



EDITORIAL COMMENT

Time to press the reset button—can we use the COVID-19 pandemic to rethink the process of transplant assessment?

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ABSTRACT

Coronavirus disease 2019 has taken a severe toll on the transplant community, with significant morbidity and mortality not just among transplant patients and those on the waiting list, but also among colleagues. It is therefore not surprising that clinicians in this field have viewed the events of the last 18 months as predominantly negative. As the pandemic is gradually ebbing away, we argue that this is also a unique opportunity to rethink transplant assessment. First, we have witnessed a step-change in the use of technology and virtual assessments. Another effect of the pandemic is that we have had to make do with what was available—which has often worked surprisingly well. Finally, we have learned to think the unthinkable: maybe things do not have to continue the way they have always been. As we emerge on the other side of the pandemic, we should rethink which parts of the transplant assessment process are necessary and evidence-based. We emphasize the need to involve patients in the redesign of pathways and we argue that the assessment process could be made more transparent to patients. We describe a possible roadmap towards transplant assessment pathways that are truly fit for the 21st century.

Keywords: information technology, patient perspective, transplant assessment

INTRODUCTION

Ever since its first description, coronavirus disease 2019 (COVID-19) has triggered worldwide and unprecedented disruption in healthcare. The field of renal transplantation has been particularly affected and considerable mortality has been reported in recipients with COVID-19 [1]. This, together with the disruption in healthcare overall, led many transplant programmes to cease listing and surgical activity for some time

during 2020. As of December 2020, the pandemic has also caused significant mortality in healthcare workers. Not surprisingly, transplant teams have perceived the pandemic mainly as a catastrophic event, with a mindset of trying to restore transplant listing and surgical activity and return to the status quo ante. Here we argue that transplant teams can also regard the current situation as an opportunity. We consider the pandemic as a disruptor in a positive sense, i.e. a unique event that allows

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us to question established practice and refocus and redesign transplant assessment and listing pathways. As a group of clinicians supported by one of our patients, we propose a rethink of transplant assessment pathways, outline an early vision of what success might look like and discuss the limitations of such an approach.

TRANSPLANT ASSESSMENT: THE STATUS QUO AND ITS SHORTCOMINGS

The fact that many aspects of transplant assessment lack a robust evidence base has been noted before. In comparison, procedural aspects of transplant listing have received much less attention. Considerable heterogeneity exists with regards to thresholds for starting transplant assessment, the extent to which patients are empowered as part of the decision-making process and how this is embedded in a holistic care pathway. The amount of information given to patients and the platforms used to provide it also vary widely.

It is worthwhile dissecting the pathway in more detail (Figure 1). Traditionally, teams still rely on paper and the postal system for the communication process. In our institution, a

