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Research on MI in Equipoise:

The Case of Living Organ Donation

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Abstract

Residual ambivalence prior to live organ donation has been shown to predict worse physical and psychological outcomes for the donor following surgery. We are studying whether MI can help individuals who have agreed to become living organ donors to resolve residual ambivalence about their decision. In this situation, ethical practice demands that the counselor take up a stance of equipoise, equally welcoming of strengthened resolve to donate or a decision not to do so. This paper describes our adaptations of MI for this unique application.

Keywords

motivational interviewing; equipoise; organ donation

The question raised by this symposium is whether or not motivational interviewing done from a position of equipoise is, in fact, MI. Well, my colleagues and I are embarked right now on a study in which we are doing, or so we believe, MI in equipoise. My intention in this paper, then, is to describe the context in which we are working, as well as the intervention we have developed, and ask you to consider this question: Are we, in fact, doing MI in equipoise?

THE CONTEXT OF THE INTERVENTION

Living Organ Donation

Living organ donation involves donation of a kidney, most typically, or more infrequently a part of the liver, to someone else who needs it. The impetus for the development of living organ donation several decades ago was the fact that there weren't enough deceased donor organs to go around; more people needed transplants than could be provided by people who had died. As it turns out, the outcomes from living organ donation are generally superior to those from deceased donor organs; people who receive a kidney or liver segment from a living donor survive longer after the transplant, are less likely to have rejected the organs, and more likely to have a high quality of life.

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But this procedure has raised a concern in the medical profession because it is a unique medical situation: the person donating the organ is undergoing major surgery, which has obvious risks no matter how well it's done. The donor is healthy and can receive no possible medical benefit from it, yet may potentially be harmed by it. The medical profession, of course, operates from the principle, "First, do no harm." So within the profession the question has repeatedly been raised: should living donation even be permitted, given that it may do harm to someone who is not otherwise at risk?

The answer to this question that has allowed living organ donation to continue is that the surgical risk to donors has become low (particularly for kidney donors), and most donors report positive outcomes from having been a donor. In the case of donors who are related to their recipients, the perceived costs of not being able to donate and knowing that the recipient will not survive may much higher than those associated with surgery. Dew and colleagues (2007) reported that more than 95% say that they would donate again if they were in the same situation, and 72% report positive feelings about themselves as a result of their donation. So there is a benefit received, though it is not a medical one: it is the benefit of feeling better about who they are. People who have donated often say that it is the most meaningful thing they've ever done in their lives, knowing that they have given the gift of life to someone else. And in general they do not appear to suffer any harm: when asked about their perceptions of their physical functioning, their psychological well-being, and their social well-being, they report average levels equivalent to the general population or better.

So it appears that donors, as a group, are not suffering and are reporting benefits from having done so. However, a minority of donors do report negative outcomes: 24% across multiple studies report significant psychological distress in the aftermath of their donations, 12% report that their health is worse, and 25% worry about their health in the present and future (after all, if you've given up a kidney, you have only one kidney left), and 23% report financial distress.

Given that a minority of living donors does report negative outcomes, the profession has begun to ask, What can we do to predict who is likely to experience those negative outcomes? And, once we can predict those outcomes, how do we prevent them—don't we have an obligation to do what we can for these generous people to prevent them from suffering from their generosity?

To understand the negative outcomes it's important to think about how a person actually makes the decision to donate an organ. As the pioneering researcher Roberta Simmons (Simmons, Marine, & Simmons, 1987) described, this is a major, high-stakes life decision. It is irreversible: once you've donated an organ, you cannot go back. The outcome of the decision is not assured; the person to whom you donate may not live, and their body may reject the organ; your medical safety is likely, but not guaranteed. It affects the donor's most central relationships: if I'm donating to a family member or loved one I'm giving something to that person that that person can never reciprocate, but if I choose not to donate that obviously affects the relationship as well; my decision also affects the other people in my family to whom I'm not donating, since I am now potentially medically compromised. It's a decision made in crisis, and there is often little time to make it. It is a decision of a type that is unfamiliar, for which there are no clear norms. And of course it is an altruistic decision: I gain nothing from doing this other than whatever I gain from helping someone else.

