

The kidney transplant failure experience: a longitudinal case study

Purpose—To explore participants' experiences of kidney transplant failure.

Background—Kidney transplants are effective and efficient but not without complications. About 7% to 12% of kidney transplants fail within a year, and rates of failure increase over time. Graft failure can have profound effects, often resulting in depression and, occasionally, suicidal feelings. Despite these issues, the personal dimensions of graft failure have been poorly researched.

Methods—One donor-recipient couple experienced irreversible graft rejection immediately after a kidney transplant. This article is a longitudinal case study of this family's experiences. Data were collected through 3 semistructured interviews, conducted before the transplant and at 3 and 10 months after the transplant. Interviews were recorded, transcribed verbatim, and data coded into categories arising from the participants' accounts.

Results—Transplantation represented a significant source of hope. Fear of transplant failure was a major concern, but was dealt with by using emotion-focused coping mechanisms. Graft rejection was devastating, causing feelings of grief, loss, suicide, and depression. Depression improved as physical health and a sense of personal control improved. The recipient felt inadequately prepared for graft failure and poorly supported by health professionals.

Conclusion—The primary source of grief and depression appeared to be related to the recipient's "loss of imagined future" (ie, the life that she anticipated after transplant). Study findings have potential implications for the provision of care, information, and support for patients and their families before and after transplantation and for future related research. (*Progress in Transplantation*. 2009;19:114-121)

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End-stage renal disease (ESRD) is a chronic, debilitating illness that affects many aspects of patients' and their families' lives. Common problems include lethargy, declining health, demanding treatment regimes, changes in body image, unemployment, and depression.¹ Although several treatment options are available (eg, hemodialysis, peritoneal dialysis), kidney transplantation is recognized as the treatment of choice for most patients.²

A successful transplant can offer almost complete physical recovery from ESRD, thus greatly improving quality of life. It may also increase long-term survival and, compared with prolonged dialysis, is the most cost-effective treatment option.³ The procedure is also highly successful and, in the United Kingdom, carries a mean 1-year graft survival rate of more than 90%.⁴ Consequently, the prospect of transplantation is a significant source of hope and optimism for many patients.

However, kidney transplants are not without complications, such as transplant failure, disability, and even

death. Causes of transplant failure vary, but graft rejection (acute, in the first few weeks after transplantation, and chronic, in the months or years after transplant) is one of the most common factors. Between 7% and 12% (live vs deceased, respectively) of all kidney transplants (n=215) fail within the first year.⁵ Rates of graft failure also increase over time; approximately 20% fail within 5 years, 40% within 10 years,⁴ and 50% within 15 years (written communication, UK Transplant, July 2008). Therefore, as the life of a transplanted kidney is finite, understanding the impact of graft failure on patients and their families is of particular importance to health professionals, because all living transplant recipients will eventually be affected in this way.

The impact of graft failure on recipients and their families, regardless of time since transplantation, is often profound.⁶⁻⁸ Feelings of grief, loss, and anger are common, often resulting in depression and even suicidal ideations, which may require clinical intervention.^{6,9-11} Live transplant recipients also often have to

contend with feelings of guilt for having seemingly put their donor through a major surgical procedure unnecessarily.¹² Transplant failure is also associated with a variety of other physical and psychosocial problems. Examples include pain, lethargy, altered body image, family issues (eg, increased recipient dependency), and the necessity for some form of dialysis in order to survive, all of which can significantly compound depression further.

Despite these issues, the personal dimensions of graft failure, from the perspective of patients and their families, are poorly researched and, therefore, poorly understood. Few empirical studies have explored this area. Most existing data are from clinical and, or anecdotal evidence¹⁰ or from several small-scale, largely descriptive studies^{6,7,9} conducted in the United States in the 1980s. The lack of relevant, up-to-date research in this area significantly limits the insight and understanding of the transplant failure experience that could also be used to inform and develop clinical practice. This is, therefore, an area in need of further research.

Methods

Aims

The goal of this study was to explore the transplant failure experience from the participants' perspective.