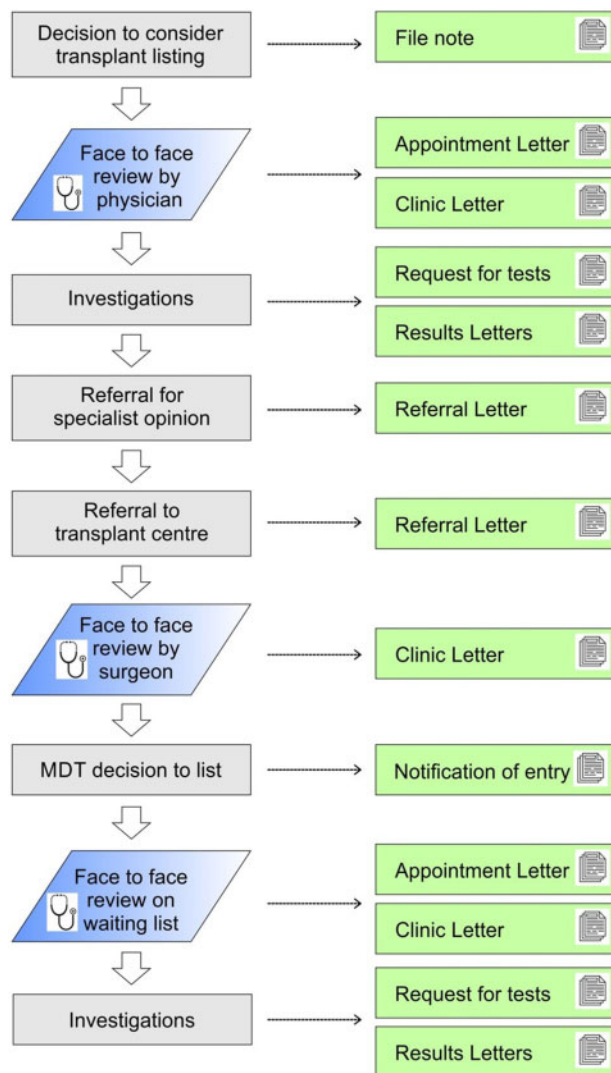


FIGURE 1: Process of transplant assessment—traditional approach.

straightforward transplant candidate may thus accumulate ~30 different documents during the process of transplant assessment. Some of the aspects are now via e-mail, such as the initial referral for transplant listing and the referral to the transplant centre. However, such a mixed economy also incurs governance risks around duplication of work in terms of printing, photocopying and scanning and filing documents.

Shared decision making with patients is an increasingly recognized paradigm of renal care [2]. Lee et al. [3] reported that shared decision making not only increased the uptake of home dialysis, but also led to more live donor transplants. We believe that the traditional model of transplant assessment has considerable shortcomings in this regard. Typically patients will be updated by sending them copies of clinic letters and informing them of decisions, for example, the decision to list. Barriers to listing and activation on the waiting list, however, are often not clear or transparent to patients [4]. We would suggest that this is particularly true in complex patients, who often have a significant comorbidity burden. It is easy to see how this situation can cause uncertainty, confusion and frustration for patients and relatives.

WHAT DO PATIENTS WANT?

From a patient perspective, the transplant assessment process brings with it various significant stressors and takes a considerable emotional toll. This is the case whether a transplant is expected to come from a living or deceased donor, albeit in different ways.

As things currently stand, it is commonplace for potential transplant recipients to have contact with a variety of different hospital departments, all of whom are responsible for various aspects of the assessment process. This can often be confusing, particularly if the patient feels as if he/she is the one inadvertently becoming responsible for 'keeping track' of lists of appointments and things to follow up on. Such insecurity may be worsened if there is no holistic approach to care and when patients feel that providers' efforts, however well-meaning, are not coordinated. Navigating this is particularly challenging at a time when the patient is also dealing with the increasing physical impact of their kidney disease and with side effects of medication. In this regard, chronic fatigue may be particularly relevant and patients often describe 'brain fog' during this time. The issue is further compounded by the fact that patients often experience an increasing impact of their condition on lifestyle, work and relationships around the time of transplant assessment.

It is therefore not surprising that in a recent study into patient perspectives on the liver transplant waiting list, two of five topics related to coordinating care, namely executing the care plan efficiently and utilizing interdisciplinary communication and coordination of care [5]. A digital health 'roadmap' or record could help with this, provided that it is in a format that is comprehensible. However, this would have to be kept up to date as required. If this is offered, but not well executed, it could have a detrimental effect and lead to patients feeling even more confused and ill-informed, leading to the need for additional queries and communication.

Another significant issue potential recipients often face during the transplant assessment process is a lack of clarity around what to expect. Communication is vital, and clear expectations [5] of what is going to happen and how long it is projected to take go a long way towards allaying patient concerns that they have been forgotten. It is also worth bearing in mind that

patients may be experiencing considerable stress during appointments and missing key messages, such as the time line for the listing and wait. It would be beneficial if patients were always aware of these time lines, preferably in written or electronic form. This is particularly important if somebody spends a long time waiting for a transplant after having been activated on the list, which often occurs in those who are highly sensitized.

