


# Experiences of adults living with a kidney transplant—Effects on physical activity, physical function, and quality of life: A descriptive phenomenological study

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## Abstract

**Background:** Although kidney transplantation is the best treatment for kidney failure, scarce research has examined its effects on physical activity, physical function and quality of life.

**Objectives:** To investigate the experiences of a group of adults living with advanced kidney disease focusing on quality of life, physical activity and function and to see how findings differ in a group of kidney transplant recipients.

**Approach:** Individual semi-structured interviews were conducted with adults with advanced kidney disease ( $n = 10$ ;  $70.5 \pm 8.9$  years) and adults who had received a kidney transplant ( $n = 10$ ;  $50.7 \pm 11.5$  years; transplant age:  $42.7 \pm 20.9$  months). Interviews were transcribed verbatim, thematically analysed and composite vignettes developed.

**Findings:** Individuals with advanced kidney disease described a sense of loss and alteration to their life plans. Kidney transplant recipients reported increased freedom, independence and a return to near normality, with improved quality of life, physical activity and function compared with their pre-transplant lives. However, transplant recipients also described living with anxiety about the health of their transplant and fear it may fail.

**Conclusion:** Whilst adults living with advanced kidney disease often experience a reduced quality of life, physical activity and function, kidney transplantation can help facilitate a return to pre-disease levels of physical activity, physical function and quality of life. However, transplant recipients also reported living with anxiety around their new kidney failing. This study demonstrates the variability in the lived experiences of adults living with advanced kidney disease or a kidney transplant and highlights the need for patient-centred care.

## KEYWORDS

chronic kidney disease, kidney transplant, physical activity, quality of life, well-being

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## INTRODUCTION

Receiving a kidney transplant remains the optimal medical treatment for chronic kidney disease (CKD) and kidney failure (Tonelli et al., 2011). The 5-year mortality of kidney transplant recipients is 47% lower than individuals on the transplant waiting list, who typically receive another form of kidney replacement therapy (KRT), such as dialysis (Kaballo et al., 2018). Between 2018 and 2019, 7959 adults in the United Kingdom (UK) started dialysis (UK Renal Registry, 2021), with only 3272 transplants performed (NHS Blood and Transplant, 2018). This, coupled with the incidence of kidney disease increasing and the availability of suitable organs for transplantation ceasing to increase reflects, at least in part, the ageing and increasingly comorbid renal population (who may be unsuitable for transplantation), as well as a growing demand for kidney transplantation (UK Renal Registry, 2021).

## LITERATURE REVIEW

Although the benefits of kidney transplantation are well known (i.e., restored kidney function), there is little qualitative evidence representing people's experiences of living with their transplant and how these may differ from pre-transplant life with advanced CKD, which may be useful in demonstrating the transplant efficacy. Indeed, congruent with a systematic review (Jamieson et al., 2016), Orr et al. (2016) reported that adult kidney transplant recipients identified four key themes (increased medicalisation, fear, gratitude and coping) characterised their post-transplant lives. As such, returning to a 'normal life' following a kidney transplant may not always be possible.

More specifically, fear of transplant failure and challenges surrounding immunosuppressant use have previously been shown to reduce quality of life (QoL) in kidney transplant recipients (de Brito et al., 2015). Many also report feelings of survivor guilt, as well as social isolation given the removed contact with their dialysis unit where they have previously spent considerable time (Jones et al., 2020). Qualitative research also identified a willingness to tolerate greater side effects, such as increased medicalisation, to maintain transplant health, with 88% of respondents valuing the survival of their transplant over their own life (Howell et al., 2012).

Whilst the efficacy of a kidney transplant is assessed medically and individuals are typically reclassified to a CKD stage based on their restored kidney function (Provenzano et al., 2020), any other impact on the individual's life is not routinely used to guide clinical treatment. Previously, Lorenz et al. (2019) developed a conceptual framework following semi-structured interviews to characterise the psychosocial impact of a kidney transplant, highlighting the burden and stressors faced by kidney transplant recipients. This framework allows insight into the lived experience of these individuals, however, sheds little light on the impact of the transplant on physical activity or physical function.

