9-13-2010

Decision Making by Patients Awaiting Kidney Transplant

Daniel Solomon

Recommended Citation

Solomon, Daniel, "Decision Making by Patients Awaiting Kidney Transplant" (2010). *Yale Medicine Thesis Digital Library*. 95.
http://elischolar.library.yale.edu/ymtdl/95

DECISION MAKING BY PATIENTS AWAITING KIDNEY TRANSPLANT

A Thesis Submitted to the
Yale University School of Medicine
In Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine

by
Daniel A. Solomon
2010

Abstract

DECISION MAKING BY PATIENTS AWAITING KIDNEY TRANSPLANT

Daniel A. Solomon, Nicole Rabidou, Sanjay Kulkarni, Richard Formica, Liana Fraenkel.
Department of Internal Medicine, Yale University School of Medicine, New Haven, CT.

Involving patients in medical decisions by acknowledging patients' personal values and individual preferences has become an important goal of providing ethical medical care. Despite a general movement towards a model of shared decision-making, many patients do not fully meet their preferred role in practice. The decision whether or not to accept a kidney once it is offered to a patient awaiting transplant has historically been made predominantly by the transplant surgeon with little involvement from the patient. Because dialysis can provide long-term renal replacement, declining a kidney is a viable option. Patient changes over time and inherent heterogeneity of donor kidneys make this an authentic decision requiring careful analysis of costs and benefits from the patient perspective. The purpose of this study is to improve our understanding of how patients and transplant surgeons prioritize different factors when deciding whether or not to accept a kidney that has become available, in order to empower patients to become more involved in the decision-making process. *Phase I*: We developed a comprehensive list of factors that patients *might* consider important through qualitative interviews with patients, and deliberation with a transplant surgeon (SK) and a transplant nephrologists (RF). *Phase II*: We quantified the relative importance of each factor for patients on the transplant list and for transplant surgeons with a computerized survey using Maximum Differences Scaling. We developed relative importance scores using Heirarchical Bayes analysis, and tested for associations between patient characteristics and relative importance scores using Spearman's correlation coefficient and the Mann Whitney U test for continuous and categorical variables respectively. Of the factors evaluated, patients placed the greatest value on *Kidney quality, How closely matched you are to the kidney,* and *How strongly your surgeon feels you should accept the kidney*. Relative importance of different factors did not change based on patient demographic characteristics. Patients who are on the waiting list longer give less importance to *kidney quality* (standard beta estimate -0.23, p value 0.03) and more importance to *How difficult it is for you to be matched to a donor (ie whether or not you are sensitized)* (standard beta estimate 0.28, p value 0.01). Surgeons placed the greatest value on *Kidney quality, How difficult it is for the patient to be matched to a kidney (ie whether or not the patient is sensitized)*, and *The age of the donor*. This pilot study suggests a role for standardized education tools to help empower patients to be involved in this difficult decision. Development of decision aids can be guided by the results of this project.

Acknowledgements

I would like to express my deep gratitude to my mentor, Liana Fraenkel. You have been inspiring to work with, and I am grateful for all your help, support and guidance throughout this project. Thank you for reassuring me when I had my doubts, listening to me when I had concerns, and having confidence in me all the way through. I admire your commitment to the integrity and value of your research, teaching and mentorship alike. I feel so fortunate for the opportunity to work with you.

This project would not have been possible without the help of Nicole Rabidou, in gathering much of the data along the way. I would also like to thank Sanjay Kulkarni, and Richard Formica for lending their expertise and perspectives in the field of kidney transplantation. I would also like to thank Dr. Peggy Bia for her thorough review of my thesis and for her thoughtful input and suggestions.

Sonja, thank you for your devotion and companionship. Although at times we have had *more* fun, it was reassuring and comforting to go through it together.

I would finally like to thank my family for their encouragement and support in all my pursuits. I am so grateful for the opportunities you have provided me, and I am so lucky to have such a loving and caring home.

Table of Contents

Preface

On my ambulatory rotation during third year of medical school, I met a 56-year-old woman named Esther who came into the office complaining of increasing fatigue, decreased concentration, and general aches and malaise. She had previously been diagnosed with stage 4 chronic kidney disease, and her baseline creatinine, rising steadily, was now at 7.1. She was well known to the medical office, visiting every two weeks or so with the same chronic complaints.

All of Esther's doctors – her primary physician, her cardiologist and her nephrologist – had been advising her to consider preparing for dialysis for over a year, but she adamantly refused. Dialysis was simply not an option. I talked with Esther for over an hour that afternoon about each of her complaints and the effect that her disease was having on her life. Each time I brought up dialysis, she steered the conversation away, and I followed her cue. But for a woman who seemed to have a wonderful support system, with so many friends and interests, I was puzzled as to why she was so firmly opposed to the idea. Out of curiosity as much as anything else I finally asked directly why she would not talk about dialysis.

Esther blushed. "Well, I had a friend who was put under anesthesia for an operation, and she never woke up. Now they tell me I need to have an operation in my arm before I can start dialysis, and I am too scared to go through with the surgery." I had expected a prepared speech on the burden of dialysis, the loss of three days a week, the inability to travel, the hassle, the frustration, the pain. But Esther's fear was more personal, more specific.

My encounter with Esther piqued my interest in better understanding how patients make decisions and the role of the physician in the decision-making process. In honoring Esther's decision to forgo dialysis, each of her doctors respected her individual autonomy, a principle that is paramount in this age of practicing medicine. And yet, her decision was based on unfounded assumptions and an irrational fear. By respecting her autonomy without probing her underlying beliefs, it seems as though her physicians missed an opportunity to provide expert guidance, and meaningful care.

What does it mean to make an informed decision? How can doctors best empower patients to make their own decisions? What responsibility do physicians have to explore a patient's reasons for making a decision? Do physicians have an obligation to challenge patients when they think it is in the patient's best interest? These questions form the backdrop for this study.

Background

Shared decision-making

History

Through the first half of the 20th century, paternalism was the cultural standard for providing medical care, with physicians playing the dominant role in the doctor-patient relationship and the central role in decision-making. In this model, the physician diagnoses the patient's medical condition, and selects the appropriate management to restore health or alleviate pain. The doctor then provides the patient with the requisite information to consent to the proposed intervention (1).

In 1957, Michael Balint published a paper that pioneered a movement to consider the patient's perspective of his own illness and to reconsider the balance of power in the physician-patient relationship (2). This was complemented by George Engel's biopsychosocial model of care, developed in the early 1960's. Engel's landmark paper, published in 1977, emphasized that biological disease must be considered in the psychosocial context of a patient's life, and concluded that the patient's experience of disease should be illuminated in the course of medical care (3,4).

Historically, acceptance of paternalism wrested upon several basic assumptions. First, for most illnesses, there is a single best management strategy or treatment. Second, doctors are uniformly educated about current treatment guidelines, so there is consistency in management of a given disease. Third, given their rigorous training and expertise, doctors are best equipped to guide management when more than one option exists. Finally, bound by their code of ethics, doctors always act in the best interest of the patient (1,5).

Technological innovation, clinical research and cultural changes in the 1980's brought into question these fundamental assumptions. Pharmaceutical and surgical advances amplified the element of choice in medical decision-making. With multiple treatment options, there were new risks and benefits that had to be weighed, and physician authority to make value-based decisions was questioned (6,7). Moreover, research on variations in treatment between patients with the same disease showed a striking lack of uniformity between different care providers (8-12). Not only were physicians making value judgments on behalf of patients, their decisions lacked consistency. More recent studies have further shown that physicians are poor predictors of patient preferences (13, 14). Finally, a concurrent rise in health care costs in the 1980’s and 1990’s put additional pressure on the health care system to strive for uniformity and efficiency (15).

Amidst the backdrop of the emerging biopsychosocial model of care, demand for evidence-based quality improvement and consistency encouraged doctors and patients alike to advocate a new treatment model that involved the patient in the decision making process (1, 5, 6, 16-18).

Potential advantages

Including patients in decision-making has theoretical, ethical and practical benefits. First, since only patients can truly know their own values, *they* are best suited to consider the risks and benefits of each choice in the context of their beliefs, preferences, and needs (19). Furthermore, giving patients the power to make their own decisions fosters the bioethical principle of autonomy, which states that rational beings have the right to make informed decisions without coercion (20). More specifically, ethicists have argued that all people have a right to determine what happens to their own bodies, and thus the power for patients to choose is an end in itself (21). Clinicians further believe that shifting the power in the doctor-patient interaction can improve the treatment relationship by cultivating trust and respect (22). In sum, patient participation drives personalized medical care, and ideally results in increased patient knowledge, satisfaction, adherence to treatment, and improved outcomes (23).

Potential disadvantages

Although autonomy has been embraced as a core bioethical principle and ethicists hail the power to choose as a self-evident right, choice has been shown to have a harmful effect on some patients. In some cases too many choices can be debilitating, and has been shown to increase stress and despair (24). Further, one study showed that patients who preferred more choice and ownership of decisional control were ultimately less satisfied with outcomes, perhaps due to failed expectations (25). When patients have more control over the decision-making process, they may also have a greater sense of culpability for adverse outcomes (26). Especially when stakes are high, some patients may wish for their doctor to reassume decision-making responsibility so they will not suffer guilt or blame themselves for a poor outcome (27). Moreover, it has been argued that patients may *not* be in the best position to value outcomes because they cannot anticipate how they will adapt to the consequences of their decision (28). Doctors, with experience and perspective, might offer better insight into functional and emotional outcomes for each choice. Furthermore, even if patients are adequately informed, they might lack the foundational knowledge or framework to organize the costs and benefits and synthesize a rational decision. Finally, including extensive discussion about patient preferences, values and beliefs can be a cumbersome and time-consuming model of care and hinders physician efficiency (29).

Different models for patient involvement in decision-making

In response to the failings of paternalism, two models of decision-making emerged, informed and shared, both of which focus on involving patients in decisions in order to increase their engagement in, and ownership of their own health (29). While both models are grounded in the values of patient-centered care, patient empowerment and evidence-based patient choice, the role of the physician differs in each model.

Informed decision-making is founded on the theory that the patient should be the sole decision-maker when there are two or more rational choices,[1] and it is based on the fundamental assumption that physicians should never make a choice on a patient's behalf (31). The role of the physician, then, is to provide all the relevant information to the patient, empowering the patient to make his own choice (1). In this model, information exchange is largely unidirectional from the doctor to the patient, and is mostly medical in nature (5). This model assumes that patients are aware of their personal values and biases, and are best equipped to make a decision that balances their own beliefs with the relevant medical knowledge.

Shared decision-making entails an exchange between physician and patient and collaboration over the final decision (1, 5, 30, 32). In contrast to the informed model, both physician and patient are involved in the decision-making process, information exchange is bidirectional and is both medical and personal in nature, and both physician and patient may express treatment preferences (5). Proponents of the shared model submit that while patients are the best judge of their own values, physician perspective and experience may be necessary to elicit the relevant preferences. Furthermore, if patients interpret information through filters of their values and beliefs and without objective insight into their own biases, the intended message may be lost or transformed (33,34). Thus, patients may not be fully equipped to make a nuanced decision without an exchange about personal values with the physician.

---

[1] It is important to note that many actions in medical care are not true decisions that require patient input (30). The presence of a decision is defined by the degree of choice and certainty. When there is only one treatment modality, or there is medical consensus that one treatment is certainly the best option, the element of choice is diminished. E.g: for the treatment of a simple urinary tract infection, in an otherwise healthy patient, prescribing a course of antibiotics is not a true decision. A decision requires two or more viable options – one of which may be to remain with the status quo.

Significance of Patient Preferences

In a discussion of how to best serve patients, it is important to consider the actual perspective of real patients. A previous study showed that patients' conception of participation may differ from physicians' or investigators'. Patients view decision-making as an ongoing process that exists in a broad social context (35), whereas many clinical studies aim to explore decisions at a discrete point in time in isolation from contributing social factors (36, 37). In addition, while studies often assess patient preferences in isolation from their doctor's opinions, many patients view their doctor's recommendations as a key factor in decision-making. Finally, many studies have shown that not all patients even want to participate in medical decision-making, or that they want varying amounts of control over the final decision (14, 38-41).