The issue of transparency and clarity still applies when patients are listed: studies report that some patients are unaware of the allocation process [6] or even their status on the waiting list [4]. It is also important to acknowledge that being on the waiting list may in itself be stressful. The psychology of being waitlisted has been described in great detail, with hope, constant preparedness and also uncertainty as key emotional factors [7]. Transparency is equally important when, for whatever reason, the transplant listing is stopped [4]. An editorialist emphasized that kidney patients encounter difficulties while making decisions about transplantation and noted that renal units could do more to inform and support these decisions [8].

Another recurring theme in patient feedback, and one that is particularly difficult to achieve for most centres, is the request for continuity of care and for one named clinician as the central point of contact for all queries or concerns. Most patients would also like to see that named care provider semi-regularly. This would provide additional reassurance that transplant assessment is progressing at a reasonable speed [8].

Patients also acknowledge that as a group they vary greatly in their ability and willingness to utilize technology in their medical treatment. Some may prefer information technology (IT) and find it easy to navigate, while others may be very hesitant to adopt it or even unable to do so and may find themselves feeling more isolated and 'cut off' from their renal team at exactly the time they feel they need consistent support.

WHAT WOULD THE IDEAL TRANSPLANT ASSESSMENT PROCESS LOOK LIKE?

We propose that transplant teams should view the COVID-19 pandemic as a (unique) opportunity to rethink and redesign their pathways for recipient assessment. The fact that recipient assessment is a relatively structured pathway should help in this regard (Figure 2).

The first major rethink we believe should be around the need for face-to-face assessments. In our institution, we rely on a detailed face-to-face assessment and clinical examination by a physician, whereas the subsequent surgical review for listing is now often virtual, i.e. via video clinic. Only high-risk recipients or those with abdominal pathology or obesity are still seen face to face by the surgical team. We feel that this approach is safe and works well as long as physicians and surgeons know and trust each other, but we acknowledge that this may be more difficult to achieve in larger centres or with larger catchment areas. A welcome side effect of our approach is that we probably spend slightly less time with straightforward recipients but much more time with complex cases. We also acknowledge that the current percentage of virtual care in transplant assessment is to a large extent borne out of necessity, practicalities and availability of resources during the pandemic but not based on any substantial evidence. We suggest that teams now take the opportunity for conscious and careful reflection on the safe and efficient balance between virtual and face-to-face assessments. It should also be acknowledged that

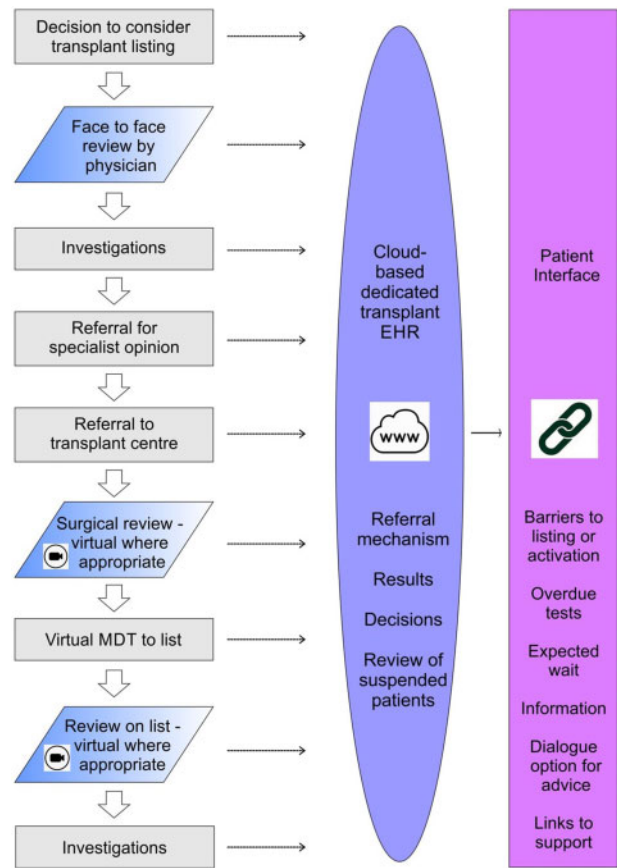


FIGURE 2: Proposed 'ideal' model of transplant assessment.