Study Design

This research forms part of a doctoral study that explored donor and recipient experiences of live-related kidney transplantation. Findings from this qualitative research are discussed elsewhere (P. Gill, unpublished data, December 2006).^{13,14} In the original study, 11 families (11 donors and their 11 recipients) undergoing live kidney transplantation were recruited from a regional kidney transplant center in Southwest England between July 2003 and February 2004.

From this cohort, one recipient, who received a transplant from her husband, experienced irreversible acute graft rejection several days postoperatively, despite aggressive treatment. The experiences of this family were unique and, subsequently, added a different dimension to the research. This article is a longitudinal case study of this family's experience of acute transplant failure.

Participants' Demographics

The family volunteered to participate in the study after receiving a participant information pack from the transplant center's live transplant coordinator (who was responsible for identification and recruitment of potential participants). The researchers were not involved in the care and treatment of any participants in the study.

To ensure anonymity, limited personal information on the participants is provided. The donor (male) and recipient (female) were both in their late 40s, had professional occupations, and had been married to each other for almost a decade. Both had been married before, and the recipient had 2 teenage children from her previous marriage. The cause of her renal failure was polycystic kidney disease, which was diagnosed 12 years before transplantation. Polycystic kidney disease is a congenital, progressive condition in which both kidneys enlarge with the development of multiple cysts that cause a slow deterioration in renal function and eventually end-stage renal failure.¹⁵

As she experienced slow onset renal failure, she was able to have a preemptive kidney transplant in the autumn of 2004. A preemptive transplant is a transplant performed while the patient still has some remaining renal function. Consequently, patients who undergo preemptive transplants often spend little or (as was the case with this participant) no time on dialysis before transplantation.

Data Collection and Analysis

Data were collected by one of the authors (P.G.) through a series of 3 recorded semistructured interviews, conducted before the transplant and at 3 and 10 months after the transplant. Donor and recipient were interviewed separately, in private, in their own home. Each interview lasted between 30 and 90 minutes.

Interviews were transcribed verbatim and data coded into categories arising from participants' accounts. All interview transcripts were constructively explored independently and then collectively by both authors to discuss emerging themes, theories, and categories. It has been argued that involving an additional experienced qualitative researcher may help guard against potential lone researcher bias and provide additional insights into theme and theory development.^{16,17} The purpose of these sessions, however, was not to seek concordance of opinions regarding thematic generation, but to constructively extend interpretation of the data and emerging themes.

Data have been presented in chronological order (ie, before the transplant, 3 months and 10 months after the transplant), to allow a logical explication of the participants' experiences over time.

Ethics

The local research ethics committee granted approval in May 2003. Written informed consent was obtained from the participants before the first interview, and verbal consent was obtained before all the subsequent interviews. Respondents were assured of anonymity and confidentiality and advised that they could stop the interviews or withdraw from the study at any time. To ensure participant anonymity and confidentiality, all names have been removed.

Results

Interviews Before the Transplant

Treatment Issues and Options. Kidney transplantation, particularly live transplantation (due to improved graft survival rates), was the treatment of choice for the participants, as it was perceived to offer the best chance of a return to “normality.” Consequently, the prospect of a successful transplant was a significant source of hope and optimism. Dialysis therapy was not something that the recipient wanted because she thought the treatment would be demanding, disruptive, and restrictive.

The decision to proceed with a live transplant was relatively straightforward for the donor, and the decision to donate was made with little or no deliberation. However, the decision to accept the offer of a kidney was arduous for the recipient, primarily out of concern for the donor’s well-being. The offer of a transplant was accepted only after the donor reassured her that it was something he really wanted to do.

Stressors and Coping Mechanisms. The participants had a number of minor operative concerns, such as pain, but the prospect of transplant failure was the major source of anxiety for the recipient. However, as she felt that she had little or no control over this prospect, she used emotion-focused coping mechanisms, such as avoidance and denial, to help deal with the possibility. In particular, she adopted a “cross that bridge” attitude when discussing the prospect of graft failure; that is, she maintained that she would “cross that bridge” only if and when it actually happened.

