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Healthcare professionals can assist patients with managing post-kidney transplant expectations

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ABSTRACT

Kidney transplantation is the preferred treatment option for end-stage kidney disease. However, transplantation is not a cure and the prospective recipient needs to carefully evaluate the risks and benefits of receiving a transplant before agreeing to have the transplant. The objective of this commentary is to demonstrate that many kidney transplant recipients have unrealistic expectations of what life after transplantation involves. After monitoring participants in a randomised controlled trial through the first 12 months post-transplantation, we question whether patients understood the impact of receiving a transplant. In our study, participants were not prepared for the considerable time and effort involved in adhering to their medications. Participants felt challenged by the constant hospital, pathology and pharmacy visits; they were fearful that their transplant could reject; and they struggled with adapting to their new way of living. This paper offers new insights into understanding the life of patients post transplantation and the challenges of informing patients about the consequences of kidney transplantation. Understanding the challenges faced by new transplant recipients can help health professionals educate patients about life post-transplantation so patients have a genuine understanding of what they are consenting to, which is likely to enhance medication adherence and ultimately, graft success.

1. Introduction

The global prevalence of chronic kidney disease exceeds 10% of the world's population.[1] Over time, the disease can progress to end-stage kidney disease, which would mean the patient requires kidney replacement therapy, either by dialysis or a kidney transplant for survival. The number of people estimated to be receiving kidney replacement therapy has increased steadily in the last 20 years, and data suggest that this trend is likely to continue, driven by demographic change, especially aging of the population; improvements in access to dialysis in countries with growing economies; and an increase in the incidence of diabetes and hypertension.[2]

For those who are fortunate to receive a kidney transplant, recipients are required to adhere to life-long immunosuppressant medication to minimise the risk of rejection.[3] Therefore, the prospective recipient needs to carefully evaluate the risks and benefits of receiving a kidney transplant before agreeing to have the transplant. Furthermore, it is important that patients fully understand what is involved in managing the transplant and what to expect after transplantation, and to be better prepared for the challenges they may face after transplantation. If patients are motivated and understand the implications of kidney transplantation, the probability of medication non-adherence and the risk of rejection are likely to be reduced and valuable healthcare resources will not be wasted.[4]

The objective of this commentary is to demonstrate that many kidney transplant recipients had unrealistic expectations of what life after kidney transplantation involves and patients did not imagine that having a transplant would be so complex and difficult.

A systematic review found that in comparison to other solid organ transplant recipients, kidney transplant recipients were the most non-adherent with 36% of kidney transplant patients displaying signs of non-adherence, twice the number observed in

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heart recipients and over five times greater than liver transplant recipients.[5] Therefore, in 2014, we commenced a randomised controlled trial (RCT) with the aim of testing an intervention designed to improve medication adherence in kidney transplant patients (ACTRN12614000608662). The project involved all five public hospitals that provide acute kidney transplantation for adults with end-stage kidney disease in the state of Victoria, Australia. The intervention consisted of a home medication review, a 20-min consumer-driven video and health coaching. Patients who were at least 1 month post-transplantation were recruited to the study and their medication adherence was measured over 12 months. The primary outcome used to measure medication adherence was electronic medication monitoring using the Medication Event Monitoring System® (MEMS, WestRock, Switzerland) and obtaining the participants' pharmacy refill records. Adherence was also assessed through self-report surveys conducted over the telephone every 3 months, where the researcher made notes of what the participants said during these phone calls. Participants were also asked to keep a diary over the 12 months they were enrolled in the study. After monitoring participants through this first 12 months post-transplantation, we question whether participants understood the consequences of receiving a transplant and fully appreciated the ongoing commitment to care for their transplanted kidney.