Adoption of a patient decision-making model to protect patients' rights and preferences raises an interesting ethical question: do patients have an obligation to make decisions or is it acceptable for them to ask doctors to choose on their behalf? If we consider patient preferences to be most important, it seems as though we should thereby honor their choice to abdicate decision-making responsibility. Some ethicists argue that patients have no duty to make their own decisions and thus may delegate decisional authority (42). Others contend that physicians should never make a choice for a patient – even if the patient wants the physician to do so – because it categorically impinges on individual rights, and sets a standard of rewarding paternalistic behaviors amongst physicians (34). A further detailed review of these ethical considerations is beyond the scope of the present discussion.

Shared decision-making versus informed consent

In practice, the process of obtaining informed consent may be indistinguishable from the doctor's role in shared decision-making, but there is an important distinction between the two (32). 'Consent' is a legal term, rooted in the element of risk, which refers to a patient's agreement to a given test, treatment, procedure or intervention. Risk is inherent in medical care. The process of obtaining consent places the burden of accepting that risk on the patient, and relieves the physician of liability for undesired outcomes. Whereas consent is a legal principle defined by the degree of risk associated with an intervention, patient decision-making is an ethical principle defined by the element of choice or uncertainty. It is important to note that choice is independent from risk and thus distinct from the legal penumbra of informed consent.

Does patient decision-making improve outcomes?

While incorporating patients into decision-making may be an end in itself as argued above, it is important to examine how it affects quality of care as measured by outcomes. Unfortunately, patient perception of control is difficult to standardize in an experimental model. Even in a regulated care setting with the same doctor and experimental controls each patient's assessment of decision-making control may still vary and thus investigators rely on patients to self-report their perception of involvement in management decisions (25, 43). With this caveat, several studies show that patients who believe they have an active role in treatment decisions generally experience better outcomes (44, 45). This is noted especially in patients with *chronic* diseases, such as diabetes and systemic lupus erythematosus, where a struggle for control seems to be defining.

Strategies to improve shared decision-making

Despite the compelling reasons to integrate patients into decision-making, and the cultural shift towards that model of care, in practice, less than half of all patients are fully satisfied with their role (46-48), which raises the question of how to empower patients in the care setting. In a qualitative study of how best to enable patient participation, Fraenkel and McGraw set out five elements essential for active patient contribution: 1) patient knowledge, 2) explicit encouragement of patient participation, 3) appreciation of patient's rights to play a role in decision-making, 4) awareness of choice, and 5) adequate time (23). These factors depend heavily on communication and interventions have been designed to focus on improving doctors' ability to properly engage and educate patients (49).

Decision aids are information interventions, geared towards improving patient knowledge, that present medical information to patients in a standardized way (17). Ranging from interactive videos or computer programs (50) to low-technology pamphlets or decision flow charts (51), decision aids are designed to encourage 'evidence-based decision making.' Though studies are limited, current evidence shows that patients who use decision aids are more informed, and make decisions that are more in line with their stated preferences (52,53). Critics of decision aids argue that each patient starts with different bases of knowledge, different values and different backgrounds, and information must be tailored to their specific needs, rather than normalized to an average patient (54).

Arguably the most important way to empower patients to contribute to decision-making is for the physician to create a safe environment, where patients can ask questions, express concerns, and voice opinions so that the doctor can provide appropriate information and guidance (55). This seems to be an overarching challenge of providing high quality clinical care and is independent of the academic model of decision-making in practice.

Kidney Transplantation as a model for Shared Decision Making

While medical practice has come a long way from the days of 20th century paternalism, there remain some medical decisions in which patients remain predominantly passive. Such is the case for patients awaiting a kidney transplant when they need to decide whether or not to accept a kidney that becomes available. The following section will review the kidney allocation policy and explore the nature of this important decision.

Kidney transplantation: background and policy

The demand for kidneys in the United States far exceeds our current supply. Though the number of transplants per year is steadily increasing, it is eclipsed by the number of new transplant candidates. In 2008, 32,586 new candidates were added to the waiting list while just 16,520 transplants were performed – 10,552 from cadaver donors, and 5,968 from living donors. As of December 30, 2009, there were 83,143 patients on the transplant waiting list (56). The debate over organ allocation has multiple layers of complexity: from a moral argument – who is entitled to the organs? – to a practical question of social and economic policy – how can we optimize the use of this scarce resource? (57,58)

The structure of the current policy is as follows. The United Network for Organ Sharing (UNOS) is the governing body responsible for national organ donation, which oversees the activity of Organ Procurement Organizations (OPOs). OPOs are non-profit agencies responsible for the logistics of transplantation: approaching families about donation, coordinating recovery, preservation and transplant of organs that become available, and managing regional waiting lists. There are 59 OPOs across the country, each responsible for a different geographic region (59).

Organ allocation works on a point system based on the following categories:

1. Age: 4 points for age < 11 years; 3 points for age 11-18 years.
2. Degree of human leukocyte antigen mismatch:[2] 2 points for zero-antigen mismatch; 1 point for one- antigen mismatch.
3. Waiting time: patients are assigned a fraction of 1 point defined by their place on the waiting list. For example, if there are 100 people on the list, the first person would receive 1 point; the second person would receive 99/100 points, the third would receive 98/100 and so on.
4. Calculated Panel Reactive Antibody (CPRA)[3]: 4 points for > 80%
5. Donation status: 4 points to patients who previously donated a vital organ or segment thereof (liver) within the United States.

A few subtle details are of note. First, there is no upper age limit. If a surgeon deems a patient suitable for transplant, the candidate can be added to the waiting list. Second, there are no points awarded for medical urgency. This is due to the availability of renal replacement therapy, dialysis, a concept I address in detail below. Third, points

---

[2] Every human has a combination of six human leukocyte antigen (HLA) proteins that are expressed on cells throughout the body. Degree of mismatch refers to the amount of antigens that differ between the patient and the donor.

[3] CPRA is a measure of the percentage of the general population that a potential recipient makes antibodies (is sensitized) against. Sensitization usually occurs as a consequence of pregnancy, blood transfusions, or previous transplantation. The greater the CPRA, the more sensitized a patient is to the general pool of donors, and thus the more difficult it is to find a suitable donor (60,61). For patients who have a CPRA > 80% it is extremely difficult to find a suitable donor, and thus patients are given an advantage for a given suitable kidney.

based on waiting time are only used to break ties among patients with equal points from other factors (62). While the system is structured around a first-come-first-serve policy, waiting time is considered secondary to other patient characteristics and predictors of graft survival.

Kidneys are offered to patients by geographic region. Local patients are considered first; if no suitable recipient is identified, the kidney is offered to the regional list, and then finally to the national list. The one exception is that a zero-antigen mismatch must be shared nationally – if there is a patient on the national waiting list that has a compatible blood type and shares all six human leukocyte antigens with the donor, that patient receives the kidney. If there are multiple zero-antigen mismatches, the patient with the most points as assigned by the allocation point system receives the kidney (57).

Kidneys are divided into two classes based on their donor characteristics: standard kidneys and expanded-criteria kidneys. Expanded-criteria kidneys have a higher probability of graft failure and are distinguished by greater donor age, lower baseline kidney function, and presence of donor comorbidities including cardiovascular disease and hypertension. At the time of enrollment on the waiting list, patients are asked if they would be willing to accept an expanded-criteria kidney, or if they are only interested in standard kidneys.

The decision to accept a particular organ remains the privilege of the transplant surgeon responsible for the care of the transplant candidate. This allows surgeons to exercise subjective medical judgment regarding the suitability of an organ for a particular patient. Though evidence-based criteria guide surgeons' decisions, there remains controversy over standard of care regarding factors such as cold ischemia time and anatomic abnormalities (63,64). If the surgeon considers the kidney appropriate for a given patient, the patient is contacted with the offer. The patient is given a time limit (usually less than one hour) to decide whether or not to proceed with the transplant.[4] If the organ is refused by either the doctor or the patient, it is offered to the next appropriate candidate until the kidney is accepted. A key point here is that patients who refuse a kidney do not lose their place on the waiting list. While no good evidence-based data exists, experts predict that less that 5% of patients refuse the offer (65).

For further information about the details of the allocation process including payback policies between different OPOs, and further details on CPRA, the reader is directed to the Organ Procurement and Transplantation allocation bylaws, found at http://optn.transplant.hrsa.gov/policiesAndBylaws/policies.asp section 3.5.

The importance of this decision

As discussed above, an authentic decision is defined by the presence of choice and uncertainty. With the advent of dialysis, we have the technology to adequately replace kidney function over a long period of time. Thus, when a patient is offered a kidney for transplantation there exist two medically viable options: to accept the kidney for transplantation, or to refuse the kidney and remain on dialysis. An exploration of each choice follows.

Accepting the kidney

Accepting the kidney offers tremendous potential benefits: better long-term survival, lower risk of graft failure, better quality of life, and lower cost. One study

---

[4] One predictor of graft survival and delayed graft function is cold ischemia time (63), so there is considerable pressure for decisions to be made quickly.

looking at mortality showed that long-term survival is better among patients on the waiting list who eventually received transplantation (66). Another study found that patients who are on dialysis less than six months have a significantly greater graft survival at five and ten years after transplant than patients who are on dialysis longer than two years (67). Finally, a critical analysis of cost and quality of life showed that patients who receive transplantation had a higher health-related quality of life score, and lower medical costs than before transplant (68).

Renal transplantation also entails considerable risks, however, which can be broken into two categories: general surgical risks and risks associated with immunosuppression and organ rejection. As with any common procedure, transplant surgery has a significant recovery period and entails risks of bleeding, infection and death. The study assessing mortality in patients with ESRD found that the relative risk of death during the first two weeks after transplantation was 2.8 times greater than for patients on dialysis (66). The major concern with any organ transplantation is the risk of organ rejection (either acute or chronic), which can result in symptoms and consequences of organ failure, further surgery to remove the offending organ, and re-initiation of dialysis (69). In order to decrease the risk of rejection patients must take immunosuppressive therapy, which puts them at increased risk for common and opportunistic infections.

Refusing the kidney

The second viable option is to turn down the kidney and remain on dialysis.[5] Despite the overwhelming benefits transplantation offers, there are two intrinsic elements of the decision that validate declining the kidney as a real option: change in patient characteristics over time, and heterogeneity of donor kidneys.

Humans change over time – physically, emotionally and psychologically – and thus, the same person may make a different decision in two different contexts. If a given patient would *never* accept a kidney for transplant, it would not be appropriate for him to be on the list at all. There are many scenarios, however, in which a patient might want a kidney transplantation at *some point in time,* but may choose not to accept the kidney in the moment it becomes available. Let us consider a patient who goes on the transplant list fully intending to accept any kidney that is offered to him. The patient might have a second, transient illness at the time the kidney is offered, which could increase the risk of severe complications associated with surgery. The patient might be dealing with a death or a crisis in the family, and is not emotionally prepared to undergo transplant in that moment. Over time the patient may adapt to dialysis, and might perceive the decision differently from when he initiated dialysis treatment. Patients perceive decision-making as an ongoing process that changes within different social contexts (39), and medical care providers must recognize the possibility for change in turn.

The second element that validates the choice to decline a kidney is the heterogeneity of donor kidneys. While surgeons presumably only offer kidneys that are of 'acceptable' quality, there is still a broad spectrum with regards to baseline function of kidney, risk of contracting a disease, likelihood of rejection, and expected graft survival

---

[5] It is notable that this decision is unique to kidney transplantation. In the case of other vital organs such as heart or liver, the technology does not exist to adequately replace the function of the failing organ. Thus, medical urgency removes the element of choice, as transplant is the only medically appropriate option.

time (70). In addition, a zero-antigen mismatched kidney has a lower risk of rejection and greater overall graft survival (71,72). Thus, a patient who is well-adjusted to dialysis or otherwise not anxious to receive a kidney right away, may choose to minimize the risk of graft rejection, or maximize the graft survival by holding out for a kidney of higher quality, or of a closer match.

