Focus Group Study of Public Opinion About Paying Living Kidney Donors in Australia

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Abstract

Background and objectives The unmet demand for kidney transplantation has generated intense controversy about introducing incentives for living kidney donors to increase donation rates. Such debates may affect public perception and acceptance of living kidney donation. This study aims to describe the range and depth of public opinion on financial reimbursement, compensation, and incentives for living kidney donors.

Design, setting, participants, & measurements Twelve focus groups were conducted with 113 participants recruited from the general public in three Australian states in February 2013. Thematic analysis was used to analyze the transcripts.

Results Five themes were identified: creating ethical impasses (commodification of the body, quandary of kidney valuation, pushing moral boundaries), corrupting motivations (exposing the vulnerable, inevitable abuse, supplanting altruism), determining justifiable risk (compromising kidney quality, undue harm, accepting a confined risk, trusting protective mechanisms, right to autonomy), driving access (urgency of organ shortage, minimizing disadvantage, guaranteeing cost-efficiency, providing impetus, counteracting black markets), and honoring donor deservingness (fairness and reason, reassurance and rewards, merited recompense). Reimbursement and justifiable recompense are considered by the Australian public as a legitimate way of supporting donors and reducing disadvantage. Financial payment beyond reimbursement is regarded as morally reprehensible, with the potential for exploitative commercialism. Some contend that regulated compensation could be a defensible strategy to increased donation rates provided that mechanisms are in place to protect donors.

Conclusions The perceived threat to community values of human dignity, goodwill, and fairness suggests that there could be strong public resistance to any form of financial inducements for living kidney donors. Policy priorities addressing the removal of disincentives may be more acceptable to the public.


Introduction

Kidney transplantation offers better survival and quality of life outcomes compared with dialysis, yet >100,000 patients in the United States alone remain on the waiting list for a deceased donor kidney—a number that continues to grow (1–3). The unmet demand for kidney transplantation has generated heated controversy internationally about introducing incentives for living kidney donors to increase donation rates (4–11).

According to the World Health Organization Guiding Principles, “organs should be donated freely, without any monetary payment” and “the prohibition on sale and purchase of organs does not preclude reimbursing reasonable and verifiable expenses incurred by the donor” (12). Financial incentives for living kidney donation are prohibited by the Declaration of Istanbul and by law in most countries (13–15). However, over the past decade, there have been increasing calls, particularly in the United States, for pilot trials of government-regulated schemes for paid living kidney donation to increase the rates of kidney transplantation (6,7,16–21). Incentivization has been urged on the basis of the lack of empirical evidence that financial incentives diminish sensitivity to risk, that financially disadvantaged people may be enabled to donate, and that incentives have been legalized for surrogate pregnancy and egg donation. These proposals have been challenged by vehement ethical critique and concerns about commodification of the body, exploitation, coercion, and jeopardizing altruism (4,9,11,14,22–24).

Such debates may affect public perception and acceptance of living kidney donation, and few studies have been undertaken to elicit community perspectives on incentives for living kidney donors. Surveys conducted in the United States, Canada, and The Netherlands suggest that the public is divided in support for monetary payment, fixed compensation, or government tax breaks for donors (25,26). However, there is little empirical evidence about the underlying values and beliefs held by the public to explain these differences.
in the level of public acceptance of financial incentives. To inform the ongoing policy debates in living kidney donation, we aimed to describe the broad range and depth of public opinion on financial reimbursement, compensation, and incentives for living kidney donors.

Materials and Methods
This article reports new data that focus specifically on public perception of financial reimbursement (payment for out-of-pocket expenses), compensation (payment for losses incurred, including lost wages), and incentives for living kidney donors (payment to encourage a person to donate who might not donate without financial gain). These data were collected as part of a national study on public beliefs and attitudes on living kidney donation (27).

