

## JOURNEYS OF SURVIVAL: KIDNEY TRANSPLANT STORIES FROM THE PHILIPPINES

<sup>1</sup>Ramon Gabriel Fernandez

### Article Info

**Keywords:** Kidney transplant, organ donation, transplant.

### DOI

10.5281/zenodo.13144344

### Abstract

Organ donation and transplantation remain the best and most cost-effective clinical approach for people in the terminal stage of organ failure. Given the growing numbers of incidences of patients treated for end-stage renal disease (ESRD) and the plummeting rate of kidney transplantation in the US and Southeast Asia, little is known about the understanding of the life stories of kidney organ transplant recipients, specifically in the Philippines. The present study aimed to provide a narrative study of the life stories of individuals who received kidney transplantation through either a live or deceased organ donor. By employing Dewey's theory of experience, the shared stories of the transplant recipients yielded the following themes: carefree life, struggles before transplant, and psychological effects of the past; support system, journey to liminality, and positive outlook in life for the present stories; giving back, fatalistic view of life and sense of normalcy for the future aspirations or stories of the respondents. Kidney transplantation goes beyond the surgical process; it encompasses lifelong social and psychological transition and transformation for kidney transplant recipients.

### INTRODUCTION

In the medical field, the process of dying is usually initiated by the failure of a particular organ. Fortunately, patients with failing organs can be given a second chance at life through organ donation and transplantation. Organ donation and transplantation remain the best and most cost-effective clinical solution for people diagnosed with end-stage organ failure. It is an exceptional life event; it is a turning point in the patient's individual story. In 2018, the Global Observatory of Donation and Transplantation reported 140,964 organ transplants worldwide. The demand for kidney transplants in the United States continues to exceed the supply of available organs, despite the relatively stable ratio of deceased donor to living-donor transplants in recent years. This challenge is compounded by the growing number of patients with end-stage kidney disease and the consequent increase in the transplant waitlist. In 2019, there were almost 59,000 adult candidates on the waiting list, with less than 23,000 patients receiving transplants annually. This situation underscores the critical need for more effective strategy to address the donor shortage and improve access to life-saving kidney transplantation. In 2017, kidney and liver transplants were the most common organs transplanted, while small bowel transplants were the least common.

<sup>1</sup> Department of Psychology, College of Education, Arts, and Sciences, National University, Manila, Philippines.

While there is information available about organ transplantation, including how to become an organ transplant donor, there is still a barrier to adequate coverage for kidney transplants. Espina, (2024) revealed that the Philippines leads Asia in living organ donation. However, NKTi further added that while this is true, there is still a lack of organ donors in the Philippines. In China, the study by Zhang et al. (2022) explored the perceived barriers of potential donors, categorizing them into four layers: personal, familial, societal, and cultural barriers. Furthermore, a study from Brunei Darussalam shows that the lack of donors and poor knowledge were the main barriers to patients receiving kidney transplants (Farah et al., 2018). Despite the number of donors in the Philippines, it is still evident that the ratio of donor recipients is not significant enough to meet the demands. Cowie et al. (2023) discussed that the most common reasons for not wanting to become a donor are doubts in the healthcare system regarding how their organs will be used appropriately, and simultaneously, the lack of knowledge on what organ donation is and how it is necessary.

Given the growing numbers of reported cases of kidney transplantation and treated end-stage renal disease (ESRD) in Southeast Asia and the US (Chan-On, 2017), little is known, however, about the understanding of the life stories of kidney organ transplant recipients. Despite the existence of studies which reported the recipient perspective, there is still a lack of understanding of the patient's experience before and after their transplants. Boaz and Morgan (2014) and Orr et al. (2007) focused on the lived experiences of patients' post-transplant and donation. Boaz and Morgan (2014) study on the return to normalcy after kidney transplantation, and Orr et al. (2007) whose focus groups were utilized to analyze quality of life. In the study, fear, gratitude, and medicalization of their lives were the common themes identified as they define a normal life. However, aside from post-transplant experiences, it is also necessary to understand the challenges faced by individuals in the transplant waiting list prior to organ donation and transplantation.

Kristensen et al. (2020) investigated the existential encounters of patients in their daily routines prior to transplantation from a living donor. The study revealed that patients express their kidney function through numerical values to make it tangible and understandable for themselves and others. It is crucial for patients to maintain a sense of normalcy during the period of waiting between donors. Evaluation and transplantation can elicit a range of emotions, including excitement, hope, and frustration. Furthermore, Cottrell et al. (2019) utilized closed-ended questions to have a clearer understanding of the patient experience. Using open-ended questions, however, revealed themes like improvements in quality of life, a return to normalcy, better health, and more energy.

Further, respondents identified concerns for the future naming duration of graft survival, fears about one day returning to dialysis or needing to undergo another kidney transplant, comorbidities, future quality of life, and the cost and quality of their healthcare (Tucker et al., 2019).

In the Philippine context, there are limited qualitative studies that explore the life experiences of patients' posttransplant. Considering this evident dearth in the literature and availability of resources, specifically in the Philippines, this study aimed to provide a narrative study about the life stories of individuals who received a kidney transplantation through either a live organ donor or deceased organ donor. This study further explored the donor-patient relationship, including the optimism, wellbeing, and support group of kidney transplant recipients.

### **Organ donation and transplantation**

The medical technique known as organ transplantation involves removing an organ from one body and implanting it into the body of a patient who has damaged organs. An organ donor is referred to as a donor, whereas a patient who receives an organ is referred to as a recipient. Both the donor and the recipient may be present in the same place, or organs may be transported from the donor site to the recipient site using an appropriate technique. Living

or brain-dead individuals can donate their organs. However, in the realm of medical and surgical science, cadaver transplantation is one of the most difficult, complicated, and dangerous specialties. Overall, the medical team must have patience, financial consideration, ethical consideration, dedication, and expertise to successfully perform a transplant. It poses a serious risk to the patient's life. Yet in medicine, it is regarded as one of the century's most remarkable cures (Deshmukh and Baheti, 2020).

