

ECONOMIC & HEALTH CONSEQUENCES OF DONATING A KIDNEY : A QUALITATIVE STUDY

Saleha Khatoon*

Vidya Vinutha Dsouza**

Objective:

To determine the economic and health effects of a person from Gujrat, India, who has donated a kidney to one of his family members under pathetic economical situation.

Study design:

We conducted a qualitative case study that explored the experiences of a person who donated his kidney to his sister under non-favorable circumstances. This study is based on personal meeting, discussions, observations and interview.

Results:

- Redefining identity- seeking normality, anxiety and disappointment, adopting a positive attitude, desiring independence.
- Family functioning - sibling support; participation in physical activities; managing medical demands, assuming responsibility, dependence on caregivers, disruption to lifestyle, pain and discomfort.
- Attitude toward the donor- obligation of gratitude, strengthened relationship, concerns about risks of gainer.

* MSW Student, St Aloysius College (Autonomous), Mangalore

** Asst Professor, PG Department of Social Work, St Aloysius College (Autonomous),
Mangalore

Conclusions:

Although transplantation offers adolescent a better chance of survival and increased freedom and energy, it poses many challenges. A multifaceted response is needed to equip adolescent transplant recipients with skills and capacities to help them achieve a sense of normality, cope with fear of death and organ rejection, gain acceptance among their peers, build confidence in resolving healthy relationship bond with sacrifice and generosity. Recently, there has been increased focus on the determinants of quality of life, psychosocial outcomes, and patient's perceptions of their experience to understand social phenomena by exploring a range and depth of meaning and experiences.

Comprehensiveness of reporting:

Indian society is characterized as a pluralistic society because it possesses complex social order. It suffers from multitude of ethnic, linguistic, religious and caste division. Most of the individuals begin the day with prayer before anything. The same act was followed by one of the families from Gujarat. But in the year 1981, the task was followed after prayer was not the same as it used to be. A 14 years old girl of the family had severe lower back pain for which her family immediately consulted the doctor. He suggested them to consult a doctor from Mumbai for emergency medical services. The patient was diagnosed with a kidney failure and seeking life for survival. When doctor advised to manage a kidney for transplant, the whole family was nervous, restless and under presser for arrangement. They were neither financially strong nor had any alternatives. They could not afford to buy a kidney and not had enough time to search for a donor. So her brother (19years) put forward his idea with regard to donating one of his kidneys to which his family initially hesitated and eventually agreed, as no other option was left. When decision was announced to the doctor and the nurses they tried to make him understand the consequences he will be facing after donating as he was just 19 years old. But still he did not step back and was ready to donate and save his sister's life. Before donating he had undergone multiple medical tests to check if he is fit to donate or not. Medical report was positive and he was fit to donate. He had no much idea with regard to the application form signed by him. Surgery took about 4 hours, after which doctor came out of the operation theatre and mentioned that it is the second successful organ transplantation surgery done all over India (in the years 1981).

The researcher would like to present the glimpse of the discussion with the organ donor to understand the complication he had gone through, to know if his religious belief was a hindrance for donating and the role of family when he took the decision for donating one of his kidneys.

Q1: As it is 25th November, 2017, How old are you now, and how many years ago you have donated kidney?

He: *Presently I am 56 years old and I donated in the year 1981 when I was 19 years old.*

Q2: Is it because of family pressure or because of your own interest you have donated to your sister?

He: *No, There were no any types of pressure from my family members. Indeed it was my own decision to donate kidney.*

Q3: Did your religious belief stop you from donating?

He: *No, I am still not aware whether my religion supports organ donation or not. But what I know is my religion says that saving one's life is more important and it is a kind of reward. Even if my religion would have stopped I would have still donated my organ to save my sister's life.*

Q4: What was the suggestion given by the doctor when you determined to donate?

He: *Doctor and nurses asked me that you are donating your organ by force or any types of under pressure from anybody. I replied to them, it's my own wish, and my innate desire is to save my sister's life.*

Q5: Did you undergo test before donation?

He: *Multiple tests were done. What I remember now is angiogram, blood test, urine test was done.*

Q6: After donating did you have any health complication?

He: *No. But now as I am getting older and I am not able to lift heavy weights.*

Q7: Why only you donated? Why not your other family members?

He: *My sister she could not donate, she had to get married and go to husband home and my brother did not confess that he wants to donate. Anyway I was not waiting for any one's decision to donate my priority was to save my sister's life.*

Q8: Why didn't you prefer buying a kidney than donating it?

He: *We could not afford to buy kidney as the price for kidney was 10,00,000 rupees in those days and we were facing financial crisis. For the surgery that was done, we had taken loan from close*

relatives so how could I afford to buy a kidney. Because of this I made independent decision of donating it.

Q9: How did you feel after donating your kidney?

He: *I was feeling proud that I was able to save the person whom I loved the most.*

Q10: What was the response given by your family when you announced your decision to donate to save your sister's life?

He: *Listening to my decision all were worried, my family in return said you will face consequences in your daily routine and for marriage proposal too. So I replied, for now I just want to save my sister. But they were happy with the decision made by me.*

Q11: Did you have issues in getting marriage proposal as you own just one kidney?

He: *No. When my parents started to find match for me, I said them to let the girl's family know about my health condition. Now I am married and my wife knows about it since our marriage was fixed.*

Q12: Legal procedure you went through before donating?

He: *I studied from Urdu medium. Even now I am very weak in English. So I am not aware as to what medical form I have signed that time.*

Q13: You donated it, is it because she was your sister or if someone was there you would do same?

He: *It was the matter of my sister's life, so I did it.*

Q14: As you donated an organ, are you further willing to donate an organ for needy.

He: *I don't know about my future and I have not thought anything with regard to this now.*

Q15: Do you have or sometimes feel guilty for donating your kidney?

He: *No. But I feel sad that she is no longer with us. After transplantation she was healthy and fine but after 2 years she expired. I miss her a lot.*

Q16: Your message about organ donation to the youth of today.

He: *Whenever situation arises in family as in my case, everyone should be ready to donate. And as being human we should have concern for others and try to save their life.*

Researcher analysis the love and the bond in the family as the main cause for the organ transplant in this family. The unconditional love for one's own sister, unavailability of financial sources was also the cause for the decision of 19 year young boy. Boys responses make it evident that the religion did not stop him or rather he was not aware about the condition's put forward by

his religion. The study also makes one realise that the satisfaction of helping one, especially the one whom you love can be tremendous in a person's life.

Organ donation this was one of the ways chosen by the individual to find meaning in his self. A life that was not his own but was of his sister too.

In the light of the above mentioned considerable facts I would like to conclude my observations with the lines of the great philosopher Martin Luther King Jr.

"Human progress is neither automatic nor inevitable... Every step toward the goal of justice requires sacrifice, suffering, and struggle; the tireless exertions and passionate concern of dedicated individuals."

— **Martin Luther King Jr.**