Title: **A feasibility pilot study for a social support intervention in kidney transplant candidates**

NCT Number: **NCT04363515**

Date: **October 1, 2024**

Attachment UUU

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Drug or Device Name(s):	Not applicable
FDA IND/IDE	Not applicable
Sponsor: University of Minnesota Clinical and Translational Science Institute	
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PROTOCOL SYNOPSIS

Study Title	Development of a social support intervention for kidney transplant candidates
Funder	University of Minnesota WERC award
Clinical Phase	Not applicable
Study Rationale	Intensive home-based group counseling with a psychologist are the only interventions that have been shown to increase rates of living kidney donation however, they are not feasible for transplant centers. A recent review on strategies to increase living kidney donation concluded that strategies directed at candidates and their social supp01t networks are the most promising based on the data available. Therefore, we propose an intervention that incorporates individualized risk communication into group counseling with patients and their support networks at the transplant center.
Study Objective(s)	**Primary** • To determine whether counseling with the shared decision aid, provided in the clinical setting to candidates along with members of their social suppo1t network, increases pursuit of transplant. **Secondary** • To determine whether the intervention influences patient knowledge about kidney transplant, decisional conflict, and hope. • To determine if the intervention influences social suppo1t group knowledge about kidney transplant and intention/motivation to support the patient through the transplant process.
Test Article(s) *(If Applicable)*	Not applicable
Study Design	Pilot randomized control trial
Subject Population **Key Criteria for Inclusion and Exclusion:**	Inclusion criteria include adult kidney transplant candidates at the University of Minnesota or Hennepin County Medical Center. Exclusion criteria include inability to consent, non-English speaking, or candidates for combined organ transplant.
Number Of Subjects	Total Number of Subjects: 60 Total Number of Sites: 2
Study Duration	Each subject's participation will last 3 months. The entire study is expected to last through November **1st** 2020.
Study Phases	(1) Screening: screening for eligibility and obtaining consent

Screening **Intervention** **Follow-Up**	(2) Intervention: group counseling session
Efficacy Evaluations	Primary evaluation measurements that will be used to assess the efficacy of the intervention
Pharmacokinetic Evaluations	Not applicable
Safety Evaluations	Not applicable
Statistical And Analytic Plan	A Student's T-test will compare means for the primaiy outcome of the number of inquiries per candidate (primary outcome). Chi-squai·ed and Student's T-tests will be used to compare secondary outcomes.
Data And Safety Monitoring Plan	The principle investigator is responsible for data quality management and ongoing assessment of safety.

TABLE 1: SCHEDULE OF STUDY PROCEDURES

Study Phase	**Screening**	**Treatment/Intervention**	**Follow-up**
Visit Number	**1**	**2**	***N/A***
Informed Consent/Assent	**X**		
Review Inclusion/Exclusion Criteria	**X**		
Bassline Survey to measure secondru.y outcomes	**X**		
Demographics/Medical Histo1y	**X**		
Randomization	**X**		
Inte1vention (group counselling session)		**X**	
Survey to measure secondru.y outcomes		**X**	
Assess primru.y outcome through medical records			**X**

1 BACKGROUND INFORMATION AND RATIONALE

1.1 Name and Description of Investigational Product or Intervention

We will conduct a pilot randomized trial to compare group counseling with transplant candidates and their suppo1t networks that incorporates the shared decision aid with a risk calculator, versus usual pre-transplant care.

1.2 Findings from Non-Clinical and Clinical Studies

Not applicable

1.2.1 Non-Clinical Studies

Not applicable

1.2.2 Clinical Studies

1.2.2.1 Human Pharmacokinetics

Not applicable

1.2.2.2 Clinical Studies in Adults

1.2.2.3 Clinical Studies in Children

1.3 Selection of Drugs and Dosages

Not applicable

1.4 Relevant References

1.5 Compliance Statement

This study will be conducted in full accordance of all applicable Hennepin Healthcare Research Policies and Procedures and all applicable Federal and State laws and regulations. All episodes of noncompliance will be documented and repo1ted according to the Prompt Repo1ting Guidelines, Attachment EEE, of the Hennepin Healthcare IRB Policies and Procedures.

