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Author

McGrath, Pamela

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ARTICLE

Living renal transplant donors' expectations of recipients' post-transplant quality of life and longevity

*Assoc. Professor Pam McGrath • B.SocWk, MA, PhD
Senior Research Fellow, Population & Social Health Program
Griffith University, Qld*

Abstract

As living renal donors face a unique decision of self-sacrifice that is not without risk, there is an ethical imperative for health professionals to understand the donors' perspective. The findings presented in this paper contribute to this area by documenting living renal donors' expectations of quality of life and longevity for the recipient, post-transplant. The longitudinal study involved an open-ended, explorative, qualitative, methodological approach, involving interviews with 20 (n=20) living kidney donors at four points in time over two years. The findings in this paper are from the first interview prior to the donation surgery. The findings on the donors' expectations for the recipients' future were predominantly characterised by a tension between an enthusiastic optimism and a realistic awareness of the medical problems associated with the kidney disease and transplantation. In terms of the immediacy of the transplant operation, the donors expressed high hopes of success combined with an informed understanding of the possibility of rejection. The donors interviewed expressed an acceptance of such risks. The important longitudinal finding is that the cohort demonstrated an ongoing high level of satisfaction with their decision making. Consequently, the findings on the living renal donors' perception about the recipients' quality of life and longevity can be viewed as reflecting an appropriately screened and satisfied group of donors.

Introduction

Considered a safe and effective procedure, living donor kidney transplantation now exceeds the number of deceased donor kidney transplantations performed annually to treat end-stage renal disease¹. Indeed, it is the treatment of choice for suitable patients with end-stage renal failure and has been shown to provide a definite survival advantage².

As living renal donors face a unique decision of self-sacrifice that is not without risk³, there is an ethical imperative for health professionals to understand the donors' perspective⁴. However, as Crombie and Franklin⁵ point out, the majority of studies in the field of live renal donation address physical health issues rather than the complexity of the living donors' experience. It is important to have an understanding of this complexity to ensure that the quality of life of the donor is not harmed⁵. In addition, there is a need for research on the donors' perspective to inform the process of systematic screening of prospective donors to ensure the integrity of the donors' decision and to minimise the risk of a poor postoperative outcome⁶. However, research exploring the donors' perspective is still in its infancy, with further work on the psychosocial aspect of the live donor experience being required⁷. As Takada⁸ argues, the experience of the live kidney donor is yet to be fully understood.

The findings presented in this paper contribute to this area by documenting living renal donors' expectations of quality of life and longevity for the recipient post-transplant. Further

findings from the same study indicate that such expectations are a key factor in pre-transplant decision making⁹. At present, there is some research available on decision making by live kidney donors^{5,6,10-12}, but most of this work does not focus on the donors' perception of longevity and quality of life for the recipient.

In addition to addressing a gap in the existing literature, the prospective longitudinal study described in this paper also addresses a major methodological limitation. A major criticism of the current research on live donor decision making is that the majority of studies are retrospective in nature, which is viewed as a limitation because of doubts over recall and reliability^{7,13}. Very few studies have prospectively followed living kidney donors for at least the first year after donor surgery¹⁴. The present findings are from a prospective study that follows participants from the pre-transplant, decision-making stage until two years after surgery. The study documents the thoughts and perspectives of the live renal donors at the time of decision making. The findings from the earlier interviews are available to be compared and contrasted with later interviews. With regards to the findings presented in this article, the important longitudinal finding is that the cohort demonstrated an ongoing high level of satisfaction with their decision making. Consequently, the findings on the living renal donors' perception about the recipients' quality of life and longevity can be viewed as reflecting an appropriately screened and satisfied group of donors.