Participants were recruited from the general public in three Australian states (New South Wales, Victoria, and South Australia) over a period of 1 month before the focus group using market research companies. To encourage rapport among group members, we instructed that a total of 12 focus groups were to be convened by three age groups (18–30 years, 31–50 years, and ≥51 years). In accordance with purposive sampling to capture a range of perspectives (28), we specified that each group had to include a range of socio-demographic characteristics (age, sex [equal representation of men and women], employment and marital status, and ethnicity). The market research companies contacted and screened participants who were registered on their company database by phone and Email until 10 participants who met the selection criteria were confirmed for each focus group. Participants were eligible if they were aged ≥18 years, were able to provide informed consent, and spoke English. A reimbursement of AU$80 was provided. The University of Sydney Ethics Committee approved the study.

Data Collection
Focus groups are used to encourage participants to explore and clarify their views to elicit a breadth and depth of data—not to reach consensus or to ascertain majority opinion (29,30). The focus group guide (Supplemental Material) was based on a systematic review of community attitudes to living organ donation (31), recent articles on financial compensation and incentives for living kidney donors (7,18,19,25,32–35), and discussion among the research team. A.T. and/or A.F.R. facilitated the focus groups from January to February 2013. Field notes on the dynamic and disposition of the group were taken. Data collection continued until theoretical saturation was reached (i.e., little or no new ideas/concepts were being expressed in subsequent focus groups). The focus groups were videotaped, audiotaped, and transcribed.

Statistical Analyses
All transcripts were imported into HyperRESEARCH (version 3.5.2; ResearchWare Inc., Randolph, MA), which is software for qualitative data management. Using the analytical process of grounded theory, A.T. read the transcripts and inductively identified preliminary concepts relating to public acceptability of any form of financial payment (reimbursement, compensation, incentivization) for living kidney donors. Similar concepts were grouped into themes and subthemes. Meaningful and relevant sections of text were coded into the relevant theme. The software generated a report of all of the themes with their corresponding coded text. The preliminary themes were discussed with A.F.R., who read the transcripts independently. This form of researcher triangulation was done to ensure that the preliminary themes captured the complete range of participant perspectives. Conceptual links or similarities across themes were identified and mapped into a thematic schema.

Results
Of the 120 participants confirmed to attend, 113 (94%) participated in the 12 focus groups convened in Sydney, Melbourne, and Adelaide, during January and February 2013. Participant characteristics are shown in Table 1. The age of participants ranged from 18 to 69 years (mean 40.2 years [SD 14.1]), and 54 participants (48%) had full-time employment status.

Five themes were identified: creating ethical impasses, corrupting motivations, determining justifiable risks, driving access, and honoring donor deservingness. These themes are described in the following section. Selected quotations to support each theme are provided in Table 2. Figure 1 shows the conceptual links among themes. There was central tension between unacceptable commercialism versus financial compensation being a defensible and legitimate solution. Financial payment to living kidney donors beyond reimbursement was perceived to have deleterious ethical implications of corruption and exploitation, and to potentially lead to poor quality of kidneys and undue risk of harm to donors. The counterargument was that it could be a defensible life-saving strategy to increase the number of organs for transplantation, as long as mechanisms were in place to protect potential donors. Reimbursement or reasonable compensation was believed to be fair and warranted, and could minimize disadvantage by removing financial barriers for potential donors.

Creating Ethical Impasses
Commodification of the Body. Providing a financial incentive to donors that went beyond reimbursement was seen to turn the body into a commercial commodity and thus reduce the inherent value of the body, which was regarded as more than the sum of its body parts. However, others thought that in a commercial society, people may find it acceptable because most things, including people’s time, could be sold (“What makes your body less of a commodity?”).

Quandary of Kidney Valuation. Participants expressed unease and uncertainty about how a kidney would be valued fairly (e.g., if a young organ would be priced higher). They also questioned the morality of quantifying the worth of someone’s donation.

Pushing Moral Boundaries. Some participants expected that payment for kidneys would open up Pandora’s box and trigger a slippery slope of an uncontrollable proliferation of organ sales, in which it would become difficult to draw the line. They anticipated that people would start selling babies (i.e., breed humans to sell them).
Corrupting Motivations

Exposing the Vulnerable. Participants believed that offering financial payment for kidneys was exploitative. They posited that individuals who were socioeconomically disadvantaged or in desperate circumstances would be most likely to respond to incentives. Some argued that the appeal of payment in these populations would be too difficult to resist and would thus be inherently coercive because it nullified their free will and ability to choose to protect their health. People who were homeless, young, or seeking asylum, or who had intellectual disabilities, drug dependencies, or gambling problems were thought to be particularly vulnerable.

