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## Prevention of Poor Psychosocial Outcomes in Living Organ Donors: From Description to Theory-Driven Intervention Development and Initial Feasibility Testing

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### Abstract

**Context**—Although some living donors experience psychological, somatic, and interpersonal difficulties postdonation, interventions to prevent such outcomes have not been developed or evaluated.

**Objective**—To (a) summarize empirical evidence on postdonation psychosocial outcomes, (b) describe a theoretical framework to guide development of an intervention to prevent poor outcomes and (c) describe development and initial evaluation of feasibility and acceptability of the intervention.

**Methods**—Based on a narrative literature review suggesting that individuals ambivalent about donation are at risk for poor postdonation psychosocial outcomes, the intervention targeted this risk factor. Intervention structure and content drew on motivational interviewing principles in

order to assist prospective donors to resolve ambivalence. Data were collected on donor characteristics at our institution to determine whether they constituted a representative population in which to evaluate the intervention. Study participants were then recruited to assess intervention feasibility and acceptability. They were required to have scores > 0 on the Simmons Ambivalence Scale (indicating at least some ambivalence about donation).

**Results**—Our population was similar to the national living donor population on most demographic and donation-related characteristics. Eight individuals approved to donate either a kidney or liver segment were enrolled for intervention pilot testing. All successfully completed the 2-session telephone-based intervention before scheduled donation surgery. Participant ratings of acceptability and satisfaction were high. Open-ended comments indicated that the intervention addressed participants' thoughts and concerns about the decision to donate.

**Conclusions**—The intervention is feasible, acceptable, and appears relevant to donor concerns. A clinical trial to evaluate intervention efficacy is warranted.

### Keywords

living organ donors; intervention development; psychosocial outcomes

## INTRODUCTION

Living donors constitute 45% of all organ transplant donors in the United States.<sup>1</sup> The rate of living donation has almost tripled in the past 20 years; over 113,000 individuals have served as living donors since 1988.<sup>1,2</sup> Most of these individuals donated either a kidney (96%) or a liver segment (4%).<sup>2</sup>

Because living donors undergo major surgery involving the removal of critical organ mass for no direct medical benefit to themselves, the protection of their well-being and the prevention of any negative consequences of donation are among the foremost priorities in transplantation. Surgical innovations and increased experience among surgical teams have together continued to drive down the risks of donor intraoperative and perioperative morbidity.<sup>3–6</sup> However, there remain ongoing concerns that donors are at risk for negative psychosocial sequelae and that these outcomes deserve increased attention.<sup>6–12</sup>

To the best of our knowledge, no preventive interventions have been systematically developed and tested for their ability to avert poor psychosocial outcomes, despite evidence that certain factors consistently predict postdonation psychological, somatic, and interpersonal difficulties.<sup>13</sup> In particular, residual ambivalence about the prospect of donation—i.e., lingering feelings of hesitation and uncertainty that remain after the prospective donor's pre-donation medical workup and that coexist with the donor's intention to donate—appears to be a critical predictor of poor postdonation psychosocial outcomes.<sup>13–16</sup> We therefore sought to develop an intervention to address residual ambivalence in living donor candidates. We hypothesized that an intervention focused on a key risk factor for poor postdonation psychosocial outcomes would have the capacity to prevent them. Preliminary data on feasibility and acceptability of the intervention, however, are needed before it is reasonable to design a clinical trial to test the intervention's efficacy at prevention.

In the present paper, therefore, we first summarize the empirical evidence on psychosocial outcomes in living donors that supports the focus of our intervention. We then describe the theoretical framework underlying our intervention, followed by the formative work we undertook to develop the intervention and collect initial data on its feasibility and acceptability.

## Psychosocial outcomes in living donors

No matter whether living kidney or liver donors are queried shortly postdonation or many years later, studies consistently show that only a small minority of donors (less than 5%) regret having donated.<sup>17–21</sup> The vast majority state that they would make the same decision to donate again<sup>22–28</sup> and report deep gratification at having been able to help another person.<sup>16,29–31</sup> Moreover, as summarized in several recent systematic reviews, numerous studies utilizing generic, non-donation specific assessments of health-related quality of life (HRQOL; e.g., the SF-36) show that donors' well-being, on average, meets or exceeds that reported in the general population once donors have recovered from the immediate effects of surgery.<sup>13,32,33</sup> Nevertheless, a growing body of studies suggest that sizable proportions of living donors experience major difficulties in the years after donation. These difficulties appear to lie predominantly in three key psychosocial domains: psychological well-being, perceived physical functioning, and interpersonal relationships.

