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JOURNAL SUBMISSION DETAILS FOR 2017

For 2017 the Transplant Journal of Australasia (TJA) will be produced in April, August and December.
Papers are submitted to the Editorial Board, which provides feedback to the author prior to publishing. All papers will be sub-edited to journal style before publication — please refer to the Guidelines for Authors for more details on this and for detailed submission information.
Welcome to 2017 and I hope you’ve all had a wonderful holiday period. What a year 2016 was! As we all know in 2016, there was a significant increase in the number of organ donations and a record number of transplants. We can all be humbled and proud of this achievement and hope for further growth in 2017.

We bid a fond farewell to Chris Ellis as National President and Elaine Kennedy as National Secretary, and thank them for their guidance and leadership over the past two years. Elaine is maintaining her activity in TNA through assisting in the upcoming TNA Conference in Melbourne, providing a wealth of knowledge and prior experience. Fortunately, Chris has transitioned into the role of National Secretary and her know-how and support, in addition to that of Julie Pavlovic (ongoing National Treasurer), have been of the utmost value to me transitioning into my new position of National President.

In some terms I am relatively new to the nursing profession, entering the field of transplantation in my first graduate position in 2009. Whilst I found it daunting and nothing like anything I had ever done before, I found my passion returning to liver transplant full time in 2011 and remaining there ever since. Joining the TNA in 2012, I have found it to be a supportive and nurturing association which has provided me with a great many opportunities and learning. I am honoured to take on this position and hope to only further develop the TNA. The year 2017 looks to bring about some exciting new developments for the TNA.

At the 2016 National Conference, we were pleased to announce the Astellas Practice Development Award, which will support a TNA member in attending an international conference and transplantation centre. Additionally, I’d like to remind all eligible members to apply for one of the TNA’s two scholarship rounds to help support them in their attendance/presentation at a conference. Whilst the first rounds of scholarships have closed, I encourage you all to apply for the second round (closing 7 July). Please keep an eye out for the email, Facebook and website updates of what opportunities and developments are still to come.

Following consultation, the TJA Editorial Board and the National Executive are delighted to announce that over the course of 2017 we will be trialling an online version of the TJA, which will be able to be viewed not only on the TNA website, but also devices such as smartphones, tablets and computers.

Lastly, a big thanks to all of our members who make the TNA such a fantastic organisation. Remember to introduce the TNA to new staff members and colleagues, and let’s see where 2017 and beyond can take us.

Katherine Bateman
TNA National President

The Transplant Nurses’ Association is now on Facebook
‘Like’ us on Facebook for all updates on the national conference, educational activities and transplant-related issues.

Katherine Bateman
TNA National President
Editorial

Advocacy

The year 2017 is shaping up to be yet another busy year for us all as donation and transplantation activities continue to rise across Australia and New Zealand. I hope you’re all ready for another record-breaking year. The TNA is also gearing up for another hectic year with local education programmes and events being carried out within the local state branches and, of course, our annual national conference in November that will be held in Melbourne. In addition, the TNA is trialling an online version of the TJA for three issues. The purpose is to make the TJA easily accessible in a format that is paperless and cost-effective. At the end of the year we will conduct a survey to evaluate the effectiveness of the online version.

Our guest editorial for this issue, written by Dr Roslyn Jones, is a poignant reminder of the significant role that we all play in building relationships between our patients and the health service, while maintaining our role as health care professional, leader, advocate, clinician, educator and scholar. “Rebuilding the foundations of medicine” explores the link between patient care, safety and satisfaction, through the different perspectives of the client, health care professionals, administrators, legislators, the public and the media.

In the current climate of increasing medical litigation, health care professionals carry medico-legal-ethical burdens on a daily basis. More than ever, we are instructed to attend workshops to enhance our communication skills, professional behaviour, ethical practice, leadership, teamwork, collaborative practice and diversity within health. Furthermore, there is an increasing number of policies and guidelines that are generated as a response to adverse events. Our guest editor is rather impressed that clinicians remain dedicated in providing excellent care in a system that is under constant scrutiny.

The reflections of Associate Professor Nick Rieger links nicely with our guest editorial. It’s an honest and sincere account of his experiences as a patient and a liver transplant recipient. It is very moving and the description of his complications was quite illuminating. His experience allows us health care professionals to consider and identify strategies to meet the challenges of caring for a colleague such as maintaining boundaries (doctor-colleague-friend), avoiding assumptions about their knowledge (limiting information as “they already know”) and managing their colleague’s access to tests results and “corridor” consultations as they seek opinions from other colleagues. It is, therefore, important for us as clinicians to maintain open and honest communication to ensure quality care for all our patients, regardless of whether they are colleagues or not.

The emerging theme for this issue of the TJA is advocacy as the other two articles describe the importance of a multidisciplinary and team approach in the development of initiatives to improve patient outcomes. Both these articles describe particular difficulties in the care of recipients post-transplantation; however, both articles showed that through collaboration, we can maintain, improve and manage the health of our patients effectively. I agree with both Dr Ros Jones and Associate Professor Nick Rieger that we should not waver in providing respectful care and communication to our patients. Their thoughtful and insightful ruminations serve as validation of the hard work that we all do, but also a reminder that we should always strive to improve.

Myra Sgorbini
TJA Editor

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GUEST EDITORIAL

Rebuilding the foundations of medicine

Dr Roslyn Jones • Medico-Legal Officer
Royal Prince Alfred Hospital, Sydney, NSW

Over the course of some 30 years of experience as a doctor in the public health system in NSW, my career has assumed various guises — a clinician, a hospital administrator, a health service planner and finally a medico-legal officer. During this span of years and roles, I have become increasingly aware of the changes to the relationship between the patient and the health care provider, whether it be by an individual clinician or a health service per se. This editorial focuses on the worrying signs of mutual distrust that are now evident within the health service and the population it serves.

Over the past 15–20 years, we have seen a growth in the number of complaints from our patients and not only an increase in medical litigation but a shift in the legal rules pertaining to the standard of care of medical practitioners. There is greater scrutiny of clinical practice by sectors outside the medical profession, including the courts. I am constantly amazed at the burgeoning of the administrative structures that have evolved in order to take part in and respond to this situation.

