TSANZ
The Transplantation Society of Australia and New Zealand

ANZSN

Consensus Framework for Education, Suitability Assessment, and Communication Before Kidney Transplantation

ANZSN-TSANZ Transplant Information/Education Working Group

Approved by ANZSN Council August 2 2024

Approved by TSANZ Board March 2024

Executive Summary

All patients with kidney failure or approaching kidney failure must have equitable access to accurate, consistent, and consumer-reviewed information, and early individualised assessment and tailored risk/benefit discussion about kidney transplantation. This should not be negatively impacted by health literacy, socioeconomic status, geographical remoteness, gender, cultural, ethnic, or linguistic background.

Ideally education should be delivered early and integrated in the clinical pathway. It should be ongoing and multi-modal and multi-disciplinary. The purpose is to support patients to make informed decisions about kidney replacement therapy options and to ensure patients understand the benefits and risks of kidney transplantation compared to dialysis or supportive care. High quality pre-transplant education empowers patients and improves their experience and outcomes post-transplant. Systems for pre-transplant education should be standardised to ensure that information about benefits and risks are communicated consistently, to minimise the risk of major gaps. In addition, pre-transplant education needs to be appropriately individualised to specific medical and social circumstances and be accompanied by an appropriate level of psychosocial support and navigation assistance.

Background

The ANZSN-TSANZ Transplant Information/Education Working Group was established in 2022 to develop a framework to promote a unified approach to education and information for patients being assessed for a kidney transplant. The need for developing this framework had been identified by ANZSN members at preceding DNT workshops (2021, 2019, 2017), where polling questions of DNT workshop participants identified a need to improve processes of education and informed consent for kidney transplant recipients. This guidance document outlines the principles of (i) education, (ii) assessment and (iii) communication to patients, their families (Whanau) and referring units. It also identifies current gaps for future improvement.

ANZSN acknowledges the Traditional Custodians of Country throughout Australia, recognises their unique cultural and spiritual relationships to the land, waters and seas and their immense contributions to society, and pays respects to Ancestors and Elders, past and present. ANZSN acknowledges and respects iwi and hapū as tangata whenua of Aotearoa and is committed to upholding the principles of Te Tiriti o Waitangi (the Treaty of Waitangi). To read our statement on Indigenous Health click here.

Members

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Education on kidney transplantation for patients

- Comprehensive transplant information should be easily and readily available to all patients, their family (whanau) and support network with the ability for clinicians to tailor specific details for individual circumstances.

- Excellent educational resources are already available through Kidney Health Australia (KHA) and Kidney Health New Zealand (KHNZ), primarily in written format. However, it is noted that this may not suit all patients and therefore they may need a multi-modal tailored approach. These have been consumer-reviewed, designed for health literacy at the Year 8-9 level and translated into multiple languages/dialects. Patients, families, and clinicians should be guided to these educational materials for consistency of content.

- Informed consent for kidney transplant waitlisting and surgery, may be enhanced by a multi-modal approach to transplant education, especially for those with lower health literacy and those from culturally and linguistically diverse (CALD) groups. Patients from CALD groups may require more time and resources to achieve a similar level of education to patients from non-CALD groups.

    - Multi-modal transplant education may be facilitated by
        - one-on-one sessions with clinicians or transplant coordinators
        - written materials
        - audiovisual aids
        - interactive sessions (e.g. education seminars)
        - patient decision aids (e.g. online decision supporting tools)
        - support groups (e.g. buddy or patient navigator)
        - Use of a communication tool such as Teach-back to check understanding

- Education should be ongoing and not a one-off event. “Information overload” is common. Patients and families can be overwhelmed when faced with kidney failure, especially with competing priorities including dialysis preparation, work, or family commitments. Time is needed to absorb the information. There should be opportunities for patients to refer back to the transplant information content and ask questions when needed.

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- A clear and accessible point of contact for patients to ask questions outside of scheduled clinic appointments is needed.

- "Reminder" education is recommended, including an invitation to re-attend a transplant education seminar. This is important because of the significant time intervals that may occur between education, waitlist activation, and transplantation.

- Information about overall risks and benefits of transplantation, should be compared to not having a kidney transplant and, therefore, being treated with dialysis or supportive care.

- While transplantation offers significant benefits for many patients, for some patients the risks of transplantation are greater than remaining on dialysis. Care and sensitivity should be taken in the early delivery of tailored risk/benefit information and discussion.

- For potentially suitable transplant candidates, the benefits of earlier transplantation to minimise time on dialysis should be communicated. The mortality risks of remaining on dialysis should be discussed in a sensitive but transparent manner. This includes that the risk of mortality of transplantation is greater than dialysis in the first several months after transplantation, which is compared to the poorer long-term survival of remaining on dialysis. The communication of risks should be tailored to each patient's medical factors.

- Information regarding the possible risks of transplantation should be sufficiently comprehensive, with emphasis on common and "rare but dangerous" complications, as well as those specific to the patient which may impact on decision-making. It is preferable to communicate to patients the general possibility of serious unexpected complications rather than an exhaustive list of rare complications.

  When discussing donor kidney offers associated with specific risks (e.g. malignancy, blood borne virus, hepatitis C, higher KDPI (kidney donor profile index) etc), the context should be compared to the risk of declining the offer and waiting for another kidney. Discussion of such complexities may not be appropriate during the initial education session or review. The initial discussion is preferred to take place in the clinic setting rather than at the time of the kidney offer. The patient's risk tolerance and understanding should be established, acknowledging that this can change from the time of transplant waiting list activation to the time of kidney offer.

