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An evaluation of the nursing care of renal transplant recipients: A qualitative study

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Abstract

Due to the complexity of their medical management, renal transplant recipients are actively encouraged to self-manage their own medication regimens, diet and lifestyle modifications after transplant. Motivation for this study arose from comments made by hospitalised renal transplant recipients regarding aspects of their clinical care that were not given high priority by the ward nurses. The aim of this study was to investigate renal transplant recipients' experience of the care they received while they were inpatients on the renal ward. In this qualitative study the stories of 12 renal transplant recipients were used to evaluate how they felt about their experiences as an inpatient. Patients felt that ward nurses did not understand the importance of immunosuppressive medication and did not value the patient's opinion. They also expressed a fear of contracting an infection. Renal transplant recipients have high expectations about the care they receive when admitted to hospital. As a well-informed group of patients, who would normally be managing their own care at home, renal transplant recipients should be treated with respect and included in decisions about their care.

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Abstract

Due to the complexity of their medical management, renal transplant recipients are actively encouraged to self-manage their own medication regimens, diet and lifestyle modifications after transplant. Motivation for this study arose from comments made by hospitalised renal transplant recipients regarding aspects of their clinical care that were not given high priority by the ward nurses. The aim of this study was to investigate renal transplant recipients' experience of the care they received while they were inpatients on the renal ward.

In this qualitative study the stories of 12 renal transplant recipients were used to evaluate how they felt about their experiences as an inpatient. Patients felt that ward nurses did not understand the importance of immunosuppressive medication and did not value the patient's opinion. They also expressed a fear of contracting an infection.

Renal transplant recipients have high expectations about the care they receive when admitted to hospital. As a well-informed group of patients, who would normally be managing their own care at home, renal transplant recipients should be treated with respect and included in decisions about their care.

Keywords

Kidney transplant, transplant recipient, patient experience, inpatient, nursing care

Background

After a kidney transplant, renal transplant recipients are educated by the multidisciplinary health care team to self-manage their complex medical therapy. Emphasis is placed on education regarding medication regimens, dietary and lifestyle modifications.

Following kidney transplantation, transplant recipients live with the possibility of organ rejection. Immunosuppressive agents are prescribed which are essential for preventing graft rejection and maintaining graft function but which increase the recipient's

vulnerability to bacterial, fungal and viral infections (Personett & Laub, 2017; Goetz *et al.*, 2017; Weng *et al.*, 2010). Patients are taught how to take their prescribed anti-rejection medications and to take steps to protect themselves from developing infections.

Immediately following transplant surgery, patients are reviewed by the transplant team every day. The frequency of clinic appointments gradually reduces although close outpatient monitoring continues and patients will be admitted to the hospital if unwell or there is any adverse change in graft function.

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To enhance graft survival and limit undesirable outcomes, kidney transplant recipients are encouraged to participate in their own care and self-management (Weng *et al.*, 2010) and are empowered to deal with most health issues that arise (Hsiao *et al.*, 2016). Kidney longevity and optimal functioning rely on the transplant recipients adhering to self-management of immunosuppressive medication, hydration, exercise, diet, symptoms of fever, diarrhoea and vomiting, sun protection and avoiding people with active infective symptoms (Gordon *et al.*, 2009). Therapeutic relationships with nursing staff have been shown to enhance the patient's participation in self-management (Weng *et al.*, 2010; Gordon *et al.*, 2009). This will aid in minimising the risks of graft loss and the development of future co-morbid conditions (Jamieson *et al.*, 2016).

Patient health outcomes are believed to be directly influenced by the nursing care received whilst in hospital (Schreuders *et al.*, 2015). When patients are admitted to hospital it is important that the initial contact with the caring staff gives patients a sense of confidence in the level of nursing care they are going to receive (Reck, 2013). A study conducted by Chandrasekaran (2016) found that anxiety levels were a contributing factor to renal transplant recipients' health outcomes, and that anxiety levels could be reduced by providing consistent and empathic care during their hospital admissions (Chandrasekaran *et al.*, 2016).