With respect to psychological well-being, a number of empirical reports have described clinically significant psychological distress in both kidney donor and liver donor cohorts, typically at a rate of about 1 in every 4 donors.<sup>16,34–44</sup> Many of these distressed individuals meet diagnostic criteria for mood and anxiety disorders.<sup>12,21,45–50</sup> These findings are striking because, consistent with guidelines and mandates in the transplant community,<sup>7,10,11,51–54</sup> donors routinely undergo careful evaluation before donation designed to screen out individuals with significant psychiatric (as well as medical) morbidity. Indeed, pre-donation assessments of living donors show uniform and high levels of psychological well-being relative to normative or comparison group levels.<sup>21,24,28,55–58</sup> Therefore, one would expect that donors would otherwise be at very low risk to develop significant psychological distress and diagnosable disorder postdonation.

The literature also contains anecdotal reports of suicidal ideation and attempted and completed suicide in donors.<sup>15,59–61</sup> In the only large-scale investigation to date, the Adult to Adult Living Liver (A2ALL) study examined data from nine centers and identified one suicide attempt, one accidental death that may have been a suicide, and one suicide, leading to an estimated suicide rate of over 2 per 1000 donors.<sup>12</sup> The A2ALL study group noted that their data were limited by their reliance on medical records reviews rather than prospective assessments.<sup>12</sup> Therefore, it is likely that the rates of suicide attempts and related psychiatric disorders were underestimated,<sup>62</sup> suggesting the development of serious psychopathology potentially attributable to the donation experience may be more common than previously realized.

Self-reported decrements in physical well-being and elevated levels of somatic distress related to the donation also appear to be relatively common among donors. Thus, in studies that have examined donors who are beyond the perioperative recovery period, up to one third of donors report that their health is fair to poor or markedly worse since donation.<sup>15,22,43,63–68</sup> Among the most prevalent, enduring symptoms is pain (e.g., around the surgical incision).<sup>15,27,31,35,63,65,69–72</sup> Recent studies have also begun to identify persistent fatigue<sup>37,43,56,63,73</sup> and ongoing worries among donors about lasting effects of the donation on their health.<sup>29,30,35,72,74–78</sup> Finally, negative body image changes (often related to the surgical scarring) have been described by donors.<sup>37,69,70,74,78–80</sup> Interestingly, although very few studies have performed direct comparisons between kidney and liver donors,<sup>26,70</sup> there is no clear trend across the literature suggesting that the degree and nature of donors' somatic distress beyond the perioperative recovery period differ markedly as a function of type of donation.

A third psychosocial domain that appears to show adverse effects in some donors pertains to interpersonal relationship strain. Although the majority of donors report that their

relationship with the transplant recipient is unchanged or improved postdonation,<sup>27,39,44,73,78,81,82</sup> relationships with other family members, including the spouse, have been reported to worsen.<sup>18,31,67,76,81,83–86</sup> Studies often do not specify which types of relationships with (non-recipient) family members have worsened (e.g., spousal vs. other relationships). However, the spousal relationship may be at particular risk for strain, given anecdotal reports of postdonation separations and divorces.<sup>15,39,81,85</sup>

Surprisingly, among donors who are beyond the perioperative recovery period, time since donation has not been consistently found to be related to the likelihood of problems in the various psychosocial domains we have discussed. In addition, it is worrisome that the specific problems that we have identified are reported in the same literature—and sometimes within the same study—that also reports that generic HRQOL in donors meets or exceeds that of the general population.<sup>21,35,42,44,46,56,71–73</sup> This suggests that generic measures are insensitive when used in living donors and, at best, should be used only as adjuncts to more sensitive, specific evaluation of potential psychosocial problems in donors.<sup>33,83,87</sup>

Which donors are at risk for these problems? This question has been difficult to answer, especially given the cross-sectional, often retrospective designs utilized in many studies in this literature.<sup>88</sup> Such design-related and other methodologic limitations may account for mixed findings to date in this still-small literature. Thus, although many variables have been examined as potential risk factors, for most, there appear to be as many studies failing to find effects on psychosocial outcomes as studies reporting such effects. This pattern of mixed findings applies to: (a) demographic characteristics including age, gender, education and marital status,<sup>14–16,24,25,29,36–39,65,89–92</sup> (b) the donor's pre-donation psychological distress,<sup>14,16,24,43,47,60,93</sup> (c) whether the donor was related (either biologically or emotionally) or was unrelated to the recipient (e.g., an acquaintance or an anonymous donor),<sup>15,25,31,38,39,65,90,92</sup> (d) whether the donor had poor pre-donation relationships with their family or with the recipient,<sup>15,16,43,60,93</sup> (e) the type of surgical procedure for donation (laparoscopic vs. open vs. mini-incision nephrectomy; left vs. right liver lobe resection),<sup>21,23,25,56,64,70–72,94</sup> (f) whether the donor had perioperative medical complications,<sup>25,38,44,46,65,70</sup> and (g) whether the transplant was successful or not (i.e., the recipient lost the graft or died).<sup>15,21,23,39,50,55,56,60,65,67,73,79,83,86</sup> Other potential risk factors (e.g., coping strategies, motives for donation), have been examined in only one or two investigations and thus strong conclusions about impact cannot yet be reached.<sup>14–16,44,82</sup>

