

AFRICAN AMERICAN MEDICAL MISTRUST BELIEFS

A Qualitative Examination of African Americans' Organ Donation-Related Medical Mistrust Beliefs

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Abstract

Medical mistrust is one of the most prominent barriers to organ donation registration for African Americans, who comprise a disproportionate number of individuals on the organ transplant waiting list. To date, medical mistrust related to organ donation has primarily been conceptualized as a fear of premature declaration of death. However, the history of African Americans' relationships with medical institutions suggests that this conceptualization may be too narrow. In the current study, we conducted a secondary analysis of focus group discussions to gain a better understanding of African Americans' medical mistrust regarding organ donation. Results revealed four categories of medical mistrust beliefs: societal distrust, distrust of general institutions, distrust of medical institutions, and organ donation-specific medical mistrust. Additionally, medical mistrust beliefs appeared to be the result of personal experiences, interpersonal communication, and exposure to the media. Our results are discussed with an emphasis on the theoretical and practical implications for health practitioners working to increase the rates of organ donation among African Americans.

A Qualitative Examination of African Americans' Organ Donation-Related Medical Mistrust Beliefs

Compared to other racial groups in the United States, African Americans comprise a disproportionate number of individuals on the waiting list to receive an organ transplant (Organ Procurement and Transplantation Network (OPTN), 2017). One way to increase the number of African Americans receiving organs is to increase the number of African American donors. Scholarship examining the barriers to African Americans registering as organ donors consistently flags medical mistrust as a significant barrier, particularly among African Americans (Kurz, Scharff, Terry, Alexander, & Waterman, 2007). Despite these findings, few studies closely examine the nuances of medical mistrust and how communication might contribute to this barrier. To intervene to affect behavior change, a more thorough understanding of medical mistrust is imperative. The current study focuses on African Americans' medical mistrust beliefs related to organ donation and contributes to the literature by focusing on why African Americans' are mistrustful of the organ donation process. Specifically, we conducted a secondary analysis of qualitative data and identified types of medical mistrust beliefs as well as the role the communication environment plays in those beliefs.

Medical Mistrust in Organ Donation

Barriers can serve as a deterrent to performing healthy behaviors and play a critical role in various behavior-change models, including the health belief model (HBM). According to the HBM, perceived barriers are defined as individuals' perceptions of the obstacles to performing a behavior (Rosenstock, 1974). Among the HBM constructs including severity, susceptibility,

benefits, self-efficacy, and cues to action, barriers perform a critical role in inhibiting health behavior (Brewer & Rimer, 2008). The presence of a barrier may mean individuals believe the costs of engaging in the behavior is too great (Champion & Skinner, 2008), or that they do not believe they have control over the situation (Montano & Kasprzyk, 2008). A recent meta-analysis ($k = 18$) discovered benefits and barriers were consistently the strongest predictors of behaviors (Carpenter, 2010).

Within the context of organ and tissue donation, medical mistrust arguably stands as the most cited barrier to registration among African Americans (e.g., Kurz et al., 2007; Quick et al., 2014). Not only is there a negative relationship between medical mistrust and organ donation intentions (Morgan, Stephenson, Harrison, Afifi, & Long, 2008; Quick, Morgan, LaVoie, & Bosch, 2014), but some research finds that medical mistrust accounts for more variance in organ donation intentions than knowledge (Morgan et al., 2008). Although it is well established that medical mistrust can be a barrier to organ donation, specific beliefs underlying this mistrust must be unpacked before campaign designers can address those beliefs with targeted messages.

Studies within the organ donation literature have often narrowly defined and focused on medical mistrust as being rooted in concerns that physicians will prematurely take organs before death (e.g., Morgan et al., 2008). For example, Morgan et al. (2008) conceptualized medical mistrust as concerns regarding premature declaration of death. Other communication scholars have conceptualized medical mistrust in a similar fashion (e.g., Quick et al., 2014; Shepherd & O'Carroll, 2014). As noted in Morgan et al. (2008), the focus on the premature declaration of death is useful when attempting to measure hesitancy to become an organ donor across racial groups. This approach, however, may not fully capture the range of medical mistrust beliefs for

African Americans. Consequently, it may not provide a full picture for health practitioners attempting to create targeted campaigns for African American communities.