Service Provision Issues. The transplant service was well evaluated by the participants. Information provision was perceived to be “patchy” at times, although the family had attended a live transplant information evening, organized by the transplant center for families considering live transplantation, which they both found informative and helpful:

The most useful thing we’ve been to was the live transplant evening, it was very positive. I know there are people for whom this hasn’t worked and they were quite open about that. But at the end of the evening, they had a load of people who’d done it. They got up on the stage, and you couldn’t tell by looking at them who’d given the kidney and who’d received it. They were all back at work leading normal lives. I know that’s a very positive take on it, but we came away thinking well if they can do it, we can too. [Recipient, first interview]

Interviews 3 Months After Transplant

The Impact of Transplant Failure. The recipient initially made a good recovery until her renal function

deteriorated several days after transplant. Despite prompt investigations and aggressive treatment (including anticoagulant and immunosuppressant therapy), her renal function worsened and, after several days, a renal biopsy confirmed that the transplant had catastrophically rejected and was therefore no longer viable. The impact of this development was profound:

When I was in hospital, it was dreadful. It was like a bereavement. . . . Part of that I think is to do with the fact that you are in an alien environment and no matter how nice people are, there is no privacy. . . . It’s hard coming to terms with something like that in a ward full of other patients, some of whom have had successful transplants. It’s a huge emotional thing, and all I could think was, what’s going to happen to me now? [Recipient, second interview]

She remained in the hospital for more than a month, during which time she had her transplanted kidney and a polycystic kidney surgically removed, in preparation for peritoneal dialysis. She also experienced various physical and psychosocial problems, such as pain, anemia, lethargy, wound infections, altered body image, and relationship issues (caused by increased dependency, which strained the marital relationship). However, the most significant effects of transplant failure were emotional, resulting in anxiety and severe depression, that got worse on discharge home:

Around Christmas time, she wanted to end it all. She was talking about jumping off the weir [a dam built across a river to control water flow] down here, but that’s when she lost it, she hasn’t been like that since. I wasn’t aware . . . she was hiding that from me because she didn’t want me to know, because she knows if I knew, I’d do something about it and my way of coping and dealing with that probably wouldn’t be what she would want. I also think she felt some angst and guilt. I suppose if somebody gives you a kidney and it fails then the last thing you want to do is to go and offload on them as well. [Donor, second interview]

At the time of this interview, the recipient was receiving medical treatment for depression from her general practitioner and, although still depressed, was no longer suicidal.

Treatment Issues and Options. Despite the graft rejection, transplantation was still perceived to be the best long-term treatment option. After transplant failure,

the recipient had to receive hospital-based hemodialysis for several weeks. However, she detested hemodialysis because she experienced a number of problems during her treatment, including infections, postdialysis hypotension, nausea, and vomiting and “listening to other patient’s horror stories of failed transplants and dialysis.”

At the time of the second interview, she was receiving continuous ambulatory peritoneal dialysis (CAPD) at home, which she found easier and more acceptable than hospital-based hemodialysis. However, dialysis was not something that she wanted and, consequently, was not something that she had properly considered or anticipated. The necessity for dialysis, therefore, compounded her depression further:

I think my wife’s mindset was not having to do anything; no dialysis, just successful and when it wasn’t . . . I mean going to dialysis, apart from the fact that it made her feel [awful], was a constant reinforcement that she was sick and she didn’t want that. The CAPD, she doesn’t have to go with other sick people . . . but all the paraphernalia upstairs reminds her that she does need that treatment. [Donor, second interview]

Coping With Graft Rejection. The recipient was struggling to come to terms with recent events and, subsequently, her primary emotion was despair. She was, however, trying to cope with her experience by “taking things one day at a time.” Her emotional well being had recently improved slightly since she started home CAPD, as it made her feel better than hospital-based hemodialysis did and made her feel like she had more control over her life.

However, her main coping mechanism was hope; hope that things would eventually improve and hope that, in time, she might be able to have another transplant (although, because of her experience, this was also a significant source of concern). The transplant failing had been devastating for the donor and recipient, as both had much invested in the transplant. They had therefore tried to support each other, as best they could, through the experience. In particular, the donor had to provide a significant amount of emotional support to his wife, and he found that providing this support was the most difficult aspect of the experience for him:

The hardest part for me has been not knowing how best to support her. I try to jolly her along, but I don’t know if that’s right. . . . Everyone says to her have a good weep, it’s good for you. But is it? I don’t know. OK, get it out of your system but let’s move on. But that’s how she deals with it and I’m different.