In contrast to the mixed or scant evidence for most putative risk factors, there is a growing evidence base indicating that residual ambivalence about donating heightens donors' risk for poor postdonation psychosocial outcomes. First characterized in Simmons' work,<sup>16</sup> this type of ambivalence refers to lingering feelings of uncertainty and hesitation about donation (e.g., feeling unsure about whether one would want to donate if someone else could do it, wishing a deceased organ would become available, being fearful about going through with donation) that remain after the donor has completed the medical workup and that coexist with the donor's intention to donate. These residual feelings must be distinguished from what, in contrast, can be termed acute ambivalence, i.e., feelings of indecision so marked that it is determined in the psychosocial evaluation that the prospective donor is unable to give adequate informed consent to proceed.<sup>7,10,11,95</sup> Residual ambivalence, instead, pertains to feelings that remain shortly before donation, despite the fact that the donor intends to proceed with donation. While acute ambivalence, resulting in a rule-out of the individual as a donor, is uncommon (<2% of rule-outs),<sup>96–99</sup> some degree of residual ambivalence before donation has been noted in up to 75% of donors.<sup>16,22,29,35,36,77,101–103</sup>

Studies linking residual ambivalence with poor postdonation outcomes include Simmons and colleagues' work with kidney donors<sup>16,93,104</sup> and later with bone marrow donors<sup>105,106</sup> showing that the greater the level of donors' residual ambivalence before donation, the more likely donors were to experience both psychological distress and physical complaints both in the short-term postdonation (e.g., several months to 1 year) and in the longer term (5–9 years). Similar findings have been reported in other studies of both kidney donors<sup>15,107</sup> and liver donors.<sup>14,36</sup> Although effects of residual ambivalence on familial relationship strain have received little attention, one report suggests that ambivalence was also associated with this domain of outcomes.<sup>107</sup>

In sum, the evidence we have reviewed on psychosocial outcomes postdonation suggests that efforts to avert poor outcomes are warranted. Although the literature on psychosocial outcomes and their risk factors has methodologic limitations, and evidence base for risk factors remains relatively small, knowledge to date regarding the most potent risk factors for these outcomes points to the potential importance of residual ambivalence. We thus hypothesized that an intervention focused on reducing residual ambivalence might be a useful prevention strategy in this area.

### **Theoretical framework for a preventive intervention with living donors**

The conceptual model underlying a given intervention may be based on a single theory or it may draw on concepts from multiple scientific perspectives.<sup>108</sup> We drew on concepts from the field of prevention science<sup>109</sup> to delineate the broad type of preventive strategy to be used. Then, given our focus on ambivalence, we drew on ambivalence-related components from the theoretical framework of motivational interviewing (MI)<sup>110,111</sup> to specify the structure and content of our intervention.

**What type of prevention strategy?**—Preventive interventions occur before the onset of a disorder or health outcome.<sup>112,113</sup> There are three classes of preventive intervention models.<sup>109,114</sup> *Selective* interventions target individuals with risk factors for the outcomes of interest. In contrast, *indicated* interventions target individuals who are prodromal for the outcomes (e.g., they already have signs/symptoms of the outcomes) and *universal* preventions are offered to an entire population regardless of risk or prodromal status.

We judged that a selective approach, targeted at prospective living kidney or liver donors with residual ambivalence, would be most appropriate. An indicated prevention intervention would not be suitable because individuals approved as prospective donors have already undergone extensive screening in order to minimize the likelihood that they have signs and symptoms of poor psychological or physical health, and prospective donors themselves perceive their well-being to be high, as reviewed earlier. On the other hand, a universal approach would be inefficient because it would require that even individuals with no prodromal signs or risk factors (e.g., no residual ambivalence) receive the intervention.

**Theoretical framework for intervention structure and content: MI**—We derived our selective intervention from the principles of MI.<sup>110,111</sup> Although using MI chiefly in order to resolve ambivalence is novel, this application fits squarely within MI's theoretical framework. To explain this, we first describe the elements of MI that are best-known in the field of behavioral intervention, and then describe how we draw on features of MI relevant to our focus on residual ambivalence about living donation.

