Benefits and Risks

About your kidney/pancreas transplant

Deciding whether or not to have a kidney or kidney/ pancreas transplant may be one of the biggest decisions you will ever make. A transplant can improve your life greatly, but it also carries serious risks.

This chapter describes the benefits and risks of a transplant.

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Improved Quality of Life

Most people who receive a kidney transplant have a better overall quality of life when compared to staying on dialysis. Most say they are more satisfied with life and feel better emotionally and physically. And, most are more likely to be able to return to work. Transplant patients usually are freer to travel since they are not tied down by going to dialysis visits. Also, we now know that people who have kidney transplants to treat their kidney disease can live longer than people who stay on dialysis.

Many problems that occur from long-term dialysis improve after getting a transplant. Some of these are:

- ***Anemia* (low blood count) improves.** The production of blood cells by the bone marrow needs the hormone *erythropoietin*, which is produced in the kidneys. The healthy new kidney will be able to produce this hormone that the diseased kidneys no longer can. The result is an improved blood count.
- **Thickening of the heart muscle (*left ventricular hypertrophy*) gets better.** This thickening can lead to permanent damage and heart failure. Much of this problem is related to fluid overload in the body that occurs when the kidneys fail. This overload decreases after a transplant, and the risk of these heart problems lessens.
- **The risk of developing blockages of blood vessels (*cardiovascular disease*) decreases.** Blocked blood vessels can lead to heart attack or stroke. The chance of this problem getting worse in patients who already have cardiovascular disease lessens.
- **Nerve damage (*neuropathy*) caused by kidney failure decreases.** Neuropathy can cause “restless legs,” pain, decreased sensation in the legs or arms, and sleeping and memory problems. These problems can become less severe after a kidney transplant.
- **Limiting fluids and the foods you are able to eat usually is not required after transplantation.** For example, your intake of phosphorous or potassium may not be restricted any longer.

Benefits of a Pancreas Transplant

Patients with type 1 diabetes may qualify for a pancreas transplant as well as a kidney transplant, if needed. A successful pancreas transplant can allow the patient to control blood sugar without needing to use insulin. Patients no longer have problems with very low blood sugars (*hypoglycemia*), or *diabetic ketoacidosis* (DKA) or coma from very high sugars (*hyperglycemia*), both of which can be life-threatening. Normal blood sugars can also prevent long-term complications of diabetes.

For diabetic patients with good kidney function, getting only a pancreas transplant can prevent kidney disease from developing. If there is minor kidney disease due to diabetes, this can get better.

For those patients who already have kidney failure due to diabetes, getting a pancreas transplant and a kidney transplant can prevent the new kidney from being damaged due to diabetes.

Diabetic patients may have other complications such as *retinopathy* (damage to the retina of the eye) or *neuropathy* (damage to the nerves of sensation or motor function). Retinopathy can cause bleeding in the eye, which can lead to blindness. Neuropathy may cause severe pain, numbness, tingling in the hands and feet, or problems with motor strength. Decreased sensation, especially in the feet, can lead to injury, sores on the feet, and increased risk of infection.

Retinopathy and neuropathy can get better after a pancreas transplant, but it may take 3 to 5 years after the transplant to really see an improvement. And, the chance that problems related to retinopathy or neuropathy will get better after a transplant depends on how much damage these conditions caused before transplant. For example, if a patient with diabetes has severe retinopathy and has had several laser surgeries to treat it, the scarring that is left from the laser surgeries cannot be reversed. This scarring decreases vision, and so the patient's vision would not be expected to improve after transplant.

What are the success rates of transplants?

Success rates of transplants are usually reported in 2 ways: *patient survival* and *graft survival*.

Patient Survival

Patient survival is the percentage of patients who are alive after transplant. It is usually measured at 1 and 5 years. Overall, the patient survival at 1 year after transplant is 97% (97 out of 100). At 5 years, patient survival is 95% (95 out of 100).