It’s not that I’ve been unsympathetic, it’s just I don’t believe that’s good for her, so I keep being positive and try to rationalize it with her. I want to keep her moving on. Out of all of this, that has been harder for me to cope with than being told that the kidney has failed. [Donor, second interview]

Interviews 10 Months After Transplant

Regaining Control. After 10 months, there was a sense that “life was improving.” The recipient’s depression had improved, she was more optimistic about the future, and had also recently returned to work. She was now able to reflect back on her experience and acknowledge how bad things had been for her at the time and how she had gone through a grieving process for her “loss” after the transplant failed:

It was very bad and very hard to see beyond what had happened or to see a future . . . or a future that I wanted anyway. I think the professor was right when he said to me, you are going through a grieving process because you’re not the person that you were and you’re not the person that you thought you were going to be. So you are grieving for the person that you’ve lost and the lost opportunity and you’re grieving for your husband because he went through so much too. It is a bereavement process really, but I was so physically ill, as well as being so far different from where I thought I should be. Also I think it was worse because all of my expectations were positive. . . . I think because of that, and the hemodialysis, I got to the stage where I just didn’t want to wake up. If somebody had said you can have a shot in your arm and it’ll all be over, I would have had it. It was that bad. . . . [Recipient, final interview]

She emphasized the importance of family support, particularly from her husband, in getting through the experience. However, the turning point for her came after approximately 6 or 7 months, when, as her physical health improved, so too did her emotional well-being:

Around May, I started to get a lot better, and I finally got to do CAPD and found that it was OK. Then I went back to work part time and went on holidays. Going back to work was a milestone, it was like, I’m not sick any longer and that was important to me. When we went on holidays, we had a week of glorious weather and I cycled over 130 miles. . . . We were cycling along one day with lovely

scenery and it was a lovely day, and I thought, thank God I didn't kill myself [laugh]. When I came back, I thought, well if I can cycle 130 miles it doesn't matter whether I'm on dialysis or not and it was a big psychological boost because I thought I can still enjoy my life. When I became well established on home CAPD, it was a pivotal moment, in that I had control over my life again. It was like, I'm not a patient anymore, I'm me. That was such a relief for us . . . because we suddenly thought it's OK. [Recipient, final interview]

The participants felt that the experience had temporarily strained their relationship, but they were now both determined to make the most of their life together.

Treatment Issues and Options. Despite everything that had happened, transplantation was still perceived to be the best long-term treatment option. The recipient had therefore been placed on the deceased kidney transplant waiting list. The prospect of a successful transplant remained a source of hope, optimism, and anxiety. Neither participant had any regrets about proceeding with transplantation and both would still, theoretically, "do it all again." Although the recipient did not particularly like CAPD, she had learned to accept it and had incorporated it into her life.

Service Provision Issues. The transplant service was well evaluated by both respondents, and they felt that, from a medical perspective, everything that could have been done for them was done. They apportioned no blame to the medical staff for the transplant failing and felt that graft rejection was, unfortunately, just "one of those things." They also felt that the medical team had kept them well informed after the graft failure, particularly about issues such as medical investigations and treatment options.

However, the recipient now felt that, in retrospect, she probably could have been better prepared for the prospect of transplant failure by the health care team. Although she had been informed about the possibility of graft rejection, she now believed that the information provided to her before transplant had been overly optimistic and potential problems, such as graft rejection, had been almost "skimmed over." She did, however, think that her opinions about this were significantly influenced by her experience.