Should patients be involved in the decision?

One could argue that patients should not be involved in the decision whether to accept or decline the kidney at all. The factors that doctors consider when assessing a kidney (specific serologies, glomerular filtration rate, histological composition etc.) are detailed and require extensive medical training to understand. Even more accessible concepts such as probability of graft failure or predicted years of graft survival are embedded in nuanced uncertainty. It may be unreasonable to expect patients to make a decision based on medical subtleties and multiple levels of probability.

Furthermore, as noted above, kidneys are already a scarce resource. By empowering patients to become highly selective, more kidneys may ultimately be discarded.[6] Disposal of a functional (albeit lower quality) kidney would mark a failure to optimize the use of a limited resource. Doctors, the argument follows, have an obligation not only to the individual patient that stands in front of them, but to all patients, and must consider the societal impact of wasting resources (73). Given the complexity of the decision, and the potential impact the decision has on society, patients should only be

---

[6] As discussed above, kidneys are offered to patients based on a point system as detailed above. If the surgeon deems it acceptable it is offered to the patient. If the surgeon or patient chooses to reject the kidney, it is offered to the next candidate on the list. The kidney is offered down the list until it is accepted, until there are no suitable candidates left, or until the kidney is no longer deemed viable based on cold ischemia time (59).

allowed to decide whether or not they want a kidney at all, and should not have any choice with regards to the characteristics of the kidney itself.

We contend that patients have an unassailable right to choose what happens to their body, especially in decisions that have the greatest impact on their health and quality of life. We acknowledge the complicated nature of this decision and thus argue for a model of shared decision-making where both parties contribute information and ideas, and both parties agree on the final choice. The challenging role of the physician would be to guide patients through the relevant medical details, and encourage patients to consider personal factors that might contribute to a better-informed decision.

We further acknowledge the fact that there are more people on the waiting list than kidneys available, but the argument that rejecting more kidneys would increase resource scarcity fails to appreciate the heterogeneity of donor kidneys. The simple fact that someone might choose to stay on dialysis rather than accept a low quality kidney indicates that low quality kidneys and high quality kidneys should not be considered the same commodity. Though there are surely some patients who would accept *any* kidney, the argument stands that if lower quality kidneys continue to be discarded, they must not be in high demand and cannot be considered a scarce resource in the same category as high quality kidneys. Societal impact cannot be assessed without understanding the demand for these organs as defined by patient preferences.

Involving the patient in the decision

In spite of the established and potential benefits of kidney transplantations, the scenarios in which a patient might choose to decline a kidney but remain on the waitlist are many, and they depend on the personal values and perspectives of the individual patient. Organ allocation models and decision rules have previously been developed (73-75), some even accounting for theoretical patient preferences for health outcomes. However, actual patient opinions, values, beliefs or perspectives about the decision making process have never been explicitly examined.

We believe that there is a role for patients to be more involved in deciding whether or not to accept a kidney once it becomes available. Given the significant impact the decision will have on the patient's life, it is important for patients to consider the choices through the lens of their personal values. We also believe that the doctor's role of providing medical expertise and perspective of previous experience is essential, and so we advocate for the model of shared decision-making, where both parties can contribute their own perspective and a decision is reached together. In order to best incorporate patients into the decision-making process, it is critical to understand how patients think about the decision, what factors they consider, how well they understand the medical risks and benefits, and what questions they might have about the process.

Statement of Purpose, Hypothesis, Aims

The purpose of this study is to improve our understanding of how patients prioritize different factors when deciding whether or not to accept a kidney when it becomes available for transplant. We first examine the breadth of factors that patients consider, how patients prioritize these factors, and the relationship between patient socio-demographic characteristics and priorities. We also determine how transplant surgeons rank these same factors and subsequently compare patients' and transplant surgeons' priorities.

We hypothesize that patients will prioritize the quality of the donor kidney and the professional opinion of the surgeon, but will also be concerned with medical and psychosocial factors that are specific to their own values and experience. We expect that the relative importance of certain factors will vary based on socio-demographic patient characteristics. Furthermore, we postulate that surgeons will prioritize the factors that contribute to quality of the kidney above factors that affect individual patient preferences.

By elucidating patient preferences, it is our ultimate goal to examine how we can improve patient care by empowering patients to be more involved in the decision-making process.

Materials and Methods

Phase I: The first task was to develop an exhaustive list of factors that patients might consider when deciding whether or not to accept a kidney.

Patient Subjects

After receiving HIC approval, the author was granted access to the kidney transplant waiting list for Yale New Haven Hospital, as well as a list of patients who have recently received transplants. Letters were sent to 40 subjects explaining the purpose of our study, and offering the choice to opt-out of a telephone interview. Patients were purposely sampled to get input from both male and female subjects, and both pre-transplant and post-transplant subjects. We could not sample by age or race as this information was not available. Patients were contacted by telephone within one week after receiving the letters. Three attempts were made to contact each patient. All patient interviews were conducted by the author.

Qualitative Survey

The author conducted in-depth individual qualitative interviews to ascertain which factors patients take into consideration when deciding whether or not to accept a specific kidney. An additional goal was to assess the language that patients *use* as well as the language patients *understand* with regards to kidney transplantation in order to ensure that the list of factors presented to patients was readily understandable as well as technically accurate.

Once contacted, patients were given one of two prompts, depending on whether they were pre-transplant or post-transplant. **Pre transplant:** *Imagine a kidney has become available. Assuming it is of acceptable quality and acceptable match, what factors – either about the kidney or about yourself – would be important to you when deciding whether or not to accept the kidney?* **Post transplant:** *When your kidney became available, what factors were actually important to you – either about the kidney or about yourself – when you were deciding whether or not to accept the kidney?* Additional prompts were used as needed to enable subjects to express their thoughts and opinions.

Interviews were conducted until thematic saturation was reached. Specifically, once the author conducted two interviews that yielded no new data, the surveys were terminated.

List of Factors

The data gathered from patient subjects were added to a Yale checklist used by transplant surgeons (Appendix 1). We modified the medical jargon, and combined technical categories in order to develop a list that was comprehensive and could be easily interpreted by doctors and patients alike. The list was reviewed by four people with complementary expertise: a patient-oriented researcher with expertise in medical decision making (LF), a transplant surgeon (SK), a transplant nephrologist (RF), and the author who conducted the qualitative surveys with patients (DS). The list was pilot tested for comprehension. The final list of factors is provided in Table 2.

Phase II: We quantified the relative importance that patients and surgeons assigned to the comprehensive set of factors derived from Phase I.

Patients

Patient Subjects

Subjects were recruited from the active transplant waiting list for Yale New Haven Hospital (compiled May 2009). Patients who had already received a transplant were excluded because the goal of the study was to critically assess how patients think about the decision that *awaits* them. Patients who had already received a transplant would view the decision from a different perspective with the hindsight knowledge of potential success or complications. Other exclusion criteria included non-English speakers and impaired hearing. The interview could not be completed for 11 subjects because of poor comprehension.

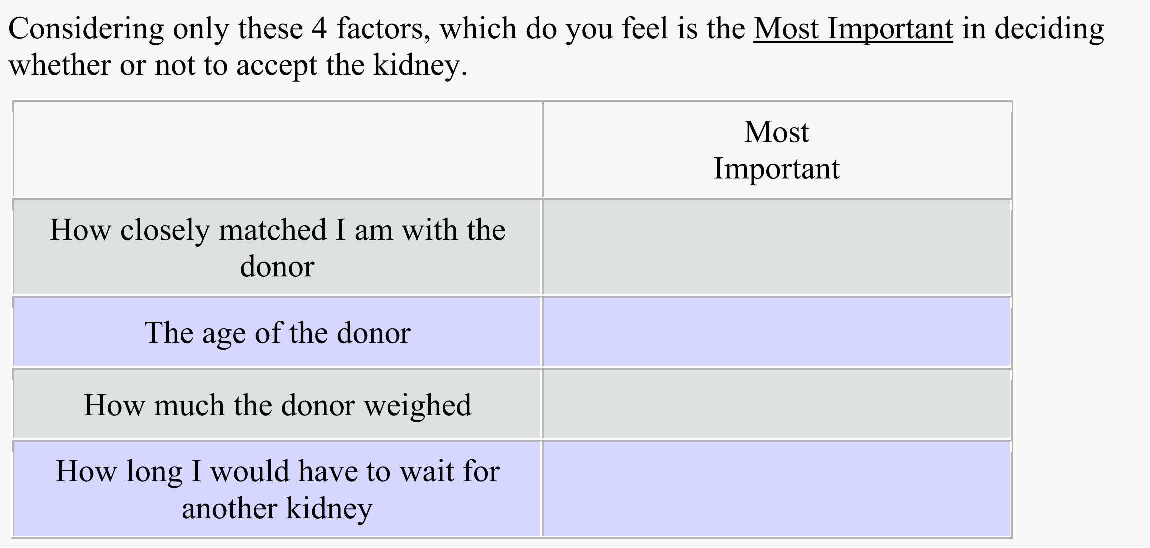
A letter describing the study was sent to all patients with the option to opt-out of the study. Patients were contacted by telephone within one week after receiving the letters. Three attempts were made to contact patients on the list. For subjects who agreed to participate, but could not complete the survey at the given time, an appointment to complete the survey was made. If a patient expressed interest but could not participate immediately, three additional attempts at contact were made. All patient surveys were conducted by the author. At the time of the survey there were 410 patients on the active waiting list, and 370 were contacted.

Data Collection

The survey consisted of a Maximum Differences Scaling (MDS) task and an assessment of patient demographic and clinical characteristics.

MDS is a task that enables subjects to assign a value to a set of factors relevant to a specific decision. Based on random utility theory, MDS was developed as an alternative to rating and ranking tasks by Jordan Louviere in 1987 as an extension of Thurstone's law of comparative judgment (76). The strength of MDS lies in its ability to effectively discriminate between different items (77).

The task asks subjects to choose the best (or the most important) item from a series of sets containing different combinations of items from a master list (see Figure 1). Because the MDS task does not ask subjects to rate any one factor using numbers or a rating scale, there is no concern for scale-related bias. MDS generates ratio data and provides estimates of the *absolute* importance, as well as the *relative* importance, of all included items.



Considering only these 4 factors, which do you feel is the <u>Most Important</u> in deciding whether or not to accept the kidney.

	Most Important
How closely matched I am with the donor	
The age of the donor	
How much the donor weighed	
How long I would have to wait for another kidney	

Figure 1: Example of MDS question in survey

We chose to use MDS because it simplifies the task for the subject, it is well suited to phone interviews, and it is able to incorporate a large group of factors.

The survey was administered by the author in one session, lasting between 10 and 35 minutes. Patients were instructed to use a pen and paper to write down answer choices in order to aid comprehension. After pilot testing with 9 subjects, the survey was reduced from 18 to 14 choice sets due to subject fatigue. No incentive was offered to participants.

After completing the MDS survey, the following patient characteristics were recorded: age, gender, race, employment, education, general health status (on a 5 point scale ranging from excellent to poor), time on waiting list and time on dialysis.

Statistical Analysis

We first report descriptive statistics of the distribution of patient characteristics. We then report the rank order of attributes and the mean (+SD) relative importance of each factor. The mean rating scores are generated using Hierarchical Bayes (HB) analysis (Sawtooth Software© HB module). HB modeling can derive stable scores at the individual level even though each respondent evaluates a fraction of all possible subsets of items. In HB modeling the averages are used to update the individual utilities in a number of iterations until estimates are stabilized. After this convergence, the cycle is run a few thousand more times and the estimates of each iteration are saved and averaged (78,79). The scores were rescaled to sum to 100 to facilitate interpretation. HB programming is built into the MDS software.

We then examine associations between subject characteristics and relative importance ratings using Spearman's correlation coefficient and the Mann Whitney U test for continuous and categorical variables respectively.

