Decision support needs of kidney transplant candidates regarding the deceased donor waiting list: A qualitative study and conceptual framework

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Graphic Design

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Background: Kidney transplant candidates face complex decisions about transplant options such as living donation or acceptance of lower quality kidneys. We sought to characterize knowledge and decision support needs regarding kidney transplant outcomes and options.

Methods: We conducted 10 interviews and four focus groups of 28 adult kidney transplant candidates from two centers in Minnesota. Transcripts were analyzed thematically using a grounded theory approach.

Results: We identified four themes: First, candidates have a limited understanding of treatment options and demonstrate confusion or a lack of awareness about waiting list outcomes and prognosis. Second, candidates desired frank discussions about likely outcomes and individualized prognosis. Third, emotional barriers impact how patients make informed decisions. Finally, participants relied on the support of family and friends to help process information, and many favored the medical community engaging their family and friends in their medical decisions. These findings were incorporated into a conceptual model to support kidney transplant candidates in medical decision making.

Conclusions: Transplant candidates had limited understanding about treatment options and outcomes on the kidney transplant waiting list. Individualized risk information and cognitive approaches that recognize how patients process information and balance competing risks may improve informed decision making.

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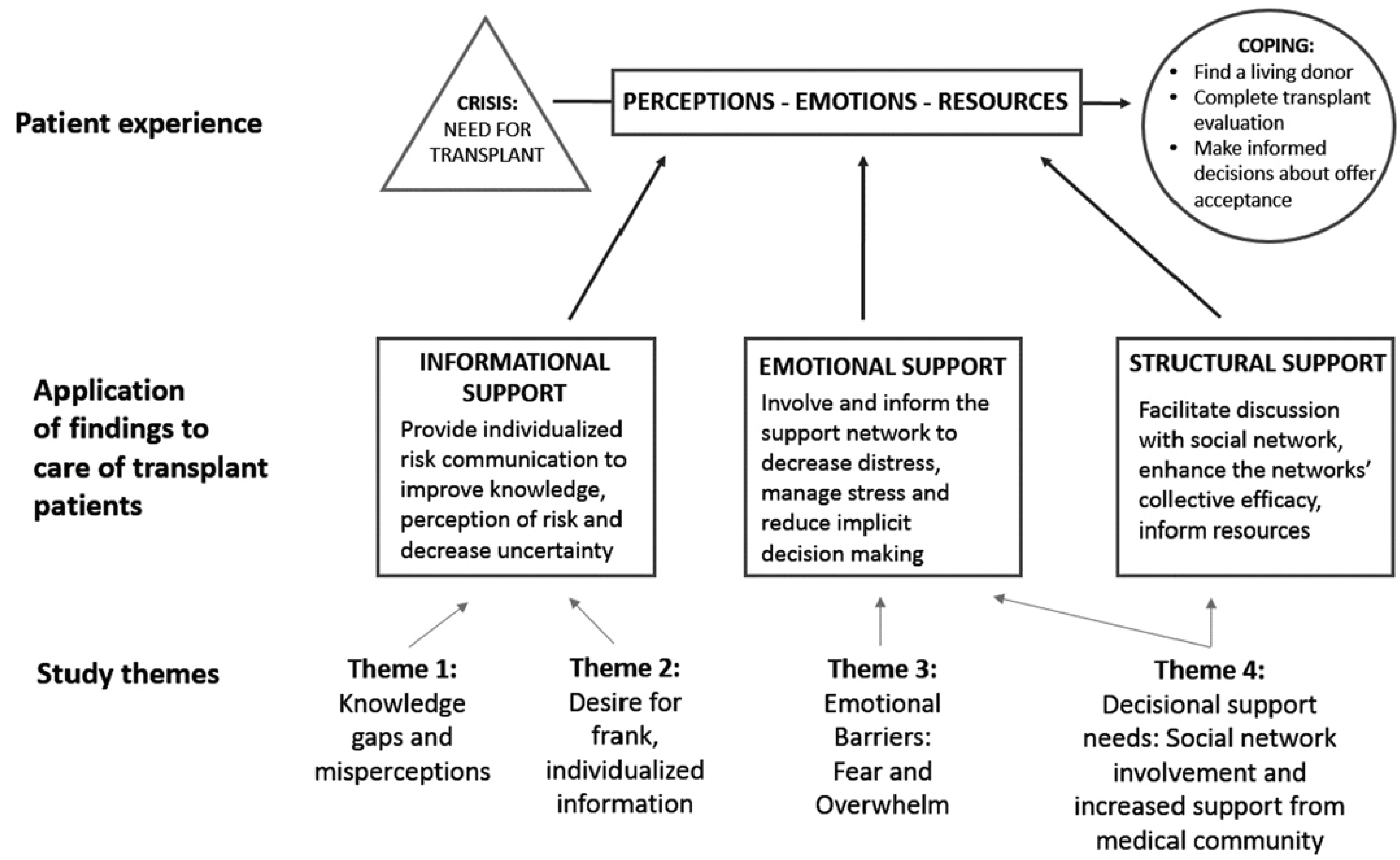


