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Improving Risk Counseling for Kidney Transplant Candidates Offered Deceased Donor Kidneys

Adnan Sharif[1,2]

[1]Department of Nephrology and Transplantation, Queen Elizabeth Hospital, University Hospitals Birmingham, Edgbaston, Birmingham, UK; and [2]Institute of Immunology and Immunotherapy, University of Birmingham, Edgbaston, Birmingham, UK

Correspondence: Adnan Sharif, Department of Nephrology and Transplantation, Queen Elizabeth Hospital, University Hospitals Birmingham, Mindelsohn Way, Edgbaston, Birmingham, B15 2GW, UK. E-mail: adnan.sharif@uhb.nhs.uk

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Risk is discussed with all kidney transplant candidates to help them decide whether to accept a donor kidney offer and proceed with surgery. As nephrologists, we contextualize risk objectively, believing that the purpose of informed consent is to provide candidates with some quantifiable measure of risk to aid decision-making. However, risk perception is multifaceted, a subjective judgment based on how risk is conceptualized, framed, communicated, and understood. It is heterogeneous and varies from person to person, depending on the individualized characteristics and experiences of both the risk communicator and the patient.

For transplant candidates, we seek informed consent on the basis of some discussion of risk or uncertainty, often in terms of probabilities. Spiegelhalter and colleagues[1] argued that uncertainty about the future can be replaced by a list of possible outcomes and an assessment of probabilities. Nonetheless, communicating deeper uncertainties caused by a lack of data is challenging. Probabilities are best treated as reasonable betting odds constructed from available knowledge and information. However, communicating probabilities relies on clear framing by the clinician and clear understanding by the patient.

PSYCHOLOGY OF DECISION-MAKING UNDER RISK

The psychology of decision-making under risk is multidimensional and encompasses different aspects of human behavior. From a behavioral science perspective, decision-making likely follows a prospect theory model, which argues that decisions are asymmetrically modeled on a personalized perspective of potential losses versus potential gains. From a transplant perspective, prospect theory dictates that candidates will react differently to potential losses (termed loss or risk aversion) versus potential gains relative to their specific situation (termed the reference dependence). Whereas expected utility theory considers only the choice a rational individual would make to achieve the maximum utility, prospect theory contradicts this by defining the *actual* behavior as opposed to the *expected* behavior of people. This can be driven by emotional rather than deliberate decision-making, influenced by personal reflections or hearsay from other patients of good versus bad experiences. For example, evidence after allogeneic hematopoietic stem cell transplantation confirms increased decisional regret after transplantation for patients with posttransplant complications.[2] Availability and affect heuristics have key roles in how people judge risk,[3] justifying the need for clearly framed risk communication.

FRAMING OF RISK FOR KIDNEY TRANSPLANT CANDIDATES

In a systematic review of prospective and cross-sectional studies, Zipkin *et al.*[4] explored the comparative effectiveness of different methods to communicate probabilistic information to patients. Visual aids and absolute risk formats improved patients' understanding of probabilistic information, whereas numbers needed to treat lessened their understanding. No single method was deemed superior and no specific studies exist for transplantation, although some examples of risk communication exist among living kidney donors.[S1]

Perception of risk depends on individual factors (e.g., demographics, beliefs, previous experience), which requires time and patience to appreciate. More important, how we deliver risk communication can be flawed. Identical information can be presented in different ways to skew decision-making by introducing framing bias (when equivalent information is expressed in different ways).[5] For example, perception of risk by kidney transplant candidates differs if mortality within the first year after transplant is framed as 98% survival versus 2% mortality. This is positive versus negative framing, in which the 98% chance of survival (positive) contrasts with the 2% chance of dying (negative), with positive framing more effective in persuading people to make certain decisions.[6] However, gain or loss framing is perhaps more relevant for communicating clinical risk because it concerns the implications of accepting or declining intervention. In cancer screening programs, loss framing (e.g., the risk of not attending routine screening) influences the uptake of screening more than gain framing (e.g., health gain by attending for screening).[S2]

Other framing biases include the distinction between absolute versus relative risk. For example, if an intervention reduces the risk for death from 20% down to 15%, the absolute risk reduction is 5% and the relative risk reduction is 25%. Although these estimates are derived from the same source data, patients are more easily persuaded by the larger reduction in relative risk.[6] The impact of framing on risk perception is also confounded by numeracy, the ability to use numerical concepts to perform basic probability operations.[6] People with high versus low numeracy scores are more likely to interpret risk estimates correctly.

These are a handful of examples of how patients can be persuaded or dissuaded from proceeding with transplantation using the same probabilities depending on how risk is framed. Improving risk communication for transplant candidates to make genuinely informed decisions must therefore acknowledge these flaws and accept the need for change.

Table 1. What is the best way to visualize probabilistic uncertainty?

Use multiple formats because no single representation suits all members of an audience.
Illuminate graphics with words and numbers.
Design graphics to allow part-to-whole comparisons and choose an appropriate scale, possibly with magnification for small probabilities.
To avoid framing bias, provide percentages or frequencies both with and without the outcome, using frequencies with a clearly defined denominator of constant size.
Helpful narrative labels are important. Compare magnitudes through check marks and clearly label comparators and differences.
Use narratives, images, and metaphors that are sufficiently vivid to gain and retain attention, but which do not arouse undue emotion. It is important to be aware of affective responses.
Assume the low numeracy of a general public audience and adopt a less-is-more approach by reducing the need for inferences, making clear and explicit comparisons, and providing optional additional detail.
Interactivity and animations provide opportunities for adapting graphics to user needs and capabilities.
Acknowledge the limitations of the information conveyed in its quality and relevance. The visualization may communicate only a restricted part of a whole picture.
Avoid chart junk, such as 3-dimensional bar charts and obvious manipulation through the misleading use of area to represent magnitude.
Most important, assess the needs of the audience, experiment, and test and iterate toward a final design.