### **Kidney organ disease**

Chronic kidney disease (CKD) is defined as a persistent abnormality in kidney structure or function for more than 3 months. According to Mayo Clinic (2023), loss of kidney function is a sign of chronic kidney disease, commonly known as chronic kidney failure. Waste and extra fluid are removed from your blood by your kidneys and then passed through your urine. If you have advanced CKD, your body may retain dangerous amounts of fluid, electrolytes, and waste. Both diabetes and hypertension are the primary causes of CKD in mid and high-income countries (Webster et al., 2017). In the incidence, prevalence, and progression of CKD, epigenetic influences play a significant role. Some people experience non-specific symptoms such as lethargy, itchiness, or loss of appetite, and diagnoses are considered when symptoms worsen or when procedures (such as blood or urine testing) show unexpected results.

Jankowski et al., (2021) stated that most patients with CKD have a high risk of enhanced cardiovascular disease and death.

### **Prevalence of kidney organ disease**

Chronic kidney disease (CKD) is becoming one of the most prominent noncommunicable causes of death worldwide, primarily due to its high prevalence. It is anticipated that over time, it will impact a growing number of people and gain more significance among the different causes of death worldwide (Kovesdy, 2022). In developing nations, chronic kidney disease is very common. The causes that affect kidney malfunction include age, sex, hypertension, diabetes, history of cardiovascular disease, hyperuricemia, area of residence, and economic status. CKD has already been recognized worldwide in public health. Lv and Zhang (2019) claimed that the global burden of morbidity and death is directly impacted by CKD through its impact on cardiovascular risk and end-stage kidney disease (ESKD). The increase in the prevalence of diabetes mellitus, hypertension, obesity, and aging are key factors contributing to the global rise of this disease, although additional factors like infections, herbal poisons, and environmental toxins are still prevalent in some areas.

George et al. (2017) highlighted growing public health concern. In the United States, the number of patients with end-stage renal disease is increasing at a yearly rate of 7-8%. However, there are still not enough kidneys available for transplantation, leading to a growing gap between the number of transplantations desired and those carried out. In 2019, more than 16,000 kidney transplants from deceased donors and 6,800 transplants from living donors were carried out in the United States; the proportion of transplants from deceased donors to transplants from living donors has remained steady over the past few years. Since everyone is aware of the potential necessity that donors may bring to their intended recipient, there are serious obstacles due to the shortage of donors and the fact that the number of ESKD patients is increasing daily. The number of adult candidates still actively seeking transplants was around 59,000 in 2019, and each year, roughly 23,000 people underwent the procedure. This imbalance is likely to worsen over the coming years due to the anticipated rise in kidney failure rates associated with worldwide obesity and diabetes. Additionally, the United States adopted new allocation mechanisms in 2014 to increase the use of underutilized kidneys and ensure fair organ distribution in the country.

### **Organ donation and transplantation in the philippine setting**

According to the "Organ Donation Act of 1991" in the

Philippines, each person may donate all or any portion of their body through a legacy or bequest under the new legislation. In the absence of the decedent's intention to the contrary, family members may also approve such a contribution. Only contributions given for therapy, research, or medical education are considered valid. Although acknowledged, international organ sharing requires Department of Health clearance. The Act's regulations are about to be created, and they will be widely publicized to promote donations. Under Republic Act (RA) 349, and as amended by RA 1056; and according to Presidential Decree (PD) 856, any person may validly grant to a licensed medical doctor (MD), surgeon, known scientist, or any medical/scientific institution or eye banks, the authority to detach at any time after the grantor's death any organ, part, or parts of their body, and to utilize the same for medical, surgical, or scientific purposes. The authorization must be in writing; and the institution granted the authorization, the particular body parts, and the particular uses must all be specified. Additionally, the written authorization must also be signed by two disinterested persons as witnesses. If the donor is a minor, the authorization may be given by the parents. A married person may grant authorization to donate organs even without the consent of the spouse. Even after death, the nearest relative may grant permission to donate the organs of the deceased. In the absence of any nearest relative, permission may be given by the head of the hospital or institution having custody of the deceased. It is illegal to remove the organs of a person who died of a dangerous communicable disease. The legal and detailed steps for obtaining a kidney are listed here. The donor and receiver must attend pretransplant orientation as the first stage. After that, they must speak with a nephrologist and a transplant surgeon, and then they must submit all necessary paperwork to the HOPE office. For live related donors, HOPE certification is required. For living, unrelated donors, an ethics examination will be done to secure HOPE certification. For cadaveric donors, requirements must be secured and updated monthly to keep an active kidney transplant file. The Philippine Health Insurance Corporation (Philhealth) introduced its Z Benefit Package for kidney transplantation in 2012 with the goal of improving the financial risk protection of its members, particularly the underserved group, to address the growing health inequity. This package provides a sizable amount to subsidize the transplant.

Since 2015, the University of the Philippines-Philippine General Hospital (UP- PGH) has been one of the government hospitals under contract to deliver this benefit package. In addition to this, there's a bill that supports people with end-stage renal disease. House Bill 983, also known as "An act providing for comprehensive renal care for patients with end-stage renal disease in all government hospitals at the national, regional, and provincial levels increasing the Philhealth benefit package for renal replacement therapy and appropriating funds therefor," aims to include comprehensive renal replacement therapy services in the coverage of treatment services provided by Philhealth in order to make them available to all Filipinos suffering from ESRD. It also supports kidney transplantation as the gold standard treatment option for ESRD. The expansion of Philhealth benefit packages for kidney transplantation or renal replacement therapy, as well as the provision of free dialysis services to indigent patients, is among the key provisions. Furthermore, all government hospitals at the national, regional, and provincial levels must establish, operate, and maintain a dialysis service facility, as it provides the highest quality of life and ensures the patient's full rehabilitation.