The Donor's Ambivalence

And so it shouldn't be surprising, as Simmons also pointed out, if we find a fair amount of pre-donation ambivalence in people who are making the decision about donating an organ.

There is fear of the surgery itself, fear of the recovery period (the pain, but also the financial effects of being unable to work for a period of time and of being unable to meet family obligations to children or spouse), and worry about the long-term health effects. There may be family pressure involved in making a decision like this: it could be an overt demand—the family comes to one of its members and says, You should donate your organ so your father or brother or sister or a child can live—but it may be a more subtle or indirect pressure, as when someone says, I'm going to die if I don't get an organ donated to me and nobody has stepped forward yet. Sometimes there's a perception that I'm obligated to donate, that my family would want me to do this whether or not I would want to. And there's also the phenomenon of "black sheep" donors, people who donate because they are alienated from their family and hope that if they do this thing, their family will finally forgive them and they will finally get the love that they were looking for. And finally, there may also be ambivalence around the recipient: not just the question of whether this person will live, so that my sacrifice will be meaningful, but also, How do I feel about the recipient taking this gift from me? Donors often have questions about what the recipient is going to do with this gift, and may have concerns about how they will feel if the recipient doesn't treat the gift with the specialness the donor thinks they ought to.

Interestingly, Simmons and colleagues' (1987) research showed that for a large proportion of donors none of these factors played any role. The choice was instantaneous and there was no deliberation: people say things like, I didn't think about it; as soon as I knew the person needed it I knew I was going to donate. On the other hand, for others there is a process of deliberation: collecting relevant information, identifying and evaluating the pros and cons of donating, and finally making and implementing a decision. And there's a small group who actually seem to postpone the decision all together, who never feel as though they made a decision even though they are on track toward donating an organ. And what they say is that they started on that journey and they never exactly decided to do it but the process just sort of carried them along, and at some point they felt like that they had to go through with it even though they themselves never really decided if this is what they wanted to do.

So a significant number of living donors report pre-donation ambivalence, and Simmons went beyond describing this ambivalence: she developed a reliable way to measure it. The Simmons Ambivalence Scale (SAS) is comprised of seven items, rated on a scale from 0–3:

- How hard a decision was it for you to donate?
- Did you know right away that you would do it or did you think it over?
- Many donors have doubts and worries going into transplant operation, even though they go through with it. Did you ever have doubts about donating?
- How would you have felt if you found out that you couldn't donate for some reason?
- How strongly do you agree or disagree with the statement "I sometimes feel unsure of not donating."?
- How strongly do you agree or disagree with the statement "I sometimes wish the transplant patient would get a cadaver organ instead of one from me."?
- How strongly do you agree of disagree with the statement "I would really want to donate myself even if someone else could do it."?

It turns out that the answers to these seven questions, which when given after the donor has agreed to donate assess what we have come to refer to as *residual ambivalence*—ambivalence after having agreed to donate that coexists with the donor's intention to donate—is the only consistent predictor of risk for poor psychosocial outcomes after donation. The

variables one might expect to predict negative reactions to donation—from demographics to psychological distress to type of surgery to outcome for the recipient—are not informative.

Now acute ambivalence—ambivalence before the development of any clear intention to donate—rules people out of donation. Someone who is that uncertain about whether or not they want to continue down the path toward donation surgery is disqualified for their own protection. The people we are discussing intend to donate yet they have continuing uncertainty co-existing with that intention. Simmons and colleagues (1977) first identified a correlation between pre-donation ambivalence in 130 pre-surgery kidney donors and negative attitudes about donation one year after the surgery ($r = .31$, $p = .001$). Switzer, Simmons, and Dew (1996) found in a sample of 343 anonymous bone marrow donors that residual ambivalence was common (positive SAS items > 0 in 62%, positive SAS items ≥ 5 in 12%) and that residual ambivalence alone predicted physical difficulty with donation and negative psychological reactions post-surgery and at one year post-donation (controlling for post-surgery reactions) in 251 of these donors who were able to be assessed at follow-up.

