



Analysis

Providing Level-of-Match Information to Perfectly Matched Unrelated Stem Cell Donors: Evaluating Acceptability and Potential Changes in Donor Availability



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Article history:

Received 1 March 2018

Accepted 16 March 2018

Key Words:

Unrelated HSC donation

High-priority donors

Donor messaging

A B S T R A C T

Patients with blood-related diseases often cannot identify a matched related donor and must seek donors in unrelated donor registries. These registries face the challenge of ensuring that potential donors are available when contacted. Donor attrition is especially problematic when there is only a single perfectly matched potential donor. One way to improve donor availability might be to present perfectly matched donors (high-priority donors [HPDs]) with more precise information about their match status. This project evaluated the impact of providing such information to HPDs at the National Marrow Donor Program (NMDP)/Be The Match. Objectives were to determine the acceptability of the new messaging to both HPDs and the donor contact representatives (DCRs) who delivered the message, consistency of message delivery, and whether the new messaging was associated with improved donor availability. Mixed methods were used to collect telephone interview data from HPDs, matched samples of non-HPDs, and DCRs. Donor availability data came from NMDP records. Key findings were as follows: (1) the HPD message was acceptable to potential donors and did not seem to produce undue pressure, (2) the message was acceptable to DCRs who became more comfortable and consistent in delivering the message over time, but (3) the new messaging did not significantly increase availability. Despite the lack of evidence for increased availability, there may be ethical benefits and little harm to providing well-matched donors with more information about their degree of matching. Research should examine stronger match status messages and delivery of new messaging to additional highly-matched donor groups.

Published by Elsevier Inc. on behalf of American Society for Blood and Marrow Transplantation.

INTRODUCTION

Since the early 1990s unrelated hematopoietic stem cell (HSC) donors have been a major and increasingly used

source of transplanted stem cells for the treatment of patients with leukemia and other blood-related diseases [1,2]. The difficulty that patients often have in identifying an HLA-matched biologically related donor and the demonstrated clinical effectiveness of unrelated HSC transplants have led to the development of large international registries of unrelated HSC donors. The National Marrow Donor Program (NMDP)/Be The Match is the largest such registry and currently lists more than 19 million unrelated donors

Financial disclosure: See Acknowledgments on page 2117.

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who are HLA typed and have indicated initial willingness to donate HSCs to an unrelated patient [3–5].

One challenge faced by the NMDP and other registries is to ensure that potential donors who preliminarily match a patient are available to donate when contacted [6,7]. Attrition rates among potential donors can be as high 60% depending on the registry and the potential donor's sociodemographic characteristics. High attrition rates are less problematic when several matched donors are identified for a particular patient. However, for a significant number of patients, there is only a single perfectly matched potential donor. For this investigation a perfect match was defined as a 10/10 HLA match—we refer to this group of donors as high-priority donors (HPDs).

Currently, all NMDP potential donors receive the same, relatively nonspecific message about their HLA matching status when they are contacted about matching a patient. An option for improving availability among HPDs would be to refine the message to more specifically communicate that the potential donor is the only known perfect match for the patient. It is unknown whether a change in messaging would be acceptable to donors and the donor contact representatives (DCRs) who deliver the message or whether a modified message would affect availability rates among HPDs. The specific goals of this investigation were to (1) examine HPDs personal and donation-related characteristics and impressions of the messaging, (2) examine DCRs' reactions to delivering the new HPD messaging, (3) determine whether DCRs could deliver the new HPD messaging consistently, and (4) determine whether the new messaging was associated with higher rates of donor availability.

METHODS

Human Subjects Research Protection

The study protocol was approved by Institutional Review Boards at the NMDP, University of Pittsburgh, and the Johns Hopkins University. All participants completed verbal consent by phone before completing study interviews. Both consent and interview were audio-recorded with the participants' knowledge.

Study Design

The study involved 2 quasi-experimental components: (1) primary mixed-methods data collection from potential donors and DCRs that compared HPDs receiving a new message and non-HPDs receiving a standard message and (2) examination of data routinely collected by the NMDP to determine whether donor availability rates differed between HPDs and non-HPDs during the time periods before, during, and after the implementation of the new messaging. These components are described separately in the following sections.

The primary data collection component involved interviews with HPDs and matched non-HPDs shortly after they were contacted by a DCR about matching a patient (study goal 1), interviews with DCRs who completed at least 1 call using the new HPD messaging (study goal 2), and recordings of DCR calls to examine consistency of message delivery (study goal 3). The NMDP database component analyzed and compared donor availability and donor and patient characteristics for all potential donors (HPDs and non-HPDs) from 3 periods: 4 months before implementing the new messaging, during the implementation of the new messaging, and 4 months after the implementation of the new messaging (study goal 4).