The investigators will perfonn the study in accordance with this protocol, will obtain consent, unless waiver of consent or other alteration is approved, and will repo1t unanticipated problems involving risks to subjects or others and SAEs in accordance with The Hennepin Healthcare IRB Policies and Procedures and all Federal requirements. Collection, recording, and rep01ting of data will be accurate and will ensure the privacy, health, and welfare of research subjects during and after the study.

2 STUDY OBJECTIVES

The pmpose of the study is to detennine whether counseling with the shared decision aid, provided in the clinical setting to candidates along with members of their social suppo11 network, increases pursuit of transplant.

2.1 Primary Objective (or Aim)

The primary objective of this study is to detennine whether counseling with the shared decision aid, provided in the clinical setting to candidates along with members of their social suppo1t network, increases pursuit of transplant.

2.2 Secondary Objectives (or Aim)

The secondaiy objectives are to:

- Determine whether the intervention influences patient knowledge about kidney transplant, decreases decisional conflict, and hope.
- Detemline if the intervention influences social suppo1t group knowledge about kidney transplant and intention/motivation to suppo1t the patient through the transplant process.

3 INVESTIGATIONAL PLAN

3.1 General Schema of Study Design

3.1.1 Screening Phase and Baseline Assessment

Potential subjects will be screened using the protocol inclusion and exclusion criteria. Potential subjects will be reached out to over the phone before their initial appointment at the clinic to see if they express interest in hearing more about the intervention. Those whom want to learn more about the intervention will then be met with during their first kidney transplant counseling appointment at the transplant clinic. Permission (info1med consent) will be obtained during this appointment, if the patient would like the participate in the intervention. After the patient has completed the health assessment phase and is officially a candidate for transplant, they will be emolled in the study.

3.1.2 Study Intervention

Participants in the intervention group first undergo usual pre-transplant counseling, and will then undergo a group counseling session with members of their suppmt network at the transplant center. The session will include 1) a description of general options for treatment of end stage kidney disease, 2) the likely outcome of each of those options specific to the transplant candidate utilizing the decision aid, 3) a presentation of common reasons to pursue or not pursue each of those options (including common barriers to living donation), and 4) a discussion of how the suppo1t network can be involved in the transplant process. Tllis discussion will be info1med by focus groups conducted in a previous study.

The group counseling session will follow a general script and will be facilitated by the principal investigator or a trained transplant educator, with recording and random review of the sessions to ensure quality and consistency of the content. Printed results of the decision aid output will be shared with the clinical transplant team to replicate clinical practice.

The control group will undergo the usual pre-transplant counseling and clinical evaluation conducted by the transplant center team. The control group will be info1med about the availability of the online shared decision aid by a member of the research team.

3.1.3 Part 2 (Use an appropriate descriptor such as "Open-Label Treatment")

Not applicable

3.1.4 Follow-up

Not applicable

3.2 Allocation to Groups and Blinding

The enrolled study participants will be randomized via computer into either the intervention or control group. Pa1ticipant and researcher blinding is not feasible for the intervention, but asce1tainment and statistical analysis of outcomes will be performed by an analyst blinded to group assignment.

3.3 Study Duration, Enrollment and Number of Sites

3.3.1 Duration of Study Participation

The study duration per subject will be up to 3 months. There will be one day of screening and one day that the inte1vention takes place. The remainder of the time is allotted for patients to undergo standard pre-transplant care and counseling.

3.3.2 Total Number of Study Sites/Total Number of Subjects Projected

The study will be conducted at two investigative sites in the United States.

Recruitment will stop when approximately 60 subjects are consented (7 patients in the control group + 8 patients + 6-7 friends and family each in the inte1vention group).

3.4 Study Population

3.4.1 Use of Vulnerable Populations and Patients Who Opt Out of Research

Vulnerable populations and patients who opt out will not be included in the study.

3.5 Inclusion and Exclusion Criteria

3.5.1 Inclusion Criteria

1) Adult males or females.

2) Kidney transplant candidates.