even experienced clinicians may suffer from unconscious bias, hence there is probable benefit if complex and borderline cases or those with a high body mass index are always assessed by two clinicians face to face before they are waitlisted or excluded from listing. This will provide additional reassurance to all parties that a balanced and careful decision has been made. Finally, we should seek the views of patients and relatives on this important topic. In our experience, patients approaching transplantation value face-to-face time with an experienced clinician even more than before the pandemic. As a transplant community, we should therefore ensure that the waitlisting process includes sufficient face-to-face time.

A similar rethink has occurred in our approach to review of the waiting list. Many of our follow-up appointments early after the initial listing are now virtual, especially in younger recipients and those with few or no comorbidities. Again, this has provided us with some extra capacity to schedule additional face-to-face reviews for high-risk recipients, the elderly and those waiting for combined transplants and patients who have waited a long time already.

In terms of information technology, we believe the time has come for a dedicated cloud-based approach (Figure 2). This will have numerous advantages. First, it will bring transplant-related information together in a way that avoids barriers between the electronic health records of different providers. Another advantage would be ease of access across the entire catchment area, for example, in outreach clinics, dialysis units or patient information meetings. Moreover, it will enable some form of patient access so that barriers to transplant listing, pending investigations and their results are transparent to

patients and their families. For patients who are already waitlisted, transparency should include the current status on the waiting list as well as the expected waiting time. A cloud-based location would also serve as an ideal location for a portfolio of patient information relating to transplantation, the assessment process and life after a transplant. External links, to patient information portals, for example, could also be provided.

It is also important that any cloud-based transplant assessment technology needs to mirror and enable the multidisciplinary assessment process. As a team, we have found the multidisciplinary approach involving transplant surgeons, coordinators, nephrologists and their specialist nurses, radiologists and anaesthetists uniquely helpful, especially when assessing complex or high-risk transplant candidates. All members of the multidisciplinary team (MDT) need to have access to the information and their contribution must be documented in a way that is accessible and visible to all members of the MDT. Such a cloud-based approach could also help with timetabling, scheduling and documenting MDT meetings and with documenting outcomes and decisions. These, too, need to be transparent and accessible to patients. We also feel it is time to consider patient attendance at such MDT meetings. Based on our experience, we feel that a significant proportion of complex and high-risk patients would value the option to participate in this crucial part of the decision making regarding transplantation. A bespoke cloud-based system could provide such a facility in a confidential and safe manner and also alert patients when their case is scheduled for decision at an upcoming MDT meeting. Finally, given the widespread practice of recording customer interactions in the corporate world, one may consider recording MDT meetings. In the spirit of total transparency, patients could, even if they decide not to attend, access a recording of their case discussion and decision making later on if they so wish. Finally, such a cloud-based system should also include an option for dialogue with the medical team and links to providers of additional support, such as psychologists or social workers.

CAN WE GO ONE STEP FURTHER: WHICH ELEMENTS OF MEDICAL ASSESSMENT ARE REALLY NECESSARY?

A detailed review of all medical aspects of the transplant assessment process is beyond the scope of this article. However, given how constrained access to all aspects of healthcare has been during the pandemic, one has to wonder whether all current elements are really essential. As an example, access to myocardial perfusion scans has been severely constrained or non-existent for much of 2020. Others have recently argued to abandon cardiac screening for asymptomatic transplant candidates [9]. Kidney Disease: Improving Global Outcomes guidance currently in draft still suggests that asymptomatic transplant candidates at high risk for coronary artery disease or with poor functional capacity undergo non-invasive screening [10], but there are clearly mounting doubts as to whether the evidence backs this approach. These concerns have been augmented further by the International Study of Comparative Health Effectiveness with Medical and Invasive Approaches—Chronic Kidney Disease trial and the notion that an interventional strategy in patients with CKD and stable coronary artery disease has no advantage over best medical management [11]. A more definitive answer is expected from the Screening for Asymptomatic Coronary Artery Disease in Kidney Transplant

