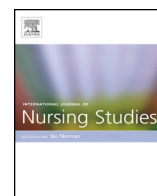




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Renal transplant failure and disenfranchised grief: Participants' experiences in the first year post-graft failure – a qualitative longitudinal study

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ABSTRACT

Background: Renal transplant failure has a devastating impact on patients and their families. However, little research has been conducted in this area, which limits insight and understanding of the transplant failure experience that could subsequently inform clinical practice.

Objectives: To explore participants' experiences of renal transplant failure in the first year post-graft failure.

Design: A qualitative, longitudinal study informed by Heideggerian hermeneutics.

Participants and settings: A purposive sample of 16 participants (8 recipients, 8 'significant others') from a regional renal transplant unit and 3 District General Hospitals in South-West England.

Methods: Data were collected through a series of three recorded, semi-structured interviews in the first year post-renal transplant failure. Data analysis was informed by a three-step analytical process.

Results: Renal transplantation was the treatment of choice and had a transformative effect on the lives of all participants. Graft failure has 2 distinct phases; failing and failed and the transition from one phase to the other is unpredictable, uncertain and stressful. Transplant failure had a devastating impact on all participants, regardless of time since transplantation and resulted in feelings of shock, grief, loss, anger, guilt and depression. Dialysis was disruptive and demanding and served as a constant reminder of transplant failure and lost freedom. Participants grieved the loss of their 'previous life' and 'imagined future' but, beyond the understanding of close family members, these losses appeared unrecognised, particularly by health professionals. Participants used various coping mechanisms to deal with stressors associated with transplant failure. Factors affecting coping and adjusting included improved physical health and social support, which was especially important within the marital dyad. Healthcare services were positively evaluated, although information concerning the prospect of transplant failure and support post-graft failure could be improved.

Conclusion: Renal transplant failure has a profound impact on recipients, spouses and other close family members and appears to resemble a form of disenfranchised grief. The theory of disenfranchised grief provides a coherent explication of participants' experiences in this study, which should help inform clinical practice, particularly in relation to the provision of information and emotional support post-graft failure.

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What is already known about the topic?

- The impact of renal transplant failure on patients is often devastating and feelings of grief, loss and depression are common.
- The return to dialysis compounds depression further as it is disruptive and demanding.
- Psychosocial adaptation is possible, but depression usually only improves when physical health improves.

What this paper adds

- Renal transplant failure has two distinct phases; failing (progressive and irreversible) and failed (return to dialysis). The transition from one phase to the other usually takes several months or more and is associated with considerable uncertainty and anxiety.
- The impact of transplant failure on spouses and other close family members is also profound and further exacerbated by fear and concern for their loved ones, particularly since they are the main source of social support, which in itself can often be onerous.
- The renal transplant failure experience has the fundamental features of disenfranchised grief. Evidence from this study indicates that the theory offers an apposite framework for understanding the impact of and emotional response to kidney transplant failure in recipients, spouses and other close family members.

1. Introduction

Renal transplantation is the treatment of choice for most patients with end-stage kidney disease (ESKD) (BTS/RA, 2011). Transplantation often has a transformative effect on patients and their families and can significantly improve quality of life (Gill, 2012). However, despite continued improvements in anti-rejection regimens, the life of a transplanted kidney is potentially finite. Rates of graft failure vary and are associated with a number of factors, such as type of donor and time since transplantation. Average graft survival rates for first time, adult renal transplant recipients in the UK are provided in Table 1.

Causes of transplant failure vary, but graft rejection is the most common factor (Sellares et al., 2012). The impact of transplant failure is considerable for patients and their families and feelings of grief, loss, anger, depression and even suicidal ideations are common (Streltzer et al., 1983; Carosella, 1984; Hudson and Hiott, 1986; Ouellette et al., 2006). Transplant failure can also cause a variety of other problems such as lethargy, diet and fluid restrictions, body image issues, increased dependency and the necessity for

dialysis, which can compound depression further (Gill and Lowes, 2009).

Despite an emerging evidence base, the impact of transplant failure on patients and their families is under-researched, which significantly limits insight and understanding in this area. An extensive literature search was undertaken in 2008 and 2012–2013, using appropriate scholarly databases, such as CINAHL and MEDLINE. The following search terms were used, in various combinations: renal, kidney(s), transplant(s), transplantation, graft, failure, failing and rejection. However, very few empirical studies were found that explored the personal perspectives of renal transplant failure. Most of the relevant, available evidence is over 20 years old and/or in the form of case studies and/or clinical and anecdotal data (Carosella, 1984; Hudson and Hiott, 1986; Viswanathan, 1991; Gill and Lowes, 2009), which limits the scope and wider relevance of findings. The two most appropriate, comprehensive studies were conducted in the USA (Streltzer et al., 1983) and Canada (Ouellette et al., 2009). Both studies used primarily qualitative methodologies and highlighted the potentially devastating impact associated with renal transplant failure and the subsequent return to dialysis for renal transplant recipients.

However, both studies were conducted retrospectively, with some data collected over a decade post-graft failure. Participant responses were therefore subject to potential recall bias. Furthermore, most available research only explores recipients' experiences of transplant failure and has failed to adequately explore the impact on spouses and other close family members (and therefore the impact on marital and family life), despite anecdotal evidence indicating that they are often affected in a similar way to transplant recipients. The retrospective design of most studies also limits understanding of how participants cope and adjust to transplant failure and there is an inadequate awareness of patient and family needs and expectations for information and emotional care and support pre and post-graft failure.

This lack of evidence significantly hinders understanding of the transplant failure experience that could be used to inform related practice and research. This prospective, longitudinal study was therefore undertaken to explore these complex issues in the first year post-graft failure, from the experiences of recipients and their spouses/significant others.

2. Methodology

2.1. Study aims

The aims of the study were to explore participants':

- Experiences of renal transplant failure.
- Coping mechanisms and factors that helped to facilitate emotional readjustment.
- Perceptions of health care service provision, pre and post-transplant failure.

2.2. Research approach

Given the study aims, the research was undertaken using a phenomenological, longitudinal approach, informed by

Table 1
Graft survival rates over 1, 2, 5 and 10 years.

| Time since transplant | Brain dead donor | Living kidney donor |
|-----------------------|------------------|---------------------|
| 1 year | 94% | 97% |
| 2 years | 91% | 95% |
| 5 years | 85% | 91% |
| 10 years | 71% | 78% |

Data from NHS Blood and Transplant (2014).

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