Primary Data: Mixed-Methods Component

Donor and DCR participants

Participants in the HPD group were NMDP (US) registry members identified as the only 10/10 HLA match for a patient between September 4, 2015 and September 2, 2016 who were requested by a transplant center for a specific patient, were contacted to discuss their potential status as a donor, and spoke English. During the primary data collection period all HPDs received the new message about their match status. Potential participants were excluded if they did not have telephone access. A comparison group of non-HPDs contacted to donate during the same study period was identified, and they all received the standard NMDP messaging in use at the time of this study. Members of the comparison group were matched to the HPDs based on age (± 2 years), ethnicity/race, sex, whether they had been contacted (and if so, whether they responded or not) by the NMDP to assess commitment to

donation previously ("presearch"), stage in the donation process, and decision whether to proceed as a potential donor. Our goal was to enroll 2 non-HPD comparisons matched to each HPD. All DCRs who made at least 1 call to an HPD during the study were interviewed about the experience after their first 3 HPD calls and again at the end of the study. DCRs who completed < 3 calls total were interviewed only at the end of the study period.

Procedures

HPDs received the new message about match status and non-HPDs continued to receive the standard message.

HPD messaging. We considered several ethical issues in determining how to modify the message to be delivered to HPDs about their match status. These issues included potential effects on donor autonomy and emotional well-being. Our primary concern was that knowledge of being the only perfect match for a patient might influence a potential donor to proceed with donation despite reservations. In crafting the HPD messaging, we sought to avoid using language that would exert undue pressure [8]. DCRs at the NMDP were trained to deliver the HPD messaging. They contacted potential HPDs by phone at the usual predonation time points and incorporated HPD messaging into their existing script guides. Specifically, DCRs informed the HPDs as follows: "Based on the information we currently have, you are in the unique position of likely being a perfect match for this patient." If the responses to the subsequently administered health history questionnaire indicated that the donor was still eligible to donate, a second message was delivered: "You are the only perfect match for this patient. Because it is highly likely you will be selected for donation should the patient proceed, it is very important you consider continuing with the donation process."

Comparison group messaging. Non-HPD comparisons received the following standard message: "The patient's transplant center has determined that you are a match for the patient." DCRs delivered this message near the beginning of the call.

After DCR contact with the potential donor and the delivery of the new or standard messaging, potential donors who agreed to release contact information for the research study were contacted by an interviewer at the University of Pittsburgh. The interviewer described the study and answered any questions before obtaining consent. Single 20-minute qualitative/quantitative interviews were conducted by phone either immediately after consent or scheduled for another convenient day and time, and participants received a \$30 honorarium. DCRs participated in 1 or 2 qualitative/quantitative interviews based on the number of HPD calls they completed: an interview after the first 3 HPD calls to allow them to gain comfort with the message and again at the end of the study regardless of the number of calls completed to ensure that we had a similar cross-sectional time point for all DCRs.

Study measures

HPDs and non-HPDs. The following closed-ended items were administered. All have been used extensively in our previous research with HSC registry members [6,7,9–12]. For sociodemographics, standard characteristics were collected as well as whether the participant had donated blood/plasma or money/time in the past year. Context for joining the registry was assessed with items assessing both situational (eg, drive for a specific patient) and locational (eg, at college or university) contexts. Four yes or no items asked about the most recent call from the DCR including if they remembered joining, knew why they were being contacted, had spoken with that staff person in the past, and had all of their questions answered by the staff member. Donation-related variables included 3 yes or no items about interactions with others including whether the participant discussed donation with someone before making their decision to continue with the donation process and if anyone encouraged or discouraged joining the registry or donating. Ambivalence about donating was measured with a 7-item scale [12,13]. Each item had 4 response categories, and responses to items were averaged to create a scale score. A higher score indicated greater ambivalence, for example, "How hard of a decision was it for you to decide whether to donate?" (1 = not at all hard, 4 = very hard). Open-ended questions included questions about motives for joining the registry and their conversation with the DCR including what they remembered from the call, how they felt when they were told they were a match, their impression of the person who contacted them, and whether they were told anything about the patient, including how well they matched. HPDs were specifically asked how they felt when they were told they were the only perfect match.

Donor contact representatives. Closed-ended items encompassed sociodemographic and employment characteristics, including months of employment at the NMDP and months of making calls to potential donors. DCRs were also asked a series of questions about the HPD calls, including their overall satisfaction with the new messaging, satisfaction with the message wording, comfort in delivering the message, perceived favorability of the potential donor's reactions, beliefs about whether the messaging would lead

to greater availability, and whether they believed the messaging caused undue pressure on the potential donor. These items were assessed on 5-point response scales (eg, very satisfied to very dissatisfied; strongly agree to strongly disagree). Open-ended questions included what DCRs liked or disliked about the new messaging and whether they believed the new messaging would affect potential donors' decisions.

DCR message delivery consistency was assessed as the ability of the DCR to deliver the HPD message in a way that was consistent with the scripted message in the transcripts of donor contact calls. This was coded as a binary variable by a member of the research team, who determined whether the message delivered matched the messaging script at both points in the donor conversation (before and after the HHQ).