Renal transplantation at The Princess Alexandra Hospital

The Princess Alexandra Hospital (PAH) is a 600-bed, public hospital located in Brisbane, Australia. The PAH Renal Transplant Unit adopts a multidisciplinary and collaborative approach to patient care, providing comprehensive pre- and post-transplant services. The unit performs over 110 renal transplants each year, of which 40 are from living kidney donors. The first live kidney donor transplant at the unit occurred in 1981¹⁶. The unit maintains the highest survival rate for recipients for all Australian and New Zealand-based centres. With close affiliation with the urology and nephrology departments, the renal transplant unit provides intensive, short- and long-term follow-up for renal transplant recipients and their families¹⁵. In Queensland, there are 1,592 patients on dialysis out of a total of 8,528 in Australia, and in the PAH alone there are 397 patients on dialysis¹⁶. By April 2009, the number of transplants performed at the PAH reached 3,000.

The research

The participants were enrolled through the project officer for the study who was under contract with CQUniversity and independent of the hospital. The project officer was provided with a list of potential donors who were being tested for compatibility with the recipient and their contact information. This information was provided by the transplant co-coordinator at the hospital who had gained verbal consent to do so from each potential participant. All potential participants had been informed about the study from the hospital, both verbally from the co-coordinator and in writing through a letter outlining the details of the study. The participants were enrolled from this list through an initial telephone call, followed by the project officer providing written project descriptions of the project and an invitation for voluntary participation in the research. At this stage, signed consent forms from the participants were collected and enrolment occurred. Participants were not screened for the study *per se*, but all participants underwent both a clinical and psychosocial assessment to be accepted as suitable to be a living kidney donor in the PAH renal transplant programme. Prior to interviewing, participants were again informed of their ethical rights (for example, informed consent, confidentiality, right to withdraw). The University Ethics Committee and the Queensland Health Department Human Research Ethics Committee approved the study.

A total of 20 (n=20) participants were enrolled at Time 1 (T1): pre-transplant interview and were followed up longitudinally over three points in time – Time 2 (T2): three months post-transplant. Time 3 (T3): one year following, Time 4 (T4): one year following T3. One of the participants died during the study, leaving the final group number at 19 at T4. All

participants were enthusiastic about their involvement in the study, chose to participate through telephone interviews, noted the time for the next interview at the close of the each interview, and were welcoming when contacted by telephone for subsequent interviews. The T1 enrolment procedure was complicated by the fact that it was difficult to identify the ultimate donor when there were several potential donors for the one recipient under assessment or where the potential participant under assessment was eventually found to be clinically incompatible. The waiting time for the transplant was in many cases immediate once the donor was assessed as compatible. Thus, in order to obtain the pre-transplant interview for the correct donor, it was necessary to interview some participants who did not progress to the transplant stage. Thirteen (n=13) interviews were conducted with potential T1 participants who did not become donors.

The participants were all of adult age and had the following range of relationships to the transplant recipient: daughter (n=4), son (n=1), husband (n=6), wife (n=4), sister (n=2), nephew (n=1), partner (n=1) and friend (n=1). Because the participants were enrolled from a small, identifiable group from the hospital, the informed consent procedures gave a strict commitment to confidentiality and a guarantee that no further identifying information would be presented or published with the findings. Hence, further demographic description will not be provided to protect the identity of the participants.

Research design

An open-ended, exploratory, qualitative design was utilised for the study. Qualitative research is used to provide in-depth insights on consumer experiences and, thus, is an effective means of gaining rich insights into the decision-making experience of living kidney donors^{17,18}. Such an approach is particularly appropriate where little is known about an issue^{19,20} and, thus, is well suited to a study on the experience of Australian living kidney donors for renal transplant.

Interviews

The exploration of the renal donors' experience was conducted through an iterative, qualitative research methodology using open-ended interviews conducted at a time and location chosen by each participant. The interviews were conducted by an experienced researcher with a background in psychosocial health research employed by the university and, thus, was independent of the hospital. All participants chose to do the interviews through speaker-phone.