Image 1. The kidney transplant candidate support framework illustrates how the themes developed from these data can be applied to help patients cope with end–stage kidney disease and the need for transplant.

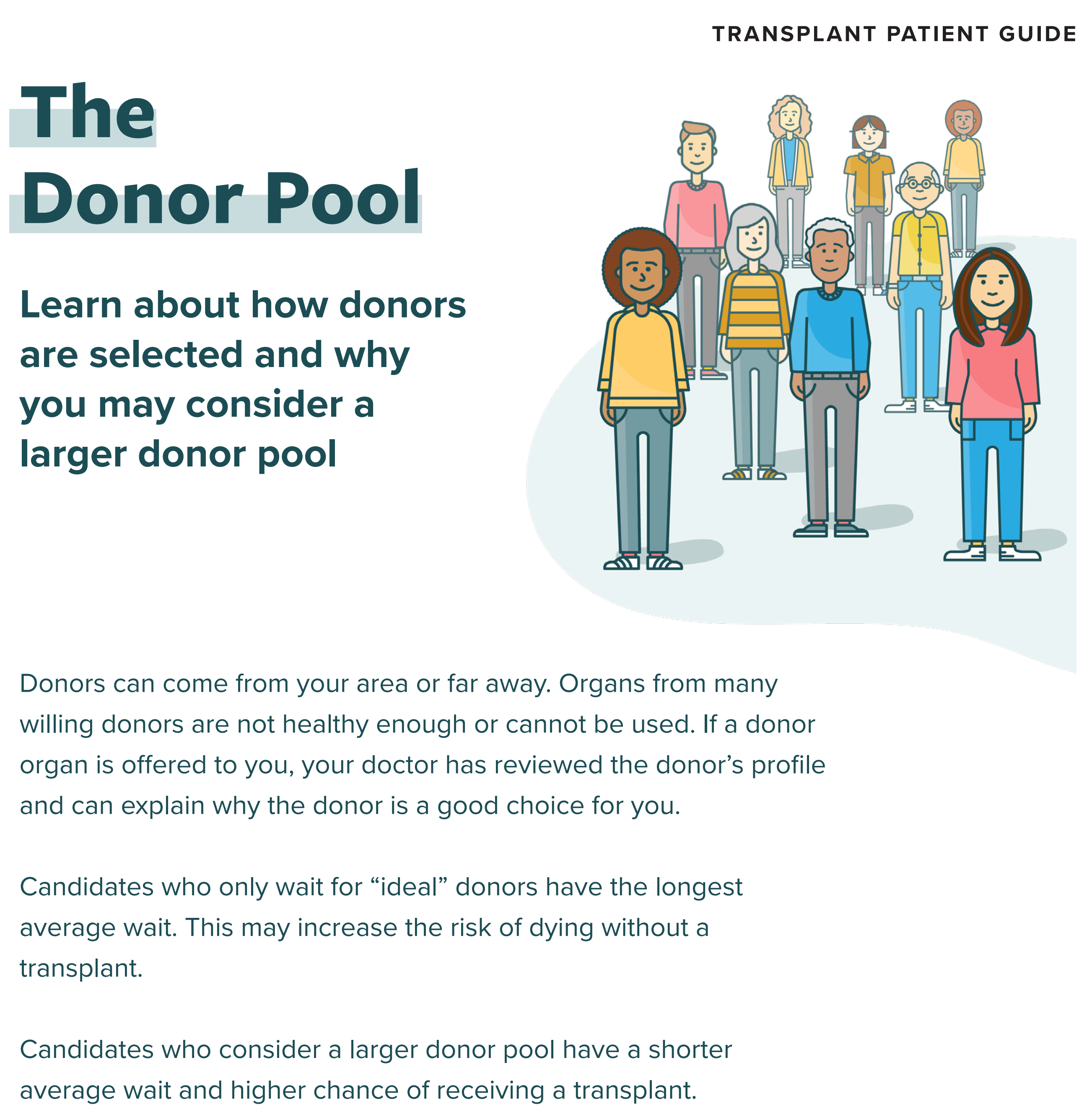


Image 2. Understand donor pool (Grace Chandler, Cory Schaffhausen, Sue Chu).

An organ offered to you may vary in the quality. The quality depends on many things including donor age, weight, other health issues, and time the organ is transplanted.

An organ offered to you may also vary in the potential risk of disease transmission. Donor history affects potential exposure to infectious disease. All donors have been tested for infections. With modern testing, infections from donors that have tested negative are extremely rare.

Your doctor will consider both the benefit of using the donor and the risk from dying while waiting if there is not a future offer.
Some donors with a history of potential exposure to infectious disease are otherwise younger and have healthier livers than average donors.

One common reason today is the opioid epidemic. This has resulted in donors who have died of an overdose. However, these donors are often younger and otherwise healthy. The government labels some donors as "PHS Increased Risk" if the donor history meets certain criteria for a potential exposure to infectious disease.