Candidates trial (ClinicalTrials.gov NCT03674307) [12]. We believe that the pandemic should make us rethink, can we really justify delaying the listing process by months in an asymptomatic low-risk patient who as a result of the pandemic waits months for a myocardial perfusion scan and where is the evidence to support this approach? This is probably even more appropriate for repeat cardiac investigations in asymptomatic waitlisted patients and also for other investigations, for example, routine chest imaging. We suggest that physicians and surgeons involved in transplant listing and their teams use the pandemic as an opportunity to reflect more consciously on all elements of the medical assessment and agree on a diagnostic approach that is backed by current evidence, not habit or tradition. Anaesthesia and critical care input into this evolution may also be of significant benefit.

CAVEATS AND PITFALLS

One major caveat in redesigning transplant assessment pathways will be the challenge to bridge the 'digital divide' [13]. In brief, this term describes that all attempts to empower patients by digital means will only ever reach a part of the population that is already quite well-engaged, whereas another substantial part of the patient population is essentially ignored [14, 15]. This pitfall is all the more relevant for the following reasons. First, younger, better educated and more IT literate patients and their families are more likely to be aware of service redesign, be it via a formal consultation or through social media and networks. Along the same line, this cohort of patients is then more likely to volunteer as patient representatives and participate in discussions around service redesign and thereby influence service development. Finally, enthusiastic clinicians and managers may be biased towards service redesign around enhanced use of technology: such projects are often perceived as more interesting and likely to attract positive publicity. We suggest that during any service redesign we should ensure good participation from a variety of patients and not just the younger and more IT literate.

We should also not lose sight of additional barriers that are often overlooked. A good example is that of transplant candidates who have severe visual impairment. A recent encounter with one such patient prompted us to reflect and record an audio version of our existing brochure for transplant candidates. Similarly, we found very little in terms of patient information for patients for whom English is not the first language, which prompted us to provide a patient information video in Urdu and Gujarati. We suggest that clinicians proactively seek out feedback from such patient groups and fine tune their approach.

CONCLUSION

The COVID-19 pandemic has been a unique challenge to renal patients and their healthcare providers. This has included disruption of transplant activity and listing, but it also affected working patterns and resources more widely. Importantly, we have also lost patients and colleagues to COVID. We do not in any way wish to ignore the suffering and loss caused by the pandemic. However, we argue that the pandemic can also work as a disruptor in a positive sense [16]. Rear Admiral Grace Hopper (1906–92) [17] is credited with the quote that "[t]he most dangerous phrase in the language is "we've always done it this way"". The statement was made in 1976 in relation to new laws around data processing. We suggest that this also applies to transplant assessment, where traditional pathways and practice deserve scrutiny and careful reflection. In the cold light of

the post-pandemic dawn, much of current practice is based on habit and a risk-averse philosophy [18], but not on robust evidence. We owe our patients an efficient, evidence-based and transparent transplant assessment process [19], but much of our current practice is neither. Prompted by our experience during the pandemic, we should now rethink the process of transplant listing. Instead of small-step evolutionary service development, we should find the courage to define an 'ideal' assessment process. Such redesign should not only include the process and IT aspect, but also the diagnostic procedures during the assessment of the transplant candidate. In this regard, we should question all elements that are not well-supported by current evidence. This process of reflection and service redesign must also involve our patients, for whom transplant assessment often occurs at a time of physical decline and emotional upheaval, with similar strain on families and loved ones. It is incumbent upon us as the transplant community to design an assessment process that is efficient, transparent and well-designed to help us support patients through this uniquely difficult period in their life, nurture their hope [20] and maximize their chances of a successful transplant.

CONFLICT OF INTEREST STATEMENT

Alexander Woywodt is a Member of the CKJ Editorial Board. The results presented in this article have not been published previously in whole or part.

DATA AVAILABILITY STATEMENT

No new data were generated or analysed in support of this research.

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