Inevitable Abuse. Skepticism among participants about the feasibility of a regulated system for financial compensation or incentive was expressed, because they feared that such a system opened an opportunity for corruption, crime, and abuse. Some participants viewed that people were not always ethical and could subvert the regulations, and they remarked that “the government would become the black market.” They also suggested that donors and physicians could manipulate the system (“If I’m getting AUD$10K for a kidney, I’ll go halves with the doctor.”).

Supplanting Altruism. Participants believed that living kidney donation should be a gift given out of the goodness of their hearts without any financial inducement. Financial payment was seen to override genuine goodwill, and would cheapen the act of donation to one of selling. Some described it as a debasement of common humanity. They also expressed that it would change the community perception of donors to one of suspicion and judgement. Some argued that reimbursement could impinge on people’s motivation to donate, and that people had already donated without reimbursement.

Determining Justifiable Risk

Compromising Quality. Some participants believed that financial payment would result in the donation of unhealthy kidneys, thus lowering the overall quality of kidney donations. They expressed concern that people may lie about their health in desperation to be accepted as a donor, or would not make the lifestyle changes needed to give a healthy kidney. In addition, reference was to paid blood donation in the United States, which was described as being “not as safe as the Australian system [which does not allow payment of donors].”

Undue Harm. It was contended that payment in itself could not offset or justify the risks to long-term health associated with living kidney donation. Participants were concerned about the risks of survival, physical vulnerability, and the effect of donation on the general well-being of donors. In one focus group, some participants argued that soldiers were paid to risk their lives, although this was refuted by another who stated that “It’s not a job. You’re not doing it every day. You’re not able to give some kidney every day.”

Accepting a Confined Risk. Financial payment was deemed acceptable by some participants because the risks of kidney donation were confined to the individual, not society or another person. In comparison, other forms of incentives, such as a baby bonus (a payment given by the Australian government to families after the birth or adoption of a child before March 2014), were believed to have worse consequences (e.g., a child who was not raised properly could be a risk to society in the future).

Trust Protecting Mechanisms. Some participants felt confident that adequate mechanisms, such as medical, psychologic, and financial screening, would be established to prevent the vulnerable or those with medical risks from donating a kidney. The context of living kidney donation meant that control measures could be implemented (i.e., physicians could prevent kidney donation), unlike the baby bonus initiative, which could not be policed because one cannot stop someone from having a baby. An option for payment was regarded by some as favorable if the process of financial compensation or incentivization was transparent and strictly regulated.