Although daily physical activity (Antoun et al., 2022a, 2022b) and physical function (Wilkinson et al., 2021) are often reduced in

people with CKD, and are known to reduce their QoL (Antoun et al., 2022a, 2022b), increased physical activity has been shown to contribute to increased health-related fitness and QoL within kidney disease (Riess et al., 2013; Stefanović & Milojković, 2005). In transplant recipients, increased physical activity is also associated with a reduced risk of a cardiovascular event (Kang et al., 2019) and preserved kidney function (Masiero et al., 2020). Given these associations between physical function, mortality and QoL in people with a kidney transplant (Brar et al., 2021), physical activity and physical function are important outcome measures to monitor transplant success. Whilst the impact of kidney transplants on QoL has previously been investigated (Wyld et al., 2012), how this may differ to people living with advanced CKD and any impacts on physical activity and physical function has yet to be explored and can provide helpful insights into more holistic transplant efficacy.

The purpose of this phenomenological study was to use the composite vignette approach to present the experiences of adults living with advanced CKD and kidney transplant recipients. Specifically, we aimed to address the question, "How does a kidney transplant impact QoL, well-being and physical activity behaviours in individuals living with kidney disease?"

## METHODS

This study was approved by the South Central - Berkshire A Research Ethics Committee (19/SC/0302) and registered on the Clinical Trials.gov website before enrolment (NCT04427800) and was adopted onto the NIHR portfolio (44737). Study methodology was designed and conducted using an empirical phenomenological approach and in line with Lincoln and Guba's (1986) criteria for rigour in qualitative research and was reported using the Consolidated criteria for Reporting Qualitative research (COREQ) checklist (Tong et al., 2007).

### Study design

A descriptive phenomenological study design, consisting of one-to-one semi-structured interviews was used. Data were collected between October 2019 and 2020.

### Study participants

In total, 20 adults with kidney failure (10 pre-KRT and 10 post-transplant) were recruited from the (HOSPITAL SITE REMOVED FOR REVIEW) a UK-based National Health Service (NHS) regional kidney and transplant centre with a catchment population of 2.2 million in the South of England. Random sampling of individuals meeting the eligibility criteria was utilised to identify participants and continued until saturation was reached.

## Data collection

Individual semi-structured interviews were conducted by the first author (Joe Antoun). Whilst these were initially face-to-face in the participants' home ( $n = 3$ ), due to restrictions imposed by the SARS-CoV-2 pandemic, the remainder ( $n = 17$ ) were conducted via telephone. Through Patient and Public Involvement and informal discussions with adults living with CKD, a telephone call was ranked more preferable than video conferencing and has previously been used by our team (Antoun et al., 2021; Antoun et al., 2022a). Irrespective of whether interviews were conducted face-to-face or via telephone, all were undertaken whilst the participant was at home, at a time of their choice, to mitigate any potential influence this may have (Elwood & Martin, 2000).

## Interview guide

An interview guide comprising 11 open-ended questions developed through a review of the literature and informal discussions with potential participants and within the research team, was used to explore aspects of QoL, wellbeing and habitual physical activity behaviours. Throughout the interviews, physical activity was considered as an overarching construct that included both exercise and sport, and participants were asked to describe their experience of physical activity, rather than providing objectively assessed levels. Participants were informed that the researcher was not part of their clinical team. The interviews explored participants understanding of the impact of their kidney disease or transplant on aspects of their life, using the topic guide flexibly, with prompts and probes to encourage participants to expand on topics when needed. Data collection continued until little new data and new themes emerged within interviews and concepts were well developed (data saturation; Green & Thorogood, 2004), after which, several additional interviews were conducted to confirm this impression. All interviews were audio recorded, transcribed verbatim and subsequently anonymised. Completed interviews ranged from 15 to 31 min (mean length:  $22.8 \pm 4.9$  min).

## Data analysis

Transcripts were analysed using the NVivo 12 software package (version 12.0, QSR International). Coding and thematic analysis were undertaken by the first author (Joe Antoun) using a systematic approach (Fereday & Muir-Cochrane, 2006). The first stage of this involved developing a code manually to organise similar and related texts to assist with the interpretation of the data. In the second stage, data were individually summarised, and any initial themes were identified. Initial themes were subsequently revisited, codes applied, and then regrouped into more appropriate groups. Finally, these codes were corroborated by ZLS and DJB. An abductive approach was taken to create codes from within the pre-determined topic

summaries, to generate families of ideas or similar overarching themes. Quotes were subsequently extracted from the transcripts and aligned to appropriate themes and codes.