Morgan and colleagues (2008) acknowledge that African Americans' mistrust likely extends beyond that of concerns that physicians will remove organs before death. Moreover, recent work by Williamson, Reynolds-Tylus, Quick, and Shuck (2017) suggests that African Americans' mistrust is related to more than premature organ removal. In Williamson et al.'s (2017) study, African Americans tied their mistrust of medical institutions to their mistrust of other institutions, like the government. Given that African Americans have suffered a long history of maltreatment at the hands of medical institutions (for review, see Washington, 2006), culturally specific medical mistrust beliefs may exist for African Americans.

RQ1: What medical mistrust beliefs are held by African Americans regarding organ donation?

Medical Mistrust and the Information Environment

When considering medical mistrust as a barrier, it is crucial to not only understand the conception of this barrier, but also the underlying sources of the beliefs. Health campaigns are not isolated events; campaign messages exist in the larger communication environment, competing against messages from other sources (Randolph & Viswanath, 2004). Therefore, it is important for health practitioners to not only know what medical mistrust beliefs exist, but also how the communication environment helps to form those beliefs. Harrison, Morgan, and Chewning (2008) highlight the need to address the larger communication environment in organ donation campaigns, specifically news and entertainment coverage of organ donation and transplantation.

Prior scholarship has alluded to the role of television news and entertainment media in the formation of medical mistrust beliefs (e.g., Morgan et al., 2005; Quick et al., 2014). These studies, however, do not specifically examine the influence of media in a way that allows for a detailed look at how various communication channels contribute to medical mistrust beliefs. Several studies cite medical mistrust as a barrier and address the media environment (Feeley & Vincent, 2007; Feeley, O'Mally, & Covert, 2016; Quick, Anker, Feeley, & Morgan (2016), however, they do not directly examine the way African Americans interpret their exposure to news and entertainment, and how their subjective interpretations and racial identity may influence medical mistrust beliefs and organ donation behavior.

RQ2: What aspects of the communication environment do African Americans' report are influencing their medical mistrust beliefs?

Method

The current study employs a secondary analysis of a focus group study examining African Americans' perceptions of organ donation. The moderator guide for the larger study was guided by the health belief model. In discussions of barriers, medical mistrust emerged as the prominent theme for further analysis. We therefore conducted this secondary analysis to more carefully examine the nuances and sources of this key barrier by examining African Americans' medical mistrust beliefs.

The focus group study was approved by the Institutional Review Board at the authors' university; all participations were provided with written informed consent. Portions of the consent were read aloud during the focus group and participants were given time to read the consent information and ask questions. They were also provided a copy of the consent form

along with contact information to take home. All personal identifiers were removed so that participants are not identifiable.

Study Design

Focus groups were utilized in the original study to gain a more nuanced understanding of participants' beliefs related to organ donation. According to Bloor et al. (2001), the introspection that occurs during focus groups allows participants to collectively question their beliefs and uncover rationales that previously existed as implicit assumptions. The focus group setting allows participants to share stories, as well as agree with or challenge the ideas of other participants (Lindlof & Taylor, 2010). This process not only allows researchers to gain valuable insight about the topic of interest, but also empowers participants, validates their experiences, and encourages the free expression of ideas (Madriz, 2000).