Organ transplantation is currently a viable therapy option in the Philippines. This includes kidneys, pancreas, liver, and soon, the heart and lungs. For paired organs such as the kidney, the donor may be a living donor or a cadaver in a "brain dead" state. For single organs such as the pancreas, liver, or heart, the donor must be a cadaver. In the Philippines, as in the whole world, the biggest obstacle is the paucity of organ donors, which is somewhat addressed by the practically universal acknowledgment of "brain death." In this country, the additional

financial barriers that patients face in accessing dialysis make kidney transplantation an essential necessity. If donor sources are restricted, there will be disagreements over the moral and legal elements of living non-related gifts. Solutions presented in wealthy countries may have little relevance to our situation now. All our people should have access to donor organs. The only way to meet this requirement is for the public to be aware of and understand the issues surrounding organ donation.

## **METHODOLOGY**

### **Research design**

A qualitative research approach was employed for this study to better understand the narratives presented. A qualitative-narrative research method was chosen as it addresses the “how” and “why” research questions, allowing for a deeper understanding of experiences, phenomena, and context. Qualitative research enables exploration of questions that cannot be easily quantified, providing insight into human experiences. Additionally, it offers a clear depiction of the issues, challenges, and concerns faced by participants, facilitating informed decision-making (Cleland, 2017).

Specifically, a narrative approach, which focuses on describing experiences and providing interpretation, was utilized in this study.

Narrative research involves the collection and analysis of people’s story (Cleland, 2017). This approach was deemed the most suitable for detailing the life stories explored in this study.

### **Participants**

The study focused on narrating the life stories of 8 kidney organ transplant recipients. Convenience sampling was utilized to select participants due to the limited nature of the study. Specifically, individuals endorsed by the National Kidney Transplant Institute were contacted for participation. According to Beitin (2012), research sample sizes can range from a minimum of 6 participants to a maximum of 12 participants, as cited by Kim (2015). Similarly, Creswell and Miller (2000) suggests that narrative research is particularly effective in capturing in-depth stories of either one person or a few individuals, emphasizing the acquisition of detailed information about a limited number of individuals' lives.

The inclusion and exclusion criteria for participants were as follows: individuals aged 18 to 60 years old, recipients of kidney transplants from either living or deceased donors, and recipients of kidney organ transplants within the last five years.

### **Measures**

The instrument used in this study consisted of guided questions generated from the research question. A semi-structured interview method was employed to gain a better understanding of the participants' life stories in relation to their experience of receiving a new kidney organ. The guide questions explored their experiences before the transplant, after the transplant, and their outlook on life in the future, including their aspirations. The questionnaire developed by the researchers was validated by Subject Matter Experts in the field of Psychology, including one with expertise in the medical field.

### **Procedure**

After obtaining approval for the study, a letter was sent to the NKTi Human Organ Preservation Effort (HOPE) division to request information on potential study participants. Once the NKTi HOPE division released the organ recipients' information, they were contacted to confirm their participation. Upon confirmation, participants were scheduled for either an online or face-to-face interview, based on their preference. Prior to the interview, participants received electronic consent forms detailing the study's purpose, background, potential risks and benefits, voluntary nature of participation, their rights, and the confidentiality of their information.

Subsequently, interviews were conducted based on participants' preferred schedules and modalities. The recordings of the interviews were then transcribed and processed to generate themes and codes for the study. The researchers utilized Dewey's three-dimensional space narrative structure approach, focusing on interaction, continuity, and situation, to find meaning in the responses of the participants. This approach, rooted in the philosophy of experience, provided insight into the personal and social context of the participants' experiences, making it suitable for understanding their narratives. To validate the themes and codes generated from the study, triangulation was conducted. Triangulation involves utilizing multiple sources of information and analyzing evidence to establish coherent themes or conclusions. The generated themes and codes were reviewed by the research adviser and discussed with subject matter experts to enhance credibility and validity. Finally, participants were provided with the themes and codes for feedback to validate and ensure accurate interpretation of their responses.

## **RESULTS**

Table 1 presents the demographic profiles of the 8 respondents who participated in this study. The table presents the participants' gender, age, period after transplantation, type of donor, and reason for transplantation.



**Table 1.** Demographic profiles of the respondents.

Name	Sex	Age	Months/Years after transplantation	Type of donor	Reason for transplantation
Jose	M	56	Less than a year	Living	Diagnosis of CKD stage 3
JP	M	27	1 year	Living	Diagnosis of CKD stage 5
Anj	F	30	3 years	Living	Shrinkage of both kidneys
Carly	F	38	Less than a year	Deceased	Diagnosis of CKD stage 5
Ivy	F	30	Almost 4 years	Living	Diagnosis of IGA Nephropathy
RA	F	31	Less than a year	Living	Shrinkage of both kidneys
V	M	28	Less than a year	Living	Kidney complication
Jo	F	27	Less than a year	Deceased	Rejection of first kidney transplant

### **Stories of the past**

The recipients' lives before receiving kidney organ transplants were identified as the stories of the past in this study. Three themes emerged from the analysis of the shared stories of the past of kidney organ transplant recipients, including carefree life, struggles before transplant, and psychological effects.

#### **Carefree life**

Prior to learning about their sickness, recipients JP, Ivy, and RA admitted that they had abused their life. Among the unhealthy habits were maintaining an improper eating pattern, neglecting importance of hydration or water intake, consuming large quantities of alcoholic beverages, and getting little to no sleep. Some of these recipients were once also easygoing people since they said that their peers never experienced difficulties when they accepted their invitations to join spontaneous gatherings.

#### **Unhealthy lifestyle**

“When we broke up, I became addicted to alcohol...” - JP

“I really cannot say either... or then, I have never liked water instead I like salty.” - Ivy

“...I must finish everything I’m doing even if I feel I need to pee, as long as I finish everything I do, then I don’t drink water aside from that I always eat fast foods something like that ...” - RA

#### **Easygoing**

“As in, when there is an invitation to go out, just go out without hesitation. Like abuse. When someone invites you to drink, it’s like nothing, just go.”- JP

“Then just happy go lucky, go here go there, but I did not drink even I did not smoke maybe because of not eating healthy.” - RA

#### **Struggles before transplant**

Aside from the fact that these individuals were carefree before learning about their illness, they also faced difficulties prior to transplantation or while undergoing dialysis. The recipients discussed dealing with hardships related to their illnesses, including feeling easily exhausted from everything and how their physical restrictions ultimately affected their ability to do their jobs. Additionally, a few of the recipients experienced discrimination at the workplace, leading some to stop working, which caused almost all recipients to experience financial hardship as they awaited transplantation.