She also felt that the emotional support provided to her by the transplant team, particularly after discharge home, was totally inadequate and unacceptable. Although she had been offered support by a renal psychologist, she felt that it had been offered in an unsatisfactory way. She therefore felt that this aspect of the transplant service needed to improve in future,

to ensure that other patients were better supported than she had been:

When I went a bit loopy, I had an answer phone message saying this is the renal psychologist, if you want to talk to me, ring me up. But when you are in that state of mind, that's the last thing you can do. I wanted somebody to show some interest. Like how are you? Is there anything we can do? And nobody really did. . . . I wanted someone to talk to who wasn't my husband, because I couldn't go on weighing him down. But there was nothing. In fact, what eventually happened was that my poor professor copped it and he's probably still washing his shirts now. He was a star and all I could do was cry, with patients stacked up outside his clinic, and he just sat there with the tissues. . . . [Recipient, final interview]

Discussion

As demonstrated in this and other studies, graft rejection can have a devastating impact on patients and their families and often causes feelings of grief, loss, depression, and even suicide.^{6-9,11,18} The impact on live donors, particularly spouses, is likely to be profound, because they too have a vested interest in the transplant, the recipients' health and well being, and, along with others, often play an important role in supporting recipients through the process. Consequently, they frequently experience similar emotional reactions, such as anger, disappointment, depression, guilt, grief and, occasionally, even suicidal thoughts.^{12,18-22}

In the current study, depression appeared to be exacerbated by several other factors; such as lethargy, body image issues and, in particular, the fact that the recipient had not properly considered or anticipated the prospect of graft rejection, despite being informed of the possibility by the transplant team. The prospect of graft failure is a major concern for transplant recipients, yet many (including this participant) use emotion-focused coping mechanisms, such as avoidance and denial, to deal with the possibility of rejection (P. Gill, unpublished data, 2006). If used appropriately, emotion-focused coping mechanisms can help to minimize stress and anxiety in situations where individuals feel that they have little or no control.²³ In the original study, participants reported that using such coping mechanisms moderated the stress associated with the fear of graft rejection and allowed them to "move on with their lives" after transplantation without the constant fear of something that may not affect them for many years (P. Gill, unpublished data, 2006).

However, the use of such coping styles may exacerbate the emotional impact of graft rejection because

recipients have not properly anticipated transplant failure or considered how they would cope with it, if and when it actually occurs.^{9,12} It could, perhaps, be suggested that kidney transplantation has become a victim of its own success thanks to improved graft survival rates, because patients may now feel that transplant failure is something that probably will not initially affect them in the short term.

Graft rejection also resulted in the need for hemodialysis and, subsequently, CAPD, neither of which were wanted or expected by the recipient. Such unanticipated, uncontrollable, and undesirable events following rejection, particularly if problematic, can compromise a patient's sense of control, causing feelings of helplessness and hopelessness, which can further compound depression.^{1,9,24} Increasingly, kidney transplants are now performed preemptively. Therefore, many recipients, including the recipient in this study, undergo transplantation with little or no experience of dialysis. Consequently, they have not learned how to cope with dialysis or how to incorporate the demanding regime into their lives. This lack of preparedness, coupled with unanticipated rejection, would appear to significantly exacerbate depression and also serve as a constant reminder of an unsuccessful transplant.

Both donor and recipient viewed the live transplant as a significant source of hope and optimism that would help restore their life together. However, when the transplant failed, both the donor and, especially, the recipient lost their hopes, dreams, and expectations for the future, and interpretation of the data suggests that this was the primary source of her grief and depression. Baines and Jindal⁸ formulated the theory of "loss of imagined past" to help account for the feelings of grief and loss that some transplant recipients experience after a successful kidney transplant. They propose that some recipients grieve for the period in their lives, before transplantation, that they "lost" because of their ill health. However, in this study, it would appear that the converse is true. That is, following the rejection of her kidney transplant, the recipient grieved for the "loss of her imagined future." Some recipients of failed transplants are often preoccupied with their loss and its implications for their future.⁶

Depression associated with graft rejection is usually temporary, however, and generally improves as physical health improves,^{6,25} possibly because patients may subsequently feel that they have begun to regain control of their lives. Evidence suggests that many patients are eventually able to cope and adjust to the experience⁹ as with this recipient, who gradually became accustomed to CAPD and subsequently enjoyed an improved quality of life and sense of well-being. However, given the suicidal feelings reported in this and other studies,^{6,10} suicide in some recipients and/or

live donors may always be a possibility because of the trauma of graft rejection. Patients' ability to cope and adjust to this outcome should therefore be of considerable concern to health care professionals.^{6,7}

Implications for Clinical Practice and Related Research

Nurses and other health professionals have an important role to play in caring for and supporting recipients, donors, and their families through the rejection experience and facilitating their emotional adjustment. Support from family and friends is essential in helping patients adjust to their loss and should, therefore, be encouraged.⁷ However, in this study, both recipient and, especially, donor emphasized the difficulty of supporting each other through the process. It is therefore imperative that family members are also provided with care and support by the health care team and not left to "pick up the pieces" on their own.