## Composite vignettes

In the second stage of data exploration, the composite vignette technique was used. This technique can be viewed as a form of creative analytical practice that provides a new, deeper understanding of varied experiences (Spalding & Phillips, 2007) and has not been used in transplant recipients and only in one study (Antoun et al., 2022a, 2022b) involving people with kidney disease. Specifically, in line with Bradbury-Jones et al. (2014), the data are presented via storytelling and combined quotes from the identified themes to create separate composite vignettes for adults with CKD and transplant recipients. Quotations and descriptions that best described the themes previously extracted were set aside and creatively weaved together to present the narrative using the voices of those living with CKD or a kidney transplant. The remaining authors acted as critical friends reviewing and revising the drafts of vignettes several times to establish consistent and meaningful storylines.

## RESULTS

In total, 20 individuals participated in this study, representing two groups: adults with stage G4 CKD ( $n = 10$ ;  $70.5 \pm 8.9$  years; 7 male) and adults who had received a kidney transplant ( $n = 10$ ;  $50.7 \pm 11.5$  years; 6 males; transplant age:  $42.7 \pm 20.9$  months). The themes identified through the thematic analysis are presented in Table 1. These denote the key thematic areas discussed concerning life with kidney disease and/or post-transplant on QoL, well-being and daily physical activity. The composite vignettes presented aim to elucidate the lived experiences of adults living with advanced kidney disease and a kidney transplant. Our intention was not to compare the two groups, nor do we encourage our readers to do so. The composite

**TABLE 1** Summary of the themes identified during thematic analysis

Chronic kidney disease stage G4	Increased awareness of condition
	Difficulties with activities of daily living (ADLs)
	Reductions in physical ability
	Alterations of life plans
Post-transplant	Increased engagement with ADL
	Improvements in physical function
	Transplant-related anxiety
	Improved freedom and independence

vignettes presented are also contextually and temporally bound so whilst it is hoped that these experiences may resonate with some readers, the individual experiences to these stages of CKD may differ.

### Composite vignette of adults living with advanced CKD (Stage G4)

*I find everything difficult. I am constantly being sick, especially in the evenings and I am not capable of doing anything. I normally feel so rough, I just don't go out. I have got no enthusiasm for anything. The duration of sleep has also certainly changed. I tend to wake during the night to go to the toilet and I properly struggle to get back to sleep. My mood has dropped but I find it is because I feel sick all the time; the change in diet does not help either. The lack of proteins that I love, like cheese and eggs and meat is challenging. I don't want to do anything. I just sit down and watch the television, until my wife forces me to do things of course! We used to go abroad to see friends quite often, but we don't go abroad anymore so that was curtailed, we have to stay here [locally to UK] now. I would think, well, if I say that up to 2 years ago, I would walk from my home to the high street twice a day as a regular occurrence and that would take me 15 min to get to the high street and 15 min back, but now if I did that, I would be sitting on people's garden walls because I would be breathless on my way down. My legs will also swell up, so it is quite difficult to maintain any sort of exercise and you get quite exhausted just doing short walks. I think I get tired whatever happens. Something just comes over you. I just don't have the same energy levels as I used to. I find that I get more breathless now after certain jobs; simple jobs like bending down to tie my shoelaces, are more difficult. I guess that at the moment I'm trying to programme my brain for dialysis, because I'm going to have to be motionless for pretty much 4 hours. So that's what I'm currently worried about.*