A goal emphasized in most previous clinical and research applications of MI is the enhancement of individuals' motivation for behavior change.<sup>115–117</sup> The change may involve refraining from activities (e.g., abstinence from substance use or other harmful behaviors)<sup>115,118,119</sup> or initiating new behavior (e.g., health promotion activities).<sup>120–122</sup> MI

has been found efficacious across these many applications.<sup>115–117</sup> However, equally important in both the theory<sup>110,111</sup> and practice<sup>123</sup> of MI is its focus on exploring and resolving ambivalence—no matter what the individual’s ultimate choice is regarding any behavior they might undertake (or decision they might make). Indeed, the conceptual framework underlying MI—integrating Rogers’ client-centered counseling theory<sup>124</sup> augmented by Janis’ decision counseling approach<sup>125</sup>—does not presume that a certain direction of client action is “preferred” or should be promoted over any other course. This sets MI apart from other “behavior change” approaches,<sup>126,127</sup> where movement toward change or client action in a specific direction is the key indicator of success (e.g., the transtheoretical model<sup>128</sup>). Rather, the theoretical underpinnings of MI assert that the interventionist’s foremost goal is to facilitate the client’s ability to freely choose a course to take (i.e., select a behavior, or make a decision, including the decision to take no action) consistent with the client’s own values and goals.<sup>110</sup>

We focused on this neglected application of MI. Specifically, we drew on the concepts on which MI itself has drawn in exploring and resolving ambivalence, namely the notion that people become increasingly committed to what they hear themselves defend.<sup>110,111,115,129</sup> This is especially so when they possess inconsistent or discrepant cognitions—e.g., intentions that conflict with their beliefs about what they should do or what they would prefer to do. The presence of these discrepancies creates discomfort, including ambivalence.<sup>129</sup> In the section on intervention development below, we explain how this premise is translated into action as MI is carried out.

In sum, our goal of developing an MI-based intervention with prospective donors was neither to encourage nor discourage donation, but to enable them to resolve residual ambivalence in order to reach *their own* final choice as to whether to proceed with donation or not. Among individuals who do become donors, the resolution of ambivalence will, we hypothesize, prevent poor postdonation psychosocial outcomes.

## METHODS

### Assembling the intervention development team

We assembled an interdisciplinary team to ensure that the intervention met clinical standards for MI and was also relevant to prospective donor (PD) concerns, based on existing literature and clinical practice. The team included members representing clinical transplantation (individuals from nursing, consultation-liaison psychiatry, surgery), behavioral medicine and medical sociology (experts in design, development and evaluation of psychosocial interventions in transplant-related populations), and motivational interviewing. The team’s primary concerns were not only to develop the intervention, but to understand PDs’ impressions of it so that we could modify its content and/or procedures as needed.

### Assessing individuals potentially eligible for the intervention

We gathered information about background characteristics for living donors at our center in order to determine whether they were similar to the donor population nationally (and thus would constitute a representative subpopulation in which to examine intervention feasibility and acceptability). We also reviewed results of recent surveys examining ambivalence conducted at our center to determine whether there were likely to be sufficient proportions of living kidney and liver donors at our center who experienced residual ambivalence in order to justify offering an intervention to these individuals.

## Recruiting representative patients

With institutional review board approval, we recruited and obtained informed consent for participation in feasibility testing of the intervention from individuals who had completed their medical evaluation (including the psychosocial component) and been approved to serve as living donors in the University of Pittsburgh Living Donor Kidney and Liver Programs. We aimed to enroll 5 to 8 individuals. This sample size was based on our own and others' intervention development work, which has suggested that studying a small number of participants (<10) will be sufficient to expose major problems with intervention structure, format and content design that should be corrected before proceeding to a larger-scale effectiveness study.<sup>130,131</sup> We used purposive sampling in order to help ensure recruitment of PDs who varied in demographic characteristics, their relationship to the transplant patient (e.g., related vs. unrelated) and whether they were considering kidney or liver donation.

The key inclusion criterion for enrollment was that PDs have a score exceeding zero on the Simmons Ambivalence Scale,<sup>16</sup> indicating the presence of at least some degree of residual ambivalence. The measure is comprised of 7 items focused on lingering hesitation and uncertainty about donation. Each item is rated on a 4-point scale indicating how strongly the respondent feels about the item (e.g., "I would really want to donate, even if someone else could do it, 0 = agree a lot; 3 = disagree a lot). The 7 items are summed and a score exceeding zero has been used to identify respondents with at least some ambivalence.<sup>16,101,105,106</sup> Simmons<sup>16</sup> demonstrated both the construct validity of the measure (based on assessments of convergent and discriminant validity), and she and others have found it to have predictive validity in prospective studies.<sup>16,94,106</sup> Its internal consistency reliability has been found to range from .78 to .83 in kidney and liver donors.<sup>16,101</sup> A recent editorial supports the choice of this scale for the empirical measurement of ambivalence in living donors.<sup>132</sup> This screening measure was assessed via a brief telephone call at the time that informed consent was obtained. Study participants were also required to be aged 18 or older, English-speaking, and have access to a telephone.