#### **Physical limitations**

"I get tired very quickly! I was so out of breath that time I couldn't work anymore." - JP

"I am like a withered vegetable, without strength. That's why I was always dizzy so I couldn't work and since I got sick." - Anj

"I feel I'm always tired suddenly, after the last thing that happened to me was when my feet were numb, as if I couldn't walk properly." - Ivy

### ***Stigma/Discrimination at workplace***

"Of course, yes. Because how you apply corporate is what I'm used to. How will a company hire you if you can't do anything hmm it is three times a week, MWF, you are on dialysis." - Jose

### ***Financial burden***

"Then our lives are still difficult because of dialysis, every three days, I'm still in Medical City undergoing my dialysis." - RA

"First, finances, because my medicines are so expensive, I started with P54,000 per month and after six months, it became P27,000 per month." - Carly

### ***Psychological effects***

Since their illnesses prevented them from doing whatever they wanted, participants in this study undoubtedly experienced psychological effects while dealing with their diseases. Specifically, Ivy, who was diagnosed with PTSD, severe depression, and anxiety, needed isolation from her loved ones. Other recipients, however, experienced fear and anxiety, denial, and frustrations during their pre-transplantation.

### ***Fear and anxiety***

"My anxiety became too much, even when I went to the CR or left the house." - RA

"Of course, in my family... then I'm thinking about what... because sir, I'm thinking about my family, then I also think that people will cry for you for just a week, you will be just a story after that." - V

### ***Isolation***

"You haven't been with anyone for a year, you're just in your room, it's so... just, there's something going on... it's crazy, crazy." – Ivy

"My self-confidence dropped, as in zero. I don't leave the house, I only go out once I have a session but I wrapped up myself..." - JP

### ***Denial***

"So, we were still in denial at that point. 'I won't get dialysis first, I won't get dialysis first.' It took almost a month like that so on April 22 when I couldn't take it anymore, I was hallucinating, as in I was losing myself..." - RA

"First thing that came to my mind, I didn't take it seriously. What... as in I said... Uhh because the doctor told me to think that I'm a normal child, I'm normal but I just must endure." - Jo

### ***Frustration***

"I was frustrated actually... I should be graduating college. I will graduate in a few months. So, Jo's world collapsed again. Charot! But then, like I said, what's the point of not letting me graduate first? It's so... bad. I have never been employed." - Jo

### ***Stories in the present***



The lives of the recipients after receiving kidney organ transplants were identified as the stories in the present in this study. Three themes emerged from the analysis of the shared stories in the present of kidney organ transplant recipients, including (1) Support System, (2) Journey to Liminality, and (3) Positive Outlook in Life.

### **Support system**

Evidently, family and friends are the ones people will expect when talking about a support system. Thus, when the discussion of having a support system came into play, transplant recipients JP and RA enthusiastically talked about the support and encouragement they received from their loved ones as they dealt with their post-transplantation period of life.

#### ***Familial support***

“It's like others are leaving you behind, right? Because 'they're already sick,' as if they're just waiting for you to weaken. But for me, they didn't. Instead, they embraced me even more, loved me even more.” - JP

#### ***Social support***

“...I am very lucky with my friends from the beginning they are there for me. Ahn I'm in the hospital or they knew I was sick. On April 22 they made a page forming, what I will pay in the hospital is Php 1.2 million they provided Php500,000.00. They asked for help everywhere and they sold something...” - RA

### **Journey to liminality**

Subsequently, recipients welcomed their new "normal" life as soon as they received their new kidney organ, since they realized, they couldn't continue to live the same way they had before discovering their conditions and after the transplant. As would be predicted, recipients have restricted physical activity and have become more cautious with their eating habits after transplantation. However, recipients also expressed gratitude for getting at least a second opportunity in life, despite having limits on their daily ability to function properly.

#### ***Limited physical activities***

“It's hard, it's hard. I can't even walk, and the stitches hurt...” -JP

“You can't lift heavy, you can't stress, you can't overwork.” – Anj

#### ***Cautious food intake***

“Like that with water there is also a limit, I don't drink too much.” -V

“The problem now is I'm not allowed to eat ordinary food that you can buy anywhere. My foods will be enriched now, to be honest. We can't eat at the carinderia because then style of cooking in carinderia is sometimes unhealthy. -Jose

### **Positive outlook in life**

Despite every negative feeling that they went through, the recipients continued to look for the positives, which made them respect life even more than they had in the past. In particular, Recipient JP said that life is beautiful. On the other hand, some of the recipients currently seemed to take their existence more seriously. The recipients stated that their relationships with their families had improved since receiving their new kidneys, as compared to before. While RA had post-transplant gratitude, Anj had the impression that time was valuable.

#### ***Cherishing Life***

“I think that life is fun to live, as if it is good to live. It's good to be alive, I thought ‘wow what God has done’. It's good to be alive so I thought to enjoy life, enjoy every single moment of your life...” -JP

#### ***Optimism***

“Every day is positive; you must be happy. Even if the people around you are negative, take them as positive, how can you turn the negativity you see in our environment into something positive...” - JP

### ***Increased affection for the family***

“And my family is still there for me, you know, just to make our family bond stronger with the relatives, right? They just get closer again, like before when they weren't, now it seems like they're reconnecting and getting closer again.” -RA

“We used to not say hello, like that. But now they say hello to each other. How are they, we are having a video call today. It's not like before, we don't even call to say hello... now we always say hello...”-Anj

### ***Increased value for time***

“It's like a life extension. So, you don't know how long this kidney will last, but we are praying that kidney will last longer, so we want our experience to be a happy one with me that I'm not on dialysis that I'm transplant like that...” -Anj

### ***Sense of gratitude***

“Yes, because for me that depth of gratitude that will be called, that's what I'm basing on, not what they showed me when I was sick. Regardless of all that, whatever it is, the important thing is that they helped me.”-RA

### ***Stories of the future***

The future and aspirations of the recipients after receiving kidney organ transplants were identified as the stories of the future in this study.