The independent variables we examine are: age (continuous variable), education (categorical variable: college education versus no college education), race (categorical variable: white versus non-white), gender, self-reported overall health status (categorical: excellent/very good versus good/fair/poor), and waiting time (continuous variable). The dependent factors we will assess are *kidney quality* (average of relative importances assigned to *'overall kidney quality'* and *function of 'kidney at time of death'*), *'how strongly your surgeon feels you should accept the kidney,' 'the risk of contracting a disease from the donor kidney,'* and *'how difficult it is for you to be matched to a kidney (i.e. whether or not you are sensitized).*

We hypothesized that age and gender would not be associated with a change in relative importance of any factor; that White race would be associated with greater importance of the surgeon's opinion; that good health status would be associated with greater importance of kidney quality and the risk of contracting a disease; and that increased waiting time would be associated with decreased importance of kidney quality.

Finally, we report, verbatim, unsolicited comments from subjects during the interview.

Surgeons

Surgeon Subjects

Surgeon subjects were identified through the American Society of Transplant Surgeons (ASTS). Three attempts were made to contact surgeons on the list. For surgeons who agreed to participate, but could not complete the survey at the given time, an appointment to complete the survey was made. All surgeon surveys were conducted by a collaborating physician (NR).

Data Collection

The survey consisted of a Maximum Differences Scaling task and an assessment of surgeon demographic and practice characteristics. An analogous list of factors for the surgeons was compiled by changing the subject of each factor from "you" to "the patient" appropriately, and by removing the factor '*How strongly my transplant surgeon feels I should accept the kidney'* (Appendix 2).

The MDS survey using the modified list was administered to surgeons in one session, lasting between 8 and 15 minutes depending on the subject. The survey consisted of 18 questions. Subjects were encouraged to use a pen and paper to write down answer choices in order to aid comprehension. No incentive was offered to participants.

After completing the MDS survey, the following surgeon characteristics were recorded: age, gender, race, how long they have been practicing, and whether they work in an academic setting or a private setting. Specific geographic and institutional data was collected from the ASTS website (www.asts.org).

Statistical Analysis

We first report descriptive statistics of the distribution of surgeon characteristics. We then report the rank order of attributes and the mean (+SD) relative importance of each factor, using HB analysis. Finally, we compare the patients' and surgeons' relative importances, by removing the additional factor *'How strongly my transplant surgeon feels you should accept the kidney'* from the patient list and then rescaling the relative importance scores.

Results

Phase I:

Patient Characteristics

A total of 40 patients were contacted by mail: 10 male patients pre-transplant; 10 male patients post-transplant; 10 female patients pre-transplant; 10 female patients post-transplant. Two subjects opted out of the study, 18 could not be reached, 6 declined to participate. Fourteen patients participated in the survey: 6 male patients pre-transplant, 3 male patients post-transplant, 3 female patients pre-transplant, and 2 female patients post-transplant.

List of Factors

Table 1 is a list of criteria that patients found important in the qualitative telephone survey.

Table 1: Factors reported by patients
How closely matched you are to the donor
The overall quality of the kidney
Whether the donor smoked cigarettes
Whether the donor drank excessive alcohol
Whether the donor used drugs
The race or ethnicity of the donor
The general health of the donor
The risk of contracting a disease from the donor kidney
How well you are able to tolerate dialysis
The burden that you feel dialysis puts on your family or your caregivers
How healthy you feel in general when the kidney becomes available
The results of your most recent blood test
How strongly your transplant surgeon feels that you should accept the kidney
Whether or not your family thinks you should accept the kidney
How long you have already been waiting on the waiting list
How long you would have to wait for another kidney if you pass on this one
How long the kidney is expected to last

After addition of several factors from the official Yale transplant checklist, and review with collaborating experts, the final list of factors was developed (Table 2).

Table 2: Final list of factors for patients
The age of the donor
How difficult it is for you to be matched to a kidney (i.e whether or not you are sensitized)
How much the donor weighed
How closely matched you are to the donor
How the donor died
The amount of time the kidney is outside the body before your transplant surgery
The amount of time it would take for the kidney to start working in your body
The overall quality of the kidney
The function of the donor kidney at the time of death
Whether the donor smoked cigarettes
Whether the donor drank excessive alcohol
Whether the donor used drugs
The race or ethnicity of the donor
The general health of the donor
The risk of contracting a disease from the donor kidney
How well you are able to tolerate dialysis
The burden that you feel dialysis puts on your family or your caregivers
How healthy you feel in general when the kidney becomes available
The results of your most recent blood test
How strongly your transplant surgeon feels that you should accept the kidney
Whether or not your family thinks you should accept the kidney
How long you have already been waiting on the waiting list
How long you would have to wait for another kidney if you pass on this one
How long the kidney is expected to last
How old you are

Phase II: Patients

Patient Characteristics

Table 3: Subjects' Characteristics (N=104)

Table 3: Subjects' Characteristics (N=104)

Characteristic	**n(%)**
Age, years (mean +/- SD)	55.2 +/- 12.61
≥ 60 years old	48 (46.2)
< 60 years old	56 (53.8)
Gender	
Male	58 (56)
Female	46 (44)
Race	
White	68 (65.4)
Black	26 (25)
Hispanic	10 (9.6)
Education	
Did not finish high school	11 (10.6)
High School Graduate or GED	52 (50)
College Graduate	41 (39.4)
Employment	
Full Time	28 (26.9)
Retired	25 (24.0)
Disability	35 (33.7)
Perceived Health	
Excellent/Very Good	44 (42.3)
Good/Fair/Poor	60 (57.7)
Time on Waitlist	
≤ 2 years	72 (69.2)
> 2 years	32 (30.8)
Worried about contracting disease from donor kidney?	
No	74 (71.1)
Yes	30 (28.9)

A total of 337 patients were contacted by mail. Four patients opted out before they were contacted for the study. 141 patients could not be reached to complete the survey; 70 patients declined to participate; 7 patients had already been transplanted; 11 patients were excluded for poor comprehension. A total of 104 patients participated in the study.

Patients in the study ranged from age 22 to 79 with a mean (+SD) of 55.2 + 12.6, Mean time on dialysis (+SD) was 3.27 + 4.25 years, and mean time on the waiting list was 2.61 + 2.60 years. Further details regarding patient characteristics are provided in Table 3.

Relative Importance of Factors

Patients' importance scores, ranked from most to least important, are provided in Table 4. Overall kidney quality was the most important to patients. The surgeon's opinion and the risk of contracting a disease both play a significant role in patients' decision making. The only habit of the donor that patients found important was whether the donor used drugs. Despite being raised as a potential factor in Phase I, the donor's race/ethnicity was of no importance to patients relative to other factors.

If we collapse the factors into different categories based on the type of value they represent, we can better conceptualize how patients think about this decision. Different categories of factors are presented in Table 5.

By adding the relative importance scores of factors in each category, we can compare the relative importance of each category for patients (Figure 2). Factors that contribute to the success of the operation were the most important to patients, but patients considered all categories important in the decision making process.

Table 4: Relative Importance of Factors for Patients

Rank	Factor	Scaled Importance Score (+SD)[7]
1	The overall quality of the kidney	9.83 + 0.77
2	The function of the donor kidney at the time of death	9.27 + 1.04
3	How closely matched you are to the donor	8.87 + 1.36
4	How strongly your transplant surgeon feels that you should take the kidney	7.71 + 2.77
5	How long the kidney is expected to last	7.64 + 2.04
6	The risk of contracting a disease from the donor kidney	7.49 + 2.56
7	The general health of the donor	6.80 + 2.17
8	How long you would have to wait for another kidney if you pass on this one	5.35 + 2.61
9	Your ability to tolerate dialysis	4.66 + 3.05
10	How difficult it is for you to be matched to a kidney (i.e whether or not you are sensitized)	4.43 + 3.11
11	How healthy you currently feel in general	4.29 + 2.68
12	Whether the donor used drugs	4.03 + 3.24
13	The amount of time the kidney is outside the body before your transplant surgery	3.62 + 2.04
14	The amount of time it would take the kidney to start working in your body	3.09 + 2.22
15	How long you have already been waiting on the waiting list	2.98 + 2.44
16	The age of the donor	2.86 + 2.37
17	How the donor died	1.62 + 1.92
18	The burden you feel dialysis puts on your family or caregivers	1.54 + 2.40
19	Whether the donor drank excessive alcohol	1.24 + 2.07
20	The results of your most recent blood tests	0.81 + 0.91
21	Whether the donor smoked cigarettes	0.63 + 1.36
22	How old you are	0.59 + 0.92
23	Whether or not your family thinks you should accept the kidney	0.44 + 0.99
24	How much the donor weighed	0.23 + 0.46
25	The race or ethnicity of the donor	0.00 + 0.00

---

[7] The scaled importance score is a relative value score that compares the importance of each factor *relative* to all the others. The total value of importance is set as a constant at 100, thus all scores will sum to 100. The relative importance scores are measures of how important each factor is in the context of all factors.

Table 5: Categories of Factors
Kidney Quality
Overall kidney quality
Function of the donor kidney at time of death
Transplant Outcome/Graft Survival
How closely matched you are to the kidney
How long the kidney is expected to last
The amount of time the kidney is outside the body before your transplant surgery
The amount of time it would take the kidney to start working in your body
Risk of Communicable Disease
Risk of contracting a disease from the donor kidney
Donor Factors
The general health of the donor
Whether the donor drank excessive alcohol
Whether the donor smoked cigarettes
Whether the donor used drugs
How much the donor weighed
The age of the donor
The race or ethnicity of the donor
How the donor died
Patient Factors
How healthy you feel in general
The results of your most recent blood tests
How old you are
Your ability to tolerate dialysis
The burden that you feel dialysis puts on your family or caregivers
Whether or not your family thinks you should accept the kidney
Time to Transplant
How long you would have to wait for another kidney if you pass on this one
How long you have already been waiting on the waiting list
How difficult it is for you to be matched to a donor (ie whether or not you are sensitized)
Surgeon’s Opinion/Advice
How strongly your transplant surgeon feels you should accept the kidney

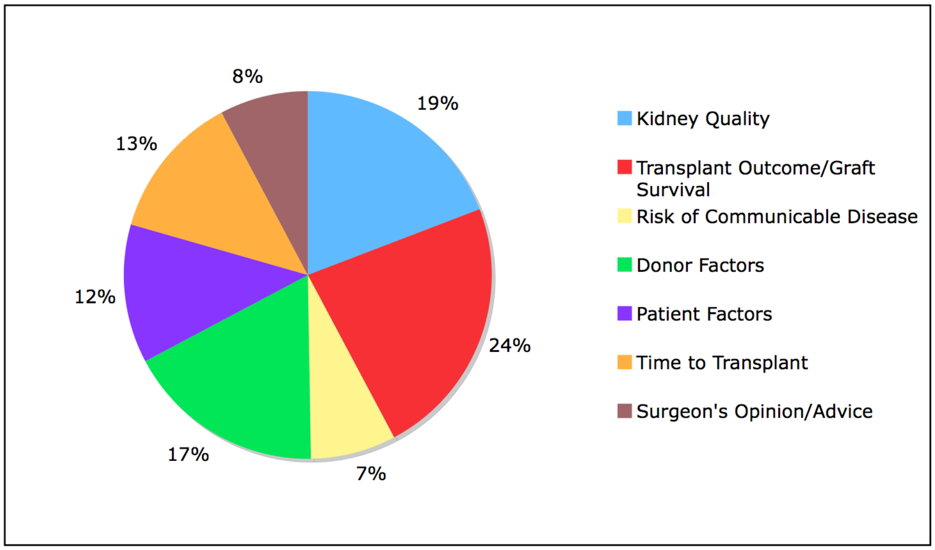


Figure 2: Distribution of relative importance for patients by category

Associations between subject characteristics and relative importance scores

We found no association between race, education, gender or health status, and the relative importance that patients assigned to the quality of the donor kidney, their surgeon’s recommendation, the risk of contracting a disease, or how difficult it is for them to be matched to a kidney (whether they are sensitized). The amount of time patients had been on the waiting list was not associated with importance of the *surgeon’s opinion* or *the risk of contracting disease*, but it *was* associated with importance of *kidney quality*, and importance of *how difficult it is for you to be matched to a kidney* (Table 6). Specifically, waiting time was inversely related to the relative importance assigned to the quality of the kidney, and directly related to how difficult it is to be matched. These associations did not change when we include other demographic factors into the model.