As information related to medical mistrust arose spontaneously during focus groups, it provided an opportunity to examine the ways in which medical mistrust beliefs may be discussed when prompted by associated information (e.g., organ donation). Given the lack of information of scholarship explicitly examining African Americans' medical mistrust beliefs, the dataset presented a unique opportunity to investigate medical mistrust. Thus, for the current study, a secondary analysis of the qualitative data obtained in the larger project was undertaken; part of the dataset was reanalyzed by focusing on a concept that was present, but not specifically addressed by the primary study (Hinds, Vogel, & Clarke-Steffen, 1997). Secondary analysis of this data was appropriate as the goal was to investigate new research questions (Heaton, 2008) and had the possibility of producing useful findings that were not present in the primary study (Hinds et al., 1997).

Study Setting

Focus groups for the primary study were held in locations convenient for participants. Focus groups were held in one of two locations. Most focus groups (n=4) were held at the African American Task Force headquarters in downtown Chicago. The other focus group was held at a community center 30 minutes away for potential participants unable to travel to the African American Task Force headquarters.

Study Population

Participant age ranged from 18 to 78, with a mean age of 51 ($SD = 15.91$). Most participants were female (84%). Approximately one-third of participants identified as registered organ donors. Participant demographics are presented in Table 1.

Recruitment

Participants (N = 62) were recruited by Gift of Hope Organ and Tissue Donor Network, a local organ procurement organization (OPO) in the Chicago area. The OPO's African American Task Force recruited African American participants via snowballing sampling techniques. Snowball sampling techniques were utilized given both the topic (Liu & Pompper, 2012) and the ability to recruit a hard-to-reach group in a more pragmatic and culturally competent manner (Sadler, Lee, Lim, & Fullerton, 2010). Initial participants were identified by zip codes with low rates of organ donation. Recruitment letters were emailed, mailed, and delivered in-person. These individuals were then asked to pass along information to other possible participants.

Data Collection

During the summer of 2015, focus groups (N = 5) were conducted in Chicago, Illinois as part of a larger study. Focus groups were held over three days and moderated by two African American women. The moderator utilized a semi-structured interview protocol that was guided by the health belief model. First, participants were read the consent information, a short demographic survey was administered, and ground rules were covered (e.g., turning off electronics). After that, participants were asked questions aimed at eliciting their perceptions of severity, susceptibility, benefits, barriers, self-efficacy, and cues to action.

Data Analysis

As part of the larger study, focus groups transcripts were recorded and transcribed verbatim and uploaded into qualitative software, Dedoose (Dedoose, 2016) for analysis. For the current study, excerpts coded as medical mistrust in the previous analysis were exported and subjected to analysis. Analysis was conducted inductively. Two of the authors (XX and XX) reviewed excerpts for emergent categories. Once codes were settled upon, all excerpts were coded independently. Any discrepancies were resolved through consensus. Quotations were selected from across the entire sample for inclusion based on their exemplariness. We were mindful to ensure a sample that was representative of participants' experiences.

Results

There were mentions of medical mistrust in each of the five focus groups, however three of the focus groups had more substantial discussions of medical mistrust. Although the ways in which medical mistrust came up in the focus groups varied by focus group, taken together these discussions of medical mistrust related to organ donation provide a picture of the ways in which these participants view medical mistrust. The analysis provides insight as to the type of medical

mistrust beliefs that are held, as well as the sources of the beliefs. Below, themes found across all five focus groups are discussed.

Types of Medical Mistrust Beliefs

Four types of medical mistrust were present in African Americans' sentiments related to medical mistrust: societal distrust, distrust of institutions, distrust of medical institutions, and organ donation specific mistrust. These beliefs extend beyond physician mistrust to encompass historical and current race relations. The medical mistrust beliefs described by participants represented a continuum of more general societal mistrust to organ-donation specific medical mistrust.