In general, patients who receive a transplant can live longer than if they stay on dialysis. This is especially true for patients with diabetes and kidney failure. This may be because the transplant lowers the risk that cardiovascular disease will get worse, but staying on dialysis keeps this risk higher. In the first few months after a transplant, there is an increased risk of having problems that could cause death. These problems may be caused by complications from surgery, infections, or heart attack or stroke. Over time, the risk of these life-threatening problems decreases.

Graft Survival

Graft survival means that the transplanted organ is still functioning. Kidney graft survival after 1 year for a deceased donor kidney is about 90% (90 out of 100 will still be functioning). For a kidney from a living donor, the 1-year graft survival rate is about 94% (94 out of 100 will still be functioning).

Another way to think about graft survival is the "half-life" of the organ. The half-life is the number of years that has gone by in which half a group of patients still have kidneys that are functioning, and the other half do not have functioning kidneys. Think of it as an average amount of time the kidney may function. The half-life of a deceased donor kidney transplant is about 7 to 12 years. The half-life for a living donor transplant can be 15 to 20 years, or more.

Survival for kidney transplants for UWMC's transplant center is 91.33% for deceased donor transplants (about 91 out of 100) and 90.57% for living donor transplants (about 91 out of 100).

What affects patient survival after transplantation?

Patients with kidney failure who receive a kidney transplant can live longer than if they stay on dialysis, But, transplant patients still have a higher risk of death than the general population.

The most common causes of death after transplantation are:

- Cardiovascular (heart) disease
- Stroke
- Infections
- Cancers

We will work with you after your transplant to lower your risk of these types of complications.

Heart Disease and Stroke

Many patients have severe cardiovascular disease at the time of their transplant. This may affect the success of their transplant and may increase their chance of dying after transplant.

Kidney disease and high blood pressure are risk factors for cardiovascular disease. These problems are a major cause of patient death after a kidney transplant. If you smoke or have diabetes, the risk of developing these problems can be higher.

We will talk with you about ways you can decrease your risk of developing heart problems or stroke. This may include good blood pressure control, taking medicine to lower cholesterol, and taking aspirin to decrease your risk of having a heart attack or stroke. Because smoking cigarettes can increase the risk of these problems, as well as the risk of some cancers, we require that you not smoke in order to get placed on the transplant list. We also require that you continue not to smoke after receiving your transplant.

Infections

The medicines all transplant patients must take to prevent rejection of the new organ weaken their immune system. This can increase the chance of getting infections. Most of these infections are minor and can be easily controlled, such as a urinary tract infection. Rarely, infections can be much more severe, difficult to control, or even life-threatening.

We closely monitor all patients to try to detect signs of infection early. We also do screening tests before and after transplant for certain types of infections to assess possible infection risk or early signs of these infections.

Cancer

Transplant patients can be at higher risk of some types of cancers, especially skin cancer. Protecting your skin from the sun by using sunscreen and protective clothing can help decrease your risk of skin cancer.

Patients who have had skin cancer in the past have to be especially careful. We recommend regular evaluation by a *dermatologist* (skin doctor) for these patients.

Lymphoma is a type of cancer of the white blood cells. The risk of lymphoma is higher in transplant patients, but it is still rare. The average rate of lymphoma in transplant patients is about 1% (1 out of 100).

We advise all transplant patients to follow recommendations for health screening tests, such as colonoscopy. Women may have a higher risk of cancer of the cervix after transplant, so it is important to continue to have routine PAP tests. Men should be screened for prostate cancer.

Surgical Complications

About 5% of kidney transplant patients (5 out of 100) and about 10% of kidney/pancreas patients (10 out of 100) have major complications from surgery. These complications can include:

- Blood clots
- Bleeding
- *Lymphocoele* (buildup of lymph fluid)
- Urine leak
- *Renal artery stenosis* (narrowing of the renal artery)

Blood Clots

There is a risk of developing blood clots in the legs after any type of surgery, including transplant surgery. Clots in the legs could travel to the lungs and cause breathing problems and require blood-thinning medicine. We follow standard care procedures to lessen the risk of this problem occurring. One of these is that you will wear compression stocking on your legs after surgery until you are able to get up and walk around. These stockings help increase blood flow in your legs, and this helps keep clots from forming.