This first composite vignette sought to present the experience and impact of living with CKD on QoL, wellbeing and physical activity. A common experience faced by all was the overwhelming symptom burden of CKD and the impact this had on QoL. Common symptoms reported, such as tiredness, fatigue and reduced perception of wellbeing, have previously been identified as key contributors to reduced QoL in advanced CKD (Almutary et al., 2016). In a similar cohort of adults with advanced CKD (not requiring dialysis) assessed using the Leicester uraemic symptom score, excessive tiredness, disordered sleep and pain were most commonly reported, with this increased symptom burden being associated with a reduced QoL (Brown et al., 2017). This vignette also describes a reduction in overall physical activity levels, both structured exercise and activities of daily living (ADLs), mainly due to lack of energy and physical ability. A previous study within this population highlighted the high prevalence of frailty within CKD and the high burden of reduced physical function, assessed through the use of the short physical performance battery, translating to reduced abilities to perform typical ADL (Walker et al., 2015). Previous work by Antoun et al. (2022a, 2022b) highlighted a greater reduction in physical ability in individuals who have reached kidney failure and require KRT, which

early physical activity interventions may help to prevent. This reduction in physical ability is particularly important, as a reduction in ADLs has the potential to impair independence, QoL as well as the potential to lead to a deteriorating sense of self (Bristowe et al., 2019).

### Composite vignette of adult kidney-transplant recipients

*Day-to-day life is totally different to the way it was before; from when I was on dialysis. I am happier to go out on my own now in the car. I hardly drove at all on dialysis because I just felt so tired all the time. It is like your time is your own again and I can do things again, like holidays and stuff, which I couldn't do when I was on dialysis. It was nice to be able to plan things and do things. I get up in the morning and every day is like my first day of being normal. I do everything that I want; I see my grandchildren and I drive, I also shop myself normally, so I am like any other person. I used to spend a lot more time sleeping when I was in discomfort, so I would say that has improved after the transplant; I am sleeping through the night and not waking up with discomfort. I'm coping a lot more with that sort of thing [activities of daily living], energy wise, like a day out with my daughter, that has definitely improved, whereas before, I could hardly do a whole day out. I go out a lot and I walk a fair distance, but I probably don't walk as far as I should but generally, I would say that the impact on my life is amazing. I have improved [increased] my exercise compared to me having kidney disease. I have been swimming and done a few fitness classes and things since my transplant. I always used to feel so tired [pre-transplant] and I also felt sick as well, but now, I can do what I want. However, if anything went wrong [with the transplant], I think it worries me more than anything because I know the specialist treatment that I need if anything does go wrong. It [dialysis, pre-transplant] affected my confidence to be fair. A lot of scars and stuff from dialysis, which don't bother me anymore, but at the time of the transplant, I always covered up. The thing is though, I find life can be quite difficult because of the rest of my medical problems; the kidneys do not bother me anymore.*

This second composite vignette aimed to present a collated experience of individuals following a kidney transplant, and the impact of this on their QoL, wellbeing and physical activity. The most reported change post-transplant was an improved sense of self, where individuals described increased feelings of wellness and a return to 'normal' life. This builds upon previous research which has shown that, compared to pre-transplant, kidney transplant recipients report significantly improved health-related QoL in both the general and kidney-specific domains (Kovacs et al., 2011). Congruent with Madariaga et al. (2016), our findings highlight the potential impact of transplant-related medications, such as immunosuppressants, on QoL and incidence of comorbidity complications. People in the present study who are living with a kidney transplant also reported heightened anxiety and concern around the preservation of the health of their transplant, which, in certain instances, led to restrictive behaviour (i.e., reduced socialising or travelling abroad) to mitigate

risk. Our findings support previous qualitative investigations (Tucker et al., 2019) which found that, although kidney transplant recipients experienced improvements in QoL and a return to normalcy, longer-term implications were an ongoing concern with the lifetime of their transplant and a potential need in the future to resume some form of dialysis KRT.

## DISCUSSION

This study aimed to explore the experiences of adults living with advanced CKD and those who have received a kidney transplant, focusing on their QoL and daily physical activity behaviours. For the first time in kidney transplant recipients, the experiences of these individuals have been presented using the novel composite vignette technique. The principal findings show that individuals living with a kidney transplant demonstrate improved QoL, independence and physical activity levels, when compared to themselves pre-transplant. In contrast, advanced CKD is characterised as an increased awareness of their condition through the deterioration in their physical function and subsequent reductions in QoL. However, it was noted that those living with a kidney transplant described transplant-related burdens, such as increased anxieties, which may have implications regarding general well-being and QoL.