## Developing the intervention

**Defining intervention structure, format and timing relative to donation—**We structured intervention sessions to be consistent with fundamentals of MI: MI is, by design, (a) nonconfrontational and collaborative, and (b) brief.<sup>110,115</sup> With regard to the former, we judged it important to adhere to the principle that the MI interventionist does not present an array of choices that a client might make but instead works to promote clients' own reflections on the choices they face, in the context of their values and goals.<sup>110,115,123</sup> The interventionist guides the client to explore his/her own arguments for and against a certain course of action. Thus, the interventionist seeks to evoke clients' expressions of their desire, ability, reasons and need to make a behavioral or decisional choice in one direction vs. another.<sup>110,115</sup> Clients hear themselves explain their own motivations, and hear those explanations reflected again by the interventionist. This approach is thus based on an assumption of client autonomy.<sup>110,115</sup> As such, MI is congruent with the ethical principles and standards for living donor organ transplantation, namely that PDs reach an autonomous decision to proceed (or not) with donation without experiencing coercion or undue pressure in favor of one choice vs. another, and with appropriate reflection on their possible courses of action.<sup>7,51,53</sup>

We judged that our MI-based intervention would most appropriately be conducted after PDs' medical evaluation was completed. This is consistent with recommendations that they be given the opportunity to "cool off" before the donation surgery occurred, i.e., a chance to reflect on and reach a final decision about whether or not to donate.<sup>7,51,133</sup> Such a cooling

off period is especially important for PDs who have some residual ambivalence regarding whether or not to donate (i.e., the PDs targeted for our intervention).

With regard to intervention duration, MI-based interventions are usually brief (often 1–2 sessions, totaling only 1–2 hours, and offered within a short timespan of days or a week), and they can be conducted by telephone.<sup>115</sup> The latter feature is an important asset since many PDs do not live near their Living Donor Transplant Program. MI's brevity is also a strength because more lengthy interventions (even those lasting just a few weeks) would not be feasible within the context of the donor evaluation process. Approval for donation and donation surgery may take place relatively quickly once donors have completed their medical evaluation; a brief intervention is ideal for this short timeline.

In sum, we designed a 2-session telephone-based intervention employing MI principles of nonconfrontational but guided discussion of PDs' remaining concerns about donation. We aimed for each session to last approximately 45 minutes, be conducted 5–7 days apart, and scheduled at PDs' convenience. For purposes of our developmental work, the interventionist was a team member with extensive MI experience as an interventionist and trainer.

**Developing the content of intervention sessions**—The content was designed to achieve our key goals: to assist PDs to resolve residual ambivalence about donation and to build their motivation for making their final decision about whether or not to proceed with donation. The content was developed through a series of meetings of team members in which each possible component of the sessions was discussed, with role playing of segments of the sessions in order to further develop interventionist guidelines. In general, the sessions incorporated standard MI techniques such as the use of open questions, reflective listening, affirmations of the PD's strengths, and the provision of frequent summaries of the discussion in order to ensure that the PD feels "heard" and respected.<sup>110,123</sup> Each session had specific components to be covered, and we prepared a manual outlining each component and the types of queries that the interventionist would use in semi-structured fashion to guide the discussion.

Session 1 begins with introductory comments designed to establish a collaborative relationship that is nonjudgmental and confidential, and to recognize the PD's personal choice and control with regard to the donation decision. PDs are assured that the content of the phone calls would not be revealed to transplant candidates or the transplant team. (As specified in the informed consent for study participation, however, study subjects were aware that if they were found to be at risk for harm to themselves or others, e.g., they reported suicidal ideation, the research team would take immediate steps to ensure their safety.) Discussion in Session 1 then moves to understanding the PD's "story," i.e., how the PD came to consider living donation and their experience with the evaluation for it. Next, the nature of ambivalent feelings is explored, with an emphasis on clarifying whether the PD is leaning in one direction or another in terms of proceeding with the surgery and identifying factors that remain as concerns. This discussion incorporates a review of the PD's responses to the Ambivalence Scale administered at the time of study enrollment. The session continues with consideration of whether there are additional actions that the PD might take in order to resolve residual ambivalence (e.g., obtaining more information from the Living Donor Program or other sources in order to address concerns; talking further with family members). Specifics of a plan that could be undertaken before the second session are discussed, and the PD's commitment to carrying out the plan is elicited. The session closes with a summary of the key points covered during the session, including the plan for actions the PD will take before the second session. The second session is also scheduled.