There are state and federal bodies that register and oversee clinical practice, accredit hospitals and investigate complaints. At a local hospital and district level there are now staff and structures that deal with the process of handling this increasing number of complaints, investigating adverse outcomes and managing the litigation cases that have both become greater in number and complexity. There are now legal officers, media officers, risk managers, complaint officers, privacy officers, and clinical governance personnel, categories of staff that did not exist 25 years ago. And while these structures are put in place in order to respond to concerns, investigate adverse events and instil systems that will conform with changes to health legislation and practice, there is an element of defensiveness to this structuring.

In this environment, it is easy for practising clinicians to give way to a sense of distrust, anxiety and defensive medicine. Language has changed from that of ‘care’ and ‘service’ to that of ‘rights and responsibilities’, with ‘zero tolerance’ to the slightest sign of aggression, and consent forms that list any possible complication from a procedure in an effort to prove that the patient was indeed advised of the complication prior to the operation. But why are there these signs of discontent and dissatisfaction? Do clinicians really provide worse medical care today than previously? Do we communicate less with our patients?

I would suggest that this expression of dissatisfaction and loss of trust is multifactorial, reflecting in part a shift in the public’s attitude to medical practitioners that has occurred from around the 1970s, with challenges to the doctor’s authority and an examination of the unequal power relationship between doctor and patient. Along with this we have witnessed the very strong hold of consumerism so that we now have ‘consumers’ of healthcare and patients morph into ‘clients’, the very term suggesting a commercial contractual relationship.

And across society consumers have growing ‘rights’ and ‘entitlements’. Each individual within our society has ‘rights’ to ‘health’ and medical service provision within a time frame that does not equate with a system based on prioritisation. Then, when there are problems, as inevitably there will be at times, when these high expectations have not been met, when an individual’s ‘rights’ as a consumer and someone who matters have not been observed or valued, someone must be responsible, and must be seen to be held responsible so that they can be called to account.

This rise of consumerism has affected not just healthcare but also any good or service in general, including that of the services provided by law firms. Throughout the 1990s, the legal profession underwent regulatory reforms, many of which concentrated on competition policies. Competition was seen to be positive and progressive, giving consumers the right to choose and ‘get the best deal’. This has resulted in ‘self-deregulation’ that has produced changes in law practices such as relaxing the previous restrictions on fee structures and advertising.

Consequently, legal firms solicit through advertising widely for potential clients who have allegedly been harmed in accidents and medical misadventure with the lure of ‘no win no pay’ contracts, an environment which feeds a feeling of being wronged and that someone has to pay. The media too fuel this sense of righteousness by sensationalising the personal narratives of those who have been harmed, not infrequently getting vital details wrong in the process. Media reports will often use emotional and offensive language such as ‘bungling’ and ‘outrageous’, rather than deploying their professional obligations to report with accuracy, objectivity and balance. Instead, their bottom line is to sell news, which is aided by this sensationalism.

In some sense, however, some may be surprised to witness this growth in complaints and litigation at a time when our
health services can now offer to our patients with a range of afflictions who present at our doors so much more than ever before. People are living longer, are diagnosed earlier, are cured or kept alive with diseases that were previously incurable, are given new joints to improve their quality of life, stents to relieve their blocked arteries, so much more is available than could have been offered 20–30 years ago. In addition, practices within public hospitals have changed radically in response to or in anticipation of the increasing expectations within the community for a greater involvement in and say about their own health care. Such changes include ‘consumer consultation’ on hospital boards and ethics committees, for example, policies and practices that stress the process of ‘informed consent’, and the development of an ‘open disclosure’ system when adverse events occur. There are more policies and procedures for any eventuality than ever before: we have patient leaflets on many aspects of their care and what to expect on discharge; and we have intensive training for hospital staff on a wide variety of areas that extend beyond clinical aspects to areas such as privacy, safety, and an awareness of the needs of minority groups, and various religious practices and observances.

But these extensive advances in healthcare, both in technological terms and in the approach to illness management, rather than appeasing the public and injecting a sense of trust and admiration, lead to increased expectations that of course cannot always be met. The improved diagnostic and screening tools, treatment modalities, speciality services and multidisciplinary approaches to disease management generate a growth in expectations that cure for each and everyone is possible, despite the state of imperfect bodies or the complexity of the medical diagnosis or intervention. We should all be able to live a long and disease-free existence, experience the perfect delivery of a perfect baby, have access without wait to all possible medical procedures, and to have them performed without complication, no matter the complexity or the scarcity of available resources and donors or the cost. In some respects, religious faith has been supplanted by a faith in progress, the faith in God's Will will be done has been replaced with a faith that science will prevail and find the elusive cure in time.

So when there are unmet expectations, which are inexorable, there is anger, complaint and, at times, litigation, all signs of distrust between patients and the public at large on the one hand and healthcare providers on the other. The inevitability of death or morbidity seems to have been forgotten. After all, progress has extended to providing guidance with ‘Doctor Google’ that informs all of what is possible and the net allows direction in accessing the right doctor with low complications according to satisfaction reviews and complication rates. The public believes itself to be informed and in control within this environment. When things go wrong, someone must be blamed.

This high level of patient expectation is in a milieu of the many uncertainties and ethical dilemmas that are always present but that have been escalated with these rapid advances in medicine. These include choices about who should receive scarce resources; the quagmire of establishing the yet unclear clinical significance of the many investigations that can now be ordered, especially in the area of predictive/presymptomatic genetic testing; legal challenges over the ownership of tissue, such as embryos in IVF services; and the management of unforeseen complications that may develop from new technologies, an example being the acquisition of HIV and hepatitis B and C that we witnessed following the introduction of coagulation factor replacement for the treatment of haemophilia.