Right to Autonomy. Some argued that regulated compensation or incentives could be an option, because it could never force individuals to donate (“No one’s holding a gun...
<table>
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<th>Theme</th>
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| **Creating ethical impasses** | **Commodification of the body**  
But it’s putting your body up for sale. It’s making your body a commercial commodity. (woman, FG3)  
But you can buy and sell anything. What makes your body less of a commodity…? (man, FG8) |
|                               | **Quandary in kidney valuation**  
You’re going to get this $10,000 for a 50 year old, a 60 year old? (man, FG12)  
Is mine worth more than yours? (man, FG2); How do they get that, that kind of valuation figure? (woman, FG2) |
|                               | **Pushing moral boundaries**  
It’s putting a price on someone’s donation. (woman, FG5)  
It just makes me feel uncomfortable because it is a bit of a Pandora’s Box—What do we rate the rest of our organs? (woman, FG2) |
|                               | **Corrupting motivations**  
If you start putting a dollar value on things, you’re going to find that the people who have less to start with are the ones that are taken advantage of. (man, FG1)  
If they are homeless or have some sort of financial difficulty, they will find this very appealing in some situations. (woman, FG10)  
I hate this phrase but the boat people would come here to do that. (woman, FG12)  
It’s not so much a free will thing, you’re just being biased by money and if you’re poor, nice option, shame about the health. (woman, FG2)  
It’s bribing people. (man, FG2)  
If I had a couple of kids and they didn’t have necessarily have the mental ability to make decisions for themselves, they might have Down’s syndrome, I might see that as an option. They may not know any difference, I’m going to put my two kids up, if they’re able to donate a kidney and I’ll get 20 grand, thanks. (woman, FG2)  
So you’ll get a young couple around 20 or something, you go and give your kidney up so we get $10,000. (man, FG3)  
They may be desperate to get some monetary benefits, then they let go [of] their health and choose money instead of their own health and there could be a problem. (man, FG9)  
It’s exploiting poverty. (woman, FG9)  
There’s always an element that you can twist the system. ‘If I’m getting 10 grand for a kidney, I’ll go halves with a doctor.’ (man, FG1)  
The government would become the black market if people do it for the wrong reasons. (woman, FG2)  
For example, the $5000 baby bonus and in some situations you get teenage girls who have a baby, get $5000 and that’s very nice, that one is out to have another (baby). So it’s open to abuse. That sort of thing is open to abuse. (woman, FG3)  
As long as this doesn’t get corrupt that you have 21 year olds or 22 year olds, you know, donating their kidney because they want to get a new car or whatever or want to travel go on a Europe trip, like as long as it’s a much more informed decision than just doing it so that you can have that cash to support your lifestyle. (woman, FG5)  
Unfortunately, not everybody is ethical. (man, FG7)  
Once you open up that market idea, it just brings so much more potential for a black market… ‘[H]ey, look, I’ve got this lovely baby kidney, what can I get for it?’ (woman, FG7)  
There still enough corruption in Western society for somebody to organize that sort of thing. (man, FG8) |
|                               | **Inevitable abuse**  
There’s always an element that you can twist the system. ‘If I’m getting 10 grand for a kidney, I’ll go halves with a doctor.’ (man, FG1)  
The government would become the black market if people do it for the wrong reasons. (woman, FG2)  
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There still enough corruption in Western society for somebody to organize that sort of thing. (man, FG8) |
|                               | **Supplanting altruism**  
Because at the moment it’s a gift, once [payment] happens then the motivation is changed and people could be doing it for the wrong reasons because they want the money or they’re desperate for the money. So it’s not coming from the same place. (woman, FG12)  
It cheapens it. (woman, FG12) |
Table 2. (Continued)