NMDP Database Component

The NMDP provided donor and patient characteristic data and donor availability data (defined below) for all HPDs and non-HPDs before (May 21, 2015 to September 3, 2015), during (September 4, 2015 to September 2, 2016), and after (September 3, 2016 to December 31, 2016) implementation of the new messaging. The “before” and “after” periods were combined and compared with the “during” period for analysis. HPDs and non-HPDs belonged to 4 mutually exclusive groups depending on their HPD status and the period in which they were contacted: (1) HPDs during the new messaging period, (2) HPDs during the standard messaging periods, (3) non-HPDs during the new messaging period, and (4) non-HPDs during the standard messaging periods. We were interested in 2 categories of potential donors: “available” (potential donor agreed to move forward toward donation when contacted) and “not available,” which included “not interested” (potential donor is not interested in continuing as a potential donor) and “temporarily unavailable” (potential donor is unable to consider donation because of personal or medical reasons). We excluded donors who could not be contacted.

Data Management and Analysis

For the primary data collection component, closed-ended interview responses were entered directly into the data collection software Qualtrics (Qualtrics, Provo, UT) as interviews were conducted. HPD versus non-HPD comparisons for interview data were made using test statistics appropriate for the level of measurement (chi-squared, *t*-test, or Fisher's exact tests). De-identified open-ended responses were transcribed from the recordings and downloaded for qualitative analysis using NVivo software (NVivo for Mac) [14] and coded by one of the authors (R.F.) using an iterative emerging thematic coding scheme. We use “very common” to refer to themes present in more than 50% of responses, “common” for 25% to 50%, “less common” for 10% to 25%, and “uncommon” for <10%.

For the NMDP database component, donor availability data were received from the NMDP and analyzed using difference-in-differences linear regression models with the statistical software package Stata (Stata 14) [15]. The difference-in-differences model evaluates the effects of changes in variables

in quasi-experimental studies where randomization is not performed and assumes that differential changes in donor availability between HPDs and non-HPDs during the new messaging period—compared with before and after it—are attributable to the new messaging after controlling for relevant donor and patient recipient characteristics [16–18]. We estimated 3 specifications of the model: without control subjects, with control subjects for donor characteristics, and with control subjects for donor characteristics and patient characteristics known to the donor at the time of the NMDP request.

RESULTS

Primary Data: Mixed-Methods Component

HPDs and non-HPDs

Of the 98 unique HPDs who received the messaging and were eligible to participate in study component 1, 63 (64%) consented and were interviewed (Figure 1). HPDs who participated in the interview portion of the study did not differ from nonparticipants on gender, age, race, or presearch status. One hundred eight (58%) of the 185 eligible matched control subjects consented and were interviewed. Forty-seven of the HPDs had 2 matched control subjects interviewed, 11 had a single match, and 4 HPDs did not have a matched control subject. Nearly all participants who consented to be interviewed (97%) were available for donation when contacted by the NMDP. HPDs, and non-HPDs were treated as independent samples because there was no evidence based on an analysis of the Ambivalence scale—known to be associated with availability—that individuals in matched pairs or triplets were more similar to each other than they were to other individuals in the sample.

Quantitative results. As expected given the matching procedure, HPDs did not differ statistically from non-HPDs on any sociodemographic characteristics (Table 1). HPDs and non-HPDs were also similar on all other variables, with the exceptions that HPDs were significantly less likely to have previously spoken with the DCR who informed them about their match status ($\chi^2 = 5.92$; $P = .018$) and more likely to have been discouraged from donating by someone ($\chi^2 = 4.05$; $P = .044$).