Societal distrust. Participants expressed distrust of organ donation based on societal distrust; this societal distrust was rooted in a distrust of others as well as witnessing societal discrimination toward African Americans. For some participants, there was distrust of society generally. In these cases, medical mistrust was simply an extension of being distrustful of the world. One female non-donor likened it to being afraid to open one's door for strangers in today's world:

But it's hard to give, to just put an X in a box and just say I'm going to give my organs and you don't know where they're going. And like the lady said, the majority of the people I talked to, our society is so corrupt that you don't want to experience any other negativity. So you're afraid to even give your organs to anybody. We're afraid to open the door when people come to our door and we have never seen them before. So we are definitely afraid to be bedridden somewhere and someone know that, cause at some time or other, somebody in the hospital has to know you're an organ donor even if it's just from your own personal conversation. And to me that puts you at risk.

For other participants, societal distrust was rooted in historical discrimination as well as more recent events of discrimination and oppression. For example, participants revealed that the things that have happened historically have led people of color to "believe that we would be

disposable parts for people.” This type of medical mistrust reflects a mistrust they believe is especially pertinent to the African American community. A female registered donor explained that she understood the mistrust, even though she, herself, had decided to become a donor:

Now I understand what everybody is saying. As Black people, we’ve been through so much. And oppressed. And we have an attitude about different things in society. You know what I’m saying, we’ve been abused and used. And so, and slavery. And so all of this is carrying over and everybody has, and they have a right to their opinion, I don’t take nothing from nobody.

In addition to this, participants expressed the idea that organ donation was just like every other part of society in which African Americans were mistreated. One female non-donor was steadfast in her opinion that African Americans’ organs would be taken, even without consent due to the current treatment of African Americans:

I’m just saying that with the climate, and the environment that exist today. With the African-American community, and I don’t care what we’re dealing with, OK? We are being, abused, misused and everything. So there are... this is just, it’s just my belief.

Distrust of institutions. Participants’ medical mistrust beliefs were also tied to a mistrust of institutions broadly. At times, medical mistrust related to organ donation was the result of a general distrust of government. To the extent that the government plays a role in oversight of organ donations, distrust of the government was tied to distrust of the organ donation process. A male non-donor explained how he believed the government cannot be trusted to tell the truth given its track record. He underscored that this is particularly the case for African Americans:

The government has a history of lying. And I know where you’re coming from, look, the government saying that we’ve got rules and regulations, and all of this. And, we’re going to create this list— Everybody knows that Iraq didn’t have weapons of mass destruction. It was a lie. And the American government has been lying since they wrote the Declaration of Independence. It was a lie, and they haven’t stopped lying. Now, of course, you know organ donation will help the living, but saying we trust the government in terms of how they are regulating. That’s nonexistent. Especially for Black folk.

As with societal discrimination, distrust of institutions pointed to a historical trend that demonstrated that African Americans could not trust certain institutions, particularly the government. A female non-donor explained that African Americans, because of what happened to our ancestors, are still wary of government institutions.

You know what – and it’s sad that we as Black people have gotten messed up by the government, and we have a tendency to not trust the system based on, based on what has happened to our ancestors, to have carried on. You see what I’m saying, and I’m just hearing this, the government this – yes, the government has done a lot of things and is still continuing to do today.

Distrust of medical institutions. Participants’ beliefs regarding medical mistrust also narrowed to reflect a distrust of medical institutions more specifically. Participants did not trust medical institutions or personnel. They also expressed a skepticism and fear that African Americans would be used for experimentation. As proof, several individuals pointed to the infamous Tuskegee Syphilis Study in which African American men were not given penicillin and their syphilis was allowed to progress. For example, one male non-donor explained:

Personally, I wouldn’t do it. Just because, going back to the experiment thing. They still do a lot of stuff that we don’t know about and stuff that we do know about. Like, when they tested syphilis and all that other stuff on us in the 1970’s.

This orientation towards historical discrimination was not exclusive to the Tuskegee study; several participants referenced the treatment of African Americans during slavery. One participant commented that “we’re only a couple of generations from slavery.” It is clear that African Americans believe the idea of experimentation and mistreatment has been a historical recurrence, and one that is unlikely to end soon. One female non-donor described feeling as though physicians had genocidal motives:

So, even feeling that way towards doctors, I would still want to be an organ donor. But, I know they will remove parts from you, because maybe they are saying we don’t want you to populate anymore. So it’s genocide in a way... genocide of your race. We’re going to

remove this so you won't bear any more children. So, this is the way I'm feeling personally towards the doctor and especially that she was not of my race.