Session 2 begins with reminders to the PD about the purpose of the sessions and their confidentiality, followed by a discussion of any steps the PD took since the last call in order to address factors linked to residual ambivalence, and whether those steps affected the PD's views about donation. This discussion of steps taken by the PD provides an important rationale for the second session: to ensure that the PD would have an opportunity to consider results of enacting the plan and think about any other steps that might be important to take. Equally important for Session 2, the interventionist then introduces a standard MI task, the Values Card Sort,<sup>110</sup> which is designed to assist the PD to recognize the values most important to him/her (e.g., family, compassion, achievement, belonging), how the PD is living out those values, and how proceeding with (or deciding not to proceed with) living donation is linked to those values. The session closes with a summary of the discussion across both sessions, affirmation of the PD's efforts in considering donation options, and consideration of whether the PD might engage in any other steps or plans to address any other concerns regarding decisions about living donation.

### **Assessing intervention feasibility and acceptability**

We examined whether PDs were willing to enroll and complete the sessions, whether both sessions were successfully conducted in the short timeline before any donor surgery, and how many days elapsed between sessions. We obtained PD ratings of satisfaction and acceptability of the sessions using the Client Satisfaction Questionnaire,<sup>134</sup> a survey with 8 closed-ended ratings, as well as open-ended items regarding PDs' impressions. The scale was administered during a telephone assessment conducted within 1–3 days after the second intervention session. The assessment was conducted by a team member who received no other information about the specific discussion that occurred during the intervention sessions.

## **RESULTS**

### **Individuals potentially eligible for the intervention**

As shown in Table 1, living kidney and liver donors at our center were similar to donors nationally on distributions of gender, age, and relationship to the transplant patient. They differed from national distributions on ethnicity. The ethnicity distribution at our center more closely mirrors the population in the region served by our center.<sup>135</sup> The data in Table 1 suggest that donors from our center would generally constitute a representative cohort from which to sample in the initial phases of examining feasibility and acceptability of the intervention, but that we should pay attention to ethnicity and consider oversampling on this factor in an eventual study of intervention effectiveness.

In order to determine whether there were likely to be sufficient proportions of living kidney and liver donors at our center who experienced residual ambivalence in order to justify an intervention, we reviewed two surveys of center patients. In a recent study of 77 prospective liver donors (representing 73% of eligible PDs during the enrollment period), we found that 74% endorsed at least some degree of ambivalence on the Simmons Ambivalence Scale.<sup>101</sup> We also previously surveyed 85 kidney donors (82% of eligible donors) who had completed kidney donation surgery an average of 2.2 years ( $SD=1.0$ ) earlier.<sup>136</sup> They were asked to retrospectively rate their level of ambivalence before donation, using the Ambivalence Scale, and 80% endorsed at least some ambivalence (L. Myaskovsky, personal communication).

## Characteristics of study participants enrolled to test intervention feasibility and acceptability

We initially approached 14 PDs. Of these, 4 showed no residual ambivalence about donation (Ambivalence Scale scores of zero). Of the remaining 10 individuals, one refused to enroll and 9 gave consent. However, one PD's intended recipient received a deceased donor transplant 1 day after enrollment and thus the PD could not participate in the study. The final sample therefore included 8 PDs. As shown in Table 2, these PDs varied in terms of demographic and donation-related characteristics.

## Feasibility and acceptability of the intervention

All PDs completed both intervention sessions before any donor surgery. (Six donors went on to donate; in the other two cases deceased donor transplants were performed before the PDs' scheduled surgery.) Sessions averaged 47 minutes ( $SD = 15$ ). An average of six days ( $SD = 4$ ) elapsed between the first and second session; all PDs except one completed both sessions with one week (one PD had two weeks between sessions).

PD ratings of the acceptability of the sessions and their satisfaction with them, based on the CSQ, are shown in Table 3. Ratings fell in a very narrow range, with most ratings at the highest or next to highest point on the 4 point scale for each item. PDs thus viewed the sessions as good to excellent in terms of quality and relevance for prospective living donors, they felt satisfied with their participation, and they would recommend the sessions to other living donors. PDs' comments concerning intervention features that they liked most and least are shown in Table 4, categorized according to whether the comments pertained to session content or to procedural or structural issues. In general, comments indicated that the content of the intervention was appropriate for PDs and sensitive to their concerns. In terms of structure, PDs liked the brief, telephone-based format. Overall, PD comments indicated that they appreciated the opportunity to discuss remaining concerns that they had about donation. Even so, one PD noted that it was difficult to schedule and complete both sessions given other preparations for possible donation. (This was not the PD who required two weeks to complete both sessions, however.) In addition, although confidentiality of the discussion was emphasized during each session, one PD suggested that it might need to be emphasized even more.