Motivation for this study arose from comments made by several renal transplant recipients to the renal transplant coordinators regarding the care they experienced as inpatients during subsequent admissions after their transplant. They felt that aspects of their clinical care that they had understood as critically important were not given the same high priority by the ward nurses. The aim of this study was to investigate the renal transplant recipients' experience of care during inpatient admissions to hospital.

Apart from information about admissions at the time of surgery, there is little in the literature regarding the management of kidney transplant recipients during subsequent inpatient admissions, which may or may not be for reasons related to the kidney transplant. In Australia, the Kidney Health Australia — Caring for Australasians with Renal Impairment (KHA-CARI) Guidelines (Chadban *et al.*, 2012) have been adapted from guidelines published by the US group Kidney Disease Improving Global Outcomes (KDIGO). The KDIGO Guidelines for the Care of Kidney Transplant Recipients (Kasiske *et al.*, 2010) state "The guideline makes recommendations for immunosuppression and graft monitoring, as well as prevention and treatment of infection, cardiovascular disease, malignancy, and other complications that are common in kidney transplant recipients including hematological and bone disorders" (p. 1). The KHA-CARI Guidelines underpin practice in the care of renal

transplant patients in the renal service where the study was conducted and are congruent with the transplanting hospital.

Methods

This study utilised a descriptive qualitative approach. Renal transplant recipients were interviewed to gain their perspective on a recent admission to the renal ward. Twelve participants were interviewed over a period of 12 months by a clinical nurse consultant who was not employed in the renal transplant service. Interviews were conducted in a clinic consultation room for privacy and began with the open-ended question "Please tell me about your recent hospital stay including the care you received" Apart from this there were no other formal questions and the interviews developed from the patient's experience. Interviews were transcribed by the nurse conducting the interview and thematic analysis was used to analyse the data (Braun & Clarke, 2006). Thematic analysis involved searching the data to find repeated patterns of meaning and encompassed coding the transcripts; searching for themes; revising, devising and naming the themes.

Approval for a low/negligible risk research project was granted by the South Eastern Sydney Local Health District Ethics Committee. Participants were provided with a study information sheet and signed a consent form indicating their willingness to participate. Participants were given the option to not participate, but all patients who were approached agreed to take part.

Participants

The renal transplant recipients who participated in this study were a convenience sample who met the inclusion criteria of having had a recent admission to the renal ward. Kidney transplant recipients may require admission to hospital at any stage after transplant surgery and may be admitted for a variety of reasons including those unrelated to their transplant. Participants in this study ranged from two to 74 months post-transplant and reasons for admission included routine protocol biopsy, the investigation of suspected graft rejection and treatment of bacterial or viral infections. Information regarding the participants is provided in Table 1.

Results

Twelve interviews were conducted with renal transplant recipients. Originally 20 patient stories were planned but as no new information was being voiced after 12 interviews it was felt that data saturation had been achieved.

The interview data showed three main themes, which were: "Immunosuppression is something special"; "They think they know better" and "I'm afraid of getting an infection".

Table 1: Demographic data for renal transplant recipient participants

ID	Months post-transplant	Age (years)	Gender	Reason for admission	Length of stay (days)
1	13	62	F	Pneumonia	4
2	5	42	M	Infection	18
3	4	53	M	Infection	8
4	5	63	F	Diarrhoea & vomiting	10
5	10	31	M	Renal biopsy	1
6	2	54	F	Elevated creatinine	2
7	36	57	M	Pneumonia	5
8	48	65	F	Gastroenteritis	4
9	60	55	F	Perforated bowel	7
10	74	58	M	Colonoscopy	1
11	72	61	F	Fractured arm	56
12	24	57	F	Urinary tract infection	5

Immunosuppression is something special

At the time of transplant, much of the education given to patients focused on assisting patients to take their medication correctly. Consequently, renal transplant recipients viewed their immunosuppression as special medication that they felt the nurses on the ward did not fully appreciate. In many cases patients were not allowed to administer their own medication, but had to relinquish the responsibility to the nurses.