3) Additional criteria *as* required.

3.5.2 Exclusion Criteria

1) Non-English speaking individuals.

2) Individuals with impaired ability to consent.

3) Candidates for combined organ tTansplant.

4) Patients who choose to opt out of research.

Subjects that do not meet all of the enrollment criteria may not be enrolled. Any violations of these criteria must be repo1ted in accordance with IRB Policies and Procedmes.

4 STUDY PROCEDURES

4.1 Screening Visit and Baseline Assessment

- lnfo1med Consent
- Medical Record Review

4.2 Study Intervention

4.2.1 Visit 1

- Demographic survey
- Evaluative survey

4.2.2 Visit 2 and Visit 3

Not applicable

4.3 Part 2 of the Study (e.g. Open-Label Treatment)

Not applicable

4.3.1 Visit 4

Not applicable

4.3.2 Visit 5

Not applicable

4.4 Follow-up

- Medical records

4.4.1 Visit 6

Not applicable

4.4.2 Visit 6: End of Study

Not applicable

4.5 Unscheduled Visits

Not applicable

4.6 Concomitant Medication

Not applicable

4.7 Rescue Medication Administration

Not applicable

4.8 Subject Completion/Withdrawal

Participants may withdraw from the study any time without prejudice of their care. The infmmed consent document stipulates that we will retain data collected prior to study withdrawal. Pa1tial withdrawal (no further active paiticipation but with ongoing data collection after withdrawal from health record) will be requested if a participant wishes to cease pa1ticipation, as per the informed consent document.

4.8.1 Early Termination Study Visit

Subject's data from after withdrawal from the study will be not be used.

5 STUDY EVALUATIONS AND MEASUREMENTS

- Informed Consent: infmmed consent will be used to infmm patients about the inte1vention and their rights if they choose to participate.

- Medical Record Review: medical records will be reviewed to ensure that patients meet inclusion/exclusion criteria for intervention. They will also be used during follow-up to assess our primary outcome variable, to determine if the patient engaged in pursuit of transplant.

- Demographic survey (see appendix): This survey will be used to understand the population participating in the intervention.

- Evaluative survey (see appendix): This survey will assess our secondary outcome measures, to determine whether the intervention influences patient knowledge about kidney transplant, decisional conflict, and hope. Also, to determine if the intervention influences social support group knowledge about kidney transplant and intention/motivation to suppmt the patient through the transplant process.

5.1 Screening and Monitoring Evaluations and Measurements

5.1.1 Medical Record Review and demographics questionnaire

- Race
- Ethnicity
- Household income
- Education level
- Blood type
- Calculated panel reactive antibody age
- Time on dialysis
- Diabetes
- Gender
- BMI
- Cause of kidney failure
- Comorbidities (hypertension, cerebrovascular disease, peripheral vascular disease, and malignancy)

5.1.2 Physical Examination

Not applicable

5.1.3 Vital Signs

Not applicable

5.1.4 Laboratory Evaluations

Not applicable

5.1.4.1 Hematology

Not applicable

5.1.5 Other Evaluations, Measures

Not applicable

5.2 Efficacy Evaluations

Baseline and outcome evaluations will be used to test for intervention efficacy. These measures will include: pursuit of transplant, patient knowledge about kidney transplant,

patient decisional conflict, patient hope, social support group knowledge about kidney transplant and social support group intention/motivation to support the patient through the transplant process. A process evaluation will be conducted to ensme the intervention is implemented with fidelity and to assess what worked and did not work dming the implementation process.

5.2.1 Diagnostic Tests, Scales, Measures, etc.

Baseline evaluations will be administered before pruticipation in the intervention. After the intervention is complete, the outcome evaluation smvey will be administered. These smveys will have the same questions and measurements (listed above) in order to test for intervention efficacy/effectiveness.

5.3 Pharmacokinetic Evaluation

Not applicable

5.4 Safety Evaluation

Subject safety will be monitored by the principle investigator.