Three (3) themes emerged from the analysis of the shared stories of the future and aspirations of kidney organ transplant recipients, including (1) Giving Back, (2) Fatalistic View of Life, and (3) Sense of Normalcy.

#### ***Giving back***

After the transplant, recipients felt an immense amount of gratitude due to the fact kidney donors gave their kidneys to recipients out of a sense of compassion. In light of this, quite a few of the respondents expressed a desire to serve as advocates for both those in need of kidney transplants and their fellow recipients such as recipients RA and Jose. The fact that their families had supported them in every manner, particularly financially, some also wished to return the favor by working again.

#### ***Advocacy***

“Right now, the most advocacy... my advocacy is like to call it, it's like getting a kidney transplant, that dialysis once they asked me, I saw it on the page, I saw them in the dialysis fields, I saw them at KTPH, and I answered every time.” -RA

“Before I forget, I want to advocate for an organ donation. To be an advisor to those who are planning, making plans, and to help those who are doing fund raising...” Jose

#### ***Familial responsibilities***

“To give my mother a good life somehow, that I can experience giving from me. I want to give not always my sibling.” -V

“...Number 1 is that I wish my youngest could take medicine because he is very serious in study. That will take another 5 years, so I must be productive again.” Jose

#### ***Fatalistic view of life***

Due to prior the illness they had endured even before receiving transplanted organs and their fear that it might occur again, the respondents in this study, specifically Ivy, Jo, and Carly wanted to take care of their eating habits and way of life. Several of the participants, however, felt the need to pause and reflect on what they ought to do with their life such as Anj who wanted to travel to other cities.

#### ***Fear of recurrence of the disease***

“Careful/Caution/Beware, because it's hard especially when you get rejected, as much as possible be careful

with food but sometimes still tasting pork, like that.” – Ivy

“I look at life that I’m afraid. I have so many fears. I’m afraid that might get sick like that, I don’t want to.” – Jo

“I don’t want to be stress, I don’t want to be tired, I don’t want to stay up late, because it’s dangerous for the kidneys. Those are not allowed in the kidney.” Carly

### ***Uncertainties***

“So now, that’s what I want to do, to be able to travel. I don’t want to do anything other than to make money and to travel...” -Anj

### ***Sense of normalcy***

A new kidney organ signified an entirely new beginning for the participants in this study. As a result, when asked about their aims, nearly all of them expressed desire to go back to work, finish their education, and have a secure future for themselves and their families. It is incredible to note that these individuals decided to pursue their ambitions in life despite all the difficulties they had to endure.

### ***Return to work***

“Although my business has stopped, I will continue it, I hope I can revive at least, am employee, I have a fixed income and I can survive the business that has stopped temporarily.” -Jose

“I look forward to working back in the office because I usually work online.” – Jo

“Of course, we still must work in the way we can so that we can also provide for our needs...” -Carly

### ***Continuing education***

“Once I fully recover sir, what I want to do in life is I will study for six months and after I study for six months, I leave sir, I will work hard and save money.” –V

“And until I graduate.” -Ivy

### ***Stable life***

“I just really wanted before, sir, my previous plan was to have my own compound sir, then when I have done all that and the money is making money, I can probably retire sir, and that the moment I will go back to the Philippines. That’s just my plan in life, sir.” - V

## **DISCUSSION**

### ***Stories of the past***

Prior to undergoing transplantation, (1) carefree life, (2) struggles before transplant, and (3) psychological effects were the themes generated based on the stories shared by the kidney transplant recipients. In understanding the life stories of kidney transplant recipients, it is important to account what led to the disease, and the lifestyle of the respondents. This is to provide a framework for the public in understanding how certain lifestyles affect the prognosis of any disease. From the narratives of the recipients, several respondents stated that they engaged in an unhealthy lifestyle such as binge drinking, overworking, and eating salty and junk foods which led them to having kidney complications. Consistent with his finding was a study done by Idriyanti et al. (2019) which found that alcohol consumption and the consumption of unhealthy beverages (for example, caffeinated, carbonated, and alcoholic drinks) may play a role in the development of CKD.

It is evident that prior to receiving a new organ through transplantation, dialysis patients experience different kinds of struggles. Throughout the interview, among those struggles were focused on the stigma or discrimination they experienced in the workplace or employment, the financial burden, and the physical limitations of their diagnosis. Castle et al. (2023) determined that non-pharmacological interventions such as optimizing diet, active physical activity, and exercise are vital in the prevention and even in managing the treatment of CKD. This, however, becomes a struggle on how people can adapt to these potential kidney-specific solutions.

Following the diagnosis, patients felt the struggles of physical limitations. Recipients reported having weaker immune systems, frequent shortness of breath, and fatigue that prohibits them to participate in their regular physical activities. In terms of physical limitations which often resulted in stigma/discrimination in the workplace, Takahashi et al., (2018) compared the data between kidney recipients and the dialysis population in terms of physical activity levels where they found out that the former is higher than the latter.

The struggles of kidney transplant recipients are anchored on the physical limitations that hinder them from functioning which even affects their work. Tsutsui et al. (2017) support this experience in their study which revealed that patients on dialysis were predominantly affected by physical struggles such as constant hospital visits, and physical distress often leading to unemployment.

Additionally, among the struggles of dialysis patients are the financial burden that comes along with the treatment. Ng et al (2021) analyzed the significant relationship of financial hardships due to cost of treatment and reduced productivity among patients with ESKD on dialysis. This presented the struggles of dialysis patients in terms of financial constraints due to the costly process of dialysis.