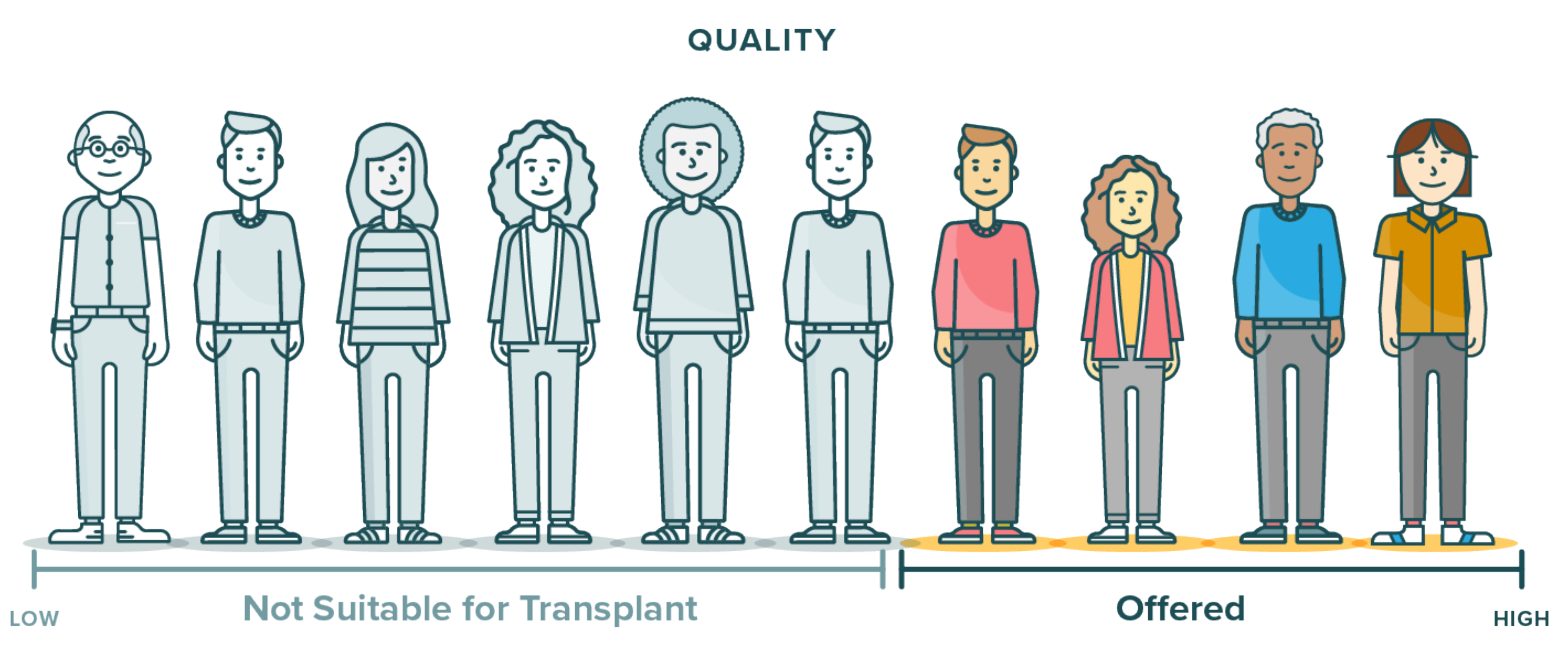
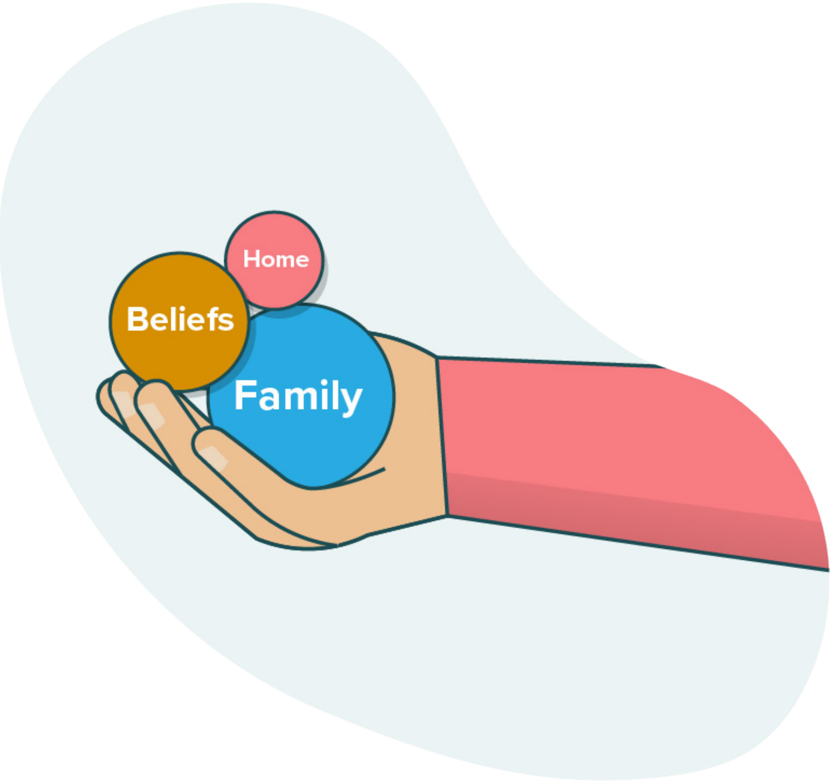


Image 3. Donor Profile (Grace Chandler, Cory Schaffhausen, Sue Chu).