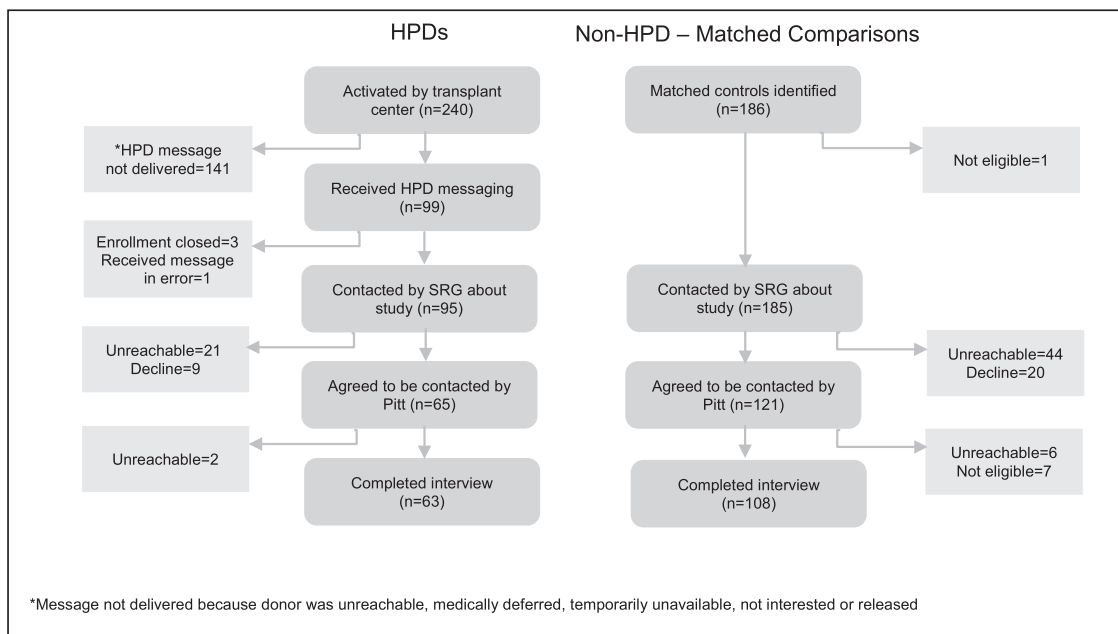


Figure 1. Sampling flowchart for study component 1, mixed-methods investigation.

Table 1
HPD and Non-HPD Comparisons for Study Component 1: Quantitative Findings

Characteristics	HPD (n = 63)	Non-HPD (n = 108)	χ^2 or t-test*	P
Age, mean (SD); range, 19–60	38.43 (11.11)	38.32 (11.09)	.06	.951
Sex, % female (n)	67 (42)	60 (65)	.71	.398
Education, % \geq bachelors (n)	57 (36)	62 (67)	.40	.528
Employment, % employed (n)	92 (58)	94 (101)	—	.762
Relationship status, % married/partnered (n)	51 (32)	65 (70)	7.25	.203
Children, % with children (n)	56 (35)	60 (65)	.35	.553
Race/ethnicity, % (n)			—	.688
African American	14 (9)	11 (12)		
Asian or Pacific Islander	13 (8)	14 (15)		
Hispanic or Latino	10 (6)	7 (8)		
Mixed or Multiple	5 (3)	3 (3)		
White	57 (36)	65 (70)		
Blood donor, % blood/plasma donor (n)	76 (48)	74 (80)	.10	.758
Other donor, % donated money/time in past year (n)	73 (46)	84 (91)	3.16	.076
Joining and matching				
Context for joining, (check all that apply) % (n)				
Blood drive or blood donation center	27 (17)	19 (20)	1.68	.195
Workplace	10 (6)	15 (16)	.99	.319
Church, synagogue, or mosque	8 (5)	15 (16)	—	.232
Marrow drive in community	29 (18)	32 (35)	.27	.601
College or university	24 (15)	26 (28)	.10	.758
Drive for a specific patient	19 (12)	24 (26)	.58	.446
Drive for a specific ethnic group	11 (7)	7 (7)	1.14	.287
Online	8 (5)	15 (16)	—	.232
When contacted about being a match... % (n)				
Remembered joining the registry	95 (60)	93 (99)	—	.748
Knew right away why being contacted	86 (54)	79 (85)	1.29	.312
Spoke with that staff person before	2 (1)	13 (13)	—	.018
Staff member answered all questions	98 (62)	99 (107)	—	1.00
Donation-related behaviors and feelings, % (n)				
Needed to discuss donation with others	32 (20)	39 (42)	.88	.349
Encouraged to join/donate	41 (26)	42 (45)	.01	.920
Discouraged from joining/donating	40 (25)	25 (27)	4.05	.044
Ambivalence, mean (SD); range, 1–4	1.53 (.50)	1.54 (.52)	-.05	.962

* Dashes in a cell indicate that Fisher's exact test was performed.

Qualitative results.

Reaction to “only perfect match”. When HPDs were asked how they felt when learning they were the only perfect match, 2 common themes emerged: they felt *happy/excited* or *surprised/skeptical* (Table 2). A less common response was feeling *nervous/scared/overwhelmed*. This response—often qualified with other emotions like surprise or happiness—tended to focus on what failure to donate could mean for the patient. Others noted that knowledge that they were a perfect match impacted their decision, and a smaller subset indicated they felt pressured by the messaging, although they did not necessarily perceive the pressure as negative. Finally, it is noteworthy that some donors (10% to 25%) did not recall being told they were the only perfect match for a patient.

Ability to make donation decision without pressure. The overwhelming majority of potential donors indicated they were able to make the donation decision without pressure from others. An uncommon theme in response to this question was that a few donors believed they could make whatever choice they wanted but also suggested they felt *internal pressure*. Despite a few indications of self-motivated pressure, however, most respondents indicated that they felt no pressure at all.

Feelings about decision to donate. A common theme that emerged in response to the question about decision-making was that many potential donors believed it was *not a decision*

at all—their choice was already made. An uncommon response was that the donor *needed time to think* about the decision and speak with family members or friends. Another common response to this question was to restate emotions discussed earlier, including feeling *happy/excited*, *surprised/skeptical*, and *nervous/scared/overwhelmed*.