Table 6: Change in relative importance of factors based on waiting time

Factor	**Standardized beta estimate***	**P value**
Kidney Quality	-0.23	0.03
How difficult it is for you to be matched to a kidney	0.28	0.01

*Model contains factor plus age, gender, race, deduction and health status.

Unsolicited comments from respondents

<u>On the surgeon's opinion</u>

Many patients were passionate about the role of the surgeon (doctor) in their decision making process. There was a stark contrast between subjects who think the surgeon's opinion is most important and those who do not value or mistrust the surgeon's opinion.

It all comes down to the doctor. If he thinks it is good enough to offer, then I am going to take it. (subject #14)

If the surgeon recommends I take it, then I wouldn't even question it. (subject #63)

Sometimes I don't trust the doctors. If I say that something is important to me, they have to understand that it is important to me. I had a kidney transplant about 5 years ago, and there were some complications – I started to lose my vision because there were pockets of fluid building up behind my eyes. I can't go blind – I am an engineer. But the doctors didn't listen to me…all they said was 'well at least you have a kidney.' They have to understand that I don't think about it that way […] I think about it so differently, so I have to be in charge of my own decisions.' (subject #42)

<u>On the factor "how healthy you feel, in general, when the kidney becomes available"</u>

Different patients interpreted this factor differently, and chose this factor for different reasons.

If I am not feeling as good, then I wouldn't be so choosy, but if I feel as good as I do right now, I think I would only take the kidney if it was a perfect match. (subject #17)

If I am feeling sick when the kidney is offered to me, I think the surgery would be riskier. I want to be as healthy as possible before I go for my surgery. (subject #89)

<u>On accepting any kidney at all</u>

There were some patients in the study who insisted they would accept any kidney that became available.

I don't care about anything at all. I just want whatever kidney I could get. (subject #2)

I would take any kidney to give me a couple of good years with my grandchildren. I am already pretty old, so I would be satisfied with any good time I could have left. (subject #28)

God will provide it to me. And when God sends me a kidney, I would be a fool to turn that down. (subject #44)

You are talking to the wrong person. If there was a kidney available I would fly halfway around the world to get it. (subject #57)

If a kidney became available, that would be the happiest day of my life. Nothing else would matter except getting to the hospital in time. (subject #67)

I will take any kidney to be free from dialysis. I want to live free. (subject #83)

On turning down a kidney

Aside from the factors on the list, there were other reasons, both personal and philosophical, that patients offered as to why they might turn down a kidney. Some samples are included below.

I turned down a kidney in the past. My first transplant went wrong and I was in the hospital for six and a half months. I couldn't face going through that again, so I turned down a kidney when it was my turn. (subject #1)

I've thought about this very hard – what I would do when I get the phone call. I have decided that one reason I would turn it down would be to give it to a child or someone younger than me. (subject #22)

At some point in my life I will want a kidney transplant, but right now I would not accept any kidney. I am on nocturnal dialysis, which runs for 8 hours each night, and I feel great and rested every morning. My health is excellent[...]I feel perfectly well. Dialysis is just part of my life now, like everything else – I would not risk everything that is going right to get a kidney transplant where everything could go wrong. Surgery, recovery, immunosuppressant medications, rejection – no thank you. I run a large company, and I am there everyday working hard. One day I will be ready for a transplant, but even then I would only do it if it is a 6 point match – my health is too good to take on all that risk, so I would wait for the perfect kidney. (subject #50)

Phase II: Surgeons

Surgeon Characteristics

A total of 171 surgeons were called, 110 could not be reached, and 4 refused to participate in the study. A total of 57 surgeons participated in the study. The mean age (+SD) of the surgeons was 43.4 + 6.9, and they had been practicing for a mean (+SD) of 10.0 + 7.5 years. Fifty-four (94.8%) were male, 41 (71.9%) were White, 2 (3.5%) were Black, and 9 (15.8%) were Asian. Forty-eight (84.2%) worked in an academic setting and 9 (15.8%) worked in a private setting.

Relative Importance of Factors

Surgeons' importance scores, ranked form most to least important, are provided in Table 7. Surgeons were most concerned overall kidney quality and whether or not the patient is sensitized. Of note, the risk of contracting a disease was very important to them Drug use was the only donor habit surgeons found mildly important. Race or ethnicity of the donor was not at all important to the surgeons.

If we collapse the factors into categories as illustrated in Table 5, we can see the relative value of each category for surgeons in Figure 3. Surgeons considered all categories important, with an emphasis on donor factors.

Table 7: Relative Importance of Factors for Surgeons

Rank	Factor	Scaled Importance score
1	The overall quality of the kidney	10.05 + 0.39
2	How difficult it is for the patient to be matched to a kidney (i.e whether or not the patient is sensitized)	9.07 + 1.48
3	The function of the donor kidney at the time of death	8.91 + 1.29
4	The age of the donor	8.47 + 1.37
5	The risk of contracting a disease from the donor kidney	7.71 + 2.84
6	How long the kidney is expected to last	7.29 + 2.05
7	The general health of the donor	7.14 + 2.46
8	The patient's current general health	6.87 + 2.18
9	The amount of time the kidney is outside the body before transplant surgery	6.14 + 2.88
10	How long the patient would have to wait for another kidney if he/she passes on this one	5.40 + 2.54
11	Patient's ability to tolerate dialysis	4.25 + 2.73
12	Whether the donor used drugs	3.44 + 3.26
13	How long the patient has already been waiting on the waiting list	3.24 + 2.27
14	How the donor died	3.09 + 1.95
15	How closely matched the patient is to the donor	2.16 + 2.17
16	The age of the patient	2.12 + 1.11
17	The amount of time it would take the kidney to start working in the patient's body	1.76 + 1.75
18	Whether or not the patient's family thinks he/she should accept the kidney	1.12 + 1.45
19	The results of the patient's most recent blood tests	0.58 + 0.89
20	The burden the patient feels dialysis puts on his/her family or caregivers	0.51 + 1.29
21	How much the donor weighed	0.38 + 0.33
22	Whether the donor smoked cigarettes	0.25 + 0.87
23	The race or ethnicity of the donor	0.04 + 0.05
24	Whether the donor drank excessive alcohol	0.00 + 0.00

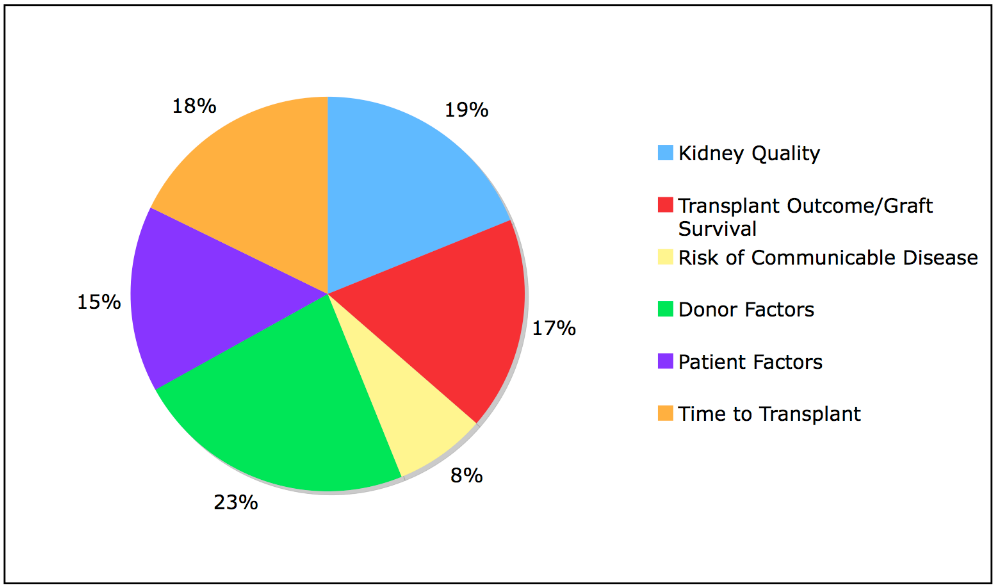


Figure 3: Distribution of relative importance for surgeons, by category

Comparison between patients and surgeons

A comparison between the importance scores for patients (after removal of *How strongly the surgeon feels you should accept the kidney*) and surgeons is depicted in Table 8.

Table 8: Comparison of Relative Importance between Patients and Surgeons

Factor	**Patient Importance Score* + SD (Rank)**	**Surgeon Importance Score* + SD (Rank)**	**p value**
The overall quality of the kidney	5.22 + 0.94 (1)	5.15 + 1.26 (1)	0.84
How difficult it is for the patient to be matched to a kidney (i.e whether or not the patient is sensitized)	0.93 + 1.57 (10)	3.66 + 1.50 (2)	<0.0001
The function of the donor kidney at the time of death	4.01 + 0.98 (2)	3.25 + 0.99 (3)	<0.0001
The risk of contracting a disease from the donor kidney	2.96 + 1.66 (4)	3.05 + 2.21 (4)	0.68
The age of the donor	0.29 + 1.43 (15)	2.71 + 1.06 (5)	<0.0001
How long the kidney is expected to last	2.68 + 1.35 (5)	2.30 + 1.02 (6)	0.06
The general health of the donor	2.19 + 1.09 (6)	2.01 + 1.66 (7)	0.42
The amount of time the kidney is outside the body before transplant surgery	0.76 + 1.08 (12)	1.88 + 1.43 (8)	<0.0001
The patient’s current general health	0.91 + 1.50 (11)	1.80 + 1.30 (9)	<0.0001
How long the patient would have to wait for another kidney if he/she passes on this one	1.58 + 1.51 (7)	1.31 + 1.45 (10)	0.28
Patient’s ability to tolerate dialysis	1.16 + 1.81 (8)	0.65 + 1.41 (11)	0.13
How long the patient has already been waiting on the waiting list	0.31 + 1.42 (13)	0.21 + 1.10 (12)	0.64
How the donor died	-1.25 + 1.14 (17)	0.21 + 1.02 (13)	<0.0001
Whether the donor used drugs	1.13 + 1.68 (9)	-0.07 + 2.11 (14)	<0.0001
The age of the patient	-2.41 + 1.41 (20)	-0.36 + 0.69 (15)	
The amount of time it would take the kidney to start working in the patient’s body	0.29 + 1.20 (14)	-0.75 + 1.21 (16)	<0.0001
How closely matched the patient is to the donor	3.71 + 1.33 (3)	-0.83 + 1.32 (17)	<0.0001
Whether or not the patient’s family thinks he/she should accept the kidney	-2.67 +1.24 (21)	-2.09 + 1.21 (18)	0.001
The results of the patient’s most recent blood tests	-1.56 +0.86 (19)	-2.20 + 0.93 (19)	<0.0001
How much the donor weighed	-3.22 +1.14 (23)	-2.49 + 0.55 (20)	<0.0001
The burden the patient feels dialysis puts on his/her family or caregivers	-1.14 + 1.47 (16)	-2.81 + 1.33 (21)	<0.0001
Whether the donor smoked cigarettes	-4.01+ 2.19 (22)	-3.67 + 0.99 (22)	0.005
Whether the donor drank excessive alcohol	-1.54 + 1.56 (18)	-6.43 + 0.43 (23)	<0.0001
The race or ethnicity of the donor	-10.33 +0.45 (24)	-6.48 + 0.81 (24)	<0.0001

*These are mean raw scores, not rescaled to 100

In general, the patient and surgeon rankings were strikingly similar, from top to bottom. They share five of the first seven factors in common, and seven of the last eight. Both patients and surgeons thought *kidney quality* was most important, and gave statistically comparable importance to that factor (p=0.84). Patients and surgeons both gave the same high value to the *risk of contracting a disease from the donor kidney* (p=0.68). Neither patients nor surgeons gave value to the race of the donor, or to the drinking or smoking habits of the donor. Overall, patients and doctors seem to be concerned with the same factors, and they seem to consider the same factors unimportant.