For those working in the field of transplant medicine, these ethical dilemmas are well known. It is possible that transplantation has raised more ethical, legal and policy questions than any other medical technology. The scarcity of organs raises issues of equity and we have seen the development overseas of black markets in organs and financial incentives for those who donate. In addition, there have been the competing rights and interests of donors and recipients, with challenges regarding consent, especially in cases that involve minors. The removal of tissue from a child when there is no benefit to that child poses significant ethical problems. As well, there has been the redefinition and expansion of the definition of death, with the addition of brain death to the previous long-accepted cardiopulmonary death. And clinical staff carry these burdens on a day-to-day basis.

As practising clinicians working in this taxing area, it is understandable that some may not feel valued, and that any less than an ideal outcome will result in litigation or complaint. Certainly complaints are received in relation to transplant medicine, with many of the recurring themes of waiting lists and surgical complications. Furthermore, as transplant units for certain organs are centralised, coordination of medical services can be the focus of complaint. In addition, this area of medicine deals with the chronically unwell and their families, who have frequent hospital admissions, often of long durations. So this population is educated with respect to hospital practice and the significance of symptoms that the patient may be experiencing. The patient and family are fully aware of the importance of maintaining the best clinical condition so that they can be judged to be a recipient of a donor’s organs. As such, they complain if something in the clinical management is judged to jeopardise their long-term chances.

And, of course, there have been instances of litigation involving transplantation that may involve such aspects as surgical problems, waiting list determinations or the acquisition of infectious diseases. However, one must remember that the
rates of litigation overall are very low when considering the numbers of occasions of service. Further, when considering this very ethically confronting, technically difficult and emotionally charged area of medicine, together with the enormous coordination that the transplant programme demands, the low numbers of complaint and litigation give those who work in this field credit.

Of course clinicians may make mistakes or fail to communicate effectively and health services may be overstretched, resulting in delays and coordination difficulties. Each of us knows of patients who have not received good care in our hospitals, of genuine medical mistakes that have had horrendous results, and of unsatisfactory patient experiences as a direct outcome of not being treated with due respect and courtesy. And patients do need to be able to raise their concerns, to have adverse events investigated and to be listened to, both by individual practitioners and by the system as a totality. Patients need to be afforded a second opinion, an avenue by which grievances can be heard and, of course, fundamental to all care provided, be made aware of both the benefits and risks of any medical intervention and of not following medical advice. Health services too have an obligation to investigate adverse events and to change practices in order to avoid the event being replicated.

My overall concern is that we do not allow a ‘them and us’ situation to develop but to concentrate on the satisfying aspects of medicine. Our health service has long been based on just that — ‘service’, built incrementally on the foundation of a fundamental desire to improve health outcomes for those we serve. Australia has a reputation for its soundness of health care provision that extends to not only expensive, high-tech super-speciality services but to general practice, public health services and emergency care. Our health system has been based on need and equity-quality health care that is available to all equally according to relative clinical needs, as a reflection of the values we deem to be important in our society. I am constantly impressed by the dedication of clinical staff of the public hospital in which I work. They have already undergone an extended duration of training, then work long hours, face protracted periods of being on-call, constantly update their skills and knowledge, explore improvements in their speciality by trialling new techniques and participating in research, engage in quality reviews and generally carry substantial responsibility on a daily basis.

Despite the changes in patient expectations and the structures that scrutinise medical practice, we must not lose sight of the fundamentals of medicine — caring, open communication, taking time to listen, and showing respect and consideration for the patient. We should not overlook the real differences our clinicians make to the lives of so many and actively realise opportunities to re-establish the valuable, rewarding fiduciary relationship upon which medicine relies. I also do not want to experience any demise in the fundamentals of our public health system that have historically been based on equity. To achieve this, I would encourage public involvement in difficult medical issues that concern resource distribution and service provision so that we can not only preserve but also strengthen the foundations upon which our public health system is based.
REFLECTIONS

My liver transplant: A surgeon’s experience on the other side

Associate Professor Nick Rieger • MBBS, MS, FRACS
Colorectal surgeon and liver transplant recipient

It is now two years since I had a liver transplant. My transplant in the month of January was a very special new year’s gift. I am a 53-year-old specialist colorectal surgeon and have been practising for 18 years. The most intriguing aspect of my transplant experience is that in 1992, as part of my surgical training, I was the surgical registrar in a Hepatobiliary Unit when the unit undertook their first liver transplant. Coming back onto that unit as a patient was not part of my professional plans.

My diagnosis was autoimmune hepatitis with a high titre of an anti-smooth muscle antibody, so high that, in fact, I was initially misdiagnosed with multiple myeloma. My diagnosis was late in the disease process. I had ignored symptoms and attributed tiredness and general ill-health to overwork. At diagnosis I already had ascites, I was jaundiced, my albumin level was 19, my INR score was 1.9 and my initial MELD score was 22, indicating end-stage liver failure.

The first step of my treatment involved a week-long assessment for transplantation as an inpatient at FMC. The week involved consultation with the liver transplant unit coordinators in which they spent time explaining the process of transplantation from the point of view of the donor and recipient. Importantly, all aspects of my mental and physical health were assessed. If I failed to satisfy the requirement of being in otherwise good health, I would not be able to become a transplant recipient. This was at the forefront of my mind. It was an emotional and difficult week. I had to let it all happen, let it all be at the mercy of the system. Two weeks later I learned of my suitability for transplantation and I was placed on the list for a liver transplant.

The most challenging aspects of the transplant process were the lack of control, the waiting and the uncertainty. I had a number of factors to obsess about: blood group, who was sicker than me on the waiting list, recent car accidents and so on. I toyed with the balance of probabilities that might answer the question, “What are my chances, and, will I die waiting?” I was at the mercy of outside events and I couldn’t plan or determine what would come next. This was a great challenge for me as I had lived my life thus far in a manner of good-natured order and control. In the end, I only waited six weeks, but it felt like years.

Although I was not afraid of the operation, I was scared about dying. I did understand that acute rejection could mean death, and that surgical complications, particularly around vascular anastomoses or the bile duct meant disaster and potential protracted problems. I remember feelings of terrible vulnerability at the time of surgery and particularly being in the holding bay in theatre at 5 o’clock in the morning and watching my wife, Sue, walk away by herself to cope with the day ahead after no sleep the night before. I was under the care of the transplant team and she just had to wait.