6 STATISTICAL CONSIDERATIONS

The sample size (n=60) will be sufficient for conducting statistical analysis of the intervention. A Student's T-test will compare means for the prima1y outcome of the number of inquiries per candidate. Both a Chi-squared and Student's T-tests will be used to compare seconda1y outcomes.

6.1 Primary Endpoint

Prima1y endpoint: pursuit of transplant

6.2 Secondary Endpoints

Secondaty endpoints: patient knowledge about kidney transplant, decisional conflict, and hope. Also, social suppo11 group knowledge about kidney transplant and intention/motivation to suppo1t the patient through the transplant process

6.3 Statistical Methods

A Student's T-test will compare means for the prima1y outcome of the number of inquiries per candidate between and within the intervention and control groups. Both a Chi-squared and Student's T-tests will be used to compare secondruy outcomes between and within the intervention and control groups. This is a feasibility pilot study; therefore, it is not powered to test anything. We will be collecting data that we could adjust for (i.e. demographics), but we will not be adjusting, because the main goal of this particulru· study is to gauge if the intervention is feasible.

6.3.1 Baseline Data

Baseline and demographic characteristics will be summarized by standard descriptive summaries (e.g. means and standard deviations for continuous variables such as age and percentages for categorical variables such as gender).

6.3.2 Efficacy Analysis

The prima1y efficacy endpoint will be the change in pursuit of transplant between the baseline and the outcome evaluation. Secondary endpoints will include the change in patient knowledge about kidney transplant, patient decisional conflict, patient hope, social supp01t group knowledge about kidney transplant and social support group intention/motivation to support the patient through the transplant process between the baseline and outcome evaluation. All measurements will be compared with the control/no treatment group measurements.

6.3.3 Pharmacokinetic Analysis

Not applicable

6.3.4 Safety Analysis

Not applicable

6.4 Sample Size and Power

The sample size will be n=60, with 30 patients consented from each site. This is a feasibility pilot study; therefore, it is not powered to test anything.

6.5 Interim Analysis

Not applicable.

7 STUDY MEDICATION (DRUG, DEVICE, OR OTHER STUDY INTERVENTION)

7.1 Description

7.1.1 Packaging

Not applicable

7.1.2 Labeling

Not applicable

7.1.3 Dosing

Not applicable

7.1.4 Treatment Compliance and Adherence

Not applicable

7.1.5 Drug Accountability

Not applicable

8 SAFETY MANAGEMENT

8.1 Clinical Adverse Events

Clinical adverse events (AEs) will be monitored throughout the study by the principal investigator.

8.2 Adverse Event Reporting

Since the study procedures are not greater than minimal risk, SAEs are not expected. If any unanticipated problems related to the research involving risks to subjects or others happen during the course of this study (including SAEs) they will be repo1ted to the IRB in accordance with IRB Attachment GGG: Unanticipated Problems Involving Risks to Subjects or Others. AEs that are not serious but that are notable and could involve 1isks to subjects will be summarized and submitted to the IRB at the time of continuing review.

8.3 Definition of an Adverse Event

An adverse event is any untoward medical occmTence in a subject receiving a test a1ticle and which the occmTence does not necessarily have a causal relationship with the treatment. An adverse event can therefore be any unfavorable and unintended sign (including an abn01mal laborato1y finding), symptom, or disease temporally associated with the use of the test a1ticle, whether or not related to the product.

All AEs (including SAEs) will be noted in the study records and on the case report f01m with a full description including the natme, date and time of onset, dete1mination of non-serious versus serious, intensity (mild, moderate, severe), duration, causality, and outcome of the event.

8.4 Definition of a Serious Adverse Event (SAE)

An SAE is any untoward medical occunence that

- results in death,
- is life-threatening,
- requires inpatient hospitalization or prolongation of existing hospitalization,
- results in a persistent or significant disability/incapacity, or
- is a congenital anomaly/bi1th defect.

8.4.1 Relationship of SAE to study drug or other intervention

It is unlikely that there will be any SAEs in relation to the intervention, as the inte1vention is a social suppo1t inte1vention.