After transplant surgery, a blood clot could also form in an artery or vein of the transplanted organ. This is rare, but if it occurs surgery may be needed to remove the clot. A blood clot could cause loss of the transplanted organ.

Bleeding

Because of the nature of this surgery, and also the increased bleeding risk from kidney failure and medicines such as warfarin (taken by some patients), you may require a blood transfusion. If bleeding is severe, you may need another surgery to find the source of the bleeding and to stop it.

Lymphocoele

Lymph vessels are small tubes next to arteries and veins that carry fluids from the tissues of the body back into the large veins and the heart. Since they are very small, injury to these vessels often occurs in the area of the transplant surgery. This can cause lymph fluid to collect in the area around the transplanted organ. This buildup of lymph fluid is called lymphocoele.

Usually this is a minor problem, but sometimes the amount of fluid that builds up in the area is large and causes swelling or puts pressure on the transplanted organ. If the fluid buildup causes such problems, it may need to be drained. Usually it is drained through the skin using a small needle. Rarely, another surgery is needed to drain the fluid. Most of the time, the fluid goes away on its own.

Urine Leak

A urine leak can occur if there is a small opening where the *ureter* of the transplanted kidney connects to your bladder. The ureter is the small tube that drains urine from the kidney to the bladder. A urine leak may be suspected if there is concern about how the transplanted kidney is functioning. Signs of a urine leak can include:

- Unexpected pain in the area of the transplant
- Fluid draining from the incision

A urine leak is first treated by placing a catheter in the bladder to drain it and relieve pressure in the bladder. The catheter may need to stay in place for an extended period of time, since often this is all that is needed to let the area heal on its own. But, sometimes surgery is needed to repair the connection of the ureter to the bladder.

Renal Artery Stenosis

Renal artery stenosis is a narrowing of the blood vessel that supplies blood to the kidney transplant. It may be related to the way healing has occurred where the vessels are connected.

This problem is rare. It can be seen 2 to 3 months or longer after the transplant. If it is severe, it may cause a large decrease in blood flow to the kidney. Possible signs of this problem may include:

- High blood pressure that is getting worse
- New leg swelling
- Kidney function that is getting worse

An ultrasound of the kidney and artery may be done to check for this problem. If there is concern, other tests such as an *angiogram* may be needed to see if there is major narrowing of the artery. An angiogram is an imaging test that uses X-rays and a contrast agent (also called “dye”) to study blood flow in arteries and veins.

Renal artery stenosis can often be treated by dilating the artery with a balloon at the time of an angiogram. Rarely, surgery may be needed to correct the problem.

Medical Complications

Delayed Graft Function

Sometimes the kidney transplant does not work right away because of the "shock" from being removed from one person and placed in another. This can happen in 10% to 30% of patients (10 to 30 out of 100) who receive a kidney from a deceased donor. It can happen in up to 2% of patients (2 out of 100) who receive a kidney from a living donor.

Most of the time the kidney will function, but it may take a few days or even a few weeks. There is nothing anyone can do to speed up this process. You will need to continue dialysis until the kidney starts to function well enough on its own. In a small number of patients, the kidney may never work and may need to be removed.

Rejection

Rejection is the body's natural response to the foreign kidney or pancreas. You need to take anti-rejection (also called *immunosuppressive*) medicines so that your body's immune system does not reject the transplanted organ. Rejection causes inflammation in the transplanted organ. If it is not treated, it will cause scarring and permanent damage.

The 6-month period just after transplant is the time of highest risk for rejection. Rejection occurs in about 15% to 20% of kidney transplant patients (15 to 20 out of 100). The risk of rejection for pancreas transplants is a little higher.

Reversing rejection is most successful when it is caught and treated early. The only way to know with for sure if there is rejection is to do a *needle biopsy* of the transplanted organ (see "Biopsy" section on page 2-8).

Early Rejection

Most bouts of *early rejection* (within 6 months after transplant) can be treated and reversed. Early rejection can happen even when the patient is taking their anti-rejection drugs correctly. Often, early rejection does not cause any symptoms. Your doctor may be concerned about rejection based only on changes in blood tests for kidney function.