The T1 interviews began with an invitation to the donor to talk about their relationship with the recipient and the factors that contributed to their decision to donate a kidney. The participants were assured there were no right or wrong answers and that the interviewer was keen to hear the unique

details of the participant's story in their own words. Through the process of active listening inherent in open-ended interviewing, the discussion explored the decision-making and psychosocial dimensions of the donor's experience. The line of questioning included the techniques of probing, paraphrasing and reflection to explore each participant's experience²¹. The interviews lasted for approximately one hour and were audio-recorded. They were transcribed verbatim by a research assistant independent of the hospital.

Analysis

The language texts were then entered into the QSR NUD*IST (N5 1995) computer program and analysed thematically. All of the participants' comments were coded into "free nodes", which are category files that have not been pre-organised but are freely created from the data. The list of codes was then transported into a Word file (Word 97) and organised under thematic headings. The coding was established by an experienced qualitative researcher and completed by the project officer with extensive experience in coding qualitative data. There was complete agreement between researcher and project officer on the coding and emergent themes. The findings from the codes developed from the T1 pre-transplant interviews in relation to the donor's perception of the likely longevity and quality of life of the recipient are presented in this article. Further findings on different topics from the longitudinal study based on the same methodology are currently being published⁹.

Findings

Optimistic about the success of the transplant

Although anxious about the surgery, the donors were predominantly optimistic about the success of the renal transplant operation for the recipient. From discussions with the renal team, the donors held the perception that live renal transplants had high success rates, for example:

They're expecting a good result hopefully. Apparently with live donor transplantation there's a success rate of about two to three per cent better than a cadaver; 98% success rate.

Awareness of the possibility that the kidney could be rejected

Participants demonstrated an informed awareness of the fact that the success of the transplant was not guaranteed and that there was a possibility that the recipient could reject the kidney. This awareness was fostered by the information provided by the renal specialist and staff on this topic, for example:

...the transplant coordinator has said to us the chances of rejection. It can happen.

In addition, questions on how the donor would accept rejection were asked during the prerequisite clinical assessment process. The realistic expectation noted by the donors was that the risk of rejection was not just immediate but would require monitoring over time, especially during the first year of post-transplant, for example:

You'd probably consider it to be a year. Particularly initially the first three months where there's intense focus on making sure that the kidney isn't being rejected. So that sort of goes through for a year.

The donors relied on an optimistic acceptance of the risk and a belief in a likely positive outcome as a way of dealing with the anxiety about this issue, for example:

... and I know that the risks are there but I wanted to take them because the risks are very low compared to the success rates.

In anticipation of success, the donors articulated a wide range of expectations and hopes for the future for the recipient.

Freedom from dialysis

For those recipients who were already on dialysis, a major positive expected outcome was freedom from the constraints and demands of regular dialysis, for example:

... and he's got the freedom of not having to dialyse four times a week.

It's just that he won't be caught up with the dialysis machine.

Return to normal

Most but not all donors described their future expectations for the recipient in terms of a return to normalcy. Normalcy is defined in this context as the life the recipient was living prior to the illness, whilst taking into consideration the recipient's present age. The word "normal" was used as the basic reference point in the discussion of future expectations, as can be seen by the following examples:

Fifty years ago [name] just would have died. Whereas now she can pretty much live a normal life without too many complications and that's very comforting.

Well that he should get back to normal hopefully. Yeah, well that's what he's thinking.

Oh I'm hoping that it will get her back to practically a normal life. Like that she's not tied to the machine every second day.

The expectation of the return to a normal lifestyle was expressed in very positive but realistic terms, for example:

We're very enthusiastic. I'm certainly very enthusiastic about it. I'm probably a bit aware that I could be setting myself up for a fall which is always a possibility in these sorts of things. But, yes, I'm very much looking forward to a bright new future if all goes well.

There was only one comment which, for confidentiality reasons, cannot be provided verbatim, that indicated a fairly unrealistic expectation that the recipient would return to their youthful personhood.