Organ donation specific. A common form of mistrust was distrust of the organ donation process itself. Several participants expressed the belief that by being an organ donor, medical staff would not work to save their lives in emergency situations. For example, an exchange between three female participants (both donors and non-donors) suggests it is a common belief. As one of the female registered donors shared her belief that organ donation "...is the right thing to do, I just don't think that the medical staff will work as hard to save me if I have viable organs," other participants chimed in that they agreed and added that many other African Americans also believed medical staff would not work to save the lives of organ donors.

Participants' concerns that physicians would be overhasty in withdrawing treatment did not always reflect an accusation of intent on the part of physicians. Occasionally, participants felt that physicians are sometimes simply wrong about whether a person is dying. One female non-donor recounted her experience of watching her mother live past doctor's expectations:

My mom, she passed away two years ago, she had heart attacks for over thirty years. So, had she been a donor, there's a lot times when they would have said, "she's checking out". But she never did. So, that's one of the things I look at when you look at someone... when is the time to... because they try to get us to not have a do not resuscitate... and she lived ten years after the time that she thought she was not going to make it.

Interrelationships. It should be noted that these types of medical mistrust beliefs are not necessarily mutually exclusive nor do they operate in isolation. For instance, in response to individuals' concerns about the organ donation process and premature declaration of physicians, one of the moderators explained that a separate entity (i.e., not emergency department physicians) coordinated the organ donation process, and that the entity, an organ procurement organizations (OPO), was federally mandated. Although this was intended to assuage participant

distrust of the organ donation-specific mistrust, participants immediately questioned whether the OPO, as a government organization was as “upfront and honest” as she claimed.

These categories are obviously related and intertwined. It was apparent from participant discussions that the differing levels of medical mistrust beliefs fed into one another. A male non-donor described distrust of medical institutions as related to distrust of institutions more generally, and transitioned into how this meant organ donation-specific mistrust existed.

I feel like again, you read more and more about back in the day. It's like, they were experimenting on slave women and all this other stuff. Why would they stop? There's more money to be made. Again, I'm still skeptical about... it'd be different ... it's kind of like the institutions aren't made for us. Being honest. They weren't made for us directly. I feel like a lot of times that's where Black people's skepticism comes from... stuff from way back. Even my grandma, I mean, don't be an organ donor because they're not going to save you.

Role of the Communication Environment

Participants alluded to the role communication may play in the formation of these beliefs. In describing their medical mistrust beliefs, participants often discussed the sources of these beliefs. When discussing the sources of their medical mistrust beliefs, participants cited direct experience, interpersonal experiences, and mediated information.

Direct experience. Participants discussed their own negative, personal experiences with the medical system as sources of their medical mistrust. Often times, this was in regard to distrust of medical institutions, specifically. One participant, another female non-donor, believed the hospital took her “mother-in-law's heart, while it was still good.” She explained a series of events she described as “suspicious” and remarked that “I know they took her parts. Because she had some good ones.” Unexplained medical actions resulted in the participant's belief that organs were taken from her mother-in-law.

Another participant discussed her distrust of physicians stemming from a surgery she had last year on her uterus:

I do believe that doctors will remove parts from your body that should not be removed for whatever purpose or whatever gain. I do believe that because it has happened to me last year. I'm still trying to recover from a uterus being removed that I was told was unhealthy. But, I have no record or pictures to show that it was. And, I'm still trying to recover from that. And, for them to say, oh we're going to go back in and correct what we did wrong. No, not with me you're not.