Later Rejection

Rejection that occurs more than 6 months after transplant can be more difficult to treat, and success rates are not as high. When rejection happens later on, it is often because the patient has not been taking their anti-rejection drugs properly.

Signs of later rejection of a kidney transplant may include:

- A decrease in urine output
- Fluid retention
- Weight gain
- Pain or swelling in the area of the transplant
- Flu-like symptoms such as fatigue, aches, and fevers

Biopsy

A needle biopsy of your transplanted organ may be done if there is concern about rejection. It may also be done to rule out rejection as a cause of abnormal function of the transplanted organ.

A needle biopsy involves inserting a thin needle into the transplanted organ. Small pieces of tissue are removed through the needle. The procedure is done very safely under local anesthesia, and ultrasound is used to guide the needle into the organ. There is a small risk of bleeding from a needle biopsy.

After the needle biopsy, a *pathologist* will look at the tissue samples under the microscope. A pathologist is a doctor who examines tissues and cells to diagnose health conditions.

If you need a biopsy to check for rejection, you will be monitored after the procedure to make sure you did not bleed or have any major complications. Your doctor will talk with you about the procedure and complications in more detail, if needed.

See Chapter 16, “Transplant Renal Biopsy,” for more information about having a biopsy.

Chronic Allograft Nephropathy

Chronic allograft nephropathy is when problems cause the kidney function to get worse slowly. It is also known as “chronic rejection.” It is different from “acute rejection,” which usually happens more quickly. This type of damage to the kidney transplant may be due to the immune system. Other issues such as high blood pressure or high cholesterol may also cause slow damage to the kidney. In some cases, the original cause of your kidney disease can also affect the kidney transplant and damage it.

Your doctor will watch for any signs of these problems. Like diagnosing rejection, sorting out the reasons for chronic problems with the kidney transplant often requires doing a needle biopsy. Whatever the cause, we know that good control of blood pressure can help slow down the rate of kidney function decline. Your goal blood pressure is 120 to 130 over 70 to 85.

Infection

Infection has already been mentioned as a possible life-threatening complication after transplantation. The anti-rejection medicines you need to take after transplant to keep your body from rejecting the organ will lower your immune defense system. This will make you more open to getting infections.

Your infection risk is highest in the 6 months just after transplant, when the doses of anti-rejection medicines are highest. You are also at higher risk during treatment for rejection. Over time, your risk of infection declines as your doses of anti-rejection medicines are lowered. But, your infection risk is always higher than if you were not taking these medicines.

Infections may be caused by bacteria, viruses, or fungus, and they may be life-threatening if they are not found and treated early. In the first 6 months after transplant, you will be asked to take certain antibiotics to help prevent some of the more common types of infections we see. This helps prevent many infections that might occur otherwise.

We ask patients to watch for and report any symptoms that may indicate that an infection is developing. Some of these symptoms are:

- Fever
- Cough
- Night sweats
- Sore throat
- Abdominal pain
- Diarrhea
- New headache

Cancer

Cancers are another possible life-threatening complication after organ transplant. Immunosuppressive medicines increase the risk of these cancers:

- **Skin cancer:** The risk of skin cancer for transplant patients is much higher than in the general population, and the cancer can be more severe and aggressive. *Squamous cell* and *basal cell carcinoma* are the types of skin cancer seen most often. If you had skin cancer before receiving a transplant, your risk is even higher.

  We recommend that you see a dermatologist for close monitoring after your transplant. All transplant patients should avoid long, unprotected sun exposure and should use sunscreen regularly.

- **Lymphomas:** Most lymphomas that occur after transplant are classified as the "non-Hodgkin's" type. They are also called *post-transplant lymphoproliferative disease,* or PTLD. Early signs of lymphoma may include unexplained weight loss, fevers, or enlarged lymph nodes. If you have lymphoma, you will need to see an *oncologist* for treatment. An oncologist is a doctor who specializes in cancer treatment. PTLD is a very rare complication. It occurs in only 1% or fewer kidney transplant patients (1 out of 100).

Joint and Bone Disease

Kidney disease can cause bone problems. Transplant medicines are also linked to bone loss.