I suffered a full quota of postoperative complications and these difficulties were compounded by the fact that I was a medico, and therefore a terrible patient. I had drug-induced diabetes requiring insulin; a severe steroid-related tremor; medication-related rash; paralytic ileus; Clostridium difficile colitis; hospital-acquired pneumonia; mania; confusion; hallucinations (for three weeks a Moroccan man visited my room to sell me Persian rugs); opiate dependence; and pleural effusions (three chest drains). However, the worst complication was mania.

Steroids created my greatest problem. After a mild rejection episode I was put on 200 mg of prednisolone for three days. This was on top of a background of a daily dose of 20 mg. I became acutely psychotic and I was completely unmanageable to my family and the transplant unit. I had to be readmitted to hospital for three days to be placed on sedatives to calm down, and so that my family could have a much-needed break from me. During my manic episodes I took cars for test drives; bought expensive things on the internet; I had persecutory delusions; I was angry and rude to everyone near me; and, I had mild suicidal ideation. I felt that my marriage would break up and that I would die. My state of mind and behaviour during this time was extremely distressing for my family and me. It took four months to settle with the help of a psychiatrist, psychologist and antipsychotics. I will never, ever, prescribe steroids lightly again.

From my reading, psychiatric symptoms after taking steroids are common and include hypomania, mania, depression and psychosis. Symptoms are dose-dependent and usually occur in the first few weeks of therapy. Severe psychiatric illness is uncommon (<2%) with doses less than 40 mg per day.
of prednisolone but may increase to up to 20% with doses above 80 mg per day. My feeling is that health professionals underestimate the negative side effects of steroids and also fail to adequately manage the situation when it arises.

After my transplant, it took me more than 12 months to accept and be content in my new life. I struggled with adjusting to a new identity as a transplant recipient due to associated feelings of being undeserving. After psychological care and with time I now feel that I am the strongest and happiest that I have been for many years. I returned to work full-time after six months and I now live an active life. The best suggestion I had from a colleague and friend was to go to an exercise physiologist and gym. Following my transplant I was deconditioned and weighed only 78 kg. I was weak, tired and I had no stamina. The initial weight I could bench press was 13 kg. I still go weekly and can bench press over 91 kg and squat over 110 kg! A remarkable turnaround. In addition, I go to yoga once a week and my dog gets walked twice a day.

It is now over two years since my transplant. I have been very lucky with a great outcome so that I can get on with my life with few restrictions. I am, however, scared about the future. I fear that my 'bubble' of recovery and good health may burst. Immunosuppression does carry potential complications. It is important that I closely monitor my general health.

I keep regular appointments and am always eager to know how I am going. I am very attentive to my blood test results. I understand the privilege of being able to look up my test results myself. It has made me understand how vulnerable all patients are and how anxious people are when they see their doctor.

Am I a better person? Probably not, but I listen to and accept other people more. I have a greater understanding of other people's issues and spend more time with my own patients to give detailed explanations and reassurance. I see the world with different eyes and appreciate everything around me.

It is incredible what a human body can withstand and how wonderful and transforming a transplant can be. There are many people to thank. Most important are the people and families who agree to donate their organs. Transplantation is not about the recipient but really more about the donors who enable people like me to get better. Heartfelt thanks go to the staff that have and still do care for me, my family, and my friends and colleagues.
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ARTICLE

The potential of a patient-centred video to support medication adherence in kidney transplantation: A three-phase sequential intervention research

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Abstract

Kidney transplantation is an effective treatment if patients adhere to their prescribed medications, whilst non-adherence jeopardises graft survival. This paper aims to outline the design, development and evaluation of a video, which was created in partnership with patients, to support medication adherence in kidney transplant recipients at 1–4 months post-transplantation. This study formed part of a larger, three-phase intervention research project. Patients were recruited from five hospitals that offer adult kidney transplantation in Victoria, Australia. During Phase One, 25 patients who had maintained their graft for ≥8 months or had experienced a graft loss due to medication non-adherence were interviewed. The transcripts of the interviews were analysed to identify potential storytellers and the story plot. In Phase Two, storytellers of both genders, different ages and ethnicities were involved in the videotaping process. The first draft of the video was evaluated by an expert panel using content validity. During Phase Three, the final 18-minute video, which addressed transplant medication management, was viewed by 33 newly transplanted kidney recipients. To them, the video reiterated the importance of medication adherence and 62% thought the video contained helpful tips. Upon concluding the intervention period, five participants from the intervention group participated in a focus group to evaluate the acceptability of the video, which revealed a mixed reaction from the participants that are mainly positive. Using patients’ stories, which is a novel way of engaging newly transplanted kidney recipients, has the potential to support medication adherence and promote long-term graft success.

Introduction

In kidney transplantation, patients must care for their graft by committing to a lifetime of immunosuppressive medications, except for transplantations between identical twins1-3. Otherwise, if the immune system is not suppressed sufficiently, rejection is often inevitable in non-adherent patients. Due to the essential need of immunosuppressive medications to minimise the risk of rejection, the patients need to deal with common side effects arising from this regimen4-8.

Addressing the side effects of immunosuppressive medications is equivalent to needing more medications, for example, prophylactic antibiotics to prevent contraction of infections5,6 and proton pump inhibitors to inhibit gastric acid production7. The medication regimen is further complicated by comorbidity, which affects about 25% of patients at the time of transplantation8. The resulting medication regimen is complex with multiple medications, each with a specific dosing instruction and requirement.

To ensure successful management of the complex medication regimen, it is essential to equip the patients with adequate information through education to encourage active involvement in treatment. In Victoria, Australia, a kidney transplant recipient commonly receives medication...
education through verbal instruction, demonstration and written material\textsuperscript{13}. Unlike the aforementioned approaches, a video can be viewed at the patient’s pace in the presence of family or friends\textsuperscript{14}, and repetitively.