Though the similarities between doctors and patients were many, there were also several factors to which surgeons and patients gave different value. We will highlight a few important differences to note. Surgeons were more concerned than patients about the *age of the donor*: fifth most important with importance score 2.71 versus 15th most important with importance score 0.29 (p<0.0001). Surgeons gave more importance to *how difficult it is for a patient to be matched to a kidney (ie whether or not the patient is sensitized)*: second most important, with importance score 3.66 versus 10th most important with relative importance of 0.93 (p<0.0001). Finally, patients gave more importance to *how closely you are matched*: third most important with relative importance of 3.71 versus 17th most important with importance score -0.83 (p<0.0001).

Discussion

In this pilot study, we used Maximum Differences Scaling to measure the different factors patients and surgeons consider when deciding whether or not to accept a kidney transplant. This is the first study, to our knowledge, that explores the patient's perspective of this unique decision.

We found that patients were most concerned with kidney quality and factors that affect transplant outcome or graft survival. Our quantitative data show that the surgeon's opinion was very important to patients in general, but there were patients who expressed mistrust in doctors and preferred to be the primary decision maker. Our hypotheses that variations in patient demographics would be associated with changes in the importance of different factors were largely disproved; only increased time on the waiting list was associated with significant changes in factor importance. Furthermore, we found that surgeons value similar factors to patients, with kidney quality being the most important.

Discussion of patient preferences

One aim of the present study was to examine potential associations between patient characteristics and the importance of different factors. Previous studies of patient perspectives of treatment decisions have shown variation in preferences based on age, socioeconomic status and education (80). One prior study on disparity of access to kidney transplantation found that patients' treatment preferences and outcome expectations differed by race with Black patients significantly less likely than White patients to want a transplant, and less likely to be certain of that preference (81).

In our study, we found *no* association between race, education, age or gender and how patients ranked any of the factors. This is encouraging for two reasons. First, it is a good measure of quality control, as it suggests the survey design, format and length were equally accessible to subjects regardless of their demographic characteristics or level of education. It supports the validity of this study, and it reinforces the concept that MDS can be used effectively for investigational or educational purposes (77). Second, while we are sensitive to the importance of individual patient variability, there were no conflicting preferences of different patient subgroups. Thus, a common approach to care and education can be used for all patients.

Time on the waiting list was associated with two notable changes in relative importance of different factors. First, increased waiting time was independently associated with decreased importance of *kidney quality*. In other words, the longer patients were waiting, the less they cared about the quality of the kidney they receive. A previous study has shown that both physical and mental quality of life decline over time on dialysis (82). As quality of life declines, patients likely become more anxious for change and would favor the risk of transplantation with a lower quality kidney. Further, patients who wait longer might tire of dialysis and the waiting process and become more willing to accept any kidney regardless of quality.

Increased waiting time was also associated with a greater importance of *How difficult it is for you to be matched to a kidney (ie whether or not you are sensitized)*. We suspect, in this case, that increased time on the waiting list is acting as a marker for patients who are actually sensitized. Patients who are sensitized have a longer mean waiting time, because it is more difficult for them to find an appropriate match (60), and are far more likely to value this factor because they understand its implications on their chance of being offered a kidney. In order to test this hypothesis, we would have to collect subject calculated panel reactive antibody (CPRA) percent.[8]

Given that older patients make up most of the population on the extended-criteria donor list, it is interesting to note that increased age was not associated with a decreased importance of kidney quality in our study.[9] One potential explanation for why this

---

[8] Recall, CPRA is a measure of the percentage of the general population that a potential recipient makes antibodies (is sensitized) against. For patients who have a CPRA > 80% it is extremely difficult to find a suitable donor, and thus patients are given an advantage for a given suitable kidney.

[9] Expanded-criteria donor (ECD) kidneys are distinguished by greater donor age, lower baseline kidney function, and presence of donor comorbidities including cardiovascular disease and hypertension and have a higher probability of graft failure. Most of the patients on the ECD list are older than 60-years-old or

discrepancy was not elucidated lies in our study is that the survey assessed relative value of factors. While older patients may be willing to take a lower quality kidney, it was still more important than any other factor on the list. As opposed to increased waiting time where the importance of other factors increased as the importance of kidney quality decreased, there were no other factors more important for older subjects, so its *relative* value remained constant.

Patients who would accept any kidney

Some respondents insisted they would accept any kidney that becomes available, as evidenced by comments during the surveys. These patients believe that remaining on dialysis is not an acceptable option. The most common explanation patients offered for this view was the overwhelming burden of dialysis, but other reasons included religious beliefs, and advanced stage of life. One previous study of women with early stage breast cancer showed that many patients do not acknowledge “doing nothing” as a real option (83). We suspect that some patients might similarly equate refusing the kidney with “doing nothing,” which could devalue the option to stay on dialysis.

Understanding that some patients do not perceive this to be a real decision is significant for two reasons. First, while such patients may still value some factors more highly than others, quantitative analysis on the relative importance of the different factors is relevant only in the context of a real decision with two or more acceptable choices. The MDS task is only pertinent if preferences actually inform the subjects’ ultimate decisions – i.e. if the subjects are *willing* to make trade-offs. Second, this finding emphasizes the importance of the physician’s educational role at the beginning of the

---

diabetics greater than 40-years-old, and thus there is strong evidence to suggest older patients will accept lower quality kidneys.

care-providing relationship. Patients must be armed with the knowledge to understand the *real* nature of the decision so they can properly grapple with the choices from a personal standpoint.

Surgeon Preferences

The vast majority of the surgeon subjects were white males, consistent with the demographics of transplant surgeons in general. Given the homogeneity of our sample, we did not have enough respondents to parse out variations in relative importance based on race, age or gender. That being said, the general profile of surgeons is changing with more women and more minorities entering the field. It will be interesting to see if preferences and practice differ across demographics as the population of transplant surgeons becomes more diverse.

Comparison of Patients and Surgeons

Similarities between patients and surgeons

It is worth emphasizing the significant overlap between the factors the surgeons and patients considered important. This suggests either that patients and surgeons value similar factors at baseline, or that there already exists good communication between care providers and patients with regards to medical risks and benefits as well as patient preferences. The notion that doctors and patients seem to consider the same types of factors important is encouraging because it indicates that there is common ground on which to build educational materials such as decision aids to streamline communication.

It is particularly interesting to note that both patients and surgeons are very concerned with the risk of contracting a disease from the donor kidney, even though, with current screening methods, the risk is extremely low – estimates for contracting a disease from a donor kidney range from low risk at 1:315,000 to high risk at 1:10,000 (84). This finding is likely due to patients' and surgeons' heightened perception of risk in the context of decisional power. A study from the core decision-making literature demonstrated that increased perception of control, defined as 'command over outcome,' is associated with a decreased perception of risk, whereas increased perception of volition, defined as 'command over exposure to risk itself,' is associated with increased perception of risk (85). Applied to our study, this concept suggests that transplant surgeons would underestimate intra-operative risks they can control, such as bleeding or damage to a surrounding organ, and overestimate the risks to which they willingly expose the patient that they cannot control, such as the risk of contracting a disease.

A recent study, looking at patient responsibility in decision-making, builds on the concept of perceived risk to show that greater responsibility over decision-making may decrease the likelihood of patients' willingness to accept risky procedures (26). In the present study, although the risk of contracting a disease is very low, patients are highly sensitive to the risk when they bear decision-making responsibility.

The perception of disease transmission is paramount to both patients and doctors alike. Our findings illustrate the importance for surgeons to be aware of their own perspectives and biases, and the demand for patient education about risk of disease transmission.

Differences between patients and surgeons

Although patients and surgeons significantly overlap in their priorities, sharing five of the top seven factors, there were several noteworthy differences. First, transplant surgeons are much more concerned than patients about the age of the donor. It has been well established that kidneys from donors greater than 56 years old have a significantly decreased graft survival at 1 and 2 years post transplant. Because this is likely due to decreased functional reserve at the time of transplant, increased donor age is a predictor for decreased graft survival (72,86,87). While surgeons are familiar with the current literature on importance of donor age, patients might have attached less importance because they did not view age of donor as a marker of quality.

The next notable difference is that doctors give greater importance to *how difficult it is for a patient to be matched to a kidney (i.e. whether or not the patient is sensitized)*. The difference may be explained as follows. All surgeons understand the concept of sensitization and the difficulty for sensitized patients to find a proper match. They further know that the UNOS allocation policy gives preference to sensitized patients. This uniform understanding is evidenced by the consistency with which surgeons favored this answer, reflected in the small standard deviation of relative importance, 1.48. In contrast, patient understanding of this concept varied. While patients who are sensitized are likely to understand the implications of sensitization on the chances of finding a suitable donor, those who are not sensitized are less likely to be aware of this concept and to use it in their decision-making. This disparity is reflected in the large standard deviation of relative importance, 3.11, which suggests there was a broad distribution of importance scores for this factor. This is an example of the evaluability hypothesis, that predicts one factor might be undervalued because it is more difficult to evaluate, or is less accessible to the subject (88).

A third important distinction is that patients valued *how closely you are matched to the donor* much greater than surgeons. This discrepancy likely indicates patients' belief that proximity of match is a predictor of transplant outcome or risk of rejection. While there is a substantial graft survival benefit for zero-antigen and one-antigen mismatched kidneys (71), there is only a minimal survival difference associated with a small change in proximity of match thereafter. One study showed that mean graft survival of 1-4 antigen mismatch (9.6 years) was only slightly greater than mean survival of 5-6 antigen mismatch (8.6 years) (72). Surgeons would likely prefer a fully matched transplant, but they found *degree* of match less important.

These differences between patients and surgeons point to important areas for further patient education.

Understanding the Patient Perspective

As we try to define discrete factors that patients take into account, it is important to question how patients *actually* make decisions. Decision-making and preferences are deeply rooted in broader concepts of health, illness and disease as well as transient emotional states.

We each view our choices from the perspective of our individual frames of reference. Let us consider the factor, "*How healthy you feel, in general, when the kidney becomes available.*" As evidenced by patient reflections during the survey, patients interpret this choice differently. Some patients would be *less* likely to accept the kidney if they are feeling well because they would rather stay the course in their current state than undergo a procedure that entails its own risks and complications. Other patients would be *more* likely to accept the kidney if they are feeling well, under the assumption that surgery would be riskier if they have another, transient illness at the time of transplant.

On the surface, these are simply two different, equally rational, interpretations of the given factor, *how healthy you feel, in general*. If we dig deeper and explore the meaning of these interpretations, the disparity seems to stem from a fundamental difference in patients' perceptions of their chronic renal failure. The patients in the first group understand *how healthy you feel* to define their present location on the overarching course of their kidney disease. At one point, renal failure may have a minimal, acceptable effect on the patient's health; at another, the burden of disease may be unacceptable. Patients in the second group understand *how healthy you feel* to define presence or absence of an illness separate from their chronic kidney disease. This understanding of the term 'healthy' is *independent* from the underlying illness. For these patients, chronic renal failure is intrinsically unacceptable and does not contribute to their conception of *how healthy you feel* in the moment. If we follow this example through to the point where the patient must choose whether or not to accept a kidney that has become available, we see that the final decision may be driven as much by this personal abstraction of health as by discrete factors about the donor or the kidney. This is a concrete example of how preferences are formed in the context of our individual frames of reference, and are intimately embedded in our definitions of health, disease and illness.

Furthermore, patients are likely overwhelmed by emotion – excitement, fear, hope – when they are offered a kidney and these emotions may be more operative in their thinking than discrete objective factors. While patients may objectively evaluate factors in the context of our survey, it is difficult to recreate the emotional charge of the actual decision.