An important part of the expectation of normalcy was the idea that the recipient would return to work, for example:

... and he's hoping that by three months time he's going to be back to work.

The sense of normalcy extended to embracing significant life goals such as having children, for example:

... and the other thing that we are particularly looking at is having children as well. So that's a really big issue. We'll get [name] healthiest: that's the primary thing and then if we can have children after that. [Interviewer: And the doctors are saying that's all quite realistic?] Yes. The way it's been described as, it should be about a five-year window after a year or two where we should be able to have children.

Restored to health

At the core of the expectation of normalcy was the notion that the transplant would ensure the recipient's restored health. The comments on this topic ranged along a continuum from realistic to unrealistic. The expectations of full health as an outcome were high and included longevity, for example:

So he'll just have the normal life span.

I think the whole thing is to get him better and I don't think that it's only going to last five or 10 years. I think it's going to last him forever. You know there's no point in thinking the other way.

There were estimates of the survival time offered by a renal transplant that ranged from five to 30 years.

Examples were provided by some of the participants of other people they knew or knew of who had undergone renal transplants and were living long lives. However, there were many qualifications to these high expectations. There was evidence that, for some, the expectation of health was cautious and mindful of the limitation of the transplant intervention, for example:

So you know, transplant is not really a cure. It's a treatment they tell you.

The realistic statements were accompanied by a sense of uncertainty, for example:

Nothing's guaranteed these days, so I mean with all the new technology and drugs and everything, they say everything should be fine, but you never, never, know.

It is a very unknown quantity and this is what's scary about it. No one knows. It's so uncertain.

Awareness that the renal specialist could not make exact prognostic predictions was also apparent, for example:

They [doctors] can't really give you a definite prognosis. It depends. You never know what might happen. It may fail. It may not work at all. It may work for a year. It may fail. So we realise that but I do plan on it working for 20 years.

Some of the participants were aware that there was a possibility that the disease that caused the renal failure could return, for example:

She will have a lot better quality of life than she has now but the disease that she has there's every chance that it will come back again to my kidney ... because it's in her immune system. So they're saying another 10 years, so she may get 10 years. Yes, if all goes well she might get a lot longer.

Some spoke of the possibility of the recipient requiring another transplant as some stage in the future, for example:

Then with the expectation that [name] will probably need another kidney in about 10 to 20 years time.

I mean [name] could need three kidneys in her life. But who knows?

For most but not all, the notion of full health was qualified by an understanding that the recipient will need to be maintained on an anti-rejection and therapeutic drug regimen, for example:

... and from what they can tell the kidney could last him ... as long as he takes his medication ... careful of the sun... drink more fluids ... As long as he does what they tell him, he'll be fine.

Because she's been on them before I know what the effects are ... that rotten prednisolone that keeps you up at night. Another issue for women is facial hair. That's a big issue that can be very embarrassing

The expectation that recipient will not return to full health

Although the majority had expectations of a return to health, normalcy and longevity for the recipient, there were some who did not share these expectations, for example:

She won't be back to normal I don't think. I don't expect that.

He'll never be like he was before.

Just do not know

There were some donors who reported that they did not have any idea of prognosis or likely long-term outcome for the recipient of the live renal transplant. For these people, prognosis or longevity was not a defining issue in their donor decision making, for example:

She does not really know what the outcome will be – just focusing on the process and going from there.

Such participants were not told or did not ask their doctor what the likely post-transplant prognosis was for the recipient, for example:

No, I haven't asked ... no, they haven't said anything like that at all about the outcome for her, like, umm, I imagine that, umm, she'll get back to her normal life once it's done, once she's had the transplant.

Indeed, one participant was angry because the renal specialist would not provide information on either the expected survival of the recipient or whether the donor's operation would shorten their life. The lack of information from the doctor of what to expect post-transplant for the recipient often led to a negative view of the possible outcome, for example:

All the doctors are saying that she'll be much better so forth. But I think she'll probably be kind of worse off in the fact that she's going to have to take all these anti-rejection drugs and she'll be immune-compromised for the rest of her life and all the rest of it.