## DISCUSSION

Our initial work to develop an intervention to address PDs' residual ambivalence about the prospect of donation arose from a growing literature on postdonation psychosocial outcomes and their predictors. We designed the intervention within a selective prevention model, i.e., focused on PDs who had completed the medical evaluation and been approved for donation surgery yet who expressed residual ambivalence or hesitation about donating. We believed that the theoretical framework of MI would be particularly beneficial for guiding interventionist efforts to assist PDs to think about and weigh their concerns about donation in order to become fully "at peace" with their decision about donation (no matter whether they continued to proceed with the plan to donate or decided not to donate).

Our initial examination of the acceptability and feasibility of our newly developed intervention suggests that PDs are willing and able to participate in both sessions of a brief MI-based intervention. Although our group of study participants was, by design, small, we selected them to represent the diversity of living donors—in type of relationship to the transplant patient, whether they were donating a kidney or liver segment, and in demographic characteristics. Across these individuals, we found consensus that the intervention content was relevant to the concerns they faced and that the structure of the

intervention (e.g., telephone-based, 2 sessions within a brief time period before any surgery) was viewed favorably. Ratings of acceptability and satisfaction were also high. With regard to intervention structure in particular, open-ended comments suggested that the telephone-based approach was a strength due to factors related to convenience as well as to preserving confidentiality. This is consistent with an extensive body of work showing that despite the loss of some nonverbal information, telephone-based intervention and data assessment strategies are no less equally effective and yield data of comparable quality to face-to-face strategies.<sup>137,138</sup> Indeed, telephone-based approaches can be preferable for discussion of sensitive topics.<sup>139</sup>

PDs offered valuable comments for revisions to the intervention. For example, the comment that some questions posed by the interventionist seemed to be redundant or covering ground that had already been addressed suggested that our manual should be revised to further tighten up the outline for the components to be addressed in each session, and the possible queries to be used by the interventionist to direct the discussion. A comment by one PD concerning difficulties with interruptions during the telephone-based sessions and another comment about the need to be able to focus during the sessions suggested that we needed to bring up these issues when initially scheduling sessions to help ensure that the timing would be optimal for PDs. A PD comment also indicated that assurances of confidentiality should be even further emphasized.

A possible limitation of the present study is PDs were aware that we were developing and pilot testing a new intervention, and that we would be asking for their opinions of it. They may have felt that they could give only predominantly positive comments. We attempted to minimize this potential bias by having a team member separate from the interventionist call to obtain PDs' evaluation of the sessions. We also believe that our decision to focus on the PDs' ratings of acceptability and satisfaction, as well as their comments, helps to reduce the risk of developing an intervention based solely on what we considered important or useful to PDs rather than what PDs themselves thought would be helpful.

Following revisions of the interventionist manual, intervention content, and general intervention procedures, the most critical steps for the future are to formally test the efficacy of the brief intervention for the prevention of poor psychosocial outcomes in the domains we initially identified: psychological distress, somatic complaints, and interpersonal relationship strains postdonation. It will be equally important to consider whether any effects of the intervention on these postdonation outcomes are mediated, or accounted for, by the ability of the intervention to reduce levels of residual ambivalence before donation. It may also be the case that any intervention effects on residual ambivalence or psychosocial outcomes may be more pronounced in some donors than others (i.e., other donor predonation characteristics may moderate any intervention impact). However, to date, the literature provides little evidence for generating hypotheses in this regard. A critical issue for testing the intervention will be the choice of a comparison condition in order to control for "attention"—i.e., the fact that donors had a skilled individual talking with them over the course of two phone calls totaling about 90–95 minutes. Is it the MI-based intervention that might be beneficial or the sheer attention that the donor would receive regarding issues relevant for their health and well-being? Finally, there will be other important issues to consider as well in planning how an intervention—if effective—might be disseminated into routine clinical care. Those issues will pertain, for example, to costs and resources needed for offering the intervention, and to how to address potential tensions between the need for PDs to have a confidential forum for discussing their concerns vs. any need of Living Donor Programs to learn of new, previously unidentified concerns or issues voiced by PDs during their intervention sessions. The results of efficacy testing and consideration of issues of dissemination may yield important insights

into practical, scalable strategies to enhance the safety and well-being of individuals who have generously come forward to help another individual in need.

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**Table 1**

Living organ donor characteristics at the University of Pittsburgh in comparison to the national donor population, 2006 – 2010.