8.5 IRB/IEC Notification of SAEs and Other Unanticipated Problems

The Investigator will promptly notify the IRB of all internal (occmring in subjects enrolled at this site) unanticipated problems involving risks to subjects or others, and Serious Adverse Events that are related to the research activity. Rep01ts will be submitted to the IRB in accordance with the timeline below. External (at other sites) SAEs that are both unexpected and related to the study intervention will be reported promptly.

Category of Prompt Report	Initial Notification
Internal (occmring in subjects enrolled at this site), related (or more likely related than unrelated) SAE	5 days
Internal, unrelated SAE	30 days
External SAE and AEs need not be repo1ted unless it represents an unanticipated problem	A brief summaiy of impo1tant AEs may be repo1ted at time of continuing review
Unanticipated Problems Involving Risks to Subjects or Others	5 days

8.5.1 Follow-up report

If an SAE has not resolved at the time of the initial repolt and new info1mation ai·ises that changes the investigator's assessment of the event, a follow-up repo1t including all relevant new or reassessed info1mation (e.g., concomitant medication, medical histo1y) should be submitted to the IRB. The investigator is responsible for ensuring that all SAE ai·e followed until either resolved or stable.

8.6 Investigator Reporting of a Serious Adverse Event to Sponsor

Not applicable

8.7 Medical Emergencies

Not applicable

9 STUDY ADMINISTRATION

9.1 TREATMENT ASSIGNMENT METHODS

9.1.1 Randomization or Other Assignment

Randomization will be computer generated and stratified by site.

9.1.2 Blinding

Blinding is not feasible due to the nature of the intervention.

9.1.3 Unblinding

fu the case of a SAE the PI will be unblinded.

9.2 Data Collection and Management

We will keep a master list containing all PHI and subject ID numbers separate from data fo1ms that have only a study ID number. The master list will be in a locked file cabinet. We will keep a copy of all data on REDCap, a password protected electronic database which meets Health fusurance Po1tability and Accountability Act (HIPAA) and University security requirements, with the original paper copy locked in a cabinet.

9.3 Confidentiality

All data and records generated during this study will be kept confidential in accordance with fustitutional policies and HIPAA on subject privacy and that the fuvestigator and other site personnel will not use such data and records for any purpose other than conducting the study.

Data will be stored in REDCap, a password protected electronic database which meets Health Insurance Po1tability and Accountability Act (HIPAA) and University secmity requirements. The original consent fo1m, HIPAA authorizations and any wlitten study c01Tespondence will be kept in a locked cabinet in the secured office suite. Only the signed consent fo1m will include patient name, phone number, address and EHR number; all other data stored separately will be linked by a de-identifiable number. A scanned copy of the consent f01m will be placed in the pa1ticipant's EHR. All members of the research team who have access to the data will have completed required Good Clinical Practice and Human Research Protections for Biomedical Study Teams and any other IRB mandated training.

No identifiable data will be used for future study without first obtaining IRB approval. The investigator will obtain a data use agreement between the provider (the Pl) of the data and any recipient researchers (including others at Hennepin Healthcare) before sharing a limited dataset (PHI limited to dates and zip codes).

Risk of breach of confidentiality will be minimal as all data will be linked to a unique numerical ID which does not contain any personally identifiable health info1mation. No personally identifiable health info1mation will be collected for this study. fu the event of a breach of confidentiality, pa1ticipants will be notified and corrective actions will be taken as approp1iate. The IRB will be promptly notified of any confidentiality breaches.

9.4 Regulatory and Ethical Considerations

9.4.1 Data and Safety Monitoring Plan

The principle investigator will provide oversight of the data and safety monitoring plan. All data and records generated during this study will be kept confidential in accordance with Institutional policies and HIPAA on subject privacy and that the investigator and other site personnel will not use such data and records for any purpose other than conducting the study. All data will be stored in REDCap, a password protected electronic database which meets Health Insurance Portability and Accountability Act (HIPAA) and University security requirements. We will keep a master list containing all PHI and subject ID numbers separate from data forms that have only a study ID number. The master list will be in a locked file cabinet. No identifiable data will be used for future study without first obtaining IRB approval.