Interpersonal communication. Many participants discussed the relaying of information regarding medical mistrust beliefs, specifically distrust in medical institutions and organ donation-specific mistrust, through conversations. A male non-donor remarked that “there’ve been people talking in the community among themselves, centered around organ donations and distrust of health services.” Participants also expressed the view that these views were passed down among family members and is inherent in how African Americans tend to be raised. One of the male non-donors talked about hearing sentiments of distrust “when you’re a kid and then you grow up and either you say it to your kid or you learn and you spread new information.” Among the ideas passed on are references to Tuskegee. Another female non-donor explained, “I think the skepticism which I heard growing up was that Blacks were not given the penicillin when they needed it, and that we should be used for an experiment.” Participants conveyed they had been told to be distrustful from other family members as well as individuals in the community.

Mediated information. The most prevalent source of organ donation-related beliefs among these participants, however, appeared to be mediated information. Participants cited a variety of media sources while describing their distrust of medical institutions, organ donation specific distrust, and distrust of institutions. For instance, some participants brought up entertainment media. A female non-donor recounted a line from a movie that stuck with her and

made her hesitant to interact with medical institutions, “‘Well, you know she’s a donor, get her heart, she’s not going to make it.’ You see movies like that, so it makes me kind of scared.”

Perhaps most surprisingly, participants pointed to informational, presumably credible sources as the source of their beliefs. Specifically, participants often cited news sources as the sources of their beliefs. At one point, as participants were discussing their knowledge of black market organs and their belief that systems were not made for African Americans, one participant expressed her knowledge of black markets for organs had come from “news channels and national geographic stuff. Informative channels.”

Participants also pointed to specific news stories they had heard related to organ donation. They often brought up these stories to demonstrate that the system was unfair and thus should not be trusted. Participants believed doctors viewed certain groups as unimportant and thus they would let you die to give organs to someone “more important.” A female non-donor could not remember the details, but recalled hearing on the news that a famous tennis player who died mysteriously and “all her organs were taken.”

The news stories participants pointed to were not always vague recollections. Some of the discussions involved very specific news stories. As demonstrated in the exchange below between two participants, these stories resonated with participants and were used as evidence for why they could not trust the organ donation system.

Female registered donor: But I was thinking about the young man. I don’t know if he lived in Chicago or not. You all probably heard the story. He was like 15, 16. He needed a heart really bad. But he had been involved in crime. But he was laying there sick, as if his life had turned around. But anyway, he got heart. I think it was last year since it happened, he died. He had a car accident, and he was out clowning again. And he died, and he had somebody’s heart. And I think they had to go to court, to get him the heart because the court didn’t want to give him the heart because of the lifestyle he was living...

Female non-donor: It's stuff like that. Why would they have to go to the court to get him a heart, based on his lifestyle? I'm sure he's not the only person that needed an organ donation and still didn't change their lifestyle. I'm sure he wasn't the only person, but he was an African-American young man. Right? So why would he have to go to court for that? Why would he have to, why would they have to? If there was an organ for him that his body, and his body – give him the organ. That's why we need a Black registry for Blacks, where Black people can go and donate their own organs into other African Americans.

Their descriptions were not only about stories involving African Americans, but other minorities as well. These stories were used as evidence that as members of a minority group they should not trust systems that preference the majority.

Male non-donor: That Mexican girl needed a kidney, and her brother was about to be deported and they'd rather let this woman die.

Female non-donor: See they change the rules. When they involved, everything is top-flight and stuff, but let somebody else be involved – you know what I'm saying. See like a life is life right? It's the same thing with the African-American boy. He needed in an organ and they started trying to judge him on how he used to live his life. Now this young lady, she need an organ, her son is here, brother is here illegally, she can't do that. To save her life.

Male non-donor: Could've sent her back there with a good kidney to save her life. But they ended up laying her on her deathbed I guess.

Female non-donor: If organ donation is about saving a life, then you just save a life.