2. Patient education: does it always happen?

In Australia, approximately 70% of kidney transplants come from a deceased donor and the number of living donor transplants have been falling as a proportion of all transplants since 2009.[6] For patients who receive a transplant from a live donor through elective surgery, there is the opportunity to plan and educate patients about their medication and life after transplantation.[7] In the case of those participants in our study who received a transplant from a deceased donor, details of what to expect after transplantation were often limited to the immediate acute post-operative setting. Ideally, patients are informed about the advantages and disadvantages of transplantation whilst they are on the waiting list to receive a transplant. However, nephrologists' appointments were constrained by time; decisions were often made quickly and under situations where planning for care was difficult. The risks and benefits of transplantation were hard to explain at the time of organ offer due to the urgency to get the patient prepared for surgery. The shortage of available kidneys for transplantation may further accentuate this situation. For example, at the end of 2013, there were 86,965 Americans on a kidney transplant waiting list and the median waiting time for a transplanted kidney in the United States is 3.6 years.[8] In Australia, the demand for transplants also far exceeds the supply of kidneys, with 1123 Australians on a kidney transplant waiting list at the end of 2014.[9] Whilst many hospitals offered a pre-transplantation education session, patients on the waiting list often either perceived the information to be irrelevant to them because they did not expect to receive a kidney in the near future or had not recently attended the session and forgotten what was said.[7]

Additionally, patients who are waiting for a transplant can be a vulnerable population; patients on dialysis are often overwhelmed with the complexity of life-saving dialysis treatment, and their cognition and memory are impaired because of the nature of the kidney disease.[10] Some participants in the RCT had an unfailing belief that they could be ‘fixed’ by a transplant, where their old organ was removed and a new one was put in. However, because there is a limited number of suitable transplants available, the transplant healthcare team are sometimes forced into a situation where it is necessary to use organs from older donors, which are less ideal due to ageing but are needed to bridge the gap between supply and demand. As a result, a patient might receive a non-ideal or marginal organ. A marginal organ refers to the use of suboptimal quality grafts from non-heart-beating deceased donors, or living donors from elderly; hypertensive, diabetic, nephrolithic, or obese people; or living donors with some acceptable medical risks, such as a history of malignancy or potential transmissible infections.[11,12] The kidney transplant recipient may encounter delayed graft function and a decrease in graft survival. However, the use of marginal organs will give the recipient an opportunity to improve their quality of life rather than stay waiting on dialysis for a better kidney to come along.[12]

There is also an economic imperative influencing the situation; compared to dialysis, kidney transplantation is more cost-effective, saving approximately $77,000 per patient annually in Australia when compared to hospital in-centre dialysis treatment.[13] When participants were enrolled into the RCT study they were asked whether they received their transplant from a live or deceased donor, it was surprising that not all participants had a thorough understanding of the origins of their transplant. Some participants reported that they hadn't been told where their transplant had come from or whether their transplant was from an ideal or marginal donor, and they did not understand the donor system that transplants could come from an anonymous living or deceased donor. These participants were fundamentally reliant on the transplant healthcare team to help them with decisions concerning their care and at times, a paternalistic approach might have been employed to take the difficult decisions away from the patient.

3. Life after kidney transplantation

3.1. Living with medication and a new chronic illness

Kidney transplantation can be seen as a means to improved health, as patients on a waiting list have higher mortality rates and lower quality of life compared with those who have received a kidney transplant.[14–16] However, participants in our study were susceptible to illness because they are required to take immunosuppressant medications to prevent their body rejecting the newly transplanted kidney. During the 12 months that participants were followed, many dealt with viral infections as a result of being immunocompromised, participants were in and out of the hospital or they battled an illness, such as a cold or flu that took months to recover from.

Only after patients had received their transplant did they come to the realisation of what was involved in maintaining their graft. Many participants in the RCT were not prepared for the time and effort involved in adhering to prescribed medications; ensuring they took them with or without food, maintaining the correct timing and keeping up with hospital visits and the prescriptions. The recognition that the medication was for life and the reliance on medication was hard for some participants to get used to. One participant spoke of her frustration with taking the medication every day and organising the medications, causing her to consider whether she made the right choice in accepting a transplant and whether dialysis would have been a better option.

Whilst participants were informed briefly of the long-term side-effects of the medications (particularly tacrolimus, mycophenolate and prednisolone), participants were not aware of the less severe but immediate side-effects. Participants had noticed their hair was falling out, their face was noticeably swollen and the medication was making them feel sick, rather than making them feel better. One participant held the medication [prednisolone] responsible for some of the medical problems he was experiencing, even going to the extent of wishing he was back on dialysis because he felt so run

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