Today, bone and joint problems are less common in transplant patients. This is because we now use corticosteroid drugs (also called "steroids") less often for anti-rejection treatment. Most problems related to bone and joints are due to steroids. Bone loss, mostly in the spine and hip bones, can lead to *osteoporosis* (thin, weak bones) and increase the risk of fractures. Your doctor will talk with you about whether you may be at higher risk for this problem, and what treatment you may need to preserve your bone density.

People with diabetes may have low bone density if they also have *peripheral neuropathy* (nerve damage in the outer limbs). This is especially true if the nerve damage is in their feet and ankles, which can put them at risk for fractures in these areas. It is not clear whether corticosteroids add any more risk since the bone loss due to steroids usually does not affect feet and ankles as much as other areas.

Steroids can also cause a bone problem called *avascular necrosis* (AVN). AVN can lead to arthritis, mostly in the hip joint. But, it may also affect other bones such as the kneecap and some bones in the wrist. This problem is not seen as much as it once was due to less use of steroids.

Gout

Gout is a painful, red swelling of a joint, usually the big toe. It can occur after transplant as a side effect of some of the transplant medicines. Patients who have had gout before transplant are at highest risk for it after transplant.

Diabetes

Some patients who do not have a history of diabetes may develop diabetes after their transplant. This is from the way the anti-rejection drugs affect how the body makes and uses insulin. These drugs make insulin work less effectively.

You may need to start medicine, either pills or insulin shots, to control your blood sugar. Short-term problems of not controlling blood sugar can include a higher risk of infections. Long-term problems can include damage to your kidney, eye problems, and higher risk of heart disease.

We can predict if some patients may have a higher chance of developing diabetes after transplant. These patients are overweight or have a family history of diabetes. Some patients who have type 2 diabetes, "pre-diabetes,"or "borderline" diabetes do not need diabetes treatment when they are on dialysis before transplant. After transplant, these patients will almost certainly need treatment for diabetes.

For overweight patients, even a small weight loss and regular exercise can improve blood sugar control. This can reduce the chance of needing insulin or pills, or at least lower the amount of medicine needed.

Medicine Side Effects

(See "Medicines" section for more complete information.)

Each anti-rejection medicine can have certain side effects, as well as the general complications listed above.

Tacrolimus is the most commonly used *calcineurin inhibitor* drug. It may cause:

- Shakiness or tremor
- Headaches
- Heartburn
- Diarrhea
- *Hyperkalemia* (high potassium levels)
- Mild hair loss (usually lessens over time)
- Diabetes
- Gout

Mycophenolate may cause:

- Heartburn
- Diarrhea
- Hyperkalemia
- Low white blood cell count
- Low red blood cell count (*anemia*)

Questions?

Your questions are important. Call your doctor or health care provider if you have questions or concerns. UWMC clinic staff are also available to help.

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Cyclosporine may cause:

- Increased hair growth
- Darkening of the hair on the face and body
- Oily skin
- High blood pressure
- High cholesterol levels
- Gout

Prednisone may cause:

- Thinning of the skin
- Bruising
- Joint and bone disease

Many patients gain weight after transplant, and usually prednisone is blamed for this. But, many patients who are not on prednisone also gain weight. This may be due to improved appetite and improved sense of well-being after transplant. We counsel patients to be aware of this. Monitoring your diet and doing regular exercise can help keep you from gaining too much weight.

What can I do to avoid complications?

Many patients ask this question after transplant. To some degree, things such as risk of early rejection and infection are not things you can control. But, we stress the things you can control. This includes the importance of understanding all your medicines and taking them correctly, especially your anti-rejection drugs, to help things go as smoothly as possible.

We know that we ask a lot of you, especially right after your transplant. We ask you to have many clinic visits and blood tests, but this is so that we can find any problems early.

We want you to tell us about any problems or concerns that you may have. We would rather have you call about something that turns out to be minor than not to hear about an issue that turns out to be important. Even after you return to your referring doctor for longer-term follow-up, we are always available to you for problems related to your transplant. Please feel comfortable asking us for help.

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