Even if there are broader forces that drive patient decision-making, there is still a great deal to learn from our study of discrete factors, as we should encourage decisions made upon objective values rather than subjective emotional states. Patients are more likely to be satisfied with their decision and less likely to regret the decision if it is reasoned through rationally. By elucidating the factors patients deem important, we are able to understand what is important to patients *before* the decision point, and we can thus prepare them better to make a sound decision. If we address these discrete, objective factors in the planning stages through educational tools or extra sessions with a patient advocate or educator, we can prepare patients to make an informed decision driven by established values rather than transient emotions.

Strengths

The strength of our study is the use of Maximum Differences Scaling. The two most common approaches to prioritizing factors are ranking analysis and rating scales, and we submit that MDS is preferable to both these techniques for the purpose of our study. Ranking tasks are limited by the number of factors subjects can keep in mind, whereas MDS is able to handle an exhaustive list of factors. MDS also has several important advantages over rating scales in the context of our study:

- The question format is easy to understand, and respondents from diverse socio-demographic backgrounds have been shown to be able to provide reliable data.
- It demonstrates greater discrimination among items and is better able to discriminate between segments of the study population. Thus, MDS produces more accurate estimates of individual as well as group-level preferences.

- Because each task generates more information about respondents' preferences, MDS is more efficient than rating scales.
- Scale-related response bias is not a concern because respondents make choices instead of indicating their preference using rating scales. This is an extremely valuable property for cross-cultural research studies, where subjects across different cultures may systematically differ in the way they use rating scales.

Limitations

The greatest limitation of this study is the small sample size of subjects, both patients and surgeons. The small number of subjects makes it difficult to determine differences between subject groups, and the low response rate limits the generalizability of our findings.

Future Directions

Development of Decision Aid

In keeping with the objective to empower patient involvement in the decision-making process, we recommend the development of a standardized decision aid that would be introduced to patients as soon as they are placed on the transplant waiting list. Such an educational tool would provide information and guidance to help patients better understand the nature of the decision, and enable them to think critically about their choices. Preparing transplant candidates with this information early in the process would allow patients to consider the weighty risks and benefits over time, and empower them to ask questions before a kidney becomes available. Our study shows that patients awaiting transplant do not differ based on demographic characteristics, and thus a standardized decision aid would be appropriate for all transplant candidates. While each patient's needs must certainly be addressed individually, information tools can be developed to meet the general needs of the transplant population. This resource would improve patients' funds of knowledge and enrich communication with physicians.

MDS could be used as the model for a decision-task because it is simple for patients to use, and it would introduce patients to the factors they should think about and discuss with their doctors. This model would provide a framework for patients to get involved in making an informed decision.

Research Question: Preemptive Kidney Transplant

We interviewed a subset of subjects who are on the transplant waiting list but are *not* on dialysis. This is consistent with a trend in kidney transplantation called "preemptive kidney transplantation." The concept is that the patients with kidney failure are placed on the transplant waiting list before they reach end stage disease, so they can receive a transplant before requiring dialysis. This is an attractive option for many patients as it avoids the morbidity of dialysis and dialysis-related procedures such as fistula placement (89). Patients would not have to cut back from their employment to take on dialysis, and the overall cost to the patient of managing the kidney disease would be decreased. Furthermore, studies have found that preemptive transplant may decrease the rate of delayed graft function and improve patient and graft survival (90,91). This is a strategy that is being implemented more commonly in an effort to improve patient quality of life, as well as health outcomes, and is championed by some as the optimal mode of renal replacement therapy (92).

Despite the benefits of this treatment model, there are also theoretical detriments. First, in a field where there is already a limit on resources, giving kidneys to patients before the need for dialysis would mark a failure to maximize native kidney function. Further, studies have shown that there is a slightly higher rejection risk in preemptive transplant recipients, possibly because they lack the immunosuppressive effects of uremia, which could help prevent early rejection (89).

Wide-spread adoption of preemptive transplantation strategy also raises several ethical issues. First, patients who are already waiting on dialysis waiting would be disadvantaged because they would be part of a much larger pool, and thus more likely to be competing for kidneys with more people with the same HLA-genotype (92). Second, a study of prevalence of preemptive transplant showed that race, ethnicity and education are all independently associated with preemptive transplantation, suggesting this practice currently puts some patients at a disadvantage, and contributes to existing transplant disparity (89).

With regards to the present study, the practice of preemptive transplant raises interesting questions about decision-making. Instead of choosing between accepting the kidney versus staying on dialysis, the patients must decide whether to take the kidney now, versus taking the chance that another kidney will become available before they require dialysis. If a match comes up relatively quickly, or the patient’s kidney function declines very slowly, it is conceivable that a kidney would be available for transplant before it is medically necessary, or even before the patient feels unwell. An interesting follow up study, given the increasing popularity of preemptive transplants, would be to compare the relative importance of factors for patients already on dialysis against those of patients who are attempting to avoid dialysis altogether.

Conclusion

In an effort to understand how patients make difficult medical decisions, and to define the appropriate role of the physician in the decision-making process, I drew several personal conclusions from this study.

As I was working on this project, aimed at examining and defining patient preferences, I gained an appreciation for the complex nature of preferences themselves. They are shaped by contextual factors such as culture, upbringing and education, and they reflect distinct personal characteristics such as values and beliefs. On a deeper level, however, they are embedded in our emotions and our personal concept of health and illness.

So how does this developing concept of patient preferences inform my own understanding of shared decision-making? First, it emphasizes the power of the relationship and communication between doctors and patients. It heightens the goal of providing a safe environment for patients to ask questions and to express and explore their own perspectives, values and understandings. Doctors have the incredible power, owing to their knowledge and perspective, to guide patients along in their thinking, to challenge patients to reflect on their preferences, and to empower patients to make informed decisions.

Second, it highlights, for me, the inherent value of the *process* of asking questions about patient preferences. My goal in caring for patients as a future physician is to relieve suffering through mindful, patient-centered care. The act of thinking about how to empower patients, or how to define patient preferences, or how to understand patient perceptions, naturally brings the patient into the focus of medical care. While the task of understanding the patient's perspective through the lens of each individual's world-view may be impossible, by asking these questions we may be able to do better. More importantly, perhaps, by searching for answers to these questions, we can more clearly define our own values and priorities, and reinforce our commitment to serving others to the best of our ability.

Appendix 1

Data used by transplant surgeons at Yale University to define suitability of kidney.

- Age
- BMI
- Immunological compatibility
  - ABO
  - Tcell CDC crossmatch
  - Bcell CDC crossmatch
  - Tcell Flow crossmatch
  - Bcell Flow crossmatch
  - Presence of donor specific antibody
  - Recipient PRA
- Cause of Death
- Mechanism of injury
- Extended donor kidney
- Donor after cardiac death
- Anticipated total cold ischemia time
- Cardiac arrest/downtime
- CPR administered
- Kidney Pump Parameters if applicable
  - Resistance
  - Flow
  - Pressure
- Kidney Biopsy
  - % Glomerulosclerosis
  - Interstitial fibrosis (1+ to 4+)
  - Tubular atrophy (1+ to 4+)
  - Vessel hyalinosis (1+ to 4+)
- Kidney Anatomy
  - Aortic/renal artery disease
  - Renal mass NOS
  - Complex arterial/venous anatomy
  - Lower pole artery not reconstructable
- Social History
- CDC risk profile
- Creatinine
- Urine output
- Urine analysis
  - Presence of Hematuria
  - Presence of Proteinuia
  - Presence of Myoglobinuria
- Serologies
  - Anti-HBcAb

- Anti-HCV
- Anti-HIV I/II
- Anti-HTLV I/II
- HBsAg
- Anti-CMV
- RPR/VDRL

Medical History

- History of Diabetes
- History of Kidney Stones or other Kidney Diseases
- History of Hypertension
- History of Coronary Artery Disease
- History of Peripheral Vascular Disease
- History of Malignancy
- History of Surgeries
- Gastrointestinal disease
- Cigarette use (>20 pack years)
- Heay alcohol use (2+ drinks/day)
- IV drug use

Vital Signs

- Significant hypotension
- Urine output
- Hypoxia
- Core Body Temperature
- Use of Vasopressor Agents

Appendix 2

Factors for Surgeons
The age of the donor
How difficult it is for the patient to be matched to a kidney (i.e whether or not the patient is sensitized)
How much the donor weighed
How closely matched the patient is to the donor
How the donor died
The amount of time the kidney is outside the body before your transplant surgery
The amount of time it would take for the kidney to start working in the patient's body
The overall quality of the kidney
The function of the donor kidney at the time of death
Whether the donor smoked cigarettes
Whether the donor drank excessive alcohol
Whether the donor used drugs
The race or ethnicity of the donor
The general health of the donor
The risk of contracting a disease from the donor kidney
The patient's ability to tolerate dialysis
The burden the patient feels dialysis puts on his/her family or caregivers
How healthy the patient currently feels in general
The results of the patient's most recent blood test
Whether or not the patient's family thinks he/she should accept the kidney
How long the patient has already been waiting on the waiting list
How long the patient would have to wait for another kidney if he/she passes on this one
How long the kidney is expected to last
How old the patient is

References

1. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA.* 1992;267(16):2221-2226

2. Balint M. *The doctor, the patient and His Illness*, London: Tavistock 1957.

3. Engel G. The need for a new medical model: a challenge for biomedicine. *Science.* 1977;196:129–136.

4. Ellwood, P. A technology of patient experience. New England Journal of Medicine, 1988. 318:1549-1556

5. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision making model. Social Science & Medicine 49 (1999) 651-661

6. Eddy DM. Anatomy of a decision. JAMA 1990 263. 441-443

7. Levine MN, Gafni A, Markham B et al. A bedside decision instrument to elicit a patient's preference concerning adjuvant chemotherapy for breast cancer. Annals of Internal Medicine 1992. 117 53-58.

8. Chassin MR, Brook RH, Park RE. Variation in the use of medical and surgical services by the Medicare population. New England Journal of Medicine 1986. 314: 285-290.

9. Chassin MR, Kosecoff J, Park RE et al. Does inappropriate use explain geographic variations in the use of health care services? JAMA 1987. 258: 25333-2537

10. Roos NL, Wennberg JE. Using diagnosis-related groups for studying variations in hospital admissions. Health Care Financing Review 1988. 9: 53-62

11. Berwick DM. Health services research and quality of care: assignments for the 1990's. Medical Care 1989. 27: 763-771

12. Wennberg JE. Better policy to promote the evaluative clinical sciences. Quality Assurance in Health Care 1990. 2: 21-29

13. Suarez-Almazor ME, Conner-Spady B, Kendall CJ, Russell AS, Skeith K. Lack of Congruence in the Ratings of Patients' Health Status by Patients and Their Physicians. Med Decis Making 2001;21:113-21.

14. Cotler SJ, Patil R, McNutt RA, al. e. Patients' values for health states associated with hepatitis C and physicians' estimates of those values. Am J Gastroenterol 2001;96:2730-

36.

15. Katz SJ, Charles C, Lomas J, Welch HG. Shooting inward as the circle closes. Journal of Health Politics, Policy and Law 1997. 22 (6): 1413-1431

16. Deber R. Physicians in heallthcare management: 7. The patient-physician partnership: changing roles and the desire for information. Canadian Medical Association Journal 1994. 151, 171-177

17. Llewellyn-Thomas HA. Patient's health –care decision making: a framework for descriptive and experimental investigations. Medical Decision Making 1995. 15: 101-106.

18. Coulter A. Partnerships with patients: the pros and cons of shared clinical decision-making. Journal of Health Services Research and Policy 1997. 2:112-121

19. Charles C, Demaio S. Lay participation in health-care decision-making – a conceptual framework. Journal of Health Politics, Policy and Law. 1993; 18(4):881-904

20. Beauchamp TL, Childress JF. Principles of Bioethics: Sixth Edition. New York: Oxford Press, 2008

21. Nelson G, Lord J, Ochocka J. Shifting the paradigm in community health: towards empowerment and community. Buffalo: University of Toronto Press. 2001

22. Stewart MA, Effective physician-patient communication and health outcomes: A review. Canadian Medical Association Journal. 1995; 152(9) 1423-1433

23. Fraenkel L, McGraw S. What are the essential elements to enable patient participation in medical decision making? Journal of General Internal Medicine. 2007; 22:614-619.