Donor contact representatives

Quantitative results. All eligible DCRs participated in the study and completed at least 1 interview. By design, the 16 DCRs who completed ≥ 3 HPD calls completed both study interviews and the 7 who completed < 3 HPD completed 1 study interview. Participating DCRs were on average 38 years old (range, 24 to 60), women (87%), white (61%), had worked at the NMDP for 5 years (interquartile range, 8 to 106 months), and had been making calls to potential donors for a similar period (interquartile range, 18 to 84 months). DCRs who made ≥ 3 HPD calls (n = 16) did not differ in magnitude from those who made fewer than 3 HPD calls (n = 7) on any of these characteristics. Responses from DCRs who were interviewed twice also did not differ from first to second interview.

Most DCRs were mostly/very satisfied with the overall messaging (74%) and the specific wording of the message (74%). Additionally, most were mostly/very comfortable delivering the message (65%), believed HPDs' reactions to the messaging were positive (52%), believed the messaging would lead to higher donation rates (92%), and believed the messaging did not cause undue pressure to donate (82%).

Table 2
HPD Interview in Study Component 1: Qualitative Findings

Theme	Example Response	Frequency*
Q1: How did you feel when you were told you were the only perfect match? (HPD only)		
Happy/excited	I already knew that I was going to do it, but just knowing that I was the only perfect match well it was kind of cool. . . Being able to be the only person to help someone, I signed up and I can do it. I was excited. (HPD 60)	Common
Surprised/skeptical	Surprised because I remember when my family friend was going through it, that it seemed like it was pretty rare to have that happen. . . So to hear I was the only match that was a perfect match was pretty incredible. (HPD 8)	Common
Scared/nervous/overwhelmed	The emotions that run through you are just, they're, they're crazy, you know. They're kind of all over the feeling chart if you would. You're excited, you're nervous, scared. . . just so many emotions. (HPD 124)	Less common
Did not remember that	I don't think it was conveyed. [Because] I probably would have taken a little bit more time then to think about it, if I was told that I was "the only perfect match" for this person. Yeah, I don't think I was told that. (HPD 128)	Less common
Committed/affected decision	It's either whether I want to say "yes" and save someone's life or "no", watch someone die. So it's a pretty simple answer that I don't think I would, knowing the fact that I'm the only one, . . . not pitch in and help. (HPD 35)	Less common
Pressured	Well that put a little pressure, you know what I mean? Just like okay, this is somebody's life we have and for me to be the only match it would be ah. . . It was kind of like a little pressure, but it's good to know and you know you just want, I wanted to be able to accommodate. (HPD 157)	Uncommon
Q2: Did you feel like you could make whatever choice or decision you wanted without pressure from others?		
Yes	Oh absolutely. There was no pressure. . . I felt that they were very concerned about my well-being just as much as the recipient's. (HPD 103)	Very common
Internal pressure	I felt like . . . I would think back after . . . I made the decision not to and feel a lot regret about that. So the pressure came from myself, and not from others. (HPD 106)	Uncommon
Q3: When you were told that you possibly matched a patient, how did you feel about your decision of whether or not to donate?		
Not a decision	Well for me, it was no decision at all. Actually, in fact, the woman asked me, "Do you need time to think about it?" and I said, no, I mean, for me, nurse or not, if I can make, a difference in somebody's life, what is there to think about. (HPD 49)	Common
Needed time to think	My gut reaction was to proceed but I really felt strongly that I needed to talk to the people that I love and care about to make sure that everybody was comfortable with it because it's not super high-risk, but certainly there are risks involved. (HPD 118)	Uncommon

* Very common $\geq 50\%$; common 25%–50%; less common 10%–25%; uncommon $\leq 10\%$.

Qualitative results.

Positive aspects of the messaging. Two common themes emerged, including that the messaging *makes the situation feel concrete* and that it *provides more information* to prospective donors (Table 3). The idea that prospective donors would make a better decision if the situation felt concrete to them was viewed in a positive light by several of the DCRs, as was the fact that the messaging provided more information.

Concerns about the messaging. The most common response to this domain of questioning was that DCRs had *no concerns* with the messaging. When concerns were expressed, they included the potential that the messaging could *add pressure* on donors to move forward, that it was *uncomfortable to deliver*, and that the wording was *awkward/inconsistent/misleading*. Some DCRs who were concerned about added pressure worried that it might rush a donor into making a decision he or she might not be comfortable with, whereas other DCRs responded that they had initially worried about this but ultimately believed it *did not add pressure*. Some DCRs also believed the messaging itself was not worded as clearly as it could be, which made it *awkward to deliver* and potentially *confusing or misleading* to donors.

Impact on donor decisions. Although it was very common for DCRs to respond that the messaging would have impact, not all agreed that it would be positive. Some DCRs indicated they believed it would only make a difference for donors who were truly undecided about whether to donate. Some DCRs believed the HPD messaging would lead otherwise undecided donors to move forward; other DCRs worried that the

messaging might cause a potential donor who is "on the fence" to back out. Some DCRs also worried that the messaging would not affect donor decisions because donors did not notice it or that it would not make a difference because donors generally know what their decision will be regardless of whether or not they are the only perfect match.