Discussion

As Knoll²² notes, from the recipients' perspective, transplantation provides end-stage renal patients with the greatest potential for increased longevity and enhanced quality of life. This paper contributes to the literature on longevity and quality of life in relation to outcomes of living renal transplantation by documenting the donors' perspective. This prospective study documents the donors' perspective at the time they are engaged in decision making in regard to participating in the living renal transplant. The results from the longitudinal study indicate that the donors' perspective can be viewed in the context of a cohort who demonstrated continued high levels of satisfaction with their decision to become a donor.

The findings on the donors' expectations for the recipients' future were predominantly characterised by a tension between an enthusiastic optimism and a realistic awareness of the medical problems associated with the kidney disease and transplantation. In terms of the immediacy of the transplant operation, the donors expressed high hopes of success combined with an informed understanding of the possibility of rejection. The donors interviewed expressed an acceptance of such risks.

In cases where the recipients were on dialysis, the major positive expected outcome was that of relief from the

demands and constraints of life on a dialysis machine. The majority of donors had high expectations that the transplant would enable the recipient to return to a sense of normalcy. Such normalcy was defined as the recipient having a quality of life similar to what would have been expected pre-illness, but adjusted for age. The return to normal life included the possibility of resuming work and, in some cases, planning for possible parenthood. However, at the core of the expectation of normalcy was the notion that the transplant would ensure restored health for the recipient.

The expectation of restored health was high for many and included the idea of longevity, extending from five years to a lifetime. However, the high expectations were moderated by a realistic understanding of the uncertainty associated with post-transplant life. This included the recipient's dependency on an anti-rejection and therapeutic drug regimen, the possibility of the disease returning and, ultimately, the possibility of the need for another transplant in the future. There were only a few comments that indicated the unrealistic expectation of a return to youthful health.

However, some of the donors interviewed did not have any expectations that the recipient would return to full health. Others clearly stated that they quite simply did not know what the long-term prognosis or longevity would be. For these people, prognosis or longevity was not a defining issue in their own donor decision making. However, there was no talk of death at the time of transplantation as documented elsewhere²³.

In this study, some but not all of the donors sought information from the renal specialist to inform expectations in regard to likely immediate and long-term outcomes from the transplant. There were varied experiences in this regard which included an acceptance of the limitation of the doctor's knowledge, a concern about the medical emphasis on the positive benefits of the transplant, and anger at being left out of discussion with the specialists on this issue.

There is now an increasing demand for systematic and comprehensive screening of prospective living renal donors to ensure the integrity of the donor's decision, to decrease psychological problems, to increase satisfaction with the transplant process and to minimise the risk of a poor postoperative outcome^{6,24}. The findings presented in this article are made available to inform the health professionals involved in the assessment procedures for screening live donors by providing the perspectives of live renal donors who sustain satisfaction with their decision making.

As Rudow²⁵ notes, optimal outcomes begin with prepared, educated, uncoerced and motivated donors. Thus, it is essential that potential donors are provided with sufficient medical information on the recipient's condition and expected post-transplant prognosis and quality of life to reliably inform their decision making. As Takada⁸ argues, only with the sharing of knowledge of the recipients' renal failure, the

provision of medical information on renal transplantation, and hearing the recommendation of the treating physician, can the issue become “the donors’ own”.

Conclusion

The findings presented in this paper document the living renal donors’ perspectives on issues of longevity and quality of life for the transplantation recipient. The insights documented at the actual time of pre-transplantation decision making are from a group of donors who maintained a high degree of satisfaction with their decision to become a donor. As such, the findings make a contribution to the psychosocial literature on live renal donors and provide a baseline to inform the pre-transplantation screening process.

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