In terms of the psychological effects of their diagnosis and dialysis, Hao et al. (2021) described dialysis patients as a “highly susceptible” group when it comes to being high risk for psychiatric symptoms. Evidently, this suggests dialysis patients are prone to stress thereby making them susceptible to psychological issues such as fear and anxiety, even leading to diminished self-confidence. Consequently, denial also became a central theme among the respondents and their families in accepting the disease and the health status of their loved ones. Some patients downplayed or outright denied the severity of the illness of their loved ones. Griva et al. (2020) discussed how patient-related barriers affect timely dialysis access preparation, mentioning that denial was often used to describe patients' disengagement with services, including defaulting care, inertia in terms of decision making, or actions, such as following up with referrals.

Following the diagnosis, some patients experienced changes in their bodies which often lead to problems with their self-image consequently leading to their isolation from people and frustrations with their diagnosis. This finding is supported by a study conducted Shahgholian and Yousefi (2018) where participants expressed sentiments of being socially disconnected, experiencing physical constraints, and harboring concerns about unfavorable medical outcomes, all of which collectively contributed to feelings of sadness, depression, and hopelessness.

### **Stories in the present**

Following the transplantation, (1) support system, (2) journey to liminality, (3) and positive outlook in life were the common themes that emerged from the shared stories of kidney transplant recipients. A vital source of positive transformation for kidney transplant recipients is anchored to their support system. Recipients affirmed that social support and familial support fueled their desire to persevere. After kidney transplant surgery, several challenges arise which can further generate anxiety and depression among the recipients. In a study conducted by Hu et al. (2021), 25% of the recipient's experienced depression while 12.55% among 88 renal transplant recipients experienced anxiety. Addressing this issue, Hu et al. (2023) found that sufficient social support alleviates adverse effects of illness perception and enhances overall psychosocial adjustment after the kidney transplantation.

In the present study, recipients felt unconditional love and support from their family and social circles after receiving an organ through various ways such as financial and emotional support. They drew strength from their families and some from their significant other, reiterating that following the transplantation, a stronger bond was formed. Omid (2018) found that there was a direct and significant association between quality of life and the level of social support in patients with renal transplantation. It is therefore necessary to pay special attention to the role of families in increasing the quality of life of patients and consequently, their health promotion. Healthcare

personnel may consider the quality and quantity of support the patients need by mobilizing support resources in the community and by family participation as a low- cost and effective way to improve the quality of life of the patients.

Common factors among kidney transplant recipients are their limited physical activities and cautious food intake post- transplantation, their journey to liminality. Favi et al. (2021) discussed that it is not uncommon for kidney transplant recipients to experience feeling as if they are still in dialysis in terms of physical constraints. Further, the study indicates multiple factors including dialysis vintage, comorbid conditions, psychosocial, and socioeconomic factors, as well as chronic exposure to immunosuppression can all negatively impact the physical activity of a kidney transplant recipient.

This leads to complications far worse than limited physical activity as Kenawy et al. (2019) found that patients who have undergone kidney transplantation are at a higher risk compared to other groups in terms of developing conditions like high blood sugar

(hyperglycemia), hypertension (high blood pressure), and weight gain. This increased risk is attributed to immunosuppressant medications such as prednisolone, mycophenolic acid, and tacrolimus, which can elevate blood pressure, blood glucose levels, cholesterol, and triglycerides. To mitigate these side effects and enhance the success of renal transplantation by reducing the presence of interleukin 6, a substance that promotes inflammatory and autoimmune processes in the body, it is crucial for patients to adopt a healthy lifestyle. This includes adhering to a balanced diet and engaging in regular physical activity. In narrating the life stories of each of the respondents, it is evident that a positive outlook in life is prominent among the respondents. Note that the stress of having gone through dialysis is not immediately replaced after a transplant. In the study, the recipients also expressed their increased value for time following the transplantation as they try to retrieve the time lost during dialysis and win a little time back.

From the narratives of the recipients, a developed sense of gratitude was found. Respondents believed that regardless of the amount of help they received in their journey as a kidney recipient, they could see it as something to be grateful for. Credle (2020) paved both qualitative and quantitative data in understanding the sense of gratitude among kidney transplant recipients and how this becomes a form of coping mechanism for them. Credle (2020) further found that gratitude shows a positive relationship with better psychological health. Drawing on vested interest theory, organ transplant recipients cite this gratitude as a factor for their altruistic actions which manifests in valuing their new life, and showing compassion in helping other people who are in the same situation as they were. Recipients also affirmed that they cherish their new life given through organ transplantation. Some recipients view their life as beautiful and worth living. Credle (2020) suggested that despite the hardships they faced, recipients were able to cherish new, positive, and healthy life through strength-based strategies such as resilience, post-traumatic growth, and gratitude.

Additionally, increased affection for the family members was also common among the participants. Recipients felt they developed stronger bonds with their family after their transplant. A similar result was found in study conducted by Ralph et al. (2019) which highlights that while some participants thought their relationship did not change following transplantation, others were citing a unique connection through increased contact. Previous study also found that open communication and feeling of being supported through their medical journey and daily struggles made them feel secure (Leblond et al., 2019). Similarly, the findings of this study suggest That despite the psychological risks following transplantation, recipients remained optimistic. This supports the study conducted by Tucker et al. (2019) where recipients also expressed hopefulness and optimism as they recognize how precious their life is and the opportunities that looms before them. Further, Ibite and Kolekar (2024), suggest that optimism is associated with improved coping mechanisms, decreased stress levels, improved physical health,



and increased tenacity in achieving goals, which can be especially beneficial in the context of organ transplantation.

### **Stories of the future**

In narrating the stories of the future, including the aspirations of the kidney transplant recipients, (1) giving back, (2) fatalistic view of life, and (3) sense of normalcy emerged as the common themes among the transplant recipients. A sense of gratitude is evident among the kidney transplant recipients, especially those who had close relationship with their families during and after their dialysis and transplantation. Recipients aspire to give back to their families as a way of showing gratitude for the help they received during the course of their transplant journey. The result of the present study affirms Credle (2020) study to which participants expressed gratitude as they were able to cope with their condition. Recipients also emphasized their newfound appreciation in life, even in the small things that comes their way (Tucker et al., 2019). Additionally, transplant recipients often find themselves advocating for others as a way of giving back to those who were in the same position as they were in the past. Ranahan et al. (2021) suggested that patients who have vast information, personal and social motivations, and better self- efficacy are more likely to engage in educational and behavioral interventions for other ESRD patients. This often becomes an advocacy of those who have already received transplantation.