Consistency of message delivery. DCR delivery accuracy improved over time—message delivery was accurate 72% of the time during the first quarter of the study period and nearly 90% in subsequent periods. A very common theme that emerged when DCRs were asked about their ability to deliver the message consistently was that DCRs used the script or notes to help them convey the messages accurately. Others suggested that training and practice were helpful, which may help explain why delivery improved over time.

NMDP Database Component

HPDs during the new messaging period ($n=98$), HPDs during the standard messaging periods ($n=62$), non-HPDs during the new messaging period ($n=17,850$), and non-HPDs during the standard messaging periods ($n=11,219$) were included. Table 4 shows donor and patient characteristics and availability rates separately for HPDs and non-HPDs during the standard and new messaging periods. The characteristics of non-HPDs during the standard and new messaging periods are very similar (although in some cases, due to the large sample sizes in the non-HPD group, even quantitatively small differences attain statistical significance). Importantly, non-HPDs have virtually identical availability rates in the standard and new

Table 3
DCR Interview in Study Component 1: Qualitative Findings

Theme	Example Response	Frequency*
Q1: What things do you like about the messaging?		
More concrete	I think it gives them a good grasp on how good of a match they really are and it kinda gives them a little bit more of a concrete, something concrete that they're like the perfect match essentially, so I think that they respond very positively to it because of that. (DCR 10)	Common
More information	I can see that with certain donors. . . that information would have been very helpful to them as far as making a decision or not. Cause sometimes we'll have donors who say, "Well if I'm the only one, then I'll go forward." (DCR 8)	Common
Q2: Are there things that concern you about the messaging?		
Pressure	I do think it actually puts pressure on them. And to me, I just think that's not fair because if I find out I'm going to be the only match and I go through it and find out I'm not the best match for this person, then I'm going to worry that "is person going to find someone?" (DCR 11)	Common
[Does not add pressure]	I was concerned that maybe donors would feel pressured and have negative reactions to the messaging, but I didn't experience that at all. (DCR 7)	Less common
Uncomfortable to deliver	I'm a bit uncomfortable relaying the message to them if they're already having anxiety from being a possible match. . . To tell them that they are the best perfect match, then that might just kinda throw them into having that paper bag and needing to breathe in and out of that. (DCR 3)	Common
Awkward	I think the main thing that concerns me, I mean, just not it being in my own words is probably the hardest thing about it. I mean, I can fit it in a conversation easily enough, especially with practice it's definitely gotten a lot easier. (DCR 12)	Common
Inconsistent/misleading	It doesn't flow properly just because there are three different messages that we do have to relay to them and it doesn't go quite smoothly over the phone. Just because first we tell them that they're likely to be a perfect match. And then afterwards we say, you are the only match so I think it's just a mixed messaging that I don't like. (DCR 13)	Less common
Q3: Do you think the messaging will make a difference in donor decisions?		
Yes	Yes, I do. Again I think it is about giving them as much information and education as we can up front, so they can make that determination now, as opposed to later. (DCR 22)	Very common
No	I don't think so just because donors who usually say yes and they more forward to testing, they are usually interested so whether they're "the perfect match" or don't know if they're the perfect match yet, I think if they have that commitment in mind then they will move forward no matter what. (DCR 13)	Uncommon
For fence-sitters	With someone that's probably a little more on the fence, I do think that might sway them to say, Okay, this is, kind of scares me a little bit, but if I'm the only person that can save this other person's life then I will do it. (DCR 12)	Common

* Very common $\geq 50\%$; common 25%-50%; less common 10%-25%; uncommon $\leq 10\%$.

periods (68% versus 67%; $\chi^2 = 2.72$, $P = .099$). HPD donors during the new messaging period do not differ statistically from HPDs during the standard messaging period, with the exceptions that HPDs were more likely to be contacted at the workup stage during the new messaging period (23% versus 0%; $\chi^2 = 16.66$, $P < .001$). HPD availability was slightly lower during the new messaging period than during the standard messaging period (82% versus 87%; $\chi^2 = .83$, $P = .361$).

When we compared HPDs with non-HPDs we observed that the 2 groups present statistically significant differences on several dimensions, including sex ($\chi^2 = 17.14$, $P < .001$), age ($\chi^2 = 12.24$, $P = .002$), HLA commonality ($\chi^2 = 154.06$, $P < .001$), presearch status ($\chi^2 = 17.92$, $P < .001$), stage contacted ($\chi^2 = 713.41$, $P < .001$), and availability to continue with the donation process ($\chi^2 = 19.08$, $P < .001$).