Characteristic	University of Pittsburgh	U.S. Living Donor Population <sup>a</sup>	One-sample $\chi^2$ test (comparing center to national population)
<b>Kidney donors, n</b>	397	31,116	
Gender, % female	62.5	58.2	0.85
Age, % < 50	72.8	74.6	0.65
Ethnicity			
European American	90.9	69.7	84.3***
African American	5.8	12.0	
Hispanic American	1.0	13.7	
Asian American or Other	2.3	4.6	
Relationship to recipient			
Biological relative, first degree	54.6	50.2	7.22
Biological relative, other	9.6	7.6	
Spouse/partner	12.1	13.1	
Unrelated	23.7	28.8	
<b>Liver donors, n</b>	138	1,304	
Gender, % female	56.5	51.6	1.42
Age, % < 50	87.7	84.8	1.35
Ethnicity			
European American	91.3	78.8	17.56***
African American	2.9	5.1	
Hispanic American	2.2	11.7	
Asian American or Other	3.6	4.4	
Relationship to recipient			
Biological relative, first degree	65.2	58.7	2.62 <sup>b</sup>
Biological relative, other	10.9	11.9	
Spouse/partner	1.4	5.7	
Unrelated	22.5	23.7	

<sup>a</sup>from OPTN/UNOS<sup>1</sup>

<sup>b</sup> comparing biological first degree relatives, other biological relatives, and all unrelated donors (spouse + other) due to low frequencies in some groups.

\*\*\* p < .001, comparing European American to all other groups due to low frequencies in some groups.

**Table 2**

Characteristics of prospective donors enrolled in feasibility and acceptability evaluation of intervention.

Characteristic	No.
Gender	
Female	5
Male	3
Age, years	
20–29	3
30–39	1
40–49	2
50–59	2
Ethnicity	
European American	7
African American	1
Education	
High school	3
College	3
Post-graduate	2
Employment	
Full-time	7
Part-time	0
Unemployed	1
Marital status	
Married	5
Unmarried	3
Type of prospective donor	
Kidney, adult to adult (laparoscopic)	4
Liver, adult to adult (right lobe)	3
Liver, adult to child (left segment)	1
Relationship to recipient	
First degree relative	4
Biological relative, other family	3
Non-spouse, unrelated	1

**Table 3**

Ratings of acceptability and satisfaction with the intervention.

Client Satisfaction Questionnaire items	M (SD)
Program quality (1=poor, 4=excellent)	3.5 (0.5)
Kind of program others would want (1=no, definitely not, 4=yes, definitely)	3.6 (0.5)
Program met needs (1=none of needs were met; 4 = almost all needs were met)	3.2 (0.8)
Recommend program to others (1=no, definitely not, 4=yes, definitely)	3.6 (0.5)
Satisfied with help received from program (1=quite dissatisfied, 4=very satisfied)	3.3 (0.8)
Program helped me deal with my concerns (1=no, seemed to make things worse; 4=yes, helped a great deal)	3.3 (0.5)
Overall satisfaction with program (1=quite dissatisfied, 4=very satisfied)	3.5 (0.8)
If had it to do again, would participate in program (1=no, definitely not, 4 = yes, definitely)	3.8 (0.5)

**Table 4**

Study participants' responses to open-ended questions about their opinions of the intervention.

Features that participant:	Intervention Content	Intervention Structure and Procedures
Liked most	<ul style="list-style-type: none"> <li>• Was thought-provoking</li> <li>• Questions that I was asked were very well thought- out</li> <li>• Helped me think about what was important to me</li> <li>• Helped me look into my own persona; helped me to explain myself</li> <li>• Nice that it led me off my usual path of thinking to consider other things</li> <li>• Surprised at how much I was able to say —the level of honesty I spoke with; I viewed this as a conversation with myself</li> <li>• Gave me a chance to verbalize my thoughts and confirmed my decision</li> <li>• A supportive and confidential forum to share and vent my feelings about donation</li> <li>• Useful and helpful</li> </ul>	<ul style="list-style-type: none"> <li>• Very convenient to complete by phone</li> <li>• Convenient scheduling to accommodate my available time</li> <li>• Did not need to go anywhere; could be at home and complete it</li> <li>• Helpful that it required just 2 calls</li> <li>• Talking on the phone makes it easier to express true feelings than if face-to-face</li> <li>• Interventionist was very conscious of how people feel—seemed to be focused on understanding the donor's feelings and was not too pushy</li> </ul>
Liked least	<ul style="list-style-type: none"> <li>• Questions sometimes seemed redundant; like we had covered that ground already</li> </ul>	<ul style="list-style-type: none"> <li>• Hard to take the time to do it given everything else going on before donation</li> <li>• Hard to sit for so long on the phone without having interruptions from others at home</li> </ul>
Recommended to be changed	<ul style="list-style-type: none"> <li>• Emphasize a little more often that the conversation is confidential</li> <li>• Wish there had been more focus on things I could do to physically prepare for donation like exercise</li> </ul>	<ul style="list-style-type: none"> <li>• Make sure participants know they should be in a quiet place so they can focus on the conversation without distractions</li> </ul>