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<td>I just think society’s come to a point that if we have to accept money to do the right thing, then it’s just wrong. If we can’t empathize with people and encourage them to do something based on the goodness, and being a human being, then where are we going? (woman, FG12)</td>
<td>As soon as money gets brought into it, you question people’s morals. (man, FG4)</td>
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<td>You’re going to get people who do this not for the right reasons. Reimbursement might not necessarily be a good thing. People are doing it already for free. (woman, FG4)</td>
<td>(man, FG6)</td>
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<td>It’s bringing in a commercial aspect to it and that’s going to sway people’s decisions one way or another and it shouldn’t be. It should be a medical and psychologic aspect in the decision, not a financial one. (man, FG6)</td>
<td>And then when you’re donating you feel like, for [$10,000 you’ve done it and people might look at you and think ‘you crazy fool.’ (woman, FG6)</td>
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<td>It’s no longer about goodwill and saving lives; it’s about earning money. (woman, FG8)</td>
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<td>Determining justifiable risk</td>
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<td>Compromising quality</td>
<td>I believe that the Australian blood system is a lot safer because you don’t get paid. People don’t have that incentive to lie and to try to sneak their blood through. US blood is not as safe as the Australian system. (man, FG1)</td>
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<td>You’d get unhealthy kidneys. If people are in a desperate situation and they really want to donate a kidney but they may not be in the right health state. (woman, FG9)</td>
<td>If you’re doing it just for the money then you’re not necessarily going to do all of the lifestyle changes to make sure you’ve got a healthy kidney to give. (woman, FG9)</td>
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<td>Undue harm</td>
<td>The [soldiers are] doing their job—people in the army. (man 1, FG1); The job is saving lives. (woman 1, FG1); And that’s what giving a kidney would do as well. (woman 2, FG1); It’s not a job. You’re not doing it every day. You’re not able to give some kidney every day. (man 1, FG1)</td>
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<td>Accepting a confined risk</td>
<td>The government gives us an incentive of $5000 for having a child. Now, that brings in all these questions about why you [are] having a child. What are the implications on society afterward if you’re not going to raise your child properly? So if someone wants to receive $10,000 for giving a kidney, they’re only giving them risk to themselves, there’s no risk on society, so I don’t see any problem in being able to receive money to give a kidney if you’re inside your problem. (man, FC2)</td>
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<td>Giving a kidney doesn’t necessarily guarantee you’re going to have poor health. You can live a perfectly health fantastic life with 100 grand in your pocket. (man, FG6)</td>
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<td>Trusting protective mechanisms</td>
<td>Look at their economic circumstances, find out through psychologic screening. (man, FG10)</td>
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<td>If the checks and balances are there, then a payment option may be favorable. It has to be very transparent. (man, FG3)</td>
<td>I’m sure there would be regulations, so not anyone off the street will come and get 10 grand; there must be regulations in place so people are doing it for the best intentions, not just for 10 grand. (man, FG4)</td>
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<td>It’s a bit like the baby bonus they used to have a couple of years ago, and you know, some people were just having kids all over the place. So it doesn’t work all the time. (participant 1); Well, that doesn’t, because I don’t think that was regulated as heavy as what it could be. Or maybe not regulated because it was; it wasn’t policed anywhere near as much as what that could have been policed. (participant 2); It’s hard to stop someone having a baby, whereas a doctor can easily say, you’re not doing the kidney thing for the right reasons. You can’t stop someone from getting pregnant. (participant 1); There seems to be more opportunity for control measures that can be implemented. (man, FG4)</td>
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<td>Right to autonomy</td>
<td>Maybe I’ve got a skewed moral compass here, but forget the black market and purchasing, if we regulate kidneys for purchase by the government for 10 grand, no one’s holding a gun to anyone’s head to make a decision. If you qualify, as an adult, to make the choice. (man, FG3)</td>
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<td>Morally, I don’t want to, I don’t feel comfortable with [incentivization]. It can be a tipping factor, but it’s not going to be something that will physically force you one way or another. It’s just going to be another thing to weigh up as a pro or con. (man, FG8)</td>