Table 5 shows our differences-in-differences estimates, measuring the percentage-point change in donor availability associated with the new messaging. The top portion of the table includes the full sample, whereas the bottom portion excludes donors who were temporarily unavailable. The first column shows unadjusted results, the second column reports regression estimates controlling for donor characteristics, and the final column reports results from linear regressions that in addition to donor characteristics also controls for patient characteristics (potential donors are told the gender, age, and disease of the patient for whom they are a match). The results deliver a consistent message across model specifications and samples: The new messaging did not have a statistically significant effect on donor availability. The estimated coefficients from the regressions that include donor and patient

characteristics are small in magnitude (ranging from -1.1 to 3.9 percentage points), and none of the estimates is statistically significant.

DISCUSSION

The overarching goals of this investigation were to examine personal and donation-related characteristics of HPDs and non-HPDs and HPDs impressions of the messaging to determine whether delivering specific messaging about their status as the only perfect match for a patient would be acceptable to donors and to individuals delivering the message and whether the new messaging would result in higher donor availability. Interviews with donors and DCRs and availability data from the NMDP were used to address these questions.

Our first key finding was that the HPD message appeared to be acceptable to potential donors and did not seem to produce undue pressure. Although potential donors reported a variety of feelings about being told they were the only perfect match, the most common were being excited, happy, and/or surprised by this information. Most HPDs reported that the messaging did not cause them to feel undue pressure to donate, and when feelings of pressure were reported, they tended to be a result of self-imposed pressure/expectations internal feelings rather than because of the message. The fact that potential donors did not feel disturbed or pressured by the HPD messaging is critical and seems to indicate that providing more specific information about match status is acceptable from both ethical and practical perspectives. However, a common

Table 4
HPD/non-HPD and Patient Characteristics: NMDP Database, Study Component 2

	HPD Standard Message Period*	HPD New Message Period	χ^2 (P)	Non-HPD Standard Message Period	Non-HPD New Message Period	HPD vs. Non-HPD [†]	
	(n = 62)	(n = 98)		(n = 11,216)	(n = 17,575)	χ^2 (P)	χ^2 (P)
Donor characteristics							
Female, % (n)	58 (36)	66 (65)	1.11 (.291)	47 (5222)	47 (8,237)	.26 (.608)	17.14 (<.001)
Race/ethnicity			1.01 (.798)			46.61 (<.001)	3.22 (.359)
African American, % (n)	13 (8)	13 (13)		10 (1081)	11 (1851)		
Hispanic, % (n)	21 (13)	15 (15)		15 (1633)	15 (2586)		
White, % (n)	52 (32)	53 (52)		57 (6435)	54 (9439)		
Other, % (n)	15 (9)	19 (18)		18 (2067)	21 (3699)		
Age			2.59 (.275)			1.57 (.456)	12.24 (.002)
18-30, % (n)	35 (22)	32 (31)		44 (4964)	44 (7751)		
31-45, % (n)	31 (19)	43 (42)		36 (4079)	37 (6502)		
45+, % (n)	34 (21)	26 (25)		20 (2173)	19 (3322)		
Stage contacted [‡]			16.66 (<.001)			10.95 (.004)	713.41 (<.001)
CT stage, % (n)	85 (53)	69 (68)		62.1 (6962)	63.4 (10,966)		
WU stage, % (n)	0 (0)	23 (22)		.5 (55)	3 (45)		
Other, % (n)	15 (9)	8 (8)		37.5 (4199)	37.3 (6564)		
HLA commonality			2.82 (.243)			8.41 (.015)	154.06 (<.001)
"Good", % (n)	6 (4)	11 (11)		56 (6228)	54 (9538)		
"Fair", % (n)	84 (52)	85 (83)		37 (4163)	38 (6597)		
"Poor", % (n)	10 (6)	4 (4)		7 (825)	8 (1440)		
Presearch status			2.56 (.278)			63.86 (<.001)	17.92 (<.001)
Responded, % (n)	26 (16)	23 (23)		17 (1859)	17 (3044)		
No response, % (n)	31 (19)	43 (42)		26 (2972)	30 (5332)		
No presearch, % (n)	44 (27)	34 (33)		57 (6385)	53 (9199)		
Time on the registry			1.03 (.597)			24.56 (<.001)	2.71 (.258)
On registry < 1 yr, % (n)	13 (8)	16 (16)		22 (2421)	19 (3372)		
On registry 2-5 yr, % (n)	39 (24)	31 (30)		30 (3364)	31 (5453)		
On registry > 6 yr, % (n)	48 (30)	53 (52)		48 (5431)	50 (8750)		
Available, % (n)	87 (54)	82 (80)	.83 (.361)	68 (7640)	67 (11,808)	2.71 (.100)	19.08 (<.001)
Patient characteristics							
Female, % (n)	45 (28)	40 (39)	.45 (.503)	42 (4672)	42 (7428)	1.05 (.307)	.01 (.969)
Age			2.30 (.317)			2.46 (.293)	13.48 (.001)
<18, % (n)	8 (5)	16 (16)		20 (2249)	21 (3639)		
18-64, % (n)	66 (41)	59 (58)		65 (7241)	64 (11,193)		
>65, % (n)	26 (16)	25 (24)		15 (1726)	15 (2743)		
Disease			3.42 (.331)			2.41 (.492)	2.40 (.493)
Acute myelogenous leukemia, % (n)	32 (20)	38 (37)		32 (3560)	32 (5514)		
Acute lymphoblastic leukemia, % (n)	8 (5)	15 (15)		16 (1781)	16 (2848)		
Myeloid disorder, % (n)	16 (10)	15 (15)		15 (1652)	14 (2502)		
Other, % (n)	44 (27)	32 (31)		37 (4223)	38 (6711)		