9.4.2 Risk Assessment

The discussions about mmiality and removal from the transplant list have the potential to cause emotional distress to participants. This possibility would be explained during the informed consent process, and candidates who would not want information about potential waiting list outcomes would not be included. The risk of loss of confidentiality is also present with procedures outlined as above to keep all study material de-identified and confidential. Overall, these risks are minimal with ve1y low likelihood of causing significant harm.

Risk of breach of confidentiality will be minimal as all data will be linked to a unique numerical ID which does not contain any personally identifiable health information. No personally identifiable health infonnation will be collected for this study. In the event of a breach of confidentiality, pa1ticipants will be notified and corrective actions will be taken as appropriate. The IRB will be promptly notified of any confidentiality breaches.

9.4.3 Potential Benefits of Trial Participation

The intervention has the potential to change the par·adigm of pre-transplant counseling. This would help to better info1m patients and their suppmt networks to make critical decisions smrnunding kidney transplantation.

9.4.4 Risk-Benefit Assessment

The benefits of the study outweigh the risks. As precautions will still be taken to minimize risks, the potential benefits offer an opportunity to help educate patients and their families about kidney transplant. Furthermore, the intervention is designed to assist patients in making critical decisions regarding their care, while engaging their social support group.

9.5 Recruitment Strategy

Patients will be selected from transplant centers at HCMC and the University of Minnesota based on the inclusion and exclusion criteria. We will identify prospective subjects through their kidney transplantation counseling appointment. The subjects will likely be composed of both the principle investigator's patients and other provider's patients.

Eligible patients will be called prior to their transplant eligibility screening appointment and asked if they would be interested in hearing more about the intervention at their appointment. If the patient is interested, informed consent will be obtained by a study member during their initial screening appointment at the clinic. The intervention will only begin after patients have gone through the screening process and been identified as candidates for kidney transplant.

9.6 Informed Consent/Assent and IDPAA Authorization

Informed consent will be obtained by members of the study. The consent process will be documented in writing with the long form of consent documentation. Patients will be called prior to their transplant elgibility screening appointment and asked if they would be interested in hearing more about the intervention. If the patient is interested, informed consent will be obtained during their appointment at the clinic. Members of the study team will obtain concent. Patients will give concent for intervention participation.

We will read the consent document with the participant, beginning with a concise and focused presentation of key info1mation to assist the subject to understand the reasons why one might or might not want to pa1ticipate in the research. We will explain the details in such a way that the participant understands what it would be like to take part in the research study. The intervention will only begin after patients have gone through the screening process and been identified as candidates for kidney transplant, weeks after informed concent is obtained.

9.6.1 Waiver of Consent

Not applicable

9.6.2 Waiver of Assent

Not applicable

9.6.3 Waiver of HIPAA Authorization

Not applicable

9.7 Payment to Subjects/Families

Not applicable

9.7.1 Reimbursement for travel, pat'king, and meals

Not applicable

9.7.2 Payments to parent for time and inconvenience (i.e. compensation)

Not applicable

9.7.3 Payments to subject for time, effort, and inconvenience (i.e. compensation)

Subjects will be given a $40 Target gift card at time of participation or $40 check mailed within 30 days after participation in the inte1vention.

9.7.4 Gifts

Not applicable

10 REFERENCES

11 APPENDIX

Baseline and Outcome Evaluations

Patient Survey

1. A patient on dialysis has the same level of kidney functioning as a patient with a transplanted kidney.

   D True

   D False

   D Don't know

2. fu general, patients can live at least 5 years longer with a kidney transplant than if they stayed on dialysis.

   D Tme

   D False

   D Don't know

3. fu general, most people on dialysis are happier with the quality of their lives than people with transplants.

   D Tme

   D False

   D Don't know

4. Patient have better health outcomes if they receive a transplant before starting dialysis.

   D Tme

   D False

   D Don't know

5. If a patient waits long enough on the waitlist, a matching kidney from someone who has died will definitely become available.