Developing an intervention that effectively supports medication adherence has been proven to be difficult\textsuperscript{15}. However, previous interventions developed for kidney transplant recipients are driven largely by healthcare professionals and academics\textsuperscript{16}, whilst the service users have rarely been involved in the process. Hence, the main aim of this study was to outline the approach undertaken in designing, developing and evaluating a patient-centred video to improve medication adherence, which was underpinned by the Theory of Planned Behavior, using patients’ experiences with kidney transplantation.

**Methods**

This study was a three-phase, sequential study, which involved all five public hospitals that offer adult kidney transplantation in the state of Victoria, Australia. Data collection of this aspect of the study was conducted from 2014 to 2016. Ethics approval for this three-phase research was obtained from Monash Health and Monash University whilst the site-specific approvals were obtained from all five participating hospitals (HREC/13/SHT/10). Although the procedure involved in developing the video in the first two phases is described in detail in our previous study\textsuperscript{17}, a brief review of Phase One and Phase Two will be provided here.

**Phase One**

Phase One involved seeking the perspectives of patients with end-stage kidney disease from March to early May in 2014. All study participants were purposively recruited from each of the participating sites. To be eligible, the patients must either have maintained a kidney transplant for at least eight months or have experienced the loss of a kidney transplant due to medication non-adherence. The inclusion criteria were patients of at least 18 years of age who managed their own medications and who were able to converse in English effectively. Semi-structured interviews were conducted to explore factors that facilitate or inhibit medication adherence in adult kidney transplant recipients. Additionally, to aid the development of the video, participants were asked to provide suggestions about the type of information they thought would be helpful to facilitate medication adherence. The transcripts of the interview data were sequentially analysed to identify high-priority content and potential storytellers for subsequent videotaping.

**Phase Two**

Phase Two involved conducting the video production interviews with the storytellers in May and June 2014 and a panel of experts was invited to evaluate the drafted video in July 2014. The storytellers were selected from the pool of Phase One participants. Storytellers of all ages, both genders and various ethnicities, with a good command of conversational English, were selected for the video production interviews. The first author conducted the interview and all participants were filmed for \( \geq 15 \) minutes. The first draft of the video was reviewed by an expert panel using a content validity questionnaire\textsuperscript{18}. The four different groups of experts included (1) two content experts, who had experience in implementing a medication adherence intervention; (2) five healthcare experts including two nephrologists, a kidney pharmacist, a kidney transplant coordinator and a social worker; (3) an educational expert skilled in patient education; and, (4) two patients who had successfully maintained their kidney transplant for \( >1 \) year. The suggestions obtained from the experts were used to improve the draft. The final video was edited by a professional videographer.

The video was underpinned by the Theory of Planned Behavior\textsuperscript{19}, whereby the stories told by the storytellers were used to influence the three theoretical constructs of intention, which included attitude, social norms and perceived behavioural control. To promote medication adherence, the video was designed to influence the viewer’s beliefs about: (1) the likelihood of achieving the outcome; (2) whether others would approve of the behaviour; and (3) the perceived ease in performing the behaviour.

**Phase Three**

The last phase of the intervention research, Phase Three, was a longitudinal randomised controlled trial examining the efficacy of a multidimensional intervention, which was conducted from August 2014 to October 2016 (Trial Registry Number: ACTRN12614000608662). The multidimensional intervention, which lasted for three months, consisted of a face-to-face meeting to conduct a medication review and to view this patient-centred video followed by a series of six fortnightly health coaching telephone calls.

Newly transplanted kidney recipients at 1–4 months post-transplantation were recruited from each of the participating sites. To be eligible, they had to be able to converse in English, be 18 years of age and above, live within a 250-kilometre radius of the Melbourne central business district, self-manage their daily intake of medications and have received either a kidney transplant or a combination of kidney and pancreatic transplant from a live or deceased donor. The initial contact with eligible patients was made by dedicated personnel from each of the kidney transplant healthcare teams at the participating sites.

For those who were eligible to participate and provided verbal consent, they were approached by the research team. Each participant was randomly allocated to either the control or intervention group. For all Phase Three participants who
were allocated to the intervention group, they received a medication review and they viewed the patient-centred video in the presence of first author (JKL) during the first face-to-face meeting. After viewing the video, the participants were asked what were their thoughts about the video and if they learned something new from it. Each of the participants in the intervention group was given a copy of the video to keep, to be viewed again if they wished.

In June 2016, a focus group was conducted with intervention participants, who had completed the intervention, to explore which aspects of the multidimensional intervention were most helpful and what could be done to tailor the programme more closely to their needs. Within the context of the 18-minute video, they were asked about their thoughts on the video and how many times they viewed the video again during the 12-month trial period.

Results
A summary of the process involved in developing and evaluating the video is presented in Figure 1. A total of 25 participants were interviewed during Phase One. The Phase One interviews were analysed to identify the key information and storytellers that should be included in the video. Of the 25 participants that were interviewed in Phase One, 13 were selected to be the storytellers in Phase Two. Their stories were combined to form a coherent story.

The final video was 18 minutes’ long, produced in English, consisting of 15 sections addressing issues pertaining to medication management (Table 1). The message of the essentiality of adherence to immunosuppressive medication was conveyed by various storytellers of both genders (7 males and 6 females), diverse backgrounds (born in Australia: 8, born outside of Australia: 5) and across different ages (30 to 68 years old). Of the 13 storytellers who were involved, 2 had lost their kidney transplant due to medication non-adherence and only audio recordings were presented for these two storytellers.

Both adherent and non-adherent storytellers played a role in portraying the importance of having the right attitude and social norm in addition to taking control to ensure a successful graft outcome. These are the three elements proposed by Theory of Planned Behavior to influence one’s intention to perform a behaviour. The adherent storytellers were the positive role models who displayed an optimistic attitude about the outcome of successfully managing their complex medication routine. In contrast, the two storytellers who did not adhere to their medications confirmed that their negative beliefs and weak social norms caused their eventual graft loss. Evaluations conducted prior to the intervention implementation indicated that stakeholders, including patients and healthcare professionals, support the use of this video in the intervention. They believed
that the video reinforced the importance of adherence to immunosuppressive medications and other prescribed medications.