<td>Driving access</td>
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<td>It’s probably not a bad idea because potentially you could end up having some people donating more because they think all of a sudden they’re going to get a priority down the track. So that’s a possibility, but I certainly don’t have a problem with it as such. (man, FG10)</td>
<td>Urgency of organ shortage</td>
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<td>The whole idea is to get people off the list. If you’ve got to pay $10,000 to do so and that satisfies all of the needs that you have, so be it. (man, FG11)</td>
<td>Driving access</td>
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<td>$10,000 is very little for somebody who is going to lose their life if they don’t get a kidney. I don’t think the money side of it is going to go wrong. (woman, FG3)</td>
<td>Driving access</td>
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<td>The level of organ donation, living or cadaver, is too low. We need to lift it and it’s a valid mechanism to do it. (man, FG6)</td>
<td>Driving access</td>
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<td>In [the] Aboriginal and Indigenous community, there’s a huge risk of kidney diseases. There’s a lot of aboriginal men especially around their 50s and 60s on dialysis and they probably can’t get transplants and others from socioeconomic demographic communities that can’t really get access to kidneys ‘cause. If this is more of an incentive to get more kidneys out there, it’s certainly going to benefit a large percentage of the population that would require kidneys. (woman, FG1)</td>
<td>Driving access</td>
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<td>You would have to work out the right amount so that some people wouldn’t be losing a lot, but other people wouldn’t be profiting? (woman, FG12)</td>
<td>Minimizing disadvantage</td>
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<td>Take away the disadvantaged but don’t provide an incentive. (woman, FG2)</td>
<td>Minimizing disadvantage</td>
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<td>Penalizing them for not having the cash. (man, FG4)</td>
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<td>But what about then the socioeconomic equality of our society; for example, you get really rich people who can easily go in and take a year off work, whereas if you work down in a warehouse, you can’t donate a kidney to your kid because you can’t afford 2 weeks off work. (man, FG6)</td>
<td>Minimizing disadvantage</td>
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<td>Some people just can’t afford to take time off work, so you’d be cutting out a big section of the population if people didn’t get compensation for the work that they missed. (woman, FG8)</td>
<td>Minimizing disadvantage</td>
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<td>If they get the people better then they get them out of the hospitals so less dialysis so the operation might be cheaper than the four times a week on dialysis. (woman, FG5)</td>
<td>Guaranteeing cost-efficiency</td>
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<td>How much time would it waste filtering through all those people to find (woman 1, FG11) that they’re not compatible? (man 1, FG11) [or that] they’re not genuine? (man 2, FG11)</td>
<td>Guaranteeing cost-efficiency</td>
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<td>If you’re putting out an incentive saying, we need kidneys, we’re giving people $2000 to donate a kidney, what effect would that have on people, on that wait list, what effect would it have on the number of people actually needing a kidney? I understand if you get 100 people who actually take up that $10,000, I’m not saying, don’t do it because it’s not worthwhile, but if you have 100 people and you take up that $10,000 and yet there are 2 million who need a kidney, is that an effective driver because you are making the most minor dent. (woman, FG2)</td>
<td>Guaranteeing cost-efficiency</td>
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<td>It could cost the government more because if you get more donors, you’re going to have more people potentially having failing kidneys later. (man, FG5)</td>
<td>Guaranteeing cost-efficiency</td>
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<td>You might even find there are more people coming forward saying look, ‘I could do this because my hospital expenses are going to be covered, I’ll be reimbursed for 3 weeks work that I’m off.’ You might find that people might step up to the plate a little bit more. (woman, FG6)</td>
<td>Guaranteeing cost-efficiency</td>
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<td>It’s like the parental leave that if you’re willing to go down that path, the government’s assisting you with that. So the same approach needs to be taken with donors who are willing to donate, that some kind of incentive is going for them to go down that path so that it opens up more doors for them to be willing to do it. (man, FG5)</td>
<td>Guaranteeing cost-efficiency</td>
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to anyone’s head to make a decision...you qualify as an adult to make the choice.”).