Findings from our study highlight an increase in independence, largely as a result of reduced medical reliance and increased physical function. Such findings are congruent with a systematic review by Jamieson et al. (2016) which found five key themes characterising transplant recipients: empowerment through autonomy, prevailing fear of consequences, burdensome treatment and responsibilities, overmedicalising of life and social accountability. Our study also highlighted the psychosocial impact of transplants, notably the increased anxiety reported by transplant recipients. This anxiety was typically caused by a fear of damaging the transplant and a fear of returning to requiring dialysis, and, whilst many reported gaining independence without the overbearing nature of dialysis, for some, this was replaced by a constant concern for the transplant. Similar findings have been found elsewhere with kidney transplant recipients (Howell et al., 2012, 2017), with individuals willing to sacrifice other aspects of their health to maintain that of their transplant and forced to confront health deterioration with the uncertainty of their survival (Pinter et al., 2017).

Similar findings were also reported by Lorenz et al. (2019), where “work patients must do to care for their health (e.g., attending medical appointments, taking medications)” was identified as one of the key themes contributing to treatment burden following a kidney transplant. It is important to compare the findings presented within this paper with that of the wider literature, particularly the theoretical framework presented by Lorenz et al. (2019), which highlighted three key themes characterising the experience of those living with a kidney transplant. These are: (1) work patients must do to care for their health; (2) challenges/stressors that exacerbate felt burden and (3) impacts of burden (e.g. role/social activity limitations). Whilst the

vignettes presented within this paper provide a more positive outlook, it is important to note that individual experiences and responses to these key themes may differ amongst individuals. This suggests that whilst, medically, a kidney transplant has the potential to benefit individuals, the psychosocial impact and treatment burden is high, and continued support for individuals post-transplant could provide some solace for transplant recipients.

The beneficial impact of regular exercise on fitness, functional capacity, haemodynamic health and health-related QoL within CKD has been well reported (Heiwe & Jacobson, 2011), however, adults living with CKD have a high prevalence of sedentariness, which may be due to limitations associated with their condition and the subsequent treatment. These high levels of sedentariness have shown to be associated with poor physical function, poorer clinical outcomes and increased mortality (Painter & Roshanravan, 2013). Our findings support previous literature whereby low physical activity levels and poor function in adults living with CKD results in difficulties with ADLs, potentially impacting upon individuals' independence and subsequent QoL. Nonetheless, the present study also demonstrated an improvement in physical function and ability in kidney transplant recipients when compared with themselves pre-transplant, supporting a recent review identifying that although physical activity in transplant recipients is lower than the general population, physical activity levels are greater than in a pre-transplant population (Takahashi et al., 2018) resulting in greater physical functioning within this population group.

Transplant recipients have previously reported perceived barriers to physical activity including lack of motivation, fatigue, and shortness of breath (Sánchez et al., 2016). Within this study, individuals that had received a kidney transplant described an awareness of the need to be more physically active, now that they were able, rather than guidance from a medical professional or service, resulting in a lack of specificity with physical activity behaviours. This suggests a need for an improved follow-up service which helps to increase physical activity levels and to reduce anxieties through the introduction of further community support with other transplant recipients, such as kidney beam<sup>®</sup> (<https://beamfeelgood.com/kidney-disease>). Given that low physical activity levels in kidney transplant recipients have been associated with increased risk of cardiovascular and all-cause mortality (Kang et al., 2019; Zelle et al., 2011), further interventional studies may help to explore the potential benefits of increased physical activity on survival outcomes, and identify any potential barriers that may need to be addressed.

Individuals who are post-kidney transplant are typically reclassified based on their CKD progression. Indeed, Karthikeyan et al. (2004) found that 90% of participants, all of whom were transplant recipients, still had CKD according to clinical guidelines with a high prevalence of complications. Another similar study reported a CKD prevalence of 70% in kidney transplant recipients (Costa de Oliveira et al., 2009). It could therefore be postulated that recipients of a kidney transplant may have significant CKD and experience the deleterious effects of this on QoL and wellbeing. These effects are in

addition to those directly attributed to transplantation, congruent with the present study, which is of particular importance because the prevalence of CKD post-transplant is still high, and the longer-term implications of both the transplant and CKD have the potential to impair QoL and perceived well-being. Given this increased prevalence of CKD despite receiving a transplant, the psychosocial burden also remains high, as suggested by our findings, leaving individuals anticipating transplant failure, and diminished QoL post-transplant. Therefore, addressing the issues causing increased anxiety within this population is warranted, through further support post-transplant. However, the findings reported within this study focused on presenting the subjective experiences of different stages of kidney disease on QoL and wellbeing, with specific focus on physical activity and function following a kidney transplant, from the perspective of the participant. As such, a focus on the psychosocial impact of these stages and how they may affect QoL, wellbeing and physical activity is warranted.

