

LETTER TO THE EDITORS

Dealing with uncertainty after transplantation in times of COVID-19

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Dear Editors,

The worldwide pandemic caused by COVID-19 has had a significant negative impact on transplant activity [1] and caused uncertainty among solid organ recipients. To address this uncertainty, the European Society for Organ Transplantation organized a webinar on the 27 April 2020. The webinar was developed for patient organizations in collaboration with the European Transplant Patients' Organisations (ETPO) alliance. The aim was to exchange and discuss concerns regarding the COVID-19 virus and possible strategies to master the uncertainty. In this paper, based on the contributions of the authors, we explore the meaning of uncertainty in the context of this pandemic for transplant recipients, potential implications, and consequences, as well as strategies for coping.

What is uncertainty and what does this mean for transplant recipients in the context of the COVID-19 pandemic? Uncertainty refers to the inability to determine the meaning of illness-related events and accurately anticipate or predict health outcomes. Uncertainty results when a cognitive schema about the illness (COVID-19) cannot be formed. There are four forms of uncertainty [2]:

- Ambiguity concerning the state of illness
- Complexity regarding system of care and treatment
- Lack of information about the diagnosis and the seriousness of the illness
- Unpredictability of the course of the disease and prognosis

The COVID-19 pandemic is an ambiguous, complex, and constantly changing situation for organ recipients. There may be concerns about vulnerability to become infected with the virus, risks to the graft if they do, potential severity of the illness experience due to their reduced immune system, and chances of recovery and/or mortality. There may be uncertainty regarding access to health care or reachability of professionals for advice, interpretation of the restrictions, safety measures in the hospital, and risks if one needed to be admitted. Information on these issues may be splintered or contradicting. Misinformation via (social) media has the potential to further exacerbate concerns [3]. Therefore, uncertainty during the pandemic means that the situation is no longer predictable or structured. There is, therefore, a loss of coherence which can be a source of psychological distress [4].

What are the potential implications and consequences for recipients? From a psychological perspective, it is possible that mental health may deteriorate under these circumstances. A combination of factors such as increased free time, reduced activities, isolation, boredom, and negative news may lead to rumination, catastrophizing, or excessive worrying. Reassuringly, the first findings on the impact on mental health among transplant recipients demonstrated that only 6% report psychopathology [5]. Lifestyle and daily routines may be affected resulting in problems sleeping, alterations in diet, increased use of alcohol or drugs due to boredom or the need for distraction, and the reduced ability to exercise due to closure of facilities and public spaces. While the COVID-regulations are the same for both transplant recipients and the general population, lifestyle among this group is even more pertinent. An important aspect of recipient lifestyle is adherence to the medication regime. It is not known whether recipients may take their medications differently during the COVID-19 pandemic or not. The impact of poorer health habits and nonadherence can have far reaching consequences (e.g. [6,7]).

How might recipients optimally cope with this uncertainty? There are various ways recipients can view this

uncertainty, as a threat or as a challenge [8]. Uncertainty can be appraised as a danger or as an opportunity. Challenges afford the opportunity for gain or growth while threats may lead to harm, loss, or negative consequences. Perceiving uncertainty as a danger or threat may lead to increased vigilance. Such vigilance can be functional but may also lead to increased anxiety. Perceiving uncertainty as an opportunity could lead to creativity and benefit finding. It requires preoccupation with the positive rather than the negative. The pandemic and its subsequent restrictions create a need for redefining what is important in life. These two different reactions are likely to give rise to differing coping strategies to deal with this uncertainty.

Finally, physical or social distancing may greatly impact the ability to access both practical and emotional support. The ability to elicit social support is a major buffer for stress [9]. This buffer is important as quarantine has been demonstrated to have a negative impact on mental health [10]. Creative solutions are therefore needed to facilitate social support while maintaining adherence to the COVID-related social restrictions.

We outline below several functional strategies recommended to deal with uncertainty in relation to COVID-19:

- Selective ignoring - being aware of the impact of news on your mental health state. If this has a negative influence, a media-diet may be needed.
- Re-ordering priorities - considering and potentially adjusting personal priorities to increase alignment with the current reality. Adjusting or relinquishing unattainable goals and pursuing achievable goals helps maintain well-being.

- Strive for balance – be aware of the balance between time for things you have to do and time for things you want/like to do. In other words, in order to re-charge, there should be time for both work and relaxation.
- Acceptance – letting go of the things that are outside your sphere of control.
- Seek social support – social (emotional) support is an important source of coping and buffer against deterioration in mental health. Limit contacts who exacerbate negative emotions or mood.

The psychosocial impact of the COVID-19 virus pandemic on transplant recipients is, to date, anecdotal and speculative. Long-term consequences of the COVID-19 virus and the associated regulations (such as social distancing) on mental and physical health as well as transplant outcomes remain to be seen. Maintaining a positive focus, balance, and connection with loved ones is recommended. Transplant professionals and patient organizations are important sources of accurate information and support during this uncertain time. Assessing the impact on not only physical health but also mental health [3] should be a research priority in the coming months and years.

Funding

No funding to declare.

Conflict of interest

No conflict of interest to declare.

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