Driving Access

Urgency of Organ Shortage. Saving lives and reducing the waiting list for kidney transplants were seen as an overriding imperative; therefore, initiatives such as payment for living kidney donors were regarded by some as a valid mechanism. In particular, some thought that it may be the only way to help populations at high risk of kidney disease (e.g., Aboriginal and Indigenous people) to access kidney transplantation by expanding the potential pool of living kidney donors.

Minimizing Disadvantage. Some participants believed that reimbursement or compensation could effectively help donors and recipients who were socioeconomically disadvantaged by removing financial barriers to donation, such as providing a government subsidy or special paid leave. They advocated that potential donors who are unable to take leave or pay for donation-related expenses should not be penalized for not having the cash. Some were cautious that the amount should not provide an incentive or opportunity

Table 2. (Continued)

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<td>Counteracting black markets</td>
<td>It would take the risk off people going to black market places. Realistically, if you offer someone $10,000 versus no money to donate a kidney, it is going to be a relevant point that people will consider. And if someone’s like, ‘I really want a kidney, and they went, well, no one’s donating here, I can go buy one on the black market,’ they’re going to be putting themselves at risk. The places where you can pay for a black market kidney, the state-of-the-art care is not as good. I mean, your doctors in Australia and Western society, they’re going have a huge amount of training, and I would personally trust it more. (man, FG8)</td>
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<td>Honoring donor deservingness</td>
<td>A donor shouldn’t be out of pocket. (woman, FG10) You also need to compensate people who don’t work and people who are parents because there are payments that are associated with donation, you need to almost compensate that, the loss of that. (woman, FG2) Well, that’s not a financial gain, that’s just the person keeping on an even keel. They’re not financially gaining on it. (man, FG7)</td>
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<tr>
<td>Fairness and reason</td>
<td>If you’ve donated a kidney, surely, if you have trouble, you shouldn’t be on any waiting list. Even if I was someone that really wanted a kidney, I’d say, no worries, that person donated, they should be way above me in this list. (man, FG2) It’s a ‘you scratch my back, I’ll scratch your back’ kind of world. (man, FG8) Donors should get priority, but it should also be based on the severity of disease. It would be hard to find that, like, sliding scale. (man, FG8) What if a good Samaritan who’s been good all their life, and hasn’t had the situation of donating a kidney, but then they get sick, and then they’re put in front of someone else who’s given the kidney. It’s hard to put someone else ahead of someone who might have been waiting for years for a kidney, and someone else jumps them. (man, FG4) It’s your call to donate a kidney. What makes you so special you have to go to the top of the bloody class [list]? If my kid needs a kidney, why are you going over the top of my kid just because you’ve donated one at your choice years ago? No. I’m not interested. (woman, FG6) But realistically, you don’t donate on the assumption that you’re going to need a kidney later. (man, FG8) The word donation is just sacrificing something anyway, so you’re going to do the donation, you’re aware that you’re going to lose so much in your working life or whatever. You’ve got to factor all that in before you sign on the dotted line. (woman, FG7)</td>
</tr>
<tr>
<td>Reassurance and reward</td>
<td>They should be reimbursed because the recipient is a burden anyway on the health system, it’s costing money and by giving a donor reimbursement and getting the patient out of the medical system or the health system, it’s going to save money. It’s going to save a lot more money than being reimbursed for the leave I’ve taken from work and car parking fees. So, I’d be inclined to say yes, reimburse all costs. (man, FG11) And how much is it costing us to keep that person alive for 5 years as opposed to paying this donor out for 4 days? (man, FG2)</td>
</tr>
<tr>
<td>Merited recompense</td>
<td></td>
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FG, focus group number (18–30 years [FG1, FG4, FG5, and FG8], 31–50 years [FG2, FG9, FG10, and FG12], and ≥51 years [FG3, FG6, FG7, and FG11]).
they should be duly offered reimbursement or compensation. Kidney donors alleviated the economic burden of dialysis, as sign on the dotted line.

The word "donation" is sacrificing something anyway...you're aware that you're going to lose so much of your working life, you've got to factor all that in before you sign on the dotted line.

Participants supported reimbursement because they believed that in principle, donors should not be out of pocket or in a worse financial position.

Discussion

Reimbursement and justifiable recompense was generally accepted among the members of the public as fair and was even deemed necessary to remove financial barriers for potential donors, particularly those who may be socioeconomically disadvantaged. Introducing financial payment to incentivize living kidney donation was opposed on the basis of the potential ethical repercussions of exploitation, corruption, crowding out intrinsic motivations of goodwill and altruism, and the possible risks to the integrity and quality of living kidney donation overall. However, the perceived urgency to save lives by increasing access to transplantation and a belief in an all-prevailing personal autonomy that limited the coercive power of financial gain drove the counterargument that incentives were a valid and defensible strategy as long as they were regulated with adequate safeguards in place to protect donors.

The conflicting ethical principles are apparent in this study and are difficult to resolve. Positive beneficence for patients suffering on dialysis, respect for donor autonomy, and providing a fair benefit to the donor drive support for regulated compensation, whereas commodification of the body, threat to altruism, vulnerability, and coercion of the potential donors would deem such an initiative unacceptable to the public.

This central contention and these conflicting values may explain the discrepant and polarized views observed in previous surveys conducted with the general public (25,26,32), and they also broadly reflect many of the arguments put forward by health professionals. Existing surveys have largely been designed to quantify the proportion of the general public that would be in favor of financial reimbursement, compensation, or incentives, but do not elicit or describe the reasons underpinning their responses. In one survey study conducted by Barnieh et al. in 2011, the most frequently cited reason among the public who indicated that financial incentives were not acceptable was that kidney donation should "come from the goodness of one's heart" (25), which is also reflected in our findings. In a recent study, we interviewed transplant nephrologists and surgeons who raised similar concerns about the moral consequences and feasibility of direct financial incentives for living kidney donors, including commodification of the body, undermining benevolence; however, they also expressed support for its potential legitimacy to maximize access to transplantation and its associated health and economic gains (22). Furthermore, some professionals believe that regulated incentivization should not be dismissed without being trialed in a controlled setting in order to make evidence-based decisions.
judgements or policy decisions (6,9,20,22,36,37); however, this point about the need for trial evidence was not reiterated by the public. We speculate that ethical concerns are seen by the community as fundamental to driving policy over and above the necessity of generating research evidence. Interestingly, transplant professionals speculated that the general community may not be entirely opposed to paid donation, and they believed that an understanding of public values and public engagement in the debate was warranted (22).