During Phase Three, no participants reported negative feedback immediately after viewing the video. Sixty-two per cent saw the video as useful but the rest thought they did not learn anything new. Upon concluding Phase Three intervention period, five participants from the intervention group were involved in a focus group, which involved the post-implementation evaluation of the intervention. The focus group was held at Monash University and lasted for 77 minutes, with the consumer-centred video as one of the components that was evaluated.

In relation to the consumer-centred video, the focus group evaluation revealed a mixed reaction. One participant felt upset after viewing the video because she was not feeling well about her own situation. As she was struggling to cope with her post-transplantation life, the upward comparison with the storytellers who were portraying the message that they were enjoying their lives made her feel terrible.

“They’re all good but why am I feeling the way I am?”

(Focus Group Participant 1)

Another, however, mentioned that it was reassuring to see that kidney transplant recipients could be well. Although she was struggling with rejection episodes, she felt that seeing these storytellers, who had gone through the same experience and who remained well further post-transplantation, was quite motivating. It made her believe that she could be one of them eventually.

“I was feeling pretty awful and having the threat of rejection, all the time, and being told that it was highly unlikely that the kidney would survive. When I saw the video I thought ‘Right, they’ve done it, there is no reason why I can’t do it’.”

(Focus Group Participant 3)

A minority of participants suggested that more emphasis should be placed on the struggles that kidney transplant recipients would experience in the initial post-transplant period. One participant mentioned that he saw the video as an introduction to what kidney transplantation would involve but thought it was also important to inform the viewer of the good and bad points of transplantation, including the side effects of medications.

“There needs to be, if it is going to be taken seriously, you need a balance and it just all can’t be a happily-ever-after movie. These things can happen so just be wary of it”.

(Focus Group Participant 2)

Participants noticed that the video provided information aimed at encouraging them to remember to take their medications. One participant said that she thought that it was extremely important to include the man who had lost his transplant from non-adherence in the video and suggested that more of the video could focus on “what could happen if you don’t work out your own routine” (Focus Group Participant 3).

Although all participants were given a copy of the video, none of them viewed it again during the 12-month trial period. Some focus group participants said that the education and advice provided in the video would be used for patients who were isolated and didn’t know any other kidney transplant recipient. Focus group participants thought the video could be more beneficial if it was conducted in two stages, so newly transplanted patients could first obtain a basic understanding, which was then followed up a couple of months later with another video.

**Table 1: The 15 sections that were included in the final patient-centred video**

<table>
<thead>
<tr>
<th>Sections</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Statistics about kidney transplantation</td>
</tr>
<tr>
<td>2</td>
<td>Introducing the storytellers using their personal story of the wait time for a kidney transplant</td>
</tr>
<tr>
<td>3</td>
<td>Life at ≥8 months post kidney transplantation</td>
</tr>
<tr>
<td>4 to 7</td>
<td>Medication taking tips: Daily, holidays and dealing with forgetfulness</td>
</tr>
<tr>
<td>8</td>
<td>Being aware of the side effects and medication adjustment</td>
</tr>
<tr>
<td>9</td>
<td>Life after transplantation can be difficult</td>
</tr>
<tr>
<td>10</td>
<td>Ask questions when in doubt</td>
</tr>
<tr>
<td>11</td>
<td>Dislike taking medications but it remains a fact of life for kidney transplant patients</td>
</tr>
<tr>
<td>12</td>
<td>The message on the impact of not taking medications as prescribed conveyed by non-adherent patients</td>
</tr>
<tr>
<td>13</td>
<td>The importance of taking medications as prescribed conveyed by adherent patients</td>
</tr>
<tr>
<td>14</td>
<td>Reminder about the motivating factors: Wanting to spend more time with family members, being grateful towards the kidney transplant donor and not wanting to go back on dialysis</td>
</tr>
<tr>
<td>15</td>
<td>Acknowledgements and credits</td>
</tr>
</tbody>
</table>
Discussion

Unlike previous intervention studies aimed at improving medication adherence in kidney transplantation\textsuperscript{16}, this study was the first to include patients in the design and development of an intervention tool, the 18-minute video. The involvement of patients as active partners in the process of health research; not just as a subject in a trial has been advocated by the United Kingdom Department of Health\textsuperscript{20} and the Australian National Health and Medical Research Council\textsuperscript{21}. Through patients' involvement, a better research design of greater sensitivity and relevance to the target population can be achieved.

The storytellers that were involved in this study were real patients and they recounted their real-life story. According to previous research, an audiovisual medium containing exemplars can influence beliefs\textsuperscript{22} and alter attitudes\textsuperscript{23}. As per the Theory of Planned Behavior, altering the underlying beliefs that influence one's intention can, in turn, facilitate behavioural change\textsuperscript{24}, and the overarching objective of the three-phase intervention research project was to effect a positive change in patients' medication-taking behaviour. Whilst the video formed part of a multidimensional intervention and its efficacy could not be assessed alone, research shows that narrative material improves awareness and adherence with illness management\textsuperscript{24,25}. Hence, using patients' stories to engage newly transplanted kidney recipients, which is a novel way, has the potential to support medication adherence and promote long-term graft success.

Conclusion

This study has demonstrated the feasibility of creating a video but refinement is required. Although it was well-suited for the purpose of reiterating the importance of medication adherence and graft outcome, some participants felt that the video content made them feel dejected. The main reason was because they were not feeling well during the initial post-transplant period, unlike what was portrayed by the majority of storytellers. Hence, future projects may want to incorporate the struggles related to kidney transplant management, such as the anxiety related to kidney transplant management, the side effects of medications and how patients dealt with rejection episodes. Researchers may also want to explore the potential incorporation of a model patient enacting the behaviours, such as, how to use a specific mobile phone application to manage medications and how to fill a dose administration aid, such as a dosette. In addition, the acceptability of educating patients through the use of a series of videos can be explored as it is evident that the newly transplanted kidney recipients were receptive to the medium.

Conflict of interest statement

No conflict of interest has been declared by the authors.