From Spiegelhalter D, Pearson M, Short I. Visualizing uncertainty about the future. *Science*. 2011;333:1393–1400.[1] Reprinted with permission from AAAS.

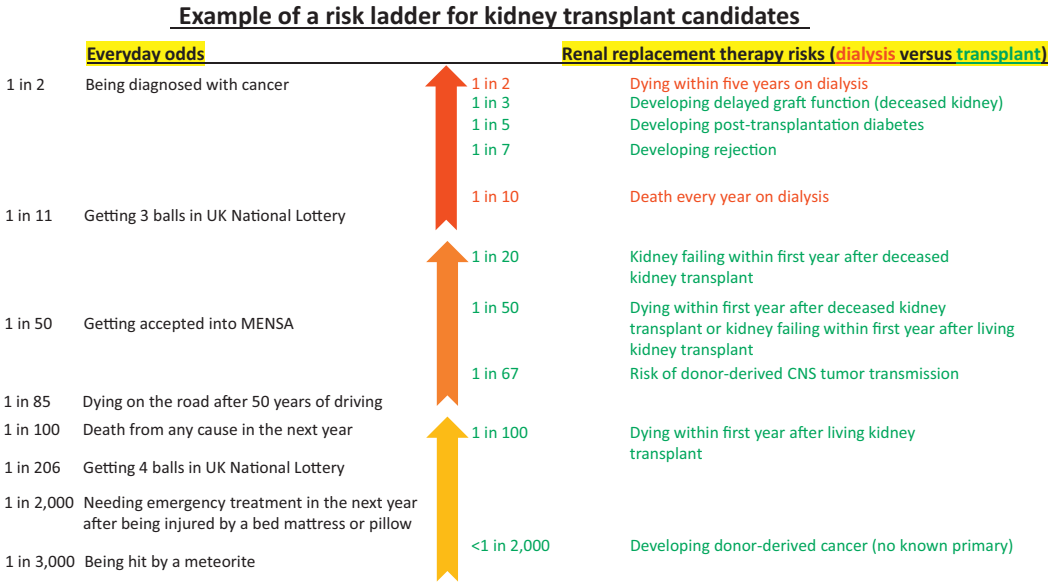

Figure 1. Example of a standard-risk ladder that can be used to aid risk communication during discussions with potential kidney transplant candidates, which will require modification for high-risk settings (e.g., donor or recipient risk factors) and different patient cohorts (e.g., non-UK cohorts).[8–11] CNS, central nervous system.

RECOMMENDATIONS TO IMPROVE RISK COMMUNICATION

Risk communication must be consistent and translatable, with a structured framework to ensure minimum subjectivity and maximum objectivity. It should be accurately framed, comprehensively delivered, and clearly understood by transplant candidates.

Simple interventions can improve risk communication, as highlighted by Spiegelhalter and colleagues[1] (Table 1). Framing bias can be avoided by giving both positive and negative outcomes by saying, for example, "Of 100 operations on people like you, we expect 95 to be successful and 5 to be unsuccessful." The statement explicitly includes the reference class "100 operations on people like you" to aid contextualization. Individuals with a low numeracy score (who struggle with interpretation of risk estimation) will benefit from qualitative explanations of risk that compare the likelihood of transplant surgery risk with everyday events. Such visual displays of risk (e.g., the use of risk ladders) can aid understanding of different risk magnitudes (Figure 1).[7] This will be especially beneficial in communities in which there are language barriers or health literacy is poor. Visual representations may substantially improve comprehension of risk, using a range of pictorial representations (graphs or population figures) to match the type of risk information that the patient most easily understands, although this can have its own bias.

Individualized risk estimation has greater influence than general risk estimation on treatment choice.[12] Single-event probabilities or conditional probabilities (such as sensitivity and specificity) are confusing to interpret and are better replaced with a discussion of natural frequencies.[5] For example, the mathematical probability of achieving a posttransplant outcome of 0.8% is more difficult to grasp compared with stating 8 in every 1000 after transplant will achieve this outcome. Risk perception also has a sociocultural component; involving family or friends in risk communication may help with comprehension to aid decision-making. Expressing ambiguity about risk, frequently given in the setting of kidney transplantation for unquantifiable risks due to lack of data, is unavoidable, but studies suggest this leads some individuals to become confused, suspicious, and more risk-averse.[1]

CONCLUSIONS

We must improve risk communication with kidney transplant candidates to help them make informed decisions, ensuring that patients understand risk adequately rather than clinicians confirming the disclosure of risk. At present, risk communication is "still more art than science, relying as it often does in practice on good intuition rather than well-researched principles."[13]

Research is required to develop and assess interventions to facilitate effective risk communication. Without such an evaluation, risk communication will remain a subjective art rather than an objective science. By shifting blame for flawed risk communications to patients, we may deny them the opportunity for transplantation because of an inability to participate actively in decision-making. Optimizing risk communication will provide opportunities for transplantation to a broader pool of kidney failure patients and must be actively explored.

DISCLOSURE

The author declared no competing interests.

SUPPLEMENTARY MATERIAL

Supplemental File (PDF)

Supplementary References.

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