They wanted me to take their anti-rejection drugs at their time and not mine. (1)

When the nurses then gave the medicine incorrectly the patients became fearful about the health of their graft, as they had been instructed about the importance of taking the medicine on time and not to miss a dose.

By the time I got to take my immunosuppression it had been about 24 hours and I was concerned I might have problems with my transplant. (5)

Renal transplant recipients felt that there was a lack of understanding among the nurses about how the drug level monitoring system worked. In the study hospital serum tacrolimus and cyclosporine levels were recorded in the trough before the morning dose. As the result would not be available until late afternoon, patients were instructed to take their morning dose immediately after the blood test and any alterations would be made to the evening dose once the level was back.

They would often give me my transplant medications before getting my blood collected for levels or they would wait to give me the medications once my levels were back. (4)

Some of the renal transplant recipients reported incidents where mistakes were made with the medication they were given.

I find at times that I am often given the wrong tablets at the wrong times and this worries me. (9)

The staff took a long time to realise I was a transplant patient and I had to keep reminding them about the importance of having my medications on time. (10)

These well-founded concerns about medication administration led to a lack of trust in the care provided by the nurses on the renal ward.

I don't trust the staff when administering me medications in hospital. I much prefer to do it myself. (7)

They think they know better

As well informed and highly motivated patients, renal transplant recipients felt they had a lot of knowledge to share with the ward nurses about their care. Renal transplant recipients manage complex medical therapy, practising high levels of self-care to maintain the best possible health for themselves and their donated kidney. The findings show that some patients admitted to the renal ward felt devalued and powerless, with all their years of experience unheard and disregarded

Staff were not willing to let me leave the ward so I would have to wait until a relative would come in and I could sneak out. (6)

I understand that the hospital has procedures to follow for discharging patients but felt I didn't deserve to be spoken to in that manner. (4)

One renal transplant recipient voiced frustration at having management of their care taken away without any

acknowledgement of the years of self-care they had managed.

I have been caring for my transplant at home for 6 years and yet they think they know better. (10)

In another interview, a renal transplant recipient was affronted at a novice nurse taking control of his care.

I had a new graduate nurse look after me and she thought she knew me better than I knew myself. (7)

While it is not clear whether the lack of respect displayed here was purely because of the nurse's inexperience, there is a clear sense of exasperation that just because they were admitted to hospital, the patient was no longer considered able to have any input in their own care.

I might get an infection

Renal transplant patients were acutely aware of their immunocompromised condition and understood that while admitted to hospital they were at risk of contracting an infection from another patient. Patients are educated about the risks of contracting infections and advised where possible to avoid any situation that may put them at risk. The cleanliness of the ward and the perceived risk of cross-infection was a big concern for patients that was voiced in many of the interviews.

I go in that shower room and I think what am I going to come out with? (3)

On previous admissions I had been in rooms with three other patients and I always get concerned about them possibly being infectious; [it] was nice to have a room on my own this time. (4)

I am always concerned about being a room with other patients as I am worried they might be contaminated. (11)

All the moving around made me feel like I was being exposed to more germs. (9)

Patients perceived that the nurses did not have the knowledge to care for their specific needs as a renal transplant recipient. They felt that they had their independence taken away from them and their fears were not listened to. They feared catching an infectious disease due to sharing facilities with other patients on the ward.

Discussion

The aim of this study was to investigate the care experienced by renal transplant recipients during admissions to the renal ward. In a systematic review of motivations, challenges and attitudes among kidney transplant recipients, Jamieson *et al.* (2016) found that clinicians should consult transplant recipients as experts and take time to ascertain what is important to