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Completing the discharge puzzle for a paediatric liver transplant patient

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The Children’s Hospital at Westmead, Sydney, NSW

Abstract
Discharge planning for a post-liver transplant paediatric patient is a collaborative process that requires a multidisciplinary approach. A successful discharge is one that involves a cohesive team that is inclusive of parental involvement. This can only be achieved if the patient and their family receive support from the surgeons, gastroenterologists, nurses, clinical nurse consultants, dietitians, occupational therapists, physiotherapists, social worker and pharmacists. This paper aims to describe the different pieces that need to fit together in order for a successful discharge to occur in a post-liver transplant patient in the Clancy Ward of the Children’s Hospital at Westmead in New South Wales.

Introduction
Discharge planning is a collaborative process and involves various teams within the hospital. This includes surgeons, gastroenterologists, nurses, clinical nurse consultants, psychologists, dietitians, occupational therapists, social workers, physiotherapists, pharmacists and child life therapists. Each group is vital in the discharge planning process and, more importantly, they work together with the family of the patient to ensure a good outcome. The discharge planning process begins post-transplant and, depending on the patient, can take up to 2–4 weeks. During this time, the patient and their family are seen by different teams to help prepare them for the discharge process. This ranges from social workers who organise transportation for families living interstate to pharmacists who provide primary education on discharge medications. Each plays a crucial part in supporting the patient and their family for discharge.

The recovery process from a paediatric liver transplant is often an arduous journey that requires a multitude of teams to ensure that the patient and their family have a successful discharge home. In a paediatric setting, a family-centred approach is vital for this to occur. The multidisciplinary team must work collaboratively to ensure that the patient and family are prepared for the second part of the journey after undergoing a liver transplant, and that is the discharge process that leads them home.

The gastroenterology team, along with the transplant surgeons, work closely together to ensure that the patient is transitioned from hospital care to home in an appropriate and timely manner. Factors that are addressed during the patient’s hospital stay include, but are not limited to, reaching therapeutic levels of immunosuppression, healing of wound sites and the close monitoring of liver function tests.

The period immediately after a paediatric liver transplant is crucial as there is a high probability of rejection of the donor organ, and the gastroenterology team and transplant surgeons must ensure that medical therapies are optimised during this time to avoid rejection. Once these issues have been addressed and the paediatric patient is stable enough to be discharged, the process of helping the patient and their family to go home becomes the next priority.

Discussion
Discharge planning is a complex process that requires communication and collaboration within a multidisciplinary team, the patient and their family. It is important to engage families during this time to ensure that they go home confident and with the appropriate skills and knowledge to help their child further recuperate at home. The gastroenterology team and the transplant team often work together in outlining the needs prior to discharge. These decisions are made alongside nurses, clinical nurse consultants, dietitians, physiotherapists, occupational therapists, psychologists, social workers and child life therapists.

Parents of children with complex healthcare needs have highlighted the importance of a collaborative relationship with health care providers in achieving family-centred care. By having a clear plan for discharge and the necessary education, skills and equipment, the families caring for children who have had a liver transplant will feel more confident and more engaged during the discharge process. These skills and knowledge include, but are not limited to, medication education, central line management, nasogastric tube management or biliary drain management. Other factors that are considered are the physical and emotional improvement of the patient, and the necessary support for their carers and families. The plan for discharge becomes...
the building blocks that create a supportive plan for nurses and clinical nurse consultants to assist the patient and their family through this process.

Nurses and clinical nurse consultants encompass many roles that occur by the bedside as well as in an outpatient setting. They support the recovery process of the child as well as their family. By providing family-centred care, nurses and clinical nurse consultants can ensure that liver transplant patients and their families get the necessary support for discharge. Much of the education that is required post-liver transplant occurs by the bedside. Depending on the condition of the patient, parents may require further knowledge in managing medical requirements such as biliary drains or central venous lines.

In addition to this, new medications that are commenced post-transplant will vary and some may be considered complex. Nurses and clinical nurse consultants must prioritise the many education sessions required for parents before discharge. They must also take into consideration the needs of both parents when planning these sessions. Many of the needs of families and patients are not limited to skills or knowledge that can be taught, but also approaching it from a holistic perspective. Many parents have reported that they have not felt prepared for hospital discharge, which resulted in the difficulty in managing their child's complex care needs at home. In order for parents to feel supported prior to their child’s discharge, members of the allied health team must support their needs as well.

An important part of the discharge process involves the role of the social worker and psychologist in supporting families post-transplant. Research on family psychological needs following a liver transplant have shown that parents of children who have had a liver transplant experience forms of trauma. Studies have also shown that patients and their families are at a greater risk of post-traumatic stress and distress post-liver transplant. Part of the care given in the transplant unit in The Children’s Hospital at Westmead includes regular interaction from the psychology team and a dedicated psychologist helps with the transition process. Both the parents and the child get regular consultations pre- and post-transplant. Ongoing management is essential to avoid post-traumatic stress disorder and distress post-paediatric liver transplant for patients and their families.

In addition to the need to address the mental health of patients and their families, it is important to highlight the importance of another allied health component to the discharge process. Physiotherapists play an important role in the rehabilitation of a patient post-transplant. Physiotherapy intervention post-transplant is integral in the improvement of a patient's quality of life. There have been numerous studies that show the importance of physical strength post-transplant. Children and adolescents post-liver transplant often have complex medical regimens that include lifelong immunosuppression. When combined with their pre-transplant condition, this population is more likely to have decreased aerobic capacity and muscle strength, an increased risk of early onset cardiovascular disease, which can then lead to obesity and chronic conditioning.