24. Kahneman D, Tversky A. Prospect theory: an analysis of decision under risk. Econometrica. 1979; 47(2): 263-291

25. Aurbach SM, Penberthy AR, Kiesler DJ. Opportunity for control, interpersonal impacts and adjustment to a long-term invasive health care procedure. Journal of Behavioral Medicine. 2004; 27(1): 11-29

26. Fraenkel L, Peters E. Patient responsibility for medical decision making and risky treatment options. Arthritis Care & Research. 2009;61(12):1674-1676

27. Deber RB, Kraetschmer N, Irvine J. What role do patients wish to play in treatment decision making? Archives of Internal Medicine. 1996; 156(13): 1414-1420

28. Kievit J, Nooij MA, Stiggelbout AM. Stability of patients' preferences for chemotherapy: the impact of experience. Medical Decision Making. 2001:21(4) 295-306

29. Adams JR, Drake RE. Shared decision-making as evidence-based practice. Community Mental Health Journal, Vol 42, No 1, Febraury 2006.

30. Whitney SN. A new model of medical decisions: exploring the limits of shared decision making. Medical Decision Making 2003; 23; 275

31. McNutt RA. Shared Medical Decision Making: Problems, Process, Progress. JAMA 2004; 292(20): 2516-2518

32. Whitney SN, McGuire AL, McCullough LB. A typology of shared decision making, informed consent and simple consent. Annals of Internal Medicine. 2003: 140; 54-59.

33. Williams S, Calnan M. The 'limits' of medicalization? Modern medicine and the lay populace in 'late' modernity. Social Science & Medicine 1996. 52: 1609-1620.

34. Parsons T, Atkinson P. Lay constructions of genetic risk. Sociology of Health and Illness. 1992 14: 437-455

35. Fraenkel L, McGraw S. Participation in medical decision-making: the patients' perspective. Medical Decision Making. 2007; 27: 533-538

36. Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making: a national study of public preferences. Journal of General Internal Medicine. 2005: 20: 531-535

37. Kiesler DJ, Aurbach SM. Optimal matches of patient preferences for information, decision-making and interpersonal behavior: evidence, models and interventions. Patient Education Counsel. 2006; 61:319-341

38. Say RE, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: a narrative review. Patient Education Counsel. 2006; 60:102-114

39. Strull WM, Lo B, Charles B. Do patients want to participate in medical decision-making? JAMA. 1984; 252: 2990-2994

40. Waterworth S, Luker K. Reluctant collaborators: do patients want to be involved in decisions concerning care? Journal of Advanced Nursing. 1990; 15: 423-427

41. Deber R. Physicians in health care management: 8. The patient-physician partnership: Decision-making, problem solving and the desire to participate. Canadian Medical Association Journal 1994. 151, 423-427

42. Schneider CE. The practice of autonomy: patients, doctors, and medical decisions. Oxford University Press: New York 1998. pp47-108

43. Greenfield S, Kaplan S, Ware JE Jr. Expanding patient involvement in care. Effects on patient outcomes. Annals of Internal Medicine. 1985; 102:520-528

44. Greenfield S, Kaplan S, Ware JE Jr, Yano EM, Frank HJ. Patients' participation in medical care: Effects on blood sugar control and quality of life in diabetes. Journal of General Internal Medicine. 1998; 3(5):448-457

45. Ward MM, Sundaramurthy S, Lotstein D, Bush TM, Neuwelt CM Street RJ. Participatory patient-physician communication and morbidity in patients with systemic lupus erythematosus. Arthritis Rheumatology. 2003; 49:810-818

46. Gattellari M, Butow PN, Tattersall MH. Sharing decisions in cancer care. Social Science & Medicine. 2001; 52:1865-1878

47. Keating NL, Guadagnoli E, Landrum MB, Borbas C, Weeks JC. Treatment decision making in early-stage breast cancer: should surgeons match patients' desire level of involvement. Journal of Clinical Oncology. 2002; 20:1473-1479

48. Bilodeau BA, Degener LF. Information needs, sources of information and decisional roles in women with breast cancer. Oncology Nursing Forum. 1996;23:691-696

49. Joos SK, Hickman DH, Gordon GH, Baker LH. Effects of a physician communication intervention of patient care outcomes. Journal of General Internal Medicine. 1996;11(3):147-155

50. Barry MJ, Fowler FJ, Mulley AG et al. Patient reactions to a program designed to facilitate patient participation in treatment decisions for benign prostatic hyperplasia. Medical Care. 1995; 33:771-782

51. O'Connor AM, Tugwell P, Wells G. Testing a portable self-administered, decision aid for post-menopausal women considering long-term hormone replacement therapy (HRT) to prevent osteoporosis and heart disease. Medical Decision Making. 1994;14:414-438

52. Estabrooks C, Goel V, Thiel E, Pinfold P, Sawka C, Williams I. Decision Aids: Are they worth it? A systematic review. Journal of Health Services Research & Policy. 2001;6(3):170-182

53. O'Connor AM, Stacey D, Entwistle V, Llewellyn-Thomas H, Holmes-Rovner M et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database of Systematic Reviews. 2003:1,1

54. Adelsward V, Sachs L. The meaning of 6.8: numeracy and normality in health information talks. Social Science & Medicine. 1996;43:1179-1187

55. Guadagnoli E, Ward P. Patient participation in decision-making. Social Science & Medicine. 1998;47:329-339

56. UNOS. UNet database 2009. www.unos.org/data, information and data accessed on December 30, 2009.

57. Gutmann T, Land W. The ethics of organ allocation: the state of the debate. Transplantation Reviews. 1997;11(4)191-207

58. Stegall MD. The development of kidney allocation policy. American Journal of Kidney Diseases. 2005;46(5):974-975

59. UNOS. Organ Distribution: Allocation of Deceased Kidneys, 2008. www.unos.org/resources, information and data accessed on December 30, 2009.

60. Remuzzi G, Chiaramonte S, Perico N, Ronco C. Humoral Immunity in kidney transplantation: what clinicians need to know. Contrb Nephrol. Basel, Karger, 2009, vol 162 pp 27-34

61. Cecka, JM. Calculated PRA (CPRA): the new measure of sensitization for transplant candidates. American Journal of Transplantation. 2010;10:26-29

62. Alagoz O, Schaefer AJ, Roberts MS. Optimizing organ allocation and acceptance. Handbook of Optimization in Medicine. 2009: pp.1-24

63. Quiroga I, McShane P, Koo D, Gray D et al. Major effects of delayed graft function and cold ischaemia time on renal allograft survival. Nephrology Dialysis Transplantation. 2006; 21:1689-1696

64. Irshad A, Ackerman S, Sosnouski D, Anis M et al. A review of sonographic evaluation of renal transplant complications. Current Problems in Diagnostic Radiology. 2008;37(2):67-79

65. Personal correspondence with Sanjay Kulkarni M.D. Yale University Division of Transplant Surgery

66. Wolfe RA, Ashby VB, Milford EL, Ojo AO, et al. Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. New England Journal of Medicine. 1999;341(23):1725-1730

67. Meier-Kriesche HU, Kaplan B. Waiting time on dialysis as the strongest modifiable risk factor for renal transplant outcomes. Transplantation. 2002;74(10):1377-1381

68. Laupacis A, Keown P, Pus N, Krueger H et al. A study of the quality of life and cost utility of renal transplantation. Kidney International. 1996;50:235-242

69. Massy ZA, Guijarro C, Wiederkehr MR, Ma JZ, Kasiske BL. Chronic renal allograft rejection: immunologic and nonimmunologic risk factors. Kidney International. 1996:49;518-524

70. Wolfe RA, McCullough KP, Schaubel DE, Kalbfleisch JD, Murray S et al. Calculating life years from transplant (LYFT): methods for kidney and kidney-pancreas candidates. American Journal of Transplantation. 2008; 8(part 2): 997-1011

71. Held PJ, Kahan BD, Hunsicker LG, Liska D et al. The impact of HLA mismatches on the survival of first cadaveric kidney transplants. New England Journal of Medicine. 1994;331(12):765-770

72. Cecka JM. Kidney Transplant in the United States. Clinical Transplant 2008: 1-18

73. Howard DH. Why do transplant surgeons turn down organs? A model of the accept/reject decision. Journal of Health Economics. 2002;21:957-969

74. Levy A. A decision-rule for transplanting non-cadaveric organs. European Journal of Operational Research. 2005;164:548-554

75. Ahn JH, Hornberger JC. Involving patients in the cadaveric kidney transplant allocation process: a decision theoretic perspective. Management Science. 1996;42(5):629-641.

76. Louviere J. The best-worst or maximum difference measurement model: Applications to behavioral research in marketing. The American Marketing Association's Behavioral Research Conference Phoenix, Arizona 1993.

77. Flynn T, Louviere J, Peters T, Coast J. Estimating preferences for a dermatology consultation using Best-Worst Scaling: Comparison of various methods of analysis. BMC Med Res Methodology 2008;8:76-88.

78. Understanding HB: An intuitive approach. Richard M. Johnson, Sawtooth Software. 2000. Available at: http://www.sawtoothsoftware.com/download/techpap/undhb.pdf Accessed January 18, 2010.

79. MaxDiff analysis: simple counting, individual-level logit, and HB. Bryan Orme. Sawtooth Software, Inc. Available at: http://www.sawtoothsoftware.com/download/techpap/inivmaxdiff.pdf Accessed January 18, 2010.

80. Robinson A, Thomson R. Variability in patient preferences for participating in medical decision making: implications for the use of decision support tools. Quality in Health Care. 2001: 10(Suppl I):i34–i38

81. Ayanian JZ, Cleary PD, Weissman JS, Epstein AM. The effect of patients' preferences on racial differences in access to renal transplantation. N Engl J Med 1999;341:1661-9

82. Merkus MP, Jager KJ, Dekker FW, Haan RJ et al. Quality of life over time in dialysis: The Netherlands cooperative study on the adequacy of dialysis. Kidney International. 1999; 56:720-728

83. Charles C, Redko C, Whelan T, Gafni A, et al. Doing nothing is no choice: lay constructions of treatment decision-making among women with early-stage breast cancer. Sociology of Health and Illness. 1998;20:71-95

84. Yao F, Seed C, Farrugia A, Morgan D, Cordner S et al. The risk of HIV, HBC, HCV and HTLV infection among musculoskeletal tissue donors in Australia. American Journal of Transplantation 2007; 7: 2723-2726

85. Nordgren LF, van der Pligt J, van Harreveld F. Unpacking perceived control in risk perception: the mediating role of anticipated regret. Journal of Behavioral Decision Making. 2007;20:533-44.

86. Alexander JW, Bennett LE, Breen TJ. Effect of donor age on outcome of kidney transplantation: A two-year analysis of transplants reported to the United Network for Organ Sharing Registry. Transplantation. 1994 Mar 27;57(6):871-6.

87. Rao KV, Kasiske BL, Odlund MD, Ney AL, Andersen RC. Influence of cadaver donor age on posttransplant renal function and graft outcome. Transplantation. 1990 Jan;49(1):91-5

88. Hsee, Christopher K. The Evaluability Hypothesis: An Explanation for Preference Reversals between Joint and Separate Evaluations of Alternatives. Organizational Behavior and Human Decision Processes, Vol. 67, No. 3, 1996

89. Kasiske B, Snyder J, Matas A, Ellison M. Preemptive kidney transplantation: the advantage and the advantaged. Journal of the American Society of Nephrology. 2002;13:1358-1364

90. Asderakis A, Augustine T, Dyer P, Short C. Preemptive kidney transplantation: the attractive alternative. Nephrology Dialysis Transplantation. 1998;13:1799-1803

91. Abou-Ayache R, Bridoux F, Pessione F. Preemptive renal transplantation in adults. Transplantation Proceedings. 2005;37:2817-2818

92. Petrini C. Preemptive kidney transplantation: ethical issues. Ann Ist Super Sanita. 2009;45(2):173-177