Discussion

Medical mistrust is one of the most salient barriers to organ donor registration, especially among African Americans (Kurz et al., 2007). We analyzed focus group discussions of medical mistrust to investigate the beliefs underlying medical mistrust regarding organ donation and the role of the communication environment in the formation of these beliefs. Below, theoretical and practical implications of our findings are discussed.

Types of Medical Mistrust

Many organ donation scholars have focused on medical mistrust as being mainly related to concerns that physicians will remove organs prematurely and have measured medical mistrust as revolving around that concern (Morgan et al., 2008; Quick et al., 2014). Although such concerns came up during the focus group discussions, our findings suggest medical mistrust beliefs extend beyond worries over premature declaration of death. Our findings expand Williamson et al.'s (2017) finding that medical mistrust seemed tied to larger historical and societal issues. In our study, participants described medical mistrust beliefs that spanned four distinct levels – starting with broad societal distrust and narrowing to concerns specific to organ donation. These levels provide nuance to a barrier to organ donation that is often conceptualized as solely about premature declaration of death.

Organ donation-specific medical mistrust beliefs are what scholars have primarily talked about as medical mistrust related to organ donation. There are, however, at least three other categories of medical mistrust not addressed by that approach. The existence of these other underlying beliefs underscores the importance of ascertaining the underlying beliefs held by target populations. It is only with knowledge of these underlying beliefs that health practitioners can understand what to address in campaigns.

The focus of organ donation specific beliefs in the current literature suggests that communication scholars are only addressing a small portion of African Americans' concerns regarding medical mistrust. Campaigns solely targeting the belief that physicians will let them die sooner may not be addressing all the underlying beliefs that contribute to medical mistrust. African Americans' concerns about organ donation are likely to be broader than concerns other than physicians allowing them to die prematurely. Some work in organ donation has begun to take this into account in their measures (e.g., Andrews et al., 2016), but it is also important to do

so for medical mistrust specifically. By only addressing some of those underlying beliefs, or ignoring how medical mistrust manifests differently for African Americans, campaigns are unlikely to be successful in overcoming this barrier and increasing the rates of organ donation among African Americans. Given that some participants held these beliefs, yet still opted to become registered donors, these individuals may provide insight into approaches to overcome medical mistrust as a barrier to organ donation registration.

These findings suggest a need to reexamine the ways medical mistrust is conceptualized and measured. Specifically, the findings raise questions as to whether current medical mistrust measures are adequately capturing the beliefs underlying medical mistrust. While measures that focus solely on organ donation specific beliefs may be useful in use across demographics, when targeting African Americans, they may be less likely to prove useful as they may only be capturing a subset of underlying beliefs. Future research will be necessary to determine which medical mistrust measures most accurately affect African Americans' medical mistrust beliefs and accounts for more willingness to register as an organ donor.

Role of the Communication Environment

Personal communication, entertainment media, and news media were all brought up as sources of participants' medical mistrust beliefs. This provides a unique look at the conception of a widely cited barrier to organ donation. The presence of direct experience and interpersonal communication in forming participants' medical mistrust beliefs suggests that day-to-day experiences and conversations can play a significant role in the formation of medical mistrust beliefs. Given that medical mistrust beliefs are tied to broader racial relations, this indicates that the passing of stories, organ donation-related and non-donation-related, plays a key role in the communication of medical mistrust beliefs. Considering the current media environment, it may

be possible to track the spread of stories throughout social media and their influence on beliefs among African Americans.

Our results suggest that media may play a prominent role in the formation of medical mistrust beliefs. For instance, a female non-donor referenced *John Q*, a 2004 movie of an African American father desperate to secure an organ for his son. These findings echo findings from Morgan et al. (2009) and Quick et al. (2014) which found negative relationships between exposure to entertainment media and willingness to become an organ donor. Our findings suggest that exposure to entertainment media should also be examined as an antecedent to the formation of medical mistrust beliefs.