   D Trne

   D False

   D Don't know

6. About what percentage of all transplanted kidneys function for at least one year?

   0 50%

   0 75%

   0 90%

   D Don't know

7. Nationally, how long do patients generally wait on the wait list for a kidney from someone who has died?

   D <1 year

   D 1-2 years

   D 3-5 years

   D >5 years

   D Don't know

8. Compared to transplants from donors who have died, how long do transplants from living donors last?

   D Shorter

   D Longer

   D Same

   D Don't know

9. What is the chance that a living donor or recipient would dies undergoing surge1y?

☐ <1%

☐ 3%

0 10%

0 25%

D Don't know

10. Do you feel SURE about the best choice for you?

D Yes

ONo

11. Do you know the benefits and risks for getting a kidney transplant?

D Yes

☐No

12. Are you clear about which benefits and risks matter most to you?

D Yes

☐No

13. Do you have enough suppo1t and advice to make a choice?

D Yes

☐No

14. I have a positive outlook toward life.

D Strongly agree

D Agree

0 Disagree

D Strongly disagree

15. I have sh01t and/or long-range goals.

D Strongly agree

D Agree

D Disagree

D Strongly disagree

16. I feel all alone.

D Strongly agree

D Agree

D Disagree

D Strongly disagree

17. I can see possibilities in the midst of difficulties.

D Strongly agree

D Agree

D Disagree

D Strongly disagree

18. I have faith that gives me comfort.

D Strongly agree

D Agree

D Disagree

D Strongly disagree

19. I feel scared about my future.

D Strongly agree

0 Agree

D Disagree

D Strongly disagree

20. I can recall happy/joyful times.

D Strongly agree

D Agree

D Disagree

D Strongly disagree

21. I have a deep inner strength.

D Strongly agree

D Agree

D Disagree

D Strongly disagree

22. I an1able to give and receive caring/love.

D Strongly agree

D Agree

D Disagree

D Strongly disagree

23. I have a sense of direction.

D Strongly agree

D Agree

D Disagree

D Strongly disagree

24. I believe that each day has potential.

D Strongly agree

D Agree

D Disagree

D Strongly disagree

25. I feel my life has value and wo1ih.

D Strongly agree

D Agree

D Disagree

D Strongly disagree

26. How confident are you filling out medical f01ms by yourself?

D Extremely

D Quite a bit

D Somewhat

0 A little bit

D Not at all

Family Survey

1. A patient on dialysis has the same level of kidney functioning as a patient with a transplanted kidney.

   D Trne

   D False

   D Don't know

2. In general, patients can live at least 5 years longer with a kidney transplant than if they stayed on dialysis.

   D Trne

   D False

   D Don't know

3. In general, most people on dialysis are happier with the quality of their lives than people with transplants.

   D Trne

   D False

   D Don't know

4. Patient have better health outcomes if they receive a transplant before sta1iing dialysis.

   D True

   D False

   D Don't know

5. If a patient waits long enough on the waitlist, a matching kidney from someone who has died will definitely become available.

   D Trne

   D False

   D Don't know

6. About what percentage of all transplanted kidneys function for at least one year?

   0 50%

   0 75%

   0 90%

   D Don't know

7. Nationally, how long do patients generally wait on the wait list for a kidney from someone who has died?

   D <1 year

   D 1-2 years

   D 3-5 years

   D >5 years

   D Don't know

8. Compared to transplants from donors who have died, how long do transplants from living donors last?

   D Sh01ter

   D Longer

   D Same

   D Don't know

9. What is the chance that a living donor or recipient would dies undergoing surgery?

   ☐ <1%

   ☐ 3%

   ☐ 10%

   0 25%

   D Don't know

10. I am confident that I could deal efficiently with unexpected events.

D Never

D Ahnost never

D Sometimes

D Fairly often

D Ve1yoften

11. I intend to help my friend or family member get through the transplant process.

D Strongly agree

D Agree

D Neither agree nor disagree

D Disagree

D Strongly disagree

12. A.re you seriously thinking about helping my friend or family member get through the transplant process?

D Yes

☐No

13. How confident are you filling out medical forms by yourself?

D Extremely

D Quite a bit

D Somewhat

0 A little bit

D Not at all