What is Right for You

Your care team will present an offer to you if the donor organ can help you stay healthy. However, you can consider the risks and benefits that match your values.



The values that are important to you can guide your decision. Your quality of life and your feelings of readiness for surgery may change while you are waiting.

Your decision can depend on long-term survival, quality of life after surgery, or other factors. Every person is different. Your medical team wants to know if you have concerns about accepting specific donor types. Discussing your concerns early will help you prepare.

In almost all cases, patients who accept a donor organ that is offered have higher average survival rates than those who decline. Even patients with high priority on the waiting list may not receive a future offer because the donor must be a matching blood type.

View how the risk of waiting compares to the risk of common donor types on the following charts.

Image 4. What is right for you (Grace Chandler, Cory Schaffhausen, Sue Chu).

Risk of Infectious Disease

You have a very low risk from accepting a donor that has tested negative for infections. Even donors labeled as "PHS Increased Risk" have tested negative. These donors have about a 4 in 1000 risk that the tests did not detect an infection. This is abut half the risk of dying in a car accident.

Risk of Getting HIV or HCV from a PHS Increased Risk Donor

Mortality Risk While Waiting

On average in the United States, about one third of patients will be removed from the list or will die on the waiting list within 3 years of waiting. Your personalized risk will depend on your location, blood type, and other factors. The Scientific Registry of Transplant Recipients (SRTR) has a calculator to view a personalized risk.

3 Year Outcomes for Candidates on the LIver Transpant Waiting List

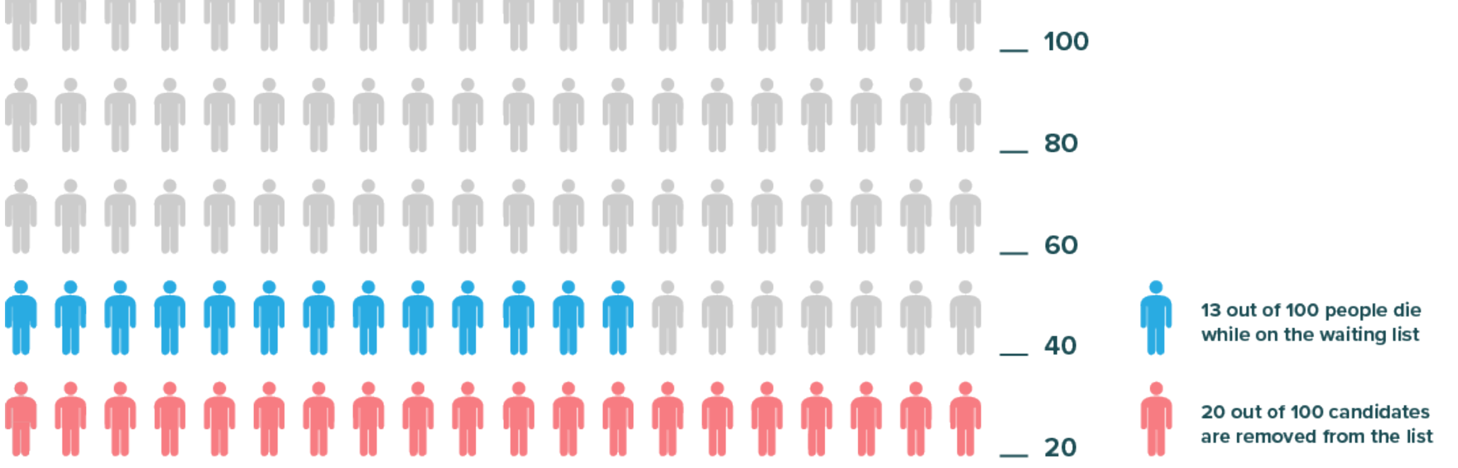


Image 5. Understand risk (Grace Chandler, Cory Schaffhausen, Sue Chu).