or angles to present. The questions were repeated: How many other people's lives did the DOD save? How did they make the decision? How to show my gratitude always and let the DOD's family know that I am doing my best to preserve the organ? How to support my LOD and assure that he/she or his/her family don't suffer in any way due to the donation.

How they express their concerns to health care professionals who are involved in their transplant follow up?

N= 133 discuss them face to face with my transplant physician / surgeon

N=106 discuss them face to face with my outpatient transplant nurse

N= 63 are not comfortable to share their problems with the transplant professionals

"I don't discuss my problems since it makes me seem ungrateful"

N= 27 discuss them face to face with an allied health professional (e.g. physiotherapist, psychologist, or dietician)

N= 16 interact with transplant professionals through a mobile application or video consultation / meeting

Other: General Practitioner (GP), Nephrologist, Fellow transplant patients, Spouse, Dermatologist

What is important for health care professionals to understand from your concerns?

N=131 Side-effects of the medication

N=101 The life style challenges

N=91 The psychosocial challenges

"I know some people who get a transplant actually can live AS GOOD or BETTER than before, and they don't have any fear but for most of us it is constant fear of death or messing up. You do not dare to live any kind of life with that thought all the time".

N=2 My symptom burden

Other important aspects

- Conceiving
- Very important! We are more than just the numbers and graphics on your papers. Some doctors forget that there is more than that. We are human beings with a soul and feelings. It's not because all the tests were very good that the patient feels well.
- They can only see things from a medical view
- That sometimes patients may feel their question/concern is silly but to make sure no patient feels that way as no question/concern is silly

- Job retention and housing. The fact that my job is of paramount importance, if I lose that I lose my home and probably everything else.
- Counselling and the necessary steps one should take to exercise and to return to work. Very little information provided on how to deal with Covid-19. Isolated myself but only told not to go out recently by clinician.

Professionals other than the transplant nurse that are essential and add value:

N=122 Psychologist

N=89 Other patients in the patient organisations

"My participation in transplant games for 36 years are most important for me. Those athletes are my friends, psychologists and confidants. This is the only added value due in my illness. And, by helping others, I am helping myself. Engagement for others is the best self-therapy".

N=79 Physiotherapist

N=64 Social worker

N= 4 Dietician

N=3 Expert adviser regarding financial issues

"An expert adviser in financial support for kidney patients/transplant recipients"

N=1 Occupational therapist

"All supports from varying disciplines should be offered as needed to support the patients transition to the next stage of recovery".

What would be the best way for health care professionals to respond to your concerns?

Most of the comments concerned being listened to and to be taken seriously. Below illustrative quotes are divided into themes to express the key suggestions from the organ recipients.

Pay attention to the psychological aspects.

"No one talks about the changes on the psychological side, and in what way it affects day life"

More recognition of the psychological impact and the availability of talking therapies.

Perhaps by asking the question about if you are coping mentally, financially etc in which case they could make a referral to the appropriate professional.

Take me as a patient seriously

" Answer questions with facts and evidence, not random ""life quotes"" like ""think positive"" or ""take it easy""

To listen and take concerns seriously rather than brushing them off because they believe "they are not transplant related "

Be honest and give proper guidance and some reassurance.

Follow up with an offer to talk things through. When I asked about my deceased donor, the transplant coordinator came to my bedside with a post it note, stuck it on the magazine I was reading and walked away. It just said male, in 50's, very good match. So impersonal and didn't feel it showed the donor any dignity.

Active listening without judging.

Person-centred care

A patient centred package should be provided to each patient and establish a need-based analysis. Not everyone will need such a package, but it should be available post transplant to provide support.

Have the TIME to listen. Make me feel that I am a person not a number on a patient list.

Speak **to** a person **not** down to a person. Speak, as a person not a doctor

The best way would be to remain close and always have time to listen.

Understand and reassure. Listen, instead of fogging patient off.

To recognise that everyone is different and thinks differently.

Partnership and collaboration

Face-to face, honest and straight forward relationships

I would like to know the facts, statistics and truth. Some patients are to fragile for this but I would like that in able to stay positive in my mind set.

Listen and work with me to find solutions. They ultimately have the last say. But we must find the right solution for me personally.

Listening and taking time - no-nonsense - direct communication with sufficient explanation.

The way it has always been done so far: hearing my concerns, showing respect & including me in the decision-making processes.

They can't do anything about it and it's just in the back of my mind. What is important for the health care professionals is to be involved with your patients in another way than the medical. In Belgium, we have Transplantoux, thanks to prof. D. Monbalieu. It's the sportclub of transplant patients, but it's a mix of patients, medical staff, donors and family. You all talk to each other in a non-professional way and share each other concerns and happy moments of live. And our health is part of our life. On top of it, we keep moving. Not everybody needs this, and I can understand that medical staff have also all a private life. But the organization is there if you would like to join and members are always happy to see and motivate each other. This is not the ultimate way, there are other possibilities.

Information and digital solutions

A website where all up to date information is available would be helpful.

I think human face-to-face interaction is utterly important, but since that is somehow hard to carry out as regularly as we would love to, I wonder if there is a programme to be implemented to foster online interaction with our physicians/specialists.

The pre transplant evaluation

Better work up process before the transplant. Or work out a way that patients can chat to other patients who have already went through the process, to get a better knowledge of what they are up against.

Adopt a team-approach

By assisting in the care of the patient to overcome the problem and eliminate the pain or concern of the patient.

Collaborate! Single professionals cannot provide the same health care as a team that collaborate can. Use the well-known principles from rehabilitation medicine regarding how to develop and implement a rehab plan. That would help many people, would help them regain a new, but different life after having their transplant!