* The standard messaging period includes the following dates: May 21, 2015 to September 3, 2015 and September 3, 2016 to December 31, 2016. The new messaging period includes the following dates: September 4, 2015 to September 2, 2016.

[†] HPD vs. non-HPD tests were performed after combining standard message and new message periods.

Table 5
Estimated Impact of New Messaging on Donor Availability, Study Component 2

Dependent variable = 1 if the contacted donor was "Available" and 0 otherwise	No Control Variables	Controlling for Donor Characteristics*	Controlling for Donor and Patient Characteristics [†]
<i>All registry members contacted in the study period (n = 28,951)</i>			
Estimated effect of the new message [‡]	-.045 (.076)	.039 (.074)	.037 (.074)
R ²	.001	.078	.079
<i>Excluding "temporarily unavailable" donors (n = 26,932)</i>			
Estimated effect of the new message	-.096 (.074)	-.011 (.071)	-.013 (.071)
R ²	.001	.109	.110

* Donor characteristics include sex, age, race, stage contacted, HLA commonality, presearch contact status, time on registry (see Table 4), and state of residence.

[†] Patient controls include the patient characteristics that are communicated to the prospective donors: sex, age, and disease (see Table 4).

[‡] Results are reported from difference-in-differences linear regressions. The estimated effects represent changes in the likelihood of a donor being "available" to move forward with the donation process (eg, a coefficient of .045 indicates a 4.5 percentage point increase in availability associated with the new messaging). Values in parentheses are standard errors.

theme from the donor interviews was that potential donors had already made up their minds to donate, and this may have lessened any possible impact of the HPD messaging.

A second finding was that the HPD message was generally acceptable to DCRs and that, although ~25% of DCRs were initially less comfortable delivering the message, they became more comfortable over time. Furthermore, DCRs generally believed the message was received as neutral or positive by potential donors and did not cause undue pressure to donate—a finding that is consistent with the findings from potential donors. After an initial introductory period, DCRs were able to deliver the message consistently in most cases.

Despite these encouraging results, our third key finding is that the new messaging did not produce a significant increase in availability among HPDs. There are several potential explanations for this finding. First, the percentage of all donors who were HPDs—and therefore the number available for this investigation—is small. It is possible that a larger study combined with initially lower availability rates could have detected an effect of the messaging where this one did not. Second, even before the implementation of the new messaging, donor availability among the HPD group was already high (87%), making further improvement in this group difficult to achieve. This rate of availability is much higher than the general rates of availability in the NMDP registry as indicated by unadjusted availability comparisons in Table 4. Finally, it is possible that the HPD message itself may not have been clear or direct enough to affect availability. This possibility seems to be supported by some HPDs who indicated they did not remember receiving/hearing the messaging. Strengthening the wording of the HPD message may therefore be needed, especially giving the finding that the current message did not appear to engender undue pressure to donate.

Limitations of the study include the relatively small sample size of HPDs and the surprisingly high pre-HPD-messaging availability rates among the HPD group, in particular. Both factors likely limited our ability to detect any potential differences between the HPD and non-HPD groups. However, the very small differences in availability between the 2 groups suggest that this particular formulation of the HPD messaging is unlikely to have a large effect on donor availability.

In conclusion, despite the lack of evidence for increased availability associated with match status messaging in this

study, there appear to be few harms to providing donors with more information about their degree of matching and possible general ethical benefits of providing more complete information. HPD status was narrowly defined in this study, and it is likely that a broader group of urgently needed donors could be identified that could also benefit from receiving increased match status information. Additional research focused on testing the effects of a stronger match status message and examining the expansion of this messaging to additional desirable donor groups (ie, with initially lower availability rates) is essential.

ACKNOWLEDGMENTS

Financial disclosure: This project was supported by funds from the National Marrow Donor Program. The contents do not reflect the views of the Department of Veterans Affairs or the US Government.

Conflict of interest statement: There are no conflicts of interest to report.

Authorship statement: All authors participated in the design of the research, selection of the analytic strategy, and manuscript preparation. L.A., D.C., K.H., and S.F. facilitated sampling and participant recruitment and data management at the NMDP. J.B., M. McNulty, and G.P. collected and managed data at the University of Pittsburgh. G.E.S., J.B., and M.A.D. analyzed the quantitative interview data, R.F. analyzed the qualitative data, and M.Macis analyzed the donor availability data. All authors interpreted data and reviewed and approved the final manuscript.

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