THE INTERVENTION

On the basis of these findings, Dew was inspired to seek to develop a pre-surgery intervention that could prevent negative outcomes by resolving residual ambivalence in living donors. This led her to motivational interviewing and to a collaboration with Zuckoff in order to develop and test such an intervention.

And this is an application of MI that, we hold, absolutely requires equipoise in the counselor as he or she enters the encounter with the client. It must be equally acceptable to the counselor that the potential donor (PD) either recommits to donating and becomes certain that is what he or she wants to do or decides not to donate. Any intent on the counselor's part to tip the client one way or the other would clearly be unethical. Instead, the outcome we are seeking is a reduction in ambivalence, regardless of the direction in which the ambivalence is resolved.

We developed a two-session intervention provided over the telephone in sessions of 30–45 minutes each. The sessions take place after the PD has been medically and psychologically cleared to donate following extensive evaluation. Session 1 begins with structuring that emphasizes confidentiality (i.e., that neither the recipient, the family, nor the transplant team will have access to any of what is discussed and that the conversations will have no impact on whether or not the PD will be permitted to donate), the goal of helping the PD feel at peace or more settled with the decision (whatever that decision is), and the PD's personal choice and control. The counselor asks about the story of the decision to donate, how the PD came to be at this place, and we listen for, reflect and explore desire, ability, reasons, and need for donating (change talk) as well as for not donating (sustain talk). The results of the SAS are used to provide feedback, exploring any of the items that the person endorsed. And the session ends with a planning process, which may involve concrete problem-solving for what needs to happen next for the PD to address his or her lingering doubts or concerns, or a more cognitive process of how to shift perspectives and come to terms with the decision the PD has made.

But what's critical from the standpoint of equipoise is that there are three pathways through the session. If it emerges that the PD has truly *residual* ambivalence—that is, the PD wants to donate, intends to donate, believes it's right for him or her, but has lingering doubts or fears and thus feels unsettled—then the counselor steps out of equipoise and does motivational interviewing as it is normally done, helping the PD move toward a full commitment to the decision he or she has already made and wishes to carry out. On the other hand, if it emerges that the PD is leaning away from donating, or has had a change of

heart, then the counselor will do motivational interviewing to help the PD move toward full commitment not to donate, to carry out his or her preferred decision and feel settled and at peace with it. And if the PD were to show *acute* ambivalence, being genuinely uncertain, then the counselor would maintain equipoise and do a decisional balance discussion, as described in "When Motivational Interviewing Is Non-directive" in the second edition of *Motivational interviewing* (Miller & Rollnick, 2002), exploring both sides of the ambivalence without trying to tip the balance one way or the other.

In session 2 the counselor reviews the plan and any progress that's been made. The plan may have been a residual ambivalence plan for the PD to get the information needed to feel less anxious or more settled—for example, plans have included the PD speaking with the surgeon about unanswered questions, talking with a family member about a lingering concern, or talking to somebody who's been through donation to reduce the sense of going into the unknown. In contrast, a change of heart plan might focus on how the PD will take the steps necessary to get off the donation path that he or she is on. Whatever the plan was, the counselor invites the PD to discuss how the plan went, whether or in what ways it worked, and helps the PD revise the plan if needed. The counselor then guides the PD through a values card sort (having mailed the cards to the PD prior to the session), with the intent to evoke and explore the PD's core values and how a decision to donate or not to donate fits with those values. The session ends with further planning for what the PD will do in the immediate and post-surgery future, a look ahead to where the PD hopes to be with in the aftermath of whatever decision he or she has made, and affirmation of the PD's courage in carrying out that decision.

LOOKING FORWARD

At the time of this writing our research team, having completed a small number of intervention development cases, is conducting a randomized controlled pilot study comparing the two phone sessions of MI with either two sessions of healthy lifestyle education by telephone or with "usual care" provided by the Living Donor Transplant Program (no telephone sessions of any kind). We will be following up participants at six weeks, three months, and six months to see whether MI does differentially reduce ambivalence on the SAS, and reduce the frequency of negative outcomes. But my question to you now, on the basis of what I have just described, is: MI in equipoise—oxymoron or new frontier?

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