In our study, it seems that members of the public have raised some new arguments, which can add to the ongoing discourse and debate on financial incentives for living kidney donation. They questioned the feasibility, fairness, and moral implications of valuing a kidney, specifically by donor age; they feared that physicians could manipulate the system; and they suspected that donors who received payment would have their motivations and actions judged, criticized, or condemned by the community. On the other hand, acceptability of financial incentives was explained by having trust in the integrity, competence, and authority of physicians to prevent medically, psychology, and financially vulnerable individuals from donating their kidney. In view of this, we note concerns among transplant professionals that despite best efforts, transplant programs are not equipped to conduct rigorous investigations to uncover deception or misinformation provided by some donors and recipients.

Although this study offers in-depth insights and documents a diverse range of public beliefs, values, and attitudes toward donor reimbursement, compensation, and incentivization, there are a number of potential limitations. The transferability of the findings to other countries is uncertain because of the different healthcare contexts, funding models, and population characteristics, although similar perspectives reported by physicians and the public in other countries suggest that the themes could be relevant beyond our national setting. Although we reached theoretical saturation (i.e., when no new concepts were emerging from subsequent focus groups) and captured a range of demographic characteristics, there may be selection bias because participants were recruited via market research companies and we could not access the characteristics of nonrespondents. The majority of participants were well educated and no participants with an education level below grade 10 were recruited. In addition, our study does not quantify frequency of responses. However, our findings can inform the development of surveys or opinion polls to assess the prevalence of opinions or concerns, as well as to ascertain any differences across sociodemographic characteristics.

A survey conducted in the United States found that public attitudes toward incentives for living kidney donation varied by ethnicity and income levels (38). We did not observe any apparent differences in opinion among the focus group participants by sociodemographic characteristics, including ethnicity, sex, age, or employment status (including poverty or reduced income). We suggest that more research could be conducted with specific population groups, and in other countries, to delineate and compare possible differences in values, attitudes, and perceptions. In addition, our study focuses predominantly on financial reimbursement, compensation, and incentives; therefore, further research is needed on public perception of other forms of support, including tax deductions, reduced health insurance premiums, and other nonmonetary rewards.

In Canada, it was recently suggested that a regulated system of paid donation could not be currently implemented; instead, consideration should be given to the removal of disincentives, such as by reimbursing lost wages, providing compensation for pain and suffering as a result of nephrectomy, or offering additional compensation to donors who participate in paired kidney exchange programs (8). These strategies are controversial and public opinion and acceptability remain unknown.

Living kidney donation programs depend on the willingness of members of the public to donate. The public holds strong core beliefs, values, and assumptions about living kidney donation. Launching compensation and incentivization initiatives will no doubt provoke reaction from members of the general public, which may in turn influence their acceptance and support for living kidney donor transplantation. For example, the primacy given to ethical principles suggests that the notion of conducting a pilot trial of government incentives may not be considered justifiable and would encounter some resistance among the community. It has been argued that public policy decisions should be based on the explicit application of ethical principles, using the evidence and theory appropriately (39). The challenge here is moral pluralism, and policy makers have a responsibility to recognize and address the conflicting moral appeals (40). The public is a key stakeholder group that needs to be actively and meaningfully engaged in policy development and current debates around financial payment for living kidney donors.

Reimbursement and equitable compensation are considered by the public as legitimate ways of supporting donors and reducing disadvantage. Financial incentivization is regarded as morally reprehensible with potential for exploitative commercialism, although some contend that it could be a defensible strategy to increased donation rates, provided that mechanisms are in place to protect donors. The perceived threat to community values of human dignity, goodwill, and fairness suggests that there could be strong public resistance to any form of financial inducements for living kidney donors. Policy priorities addressing the removal of disincentives may be more acceptable to the public.

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Disclosures
None.

References