Furthermore, the use of calcineurin inhibitors and corticosteroids is linked with diabetes, hypertension and dyslipidaemia. This makes it even more important for physiotherapy involvement after a patient undergoes a liver transplant. A study showed the positive effects of a physical programme in the functional capacity of liver transplant patients. The study highlighted the difference regular exercise had on patients as their capacity to walk longer distances increased by 19.4%. In a paediatric setting, physiotherapists conduct a variety of exercise from bubble positive expiratory pressure (PEP) therapy to strength and endurance by going for short walks around the unit. Physiotherapists also educate parents in appropriate exercises whilst in hospital as well as once they are discharged. By working closely together with families, it ensures that they are involved in the rehabilitation process. It also encourages parents and carers to facilitate exercise whilst in hospital and once they are discharged. Nurses also help with the rehabilitation process by promoting exercise and encouraging bedside therapy such as bubble PEP to help improve lung function. With the combined efforts of the physiotherapists, nurses and parents, it helps to ensure that the patients maintain regular exercise and avoid the negative effects of physical inactivity that can arise post-liver transplant.

Pharmacists are also a part of the discharge puzzle that complements the medication education staff give during the preparation for a patient's discharge. Hospital discharge is a complex multidisciplinary process that may lead to non-compliance or medication-related problems, which places post-liver transplants at a greater risk. This places an emphasis on the role of pharmacists in ensuring that families and patients have the necessary information regarding medications before going home. It is often an overwhelming time for patients and their families and the new medications such as immunosuppression therapy can be deemed complex. As part of the discharge process, pharmacists create a template that lists the medications that a patient goes home with. It contains the name of the medication, its frequency and times of administration as well as any precautions required. It is a thorough process that begins as soon as discharge planning begins.

Nurses assist with medication education by allowing parents to practise preparing and administering their child's medications a couple of weeks before discharge. During this exercise, parents are assessed in their readiness for discharge and it allows them to have an extra forum to ask
questions about their new medications. This can then be communicated back to the relevant teams or pharmacists for further support in medication education. This process highlights the need for ongoing communication between the multidisciplinary teams and feedback is vital in determining a patient and their family’s readiness to go home.

It is also important to note the contribution of occupational therapists during the discharge process, particularly for patients who undergo a liver transplant as a baby or toddler. They are instrumental in assessing developmental growth and recommend appropriate strategies and play to support their growth. Due to liver disease, the younger patients often have not met their developmental milestones. The post-liver transplant period is critical in supporting these needs. These can include simple strategies such as encouraging ‘tummy time’ once healing of the wound in the abdomen has begun, or placing toys or mobiles in strategic areas in a baby’s cot to facilitate hand and eye coordination. Nurses and parents can assist with these strategies during the hospital stay and parents can continue facilitating growth and development at home.

The role of dietitians after a patient undergoes a liver transplant is essential in ensuring that children receive the optimum nutritional requirements after their surgery. Most patients that undergo a liver transplant are malnourished pre-operatively due to their liver disease; therefore, there is a great need to commence postoperative nutrition12. Electrolyte imbalance may also occur due to the use of immunosuppression; therefore, in conjunction with oral supplements, parents and their child need to be educated on appropriate magnesium-rich food during their hospital stay and after they are discharged home. Dietitians work collaboratively with the gastroenterology team to determine the caloric needs after a liver transplant and this is then created into a management plan that is facilitated by nursing staff and the parents of the child.

A unique contribution to the discharge process and the multidisciplinary team is the role of a child life therapist. After a paediatric liver transplant, child life therapists can assist with providing appropriate play as well as distraction techniques for various painful procedures that help with the recovery process. A study that investigated parent perceptions of play-therapeutic interventions after a liver transplant showed that therapeutic play was shown to help develop coping strategies for the child’s illness. It also helped children overcome fear, deal with emotional stress and develop their self-esteem13. In collaboration with child life therapists, nurses and parents can promote therapeutic play and at the same time provide family-centred and holistic care14.

Conclusion

There have been many facets in the multidisciplinary team that have been discussed within this article. It highlights the importance of a collaborative approach and the need for partnership with parents and carers to achieve a successful discharge home. It is essential that discharge planning takes a family-centred approach as this can help prevent the negative effects of a poorly planned discharge. A successful discharge home is when parents and carers feel confident in caring for their medically complex child and their needs. It is also one that allows for a multidisciplinary effort that recognises the unique contribution of each member of the team.

References

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• Abstract
• Introduction
• Presentation of the case including nursing care and medical treatment
• Nursing outcomes/implications
• Conclusion/recommendations
• References.

Unit review and nurse/co-ordinator profile
• Title
• Introduction
• Unit, nurse or coordinator description
• Future directions
• Conclusion
• References (if applicable)
• Include pictures.

MANUSCRIPT PREPARATION

Title Page
• Title
• Complete author’s names & credentials
• Corresponding author’s name, address, phone number and e-mail.

Abstract
• 100 – 250 words

Manuscript
• 1500 – 5000 words
• Pages numbered, not including title page
• Double-spaced, including references
• Title on page one but no author identification.

References
Follow American Medical Association style. This includes the following:
• All references must be cited in numerical order in text (as superscript numbers) and listed in that order in reference list.
• Unpublished papers, personal communication place in text, not in references.

Tables, Graphs, Figures
• Labelled and numbered
• Referenced in order in body of paper
• Each on a separate page at the end of the manuscript
• Permission/reference included if published elsewhere.

Ethics
Manuscripts reporting research involving humans must include in the text a statement that the research was approved by a research ethics review committee.

SUBMISSION
• Submit manuscripts to the Editor as word document.
• Manuscripts are subject to independent review by at least two peers.
• When the manuscript has been reviewed, usually within 2 months, the editor will advise the first author whether it has been accepted for publication or if revision is recommended.
• Authors looking to publish in the TJA are invited to contact the Editor or members of the Editorial Board.
• Support and guidance at any stage of manuscript preparation is provided upon request.
• Deadlines are set by the Editor.
fit for life!

SUPPORTING ACTIVE LIVES POST-TRANSPLANT

more transplant recipients, more active, more often...

from the couch to walking around the block...
from the block to 5kms...

improving fitness, health and well being.

Astellas, World Transplant Games Federation and Transplant Australia look forward to launching Fit for Life! Program soon.

This program aims to provide resources, research and advice regarding nutrition and physical activity post-transplant for transplant recipients.

We look forward to working with the transplant community to help meet future transplant challenges and improve transplant recipient and caregiver experiences.