Furthermore, participants in our study often alluded to news stories, as opposed to entertainment media, as justification for their medical mistrust beliefs. Participants are not relying on fantastical stories; they are recounting information from what many would consider credible news stories. Participants pointed to specific stories that could be traced to recent airings on Chicago news channels. For instance, as an example of systems being set up against minority populations, participants discussed a story about a young Hispanic girl who needed a kidney, but officials wanted to deport her brother. In fact, a similar story ran in Chicago in April and May of 2015 about a young Hispanic woman, Jazmin Longoria-Lara, whose brother, a perfect match, was facing deportation (Schulte, 2015). The prominence of media in our participants' discussions suggest that future research should examine the impact of media exposure on medical mistrust beliefs.

In doing so, special attention should be paid to local and ethnic news. While some stories were likely to be heard on national news broadcasts, others like Jazmin Longoria-Lara's story, ran on local news channels. This source may be particularly important as African Americans

cited local news as a major source of information regarding health and medicine (Pew Research Center, 2010). In addition to the examination of local news, future research should also examine the portrayal of organ donation in ethnic news media (e.g., *The Chicago Defender*) and its impact on medical mistrust beliefs. Given that a substantial proportion of African Americans who consume mainstream media, also consume ethnic news media (The Media Insight Project, 2014), exposure to ethnic news media may also contribute to medical mistrust beliefs. Thus, content analyses of portrayals of organ donation in both local and ethnic news is an important avenue for future research.

Limitations

Due to the nature of our study, limitations exist that should be acknowledged. First, as our sample was comprised primarily of African American women from Chicago, we are unable to generalize to the African American population at large. Furthermore, due to the utilization of focus groups, we cannot speak to the frequency with which these beliefs are held nor how much of an impact these beliefs or communication sources have on organ donation intentions.

Although we cannot directly speak to the impact of these communication sources on organ donation intentions, work conducted by Morgan and Cannon (2003) supports the idea that interpersonal communication (e.g., family and friends) and television play a significant role in organ donation beliefs. We anticipate that social media original posts and shares would also contribute to our understanding of medical mistrust related to organ donation, among other topics. The credibility and newsworthiness of these posts deserve additional attention in the future.

Additionally, the current study is a secondary analysis of previously collected data. Hinds et al. (1997) notes two general methodologic issues in conducting secondary analysis of qualitative

data. The first is the degree to which the data generated can be used for secondary analysis. As the current investigation involved an examination of emergent themes for a concept that spontaneously emerged during all five discussions, missing data was not an issue. The second potential methodological issue with secondary analysis of qualitative data is whether the research questions differs too much from the original study's purposes (Hinds et al., 1997). The questions in the moderator guide for the original study were not designed to specifically examine medical mistrust. Given that the primary study asked participants to describe their perceptions of barriers to organ donation, a desire to understand how individuals describe a particular barrier (i.e., medical mistrust) does not differ much from the primary study aims. The secondary analysis does, however, prevent generalizations about medical mistrust beliefs. Despite these limitations, the current study provides a starting point for investigating the nuances and sources of medical mistrust. It suggests that future research in which medical mistrust is specifically investigated would be fruitful.

Conclusion

In the current study, we sought to expand our understanding of African Americans' medical mistrust beliefs related to organ donation. Our results highlight the need to consider both historical memory and the current news environments when examining medical mistrust among African Americans. We move the literature forward in three valuable ways. First, it expands our understanding of medical mistrust in the context of organ donation. In addition to this, the current study provides clues as to the sources of information forming these varied medical mistrust beliefs. Finally, the current study provides important considerations for health practitioners seeking to intervene and combat the barrier of medical mistrust in order to successfully increase the number of African American organ donors.

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Table 1. Focus group participant demographics

	Overall (N = 62)
Age (M, SD)	50.77 (15.91)
Sex Female (%)	83.87
Registered organ donor (%) ^a	44.26
Income (M, SD) ^b	55,406.98 (39,837.61)

^aOne individual did not report donor status. ^bEighteen individuals did not report income.