them in regard to their post-transplant care. Participants in this study expressed the high expectations they have for their care when admitted to hospital, and they were quick to notice when the staff caring for them did not involve them in their own care. Chandrasekaran *et al.* (2016) conducted a study to gain an understanding of the relationship between quality of care delivered during kidney transplant recipients' hospital stay and their health outcomes. They found that renal transplant recipients who received consistent and empathic care whilst in hospital had lower anxiety levels and were less likely to re-present within 30 days. The fear of handing over control of their care to people who are perceived to be novice has been shown to have an effect on anxiety and recovery, and so hospital staff who provide care for transplant recipients need to prove that they are either competent or willing to listen. Participants in this study were afraid of getting an infection, and were afraid of losing their graft and they were frustrated by staff who did not acknowledge their concerns. Renal transplant recipients are a group of patients who need to be treated with respect, kept well informed and included in decisions. As a well-informed group of patients independently managing a chronic illness, hospital staff should make the effort to communicate regularly and to discuss any changes in planned care. When transplant recipients can master and maintain their goals of care they strengthen their capacity to engage in self-management (Jamieson *et al.*, 2016).

Many of the participants' concerns about their inpatient care were motivated by fear. They were afraid of developing an infection because they know that in their immunocompromised state an infection can sometimes be fatal. These concerns are warranted, as infection still remains a major cause of morbidity and mortality in this patient cohort (Personett & Laub, 2017). Participants were also afraid of the possibility of their transplant kidney failing and potentially having to return to a life on dialysis. Many of them had to wait for years to get their transplant, and every time they are admitted to hospital they worried that something would happen that meant the kidney might stop working. Even when admitted to hospital many years after the transplant participants in this study expressed their fear of rejection and infection. Staff caring for these patients need to understand that they may be experiencing these underlying fears. The development of therapeutic relationships between hospital staff and patients has been shown to enhance the patient's ability to self-manage (Weng *et al.*, 2010). The nurse is ideally placed to provide care that inspires confidence and trust in the patients. The patient's experience of looking after themselves after their kidney transplant may contain details that will be helpful to the management of their health during their admission. The nurse can listen to the patient's concerns and advocate for them with the treating team (Gordon *et al.*, 2009).

Limitations of the study

The main limitation of this study is that it is a single-centre study with a small number of patients from one renal service. Although data saturation was felt to be achieved after only 12 interviews, the responses all relate to one hospital in a metropolitan area of Sydney. As such, the results may not be transferable to hospitals in other areas.

Implications for practice

This study emphasises the need for hospital staff to be knowledgeable and competent when caring for renal transplant recipients. In addition, they should have an understanding of the patients' deep-seated fear of losing the graft and acknowledge the years of self-management these patients have achieved. All health care workers must communicate and include patients in discussions around their individualised treatment plans and allow for patients to self-care where appropriate. Transplant coordinators and nurses in similar roles need to be vigilant in the regular evaluation of all inpatients and liaise directly with staff providing care for these patients. As transplant experts, they could also develop education resources for staff who are caring for renal transplant recipients to provide them with a better understanding of the particular needs of this patient cohort.

Implications for further research

This study could be repeated within a shorter time frame with a more systematic system of education being adopted. It may also be illuminating to study the nurses' experience of caring for renal transplant recipients and investigating issues the nurses encounter.

Conclusion

In conclusion, this study has found that renal transplant recipients experience anxiety and frustration when they are admitted to hospital, even many years after their kidney transplant operation. Their anxiety partly revolves around the possibility of losing their graft and the potential outcome of a life on dialysis that brings. This anxiety is sometimes heightened when staff do not administer their immunosuppressive medication correctly. Patients are also afraid that in their immunocompromised state they may pick up an infection from one of the other patients. Both of these are genuine concerns but participants in this study also felt strongly that the staff did not listen to them and were dismissive of the information they had to share. Renal transplant recipients are required to independently manage their own health care at home, but when they come into hospital they feel they have to hand over that responsibility to people with less knowledge than they do. Renal transplant recipients have specific care requirements

when in hospital and it is important for health care staff to be aware of these in order to provide the best care. Development of a relationship at the time of admission can help to build trust and respect to improve patient satisfaction. Very little literature exists regarding the specific care that renal transplant recipients require when admitted to hospital, but this study adds to what is known about the perception of the care received.

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