Congruently, a study by Leblond et al. (2019) found that despite the limitations after the transplantation, recipients expressed their desire to give back by making a positive impact on the lives of individuals who have gone through the same experience. In terms of the fatalistic view in life specifically the uncertainties for the future and the idea of recurrence, patients who underwent kidney organ transplant recipients often feel cautious optimism to ensure that they live a normal life, but at the same time vigilantly protect their second chance at life by maintaining a healthy resolve. Individuals experience personal concerns regarding the survival of the transplanted kidney (Kristensen et al., 2020). Recipients fear that if they do not pay attention to their physical health, kidney complications will arise once again. Jing et al. (2022) identified the relationship between the levels of fear of recurrence to the social support received by coronary heart disease. The study yielded results showing negative correlation between the total score of recurrent and positive coping style and social support. Additionally, the study identified a positive correlation between negative coping style and the recurrence fear score among the study's respondents. Cottrell et al. (2019) analyzed the life and expectations of kidney transplant recipient. This study explained the feelings of being alive again by several of the respondents in the study. In light of the sense of normalcy that recipients aspire to, respondents expressed their desire to return to work. According to De Pasquale et al. (2019), 12 months following the transplantation 38.3% among 112 recipients were able to return to work and suggests that respondents should be encouraged to work unless it poses risks to their physical health. Furthermore, research findings indicate that transplant recipients demonstrate increased motivation for work and are adept at collaborating with others. In addition, recipients also reported having a strong desire to continue their education and have a stable and secure life in the future. This drive may be because kidney transplant recipients are faced with financial burdens post- transplant.

A study by Gordon et al. (2008) discussed how kidney recipients experiences financial strain. More importantly, their study highlighted how the patients' out-of-pocket expenses related to their kidney transplantation affect their ability to afford leisure activities. This provides the framework for the sense of normalcy kidney patients often feel post-transplant. This intrinsically suggests that kidney transplant recipients' future aspirations would revolve around picking up where their life was suspended due to their disease.



## **FUTURE DIRECTIONS**

This study is far from complete in discussing the life stories of kidney organ transplant recipients, therefore, the following steps are recommended.

For the research method, the future studies may also consider conducting a quantitative approach in understanding the life stories of the kidney organ transplant recipients. Specifically, their psychological well-being may be quantified before and after they received their new kidney organ. In understanding the life stories of the kidney transplant recipients, it cannot be avoided to have respondents revisit the most difficult moments of their lives. Thus, it is important to conduct the study with proper counseling and specific intervention as seen fit to ensure that the respondents are not harmed when dealing with their emotional experience.

For the purpose of duplicating or making this research as a basis for future researches, further studies comparing the life stories of kidney organ transplant recipients from live organ donors, and deceased organ donors may be conducted. Further, future researchers can also include the life stories of organ donors. It's also important to note if there will be changes in the drawn themes and codes if the civil status and gender are considered in studying the life stories of either kidney organ transplant recipients or kidney donors. Future researchers can also take into account the number of times the participants have received an organ transplant, be it specific to kidney organ, or other organ transplantations.

Future researches can also focus in expanding the number of respondents that would participate in this study. This is to ensure that the life stories of kidney transplant recipients are accurately accounted and narrated through a larger population. Likewise, the age of the respondents can also be a variable in narrating the life stories of kidney organ transplant recipients. Further researches may compare the narrative analysis of the life stories of different age groups.

Further studies are hereby recommended to also use Dewey's three-dimensional space narrative structure that focuses on Interaction and Situation of the kidney transplant recipients and not only on the continuity of their stories.

## **CONFLICT OF INTERESTS**

The authors have not declared any conflict of interests.

## **REFERENCES**

- Boaz A, Morgan M (2014). Working to establish 'normality' posttransplant: a qualitative study of kidney transplant patients. *Chronic Illness* 10(4):247-258.
- Chan-On C (2017). A Comprehensive Analysis of the Current Status and Unmet Needs in Kidney Transplantation in Southeast Asia. *Frontiers*.  
<https://www.frontiersin.org/articles/10.3389/fmed.2017.00084/full>
- Cleland JA (2017). The qualitative orientation in medical education research. *Korean Journal of Medical Education* 29(2):61.
- Cowie S, Choy SH, Shah DM, Gomez MP, Yoong BK, Koong JK (2023). Healthcare system impact on deceased organ donation and transplantation: A comparison between the top 10 organ donor countries with 4 countries in Southeast Asia. *Transplant International* 36:11233.