The present findings need to be interpreted in the context of several methodological limitations. First, the data collection for this study was interrupted by the SARS-CoV-2 pandemic, which resulted in almost all (85%) the interviews being conducted over the phone. Although some may consider the use of telephones to reduce the quality of qualitative data obtained (Novick, 2008), it has been used successfully in the past when investigating QoL in ESRD by both Antoun et al. (2021, 2022a, 2022b) and Ferri and Pruchno (2009). Second, although the use of semi-structured interviews enables discussion and insight into individuals' perspectives, we recognise that device-based measures of physical activity were not obtained in this present study. Furthermore, we recognise that physical activity may have not only been affected by disease or transplant state but also the presence of psychosocial factors, shown to impact physical activity in this cohort (Wilkinson et al., 2021), therefore warranting further exploration in this group. Therefore, future research utilising device-based measures of physical activity of people with CKD and a kidney transplant, with measurement of the amount and intensity of any activity, would be a valuable extension of the present work. Furthermore, many of the observed differences in QoL, ADL and physical function may not only be influenced by their condition but also by age in our cohort ( $70.5 \pm 8.9$  vs.  $50.7 \pm 11.5$  years for the CKD and transplant groups, respectively) and as such, a more comparable sample may provide more accurate findings. Finally, longitudinal follow-up of these individuals would provide a further understanding of any potential changes to their QoL, well-being and physical activity status over time.

Through the novel presentation of composite vignettes, the experiences of adults living with CKD or a kidney transplant, and the impact of these on QoL, wellbeing and physical activity, have been highlighted. Despite longer-term implications of kidney transplantation, it remains a highly effective treatment for CKD and addresses the physical symptoms and the deteriorating impact on QoL caused by kidney disease. However, a review of the social support available to transplant recipients may help to identify potential barriers and solutions to the increased anxiety experienced by these individuals.

## IMPLICATIONS FOR CLINICAL PRACTICE

Findings from this study demonstrate an improvement in QoL and perceived well-being as well as a reduction in symptom burden in people with CKD following transplantation. Transplant recipients become more physically able to engage in both physical activity and typical ADL. However, transplant recipients report increased anxiety surrounding their transplant specifically, which needs to be addressed by clinical teams to further reduce barriers to QoL. For individuals with advanced CKD, certain thematic areas identified in this study, such as the increased symptom burden and reduced physical ability, should be focused upon to mitigate any further reduction in QoL, such as physical activity programmes to mitigate any CKD-related deteriorations in physical function. Findings from this study, in both adults with CKD and adults following a kidney transplant, demonstrate the variety in the impact of these common experiences on individuals at the various stages of their disease and promote a focus on more patient-centred care and the treatment of the patient rather than treatment of the disease.

## AUTHOR CONTRIBUTIONS

**Conceptualisation:** Joe Antoun, Nicholas C. Sangala, Anthony I. Shepherd, Jo Corbett and Zoe L. Saynor. **Data curation:** Joe Antoun, Nicholas C. Sangala and Robert J. Lewis. **Formal analysis:** Joe Antoun, Daniel J. Brown and Zoe L. Saynor. **Investigation:** Joe Antoun and Zoe L. Saynor. **Methodology:** Joe Antoun, Daniel J. Brown, Beth G. Clarkson and Zoe L. Saynor. **Project administration:** Joe Antoun and Zoe L. Saynor. **Supervision:** Anthony I. Shepherd, Jo Corbett and Zoe L. Saynor. **Writing – original draft:** Joe Antoun. **Writing – review and editing:** Joe Antoun, Daniel J. Brown, Beth G. Clarkson, Nicholas C. Sangala, Robert J. Lewis, Anthony I. Shepherd, Melitta A. McNarry, Kelly A. Mackintosh, Jo Corbett and Zoe L. Saynor. All authors have read and agreed to the published version of the manuscript.

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## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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