  Delivery of transplant information and education should be integrated in the clinical pathway for patients with or approaching kidney failure. Best practice is to do this at an early stage to increase opportunities for pre-emptive living donor kidney transplantation as the preferred modality of kidney replacement therapy.

- The benefits from living donor kidney transplantation should be included in the transplant education. Information and support to help patients and their families understand the assessment and process for living kidney donation are essential. This could be achieved by involving the families and friends in the process of transplant education or by providing written information regarding the benefits of living kidney donation. This should be balanced with information to patients without a medically suitable living donor that deceased donor kidney transplantation is a common alternative treatment option to achieve favourable outcomes.

Current gaps and what we advocate for:

- Resources to ensure the availability of all education materials in multiple languages and written at an appropriate health literacy level with attention to best practice principles for designing patient education materials;

- Resources to expand the buddy system and patient navigator groups to be culturally sensitive and linguistically diverse;

- Collaboration with research groups and KHA/KHNZ to develop patient decision aids to assist patients to make an informed decision on transplantation versus remaining on dialysis or supportive care;

- Collaboration with research groups and KHA/KHNZ to develop patient-centred educational materials and interactive online decision supporting tools to better understand patient's individualised risk tolerance and willingness to accept donor kidneys associated with specific risks, based on local data and patient specific factors;

- Systems and tools of education for kidney transplantation to be culturally safe, taking into account the values, cultures and beliefs of the patient and their family (whanau);

- The work by the TSANZ-ANZSN Living Kidney Donation Working Group to optimise access to and outcomes of living donor transplantation.

Assessment for suitability of kidney transplantation

- The outcome from the assessment should be based on shared decision-making, by patient, whanau/family and clinical teams.

- The criteria for assessing transplant suitability should be consistent and transparent. The principles should be based on the publicly available TSANZ guidelines. Suitable patients should be assessed as having a high likelihood of significant benefit from kidney transplantation. If the patient disagrees with a recommendation against transplantation, a second opinion (including an external opinion where feasible) should be offered.

- Early assessment, commencing prior to kidney failure, is recommended to maximise the opportunities for pre-emptive living donor kidney transplantation or timely waitlisting for deceased donor kidney transplant.

- All patients approaching or with kidney failure have the right to request an assessment for transplant suitability. The same applies to reassessment for previously waitlisted patients made inactive on the waiting list.

- Ongoing opportunity for repeat discussion regarding transplantation and reassessment is recommended, in the absence of unmodifiable absolute contraindications. Individual circumstances and perspectives can change during the journey with kidney failure. Furthermore, patients with a previous barrier to transplantation might later be considered suitable for transplantation.

- Access to pre-transplant assessment should be designed to counter inequities in access to kidney transplantation related to geographical remoteness, low health literacy, ethnicity, gender, language, and culture.

Current gaps and what we advocate for:

- Individual units to develop a system to monitor and audit their transplant assessment process and performance;

- Referring and transplant units to explore innovative pathways tailored to their local context to streamline the assessment process and improve access to transplant assessment;

- Quality improvement projects aiming to improve the current large variation in outcomes for ANZDATA Quality Indicator 3: Transplant Wait Listing (numbers of patients aged <65 years who have received kidney replacement therapy (KRT) for 6 months, and the percentage who are transplanted or on the wait list within 6 months of KRT;

- Review of ANZDATA Quality Indicator 3, to consider removal or modification of the 65 years age cutoff and to report transplant status at both 6 and 12 months after KRT start, as per the previous Victoria Renal KPI – 5;
- Kidney centres to report on transplant assessment process and performance based on known inequities within transplantation rates such as ethnicity, rural, remote and regional locality.

Communication to the patient and referring unit regarding suitability for kidney transplantation

- The outcome of the transplant assessment must be clearly communicated to the patient and the referring clinician. This is especially important in situations where transplantation is not recommended. The reasons for recommendation against transplantation require clear communication.

- Patients should be provided clarity at any given time about their status in the transplant assessment process. For instance, these include (i) active on the waiting list, (ii) currently not active on the waiting list but still under assessment, or (iii) assessed as not recommended for kidney transplantation.

- For patients temporarily on hold on the transplant waiting list, the specific requirements and the anticipated time frame for reactivation should be communicated to the patient and the referring unit at an early stage. There also needs to be a clear and accessible point of contact for patients to clarify their transplant waitlisting status.

- For patients proceeding through the transplant work up process, the remaining steps required to finalise a decision on transplant suitability should be clearly communicated to the patient, aiming to empower the patient to complete the assessment. This could take the form of a "checklist" shared between the patient and the transplant unit.

- Good documentation of the transplant education and assessment process is required. This documentation must include that the patient has been sufficiently informed, demonstrates a reasonable understanding about the benefits and risks of transplantation, and that the patient (or his/her medical treatment decision maker) has participated in the decision to choose kidney transplantation as the preferred treatment. This documentation is especially valued when a patient is being made active or inactive on the transplant waiting list, and in the lead-up to a planned living donor kidney transplant surgery. Standardised written consent forms may be useful to facilitate documentation of the informed consent process. In addition, it is important to document discussion of specific risks that may have been identified for individual kidney transplant recipients, especially if these risks are not included in standardised documents.

Current gaps and what we advocate for:

- Collaboration and resources to develop an app or online portal for shared information on the progress of transplant assessment.