- Credle L (2020). Gratitude, Resilience and Post-Traumatic Growth among Kidney Transplant Recipients.
- Creswell JW, Miller DL (2000). Determining validity in qualitative inquiry. *Theory into Practice* 39(3):124-131.
- De Pasquale C, Veroux M, Pistorio ML, Papotto A, Basile G, Patanè M, Veroux P, Giaquinta A, Sciacca F (2019). Return to work and quality of life: a psychosocial survey after kidney transplant. In *Transplantation Proceedings* 51(1):153-156. Elsevier.
- Deshmukh CD, Baheti A (2020). Need, process and importance of organ transplantation. *Asian Journal of Pharmacy and Pharmacology* 6(2):126-131.
- Espina ZE (2024). Philippines leads asia in 'living organ' donation --- nkti.
- Manila Bulletin. [https://mb.com.ph/2024/2/19/philippines-leads-asiainliving-organ-donation-nkti?fbclid=IwAR2KNJIZhh6lvImpnNkQ2nt8OLeOd6p7\\_rOJGt8V5pzeBhPhA\\_VI1HG-ywE](https://mb.com.ph/2024/2/19/philippines-leads-asiainliving-organ-donation-nkti?fbclid=IwAR2KNJIZhh6lvImpnNkQ2nt8OLeOd6p7_rOJGt8V5pzeBhPhA_VI1HG-ywE).
- George C, Mogueo A, Okpechi I, Echouffo-Tcheugui JB, Kengne AP (2017). Chronic kidney disease in low-income to middle-income countries: the case for increased screening. *BMJ Global Health* 2(2):e000256.
- Gordon EJ, Prohaska TR, Sehgal AR. (2008). The financial impact of immunosuppressant expenses on new kidney transplant recipients. *Clinical Transplantation* 22(6):738-748.
- Griva K, Seow PS, Seow TY, Goh ZS, Choo JC, Foo M, Newman S
- (2020). Patient-Related Barriers to Timely Dialysis Access Preparation: A qualitative study of the perspectives of patients, family members, and health care providers. *Kidney Medicine* 2(1):29-41.
- Hao W, Tang Q, Huang X, Ao L, Wang J, Xie D (2021). Analysis of the prevalence and influencing factors of depression and anxiety among maintenance dialysis patients during the COVID-19 pandemic. *International Urology and Nephrology* 53(7):1453-1461.
- Hu N, Wang A, Chang T (2023). Social support mediates the relationship between illness perception and psychosocial adaptation among young and middle-aged kidney transplant recipients in China. *Frontiers in Psychology* 14:1062337.
- Hu S, Li Y, Quan M, Yang S, Wan Z, Yan X, Tan Z, Liang G (2021). A study on the correlations of anxiety and depression with SelfManagement Ability and endogenous creatinine clearance rate in renal transplant recipients. *Frontiers in Psychiatry* 12:715509.
- Ibite SD, Kolekar R (2024). Optimism and Psychological Well-being Among Young Adults » *The International Journal of Indian Psychology* 12(1):2167-2171. <https://doi.org/10.25215/1201.195>
- Jankowski J, Floege J, Fliser D, Böhm M, Marx N (2021). Cardiovascular disease in chronic kidney disease: pathophysiological insights and therapeutic options. *Circulation* 143(11):1157-172.

- Kenawy AS, Gheith O, Al-Otaibi T, Othman N, Abo Atya H, Al-Otaibi M, Nagy MS (2019). Medication compliance and lifestyle adherence in renal transplant recipients in Kuwait. *Patient Preference and Adherence* 30:1477-1486.
- Kim JH (2015). *Understanding narrative inquiry: The crafting and analysis of stories as research*. Sage publications.
- Kovesdy CP (2022). Epidemiology of chronic kidney disease: an update 2022. *Kidney International Supplements* 12(1):7-11.
- Kristensen IV, Birkelund R, Henriksen J, Agerskov H, Norlyk A (2020). Living in one's own world, while life goes on: Patients' experiences prior to a kidney transplantation with a living donor. *Journal of Clinical Nursing* 29(3-4):638-644.
- Lv JC, Zhang LX (2019). Prevalence and Disease Burden of Chronic Kidney Disease. *Advances in Experimental Medicine and Biology* pp. 3-15.
- Leblond M, Achille M, Clermont MJ, Blydt-Hansen T (2019). Becoming unique: A qualitative study of identity development of adolescent kidney recipients. *Pediatric Transplantation* 24(1):e13607.
- Mayo Clinic (2023). Chronic kidney disease - Symptoms and causes - Mayo Clinic. <https://www.mayoclinic.org/diseases-conditions/chronickidney-disease/symptoms-causes/syc-20354521>
- Ng MSN, Chan DN, Cheng Q, Miaskowski C, So WK (2021). Association between Financial Hardship and Symptom Burden in Patients Receiving Maintenance Dialysis: A Systematic Review. *International Journal of Environmental Research and Public Health* 18(18):9541.
- Omidi A (2018). The Correlation of Quality of Life with Social Support for Kidney Transplant Patients. *Scientific Journal of Hamadan Nursing and Midwifery Faculty* 26(5):341-348.
- Orr A, Willis S, Holmes M, Britton P, Orr D (2007). Living with a kidney transplant: a qualitative investigation of quality of life. *Journal of Health Psychology* 12(4):653-662.
- Ralph AF, Butow P, Craig JC, Wong G, Chadban SJ, Luxton G, Gutman T, Hanson CS, Ju A, Tong A (2019). Living kidney donor and recipient perspectives on their relationship: longitudinal semistructured interviews. *BMJ Open* 9(4):e026629.
- Ranahan M, Dolph B, VonVisger J, Cadzow R, Feeley TW, Kayler LK (2021). A Narrative Review of Qualitative Studies Describing Access to Kidney Transplantation. *Progress in Transplantation* 31(2):174183.
- Shahgholian N, Yousefi H (2018). The lived experiences of patients undergoing hemodialysis with the concept of care: a phenomenological study. *BMC Nephrology* 19(1).
- Takahashi A, Hu SL, Bostom AG (2018). Physical Activity in Kidney Transplant Recipients: A Review. *American Journal of Kidney Diseases* 72(3):433-443.

- Tsutsui H, Nomura K., Ishiguro A, Tsuruta Y, Kato S, Yasuda Y, Uchida S, Oshida Y (2017). Factors associated with employment in patients undergoing hemodialysis: a mixed methods study. *Renal Replacement Therapy* 3(1).
- Tucker EL, Smith AR, Daskin MS, Schapiro H, Cottrell SM, Gendron ES, HillCallahan P, Leichtman AB, Merion RM, Gill SJ, Maass KL (2019). Life and expectations post-kidney transplant: a qualitative analysis of patient responses. *BMC Nephrology* 20:1-10.
- Webster AC, Nagler EV, Morton RL, Masson P (2017). Chronic Kidney Disease. *The Lancet* 389(10075):1238-1252.
- Zhang Z, Jin J, Luo C, Chen A (2022). Excavating the social representations and perceived barriers of organ donation in China over the past decade: A hybrid text analysis approach. *Frontiers in Public Health* 10:998737.