Patients should be provided with the opportunity to discuss their feelings and concerns with health professionals and be reassured that feelings such as grief and anger are normal emotional reactions to rejection.^{7,9} To help patients understand and cope with graft rejection, they should also be informed about their treatment options. The possibility of another transplant is often a source of significant hope and optimism for many recipients. Recipients should be informed, if appropriate, that an unsuccessful transplant does not necessarily preclude the possibility of further transplants.²² However, coming to terms with rejection and contemplating another transplant, with the associated risks, may take considerable time. Therefore, wherever possible, patients should not be rushed into making decisions about future treatment options.

Patients who are struggling to cope with or adjust to graft rejection, particularly if they are having suicidal thoughts, may require professional medical (eg, psychiatric and/or psychological) intervention.^{6,7,9,24} If required, such support should be offered in a considerate way that increases the likelihood that those who require it, actually access it. It is also, perhaps, questionable as to whether patients should opt into (eg, volunteer to undertake therapy after an informal offer of support is made) or out of (eg, decline a formal appointment for professional support, if such treatment is deemed to be unnecessary) such treatment.

Besides providing care and support after graft rejection, patients and their families should also be properly prepared for transplantation and made fully aware of potential complications, such as graft rejection.²⁶⁻²⁸ Health professionals should provide prospective families with balanced and understandable information and should encourage open and honest discussions about hopes, expectations, and concerns.²⁹⁻³⁰ Interventions aimed at promoting informed decision

making a nd p otentially m oderating t he r ejection experience, if and when it occurs, are surely prudent. However, whether information alone can properly prepare patients for the possibility of graft rejection is questionable.

Further related research (particularly of a prospective, longitudinal nature) is needed, so that the graft rejection experience, from the participants' perspectives, can be better understood. Areas in need of further investigation include the following:

- How best to prepare patients for transplantation and for the prospect of graft failure
- The use of coping styles in kidney transplant recipients and their effect, if any, on moderating stress and the graft rejection experience
- The graft failure experience, in a variety of circumstances, from the perspectives of recipients, live donors (where appropriate), and/or close family members (eg, spouses), particularly in the context of grief and loss

A 2-year longitudinal, qualitative study is currently underway as a result of this case study. This research, funded by the Research Capacity Building Collaboration Wales, will further explore participants' experiences of kidney transplant failure, in the first year after transplant failure, regardless of cause (eg, rejection), type of transplant (eg, live or deceased), or time since original transplant. This approach will allow participants' experiences to be compared and contrasted in a variety of different contexts. The improved insight could subsequently be used to help support patients and their families through what is clearly a traumatic experience. The study ends in autumn 2009, and findings will be reported in due course.

Study Limitations

This research was a single case study from a regional kidney transplant unit in Southwest England. The transplant was also live-related (spousal) and failed within several days of transplantation. The findings cannot therefore be generalized or be assumed to be representative of all patients who experience kidney transplant rejection, particularly in different circumstances (eg, those with deceased transplants or where graft failure occurs several years after transplant).

Conclusion

This case study has provided a unique insight into the personal dimensions of kidney transplant failure, an area that has been subject to little empirical research. Graft failure can have a devastating impact on patients (donors and recipients) and their families and may even result in suicidal feelings. Data suggest that the primary source of grief and depression after graft failure in this study was for the perceived "loss of an

imagined future," that is, the anticipated future that was lost when the transplant failed.

The findings from this study have potential implications for the provision of care, information, and support for patients and their families before and after transplantation (particularly after graft failure) and for future related research.

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